Multiple stigmatization of lesbian and bisexual mothers with HIV/AIDS in New York: A qualitative study.

Von der Philosophischen Fakultät der Universität Hannover
zur Erlangung des Grades einer Doktorin der Philosophie (Dr. phil.)
genehmigte Dissertation

von Hella von Unger
geboren am 12.8.1971 in Hannover

2005

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Tag der mündlichen Prüfung: 15.6.2005

Abstract

BACKGROUND: Stigmatization processes are harmful to the social standing and psychological well-being of the targets of stigma. Traditionally, social psychology has focused on the stigmatizer, i.e. groups and individuals who display prejudiced views and discriminatory behavior. Recently, a stronger focus has been placed on the experience of the targets of stigmatization and their active role in creating a buffering life space. HIV/AIDS and women's same-sex sexuality are stigmatized in the United States. To date no study has addressed how bisexual and lesbian women with HIV/AIDS experience multiple stigmatization. Parenthood, an often overlooked aspect of these women's lives, might play a significant role in stigmatization processes. This study aims to explore how the stigmas attached to HIV/AIDS and women's same-sex sexuality affect HIV positive, lesbian and bisexual mothers and their relationships to family members, sexual partners and service providers. *METHODS*: An exploratory approach using qualitative research methods was applied. Data were collected in three stages: 1) interviews with key informants (N=14); 2) screening interviews with HIV positive women with same-sex sexual experience who were also parents (N=29); and 3) repeated in-depth interviews with a smaller number of the screening participants (N=9). Data analysis was guided by grounded theory procedures and acknowledged the influence of the interview interaction on the narrative construction of participants' experience of stigmatization. *FINDINGS*: Multiple stigmatization was perceived as a problem within participants' families, sexual relationships, ethnic minority communities and service provision. Parenthood had paradoxical effects. On the one hand it amplified processes of multiple stigmatization and many participants' had been considered "unfit mothers." On the other hand it was a socially redeemable identity and women's parenting skills helped attenuate rejection and devaluation, especially from family members. Participants used a variety of strategies to manage their multiply stigmatized status, including avoidance strategies, strategies that "buffered" the emotional impact of stigmatization and strategies with which they challenged their stigmatization. *DISCUSSION*: Findings from this study suggest that multiple stigmatization amounts to a repeated, multi-faceted attack on women's social standing and sense of self. Its harmful effects can be felt in HIV service provision where the stigma attached to women's same-sex sexuality hampers health care services and social support. Stigma research and theory must pay closer attention to targets' emotional state as it seems to affect the degree of vulnerability to stigma-related harm and self-stigmatizing views. The methodological implications of conducting interview-based research on individuals' experience of stigmatization are highlighted.

KEYWORDS: Stigmatization, Lesbian, HIV/AIDS

Abstract

FORSCHUNGSSTAND: Stigmatisierungsprozesse schädigen das soziale Ansehen und psychologische Wohlbefinden von stigmatisierten Personen. Sozialpsychologische Forschung beschäftigt sich bisher überwiegend mit der Perspektive derjeniger, die Vorurteile besitzen und diskriminierende Verhaltensweisen ausüben. Die Erfahrungsperspektive von Menschen, die Ziel von Stigmatisierung sind, sowie deren aktive Leistung, sich vor Stigmatisierung zu schützen, haben jedoch in den letzten Jahren zunehmend an Aufmerksamkeit gewonnen. Untersuchungen belegen die Stigmatisierung von HIV/AIDS und gleichgeschlechtlicher Sexualität in den USA. Unberücksichtigt blieben bislang jedoch die Stigmatisierungserfahrungen von Frauen, die sowohl HIV-positiv als auch lesbisch oder bisexuell sind. Elternschaft, ein oft übergangener Aspekt im Leben dieser Frauen, könnte eine wichtige Rolle in Stigmatisierungsprozessen spielen. Die vorliegende Studie untersucht, wie lesbische und bisexuelle Mütter, die HIV-positiv sind, Mehrfachstigmatisierung erleben. *METHODE*: Ein explorativer Zugang wird angewandt und die Datenerhebung erfolgt in drei Schritten: 1) Interviews mit Schlüsselinformantinnen (N=14); 2) Screening-Interviews mit HIV-positiven Frauen, die Kinder haben/großgezogen haben und sexuelle Erfahrung mit Frauen besitzen (N=29); 3) wiederholte Tiefeninterviews mit ausgewählten Teilnehmerinnen der Screening-Interviews (N=9). Die Datenanalyse erfolgt in Anlehnung an die Grounded Theory und geht auf die interaktive Konstruktion der Daten im Gespräch ein. *ERGEBNISSE*: Mehrfachstigmatisierung wird als ein Problem in Familien, sexuellen Beziehungen, in den ethnischen Gemeinschaften der Frauen und der Gesundheitsversorgung beschrieben. Elternschaft hat widersprüchliche Effekte: Auf der einen Seite verschärft sie Stigmatisierung und viele Frauen werden als „unfit mothers“ bezeichnet, auf der anderen Seite ist mit Elternschaft eine gesellschaftlich anerkannte Identität und Rolle verbunden, die vor Stigmatisierung schützt. Stigma-Management Strategien werden beschrieben, die auf Vermeidung, Abdämpfen und Infragestellen von Stigmatisierung abzielen. *DISKUSSION*: Die Ergebnisse dieser Studie legen nahe, dass Mehrfachstigmatisierung einem wiederholten, vielschichtigen Angriff auf die soziale Stellung und das Selbstempfinden der Frauen gleichkommt. Negative Folgen treten im Bereich der Gesundheitsversorgung und in HIV Selbsthilfestrukturen auf. Stigmaforschung und -theorie müssen ein größeres Augenmerk auf die emotionale Befindlichkeit der Menschen legen, die Zielscheibe von Stigmatisierung sind, da deren Verletzlichkeit den Prozess und die Auswirkungen von Stigmatisierung wesentlich zu beeinflussen scheint. Einen weiteren Bestandteil der Diskussion bilden die methodologischen Erkenntnisse und Implikationen, die sich aus der Arbeit mit Interview-gestützten Daten zu Stigmatisierungserfahrungen ergeben.

SCHLAGWÖRTER: Stigmatisierung, Lesbisch, HIV/AIDS

Zusammenfassung in deutscher Sprache

Mehrfachstigmatisierung lesbischer und bisexueller Mütter mit HIV/AIDS in New York: Eine qualitative Studie zu Stigmatisierungserfahrungen und Bewältigungsstrategien

Einleitung

Die vorliegende Arbeit basiert auf einem Forschungsbedarf, der aus der praktischen Arbeit mit HIV-positiven Frauen erwuchs und von einer Einrichtung, die in der Versorgungsarbeit tätig ist, artikuliert wurde. *Gay Men's Health Crisis* (GMHC), eine der größten, aus der Selbsthilfe hervorgegangenen HIV Versorgungseinrichtungen in New York, äußerte den Bedarf, die Versorgungsbedürfnissen lesbischer Mütter mit HIV/AIDS zu erheben. Eine Studie hatte gezeigt, dass fast 300 Frauen, die sich als lesbisch oder bisexuell bezeichnen, allein im vorangegangenen Jahr Angebote bei GMHC wahrgenommen hatten, dass aber nur 19% dieser Frauen mit dem *Lesbian AIDS Project* (LAP) in Kontakt waren, also dem Programm speziell für Frauen, die Sex mit Frauen haben (Fitzsimmons, 2000). Der Studienbericht warf die Frage nach der ungeklärten Bedürfnislage der Frauen auf und empfahl, die Versorgungsbedürfnisse von HIV-positiven, lesbischen und bisexuellen Frauen zu untersuchen. Der Bericht wies außerdem darauf hin, dass viele dieser Frauen Eltern sind und dass hieraus resultierenden Bedürfnisse mitberücksichtigt werden sollten.

Ich beteiligte mich der Planung der angefragten Untersuchung und beschloss außerdem, im Rahmen meiner Promotion eine eigene Studie hinzuzufügen, in der ich genauer auf einen speziellen Aspekt der Erfahrungslage der Frauen eingehen würde - ihre Mehrfachstigmatisierung. Ich hatte zuvor in Deutschland eine Studie zu HIV-positiven Frauen und deren Umgang mit dem Stigma von HIV/AIDS durchgeführt (Unger, 1999) und war nun interessiert zu sehen, wie Frauen mit Mehrfachstigmatisierung umgehen. Ich hatte die Vermutung, dass das Stigma, das gleichgeschlechtlicher Sexualität anhaftet, die Gesundheitsversorgung der Frauen mitbeeinflusst und eventuell für die geringe Inanspruchnahme der Serviceleistungen des Lesbian AIDS Projects mitverantwortlich ist. Statt jedoch nur auf einen Aspekt der Lebenssituation der Frauen einzugehen, wie ihre gleichgeschlechtliche Sexualität und dem damit zusammenhängenden Stigma, erschien ein offener Zugang angemessener. Die Forschungslage zur Situation von HIV-positiven, lesbischen und bisexuellen Frauen war sehr begrenzt, und da weder ihre Mehrfachstigmatisierung noch der Aspekt ihrer Elternschaft bislang erforscht waren, wählte ich einen induktiven, explorativen Zugang.

Kapitel 1 Forschungsstand

Jedes Jahr werden in den USA mehr als 7000 Frauen mit dem *Human Immunodeficiency Virus* (HIV) oder dem weiter fortgeschrittenen, symptomatischen

Stadium der Immunschwächekrankheit, *Acquired Immune Deficiency Syndome* (AIDS), diagnostiziert. Momentan leben in den USA circa 88.000 Frauen mit HIV/AIDS, von denen die große Mehrzahl einkommensschwachen Schichten und einer ethnischen Minderheit angehört (Centers for Disease Control and Prevention, 2004). Wie viele dieser Frauen lesbisch oder bisexuell sind, ist nicht bekannt, da Daten zur gleichgeschlechtlichen Sexualität nur bruchstückhaft vorhanden sind. Große Kohortenstudien zeigen jedoch, dass ca. 20% von HIV-positiven Frauen über sexuelle Erfahrung mit Frauen verfügen und 11-12% sich als lesbisch oder bisexuell bezeichnen (Barkan et al., 1998; Zierler et al., 1999). Dieser Anteil liegt bei Studien in New York City oft noch höher (Ehrhardt et al., 1995; Simoni et al., 2000). Es ist also davon auszugehen, dass es mehrere tausend Frauen gibt, die HIV-positiv sind und sich als lesbisch oder bisexuell bezeichnen, oder zumindest über sexuelle Erfahrung mit Frauen verfügen.

Diese Frauen sind einer Mehrfachstigmatisierung ausgesetzt, die bisher noch nicht erforscht wurde. Die Stigmatisierung von HIV-positiven Frauen und von lesbischen und bisexuellen Frauen im gesellschaftlichen Kontext der USA wurden jeweils einzeln nachgewiesen. Es wurde bislang jedoch noch nicht untersucht, wie beide Stigmen zusammenwirken und das Leben von Frauen, die HIV-positiv *und* lesbisch oder bisexuell sind, und deren Beziehungen zu Familienmitgliedern, Partnern, Freunden und Versorgungseinrichtungen, prägen. Elternschaft ist ein oft übersehener Aspekt im Leben dieser Frauen, der Stigmatisierungsprozesse entscheidend mit beeinflussen könnte.

In der Sozialpsychologie wurden Stigmatisierungsprozesse bislang überwiegend aus der Perspektive derjenigen untersucht, die vorurteilsbehaftet sind und diskriminierendes Verhalten ausüben. In den letzten Jahren wird jedoch mit Hilfe des Stigmabegriffs auch die Perspektive von Menschen, die Ziel von Vorurteilen und Diskriminierung sind, stärker ins Blickfeld gezogen.[1] Der Soziologe Erving Goffman (1963) hat den Begriff Stigma eingeführt, um auf die Situation von Menschen aufmerksam zu machen, die von voller Akzeptanz ausgeschlossen sind, weil sie ein Attribut besitzen, das zu ihrer sozialen und moralischen Abwertung, also einer Schädigung ihrer sozialen Identität, führt. Goffmans Arbeit wird im ersten Kapitel kritisch gewürdigt und die Stärken und Limitationen seines Ansatzes werden aufgezeigt. Kritikwürdig erscheinen insbesondere drei Punkte: a) der verkürzte Subjektbegriff, der mit der im Symbolischen Interaktionismus verankerten Sichtweise des Selbst als Spiegelbild sozialer Interaktionen verbunden ist, und der Komplexität und Vielfalt psychologischer Umgangsweisen mit

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[1] Der Begriff Stigma überlappt mit den Begriffen Vorurteil, Stereotyp und Diskriminierung, ist jedoch umfassender, bezieht sich stärker auf soziale Interaktionen und dient – darin besteht der wesentliche Unterschied – in erster Linie zur Erschließung der Perspektive derjeniger, die *Ziel* von Ausgrenzungsprozessen sind (zur Abgrenzung der Begrifflichkeiten siehe Crocker et al., 1998; Dovidio et al., 2000; Herek, 2002b; Major et al., 2002).

Stigmatisierung nicht gerecht wird; b) die Annahme, dass soziale Normen überall gleichermaßen Wirkmacht besitzen; und c) die Limitierung des Stigmabegriffs auf die Situation von Menschen, die Normen und Werturteile, die zu ihrer eigenen Abwertung führen, teilen. In der Konsequenz führen diese Punkte dazu, dass Goffman das Potenzial von stigmatisierten Menschen und Gruppen, sich gegen ihre Stigmatisierung zur Wehr zu setzen, zu wenig berücksichtigt. In seinem Ansatz führt Stigmatisierung unausweichlich zur Schädigung des sozialen Ansehens und Selbstwertgefühls von stigmatisierten Menschen und erscheint damit als starrer, gleichlaufender und unausweichlicher Prozess.

Neuere Ansätze der Stigmaforschung in der Sozialpsychologie gehen verstärkt auf den dynamischen und situativen Charakter von Stigmatisierungsprozessen ein. Es wird aufgezeigt, dass der Einfluss von Stigmatisierung auf das Selbstwertgefühl und Selbstbewusstsein von stigmatisierten Individuen nicht gradlinig erfolgt. Es wurden Dimensionen identifiziert, anhand derer sich verschiedene Stigmen unterscheiden, wie Sichtbarkeit, Ursache/Kontrollierbarkeit und der Grad der Gefährlichkeit, die einem stigmatisierten Attribut zugeschrieben wird. Die Dynamik von Stigmatisierungsprozessen und die Varianz in den Auswirkungen von Stigmatisierung werden unter anderem dadurch erhellt, dass Stigmatisierung in den Kontext von Coping mit Stress gestellt wird. Diese Perspektive erlaubt es, die kognitiven Prozesse genauer zu betrachten, mittels derer stigmatisierte Individuen ihre Stigmatisierung wahrnehmen und deuten, sowie die Strategien, mit denen sie auf ihre Stigmatisierung reagieren. In diesem Zusammenhang wird vor allem die Minimisierung von persönlicher Stigmatisierung kontrovers diskutiert. Auf der einen Seite wird darauf hingewiesen, dass stigmatisierte Individuen unter bestimmten Bedingungen das Ausmaß ihrer Diskriminierung verleugnen oder herunterspielen, um den psychologischen und sozialen Preis zu vermeiden, den eine Selbstdarstellung als Opfer von Diskriminierung mit sich bringen kann. Auf der anderen Seite wird argumentiert, dass stigmatisierte Menschen eine Wachsamkeit entwickeln („Vigilanz“- Perspektive) und dazu neigen, sich übermäßig als Opfer von Stigmatisierung wahrzunehmen. Es steht aus, genauer zu untersuchen, welche Umstände und Faktoren die Wahrnehmung der eigenen Stigmatisierung und das Sprechen darüber beeinflussen.

Ein Desiderat der sozialpsychologischen Stigmaforschung besteht darin, dass die Konzeptionalisierung von Mehrfachstigmatisierung bislang unterblieben ist. Es wird grundsätzlich nur jeweils ein stigmatisiertes Merkmal untersucht, oder im besten Fall zwei verschiedene miteinander verglichen, nicht jedoch, wie verschiedene Stigmen zusammenwirken. Die Forschung ist zusätzlich dadurch beeinträchtigt, dass sie meist mit Angehörigen sozial priviligierter Schichten durchgeführt wird, nämlich fast durchgängig mit angloamerikanischen Studierenden, die an amerikanischen Colleges leicht in größerer Anzahl befragt werden können. Die Diskussion zu Vigilanz versus Minimisierung von persönlicher Erfahrung mit Stigmatisierung muss also durch Forschung mit Teilnehmern aus unterschiedlichen, auch weniger priviligierten, gesellschaftlichen Schichten, und durch Forschung zu Mehrfachstigmatisierung bereichert werden.

Die Auseinandersetzung mit dem Stigmakonzept zeigt, dass letzteres einen fruchtbaren Zugang darstellt, um die sozialen Ausgrenzungsprozesse aus der Perspektive derjeniger zu erforschen, die ausgegrenzt werden. Die bestehenden Limitationen müssen jedoch wie folgt adressiert werden:

1. Menschen, die Ziel von Stigmatisierung sind, sind nicht nur als Opfer, sondern auch als aktiv Handelnde zu verstehen; d.h. ihre individuellen und kollektiven Umgangsweisen mit Stigmatisierung müssen ebenso beleuchtet werden wie ihre Ausgrenzungserfahrung;
2. Das Konzept des Selbst als Spiegel von sozialen Interaktionen muss erweitert werden, so dass die Mannigfaltigkeit von psychologischen Umgangsweisen mit Stigmatisierung angemessenere Beachtung findet;
3. Die Vielfältigkeit und Variabilität in den Abläufen und Auswirkungen von Stigmatisierung müssen mitkonzipiert werden, d.h. mit einer potentiellen Heterogenität von Stigmatisierungserfahrungen muss gerechnet werden;
4. *Mehrfach*stigmatisierung von Angehörigen sozial marginalisierter Schichten muss untersucht werden.

Im Anschluss an die Auseinandersetzung mit dem Stigmakonzept im Allgemeinen wird die Forschungslage zu zwei spezifische Stigmen im besonderen dargestellt: zum einen zum Stigma, das gleichgeschlechtlicher Sexualität unter Frauen anhaftet, und zum anderen zu HIV/AIDS-bezogenem Stigma.

Der Einfluss von Kirche, Gesetzgebung und Medizin in der historisch gewachsenen Stigmatisierung von gleichgeschlechtlicher Sexualität unter Frauen wird nachvollzogen. Weibliche Homosexualität wurde als Sünde, als widernatürlich und als Krankheit dargestellt und wurde sowohl kriminalisiert als auch verleugnet und ignoriert. Alle drei Institutionen haben an der gesellschaftlichen Konstruktion des Stigmas mitgewirkt, die von ihnen geprägten Diskurse beinhalten paradoxerweise jedoch auch eine Saat des Widerstands und haben zu gesellschaftlichen Prozessen der Ent-stigmatisierung beigetragen. In den Institutionen finden momentan lebhafte Debatten statt, in denen über eine größere Akzeptanz von gleichgeschlechtlicher Liebe kontrovers verhandelt wird. Trotz der gesellschaftlichen Entwicklung zu größerer Sichtbarkeit und Akzeptanz von gleichgeschlechtlichen Partnerschaften zeigen Studien, dass die Mehrzahl der amerikanischen Bevölkerung nach wie vor sexuelle Beziehungen zwischen gleichgeschlechtlichen Partnern ablehnt und dass bisexuelle und lesbische Frauen mehr

Diskriminierung erleben als heterosexuelle Frauen. Lesbische und bisexuelle Frauen geben zum Beispiel häufiger an, ihren Job verloren zu haben und respektlos behandelt, beschimpft und beleidigt zu werden als Frauen, die sich als heterosexuell bezeichnen (Mays & Cochran, 2001). Eine Reihe von Untersuchungen legen nahe, dass Stigmatisierungserfahrungen das psychische und physische Wohlbefinden beeinträchtigen. Die meisten lesbischen und bisexuellen Frauen leiden nicht an einer psychischen Krankheit, aber im Vergleich zu heterosexuellen Frauen treten vermehrt Angststörungen und Suizidgedanken auf, was mit den Folgen von Stigmatisierung in Zusammenhang gebracht wird (Cochran et al., 2003; Matthews et al, 2002; Mays & Chochran, 2001). Der Forschungsstand zu Stigmatisierungserfahrungen lesbischer und bisexueller Frauen ist jedoch dadurch beeinträchtigt, dass die meisten Studien mit überwiegend anglo-amerikanischen und vergleichsweise wohlhabenden Frauen durchgeführt wurden. Wie lesbische und bisexuelle Frauen, die ethnischen Minderheiten und sozial schwächeren Schichten angehören, sexualitätsbezogene Stigmatisierung erleben, muss noch genauer erforscht werden.

Die Stigmatisierung HIV-positiver Frauen in den USA steht im Zusammenhang mit der Wahrnehmung von HIV/AIDS als einer Krankheit, die – vor allem in den Anfängen der Epidemie – mit schwulen Männern und Drogengebrauch in Verbindung gebracht wurde. HIV-positive Frauen hatten mit Ignoranz und Unsichtbarkeit zu kämpfen, die allerdings seit Anfang der 1990er Jahre einer größeren Sichtbarkeit gewichen ist. Das Stigma, das HIV/AIDS anhaftet, zeichnet sich durch Angst vor Krankheit, Tod und Übertragung aus und drückt sich in (oft überzogenem und irrationalem) Meideverhalten aus. Es beinhaltet außerdem eine Unterscheidung zwischen „unschuldigen Opfern“ und solchen Menschen, die für ihre Krankheit selbst verantwortlich gemacht werden. Frauen, die von einem männlichen Partner oder durch eine Bluttransfusion infiziert wurden, fallen in die erste Kategorie, während Frauen, die sich über Drogengebrauch oder Prostitution infiziert haben, moralisch abgewertet werden. Die öffentliche Wahrnehmung der neuen, übertragbaren Krankheit, die auch als Strafe Gottes für sündige Verhaltensweisen dargestellt wurde, beinhaltet klare Konnotationen mit männlicher, nicht jedoch mit weiblicher Homosexualität. HIV-positiven Frauen wird in erster Linie Drogensucht, Prostitution und Promiskuität unterstellt, und nur wenn sie klarstellen, dass sie anderweitig infiziert wurden, können sie den vorgenommenen Schuldzuschreibungen entgehen.

Studien zeigen, dass erlebte und antizipierte Stigmatisierung für HIV-positive Frauen ein großes Problem darstellen: Ablehnung, Schamgefühl und Angst verlassen zu werden rangieren neben der Sorge um ihre Kinder, mangelnder sozialer Unterstützung und Angst vor Krankheit, Sterben und Tod (Hackl et al., 1997; Moneyham et al., 1996). Fast die Hälfte der in einer Studie befragten HIV-positiven Frauen gaben an, dass

Menschen in ihrem Umfeld negativ auf ihren HIV Status reagiert und sie beschimpft, beleidigt oder abgewiesen haben, teilweise verbunden mit körperlichen und sexuellen Übergriffen (Gielen et al., 2000). Aber auch in seinen weniger offensichtlichen Ausprägungen beeinträchtigt das Stigma, das HIV/AIDS anhaftet, das emotionale und körperliche Wohlbefinden von HIV-positiven Frauen. Es schürt Angst und führt zu sozialer und emotionaler Isolation. Das Stigma wirkt sich auch auf die Gesundheitsversorgung der Frauen aus, und Angst vor Stigmatisierung wird als ein Grund für die verspätete Aufnahme medizinischer Versorgung angegeben (Raveis et al., 1998).

Die Stigmen, die HIV/AIDS und der gleichgeschlechtlichen Sexualität von Frauen anhaften, wurden bislang einzeln, nicht jedoch in ihrem Zusammenwirken untersucht. Die vorliegende Studie soll einen Beitrag dazu leisten, diese Forschungslücke zu schließen. Darüber hinaus wird ein besonderes Augenmerk auf die Rolle von Elternschaft für das Erleben von Mehrfachstigmatisierung gelegt. Diese Studie geht also folgenden Forschungsfragen nach:

1. Wie erleben lesbische und bisexuelle Frauen, die außerdem HIV-positiv sind, Mehrfachstigmatisierung?
2. Wie wirkt sich Elternschaft auf die Stigmatisierungserfahrungen der Frauen aus?
3. Wie gehen die Frauen mit ihrer Mehrfachstigmatisierung um und welche Vermeidungs- und Bewältigungsstrategien entwickeln sie?

Kapitel 2 Methode und Sample

Die Forschungsfragen zielen darauf ab, ein neues, bisher unerforschtes Thema zu untersuchen. Aus diesem Grund ist ein induktives Vorgehen unter Zuhilfenahme von qualitativen Forschungsmethoden angebracht. Qualitative Interviewmethoden dienen der Erhebung von subjektiven Sichtweisen und bieten sich an, die Erfahrung von Mehrfachstigmatisierung aus der Perspektive von lesbischen und bisexuellen Müttern mit HIV/AIDS einzufangen. Insgesamt wurde ein Grounded Theory Ansatz angewendet, der Datenerhebung und -analyse prozesshaft miteinander verbindet. Die Daten wurden in drei Schritten erhoben: 1) Interviews mit Schlüsselinformantinnen; 2) Screening Interviews mit HIV-positiven Frauen, die über sexuelle Erfahrung mit Frauen verfügen und Kinder haben oder großgezogen haben; 3) wiederholte Tiefeninterviews mit ausgewählten Teilnehmerinnen der Screening Interviews.[2]

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[2] Die Studie wurde von dem HIV Center for Clinical and Behavioral Studies an der Columbia Universität/New York State Psychiatric Institute gefördert und auf die Einhaltung ethischer Grundsätze vom NYSPI Institutional Review Board geprüft (IRB #4170, 4439). Alle Teilnehmerinnen wurden vor den Interviews über Zweck, mögliche Risiken und Prozeduren der Studie informiert und ihre Zustimmung wurde schriftlich eingeholt.

In der sozialwissenschaftlichen und anthropologischen Forschung fungieren Schlüsselinformanten als „gate-keepers“ („Türsteher“ oder besser „Türöffner“) und ermöglichen und erweitern den Zugang zum Feld. Das war in diesem Fall besonders wichtig, da das Forschungsprojekt vorsieht, Frauen zu interviewen, die mehrfach stigmatisiert sind und daher erwartungsgemäß ein hohes Maß an Geheimhaltung aus Selbstschutz an den Tag legen. 14 Schlüsselinformantinnen wurden an zehn verschiedenen Einrichtungen in New York City rekrutiert und mithilfe von „problem-zentrierten Interviews“ (Witzel, 1982, 1985) befragt. Diese Form des qualitativen Interviews beinhaltet einen vorgeschalteten Kurzfragebogen zum Erheben demographischer Daten, die Orientierung des Interviews an einem Gesprächsleitfaden (siehe Anhang), eine Tonbandaufzeichnung und die Anfertigung von Interviewnotizen (Postscriptum). Schlüsselinformantinnen wurden zu ihrer Expertise befragt und aufgefordert, soziale, rechtliche und ökonomische Merkmale der Situation HIV-positiver, lesbischer und bisexueller Frauen mit Kindern in New York zu beschreiben. Eine Diskussion relevanter Vorurteile und Stigmatisierungsprozesse wurde mithilfe eines eigens konzipierten Erhebungsverfahrens (siehe Anhang) angeregt. Transkribierte Interviews und Interviewnotizen wurden mithilfe der in der Grounded Theory beschriebenen Analyseschritte kodiert und analysiert (Charmaz, 2002; Strauss & Corbin, 1990). Erste Ergebnisse wurden den Schlüsselinformantinnen zum kommunikativen Validieren zugesandt und ihre Kommentare und Anregungen wurden in die weitere Auswertung und das Design der nächsten Interviews aufgenommen.

In einem zweiten Schritt wurden kurze, standardisierte Screening Interviews mit 29 Frauen durchgeführt, die HIV-positiv sind, über sexuelle Erfahrung mit Frauen verfügen und Kinder zur Welt gebracht und/oder großgezogen haben. Sie wurden mithilfe von Fragebögen unter anderem zu ihren demographischen Daten, ihrer Sexualität, HIV Infektion, Elternschaft, Drogenerfahrung und Diskriminierungserfahrungen befragt (siehe Anhang). Diese Screening Interviews ermöglichten es im Sinne des „theoretical sampling“ (Grounded Theory), eine kleine Gruppe von neun Teilnehmerinnen zu identifizieren, deren Erfahrungsschatz für die Beantwortung der Forschungsfragen besonders relevant schien. Diese neun Teilnehmerinnen wurden im Anschluss jeweils zweimal mit Tiefeninterviews interviewt. Anhand der Tiefeninterviews wurden die Stigmatisierungserfahrungen der Frauen im Kontext von biographischen und alltagsweltlichen Daten erhoben. Zu diesem Zweck wurde ein Interviewformat gewählt, das eine Kombination von problemzentriertem und narrativ-biographischem Interview darstellt. Narrative Interviews beinhalten in der Regel eine erzählgenerierende Frage, mit der versucht wird, die Gesprächspartner dazu zu bewegen, relativ frei und autonom zu erzählen (Fischer-Rosenthal & Rosenthal, 1997). Die Interviewerin nimmt dabei die Rolle der aufmerksamen Zuhörerin ein, die durch unterstützende Gesten und nicht-direktive Kurzkommentare zur Aufrechterhaltung der Erzählung beiträgt und erzählgenerierende Nachfragen stellt. Auch diese Interviews wurden transkribiert, Postscriptum Notizen wurden angelegt und die Analyse erfolgte in Anlehnung an die Grounded Theory. Die Datenanalyse legte ein Augenmerk auf die Interviewinteraktion als konstituierendem Faktor für die erhobenen Daten. Ausgewählte Ergebnisse der Reflexion darüber, wie die Vorannahmen und Positionierung der Forscherin im Feld die Interviews beeinflusst haben, werden im Methodenkapitel dargelegt. Im Anschluss wird das sozio-demographische Profil der Teilnehmerinnen der Studie beschrieben. Für die Teilnehmerinnen der Tiefeninterviews, auf deren Aussagen sich die Analyse hauptsächlich stützt, werden zusätzlich kurze, biographische Zusammenfassungen präsentiert.

Kapitel 3 Ergebnisse: Die Ausprägungen der drei Stigmen

Dieses Kapitel ist das erste von zwei Kapiteln, in denen Ergebnisse präsentiert werden. In diesem Kapitel wird dargestellt, wie die Frauen die Stigmen beschreiben, die ihrer gleichgeschlechtlichen Sexualität und ihrer HIV Infektion anhaften. Außerdem wird das Stigma beschrieben, das dem Drogengebrauch von Frauen anhaftet, da die Teilnehmerinnen dieses Stigma als wesentlich für das Verständnis ihrer Stigmatisierungserfahrung beschrieben haben. Nicht alle Teilnehmerinnen haben Drogenerfahrung, aber als HIV-positive Frauen sind sie häufig mit der Annahme konfrontiert, dass sie sich über Drogen infiziert haben. Diejenigen unter ihnen, die in der Tat Drogenerfahrung haben, beschreiben dieses Stigma als besonders stark, sowohl für sich als auch in Verbindung mit HIV-bezogenem oder sexualitätsbezogenem Stigma.

Die drei Stigmen haben jeweils unterschiedliche Inhalte und Konnotationen. Das Stigma, das ihrer Sexualität anhaftet, beinhaltet das Verletzen von Geschlechtsnormen und damit zusammenhängende Anklagen, sich „widernatürlich“ zu verhalten, ein Mann sein zu wollen und der Familie Schande zu bringen (letzteres wurde vor allem von Latina Teilnehmerinnen beschrieben). Oft wurden die Frauen von ihrer Familie dazu gedrängt, ihre Homosexualität aufzugeben und „Bekehrungsversuchen“ unterzogen. Die meisten Teilnehmerinnen machten in unterschiedlichem Ausmaß selbst-stigmatisierende Aussagen, standen diesem Stigma jedoch generell kritisch gegenüber. Im Bereich Elternschaft wurden Schwierigkeiten thematisiert, ihre gleichgeschlechtliche Sexualität mit dem Selbstverständnis als Mutter in Einklang zu bringen. Mutterschaft und Lesbischsein wurden als unvereinbar angesehen und die Frauen beschrieben die Befürchtung anderer, dass ihre Sexualität die psychologische, sexuelle und soziale Entwicklung des Kindes gefährden könne.

Das Stigma, das dem Drogengebrauch von Teilnehmerinnen anhaftete, wurde als besonders stark beschrieben, da es größere Schuldzuschreibungen an die Frauen beinhaltete als das Stigma, das ihrer Sexualität anhaftete. Ihr Drogenkonsum wurde als eine persönliche Charakterschwäche angesehen und war mit der Zuschreibung verbunden, nicht nur unzuverlässig zu sein, sondern auch zu stehlen und zu lügen. Da der Konsum harter Drogen wie Crack, Kokain oder Heroin in New York rechtlich unter schwerer Strafe steht, waren viele der Frauen schon einmal in Gefängnissen inhaftiert worden. Viele hatten auch schon das Sorgerecht für ihre Kinder verloren. Generell wird von drogengebrauchenden Müttern angenommen, dass sie ihre Kinder vernachlässigen, und gerade Crack-abhängigen Müttern wird unterstellt, ihre Kinder nicht nur zu vernachlässigen, sondern sogar zur Prostitution zu zwingen. Die Frauen selbst hatten oft einen differenzierteren Blick auf ihren Drogengebrauch. Keine der Teilnehmerinnen war zur Zeit des Interviews aktive Drogengebraucherin (drei waren nie von harten Drogen abhängig gewesen und sechs Frauen waren „in recovery"). Aus ihrer heutigen Perspektive nahmen sie ihre Drogensucht sehr wohl kritisch wahr, verwehrten sich jedoch gegen stereotype Zuschreibungen an sie oder andere drogengebrauchende Frauen und Mütter. Als ehemalige Drogengebraucherinnen waren sie auch heute noch einem Stigma ausgesetzt, dass ihnen unterstellte, sie wären nach wie vor nicht vertrauenswürdig und könnten jederzeit rückfällig werden.

Das Stigma, das ihrer HIV Infektion anhaftet, ist eng mit dem Stigma von Drogengebrauch verbunden, da letzterer einen Hauptübertragungsweg für HIV darstellt. Der Übertragungsweg ist dabei mit der eingangs beschriebenen Schuldfrage verknüpft. Fast alle Teilnehmerinnen erzählten von negativen Reaktionen und Meideverhalten in ihrem Umfeld, das von überzogener Angst vor Ansteckung oder Verunreinigung geprägt war. Als HIV-positiven Frauen wird ihnen das moralische Recht abgesprochen, Mutter zu werden. Dabei spielt das Übertragungsrisiko auf das Kind eine Rolle sowie die Befürchtung, dass die Mutter nicht lange genug leben könnte, um das Kind großzuziehen. Das Stigma, das HIV/AIDS anhaftet, ähnelt den beiden anderen Stigmen insofern als es negative Zuschreibungen bezüglich der moralischen Haltung und der Gefährlichkeit der stigmatisierten Person beinhaltet. Es unterscheidet sich jedoch in dem Grad der Gefährlichkeit (das HI Virus wird im sozialen Umgang als besonders gefährlich wahrgenommen) und außerdem darin, dass die körperliche Immunschwächekrankheit zum Teil auch Mitleidsbekundungen, Nachsicht und Hilfsangebote generiert.

Elternschaft kommt im Kontext der Mehrfachstigmatisierung eine ambivalente Rolle zu. Im Zusammenhang mit HIV/AIDS wird den Frauen nahegelegt, von einer Schwangerschaft abzusehen, wegen der Gefahr für das Kind, sich zu infizieren oder ohne Mutter aufzuwachsen. Im Zusammenhang mit ihrer gleichgeschlechtlichen Sexualität wurde ihnen davon abgeraten, ihre Kinder großzuziehen um sie nicht in ihrer psychosozialen und sexuellen Entwicklung zu verunsichern, und im Zusammenhang mit ihrem Drogengebrauch wurde ihnen oft das Sorgerecht entzogen und es wird ihnen unterstellt, sie seien nicht verlässlich genug, um Verantwortung für ihre Kinder zu übernehmen. Die drei Stigmen unterhöhlen also den Status der Frauen als Eltern. Gleichzeitig verschafft die Elternrolle den Frauen jedoch auch einen Zugang zu sozialer Anerkennung und wirkt damit ihrer Stigmatisierung entgegen. Einige Teilnehmerinnen beschrieben, dass ihre gleichgeschlechtlichen Partnerschaften und auch ihr Drogenkonsum von ihren Familien toleriert wurden, solange die Kinder gut verpflegt waren. Elternschaft hat daher eine paradoxe Rolle im Kontext ihrer Mehrfachstigmatisierung – einerseits treten Stigmatisierungsprozesse verschärft auf, andererseits schwächt die Elternrolle Stigmatisierungsprozesse ab und wirkt der Ausgrenzung der Frauen entgegen.

Die Mehrfachstigmatisierung der Frauen stellt keinen gleichförmigen Prozess dar. Verschiedene Stigmen entfalten in unterschiedlichen Settings ihre Wirkung. So war z.B. in HIV Selbsthilfestrukturen der HIV Status der Frauen akzeptiert aber ihre Homo- oder Bisexualität stigmatisiert, während in Gefängnissen ihr HIV Status stark stigmatisiert und ihre gleichgeschlechtliche Sexualität weitestgehend akzeptiert war. In der lesbischen mainstream community werden sie dagegen aufgrund ihres HIV Status und ihrer Drogenerfahrung und der damit assoziierten Heterosexualität zu Außenseitern. Insgesamt berichteten einige Frauen von Schwierigkeiten, soziale Unterstützung zu finden. Allerdings addieren sich die negativen Folgen der einzelnen Stigmen nicht einfach auf. Das Stigma, das Drogengebrauch anhaftet, wurde zwar als verstärkend in der Kombination mit jeweils HIV- und sexualitätsbezogenem Stigma wahrgenommen, aber das HIV-bezogene Stigma hatte auch ein sympathieschaffendes oder mitleiderregendes Element, das vorherigen Ausgrenzungen, die auf der Basis von sexualitäts- oder drogenbezogenem Stigma stattgefunden haben, entgegenwirken konnte. Außerdem wandten die Frauen Strategien an, mit denen sie sich nicht nur individuell, sondern auch kollektiv gegen ihre Stigmatisierung und die negativen Folgen zur Wehr setzten. Am eindrucksvollsten wirkt sich die kollektive Mobilisierung gegen das Stigma, das HIV/AIDS anhaftet, aus. Hier haben vor allem Zusammenhänge schwuler Männer schon früh dafür gesorgt, dass eine Gegenöffentlichkeit entstand. Aktivisten haben sich dafür eingesetzt, dass Menschen mit HIV/AIDS ein Anrecht auf medizinische Gesundheitsversorgung haben und im Bundesstaat New York wird dies auch weitestgehend umgesetzt. Für die Frauen, die grundsätzlich aus sozial marginalisierten Schichten stammen, bedeutet dies, dass sie Zugang zu sozialer Unterstützung und Gesundheitsversorgung haben, der ihnen als sozial marginalisierte, lesbische oder bisexuelle Frauen ohne HIV/AIDS nicht zugänglich wäre. In diesem Sinne haben die kollektiven Strategien des Sich-zur-Wehr-Setzens gegen HIV-bezogene Stigmatisierung praktisch zur Folge, dass Klassen-/Schichten-spezifische Nachteile teilweise ausgeglichen werden.

Kapitel 4 Ergebnisse: Mehrfachstigmatisierung managen

Das vierte Kapitel geht genauer darauf ein, wie die Frauen mit ihrer Mehrfachstigmatisierung umgehen. Ihre Stigma-Management Strategien lassen sich in drei Kategorien unterteilen. Die erste Kategorie beinhaltet Strategien, mithilfe derer die Frauen versuchen, Stigmatisierungserfahrungen vorzubeugen. Sie versuchen zu vermeiden zum Ziel von Stigmatisierungsprozessen zu werden, indem sie ihre Homo- oder Bisexualität, Drogenerfahrung und HIV Infektion geheim halten oder indem sie stigmatisierte Verhaltensweisen wie Sex mit Frauen oder Drogengebrauch unterdrücken oder einschränken. In Bezug auf das Stigma, das HIV/AIDS anhaftet, beschreiben sie, wie sie sich in den Jahren nach ihrer HIV Diagnose selbst isoliert haben, teilweise als Reaktion auf die Nachricht einer so schwerwiegenden Erkrankung, und teilweise aus Angst vor Stigmatisierung. Dies war vor allem bei Frauen der Fall, die kurz nach der Diagnose schwere Stigmatisierung erlebt haben. Die Frauen beschrieben außerdem wie sie zu einzelnen Menschen auf Distanz gingen, wenn sich diese als vorurteilsbelastet entpuppt hatten, während sie andere Menschen, die unterstützende Verhaltensformen an den Tag legten, gezielt in ihren Freundeskreis und ihr Versorgungssystem integrierten.

Die zweite Kategorie von Stigma-Management-Strategien umfasst solche, die darauf abzielen, die negativen Folgen von Stigmatisierung abzudämpfen. Hierzu gehört zum Bespiel das Verleugnen von Stigmatisierungserfahrungen oder der Schmerzen, die aus solchen Erfahrungen erwachsen. Manche Teilnehmerinnen spielten das Ausmaß ihrer persönlichen Betroffenheit von Stigmatisierung herunter oder haben bewusst bestimmte Themen vermieden, um den schmerzhaften Gefühlen, die dadurch wachgerufen werden, zu entgehen. Viele dieser Strategien beziehen sich auf das Sprechen über Stigmatisierung und die Selbstdarstellung im Interview. Eine Frau äußerte sich in abschätziger Weise über andere Frauen, die auch mit HIV/AIDS leben, lesbisch oder bisexuell sind und Kinder haben, so dass die Vermutung nahe liegt, sie grenze sich von andere Frauen ab, um ihrer eigenen Stigmatisierung entgegenzuwirken und ihr angeschlagenes Selbstwertgefühl wieder aufzubauen (und/oder sich in der Interview-Interaktion sich gegen mögliche Stigmatisierung zu verwahren). Dieselbe Teilnehmerin beschreibt jedoch auch, wie gut es ihr getan hat, mit anderen HIV-positiven Frauen zu sprechen und zu HIV Selbsthilfegruppen und in Therapie zu gehen. Sich in dieser Form soziale und emotionale Unterstützung zu besorgen, ist auch eine Strategie, mit der die Frauen versuchen, die negativen Folgen ihrer Stigmatisierung abzudämpfen. Weitere

Strategien beziehen sich auf die Wahrnehmung und Interpretation von stigmatisierenden Gesten. Insbesondere die häufig mit Mehrfachstigmatisierung konfrontierten Frauen beschreiben, wie sie bestimmte Gesten ignorieren und ihnen Wichtigkeit absprechen, zum Beispiel wenn sie von Menschen kommen, die nicht zu ihrem näheren Freundes- oder Familienkreis gehören. Sie stellen dies als eine Folge der Übersättigung mit Ablehnung und Ausgrenzung dar – sie haben in ihrem Leben schon so viel Abwertung erlebt, dass sie gelernt haben zwischen wichtigen und unwichtigen Interaktionen zu unterscheiden.

Die dritte Kategorie umfasst Stigma-Management Strategien, mithilfe derer die Frauen nicht ausweichen oder abdämpfen, sondern ihre Stigmatisierung kritisch infrage stellen und ihr entgegenwirken. Hierzu gehören: Sich selbst zu informieren (z.B. über die tatsächlichen Risiken, HIV zu übertragen) und Informationen an andere weiterzugeben (und dadurch überhöhte Ängste vor Ansteckung und Stigmatisierung abzubauen). Einige Teilnehmerinnen beschreiben, wie sie offensiv und selbstbewusst mit der Information über die eigene HIV Infektion, Sexualität und Drogenerfahrung umgehen und wie sie ihrer Stigmatisierung in Interaktionen humorvoll, diplomatisch oder provozierend/konfrontativ begegnen. Diese Kategorie umfasst auch kollektive Strategien, wie zum Beispiel Versorgungsstrukturen aufzubauen, die nicht nur intern Unterstützung geben, sondern auch nach außen hin für die Rechte der Frauen eintreten und ihre Bedürfnisse politisch artikulieren. Auch einige der lesbischen und bisexuellen Mütter mit HIV/AIDS, die an dieser Studie teilgenommen haben, haben solche Strukturen mitbegründet und/oder waren als Aktivistinnen tätig. Eine grundlegende Strategie, die für alle anderen Strategien in dieser Kategorien von wesentlicher Bedeutung ist, beinhaltet das Finden von positiver oder zumindest vielfältigerer Bedeutung in den Attributen, die mit einem Stigma behaftet sind. Um sich gegen die eigene Stigmatisierung zur Wehr setzen zu können, muss die Legitimität des Stigmas in Frage gestellt werden und dazu gehört eine alternative Interpretation der Attribute, die mit einem Makel behaftet sind. Bemerkenswert ist in diesem Zusammenhang die kreative Benutzung von Worten, die vormals zur Stigmatisierung dienten und die nun kollektiv umgedeutet und als Selbstidentifikation positiv besetzt werden.

Kapitel 5 Diskussion und Ausblick

Die Ergebnisse dieser Studie belegen die Wirkmacht der Stigmen, die im US-amerikanischen Kontext der HIV Infektion und der gleichgeschlechtlichen Sexualität von Frauen anhaften und beschreibt sie aus der Perspektive von sozial marginalisierten Frauen, die überwiegend ethnischen Minderheiten angehören. Damit wird ein wichtiger Beitrag zur Stigmaforschung geleistet, die sich bislang durch einen Mangel an Forschung mit sozial marginalisierten Personen auszeichnet. Darüber hinaus zeigt die vorliegende

Studie auf, wie Mehrfachstigmatisierung von lesbischen und bisexuellen Frauen, die HIV-positiv sind und Kinder haben, erfahren wird und welche Auswirkungen dies zum Beispiel auf die Versorgungssituation der Frauen hat. Im Kontext der HIV-Versorgungsstruktur wird vor allem die gleichgeschlechtliche Sexualität der Frauen ignoriert und stigmatisiert. Dies führt dazu, dass wichtige Informationen bezüglich der sexuellen Übertragbarkeit von HIV und anderen sexuell übertragbaren Krankheiten von Frau zu Frau nicht vermittelt werden, was sowohl die Gesundheit und das Leben der Frauen als auch ihrer Partnerinnen gefährdet. HIV-positive, bisexuelle und lesbische Frauen und ihre Familien werden in der Versorgung diskriminiert und von bestimmten Leistungen ausgeschlossen, die für heterosexuelle Paare und Familien zugänglich sind. Darüber hinaus werden Möglichkeiten zu einer umfassenderen Unterstützung der Frauen versäumt und statt dessen die Geheimhaltung der gleichgeschlechtlichen Sexualität gefördert. Innerhalb und außerhalb von Versorgungsstrukturen führt die Verflechtung von HIV-bezogener, sexualitätsbezogener und drogenbezogener Stigmatisierung zu einem hohen Ausmaß an Schuldzuschreibungen an die Frauen, die sich zu allen drei stigmatisierten Attributen bekennen. Mögliche Unterschiede zwischen der Stigmatisierung lesbischer und bisexueller Frauen mit HIV/AIDS müssen jedoch genauer untersucht werden.

Die soziale Marginalisierung der Frauen wird in zweierlei Hinsicht im Kontext ihrer Mehrfachstigmatisierung relevant: a) sie bringt eine Vielfältigkeit an Problemstellungen mit sich, denen sich die Frauen in ihrem Alltag gegenübersehen, was dazu führt, dass Stigmatisierungserfahrungen nicht immer einen zentralen Stellenwert besitzen, sondern von anderen Problematiken überschattet werden; und b) dass Stigmatisierung überwiegend in den ethnischen Gemeinschaften (communities) der Frauen erfahren wird. In diesem Zusammenhang wird die Frage diskutiert, wie die Kommentare einiger Teilnehmerinnen zu deuten sind, dass HIV/AIDS besonders stark in schwarzen communities stigmatisiert sei und sich Hispanic communities durch ein hohes Maß an Stigmatisierung im Zusammenhang mit dem Stigma, das gleichgeschlechtlicher Sexualität anhaftet, auszeichnen. Studien, die Einstellungen zu HIV/AIDS und gleichgeschlechtlicher Sexualität in der breiteren Bevölkerung untersuchen, finden keine eindeutigen Unterschiede in der Prävalenz stigmatisierender Einstellungen zwischen ethnischen Gruppen. Andere Studien mit Angehörigen ethnischer Minderheiten bestätigen jedoch die Ergebnisse der vorliegenden Untersuchung, dass einige Frauen Stigmatisierung als besonders stark in ihrer ethnischen Minderheit wahrnehmen. Verschiedene Erklärungsansätze werden diskutiert. Es ist möglich, dass die Erfahrungen der Frauen darauf hindeuten, dass bestimmte soziale Normen in diesen communities tatsächlich stärker ausgeprägt sind und damit zu größerer Stigmatisierung führen. Es ist jedoch auch nachvollziehbar, dass die Frauen ihre eigenen communities besser kennen als andere und nicht einen Vergleich zwischen ethnischen Gruppen anstreben, sondern vermitteln wollten, dass sie in ihren Communities stark von Stigmatisierung betroffen sind. Diese Sichtweise wird auch dadurch unterstützt, dass Stigmatisierung in ihrem engeren sozialen Umfeld als schmerzhafter wahrgenommen wird im Vergleich zu Stigmatisierung durch Menschen, denen sich die Frauen nicht nahe fühlen oder von denen sie nicht abhängig sind.

Interessanterweise finden sich in dieser Studie sowohl Beschreibungen von sehr starken Stigmatisierungserfahrungen als auch Aussagen, dass Teilnehmerinnen persönlich nur kaum oder gar nicht von Stigmatisierung betroffen seien. Dieses Ergebnis bereichert die eingangs erwähnte Diskussion um Wachsamkeit („vigilance“) versus Minimisierung von persönlicher Diskriminierung. Diese Studie legt nahe, dass Stigmatisierungserfahrungen mitgeteilt werden, wenn Teilnehmerinnen ein Bedürfnis haben, die Ungerechtigkeit, die ihnen widerfahren ist, zu artikulieren oder zu dokumentieren (zum Beispiel um den Status quo zu ändern), und wenn sie im Interviewgespräch Vertrauen aufgebaut haben. Die Aussagen von Teilnehmerinnen, nicht oder nur begrenzt persönlich zum Ziel von Stigmatisierung geworden zu sein, veranschaulichen hingegen zum einen die Heterogenität der Stigmatisierungserfahrungen der Frauen, die in unterschiedlichen sozialen Welten unterschiedlich viel Stigmatisierung erfahren und dies auch durch den gezielten Einsatz von Stigma-Management-Strategien mit beeinflussen können. Gleichzeitig deuten manche Aussagen im Kontext der Interviews auch darauf hin, dass situationsbezogene Faktoren wie narrative Motivationen und das Bedürfnis sich selbst und andere in einem positiven Licht darzustellen, dazu führen können, dass Stigmatisierungserfahrungen unerwähnt bleiben, als geringfügig dargestellt oder umgedeutet werden. Diese Erkenntnis verweist auf den kommunikativen Charakter interviewgestützter Daten. Der institutionelle Kontext des Interviews, die verwendeten Methoden, der Rapport zwischen Interviewer und Teilnehmern, die allgemeine Verfassung und Tagesform der Teilnehmer, sowie deren spezifisches Erinnerungsvermögen und narrative Ziele im Interview sind wichtige Einflussfaktoren, die die Darstellung der eigenen Stigmatisierungserfahrung wesentlich mitbestimmen. Stigmatisierung ist zudem nicht nur Thema des Interviews, es ist auch ein strukturierendes Element in der Interviewinteraktion. Dieser Aspekt ist bislang in der Stigmaforschung unzureichend reflektiert worden. Weitere Studien sind von Nöten, in denen die Auswirkungen des Sprechens über Stigmatisierung und die Zusammenhänge zwischen Stigmatisierung als Thema und dem aktuellen Managen der eigenen Stigmatisierung in Interviewinteraktionen stärker beleuchtet werden. Dazu bieten sich interpretative Ansätze an, die konversations- oder dialoganalytisch vorgehen.

Diese Studie legt außerdem nahe, dass Stigmaforschung ein größeres Augenmerk auf die emotionale Befindlichkeit der Menschen legen muss, die Ziel von Stigmatisierungsprozessen sind. Die emotionale Verfassung prägt sowohl das Erleben von Stigmatisierung als auch dessen Interpretation und Darstellung im Interview. Dieser Aspekt blieb bislang in der eher kognitiv ausgerichteten sozialpsychologischen Stigmaforschung als auch in Arbeiten in der Tradition des symbolischen Interaktionismus unterbelichtet. In der sozialpsychologischen Forschung werden Emotionen in erster Linie als Resultat, aber nicht als konstituierender Faktor von Stigmatisierung thematisiert. In Arbeiten in der Goffmanschen Tradition wird hingegen davon ausgegangen, dass es immer eine emotionale Verletzlichkeit gibt, das heißt, dass stigmatisierte Menschen immer die negativen Sichtweisen übernehmen und zum Beispiel Scham verspüren. Die vorliegende Studie legt nun nahe, dass es statt dessen eine Vielzahl psychologischer Möglichkeiten der Verarbeitung und Abwehr der eigenen Stigmatisierung gibt, dass aber bestimmte affektive Faktoren, wie die Verunsicherung nach dem Verlust einer geliebten Person oder der Erhalt einer schwerwiegenden Diagnose zu einer besonderen Verletzbarkeit gegenüber Stigmatisierung führen und sich dies auch in größerer Selbst-Stigmatisierung ausdrückt. Zukünftige Stigmaforschung steht vor der Aufgabe, einen umfassenderen Subjektbegriff zu entwickeln und der Mannigfaltigkeit der psychologischen Wahrnehmungs- und Umgangsformen mit der eigenen Stigmatisierung besser gerecht zu werden.

Die vorliegende Untersuchung zeigt zudem, dass bisexuelle und lesbische Mütter, die mit HIV/AIDS leben, einer Mehrfachstigmatisierung ausgesetzt sind, die für viele dieser Frauen einem andauernden, vielschichtigen Angriff auf ihr soziales Ansehen und ihr Selbstwertgefühl gleichkommt. Die Frauen begegnen ihrer Stigmatisierung aktiv, sie können sich den negativen Folgen ihrer Mehrfachstigmatisierung jedoch nicht vollständig entziehen. Diese Studie beinhaltet spezifische Limitationen, die sich aus der lokalen und zahlenmäßigen Begrenztheit der Studie und der Zusammensetzung des Samples ergeben. Die Stärke der Arbeit liegt jedoch in dem durch die qualitativen Methoden ermöglichten Zugang zur subjektiven Erfahrungswelt der Teilnehmerinnen. Qualitative Forschung erhebt nicht den Anspruch, endgültige Wahrheiten oder Antworten zu produzieren, es geht viel mehr darum, Sinnzusammenhänge zu erkennen und Fragen zu entwickeln. In dieser Studie wurden Fragen aufgeworfen zu der spezifischen Situation der untersuchten Frauen und ihren Versorgungsbedürfnissen, sowie zu methodologische Implikationen interviewgestützter Daten zu Stigmatisierung und Stigmaforschung im Allgemeinen. In diesem Sinne stellen diese Ergebnisse eine Aufforderung zu weiteren Studien dar, die diese Fragen aufgreifen und den Erkenntnisprozess weiterführen.

Contents

Acknowledgements

I would like to thank the women who participated in this study and so generously shared their knowledge and personal experience with me. My gratitude goes particularly to the HIV-positive participants who invited me into their homes and told me their life stories. Living in New York City is tough, even if you are not a woman of color who is raising children with limited financial resources while having a stigmatized sexual orientation and managing a life-threatening disease. I am impressed by these women's achievements - my deepest respect and many thanks for your time, trust, and humor.

I am grateful to the HIV Center for Clinical and Behavioral Studies at the New York State Psychiatric Institute and Columbia University. The HIV Center provided not only financial support, but also an important research infrastructure. In particular, I would like to thank Prof. Dr. Anke A. Ehrhardt for acting as my mentor and second reader; Dr. Patricia Warne for her help with communication, grants and IRB applications; Dr. Joyce Hunter for having an activist heart in the midst of academia; Dr. Pamela Collins for our discussions of stigmatization processes; and the many others who provided me with feedback and support, including Vanessa Haney, Gary Dowsett, Rita Melendez, Vicky Mays, Alan Berkman, Susie Hoffman and Jan Murphey. A second, community-based organization in NYC deserves my whole-hearted gratitude: Gay Men's Health Crisis (GMHC). This study would simply not have happened without it. I am greatly indebted to its then Director of Women and Family Services, Talata Reeves, who provided the initial impulse for this study and became a close advisor and friend. Thanks also go to Dr. Marjorie Hill and the other staff members and clients at GMHC and LAP who have supported this project at different points in time. Michelle Lopez has also been a true inspiration.

I am grateful to my main supervisor at the University of Hannover, Prof. Axeli Knapp, for her constructive criticism and thoughtful guidance over the years. Thanks as well to Drs. Mechthild Bereswill and Rolf Pohl and to the members of the Kolloquium for their support. Prof. Mindy Thompson-Fullilove at Columbia University has been a formidable teacher. Her qualitative writing group has provided intellectual life-support and has confirmed my belief that good science is compatible with a sense of social justice. Special thanks go to Kevin, Craig, Lourdes, Aana and the other members of the writing group for their friendship, feedback and support. Many more friends and loved-ones have provided crucial support, most notably Elke Bosse and Anke Neuber, Moritz, Asta and Franziska, Chucha, Milton, Marcela, Wiebke, Karyn, Kris, Bernhard, as well as my father, my stepmother and my mother. I would like to thank Betty Kulleseid, Peter Stone, Simon Garner and Alex Frith for inspiring discussions about the English language and for helping me find the right words. And last but not least, Gusta for being there and supporting me with tremendous love and patience during the most difficult phase of the work. Thank you.

Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CDC	Centers for Disease Control and Prevention
GMHC	Gay Men’s Health Crisis, community-based HIV organisation in New York
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
LAP	Lesbian AIDS Project, program at GMHC for women who have sex with women
LGBT	Lesbian/Gay/Bisexual/Transgender
NYC	New York City
STD	Sexually Transmitted Disease
WSW	Women who have Sex with Women

Introduction

When a community-based service provider articulated a need for research on lesbian and bisexual mothers with HIV/AIDS, this provided the inspiration for the current study. In the fall of 2000, Joyce Hunter, community liaison at the HIV Center for Clinical and Behavioral Studies at Columbia University and New York State Psychiatric Institute, approached me with an invitation to collaborate. Talata Reeves, director of women and family services at Gay Men's Health Crisis (GMHC), a large community-based HIV organization in New York, had approached her with the idea of conducting a needs assessment study of lesbian mothers with HIV/AIDS. These women were part of the client base at GMHC but their social support and service needs were not fully understood. A recent service utilization study had revealed that in the past year alone almost 300 women who considered themselves lesbian or bisexual had utilized services at GMHC. Three quarters of these women disclosed a positive HIV status, but only 19% had been in contact with the Lesbian AIDS Project (LAP), a program at GMHC specifically meant to provide social support, information and HIV prevention services to women who have sex with women (Fitzsimmons, 2000). The study report suggested that the current configuration of services of the Lesbian AIDS Project might not meet these women's needs. It concluded that a study was needed to assess the service needs of lesbian and bisexual women with HIV/AIDS and that their parenthood-related needs and concerns should be taken into account.

I joined Talata Reeves and Joyce Hunter in planning a needs assessment study and decided to conduct an additional, smaller study to focus on a specific aspect of these women's experience, namely their multiple stigmatization. Having previously studied HIV positive women's management of HIV related stigma in Germany (von Unger, 1999), I was interested to find out how these women in New York managed their multiply stigmatized status. I was aware of the missing conceptualization of multiple stigmatization in stigma theory and I also suspected that a study on stigmatization might help illuminate problems in the provision and utilization of HIV related services. Very little research addresses the situation of HIV positive, lesbian and bisexual women, and no study to date takes their parent status or their stigmatization experience into account. The little research available shows that these women are a highly marginalized group. Most bisexual and lesbian women with HIV/AIDS are low-income women of color with drug use experience. They are potential targets not only of the stigma attached to HIV/AIDS, but also of the stigmas attached to their same-sex sexuality, and possibly their drug use and criminal records. Studies show that stigmatization has adverse effects on the social standing and psychological well-being of its targets and that it can hamper social and medical service provision. I thus decided to explore how the multiple forms of stigmatization intersect in the lives of bisexual and lesbian mothers with HIV/AIDS and how this influences their relationships to partners, family members and service providers. The HIV Center for Clinical and Behavioral Studies agreed that the project was worthwhile, thus granting me support, and when I also received permission to proceed with my Ph.D. at the University of Hanover, I commenced this collaborative project in 2001.

Approximately 88,000 women currently live with HIV/AIDS in the United States and every year more than 7,000 women are newly diagnosed with HIV or AIDS. Large studies find that one out of five women with HIV has had sex with another woman and at least one out of ten identifies herself as bisexual or lesbian. This suggests that a considerable number of HIV positive, bisexual and lesbian women exist whose service needs might be of importance for a range of health and social service providers. How many of these women are also parents cannot be determined because no data on children or care-taking responsibilities exist for this group. My field experience suggests that many, if not most, lesbian and bisexual women with HIV/AIDS fulfill parenting roles for biological or non-biological children or have done so in the past.

In this text, I mainly speak of “parenthood” rather than “motherhood,” for a number of reasons: Motherhood is a value-laden term that carries strong connotations of heterosexuality, female gender and gender roles. It also presumes a naturalized biological connection to a child which is not always the case. This study shows various forms of parenthood in lesbian and bisexual women with HIV/AIDS, from biological to non-biological, from legally recognized to informal ones. It is important to acknowledge this diversity as many same-gender loving women who raise children together have at least one parent without biological ties to the child (this is especially the case for lower-income women who might not use modern reproductive technologies to get pregnant). However, with these considerations in mind, I also use the terms “mother” and “motherhood” at times, mainly to claim the concept for those participants who very much consider themselves mothers, whether the children they raise are biologically theirs or not.

Before introducing the chapters of this dissertation, I would like to address a topic that is not at the forefront of this study, but an implicit motivation for conducting it, namely the desire to change stigmatizing views. By focusing on women’s experience of multiple stigmatization, I aim to address a pressing concern in the field of service provision to HIV-positive women and to contribute to academic discourses on stigma theory. However, I also intend to continue a tradition of social psychology that dates back to researchers such as Kurt Lewin whose work aimed to diminish prejudice and racial discrimination in the United States. Part of my motivation to conduct this study is to create knowledge that can be used to initiate social change. This commitment to social justice did not escape my interview partners. For example, Frances was an African-American woman with HIV who raised her three children in a project in Queens. At the end of our interview, she asked me why I was conducting this study. I told her to gain a better understanding of how HIV-positive women are affected by a combination of prejudices and that I hoped this work will eventually help diminish the prejudice. Frances' response was respectful, but skeptical. She pointed out,

> Okay, but you know what? (…) You've always got some sick, ignorant people that is just going to think and believe what they want to think and believe anyway. So I mean it's good that you're trying to get an insight on how to make the ignorance get knowledge, but sometimes it's just some ignorant people just going to stay ignorant, and they don't want to try to understand. They want to discriminate. (PS10: 1371-81)

Frances' words illustrate the perceived resistance to change. Her rather pessimistic assessment was accompanied by careful efforts to keep her HIV status and her same-sex sexual experience secret in her personal life. Other participants were more optimistic that stigmatization can be overcome, and stated that this hope was one of their reasons for participating in this study. More than one participant explained that they themselves had undergone a process of becoming more aware of their own prejudice and more accepting of their own and other women's HIV infection and same-sex sexuality. For example, Molly described a learning process with regards to the stigma attached to women's same-sex sexuality.

> I used to be scared to death of lesbians. My mother taught me..I swear to God, my mother taught me that a woman would turn every which way but loose. She said, "You don't want to be one of them." And I went to prison, (…) and here I was placed in an environment where being a lesbian was the thing to be, where it was okay. Where nobody questioned it. Nobody second-guessed it. They didn't look down on you. It was okay. And I used to run groups, and I used to ask the women, "Help me to understand!" Because I was sleeping with [mock ringers?] underneath my bed because I was scared somebody was going to get me in the middle of the night. And then I learned that people are people and that their sexual orientation has nothing to do with who they are as a person. (PS08: 977-89)

Since her release from jail, Molly has started to explore her own same-sex sexuality and she now considers herself bisexual. Her story illustrates the potential for change, but it also highlights the starting position of stigma and fear. The current study does not aim to illuminate the perspective of those who stigmatize others, it is first and foremost about the experience of being the target of stigmatization, while acknowledging that the two can be connected. Social psychology has a long tradition of investigating processes of social exclusion, and the great majority of this work focuses on those who hold prejudiced views and stigmatize others. This study, on the other hand, highlights the experience of the targets of prejudice and discrimination. It is about women (like Frances and Molly) who are stigmatized on the grounds of their same-sex sexuality, (former) drug use and their HIV infection while having children in their care.

In the first chapter of this dissertation, I present the conceptual framework of stigma. Erving Goffman's original definition of the term is critically examined and more recent conceptual developments in social psychology are described. I distinguish between stigma, stigmatization, and its social and psychological consequences. Stigma refers to the negative meanings attached to a specific attribute or behavior in a particular social and historical context. As a discoursive phenomenon, it represents a special constellation of prejudiced and at times contradictory views and interpretations that prevail in a given society, setting or subculture. Stigma is constructed through images and language and provides a frame of reference and orientation for social actors. Stigmatization, on the other hand, entails the social processes whereby a stigma is applied to a specific group or person. It refers to social interactions during which individuals are devalued and rejected based on negative stereotyping and attributions of blame and moral flaws. The terms stigmatization and discrimination overlap, but given its focus on face-to-face interactions, stigmatization lacks the focus on institutionalized structures of exclusion that discrimination entails while discrimination does not include the attribution of moral taint and blame that the term stigmatization captures. Consequences of stigmatization can include social distance and mental distress for the targets of stigma. However, such outcomes are not predetermined as processes of stigmatization can be interrupted and reversed at any time and both process and outcomes are influenced by the target's use of coping strategies.

A limitation of the stigma framework is its inadequate conceptualization of the subject's internal world and capacities. In Goffman's work, a symbolic interactionist view of the self as "mirror self" prevails and individuals seem to be mere reflections of their environments. Consequently, the diversity of psychological responses to stigmatization and the targets' potential for individual and collective resistance are underestimated. In more recent conceptualizations of stigma in social psychology, stigmatization is viewed as more dynamic and flexible, but a focus is placed on cognitive processes of the targets of stigma and the role of emotions is neglected. After thus outlining the strengths and limitations of the stigma concept, I review the literature on the specific social stigmas attached to women's same-sex sexuality and HIV infection.

In the second chapter, I describe the methods of data collection and analysis and the sample of women who participated in the study. I conducted a qualitative study following Grounded Theory guidelines. A three-step study design enabled me to enter the field carefully. I first spoke to key informants who were familiar with the topic based on their professional, activist and/or personal experience. Secondly, I screened 29 women who were HIV-positive, had same-sex sexual experience and were also parents. Finally, in a third step, I selected nine participants for repeated in-depth interviews. I asked women about their experience of stigmatization in the context of their life histories. I decided to use an open, narrative interview format to give them room to express their experience in their own words and to discuss topics that were important to them. As communication based data, narrative accounts are necessarily influenced by the interaction in which they are created. I thus reflect on my specific positioning in the field and its effects on interview interactions and participants' accounts of stigmatization.

In chapter 3 and 4, the findings are presented, commencing with how participants described the stigmas attached to their same-sex sexuality, drug use and HIV/AIDS. Each stigma entails negative stereotypes, attributions of blame and notions of danger. The latter is of particular relevance in the context of women's parenthood. Their HIV infection is viewed as a threat to their children as an HIV-positive mother might transmit the virus to her child or not live long enough to raise it. Participants who openly admit to their same-sex sexuality are discouraged from raising their children because their same-sex sexuality is perceived as a threat to children's social, sexual and emotional development. The greatest challenge to the welfare of the children is perceived to lie in women's substance use. Drug using mothers are thought to neglect and abuse their children and many participants had lost or transferred custody rights when they were in active addiction. The combination of stigmas constitute a multi-layered challenge to the parent status of the women. Interestingly, being a parent seems to amplify stigmatization processes, yet at the same time it provides a counterbalance. Parenthood represents one of the few socially redeemable identities of the women and ties to biological children as well as parenting skills can protect them from harsher punishment and rejection from their family networks.

As this study focuses on the subjective experience of being stigmatized, the active involvement of the targets of stigma are at the center of attention. The fourth chapter therefore focuses on participants' strategies of managing and resisting their multiple stigmatization. Strategies are grouped into three categories: a) strategies with which women avoid becoming a target of face-to-face stigmatization, b) strategies with which they buffer the negative consequences of their stigmatization, and c) strategies with which women actively challenge their stigmatization.

The final, fifth chapter discusses these findings in the context of existing literature. I confirm other studies of women with HIV/AIDS in that stigmatization constitutes a serious problem, but not the only one. Realizing that HIV-positive, lesbian and bisexual mothers experience multiple stigmatization in the context of social marginalization is of crucial importance. Multiple stigmatization places a serious strain on the women, but it is not always their most urgent concern. Raising children in an inner-city environment, finding safe and affordable housing, making do with limited income, staying healthy while managing the medical aspects of their HIV infection and maintaining their recovery from substance use; all of these aspects often take precedence over concerns to do with experienced or anticipated stigmatization based on their same-sex sexuality, drug use or HIV infection. However, multiple stigmatization creates serious additional problems and often exacerbates these aspects of their lives.

In the context of HIV service provision, the stigma attached to women's same-sex sexuality constitutes a major problem. Lesbian and bisexual women encounter denial and prejudice from service providers and HIV positive peers and they often feel compelled to keep their same-sex sexuality private. They have difficulties getting the information and tools they need to prevent the transmission of HIV (and other sexually transmitted diseases) during sex with female partners. This involves a serious health risk, not only to their female partners, but also to the women themselves for whom any re-infection or co-infection can constitute a serious health threat given their already damaged immune system. Women's female partners are often not included in their care and a number of family-based support services discriminate against them as same-sex couples and families. The extent of stigmatization based on women's same-sex sexuality in the context of HIV service provision and peer support networks might seem surprising given the achievements that have been made with regard to creating an accepting environment for gay men with HIV/AIDS. A number of factors seem to contribute to this imbalance, including the smaller numbers of bisexual and lesbian women with HIV/AIDS and the more marginalized position of HIV-positive women in general, but findings from this study strongly suggest that existing stigma-related deficits in service provision must be addressed.

The discussion also focuses on a methodological insight of this study. When collecting and analyzing data on stigmatization experiences, it is important to reflect on the various components that influence the construction of stigmatization accounts. Women reconstructed their life stories in the interview. In order to do so they used certain words and narrative elements that some of them might have used before. In other words, in some cases, a history of storytelling had been formed in other contexts and was being repeated or reused once again. For example, some women had participated in drug treatment programs and used the interview as another opportunity of telling their story as they previously told or would tell them in an *Narcotics Anonymous* or *Alcoholics Anonymous* meeting. However, at the same time, interview accounts are always unique. They are today's interpretations of the present and past, and the social and situational context of the interview affects that which is told. Participants assessment of the interviewer and her or his social status, experience, and attitudes is important for how they relate their story. Furthermore, the methods used by the interviewer obviously influence the data that is collected. When analyzing stigmatization accounts, the researcher has to ask a number of questions: when participants describe an incident of stigmatization, did they perceive it as such when it occurred or do they interpret it differently now, in retrospect? How much does the interview interaction influence that which is told, how it is told and how it is interpreted, i.e. how actively are the interviewers involved in “creating” stigmatization accounts by the way they ask their questions and probe? How do issues such as social distance, trust, social desirability and concerns to do with self-presentation affect the interview conversation and participants’ accounts of their stigmatization experiences? Instead of assuming that there is a fixed set of incidents or experiences that can be accessed by the participant at will to be documented by a researcher as neutral observer, research on the perspective of the targets of stigmatization has to take the interpretative nature of experience into account and the influence of the social and situational context in which accounts of this experience are produced.

As an exploratory, qualitative study, this study does not aim to provide final answers, but rather to search for a greater understanding of a new subject matter. More than one interpretation of the data is possible, and the findings of this study do not pretend to answer the research questions once and for all, but to produce provisional conclusions that stimulate further research studies and more refined questions. The distinguished African-American anthropologist Zora Neale Hurston (1942) once noted, “Research is formalized curiosity. It is poking and prying with a purpose.” In this spirit, the current study hopes to contribute to a better understanding of multiple stigmatization processes and its effects on lesbian and bisexual mothers with HIV/AIDS.

Chapter 1 Background

This chapter provides an overview of stigma research and theory as it relates to the situation of lesbian and bisexual mothers with HIV/AIDS. I commence with a brief socio-demographic profile of this group of women whose experience of multiple stigmatization is the central focus of this study. In a second step, the concept of stigma as introduced by Erving Goffman and further developed in social psychology is elucidated. The remaining sections of this chapter review relevant literature on the specific stigmas attached to women's same-sex sexuality and HIV infection. These two stigmas have been studied separately, but not yet in tandem, as this research study aims to do.

1 The social problem

1.1 HIV/AIDS in women in the United States

Every year, more than 7,000 women are diagnosed with *Human Immunodeficiency Virus* (HIV) or the more progressed state of the disease, *Acquired Immunodeficiency Syndrome* (AIDS), in the United States (Centers for Disease Control and Prevention, 2004). HIV/AIDS disproportionately affects members of ethnic minorities and it has become the leading cause of death among African-American women ages 25-34 (National Center for Health Statistics, 2003). Almost 80% of the approximately 88,000 women currently living with HIV/AIDS in the United States are either African American or Latina (Centers for Disease Control and Prevention, 2004).

Research shows that these women are highly marginalized (Farmer et al., 1996). The majority of HIV positive women are low-income women of color who are subject to myriad stressful life events (Campbell, 1999; Moore et al., 1999). Their HIV infection is not always their single most important concern, it often represents only one item on a long list of problems (Ward, 1996). HIV positive women report that violence, separation from their children, poverty, drug use and housing needs constitute more urgent and significant matters than their HIV infection (Ciambrone, 2001; Mizuno et al., 2003; Smith et al., 2001). However, dealing with a life-threatening illness that is also highly stigmatizing adds a significant amount of stress to their lives (Siegel & Lekas, 2002). Struggling to meet various life demands - including raising children in low-income, inner-city environments - HIV positive women report increased levels of mental health problems such as major depression, substance use and post-traumatic stress disorder (Bing et al., 2001; Mellins et al., 1997; Murphy et al., 2002).

1.2 Limited knowledge about HIV positive women's same-sex sexuality

The sexual diversity among HIV positive women has received only scant attention. Large cohort studies of HIV positive women find that 19% have a lifetime history of sex with women and 11-12% identify as bisexual or lesbian (Barkan et al., 1998; Zierler et al., 1999). The rate of women's same-sex sexuality appears to be even higher in large urban centers such as New York City where 32% of HIV positive female participants in one study report lifetime same-sex sexual experience (Simoni et al., 2000).[1] National rates of women's same-sex sexual experience are unavailable as this information is missing in half of the case reports on women with AIDS at the Centers for Disease Control and Prevention (CDC NPIN, 1999).

Data on HIV positive women's same-sex sexual behavior is not consistently collected. This is in part due to the fact that sex between women is considered a negligible route of HIV transmission. Most HIV positive lesbian and bisexual women acquire their HIV infection through drug use or sex with men, not through sex with women (Chu et al., 1990; Kennedy et al., 1998).[2] HIV can be transmitted sexually from woman to woman – this was recently proven when a genotype test revealed matching viral strains of two

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[1] In the HIV Epidemiologic Research Study (HERS; N=869), 6.7% of HIV positive women identified as bisexual and 4.3% as lesbian (Zierler et al., 1999). Similarly, the Women's Interagency HIV Study (WHIS; N=2,058) found that 8% of HIV positive female participants identified as bisexual and 4% identified as lesbian (Barkan et al., 1998). Rates of HIV positive women's same-sex sexual experience vary greatly from study to study, ranging from 5,8% (of 1122 women with HIV/AIDS recruited in nine different states, Chu et al., 1994) to 11% (of women testing positive at four New York State testing sites in 1993-94; Shotzky, 1996) to 55% (of HIV positive female injection drug users in NYC; Ehrhardt et al., 1995). Some of these differences are due to different sample compositions (e.g. drug users vs. non-drug users) or different time frames for which same-sex behavior were assessed (e.g. in the past 5 years vs. lifetime). Overall, information on HIV positive women's same-sex sexual behavior is extremely scarce in comparison to same-sex behavior in HIV positive men. At times, available information is inconsistent (see for example the inconsistent reports of same-sex sexual experience of HERS participants in Moore et al., 1996; Kennedy et al., 1998 and Zierler et al., 1999). The suboptimal state of research reflects the generally low priority of women's same-sex sexuality in HIV surveillance and prevention. The CDC, for example, has published only one fact sheet on the topic (CDC NPIN, 1999) – and the information provided on this fact sheet has not been updated since 1999.

[2] Estimates of how many women acquire their HIV infection through sex with women versus through other routes of transmission are confounded by the risk hierarchy applied in HIV surveillance data (Denenberg, 1990). A woman's HIV transmission route is determined by the providers assessment of the *one most likely* route of transmission. Most HIV positive, lesbian and bisexual women report multiple risk behavior such as unprotected sex with men, injection drug use and unprotected sex with women. They will, however, be listed in only one risk category. The CDC explain their procedure as follows, they select "from the presumed hierarchical order of probability the 1 risk factor most likely to have been responsible for transmission. (…) Persons with more than one reported risk factor for HIV are classified in the transmission category listed first in the hierarchy" (Centers for Disease Control and Prevention, 2004: 42). Since injection drug use involves the highest probability that HIV can be transmitted (followed by heterosexual contact), a woman who has had sex with another woman *and* injected drugs will be classified under "injection drug use" only, even if she never shared needles or paraphernalia. There is not even a risk category for female-to-female sexual contact. HIV positive women whose only HIV risk factor is sex with another woman will be listed under "other/ risk factor not reported or not identified," a category that contains 17% of all AIDS cases in women (Centers for Disease Control and Prevention, 2004).

female partners (Kwakwa & Ghobrial, 2003) - but sex between women does not constitute a main route of HIV transmission.[3] The resulting lack of epidemiological interest (which stands in stark contrast to the high level of interest in same-sex sexual practices among men which contain a higher risk of HIV transmission) is partially responsible for the inadequate documentation of same-sex sexuality in women with HIV/AIDS. Other factors include hetero-normative assumptions on the part of medical professionals who do not consistently collect the information, and a reluctance of HIV positive women to report same-sex sexual behavior for fear of stigmatization (CDC NPIN, 1999).

Recent years have seen a slight increase in research on HIV positive women who have sex with women (WSW). This category refers to all women who have same-sex sexual experience, independent of how they identify themselves in terms of sexual identity categories (e.g. lesbian, bisexual, heterosexual).[4] Studies show that HIV positive women who have had sex with women are even more marginalized than the general population of HIV positive women: having particularly high rates of substance use (Kennedy et al., 1998; Young et al., 2000), they experience incarceration, violence, sex work and homelessness more frequently than HIV positive women who have never had sex with a woman (Friedman et al., 2003; Moore et al., 1996).

Studies on the mental health and well-being of HIV positive women with same-sex sexual experience are limited by small sample sizes and conflicting results: one study finds that HIV positive lesbians experience higher levels of psychological distress, anxiety and major depression than their heterosexual counterparts (Prado et al., 2002), while another study finds no differences in depressive symptoms between HIV positive women with and without same-sex sexual experience (Simoni et al., 2000). It has been suggested that the stigma attached to women's same-sex sexuality leads to poor mental health

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[3] Prior to the recent study by Kwakwa & Ghobrial (2003) which presented a convincing proof of sexual HIV transmission from woman to woman, the topic was hotly debated. There were published cases of HIV in women who were most likely infected through sex with another woman (Chu et al., 1994; Marmor et al., 1986; Monzon & Capellan, 1987; Rich et al., 1993), but there was also evidence suggesting the risk was very low or nonexistent (Bevier et al., 1995; Petersen et al., 1992; Raiteri et al., 1998). Discussions of the topic were hampered by a lack of conclusive empirical evidence as well as by a lack of understanding of women's actual sexual practices. A noteworthy exception is Laura J. Ramos' (1997) ethnographic work which provides a differentiated discussion of women's same-sex sexual practices and their possible risk of HIV transmission. Overall, the available evidence suggests that unprotected sexual practices between women (including oral sex, genital rubbing, sharing of vaginally inserted sex toys and certain S&M practices) contain a risk of HIV transmission, but that this risk is lower than for example unprotected sexual intercourse with a man.

[4] It is important to distinguish between women's sexual practices and their sexual self-identifications. Research consistently shows that women's sexual identity does not necessarily reflect their sexual experiences, for example most women who self-identify as lesbian have (had) sex with men and many women who desire or have sex with women do not consider themselves bisexual or lesbian (Diamant et al., 1999; Diamond & Savin-Williams, 2000; Gomez et al., 1996; Lauman et al., 1994; Rothblum, 2000; Ziemba-Davis et al., 1996).

outcomes (DiPlacido, 1998, Meyer, 2003; Mays & Cochran, 2001). However, it was also noted that coping resources and social support available in large urban centers can help prevent the negative mental health consequences of sexual stigmatization (Simoni et al., 2000).

The few existing studies on mental health in sexual minority women with HIV/AIDS apply different definitions of women's same-sex sexuality (e.g. lifetime same-sex sexual behavior vs. self-identification as lesbian) which might in part explain the different results. Researchers are only beginning to understand the situation of HIV positive, lesbian and bisexual women and more research on the topic is warranted (Mays et al., 1996; Solarz, 1999).

1.3 Parenthood – an overlooked topic

A topic in particularly dire need of research relates to parenthood among bisexual and lesbian women with HIV/AIDS. This aspect of women's lives is largely overlooked. The few studies that address HIV in women who have sex with women (WSW) tend to focus on sexual and drug related transmission risks and do not address whether women have children or fulfill parenting roles. Studies of HIV positive mothers, on the other hand, tend to presume that all mothers are heterosexual and do not document the sexual diversity in terms of same-sex sexual partners or self-identifications. No study to date bridges both domains and explores the situation of HIV positive women who have female sexual partners *and* fulfill parenting roles. For a study of women's stigmatization experiences, such as the current one, however, it is essential to take women's parenting role and status into account as the social implications of raising children might significantly affect their experience of multiple stigmatization.

Voices from the HIV community draw attention to the fact that HIV positive, lesbian and bisexual mothers exist (Acain, 2001; Broun, 1999; Hollibaugh, 1993; Hunter & Alexander, 1996; Porter, 1998; People with AIDS Coalition of New York, 1996). A special issue of Newsline from the People with AIDS Coalition of New York (1996) is dedicated to HIV positive lesbians, and many of the women portrayed have children. Their discussion covers a wide range of topics from the medical aspects of living with HIV disease and safer sex concerns to the lack of support and the difficulties of feeling isolated from the lesbian community. Illustrating the perception that the identities of being HIV positive, lesbian and a mother are at odds with each other, one participant is quoted as saying, "I identify myself as lesbian, *yet* I am HIV positive and I also have a daughter" (People with AIDS Coalition of New York, 1996: 9; my emphasis). The reluctance to acknowledge HIV infections in lesbian women has been described in the literature (Hollibaugh, 1993; Stevens, 1993). When these women are also mothers, they seem to inhabit an even more unfathomable subject position, and the women portrayed in the Newsline publication describe being the target of denial, prejudice and exclusion.

Stigmatization as lesbian and bisexual women might also affect HIV service provision and social support in the HIV community. A community based service provider in New York City notes that many of its self-identified lesbian and bisexual clients with HIV/AIDS are mothers who are concerned about custody issues, in particular about resuming a parental relationship with their children after a period of incarceration (Fitzsimmons, 2000). A striking majority of these clients do not access lesbian-specific services at the provider. Given that women's same-sex sexuality is (still) stigmatized in the United States, sexual stigmatization, or fear thereof, might be partially responsible for women's underutilization of these services.

This study aims to explore women's experience of stigmatization. It focuses on the perspective of lesbian and bisexual mothers with HIV/AIDS, that is a subgroup of HIV positive women which is particularly prone to high levels of stigmatization. Both their sexual minority status and their HIV infection carry a social stigma and many women in this group have further stigmatizing characteristics such as low socioeconomic status, ethnic minority background, drug use experience and criminal records. Parenthood appears to be a common occurrence which may significantly affect their experience of multiple stigmatization, for example by increasing their vulnerability to stigmatization. Prior to presenting the current state of knowledge of the stigmas attached to HIV/AIDS and women's same-sex sexuality, it is necessary to first define the concept of stigma as introduced by Erving Goffman and illuminate its application, strengths and limitations in social psychology.

2 The framework of stigma according to Erving Goffman

In the past decades, the term stigma has gained widespread use in the study of processes of social exclusion. It has been applied in various disciplines including psychology (Crocker et al., 1998; Heatherton et al., 2000; Herek, 2002a; Jones et al., 1984), sociology (Link & Phelan, 2001), anthropology (Herdt, 2001; Riessman, 2000) and public health (Herek et al, 2002a; Parker & Aggleton, 2003) and it has also stimulated interdisciplinary work (Ainley et al., 1986; Herek et al., 1998). A wide variety of social phenomena as diverse as chronic fatigue syndrome (Åsbring & Närvänen, 2002), mental illness (Link et al., 1997), ethnic minority status (Dovidio et al., 2001), homosexuality (DiPlacido, 1998; Meyer, 2003), physical disability (Hebl & Kleck, 2000), drug use (Murphy & Rosenbaum, 1999) and HIV/AIDS (Fullilove, 1989; Herek, 1999; Moneyham et al. 1996; Weitz, 1990) have been described as stigmatizing.

The concept of stigma is used to analyze the negative social responses to people with these traits or conditions. It has been conceptualized as an encompassing term for the many socio-psychological components that make up processes of social exclusion (Link & Phelan, 2001; Dovidio et al., 2000) and as a mechanism involved in the production of social inequality (Parker & Aggleton, 2003). The main appeal of the concept of stigma, however, rests in its traditional focus on the perspective of the targets of prejudice and discrimination. Since introduced into social sciences by Erving Goffman in 1963, it has served to analyze the experiences of those who possess an attribute that carries a negative, morally tainted meaning which leads to their social devaluation, rejection and discrimination. Below, I present Erving Goffman's highly influential stigma framework followed by a review of more recent conceptual developments in social psychology.

2.1 Stigma as a relational concept

In *"Stigma: Notes on the management of spoiled identity,"* Erving Goffman set out to analyze "the situation of individuals who are disqualified from full social acceptance" (1963: Preface). He defined stigma as "an attribute that is deeply discrediting" (1963:3) and that, in the eyes of society, serves to reduce the person who possesses it to a morally tainted and discounted one. Drawing mainly on research on people with mental illness, physical deformities, criminal records or homosexual identity and behavior, he argued that stigma arises in face-to-face interactions when normative expectations are not met.

In social interactions, people categorize each other and carry expectations about the social identity of the other. For Goffman, "social identity" pertains not only to a person's social status and structural attributes, such age, class and occupation, it also includes personal attributes such as honesty and moral integrity (1963:2). Expectations regarding the social identity of others usually go unnoticed. They feel ordinary and "natural," until an active question arises as to whether or not they will be fulfilled. Goffman refers to anticipations regarding what and how an individual ought to be as "*virtual* social identity" and to the categories and attributes that a person is found to actually possess as "*actual* social identity" (1963:2). When a person displays an attribute that does not fit her or his virtual social identity, stigma arises. In Goffman's framework, stigma thus constitutes "a special discrepancy between virtual and actual social identity" (1963:3). The concept is relational, in other words, stigma is not a quality inherent in an attribute, it is rather an "undesired differentness from what we had anticipated" (1963:5). Theoretically, any attribute can have a stigmatizing effect, depending on its relationship to the normative expectations that are relevant in the specific social context.

2.2 Managing a "spoiled identity"

Focusing on face-to-face interactions, Goffman describes how people with stigmatized attributes experience devaluation and status loss. Further imperfections tend to be imputed based on the original one, at times in combination with positive attributes such as a supernatural sensitivity or a "sixth sense" (1963:5). Overall, stigmatized individuals are reduced to an inferior status; they are viewed as flawed and “not quite human” and their social identity is “spoiled” (1963:5).

The main strategies of managing a spoiled identity include information management and tension control. Information management is predominantly used by people whose stigmatized attribute is not readily visible. Individuals with concealable stigmas are “discreditable” (as opposed to “discredited”) and they can often prevent stigmatization through careful management of information about themselves and their stigmatizing attribute. Goffman explains,

> When his differentness is not immediately apparent (…) this is a discreditable, not a discredited, person (…). The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where.” (1963:42)

While information management can constitute a strenuous effort and risky undertaking ranging from secrecy and withholding information to taking on a different personal identity, it can successfully prevent status loss in interactions with others. A stigmatized attribute that is visible or known about on the other hand cannot be managed in this way. It usually causes uneasiness in social interactions, for both parties involved. Stares and questions as to how the condition was acquired can be perceived as intruding, making stigmatized persons feel exposed. The awkwardness of the situation causes distress and resentment, even if the other's behavior is well intended, as when they are trying to ‘help’ or when they attempt to express their sympathies.

A hallmark feature of stigmatization is thus that it creates tension, and Goffman describes that stigmatized individuals use a variety of strategies to control and release this tension. They often engage in a "tactic cooperation" with the other person by pretending that their difference is irrelevant. Goffman refers to those who stigmatize others as "normals" and describes that they commonly try to tactfully overlook the stigma, as long as stigmatized individuals refrain from demanding full acceptance (1963: 130). Other stigmatized individuals “play the clown” and reproduce stereotypes that are applied to them in humorous ways to make others laugh (1963:110). However, tension is not always eased in this way. Some stigmatized individuals respond with “defensive cowering” or “hostile bravado,” or both (1963:17). Others try to avoid tense and awkward interactions altogether by socially isolating themselves. Goffman also notes that some try to pass by hiding or correcting their “failing”, for example with the help of plastic surgery or artificial limbs (1963:9). Yet such ‘repairs’ usually do not result in the acquisition of a fully ‘normal’ status but in a “transformation of self from someone with a particular blemish into someone with a record of having corrected a particular blemish” (1963:9). Given the inherent difficulties of interacting with "normals," some stigmatized persons seek the company of supportive others who possess the same condition or who are “wise,” i.e. accepting and sympathetic towards the stigma.[5] Support from others with the same stigma and from “the wise” can provide relief. However, Goffman points out that many people with stigmatized attributes feel ambivalent about their own stigma and also towards others with the same stigma. Not all stigmatized persons thus happily embrace the company of stigmatized others or seek to participate in segregated communities.

2.3 Damage to the sense of self

Goffman describes that stigma not only spoils people's social identity but also damages their sense of self. He uses Erikson's concept of “ego identity" to describe the “subjective sense of an individual's own situation, continuity and character that she or he has come to obtain as a result of social experiences” (1963:105). He suggests that the sense of self of stigmatized individuals is necessarily damaged due to their encounters with stigmatization and endorsement of self- stigmatizing views.

> [A stigmatized person] may perceive, usually quite correctly, that whatever others profess, they do not really "accept" him and are not ready to make contact with him on "equal grounds." Further, the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility... (1963:7) [6]

According to Goffman, self-hate and self-derogation commonly accompany a stigmatized individual's awareness of the split between self and self-demands.

Goffman’s focus on face-to-face interactions and his conclusion that stigma necessarily causes damage to the sense of self of stigmatized individuals reveal his theoretical underpinnings in symbolic interactionism. As a micro-sociological and socio-psychological perspective, symbolic interactionism is concerned with the ways in which people construct meaning and activities in interaction with others (Hewitt, 2000; Prus, 1996). Social life is understood to be contingent on shared symbols, most importantly

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[5] Goffman notes that “wise” people and family members can experience “courtesy stigma” (1963:30). They can be disqualified from social acceptance because of their relation to someone who has a stigma, such as the daughter of an ex-convict who is ostracized at school.

[6] Goffman’s use of the generic “he” indicates a pre-feminist lack of awareness for language-based gender bias and sexism. Candace West discussed the issue with him and he ceased to use the generic “he” in his later works (West, 1996).

language, and it is constituted through shared processes of "meaning making" (Blumer, 1969). In the course of acquiring a language and through interacting with others, people learn to make sense of the world, including themselves. From this point of view, our sense of self is a product of interacting with the world. One of the founding fathers of this perspective, Charles H. Cooley, introduced the notion of a "looking glass self," proposing that people are "each to each a looking-glass" (1956). According to Cooley, our sense of self develops in response to how other people respond to us and to how we imagine other people perceive and judge us. We then react to these responses and anticipated responses with feelings such as pride or mortification. Our sense of self is thus irrevocably tied to and strongly influenced by other's responses to us.

This basic premise is reflected in Goffman's understanding of self. In "Presentations of Self in Everyday Life" (1959) he analyzes everyday life interactions as carefully staged performances that involve teamwork and the co-operation of the audience. He describes two aspects, a) the "performer," a fabricator of impressions, and b) the "character," the figure that the performance is designed to evoke (Goffman, 1959: 252). The self is a "performed self," located neither in performer nor character, but assigned to the character by the audience if the performance is successful:

> A correctly staged and performed scene leads the audience to impute a self to a performed character, but this imputation – this self – is a product of a scene that comes off, and is not a cause of it. The self (…) is a dramatic effect arising diffusely from a scene that is presented and (…) the crucial concern is whether it will be credited or discredited. (Goffman, 1959: 252-3)

From Goffman's point of view, the self is a collaborative effort and it's co-creation and evaluation by the audience is of central importance. Performers employ various strategies of "impression management" and tend to offer their observers an idealized impression of themselves and the situation. Seeking positive appraisal, they attempt to embody social norms thereby expressing and re-affirming the moral values of their community. Idealization does not necessarily mean that people perform "better" or create successful, flawless selves. Individuals simply seek to present a self that seems to be what others wish it to be.[7] These strategies assist people in achieving and maintaining desired identities or images of their self in front of others. For members of stigmatized groups, this is not always possible. Their "undesired difference" discredits them in the eyes of others which – following the logic of the "looking glass self" – negatively affects the interpersonal construction of their self and consequently their sense of self.

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[7] Illustrating that idealized performances can actually involve understating one's skills and abilities, Goffman quotes a female college student who plays down her intelligence to impress her boyfriend, "One of the nicest techniques is to spell long words incorrectly once in a while. My boyfriend seems to get a great kick out of it and writes back 'Honey, you certainly don't know how to spell.'"(1959:

2.4 Resisting stigmatization

Not all stigmatized individuals conform to the pattern of endorsing (self-) stigmatizing beliefs and feeling ashamed and guilty. Goffman notes that some interpret their stigma as a “blessing in disguise” or even transform their stigma into a “cult” (1963:11). They challenge the basic notion of “normality” and point to limitations of non-stigmatized individuals.

> A person with a shameful differentness can break with what is called reality and obstinately attempt to employ an unconventional interpretation of the character of his social identity. (1963: 10)

He describes that some people “fail to live up to what we effectively demand (…) and yet be relatively untouched by this failure” (1963:6). These are people “insulated by alienation” and protected by beliefs of their own (1963:6). They bear a stigma, but do “not seem to be impressed or repentant about doing so” (1963:6). Goffman lists “Gypsies, shameless scoundrels and very orthodox Jews” as examples, but he does not explain how they achieve their “insulation” or whether they remain protected when interacting with people who hold dominant normative expectations that discredit them (1963:6). Goffman considers these unconventional views and self-protective strategies only feasible “in isolation from current contact between normals and stigmatized” (1963:12). His analysis of stigma aims to focus on “mixed contacts” when stigmatized and “normal” individuals interact with each other face-to-face . He states that people who are “not particularly concerned about their social acceptance … can hardly be analyzed by reference to stigma management” (1963: 146). He suggests that the concept of “deviance” might be better suited to study these people, as “deviance” does not presuppose a discrediting experience, while the concept of stigma does.[8]

2.5 Critical appreciation of Goffman’s approach

Limiting his framework to individuals who are concerned about being accepted by people with mainstream values results in a conceptual shortcoming in Goffman’s work. In doing so, he disregards the full range of possible responses to having a stigmatized status. Neglecting those groups and individuals who manage to resist their stigmatization,

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39) With this type of “idealized” performance, the young woman reaffirms dominant gender roles thus accommodating her boyfriend.

[8] The study of stigma and deviance overlaps. Both perspectives view deviance as the result of social processes instead of as the result of personality traits, ‘natural’ inferiority or moral flaws of certain groups or individuals. Goffman introduced his analysis as a unifying conceptual scheme for a variety of works, including work on prejudice and deviance (1963: Preface). However, as noted above, the two concepts differ in that stigma refers to negative deviations from social norms only, while deviance can also occur in a positive direction and can include "deviants" who are unconcerned about mainstream norms.

he turns a blind eye to variations of the main pattern when norms are not hegemonic and/or when stigmatization is not (successfully) enacted. This undermines his own theoretical insight. His definition of stigma as a relational concept initially implied a theoretical potential for variance depending on social context and perceptions, normative expectations and interpretations of the social actors engaged in the interaction. Yet when limiting his framework to individuals who endorse mainstream values and self-stigmatizing views, stigma appears to be an unchangeable, fixed given that cannot be changed or avoided.

Similarly, his assumption that stigma always spoils individual's ego identities seems inappropriate. This shortcoming derives from the symbolic interactionist reduction of the self to a "mirror self" which implies that individuals lack the capacity to respond to other's disapproval in diverse ways. It neglects the power of individuals to protect their sense of self, for example by focusing on another aspect of their self or by endorsing alternative views and non-stigmatizing interpretations of their attribute. As a consequence, Goffman overlooks individuals' efforts at resisting stigma and their potential to have a positive sense of self. His simplistic view of the hegemony of social norms further contributes to this shortcoming. Goffman suggests that there was only a single set of norms in place in US society in the early 1960s and that "separate systems of honor seem to be on the decline" (1963:7). Based on this premise, he concludes that stigmatized individuals tend to hold the same beliefs about identity as the rest of society which inevitably causes them to agree that they "indeed fall short of what [they] ought to be" (1963: 7). This conceptual bias ignores the power of groups, communities and subcultures to resist their stigmatization. It underestimates not only the power of the individual as described above, but also the collective power of stigmatized groups to create their own communities where alternative values and interpretations are in place and mainstream norms are not hegemonic. Goffman was unable to foresee that social movements such as the civil rights movement, the women's movement and gay liberation could create such strong communities and could successfully lobby for new legislation and greater acceptance. As I will show below, more recent conceptualizations of "stigma" in social psychology take these historical and social changes into account and are consequently better equipped to conceptualize variability in social norms and processes of stigmatization.

Overall, Goffman made a significant contribution by introducing a concept that enables one to explore the experience of groups and individuals who are devalued and rejected because they exhibit attributes that carry a negative meaning and moral taint as a result of social forces in a specific historical and situational context. The main strength of his approach lies in its focus on social encounters in which stigma is enacted and in his carefully analysis of how stigmatized individuals manage these devaluing experiences. His “microanalytic” approach in the tradition of symbolic interactionism was praised as an invaluable contribution to establishing everyday-life interactions as a rightful domain of study (West, 1996). However, his emphasis on individual behavior in face-to-face interactions has also been criticized for being too individualistic in focus and for neglecting the structural dimension of exclusions from economic and social life (Oliver, 1992). People with physical disabilities, for example, do not need to encounter another person to be excluded. The assumption that people ought to be able-bodied is deeply engrained in the institutional structure of society and this is reflected in the architectural designs of most buildings, creating what Hahn called a “disabling environment” (1983). Entrances are built in a way that routinely excludes movement-restricted people from many buildings and the opportunities they contain for able-bodied people. Similarly, “institutional racism” refers to accumulated institutional practices that work to the disadvantage of ethnic minority groups even in the absence of individual prejudice and discrimination (Blauner, 1972). These institutionalized forms of discrimination are linked to the stigmatization of people of color and movement-restricted people in social encounters. They illustrate and reproduce the hegemony of social norms, in this case relating to whiteness and being able-bodied, but they cannot be adequately theorized with the concept of stigma and its traditional focus on face-to-face interaction. It is important to acknowledge this limitation of the stigma concept: not all aspects of the social marginalization of disadvantaged groups can be described with this term. The strength of the stigma concept, however, lies in its focus on the perspective of groups and individuals who experience devaluation and status loss in social encounters in their everyday lives. It is particularly well-equipped to capture the moral arguments, fears and prejudices that characterize these processes of social exclusion from the point of view of members of disadvantaged groups. Herein lies its main appeal for researchers who have studied stigmatization processes over the past decades. Next, I describe how the stigma concept was taken up and developed further in social psychology.

3 Conceptual developments in social psychology

The term stigma overlaps with traditional social psychological terms of social exclusion (in particular prejudice, stereotyping and discrimination). A main difference, however, lies in its focus on the perspective of the target of stigma. A person who is stigmatized is the target of prejudice, stereotyping and discrimination. Stigma has been described as an “encompassing term” (Dovidio et al., 2000:5) that includes a focus on the interaction between perpetrator and target of prejudice, and most importantly, attends to the perspective of the latter. This focus on the experience of the stigmatized has been described as the main conceptual advantage of the term “stigma” (Crocker et al., 1998; Oyserman & Swim, 2001).

Social psychology has a long tradition of studying mechanisms of social exclusion. First studies on prejudice in race-relations were published in the 1930s and 1940s and the field started to burgeon after World War II. In an attempt to grasp the atrocities of the holocaust, Theodor W. Adorno introduced the notion of “the authoritarian personality” (1950). Using a psycho-dynamic model, he viewed German anti-Semitism as a feature of an authoritarian personality that fostered the displacement and projection of unacceptable impulses onto out-groups. In 1954, Gordon W. Allport published “The Nature of Prejudice” in which prejudice was no longer viewed as a feature of certain personalities, but, more generally, as a common phenomenon of social life. It was defined as follows,

> Prejudice is an antipathy based on faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group as a whole, or toward an individual because he is a member of that group. (Allport, 1954: 10).

The cognitive processes underlying prejudice and stereotyping – categorization and generalization - were understood as basic cognitive functions. Allport explained the role of categorization,

> Impressions that are similar (…) tend to cohere into categories (generalizations, concepts). All categories engender meaning upon the world. Like paths in the forest, they give meaning to our life-space. (Allport, 1954: 175)

As a form of categorization, stereotypes thus give orientation in a highly complex world. This normalizing view of stereotypes gained much support during the “cognitive revolution” in psychology in the 1980s (for a review see Fiske, 1998). The critical focus of the term prejudice, however, as “faulty and inflexible” generalization, has remained. Transcending the psychological focus on the individual, Henry Tajfel further proposed a group-level analysis. In his analysis of in-group/out-group categorization, prejudice is conceptualized as resulting from the need of the in-group for a positive social identity (1981). Overall, social psychologist have been predominantly concerned with explaining prejudice and stereotypes from the point of view of those who hold stereotypical beliefs and exhibit prejudiced behavior. However, the perspective of the “targets” of prejudice has received increased attention. In particular since the 1990s, social psychologist have intensified their efforts to shed light on the psychological implications of being the target of prejudice and discrimination (for reviews see Crocker et al., 1998; Major et al., 2002).

As part of this development, the term “stigma” has gained wider use in social psychology. It has been defined as a “function of having an attribute that conveys a devalued social identity in a particular context” (Crocker et al., 1998: 506). This definition closely resembles Goffman’s conceptualization of the term while stressing the importance of social setting and situational context in determining which group membership or social identity is devalued. In a recent review, Major and colleagues describe “the possibility that one will be target of prejudice and discrimination” as a hallmark feature of stigmatization (Major et al., 2002).

Over the past two decades, social psychologists have advanced our understanding of stigmatization processes by: 1) identifying dimensions along which stigmas differ; 2) conceptualizing variance, ambivalence and ambiguity as important features of current stigmatization processes, and 3) highlighting the active involvement of the targets in appraising and coping with stigmatization.

3.1 Stigma dimensions

Based on the insight that any attribute, trait or behavior can potentially act as a stigma, the stigma typology originally proposed by Goffman has by and large been disregarded in subsequent discussions of stigma theory.[9] A better-received conceptual development has been the identification of dimensions along which stigmatizing conditions differ. Based on the available empirical evidence at the time, Edward Jones and colleagues (1984) identified six dimensions that characterize variations among attributes or conditions with stigmatizing effects. These dimensions include,

1. *Concealability:* How visible is the stigmatized condition and can it be hidden?
2. *Course:* Does the stigmatizing condition change over time and what is its ultimate outcome, i.e. how degenerative, treatable or reversible is it?
3. *Disruptiveness:* How much does it hamper social interactions and communication?
4. *Aesthetics*: Is the condition perceived as aesthetically repellent or ugly?
5. *Origin:* How was the condition acquired and is the stigmatized person held responsible for having the condition?
6. *Peril:* What kind and how much danger does the condition pose to others?

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[9] Goffman identifies three types of stigmas: 1) “abominations of the body” such as physical deformities, 2) “blemishes of individual character” that are associated with wrongful behavior , “weak will” and “unnatural passions” such as drug use, homosexuality and delinquency and 3) “tribal stigma” that are inherited and associated with membership in a despised social group, for example based on race/ethnicity or class (1963: 4). This typology is conceptually flawed. Some attributes (e.g. obesity) fit more than one category and others (e.g. age) do not seem to fit at all. The typology further fails to accommodate the relational nature of the stigma concept. Instead of illuminating how any attribute can act as a stigma depending on its relationship to normative expectations, it classifies stigmatizing attributes on the basis of (1) characteristics of the attribute (located in the body), (2) beliefs of the stigmatizers (who accuse the stigmatized of character flaws) and (3) characteristics of the stigmatized (who form a social group). The typology does not play a significant role within Goffman's framework and it has not been developed further since. I therefore neglect it in my discussion of the concept.

Recent reviews of empirical studies find that three of these six dimension are of particular relevance for stigmatization processes in US society today (for reviews see Crocker et al., 1998, Dovidio et al., 2000). These three dimensions include concealability/ visibility, origin/controllability and peril/perceived danger. Visibility matters since the option of concealing a stigmatized condition means that face-to-face stigmatization can often be avoided. As with HIV in its asymptomatic phase, strategies of secrecy and disclosure and information management then become a major concern. The origin or perceived controllability of a condition is crucial since it is closely linked to attributions of blame. Individuals with stigmatized conditions that are believed to be controllable, such as drug use behavior, are more disliked, more rejected and harshly treated than people who are not held responsible for having a stigmatized condition (Crocker et al., 1998). This dimension is also important for the target's experience of self-stigmatization. For example, overweight women who believe that obesity is controllable (and not due to genetic factors, for example) often perceive their stigmatization as justified and tend to express higher levels of self-blame (Crocker et al., 1993). The third dimension, the perceived danger of a stigmatized condition, is also very important. Perceived danger increases the virulence of a stigma. For example that HIV/AIDS constitutes a threat to one's health and life raises fears of illness, death and dying which significantly add to stigmatizing and self-stigmatizing views.

One should note that the dimensions of controllability and danger are clearly a matter of interpretation. Different views of the danger and the origin/controllability of an attribute can co-exist. For example, some people think the stigmatized condition of obesity is a an illness with genetic causes while others perceive it as an individual's lack of will power and overindulgence in food (Crocker et al., 1993). Similarly, the perceptions of the danger of an attribute or condition can vary. In the case of HIV/AIDS, it is interesting that scientific and lay persons often assess the risk of viral transmission very differently. Scientists point out that the danger of transmitting HIV during household contact is very low while lay people often perceive this as a great danger (Herek et al., 2002a). Higher levels of perceived danger and perceived controllability are associated with an increase in stigmatizing and – from the perspective of the targets of stigma – self-stigmatizing beliefs (Crocker et al., 1998).

3.2 Variance, ambivalence and ambiguity

A multi-disciplinary team of sociologists, social psychologists, anthropologists and historians emphasize the importance of variance in stigmatization processes (Ainlay et al., 1986). Proposing a dynamic conception of stigma, these authors convincingly argue that a conceptual focus needs to be placed on the variability, change, development and reversibility of stigma.

Variance in stigmatization processes has been addressed with reference to notions of ambivalence and ambiguity (Crocker et al., 1998). It has been noted that Americans are torn between contradictory values, including egalitarianism and individualism, which prompt ambivalent feelings towards people with stigmatized conditions. Egalitarianism with its precepts of equality of opportunity, social justice and the worth of all human beings fosters sympathy for the stigmatized (Katz et al., 1986). Individualist values on the other hand include Protestant ethic ideals of freedom, self-reliance, devotion to work, and achievement. These individualist values result in beliefs that “people get what they deserve” (Crocker et al., 1998). Stigmatized people are viewed as responsible for their own fate, as dependent, insufficiently self-supporting and unwilling to work to improve their situation. Most people in the United States are torn between these values and thus respond with ambivalent and conflicting feelings, for example with pity *and* disgust, to people with stigmatized conditions (Crocker et al., 1998; Katz et al., 1986).

In addition, social norms have changed and it has become increasingly unacceptable to openly express negative feelings and attitudes against stigmatized groups over the past decades. Prejudice and stigmatization often take more subtle forms (Gaertner et al., 1986). For stigmatized groups this can result in “attributional ambiguity,” i.e. ambiguous cues make it increasingly difficult to determine whether a negative event can be attributed to discrimination or not (Crocker et al., 1998:519). The more subtle and ambivalent other’s responses are, the more difficult it is to ascertain whether someone’s behavior is influenced by prejudice and stigma or not.

Variance has also been conceptualized with regards to the outcomes of stigmatization. Goffman described status loss, shame and a damaged sense of self as the main outcomes for the targets of stigmatization. Empirical evidence on the topic paints a more complex picture. On the one hand, studies show that stigmatization causes emotional distress which can lead to mental and physical health problems (Garnets et al., 1993; Dovidio et al., 2000; Herek, 1999; Mays & Cochran, 2001; Smith & Ingram, 2004). Stigma can also indirectly harm the well-being of the stigmatized by limiting access to basic resources such as health care, education, employment, and housing (Dovidio et al., 2000; Herek et al., 1998; Mays & Cochran, 2001). On the other hand, while most researchers agree that stigmatization has negative consequences for its targets, it has also been pointed out that not all targets are affected in the same way and that stigmatization does not *necessarily* cause a damaged sense of self (Crocker et al., 2000; Dovidio et al., 2000). For example stigma seems to cause distress and mental health problems in stigmatized sexual minorities, such as gay and lesbian populations, but it is important to note that most members of these minorities do not suffer from mental health problems (Mays & Cochran, 2001; Meyer, 2003). There is thus an observable variance in how members of stigmatized groups are affected by their stigmatization. Part of this variance seems to be due to the available coping resources and individual coping strategies. The active role of the targets in the stigmatization process thus needs to be taken into account. In their special edition on the perspective of the targets of stigmatization, "Stigma: An Insider's view," the editors Daphna Oyserman and Janet K. Swim note,

> We suggest an insider's perspective to focus attention on the stereotyped or stigmatized ingroup's responses, experiences, and beliefs, and the paradox of being both an active constructor of one's everyday reality and an involuntary target of negative attitudes, behavior and beliefs that shape this reality. (…) Stigmatized groups are not simply victims or passive recipients of stereotyping but rather actively attempt to construct a buffering life space. (Oyserman & Swim, 2001:1)

3.3 Cognitive appraisals and coping strategies

How do the targets of stigmatization create such a "buffering life space?" Social psychologists suggest that it starts with how targets perceive and interpret negative events in their social world. By placing the study of the targets of stigmatization in a stress and coping framework, they view the predicament of being a target of prejudice and discrimination as a stigma-related stressor and suggest focusing on two processes: the target's cognitive appraisals and coping strategies (Major et al., 2002; Miller & Major, 2000). Cognitive appraisal refers to the act of assessing or estimating the nature or value of an event or situation. As such it constitutes an evaluative process.

> Cognitive appraisal [is] the process of categorizing an encounter, and its various facets with respect to its significance for well being. It is not information processing, per se … but rather largely evaluative, focused on meaning and significance and takes place continuously during waking life. (Lazarus & Folkman, 1984: 31)

The appraisal process is typically dichotomized into primary and secondary appraisals. The former is concerned with whether a stimulus is personally relevant, benign, or stressful, and the latter poses the question of response – that is, what is to do? (Fitzgerald et al., 1995)

In the context of coping with discrimination, cognitive appraisals involve judgments about whether an event is potentially harmful or beneficial and whether one is capable of dealing with the harmful event or increasing the likelihood that benefits will occur. When individuals are insufficiently prepared to cope with events appraised as harmful or are unable to secure potential gains, they often avoid or disengage from the situation. Alternatively, when individuals believe they are sufficiently prepared to deal with the harmful event or to acquire gains, they are likely to cope by approaching or engaging with the situation (Lazarus & Folkman, 1984; Kaiser & Miller, 2004).

The perception that oneself or one's group is a target of prejudice or discrimination constitutes a primary appraisal of threat in one's environment, i.e. an appraisal that danger to the self or the group does and could exist (Major et al., 2002). One might expect that the more individuals perceive themselves or their groups as targets, the more stress they will experience. By definition, however, stress only occurs when demands are perceived as taxing or exceeding coping resources (Lazarus & Folkman, 1984). It is thus theoretically possible that individuals perceive themselves as targets of prejudice and discrimination and yet do not experience this as stressful because they feel they have the resources necessary to cope with the threat.

Coping is defined as a person's "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources" (Lazarus & Folkman, 1984: 141). In an attempt to establish a model of coping with stigma-related stressors, Miller and Kaiser (2001) clarify that only voluntary responses classify as coping. Responses that do not serve to regulate or modify a stressful experience and that are experienced as largely outside of a person's control (i.e. involuntary responses such as physiological and emotion arousal, e.g. anger, rumination, intrusive thoughts, impulsive actions and involuntary avoidance) are excluded from this definition. The term "coping" is reserved for conscious, voluntary efforts to regulate emotions, thoughts, behavior, physiology and the environment in response to stressful events or circumstances (Miller & Kaiser, 2001: 77).

According to this model, individuals cope by engaging or disengaging with the stressful event or problem. Disengagement includes strategies such as avoidance (including physical avoidance of prejudiced people and avoidance of social comparisons with non-stigmatized people), denial and wishful thinking. Engagement, on the other hand, involves efforts that aim to enhance a sense of personal control over the environment and one's reactions (primary control) and to adapt to the situation (secondary control). Engagement strategies include problem solving (e.g., individual compensation or collective action), regulation of one's emotions and the expression of emotions such as anger or anxiety to deescalate a situation. Adaptive efforts aim to change the way one feels about the fact that a bad situation has occurred. Adaptive strategies include acceptance, positive thinking, distraction and cognitive restructuring: that is reframing one's thinking, for example by attributing negative reactions or feedback to prejudice instead of to personal failure. Or people change the value they place on domains in which they encounter discrimination and cease to base their personal identity or self-worth on that domain (disidentification).

Coping responses are dynamic, multifaceted and interdependent. People usually respond in various ways, they try several alternatives and feedback from one response may alter the next response (Lazarus & Folkman, 1984). Which responses are used to cope with specific stigmas and how well they work needs further investigation (Miller & Kaiser, 2001). Collective actions, such as political activism and public education, aim to change the social conditions that lead to stigmatization in the first place (Siegel et al, 1998). The decision to respond collectively seems to in part depend on whether stigmatization is perceived as an individual- or group-based stressor and on how much the individual identifies with the stigmatized group (Miller & Kaiser, 2001). Stigmatized groups in turn have unique histories and provide their members with different resources and traditions of coping. Not only stigmatized individuals' appraisals of stigma-related stressors, but also the resources available for coping are thus critical for understanding how they are affected by their stigmatized status.

Empirical studies on coping with sexism find that women tend to overestimate the degree to which they will cope with a sexist encounter by confronting the stigmatizer (Shelton & Stewart, 2004; Woodzicka & LaFrance, 2001). Studies investigating actual behavioral responses in stigmatizing encounters find that most women do not respond to sexist remarks, gestures or treatment by openly displaying their objection (Fitzgerald et al., 1995; Shelton & Stewart, 2004; Woodzicka & LaFrance, 2001). The lack of behavioral responses, however, does not imply an absence of cognitive coping strategies. Fitzgerald and colleagues (1995) point out that "doing nothing" (as the most prevalent response to sexual harassment) can be one of many things: it may imply a deliberate decision to ignore the situation, to pretend that it is not happening or that one does not care. The denial can be of information, of the threat posed by the situation, of one's vulnerability to being harassed or of one's affect, i.e. one's emotional responses to the incident. Alternatively, "doing nothing" may imply endurance, that is tolerating a situation because it is unavoidable, one is afraid, or does not know what else to do. These responses can be accompanied by other internally focused responses, including detachment, self-blame or reattribution. The latter involves that women might reinterpret the situation in such a way that it is not defined as harassment: they invoke extenuating circumstances (e.g. the harasser was lonely) or attempt to interpret his behavior as benign.

In terms of behavioral responses, most women report avoiding the harasser. Appeasement is also common, especially using humor. Many women seek social support and some women employ a variety of assertive responses to communicate that harassment is unwelcome. By far the least frequent response to sexual harassment is to seek institutional or organizational relief, i.e. to notify a supervisor, bring a formal complaint, or file a lawsuit claiming discrimination. It is telling that most women who did use this strategy found that it did not help them. On the contrary, they reported encountering disbelief and retaliation and many were denied a promotion or even fired from a job (Fitzgerald et al., 1995:122-123). This clearly illustrates the social costs associated with making a claim of discrimination which will be further elaborated below.

Social psychologists focusing on cognitive coping efforts have suggested that targets cope with stigma-related stressors by using cognitive processes linked to group membership (Crocker & Major, 1989; Major et al., 2002). These processes include: 1) cognitive restructuring, or changing the meaning of, stressful life events, for example by selectively devaluing domains in which one's group fares poorly and valuing other attributes or domains in which one's group excels; 2) engaging in within-group comparisons rather than in comparisons with members of more advantaged groups; and 3) attributing negative outcomes to the prejudiced attitudes of others to their group rather than to their own deservingness. The latter strategy, attributing outcomes to stigma and discrimination (instead of considering them to be one's own fault), has incited a lively discussion among social psychologists. Some authors suggest such attributions have self-protective functions in terms of buffering the self-esteem of the targets of stigmatization (Crocker & Major, 1989; Major et al., 2003) while other researchers point out that attributions to stigmatization are always damaging to individual's sense of self and self esteem (Schmitt & Branscombe, 2002). A second controversy surrounds the question of how accurately the targets of stigmatization assess the discrimination they encounter. Some authors suggest that targets are highly sensitive to cues of prejudice in their environment (vigilance perspective) and when they make judgment errors, these tend to be on the side of "false alarms" (Major et al., 2002: 266). Other authors suggest that members of disadvantaged groups tend to underestimate the extent to which they are targets of prejudice and often miss and minimize the extent to which they personally encounter discrimination. Empirical evidence exists in support of both perspectives, suggesting that the question is not, do targets respond with *either* vigilance *or* minimization, but who responds how and under what conditions (Major et al., 2002). Most social psychological research on coping with stigma focuses on the targets of racism and sexism. I review these research findings as they raise important questions about how targets perceive, interpret and communicate their stigmatization experience.

3.4 Attributions to discrimination – personal/group discrimination discrepancy

Major and colleagues (2002:262) define attributions to discrimination as a judgment with two components: a) the individual or group was treated unjustly and b) the treatment was based on social identity/group membership. Both components must be present for the target to conclude that discrimination has occurred. For example, when individuals feel that their social identity was responsible for their negative treatment, but that this was just, this does not constitute an attribution to discrimination, but a perception of “justifiable differential treatment” (Major et al., 2002: 263).

It has been noted that members of disadvantaged groups often deny that they are personally victimized, although they admit that their social group is subjected to discrimination. This reluctance to claim personal discrimination - while acknowledging that one’s group has suffered - has been found across a variety of disadvantaged groups, the most well-researched groups being women and ethnic minorities (Crosby, 1984; Kobrynowicz & Branscombe, 1997; Taylor et al., 1990). In an attempt to explain targets’ willingness to acknowledge group but not personal discrimination, some researchers point to the role of cognitive processes of information processing that highlight extreme acts of discrimination against members of one’s group.

> Given that respondents have a finite inventory of information concerning their group, a propensity by the media and within-group gossip to highlight extreme acts of discrimination could result in a large proportion of this store being devoted to discriminatory events. The proportion of personal experiences with discrimination relative to the wealth of other events might be considerably smaller. The investigation of this type of “availability of information” approach might serve to provide a cognitive basis for this discrepancy. (Taylor et al., 1990: 260-1)

Faye Crosby (1984) explains the personal/group discrimination discrepancy with conventions of politeness that make it difficult to portray one’s own suffering while group loyalty demands sensitivity to the plight of one’s group. She also notes a cognitive difficulty of inferring discrimination from individual cases and the common unwillingness of targets to identify a specific villain who caused their stigmatization, something which is required when making a claim of discrimination. This latter factor points to the social costs involved in claiming personal discrimination. Researchers believe that these are largely responsible for the denial and minimization of personal discrimination which has been observed.[10]

3.5 Minimizing personal discrimination

Social psychologists point out that perceiving oneself to be a target of stigmatization entails psychological and social costs. It involves acknowledging that you

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[10] It has also been suggested that methodological problems may contribute to the personal/group discrimination discrepancy. Major et al. (2002: 277) point out that in most studies, questions about personal and group levels of discrimination fail to specify a comparison referent. Assessments of personal discrimination are apt to be gauged against in-group targets, whereas assessments of group discrimination are apt to be gauged against salient out-groups. Given that between-group comparisons produce greater disparity than within-group comparisons, a discrepancy appears. When comparison referents are specified, on the other hand, the personal-group discrepancy is often greatly diminished (Major et al., 2002).

and your group are devalued by society at large, that negative events are outside of your control[11] and that you are likely to face similar events in the future which may threaten your belief in a just world (Stangor et al, 2002). For example, women are found to minimize the pervasiveness of sexism as they prefer not to anticipate being discriminated against again in the future (Foster et al., 2004). Female college students viewed an encounter with gender-based discrimination as only a single event and not stable over time or widespread across different settings. However, they minimized the pervasiveness of sexism only in relation to their own anticipated discrimination, but not when envisioning discrimination happening to someone else.

Making a claim to have been discriminated against also entails social costs as individuals risk being disliked, facing retaliation, or having their values dismissed (Kaiser & Miller, 2001; Shelton & Stewart, 2004). Illustrating the social costs of claiming discrimination in a laboratory experiment, Kaiser and Miller (2001) find that an African American student who attributed a failing grade to racial discrimination was perceived as a complainer (and as hypersensitive, emotional, argumentative, irritating, and trouble-making) by White male college students. He was negatively evaluated in this way, even when it was clear that the likelihood that discrimination had occurred was very high. Demonstrating that individuals are aware of the social costs of reporting discrimination, Stangor and colleagues (2002) find that women and African-Americans were less likely to make attributions to discrimination for negative events in front of men and Whites than in private or in front of other women or African Americans (i.e. members of their respective in-group). Similarly, Swim and Hyers (1999) find that targets of prejudice are more likely to report discrimination in an anonymous survey than in front of the perpetrator or members of the perpetrator's social group. In their experiments, undergraduate women engaged in small group discussions in which a male confederate made sexist comments. Although less than half of the women in the sexist-comment group responded to the sexist remarks at the time they were made, private ratings assessed after the interaction revealed that 75% of the women who had failed to respond in the situation nevertheless rated the confederate as sexist. These women perceived the confederate's behavior as clearly discriminatory, but did not say so in front of him to escape the costs that such confrontation might involve. In a similar vein, Sechrist and colleagues (2004) find that

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[11] Sechrist et al.(2004) challenge the prevalent notion that attributions to discrimination undermine an individual's sense of personal control. They suggest that while a claim to discrimination may represent an acknowledgement of not having been in control of a negative event in the past, this does not necessarily mean that the same will be true in the future. On the contrary, an individual's perceived chances to achieve positive outcomes in the future might be greater when past failures were not due to personal inability but to discrimination, i.e. an external condition that can be changed. In fact, the very act of labeling the past occurrence as stigmatization might constitute a first step to changing external conditions and to assume control over future outcomes.

female targets of (gender-based) discrimination were less likely to report having been discriminated against compared to similar others (i.e. other women) who witnessed the same event. However, under private reporting conditions, participants reported discrimination occurring to the self as often as discrimination directed at similar others. This suggests that targets underreport and minimize the extent of their personal victimization under certain conditions to avoid the social and psychological costs involved in claiming to have been discriminated against.

3.6 Benefits of attributions to discrimination

While stigmatization and attributions to stigma clearly entail negative consequences for the targets of stigma, social psychologists have also pointed out that under specific conditions, attributions to discrimination can have beneficial effects for the targets of stigma. Reporting discrimination can serve strategic purposes that promote social change in order to improve the status of one's group (Taylor et al., 1990). In terms of the individual's immediate psychological well-being, attributions to discrimination might also have a self-protective function. As external attributions,[12] attributions to discrimination enable individuals to maintain self-esteem and positive affect in the face of negative outcomes by locating the cause of failure in the prejudice of others rather than in their own actions (Crocker & Major, 1989; Major et al., 2003). This "discounting hypothesis" - proposing the beneficial effects of discounting the self as a cause of negative outcomes - is highly controversial and its proponents concede that it is not always applicable. For example, an attribution to prejudice is not self-protective when the stigmatized individual feels responsible for having the stigma, as in the case of some overweight women (Crocker et al., 1993).

Other researchers suggest that the hypothesis might only apply to members of groups who encounter discrimination on an exceptional, infrequent basis (Kobrynowicz & Branscombe, 1997). Members of socially disadvantaged groups who are faced with more stable and frequent forms of discrimination do not seem to psychologically benefit from attributions to prejudice in the same way. Schmitt and Branscombe (2002) point out that when one's group membership or stigmatized aspect of self is devalued within the broader society, attributions to prejudice have more painful implications as they imply devaluation and negative treatment beyond the immediate situational context. Furthermore, such attributions are not entirely "external" as implied by the "discounting hypothesis." Instead,

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[12] Social psychological theories on attribution distinguish between internal and external attributions (Heider, 1958). Internal (or personal) attributions assign responsibility for an event or behavior to the person while external (or situational) attributions assign responsibility to situational factors or circumstances.

attributions to prejudice involve an internal component as the occurrence of stigmatization is linked to an aspect of the self that cannot be completely discounted as a cause of the negative event (Schmitt & Branscombe, 2002). Targets of discrimination do not always blame themselves for encounters with discrimination, but they recognize that some aspect of the self is a necessary condition of the discrimination occurring in the first place. An attribution to prejudice is thus not completely external to the self. Proponents of the "discounting hypothesis" have recently acknowledged that attributions to prejudice entail both internal and external components (Major et al, 2002: 266). They maintain their claim that attributions to discrimination are less harmful to a target's self-esteem as compared to self-blame, but they acknowledge that more research is needed to determine when and how attributions to discrimination can have positive as opposed to negative effects for the targets' psychological well-being.

In terms of the likelihood that targets will perceive and make claims of discrimination, it has been noted that situational cues play an important role. Situational cues that make group membership accessible, that render individual's social identity salient and that link a negative outcome to group membership increase the likelihood that individuals will perceive and claim discrimination (Major et al., 2002). Furthermore, the more members of stigmatized groups identify with their group, the greater the likelihood that they will perceive and report discrimination. Experimental studies show that group identification does not result in greater vigilance in all situations but only in those that contain ambiguous cues and are attributionally ambiguous (for a review, see Major et al., 2002).[13] Identification with one's social group and political group consciousness seems to be both the result of perceived discrimination as well as an antecedent of attributions to discrimination. For example, women who express feminist beliefs are found to perceive higher levels of personal discrimination than women who do not subscribe to feminist beliefs (Major et al., 2001; Swim et al., 2001). Experiences of discrimination may have led some women to endorse feminist beliefs, and feminist beliefs may also increase women's awareness of sexism and their sensitivity to its situational cues. Individual characteristics such as political beliefs and group identification seem to be more influential in attributionally ambiguous situations than in situations when prejudice is blatant. Major and colleagues (2002) conclude that group status (e.g. stability and frequency of discrimination) as well as situational factors (e.g. ambiguous or non-ambiguous cues) and

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[13] Ruggiero & Taylor (1995, 1997) had suggested that members of stigmatized groups minimize their experience of discrimination independent of situational cues, but other researchers applying their study design failed to produce the same results (for a review see Major et al., 2002) and Ruggiero recently retracted four of her articles due to concerns about the validity of her results (*Personality and Social Psychology Bulletin*, 2002, 28, 284; *Science*, Dec 2001, 294 (5551), 2457).

person factors (e.g. personal beliefs and sensitivity) influence the likelihood that individuals will make attributions to discrimination in specific situations.

3.7 Missing conceptualization of multiple stigmatization

While social psychologists have made progress in understanding the cognitive appraisals and coping strategies of the targets of stigmatization, this body of research and theory has a distinct limitation: it lacks a conceptualization of multiple stigmatization. This limitation dates back to Goffman whose analysis only referred to individuals with only one stigmatizing attribute such as physical disability, criminal records or homosexuality. Following in Goffman's footsteps, most subsequent stigma theory and research discusses only one stigmatizing condition at a time, such as *either* race *or* HIV, or at best, it compares one stigma with another, such as the stigma of cancer with the stigma of HIV (Fife et al., 2000). Exceptions to the rule can be found in HIV/AIDS research where researchers noted that the HIV epidemic in the United States has mainly affected members of already stigmatized groups, such as gay men, drug users and people of color. It was recognized that the stigma attached to HIV/AIDS is linked to racism and the stigmas attached to drug use and homosexuality. As a consequence, attempts have been made to conceptualize the interaction of multiple stigmas (Herek & Capitanio, 1999; Parker & Aggleton, 2003). Herek and Capitanio (1999), for example, show that HIV/AIDS related stigma is linked to negative attitudes towards gay men in the United States and that gay men with HIV/AIDS are assigned higher levels of blame than heterosexual or bisexual men or women with HIV/AIDS. These conceptual advances in the field of HIV/AIDS related research stress the importance of investigating interrelated stigmatization processes, but they do not address the subjective experience of the targets of multiple stigmatization.

Social psychological research not only lacks a conceptual focus on the experience of multiple stigmatization, the research findings reviewed above also carry an implicit bias in that they are by and large based on the experience of more privileged social groups. Most social psychological studies on attributions to discrimination are conducted with young, White educated college students who participate in the study for course credit (see for example Foster et al., 2004; Kaiser & Miller, 2001; Kobrynowicz & Branscombe, 1997; Schmitt & Branscombe, 2002; Swim et al., 2001). The homogeneity and social status of these study samples raises serious questions as to whether the findings can be generalized and whether they are applicable to less privileged social groups. For example, do young, educated White women deal with sexism in a similar way to older, working-class women of color who are being stigmatized on more than one ground? Swim and colleagues (1998) imply that this might not be the case. They suggest that women who visibly belong to an ethnic minority live in a state of constant anticipation of discrimination and as such, may not be likely to minimize gender-based discrimination in the same way as White women. Questions concerning the experience of multiple stigmatization, however, have not been systematically addressed and more research is clearly needed.

In conclusion, while providing an excellent starting point for analysis, the framework of stigma must address the following conceptual challenges:

1. The “targets” of stigmatization must be conceptualized as both targets and active agents, i.e. a focus must be placed not only on their victimization, but also on their individual and collective strategies of coping with and resisting stigma;
2. In doing so, the concept of a “mirror self” must be expanded to be better suited to explaining the wide range of emotional responses, internal processes of meaning making and coping strategies of individuals who are the targets of stigmatization;
3. Variance in the processes and outcomes of stigmatization must be adequately addressed, i.e. the likely diversity of stigmatization experiences and its effects on members of stigmatized groups must be taken into account;
4. *Multiple* stigmatization as experienced by members of socially disadvantaged groups must be explored.

4 The stigma attached to women’s same-sex sexuality

Having introduced the general concept of stigma, I now review literature on the specific stigma attached to women’s same-sex sexuality.[14] I prefer the term “women’s same-sex sexuality” over “lesbianism” or “female homosexuality” because it better captures the diverse forms of women’s same-sex sexual attractions, behavior and identities that are stigmatized in the United States today.[15]

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[14] For purposes of better legibility of the text, I abbreviate the precise but lengthy term “stigma attached to women’s same-sex sexuality” at times with “stigma *of* women’s same-sex sexuality ,” or - following Herek and Capitanio’s notion of “sexual prejudice” (1999) - simply with “sexual stigma.”

[15] Given the absence of a standard definition of “lesbian” (Solarz, 1999), a note on my use of this terminology is needed. It has been suggested that any definition should take the following dimensions into consideration: women’s sexual self-identifications, their sexual behavior and their sexual desires or attraction (Lauman et al., 1994; Solarz, 1999). I base my definition of the term first and foremost on women’s self-identification as “lesbian,” knowing full well that there are women in committed sexual relationships with women who might not consider themselves lesbian (for example because they find the term derogatory, limiting or culturally inappropriate). Likewise, I use the term “bisexual” for women who consider themselves bisexual. Most often, I speak of “lesbian and bisexual women” as a unit because both groups are targets of the stigma attached to women’s same-sex sexuality. Overall, I perceive the labels lesbian and bisexual not as clearly separable categories, but as different points on a continuum from (sexually and intimately) oriented more to the same sex versus oriented more to the opposite sex. The complexity and fluidity of human sexuality makes clear-cut definitions impossible. For example, it is often presumed that

4.1 Negative attitudes towards lesbian and bisexual women

Results from a national household survey show that a majority of Americans oppose homosexual relationships: fifty-nine percent (58.6%) of respondents of the General Social Survey (GSS) subscribe to the view that sexual relations between two adults of the same sex are always wrong (National Opinion Research Center, 1998). This rate is lower compared to earlier surveys (during the 1970s and 80s more than 70% of GSS respondents had expressed this view), but the trend towards increasing acceptance is still embedded in a majority opposition to same-sex sexuality.

Prevalent negative stereotypes depict lesbians as sick, psychologically unstable, aggressive, man-hating, masculine, ugly, and abusive (Eliason et al., 1993; Greene, 1997; Hidalgo et al., 1976; Simon, 1998; Shockley, 1983). This stigmatizing view of women's same-sex sexuality as immoral and unnatural is rooted in specific cultural discourses that have contributed to the establishment of "compulsory heterosexuality" (Rich, 1980) as a social norm. I briefly discuss three institutions – Christian religion, the legal system and medicine - that have historically contributed to the cultural construction of sexual stigma in the United States. I also show, however, that each of these institutions paradoxically came to aid the deconstruction of and resistance to sexual stigmatization.

3.2 Religious constructions of lesbianism as a "sin"

Most of the main religious institutions in the United States oppose homosexuality, including the Roman Catholic Church, the Southern Baptist Convention, United Methodist Church, the Church of Jesus Christ of Latter-Day-Saints (Mormons), Islam, Judaism and, to a lesser degree, protestant denominations such as Presbyterian, Episcopalian, and Lutheran churches (Bennett, 1999; Hassan, 1991; Porcile-Santiso, 1991). Christian churches have a long tradition of accepting only reproductive sex between married heterosexuals; any sexual activity that does not aim at reproduction, that occurs outside of marriage or takes place between persons of the same sex is considered a sin and "unnatural vice" (Crompton, 1980/81; Porcile-Santiso, 1991). Conservative religious scholars have interpreted the bible to illustrate God's punishment of people who commit

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lesbian women only have sex with women, but this does not reflect the reality of women's sexual lives. Sexual self-identifications give an indication, but no definite statement about sexual behavior and desires as many self-identified lesbians have had sex with men and many women who identify as heterosexual have same-sex sexual experiences or desires (Diamant et al., 1999; Diamond & Savin-Williams, 2000; Gomez et al., 1996; Rothblum, 2000). Acknowledging the shortcomings of identity-based categories, I also use the terms "women who have female sexual partners" and "women-loving women" to include a broader range of women who are sexually or romantically inclined towards members of the same sex and thus a target of the stigma attached to women's same-sex sexuality.

"acts against nature," pointing to his destruction of the city of Sodom (Genesis 19), to passages in the old testament prescribing the death penalty for male homosexuals (Leviticus 20:13) and the condemnation of lesbians in the new testament (Roman I: 26). The Catholic church historically supported the execution of lesbians (Crompton, 1980/81) and now by and large subscribes to a "Hate the sin, love the sinner" approach (Bennett, 1999). Homosexuality is considered a social ill and the official stance of the Roman Catholic church in recent decades has been to call for individual conversion, social therapy and prophylaxis (Porcile-Santiso, 1991). Due to gay and lesbian activism from outside and within the church, the call for conversion receded to the background during the 1990s and was replaced by the demand that homosexuals be celibate for life (Bennett, 1999). This trend towards increased acceptance was recently reversed when the Vatican released a document in which it reiterated its traditional anti-gay principles and doctrine.

> Homosexuality is a troubling moral and social phenomenon. (...) There are absolutely no grounds for considering homosexual unions to be in any way similar or even remotely analogous to God's plan for marriage and family. (...) The homosexual inclination is objectively disordered and homosexual practices are sins gravely contrary to chastity. (Congregation for the Doctrine of the Faith, July 2003) [16]

It is beyond the scope of this chapter to describe the stances of all major churches and communities of faith towards women's same-sex sexuality. There is a great diversity ranging from accepting institutions such as the Metropolitan Community Church with its slogan "God made you queer" to less accepting ones such as the Southern Baptist Convention and the Church of Jesus Christ of Latter-Day-Saints (Mormons) who take a strict anti-gay stance (Bennett, 1999). It is also important to note that a range of views can usually be found in each community of faith. Furthermore, religious teachings are in flux. There is no uniform, static Christian view of lesbians, for example. Most religious traditions are based on multiple sources and religious scholars continuously engage in debates over how to interpret the texts.[17] Due to gay and lesbian advocacy efforts from outside and within their own ranks, most religions currently engage in a "spiritual crossfire" where a greater acceptance of homosexuality is being negotiated (Bennett, 1999). However, the traditional religious opposition to homosexuality has been a significant historical influence

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[16] Illustrating the diversity of current developments, only a week after the Vatican released this document in July 2003, the Episcopalian church confirmed an openly gay bishop at its convention in Minneapolis.

[17] For example, conservative and liberal Christians interpret the bible in very different ways. Conservative scholars interpret the book of Genesis as indicating the fall of humanity into sin and they view homosexual behavior as evidence of that sin. More liberal scholars on the other hand point out that the Bible was written in a different historical time when slavery, genocide, mass murder, and the oppression of women was considered acceptable. When looking to the bible for

that has woven the association of women's same-sex sexuality with sin and shame into the fabric of American culture.

3.3 Historical legal discourse: criminalization and denial

Secular laws prohibiting sexual relations between women date far back in European history.[18] By the 18th century, executions of women (and men) on the grounds of sodomy laws ceased with the increasing influence of the Enlightenment and new forms of social regulation of same-sex sexuality.[19] However, this did not mean that women-loving women were no longer stigmatized through the legal system. Stigmatization on the basis of women's same-sex sexuality was not limited to laws prohibiting same-sex sexual conduct. A historical case from the English legal system, where sexual relations between women were never criminalized, provides a case in point: the well-known trial *Miss Marianne Woods and Miss Jane Pirie against Dame Helen Cumming Gordon* of 1811 (Faderman, 1983, Vicinus, 1994). Dame Cumming Gordon was a gentlewoman of Edinburgh who removed her granddaughter from a boarding school and convinced other parents to do the same after her granddaughter had accused two female teachers of having a sexual reltionship. The teachers, Ms Woods and Ms Pirie, insisted that the accusations were untrue and sued the grandmother for libel. They were found innocent by the court, but as a result of the accusations, their reputation suffered, their friendship broke, and they were economically ruined as Lady Cumming Gordon delayed payment of the court-ordered compensation for over nine years. It is important to note that the ruling in favor of Ms Woods and Ms Pirie was not based on evidence that proved their friendship non-sexual. It was rather the result of reasoning on the side of the judges who could not

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guidance on the topic of homosexuality, they generally look for applicable biblical themes, like those advocating justice, love, monogamy, or caring (Hunt, 1989; Robinson, 2003; Spong, 1991).

[18] The first documented law prohibiting sexual relations between women dates back to the French code in the 13th Century where women "sodomites" were to be punished with clitorectomy (Crompton, 1980/81). With the exception of English law, most European legal codes of the Middle Ages and the Renaissance included provisions for the killing of lesbians. For example Roman Emporer Charles V. criminalized sexual activity between women in his 1532 statute where he declared that anyone who "commits impurity with a beast, or a man with a man, or a woman with a woman, they have forfeited their lives and shall, after the common custom, be sentenced to death by burning" (Crompton, 1980/81). Executions of women convicted under such laws are documented to have taken place in Germany (where a young woman was drowned in Speier in 1477 and Catherina Margaretha Linck was executed in Halberstadt in 1721), Spain (where two nuns were burned in the 16th century), France (where two women were tortured in Bordeaux in 1533) and Italy (where a cross-dressing woman who had married a woman was hanged in the district of Marne in 1580) (Crompton, 1980/81; Eriksson, 1980/81).

[19] The relinquishing of executions can be viewed as part of broader societal changes and developments of new forms of power. Michel Foucault (1979) describes the evolving disciplinary society as a society of surveillance and control. Power is no longer organized around the sovereign threat of death in the traditional model of sovereignty (i.e. negatively, 'thou shalt not') but it proceeds through administering and fostering life (i.e. positively, 'you must'). In this context, sexual

conceive of British school teachers committing such a "very abominable crime" (Vicinus, 2004). They blamed Lady Cumming Gordon's granddaughter, who happened to be illegitimate and half-Indian, for imagining practices that they thought could only occur in a "hot country" such as India (Vicinus, 2004). The judges were keen to avoid publicity and all court proceedings took place behind closed doors. Historian Martha Vicinus concludes that this lawsuit "embodies the denial, silence and danger that characterize so much lesbian history" (Vicinus, 1994).[20]

The American legal system by and large followed the English tradition in that sex between women was typically not explicitly regulated and sodomy laws were only rarely applied to sexual conduct between women.[21] However, lesbian women have been and continue to be legally disadvantaged in many ways. For example, they lack protection from employment discrimination,[22] they are denied the federal benefits and protections available to married heterosexual couples and they are prohibited from adopting children in several states (Bennett, 2002). Stigmatization also occurs in child custody cases. Some courts still assume that lesbian women are emotionally unstable and "unfit" to be mothers and that children raised by an openly lesbian mother would be emotionally harmed, molested, impaired in their gender role development, and at risk of becoming homosexual as well (Falk, 1993; McLeod & Crawford, 1998).

However, it must be pointed out that laws and regulations vary greatly from state to state, and in many places the legal discourse has been successfully used to claim rights and end discrimination of lesbian, gay, bisexual and transgender (LGBT) individuals and

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norms and the internalization of these norms become increasingly important at the expense of death penalties administered by the juridical system of the law.

[20] Because denial, silence and danger are so characteristic of lesbian (and lesbian-like) history, Vicinus recommends to pay attention to what is *not* visible and what is *not* said (1994). This also applies to the study of contemporary processes of stigmatization of women's same-sex sexuality – devaluation at times works hand in hand with denial and can be found not in the obvious and blatant, but in what is *not* being said, what is *not* being done and what is *not* rendered visible.

[21] Sodomy laws are state-specific laws restricting non-procreative sex, especially anal and oral sex. The term "sodomy" has diffuse meanings leaving much room for interpretation (Hunter, 1995). Sodomy laws have been disproportionately enforced against same-sex couples even if they technically applied to opposite-sex couples as well (Bennett, 2002). In a few instances sodomy laws were enforced against women. In the late 1930s, a woman was charged with sodomy for oral sex with another woman, but this conviction was later overturned by the Supreme Court on the grounds that sodomy required phallic penetration (Hunter, 1995). Many states overturned their sodomy laws in the past decade. Prior to the recent Supreme Court ruling on Lawrence & Gardner vs. The State of Texas (6/23/03) that found the Texan sodomy statute unconstitutional, thirteen states still outlawed consensual sex between adults of the same sex, including Alabama, Florida, Idaho, Kansas, Louisiana, Massachusetts, Mississippi, North Carolina, Oklahoma, South Carolina, Texas, Utah and Virginia (Bennett, 2002; for the recent supreme court ruling see http://www.sodomylaws.org/lawrence/lawrence.htm).

[22] No federal law bars employment discrimination of lesbian women as Title VII of the Civil Rights Act of 1964 only prohibits job-related discrimination based on race, color, religion, sex and national origin, but not sexual orientation. A patchwork of protection exists in a few states and an estimated

families.[23] For example, a non-biological lesbian mother was recently granted visiting rights to her ex-partner's child as the court acknowledged that family structures are changing and lesbian step- and co-parenthood become more prevalent (Yatar, 2001). However, the Human Rights Foundation notes, "with progress comes backlash" (Bennett, 2002:5). Achievements in ending discrimination of LGBT individuals and families have been accompanied by efforts of anti-gay groups to roll back legal protection for LGBT families through court challenges or referendums. The legal arena is thus characterized by a similar "crossfire" situation as described for the religious arena above. Active efforts to overcome the stigmatization of women (and men) in same-sex sexual partnerships incite heated discussions and are partially successful and partially met with growing opposition (see for example the recent discussion on "gay marriage;" Dupuis, 2002). .

4.4 Medical constructions of the "sick homosexual"

Medicine is the third important institution that contributed to the stigmatization of lesbian and bisexual women in Europe and the United States.[24] Women's same-sex sexuality became a topic of medical inquiry in the 19th century, and psychiatrists started to investigate what were considered gender-atypical behavior. They measured and described women's bodies, behavior , feelings, thoughts and appearances. Based on these observations, psychiatrists and sexologists created classifications and ranked female homosexuals according to the severity of their 'disorder', distinguishing between "congenital inverts" and those with less severe forms of this "predisposition" (Smith-Rosenberg, 1990: 270). "True inverts" were perceived as "mannish" or masculine, i.e. they were thought to mimick inherently male desires and behavior .[25]

> [The most extreme type of female invert] possesses of the feminine qualities only the genital organs; thought, sentiment even external

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225 municipalities (including New York City) have laws or policies that bar discrimination based on sexual orientation (Human Rights Campaign, 2001).

[23] New York State ranked among the ten most LGBT-friendly states in terms of rights and legal protections: it does not permit marriage or civil unions, but it offers domestic partnership benefits for state employers and has a good record on adoptions by LGBT individuals and couples (Bennett, 2002).

[24] Biological and medical sciences have contributed to the stigmatization of people with same-sex sexual desires, behavior and identities in many ways, but due to the limited scope of this chapter I will focus only on the psychiatric construction of the "sick homosexual". Other scientific attempts to naturalize heterosexuality, for example the denial and suppression of findings in the biological sciences that over 450 animal species in the wild exhibit some form of same-sex sexual behavior (Bagemihl, 1999), must be neglected.

[25] One of the first to describe lesbians as "mannish" was C. Westphal's in his case of Fräulein N. in the German psychiatric journal "Archiv für Psychiatry und Nervenkrankheiten" in 1869. Westphal notes that his patient suffered from a passion to love women and to masturbate ("Frl. N. litt an einer Wuth, Frauen zu lieben … und Onanie zu treiben") since she was 8 years old and classifies her condition as "conträre Sexualempfindung" (cited in Gutheil, 1994). Given her attraction to women and her dislike of "feminine" activities, Westphal concludes that she is "mannish" (daß sie sich "geschlechtlich als Mann fühle") (Gutheil, 1994).

> appearance are those of a man. … The toilet is neglected, and rough boyish manners are affected. Love for art finds a substitute in the pursuit of sciences. (Krafft-Ebing, 1935: 399)

The medical view of the ‘sick lesbian’ referred to women’s perceived non-conformity to gender norms and often highlighted the sexual aspects of this phenomenon. Sexual behavior or desires for members of the same sex were considered “abnormal” and therefore thought to require medical treatment. The more masculine women’s behavior and appearance, the more severe and irrevocable their supposed disorder was considered to be (Smith-Rosenberg, 1990).

Michel Foucault argues that this construction of the “sick homosexual” is part of a broader transformation of the social regulation of sexuality during the 18th and 19th century. Science, law and medicine engaged in a “new specification of individuals” which involved the creation of ‘the homosexual’ as a new type of person (Foucault, 1990: 42-43). The “sodomite” of previous centuries had been only a “temporary aberration”, whereas the medically investigated, measured and categorized homosexual of the 19th and 20th centuries now constitutes a new “species” (Foucault, 1990: 43). This historical development created a fertile breeding ground for stigma as lesbians could now be perceived as fundamentally different from other women.

Freud proposed a somewhat normalizing view of bisexuality, at least in theory. In clinical practice, however, psychoanalysis and psychotherapy tried to cure women’s same-sex sexual desires and aimed to reorient them back to heterosexuality (Haldeman, 1994). The pathologizing stance of the medical and psychological profession changed in the 1960s and ‘70s due to pressures from the gay and lesbian and women’s movements. In 1973, the American Psychiatric Association (APA) decided to remove homosexuality from its Diagnostic and Statistical Manual (DSM) as 58% of its membership voted in favor of this change (Gruskin, 1999). Since then homosexuality is officially no longer defined as a mental illness, but it is important to note that 42% of the membership of the American Psychiatric Association at the time still viewed it as a mental disorder. Not surprisingly, the practice of conversion therapy, i.e. therapeutic efforts to sexually reorient lesbians and gay men, still continues (Haldeman, 1994).

Paradoxically, each of these institutions – religious, legal and medical – has contributed to the cultural construction of sexual stigma while simultaneously planting seeds of its resistance. Religion not only constructed lesbianism as a sin - queer and queer-friendly religious scholars have used their faith and religious texts as a resource to argue for greater acceptance of lesbians and gays (Hunt, 1989; Spong, 1991). The legal system was not only used to prosecute gays and lesbians - it has also provided an avenue to fight discrimination and influence social norms towards greater acceptance, especially in the United States (Rayside, 2001). Similarly, the medical profession has not only contributed to the construction of stigma, but also to its deconstruction.

Early sexologists such as Magnus Hirschfeld, proposed early on that homosexuality should be accepted as an “innate condition” and an immutable part of human sexual diversity (Hirschfeld, 1896). In the second half of the 20th century, gay and lesbian medical professionals created initiatives and advocacy networks, such as the Gay and Lesbian Medical Association, to fight stigma, improve health care services for sexual minorities and foster research on lesbian health (Bradford et al., 2001; Gruskin, 1999). In psychotherapy, a field of "gay-affirmative" therapy evolved which specifically aims to help lesbian and gay clients "retain and gain self-appreciation, self-respect and pride" amidst the oppression they are subjected to (Clark, 1997: 76-77). The medical focus on sex in the early investigations of female homosexuality undoubtedly transformed the way society perceived women’s relationships with each other. Intimate friendships between women, which were previously considered non-sexual and virtuous, now became suspect (Faderman, 1981). However, by providing a sexual language, stigmatizing medical discourses also facilitated the creation of the modern lesbian identity which served as a basis for individual self-development and community building (Doan, 2001; Newton, 1984). The knowledge-production of psychiatry and sexology thus not only served to label, pathologize and institutionalize lesbians, it also acted as a resource for the targets of the stigma to describe and interpret their experience and to collectively develop a sense of identity organized around their sexual difference.[26]

Acknowledging the importance and prevalence of concurrent resisting forces, Jeffrey Weeks points out that the new regulation of sexuality, of which the stigma of lesbianism is part, has had more than a unilinear historical impact.

> The history of sexuality is as much a history of an avoidance of, or resistance to, the moral code, as of simple acceptance and internalization. Cultures of resistance may stretch from the folk knowledges and information networks which sustained an awareness of abortion and birth control when they were tabooed or unlawful, to the specific subcultures of stigmatized sexual minorities. In more recent years the resistances have often adopted more explicitly political forms as sex-reform organizations or

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[26] Ester Newton (1984) and Laura Doan (2001) point out that the scientific constructions of the “mannish lesbian” assisted in both the stigmatization of lesbianism and the formation of a lesbian identity in the 1920s. The historical example of Radclyffe Hall’s novel “The Well of Loneliness” illustrates this point. The book was strongly influenced by Havelock Ellis’ inversion theory and was banned in the UK. The highly publicized obscenity trial then acted as a crystallizing moment in the construction of a visible modern lesbian subculture and a new, explicitly sexual lesbian identity in the English-speaking world. In a similar vein, Jeffery Weeks describes how the pioneers of modern homosexual politics “borrowed the common language of their contemporaries, especially the sexologists, and simply reversed their terms. The language of sexual science that , by and larger, denied the validity of homosexuality, was turned into a language which asserted its naturalness.” (Weeks, 1989:208)

> as sexual liberation movements. They are as much a part of history as the grander organization of sexual codes. (Weeks, 1981:15)

A crucial element of both the stigmatization of same-sex sexuality and the resistance to that stigma lies in the development of gay and lesbian identities in Western cultures. It has been noted that identity categories are both the basis of oppression and the basis of political power (Gamson & Moone, 2004). From a historical point of view, the stigmatization of lesbianism is part of a discourse that has fostered the creation of homosexuality as we know it today (Weeks, 1981). The development of a modern lesbian identity has been informed by religious, medical and legal arguments and interventions, but it has also transcended its inherent stigmatizing effects by providing the basis for community-building and political organizing against the stigmatization of the group.

Having outlined some of the historical developments that contributed to the stigmatization of women's same-sex sexuality in the United States, I now turn the focus on the experience of the targets of this stigma.

4.5 Research findings on stigmatization experiences

A large national survey reveals that homosexual and bisexual women report more lifetime and day-to-day experience with discrimination than heterosexual women (Mays & Cochran, 2001). The majority (58%) of self-identified lesbian and bisexual women (compared to 36% of heterosexual women) report having experienced stressful life events at some point in their lives, such as being fired or not being hired for a job, being discouraged from continuing education, being denied a bank loan or being hassled by the police. Lesbian and bisexual women also experience more day-to-day discrimination, including, "people act as if they think you're not as good as they are" (reported by 38% of lesbian and bisexual compared to 16% of heterosexual women), being "treated with less respect than other people" (reported by 29% of lesbian/bisexual vs 14% of heterosexual participants), "received poorer service at restaurants or stores" (27% vs. 11%), being "called names or insulted" (20% vs. 6%) and being "threatened or harassed" (15% vs. 3%). This study makes an important contribution by showing that lesbian and bisexual-identified women experience more discrimination than heterosexual women. However, it fails to specify to what degree these experiences occurred in relation to women's same-sex sexuality as opposed to their gender, ethnicity, or other factors that could be possible grounds of discrimination.

The National Lesbian Health Care survey asks specifically about discrimination experiences related to women's same-sex sexuality and finds that over half of the women in the sample (52%) were verbally attacked and 6% were physically attacked (Bradford et al., 1997). However, this survey is based on a predominantly white, middle-class sample and its findings might not reflect the situation of poor or ethnic minority lesbians. In a study of predominantly ethnic minority lesbian, gay and bisexual youth at a community based agency in New York City, the proportion of those who had experienced physical violence was much larger – 40% of teenagers had suffered from physical attacks (Hunter, 1990). Half of these incidents were directly related to their sexual orientation and 61% of sexuality related violent incidents occurred in their family environment. The study finds a high correlation between victimization and suicide attempts as 44% of those reporting violent assaults suffered from suicidal ideation and 41% of the girls (and 34% of the boys) had tried to kill themselves.

3.6 The stigmatization of bisexual women

Both women who identify themselves as bisexual and those who consider themselves lesbian are stigmatized on the basis of their same-sex sexuality. However, there might be differences in the stigmatization experiences of the two groups. Research on the stigmatization experiences of lesbian women is scarce, but there is virtually no research on the specific experience of bisexual women, with few exceptions (Herek et al., 1999; Mays & Cochran, 2001). One could assume that bisexual women experience less stigmatization because they form relationships with both men and women and only the latter are stigmatized, but the little empirical evidence there is does not support this assumption. A community based study of hate-crimes finds that 15 % of bisexual women (compared to 19% of lesbian women) experienced a crime against their person or property because of their sexual orientation (Herek et al., 1999). A large telephone survey of the general population shows that attitudes towards bisexual women are as negative as views of lesbian women; in fact, in this particular survey, bisexual women were viewed even slightly less favorably than homosexual women (Herek, 2002b).

It has been suggested that negative attitudes towards bisexual individuals not only derive from the stigma attached to same-sex sexuality, but also from associations of bisexuality with sexual promiscuity and disease transmission (Herek, 2002b). Furthermore, given the prevalent binary conceptualization of sexuality (into homo- and heterosexuality), bisexual women are viewed as in denial of their “true sexuality”, experimenting, merely following a trend (“lesbian chic”), and trying to “get the best of both worlds” without having to share the full burden of heterosexism (Rust, 2000). Bisexual women not only face prejudice in the heterosexual mainstream, but also in lesbian communities. Here, they are largely perceived as a threat (Rust, 1995). Bisexual women may thus not be able to use the lesbian community as a coping resource as much as lesbian women, which might limit their ability to buffer the negative effects of sexual stigmatization. On the other hand, it is conceivable that bisexual women who are in relationships with male partners may experience less day to day stigmatization than women in relationships with female sexual partners. Bisexually-identified women in relationships with female sexual partners, however, might not be protected by their bisexual identity or their relationship history with men, and they might be stigmatized on the grounds of both their same-sex sexuality as well as their bisexuality.

4.7 Consequences of sexual stigmatization on mental health

The stigma attached to women's same-sex sexuality has adverse effects on the emotional and physical well-being of its targets (DiPlacido, 1998; Mays & Cochran, 2001; Smith & Ingram, 2004; Solarz, 1999). Stigmatization reinforces secrecy (Klitzman & Greenberg, 2002) and can foster feelings of self-doubt and self-hatred (DiPlacido, 1998). Discrimination lowers women's quality of life and increases their chances of developing stress-sensitive mental disorders (Lewis et al., 2003; Mays & Cochran, 2001; Smith & Ingram, 2004). Lesbian and bisexual women report higher rates of anxiety disorders, suicidal ideation and suicide attempts compared to heterosexual women (Cochran et al., 2003; Matthews et al, 2002). Stigmatization has adverse effects on the mental health and well-being of the targets of stigma, but it is important to note that the majority of lesbians do not suffer from psychiatric disorders despite high levels of discrimination (Cochran et al., 2003; Mays & Chochran, 2001). This suggest that many lesbians learn to cope successfully with stigma, discrimination and "minority stress" (DiPlacido, 1998). Feminists have long emphasized the need to acknowledge women's personal agency within constraining social structures, i.e. their potential to create their own lives in conditions "not of their own choosing" (Personal Narratives Group, 1989: 5). Feminists of color reflect this tenet when they emphasize the importance of portraying women of color as more than victims of oppression (Anzaldúa, 1983, Lorde, 1984a). Not only women's experiences of stigmatization must thus be highlighted, but also their individual and collective strategies of avoiding, confronting and resisting this stigmatization (Hunter, 1999).

A limitation of most research on stigmatization experiences of lesbian and bisexual women to date is that it is most often conducted with samples dominated by white, well-educated women (see for example Bradford et al., 1997; DiPlacido, 1998). The experience of ethnic minority lesbian and bisexual women and those of lower socio-economic status remains by and large neglected. This constitutes a major drawback. It cannot be assumed that their experience of the stigma attached to same-sex sexuality necessarily resembles those of more privileged, White women in all respects. It is important to take the specific social situatedness of ethnic minority women into account and its possible influence on their experience of sexual stigmatization.

4.8 Lesbian and bisexual women of color

Feminists of color point out that ethnic minority women are subject to multiple and interlocking systems of oppression related to gender, class, race/ethnicity and sexuality (Collins, 2000; Combahee River Collective, 1983; Hull et al., 1979; Lorde, 1984b; Moraga et al., 1983). These interlocking systems of oppression have been referred to as "axes of difference" since they produce social differences and inequalities among women.[27] Criticizing the overtly homogenizing, white, middle-class bias of much feminist theorizing, feminists of color have pointed out that gender does not constitute the only or most important form of oppression in their lives. In 1977, the Combahee River Collective, a Black feminist organization in Boston, wrote:

> The most general statement of our politics at the present time would be that we are actively committed to struggling against racial, sexual, heterosexual, and class oppression and see as our task the development of an integrated analysis and practice based upon the fact that the major systems of oppression are interlocking. We (…) often find it difficult to separate race from class from sex oppression because in our lives they are most often experienced simultaneously. (1983: 210-13)

Using the metaphor of a bird cage, Marilyn Frye (1983) explains that it is not an individual wire, but the combination and network of wires that create the system of oppression that restricts women's movements, choices and opportunities. Multiracial feminist theory is committed to taking into account the many forms of oppression that shape women's lives. The task is to highlight how these join, overlap and relate, both on an institutional, structural level, as well as in the experience of individuals. Because of the interlocking systems of oppression, ethnic minority women might not experience the stigma attached to women's same-sex sexuality the same way as White women or women who are members of a different class. Given that most lesbian and bisexual women with HIV/AIDS in the United States are African American or Latina, I will now review selected literature on women's same sex sexuality among members of these two ethnic groups.

African-American[28] communities tend to be more socially marginalized than white communities due to the history of slavery and present day racism in US society. Average

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[27] Prior to the 1980s, the concept of "difference" was used in feminist discourse mainly with reference to gender systems and relations, i.e. signifying women's position in relation to men. Since the late 1970s, the term has been increasingly used to draw attention to within-group differences between women (for a critical review of the implications of this shift for socio-psychological research see Knapp, 2003). Theorizing on the "axes of difference" has also taken place under the term "intersectionality" and sexuality has been described as one among multiple and intersecting systems of identity and oppression (e.g. gender, race, class) (for recent reviews see Gamson & Moon, 2004; Stewart & McDermott, 2004).

[28] In this study, the terms "Black" and "African American" are used interchangeably even though "Black" is slightly more inclusive in that it not only pertains to people of African descent whose

household incomes and education levels are lower among African-Americans compared to White Americans: although Black people constitute only 13% of the general population, they account for 25% of people with an income below the poverty line (McKinnon, 2003). Racial segregation, discrimination and negative racial stereotypes still prevail. Stereotypes of Black women have a distinct sexualized note, a phenomenon that has been described as "sexualized racism" (Collins, 2000: 129). Beverly Greene summarizes the stereotypes of African-American women held by dominant White society:

> Today's stereotypes are riddled with a legacy of ethnosexual myths that depict African American women as not sufficiently subordinate to African American men, inherently sexually promiscuous, morally loose, independent, strong, assertive, matriarchal, and castrating masculinized females (…) African American women clearly did not fit the traditional stereotypes of women as fragile, weak, and dependent, since they were never allowed to be that way. They came to be defined as all of the things normal women were not supposed to be. (Greene, 1997: 118-119)

Black feminist Barbara Smith describes a resulting "demoralization of being female *and* colored *and* poor *and* hated" [italics in the original] (1983: xxxiv). African-American families and communities have an important function as a protective barrier against and refuge from the racism of the dominant culture (Greene, 1997: 119), but these communities are described as hostile towards lesbian women (Clarke, 1983; Mays et al., 1993). It has been noted that some African-American communities historically tolerated Black gays and lesbians as long as they kept their homosexuality private (Betsch-Cole & Guy-Sheftall, 2003). However, women who were "out" or known to be "in the life", i.e. publicly identified or identifiable as lesbians, were often labeled "dyke" or "bulldagger" (Greene, 1997; Mays, 1983) and considered "racial traitors" (Gluckman, 2001:472). They were stereotypically portrayed as unattractive "man-women" and "manhaters", and if they had a feminine appearance, it was assumed that they turned to women because they had been abused or disappointed by men in the past (Greene, 1997: 111; Hall, 1998, Shockley, 1983: 85).

The stigma attached to same-sex sexuality in Black communities has been described as reflective of the larger heterosexist culture of US society (Clarke, 1983) and also as a consequence of racism (Betsch-Cole & Guy-Sheftall, 2003). Racist stereotypes construct Blacks as sexual deviants and it is argued that this creates an imperative for Black people to assert their "normality" in the sexual arena. It thus becomes difficult for a "community under siege" to acknowledge its own sexual diversity (Betsch-Cole & Guy-Sheftall, 2003: 169).

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ancestors were forcefully transported to the United States under slavery, but also to those who migrated to the US more voluntary and more recently, for example from the Caribbean.

Because African-American families and communities provide important support and protection from racism, “coming out” and risking rejection as a lesbian might be particularly difficult for Black women (Greene, 1997). However, one should not assume that all African-American women feel equally connected to their family and ethnic minority communities. A study of ethnic minority lesbian survivors of childhood sexual abuse finds that some participants do not feel part of a family or community and do not strongly identify with their racial or ethnic background (Hall, 1998). The diversity of Black women’s experiences of community and of sexual stigma within their community must thus be acknowledged.

Latina women are also subject to multiple and overlapping oppressions on the basis of gender, class, ethnicity and sexuality, in some ways similar and in others different to Black women (Moraga et al., 1983).[29] Hispanic women in the United States are from a variety of cultures of origin including Mexico, Central America, South America, and the West Indies.[30] They do not constitute a homogeneous group as their social situation differs depending on their legal status, culture of origin, class membership, and level of acculturation.[31] Like African-Americans, Hispanic people tend to be more socially marginalized than White people. Representing 12% of the total US population, Hispanics constitute 23% of the population living in poverty (Therrien et al., 2000). Two in five Hispanics have not graduated from high school (compared to one in five Black people and one in 10 non-Hispanic Whites) and the proportion of Hispanics with Bachelors degree or higher levels of education is only 10.6% (compared to 17% of Blacks and 29% of Non-Hispanic whites) (McKinnon, 2003; Therrien et al., 2000).

Migration, and the acculturation process that follows, has been described as a disruptive experience that poses specific challenges and also opens up new possibilities for Hispanic women with reference to gender roles and sexual behavior (Espín, 1997). However, in many Latino communities, women’s sexuality is viewed as a signifier for the family’s value system and honor and deviations from the prescribed heterosexual gender role are not treated lightly (Espín, 1997). Hispanic families and communities in the US are often very closely knit which can create great pressures for women-loving women to

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[29] The oppression of Latinas historically differs from that of Black women: The Spanish colonization of Latin Americas also involved great cruelties, but not the same level of racial segregation and slavery as in North America. Spanish conquistadores took Native and Black women as concubines, but they also legally married them and acknowledged, supported and passed on their inheritance to their offspring from these marriages, thus creating a “Mestizo” population (Espin, 1992).

[30] The terms “Latina” and “Hispanic” refer to racially and ethnically diverse groups of women, including mixed-race, Black and White Hispanics. Latin communities in the US vary greatly by geographic location. While the Chicana movement in Texas and California is mainly created by Mexican immigrants, the majority of Latinas in New York are from Puerto Rico, the Caribbean and the Dominican Republic.

conform to (hetero)sexual norms. Gloria Anzaldúa describes how she is continuously required to claim and negotiate her sexual difference within her South Texan Chicano/Mexican culture. She notes, “White culture may allow its lesbians to leave – mine doesn’t” (1998:264).

Hispanic communities have been described as having well-established heterosexual gender norms where the cultural concepts of “machismo” and “marianismo” promote authority, extramarital sexual activities, drinking and physical abusiveness for men, and virginity, morality, devotion and suffering for women (Asencio, 1999; Stevens, 1973). Emotional and physical closeness between women is encouraged, but such behavior is not presumed to be sexual or lesbian (Greene, 1997: 133; Hidalgo et al., 1976/77). Homosexuality is strongly disregarded and a myth in Latino communities claims that lesbianism is a sickness which originated in Anglo-American culture (Espin, 1992). Derogatory labels for lesbians include “marimacho”, “tortillera”, and “de las otras” (Anzaldúa, 1998). Because of the stigma attached to lesbianism, many Latinas keep their attraction to other women secret (Cháves Leyva, 1998; Espin, 1992; Hidalgo et al., 1976/77). In some families and communities, women’s same-sex relationships are known and tolerated without being spoken about (Cháves Leyva, 1998; Espin, 1992; Hidalgo et al., 1976/77).[32] However, parallel to the development in other ethnic groups, Latina lesbians are increasingly “coming out of the closet” (Hidalgo et al., 1976/77). This does not mean that they necessarily identify as “lesbian”, a term that seems inappropriate to some, given its roots in AngloAmerican culture (Anzaldúa, 1998). Reclaiming terms such as “tortillera” may seem a more appropriate way to express their sexual identity in their own language even though these terms used to have a strong negative association (Torres et al., 2003).

In conclusion, lesbians of color face multiple burdens of stigma. The combination of homophobia, racism and gender-based oppression has been referred to as being in “triple jeopardy” (Greene, 1997). However, it is not clear whether these multiple forms of oppression add up to increased levels of stress or whether the combination of stigmatized identities might produce a different constellation altogether that renders women vulnerable

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[31] Puerto Rico is part of the United States which gives Puerto Ricans the right to “migrate” to the mainland while other Latinas have the legal status of “*im*migrants.”

[32] It should be noted that the quiet tolerance and “silence of knowing” described by Latina lesbians (Chávez Leyva, 1998) is not limited to Latino cultures and communities. For example Elizabeth Lapovsky Kennedy (1996) describes a similar phenomenon in a white middle-class community in South Dakota where lesbians who acted discreetly and refrained from talking about their love for women were tolerated at the beginning of the last century. Similarly African American communities are known to have tolerated gays and lesbians who kept their sexuality private (Betsch-Cole et al., 2003).

to devaluation while simultaneously providing them with unique skills and resources for coping and resistance.

A study on stigmatization experiences of an ethnically diverse sample of lesbians in the health care arena finds that sexual prejudice often surfaces in combination with other prejudices relating to women's race/ethnicity and class backgrounds (Stevens, 1998). Health care providers no only displayed blatant and subtle forms of sexual prejudice (e.g. a “halt in routine” and body language that signaled discomfort following the disclosure of women's sexual orientation), they also assumed that low-income African-American were uneducated (e.g. by speaking to them as if they had hearing difficulties) and that Latina lesbian participants were unreliable, unemployed and lazy (Stevens, 1998). In the experience of study participants, stigmatization on the basis of their sexual orientation was interlaced with being the target of sexism, racism and class-ism. Negative experiences with providers’ discriminatory behavior often increased levels of distrust and women felt compelled to change their providers. A small study of self-identified African-American lesbians showed that many of these women managed to avoid face-to-face stigmatization (on the basis of their same-sex sexuality) through secrecy and avoidance (Mays et al., 1993). However, being the (potential) target of racism, sexism and sexual stigmatization creates a predicament that limits these women’s relationship choices and their interactions with family members and communities.

Racial segregation has historically been a feature lesbian communities in the United States (Thorpe, 1996) and the experience of these women suggests that racism continues to be a dividing force in lesbian communities today. Participants described their ethnic communities as homophobic and the community of mainly White lesbians as racist, but more women chose to be actively involved in their ethnic communities (where they kept their sexual orientation hidden) than in the lesbian community (Mays et al., 1993). Over the past decades, queer communities of color have grown and become more visible in large urban centers. These communities can provide a safe haven from both racism and homophobia, but Latina lesbians describe that sexism constitutes a salient form of oppression in these mixed gender niches (Ward, 2004).[33]

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[33] Jane Ward (2004) shows that for Latina lesbians sexism constitutes the most salient form of every-day oppression in an HIV organization in Los Angelos. This qualitative study is an interesting case study of the intersections of gender, ethnicity, class and sexuality in the every-day life of these women. Latina lesbians working at this queer Latino HIV prevention provider are caught in a trap – they suffer from gender-based stigmatization in this niche, but homophobia, ethnic and class prejudices keep them from exploring options elsewhere. The perceived lack of HIV related needs of queer Latina women weakens their position to apply for HIV related funding which makes them economically dependent on queer Latino men (who can access HIV/AIDS funds). Unfortunately, Ward does not challenge the basic assumption of her self-identified Latina lesbian participants that HIV is not an issue for Latina women who have female sexual partners. This misperception weaves

These examples suggest that the multiply stigmatized status of ethnic minority lesbian and bisexual women constitute an important aspect of their experience as targets of the stigma attached to women's same-sex sexuality. Being the target of more than one stigma creates a unique predicament that forces women to carefully choose their allies. Close ties to one's ethnic minority community may shape this predicament in significant ways producing both special challenges and unique sources of support.

5 The stigmatization of HIV positive women

Since the beginning of the HIV epidemic in the United States, HIV/AIDS-related stigma has been strongly influenced by associations of HIV with male homosexuality and drug use. In the first decade of the epidemic, women were considered to be unaffected by the disease, except for female injection drug users and prostitutes. Invisibility and denial as well as pre-existing prejudices against drug use and sex work accompanied the socio-cultural construction of HIV related stigma.

5.1 Fears of a new, communicable disease

When the first cases of AIDS were reported in gay men in 1981, HIV/AIDS entered public awareness as an unknown disease that had fatal consequences. The new disease triggered fears of death and dying and its communicable nature fostered fears of transmission. As mentioned earlier in this chapter, the perceived danger of a condition significantly adds to the construction of stigma (Jones et al., 1984).

Science and medicine were struggling to understand the new disease, and available information was always partial, temporary and never certain. People were afraid of the new virus and misinformation about the risks of HIV transmission via casual contact such as sharing kitchen utensils or bathroom facilities with an HIV positive person fostered negative attitudes towards people with HIV/AIDS (Herek & Capitanio, 1993; Herek et al., 2002a).[34] Rational and irrational fears were a crucial element of social responses to this new epidemic. Paula Treichler further described a social "epidemic of signification" (Treichler, 1987:32) referring to a discourse that has produced numerous meanings and diverse conceptualizations of AIDS, including viewing HIV/AIDS as a gay plague, as punishment from God, or a CIA plot to destroy subversives.

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like a thread through the article and illustrates the specific intersection of HIV related stigma and lesbian identity constructions (Hollibaugh, 1993).

[34] With regards to fears of HIV transmission, Seth Kalichman notes the paradox that "a great deal of concern is exerted over contacts with low probabilities of HIV transmission while people continue to freely engage in sexual behavior that carry real risks of HIV transmission." (Kalichman, 1998:213)

The development of HIV related stigma is characterized by attributions of responsibility and blame to people with HIV/AIDS, negative affective responses to people with HIV/AIDS (such as anger, fear, or disgust), discomfort with and avoidance of people with HIV/AIDS and the endorsement of punitive and exclusionary policies (such as quarantine or publicly identifying people with HIV/AIDS) (Herek et al., 2002a). In the United States, the prevalence of stigmatizing attitudes and beliefs peaked in the 1980s and has decreased during the 1990s. However, in 1999, one in six survey respondents still admit to feelings of disgust related to persons with HIV/AIDS, one in five say they “feared” people with AIDS, and one in four believe that people who got AIDS through sex or drug use have got what they deserve and almost half of all respondents attribute responsibility to people with AIDS for having their illness (Herek et al., 2002a).

5.2 Associations with already marginalized groups

A characteristic of the socio-cultural construction of HIV related stigma in the United States lies in the fact that HIV/AIDS has mainly affected already marginalized groups of society (e.g. initially gay men and injection drug users and now increasingly people of color) and that its main routes of transmission are socially despised sexual and drug related behavior. In the construction of stigma in general, great significance is ascribed to the ways in which the condition is acquired (Jones et al., 1984). A greater degree of blame is attributed to individuals who are believed to have acquired the condition as a consequence of their choices and willful behavior compared to those whose condition is perceived to be outside of their control. In the case of HIV/AIDS, those who acquired HIV through blood products or mother-to-child transmission have been considered "innocent victims," while those who got infected through sex or drugs have been blamed for their infection and treated as if they deserved what they got (Kalichman, 1998). The construction of AIDS-related stigma is closely linked to preexisting prejudices against those initially mainly affected by the disease:

> AIDS stigma has been layered upon preexisting societal stigma toward outgroups affected by HIV. Consequently, cultural AIDS stigma has been closely intertwined with the stigma associated with drug use, homosexuality, poverty, and racial minority status. (Herek et al., 1998: 39).

Early on, the Centers for Disease Control and Prevention (CDC) established a list of high risk categories, the “Four H’s”, in an attempt to describe the groups most at risk of HIV: Homosexuals, Hemophiliacs, Heroin addicts and Haitians.[35] This construction of "risk groups" inadvertently implied that the so-called general population was safe and

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[35] Illustrating the “epidemic of signification” (Treichler, 1987), different versions of what the CDC’s “4-H-Club” entailed soon emerged – one version included prostitutes who were also perceived as

unaffected. It amplified already existing prejudice towards members of these risks groups and fostered distinctions between “us” (the supposedly safe, general population) versus “them” (those “others” who are at risk of or infected with HIV) (Gorna, 1996; Treichler, 1999). The stigmatizing effects of these epidemiological practices were strongly criticized by HIV/AIDS activists (The ACT UP/NY Women and AIDS Book Group, 1990).

5.3 Invisibility and new visibility of HIV/AIDS in women

In the first decade of the epidemic it was widely believed that women were rarely infected.[36] In retrospect, the earliest occurrence of HIV in the United States can be traced back to a pregnant woman in New York City in 1979 (Gilden, 2001). At the time, however, this case was not related to the new illness perceived to affect only gay men. Initially labeled *Gay Related Immune Deficiency* (GRID) its name was later changed to *Human Immunodeficiency Virus* (HIV) and *Acquired Immune Deficiency Syndrome* (AIDS). In the 1990s, after years of protests and activism, women’s health and HIV/AIDS activists finally succeeded in drawing attention to the fact that women were living with and dying of HIV/AIDS as well (The ACT UP/NY Women & AIDS Book Group, 1990). In 1993, after having won a class action litigation, HIV positive women were finally included in clinical trials for new treatments, and the Centers for Disease Control and Prevention (CDC) added women-specific criteria, such as recurrent cervical cancer, to the list of AIDS-defining illnesses (Campbell, 1999).

As HIV positive women became more visible in public discourse, a main concern of politicians, journalists and policy makers centered on women’s reproductive role and the risk of vertical HIV transmission from mother to child. Women with HIV/AIDS were now portrayed as sources of infection, as “vessels” and “vectors” of disease (Gorna, 1996:167ff; Treichler, 1987). The "Baby AIDS campaign" serves as an example. In 1993, conservative politicians in New York launched a campaign to “unblind” the results of a survey of HIV prevalence in newborns and to inform the mothers who participated of their children’s HIV status (Booth, 2000). The survey was an anonymous surveillance study to determine the prevalence of HIV in newborns. Its results were intended for research

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diseased and at risk: in 1986 the media reported the four “H”s stood for “homos, heroin addicts, Haitians and hookers” (Treichler 1999:53).

[36] Heterosexual transmission of HIV was considered unlikely because women’s “rugged vagina” was thought to be less permeable compared to the more “vulnerable anus” and the “fragile urethra” through which men got infected during sexual intercourse (Treichler 1987: 37). It was also assumed that women were unable to transmit HIV to male sex partners as their bodies lacked the projectile capacity of a penis or syringe. Female prostitutes, however, whose bodies have been traditionally viewed as contaminated and contagious, were considered an exception. HIV transmission from female prostitutes to male clients was described to occur because prostitutes performed only “perfunctory external cleansing between customers” so that the vagina functioned

purposes only, not as a diagnostic tool, and none of the women received HIV counseling. Given that newborns inherit their mother’s antibodies and only develop their own immune system months after their birth, testing newborns for HIV is in effect a test of the mother’s HIV status. Women’s health advocates at the time thus objected to the “unblinding” of the study because this would mean hundreds of ill-prepared mothers would involuntarily receive their HIV test results.[37] Proponents of the campaign on the other hand highlighted supposed benefits for the babies and implied that women of color (who constituted the great majority of women tested) were unable or unlikely to get tested for HIV on their own initiative. The campaign portrayed HIV positive mothers as poor, powerless women of color who were in need of state intervention to save their "innocent" babies (Booth, 2000). This campaign struck a chord with prevalent attitudes in the general discourse and it succeeded when the Governor signed an executive order mandating that mothers be informed of their infant's (i.e. their own) HIV status in 1996. This decision represents a patronizing stance towards marginalized women and their children, yet at the same time it is unconcerned about the psychosocial consequences of an HIV diagnosis for the women. In this sense, it provides a good illustration of the new public awareness of HIV/AIDS in women which has generally been unconcerned with the health and well-being of the women while emphasizing their reproductive role and placing their rights and needs in opposition to the well-being of their children and sexual partners (Treichler et al., 1998).

5.4 Social marginalization of HIV positive women

The stigmatization of HIV positive women that accompanied their increasing visibility is closely tied to the social conditions of most women with HIV/AIDS. In 1992, sociologist Beth Schneider wrote:

> Without attention to the intersections of gender, class and race, it is next to impossible to understand the particular situation of the vast majority of HIV infected women. (Schneider, 1992: 28)

Most women with HIV/AIDS in the United States are socially marginalized, both within the HIV community and in the larger society. African American and Latina women represent one-quarter of the general female population in the United States, but account for 79% of

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as a "reservoir" of infected sperm (Kant 1985; Treichler, 1987: 49). These examples illustrate inherent biases in supposedly "objective" scientific conceptualizations of HIV transmission.

[37] HIV/AIDS activists also objected to informing the mothers of their HIV status because prior to 1996 very few medical treatments were available, and the benefits of knowing one’s HIV status did not seem to outweigh its drawbacks in terms of psychological distress and stigmatizing effects. The value of knowing one’s HIV status has increased dramatically since the development of Highly Active Anti-Retroviral Therapies (HAART), or combination therapy. These new treatments can make a tremendous difference in terms managing the disease, prolonging life and increasing well-being. It has thus become more advantageous to know about one’s HIV infection early on. These medical benefits do no undo the concerns about the lack of women’s counseling and consent to be tested in the case of the “Baby AIDS campaign”, however.

AIDS cases among women (Centers for Disease Control and Prevention, 2004). Most HIV positive women have low-incomes, many have child care responsibilities and more than a third have a history of injection drug use. These characteristics have placed HIV infected women at a special disadvantage and negative stereotypes about women of color and female drug users have permeated the discourse on women and AIDS. A few White, middle-class women with HIV/AIDS became public figures in the AIDS discourse and they were usually constructed as “innocent victims” who were infected through blood products, health care professionals or unfaithful husbands (Treichler et al., 1998:116). HIV positive women of color, on the other hand, were presented as hypersexual whores, irresponsible mothers, and threats to their communities (Hogan, 1998). Cindy Patton suggests that HIV positive minority women with competing life demands and little access to formal education have generally had a more difficult time getting involved in the kind of AIDS activism that gay men have so successfully engaged in to advocate for their needs (1998). Those who succeeded in doing so despite the odds have been treated as “exceptions,” but negative stereotypes of HIV positive women of color have by and large remained intact (Patton, 1998:xii).

5.5 Research findings on stigmatization experiences of HIV positive women

From the perspective of the target of HIV related stigma, stigmatization unfolds its negative effects both internally and interpersonally. A rich body of literature documents that an important aspect of living with HIV/AIDS involves dealing with the stigma attached to it (Barosso et al., 2000, Hackl et al., 1997, Weitz, 1990). The majority of studies on the stigma of HIV/AIDS focus on HIV positive gay men for whom the experience of HIV related stigma is closely linked to the stigma attached to male homosexuality (Siegel et al., 1998; Weitz, 1990). For HIV positive women, on the other hand, associations of HIV with female homosexuality generally do not enter the equation.[38] Their stigmatization is rather tied to negative views of women’s drug use, prostitution and heterosexual promiscuity (Roth & Hogan, 1998; Treichler, 1999).

HIV positive women describe stigma-related concerns about rejection, shame and abandonment as primary concerns in their lives and illness experiences, followed by apprehensions about their children, the need for social support, and concerns related to death, dying and despair (Hackl et al., 1997). Focus groups with HIV positive women revealed that four main themes characterize women’s stigma-related experiences:

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[38] There is anecdotal evidence that early on in the epidemic, lesbians were on a few occasions subjected to HIV related stigmatization based on people’s misperception that all homosexuals, male and female, were equally affected by HIV/AIDS (Goldstein, 1997; Richardson, 1988; Treichler, 1987). However these few instances of stigmatization by association were the exception. By and large, lesbians were thought to be unaffected by the HIV epidemic (Hollibaugh, 1993).

distancing, over-generalizing stereotypes, social discomfort, and pity (Moneyham et al., 1996). Distancing was described as people turning away and limiting or ceasing social contact once women had disclosed their HIV infection. This was perceived to be largely motivated by fear and misperceptions that HIV is highly contagious. HIV positive women also felt that others are overly preoccupied with the source of their infection, believing that only "bad" people get HIV/AIDS. This was confirmed in an Australian study where HIV positive women described that they were generally assumed to have injected drugs, engaged in sex work or had promiscuous sex, and were subsequently stereotyped as irresponsible, polluted, untrustworthy and unfit to be mothers (Lawless et al., 1996). Participants of both studies reported that health professional doubted their judgment and refused to start or proceed with a diagnostic procedure or treatment once they learned that a woman was HIV positive (Lawless et al., 1996; Moneyham et al., 1996). As a consequence, they developed a number of strategies to deal with and avoid discrimination in the health care setting, including secrecy, "shopping around" for less prejudiced services and practitioners, and avoiding or withdrawing from services and support networks (Lawless et al., 1996, Moneyham et al., 1996).

Stigmatization is also prevalent outside of the health care arena. A study of HIV positive women in the US found that 44% reported negative responses from others including loss of friends, being insulted or sworn at, being rejected by family members and physical and sexual assaults following the disclosure of their HIV status (Gielen et al., 2000). Some women face violent responses from their male partners when disclosing their HIV status (Gielen et al., 1997; Gielen et al., 2000). A nationally representative study of adults receiving HIV treatment and care in the US found that 20.5% of women experienced physical abuse since receiving an HIV diagnosis, and in half of these cases, the violence was directly related to their HIV status (Zierler et al., 2000). However, stigmatization is not restricted to blatant forms of prejudice and violence. Some people communicate social discomfort more subtly, for example by not acknowledging or talking about the illness or by being tense and uncomfortable in HIV positive women's presence. Pity, as the fourth stigma-related theme identified by HIV positive women (Moneyham et al.,1996), communicates that the other person perceives them as fundamentally different and "worse off." Pity accentuates the hardship of their situation and the fatality of their illness and is thus experienced as stigmatizing, even though it is often well-intended and generally less focused on blame and rejection as other forms of stigmatization.

Studies reveal that HIV positive women also struggle with self-stigmatization. A participant of the focus group study described above explained, "Even for myself there was a stigma, when I first found out I was HIV positive" (Moneyham et al., 1996: 164). In the Australian study, HIV positive women reported that they were not only treated as if they were “dirty, diseased and undeserving” but also that they shared this perception to some degree. Some feel responsible for getting infected and blame themselves for passing the infection on to others (Lawless et al., 1996). Endorsement of self-stigmatizing views seems to be particularly strong in HIV positive people who were recently diagnosed with HIV, who never attended an HIV support group, who know few people with HIV and whose families are non- accepting of their illness (Lee et al., 2002).

Alonzo and Reynolds (1995) point out that the experience of HIV related stigma is affected by the course of the illness and the biophysical changes HIV infected individuals are undergoing. The authors distinguish four phases of the stigma trajectory: *1) At risk*: individuals who are not yet tested but who perceive themselves at risk might develop what is called a “worried well” symptomology (i.e. obsessive over-worrying) or they might respond with denial and avoid getting tested for fear of having the life-threatening and stigmatizing disease; *2) Diagnosis*: individuals who test positive for HIV have to confront an altered identity and come to terms with the news of a shortened life span, the prospect of illness and death and what they now symbolize to society. Most newly diagnosed individuals respond with disbelief, numbness and denial followed by anger, anxiety and depressive symptoms and they have to decide whom to tell about their HIV status. First responses (for example of health care providers and loved ones) to disclosures of their HIV infection can have a significant impact; *3) Latent phase*: most HIV infected individuals remain symptom-free for a number of years; this phase is often characterized by isolation, fear of rejection, feelings of shame and self-blame and attempts to keep the diagnosis hidden. On the other hand, individuals who choose to disclose their HIV status during this asymptomatic phase can choose a time and mode that might soften negative responses; *4) Manifest stage*: during later, symptomatic stages of the disease physical symptoms such as Kaposi’s sarcoma or wasting syndrome can render the condition visible and trigger negative responses. However, responses are often ambivalent. Sympathy and pity for an ill and dying person can be mixed with disgust or fear. This phase can also include more frequent disclosures, as people with AIDS are more dependent on care takers and they might want to prepare loved ones for their death.

Alonzo and Reynolds (1995) conceptualized this stigma trajectory as a uni-linear downward development in the mid 1990s. Improvements in medical treatment options have since turned HIV/AIDS into a chronic disease (at least in industrialized countries, such as the United States, where combination therapy treatments are widely available) and it is not unusual that individuals who develop AIDS will recover when they receive appropriate treatment, thus moving from the manifest stage back to the latent phase (Kalichman, 1998; Siegel & Lekas, 2002). These medications, however, often have side effects, some of which are visible such as lipodystrophy, a fat redistribution in the body.

We may thus want to add a fifth stage to the stigma trajectory: that of the HIV infected individual on HAART who might live many years with transient symptoms or medication side effects but in relative good health. The medical management of the disease might bring unique challenges for stigma management but the individual might also find social support from peers in the HIV community. During this phase some individuals may decide to go back to work which also requires them to make decisions about how to manage the potentially stigmatizing information about their HIV status. For women, the advances in treatment and prevention of mother-to-child transmission of HIV might make pregnancy a more feasible option and these women may encounter increased levels of HIV related stigmatization when people are concerned for the well-being of the child. Overall, it is important to note the potential influence of physical changes, including pregnancy, and illness course on HIV positive women's experience of HIV related stigmatization.

5.6 Consequences of HIV related stigmatization

HIV related stigma has serious adverse consequences for women's emotional well being and physical health. Stigma fosters fear and secrecy. Women report not disclosing their HIV status because they anticipate negative responses which fosters a sense of isolation and loneliness (Gielen et al., 1997, Moneyham et al., 1996). Furthermore, stigma affects women's health seeking behavior and access to health care. A study of ethnic minority women with HIV/AIDS in New York City found that women's psychological responses to learning about having this possibly fatal and highly stigmatized disease constituted the main barrier to seeking health care (Raveis et al., 1998). Other factors such as substance use, incarceration, financial constraints, limited knowledge of treatment practices and lack of trust in the medical profession also contributed to the delay in seeking medical care. However participants' denial of being infected and their fear of stigmatization were described as the main reasons for the delay.

5.7 Coping with HIV related stigma

As mentioned earlier, HIV positive women respond to stigma by keeping their stigmatized attributes (e.g. HIV, drug use, sex work) hidden, by avoiding contact with persons whom they know or believe to be prejudiced and by carefully choosing persons and services with whom they interact (Moneyham et al., 1996). Studies on stigma management in HIV positive gay men by and large confirm these strategies (Weitz, 1990; Siegel et al., 1998). Efforts to hide their illness include concealing evidence of the use of HIV/AIDS medications and concealing symptoms of the disease, for example by wearing clothing or make-up that conceals wasting syndrome, Kaposi's Sarcoma or other skin rashes. Secrecy extends to devising plausible alternative explanations for their symptoms, for example attributing them to less stigmatized illnesses such as leukemia or cancer. Some HIV positive gay men report that they go along with jokes about people with AIDS and pretend to find them funny so as to not raise any suspicion (Weitz, 1990). While offering some protection, strategies of hiding one's illness clearly come at a price. Rose Weitz notes in her study with HIV infected gay men:

> Those who choose not to tell friends or relatives must endure their illness alone and in silence, without support they might otherwise receive. They must also endure the emotional strain caused by the secrecy itself (Weitz, 1990: 34).

Because both hiding and disclosing one's HIV status involves social risks, most people with HIV/AIDS carefully choose whom to tell about their illness and when and how. Siegel and Kraus (1991) identified four considerations that influenced gay-men's disclosure of their HIV status: fears of rejection, the wish to avoid pity, the wish to spare loved one's emotional pain and concerns about discrimination. Concealing one's HIV status can also be part of a larger effort to maintain as much normalcy in one's life as possible.

To avoid stigma, HIV positive people are found to reduce contacts with friends and relatives who prove non-supportive, maintaining social contacts mainly with "the own and the wise" (Goffman, 1963:19). In large urban areas, people with HIV/AIDS have opportunities to join support groups to replace their former social network. Although socializing with other people with HIV/AIDS reduces some stigma-related problems, it is not necessarily a safe haven as tensions along the lines of gender, race, sexuality and route of transmission can also lead to devaluation and ostracism. A study with gay and bisexual men with HIV/AIDS finds that some participants defend themselves against stigmatization by distancing themselves from other infected individuals and by attributing the cause of their infection to a more socially acceptable cause than homosexual sex or drug use (Siegel et al., 1998). Other participants are reported to be critical towards themselves. They condemn their own past behavior and seem to hope that a public confession and display of contrition will soften other's negative judgements toward them (Siegel et al., 1998; Weitz, 1990).

Based on the extent to which they implicitly accept or challenge the social norms that underlie the stigma, strategies of managing the stigma of HIV/AIDS have been identified as ranging on a continuum from reactive to proactive (Siegel et al., 1998). Reactive strategies include concealment, selective disclosure and personal attributional strategies, such as distancing oneself from others with HIV/AIDS and attributing their HIV status to a less stigmatized source of infection. These strategies have protective effects and shield individuals from social devaluation, at least some of the time, but they are limited in their effect, they do not reduce stigma and they often involve a degree of self-stigmatization.

More proactive strategies that challenge the stigma itself include: discrediting the discreditors, challenging moral attributions, preemptive disclosure, public education strategies and social activism (Siegel et al., 1998). Discrediting those who seek to discredit them can involve questioning legitimacy of act of stigmatization and the motives of those who condemn and reject them. Challenging the moral attributions inherent in HIV related stigma involves questioning the distinction between “innocent” and “guilty” victims based on the route of transmission. Moral judgments and interpretations of the disease as “punishment from God” are criticized and the disease is framed in biological or medical terms instead, for example by pointing out that “the virus does not have a morality” (Siegel et al., 1998:17). Another form of counteracting the stigma of HIV through alternative attributions consists in interpreting the disease as a source of moral enhancement rather than moral stigma. From this perspective, acquiring HIV is seen as a blessing that transformed a person’s life rather than a burden that added a moral taint. Preemptive disclosure as a third proactive strategy refers to individuals who disclose their HIV status widely in order to control the exchange of information, to bring the topic up in their own terms and to demonstrate that being infected with HIV is not shameful. Many use this strategy in combination with public education strategies whereby HIV positive individuals discuss HIV and stigma related issues in public in an attempt to alter the discourse on AIDS and change misperceptions and prejudices that contribute to the stigma of HIV/AIDS. The most proactive strategy, according to Siegel and colleagues, consists in engaging in social activism that aims at policy changes and builds resources to combat the HIV epidemic and its social sequelae.

Studies of stigma management strategies have been conducted with HIV positive men only. However, we cannot assume that HIV positive women necessarily use the same strategies as HIV positive men. Major differences exist between HIV positive men and women in terms of their social location and socio-cultural constructions of HIV related stigma. For HIV positive women, who tend to be low-income women of color, HIV related stigma is embedded in racism and discrediting notions about prostitutes and female drug users. As described at the beginning of this chapter, most HIV positive women are struggling with competing life demands, including parenthood and caretaking responsibilities, in the context of great social marginalization. Amidst the multitude of challenges, HIV/AIDS does not always constitute their single most important concern (Ciambrone, 2001; Farmer et al., 1996; Ward, 1996). The problems of HIV related stigma might thus be vast, but not the greatest of their worries. How HIV positive women manage their HIV related stigmatization warrants closer examination.

6 Conceptualizing multiple stigmatization of lesbian and bisexual mothers with HIV/AIDS

6.1 Experiencing the stigmas of HIV and same- sex sexuality in tandem

The previous sections showed that both lesbian and bisexual women and HIV positive women are stigmatized in US society. The question this study aims to explore is: how do lesbian and bisexual women who are also living with HIV/AIDS experience multiple stigmatization? The available evidence suggests that these women face a particularly difficult subject position. Both their HIV infection and their same-sex sexuality have stigmatizing effects in most social settings and the socio-demographic profile of the group implies that many of these women have further potentially stigmatizing characteristics, such as belonging to an ethnic minority, having experience of substance use and criminal records. These additional characteristics as well as their low socio-economic status most likely shape women's experience of the stigmas attached to their HIV infection and their same-sex sexuality.

The stigmas of HIV/AIDS and lesbianism have been researched separately, but no study to date explores how both stigmas are experienced in tandem. Studies of lesbian women in the context of HIV/AIDS have focused on their role as care takers of HIV infected gay men, but very few studies address the situation of lesbian and bisexual women who are themselves infected with HIV. Some of the qualitative studies with HIV positive women, however, provide brief glimpses of lesbian and bisexual women with HIV/AIDS. For example, one study notes the challenges that HIV positive lesbians face, such as disbelief and pressure from doctors to 'admit' to sex with men or sharing needles (Lawless et al., 1996). Another study mentions that children had greater problems accepting their mother's "coming out" as lesbian than her HIV infection (Wright, 2003:35). These examples illustrate the need to explore how the stigmas of HIV/AIDS and lesbianism affect HIV positive lesbian and bisexual women while taking into account that many of these women are mothers.

As described above, women's HIV infection is associated with injection drug use, sex work and promiscuity, and HIV positive women are stereotyped as irresponsible, polluted, untrustworthy and unfit to be mothers (Lawless, 1996; Roth & Hogan, 1998; Sacks, 1996; Treichler, 1999). Similarly, lesbian and bisexual women were shown to experience social devaluation and rejection due to the stigma attached to women's same-sex sexuality. Lesbianism is disregarded as immoral and unnatural and negative stereotypes depict lesbians as sick, psychologically unstable, aggressive, masculine, and abusive (Eliason et al., 1993; Greene, 1997; Hidalgo & Hidalgo Christensen, 1976; Simon, 1998; Shockley, 1983). Despite increasing public acknowledgement of lesbian and gay parents, lesbian mothers are still believed to be ‘bad mothers’ and HIV positive women are viewed as threats to their children (Falk, 1993). Both stigmas imply a failure in the expected traditional gender roles for women as caretakers and moral guardians.

6.2 Parenthood and its possible effects on stigmatization

Parenthood is not only a common yet overlooked aspect of these women’s lives, it also provides an interesting angle on stigmatization. Women are generally supposed to be healthy, heterosexual caregivers. This is even more the case when they have children and the social construction of “motherhood” takes hold. HIV and same-sex sexuality disrupt these expectations and are perceived as placing these women’s (born and unborn) children in danger. Motherhood might thus act as a catalyst for stigmatization since it increases normative expectations and adds another dimension of “peril” to the construction of the stigmas (Jones et al., 1984).

6.3 Study approach and research questions

From the subject position of stigmatized groups and individuals, stigma can be conceptualized on three levels: 1) *on a socio- cultural level:* cultural discourse, laws and regulations, social conditions, prejudiced language and imagery; 2) *interpersonally*: being stigmatized in face-to-face interactions and witnessing others being stigmatized; and 3) *intra-personally:* as anticipated stigmatization and/or self-stigmatization, including self-blame and feelings of shame. The first two levels of women’s experience of stigmatization based on their HIV infection or their same-sex sexuality have received by far more research attention than the third level. This study will focus on women’s subjective experience of their experience of multiple stigmatization. Appropriate methods are chosen to allow women to describe their experience of stigmatization on all three levels in their own words.

An investigation of the experience of the targets of stigma has to attend to the active role of the stigmatized in the stigmatization process. In doing so, this study thus aims to reach a better understanding of stigmatization processes and of coping achievements of highly marginalized women who are prone to high levels of multiple stigmatization. In short, this study aims to investigate:

a) how lesbian and bisexual women who are also HIV positive experience multiple stigmatization based on their HIV infection and same-sex sexuality;
b) how women’s role and status as parents affect their stigmatization experience;
c) how these women cope with and resist their multiple stigmatization.

Chapter 2 Methods and Sample

1 Study design, data collection and analysis

1.1 Using an exploratory approach

Investigating multiple stigmatization of HIV-positive mothers who have female partners entails exploring a new topic in an understudied population. An exploratory, inductive approach using qualitative research methods thus provides an appropriate avenue of data collection and analysis. Qualitative inquiry is defined as attempting to interpret phenomena in terms of the meanings people bring to them in a naturalistic setting (Denzin & Lincoln, 1994). My aim is to explore the meanings that HIV-positive bisexual and lesbian mothers bring to their experience of multiple stigmatization. The two main settings where I met and interviewed study participants include community-based HIV support structures and participant's homes in New York City, 2001-2003.[1]

1.2. Entering the field

As described in the previous chapter, people with stigmatized attributes often retreat to secrecy and social isolation to protect themselves from stigmatization. One of the main challenges implicated by my research questions thus lay in finding the women I was interested in. To methodologically meet this challenge, I decided to approach the field carefully with a three-step study design. As a first step, I interviewed key informants, i.e. people who were 'in the know' but did not necessarily share the stigmatized attributes. With this first step I aimed to gain initial insights into the phenomenon of multiple stigmatization of HIV-positive mothers who have female partners in New York City. I was aware that as a researcher, and an immigrant, I was an "outsider" to the field of study who needed to be educated about the social, economic and legal context of the phenomenon. I also knew that I needed additional help with recruitment and I hoped that once I developed a trusting relationship with my key informants, they would support my subsequent efforts to contact women whose stigmatization experience I was eager to learn about. As a second step, I screened women with same-sex sexual experience who were parents and HIV-positive. This provided me with a "pool" of potential interview

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[1] This study received financial support from the HIV Center for Clinical and Behavior Studies, New York State Psychiatric Institute and Columbia University (Pilot study grant award, Jan 2001), and ethical approval from the New York State Psychiatric Institute Institutional Review Board (IRB Protocols 4170, 4439).

partners from which I chose a small number of women to conduct the third step of data collection, repeated in-depth interviews.

I was fortunate in that I was able to benefit from an infrastructure of support available to HIV-positive lesbian and bisexual women in New York City. The Lesbian AIDS Project (LAP) was founded at Gay Men's Health Crisis (GMHC), a large community-based service provider to people with HIV/AIDS, in the early 1990s. This program provides social support and HIV prevention services to HIV positive and HIV negative women who have sex with women. The Lesbian AIDS Project is part of the larger women's and children's department at GMHC, and the director of this department, Talata Reeves, acted as one of my advisors. Her support was pivotal for this project. She helped me find interview partners and she also provided me with office space to conduct interviews. I made a conscious effort to also include women as participants who were not already part of these lesbian-friendly HIV support structures, and I achieved this goal in the pilot study, but the majority of my in-depth interview partners were connected to GMHC or LAP.

1.3 Step One: A pilot study with key informants

Key informants are persons who possess special knowledge and expertise in a particular setting (Gilchrist, 1992). Key informants usually provide researchers with "insider" information and links to the community, i.e. they act as gatekeepers. Eligibility criteria to participate as a key informant in my pilot study include a) familiarity with the situation of HIV-positive mothers who have had sex with women in New York City; and b) willingness to participate in an interview in the English language. Key informants had to know a number of women with HIV infection, parenting and same-sex sexual experience either through work, activism or personal experience. I was particularly looking for advocates, service providers and others whom Goffman describes as "the wise" (1963: 19), i.e. people who do not possess the stigmatized attribute but who are part of the support networks of stigmatized individuals. However, given the strong involvement of HIV-positive people as advocates, service providers, and peer educators in the field of HIV/AIDS policy and service provision, I was aware that some key informants might be members of the "target population" (i.e. HIV-positive mothers with same-sex sexual experience) themselves.

Key informants were recruited through various means (number in brackets indicates the number of participants recruited this way):

- They were suggested by community leaders and project advisors (4);
- They were identified as advocates and public speakers on the basis of published material (e.g. HIV newsletters and internet sites) (3);

- Local health and social service providers to women with HIV/AIDS were contacted and these organizations identified a person within their organization who had appropriate expertise (2);
- The study was announced at HIV-related public events and participants referred themselves (2);
- Participants were chain-referred by other key informants (3).

Fourteen female key informants were interviewed March-June 2001. Their informed consent was sought prior to the interview and they were each reimbursed with $20 for their time. The format of a “problem-centered interview” (Witzel 1982, 1985) was chosen as it provides a structured focus on a specific problem (in this case, the stigmatization of lesbian and bisexual mothers with HIV/AIDS in New York from the perspective of key informants) while allowing some flexibility in the application of the interview guide. Problem-centered interviews include a short questionnaire assessing basic demographic data, an interview guide, tape-recording of the interview and post-interview notes assessing the immediate subjective impressions of the interviewer (Witzel 1982, 1985). The fourteen interviews with key informants lasted between 1-3 hours each. Participants were encouraged to discuss their area of expertise and to describe characteristics of members of the “target population” in terms of socioeconomic status, race/ethnicity, sexuality, drug use, incarceration, motherhood, HIV service provision and stigmatization experiences. They were also asked to describe social structures and contextual factors such as laws, policies and regulations (e.g. with regards to drug use or child custody) that affected the lives of HIV-positive mothers who had female sexual partners in New York City (for interview guide, see appendix).

To stimulate discussion of multiple stigmas, I administered a model that involved the visualization of labels including “HIV+”, “lesbian”, “drug user”, “woman of color”, “bisexual”, “sex worker”, and “mother” (see appendix). Participants were encouraged to describe stereotypes (“prejudices”) associated with each label and specific incidences of stigmatization (“discrimination”) that they witnessed or experienced in association with the label. Key informants could pick and choose which label or label combination they wanted to discuss and additional labels could be added. Participants added the labels “butch”, “femme”, “cachapera/ tortillera” (a derogatory Spanish term for Latina lesbians), and “class” as these marked important differences in women's stigmatization experiences.

I took notes during recruitment procedures and immediately after each interview. Post-interview memos captured the situational context (e.g. setting, interruptions, privacy) and my subjective impressions of the interview, including rapport, highlights, surprises and regrets about the interview. All interviews were audio-taped and transcribed verbatim by a transcription agency. I double-checked the accuracy of the transcriptions to increase descriptive validity of the data (Maxwell, 1992). This turned out to be essential as the professional transcribers seemed rather unfamiliar (to say the least) with the language and culture of HIV/AIDS, drug use and, in particular, women's same-sex sexuality.[2] I conducted a preliminary analysis (using grounded theory procedures as described below) to get a first understanding of the local situation of HIV-positive bisexual and lesbian mothers. I was especially interested in their socio-demographic profile, the kinds of stereotypes they were confronted with and how stigmatization affected their lives from the perspective of people in their support system. Preliminary findings were reviewed by participants for validation purposes in October 2001, a procedure also referred to as "member checks" (Taylor & Bogdan, 1998). The feedback from key informants was incorporated into the analysis and the design of the subsequent steps of the research project.

1.4 Step Two: Screening Interviews

As a second step, from September 2002-January 2003, I screened 29 women who had children or parenting experience, who were HIV positive and infection and reported lifetime experience of sex with women.

The pilot study with key informants had revealed that parenthood comes in different forms. Some women have biological children, but not all have these in their care. Non-biological forms of parenthood are also very common, e.g. women care for biological children of their female partners or children of other people in their extended families. Some women adopt these non-biological children, but most of the time, such arrangements remain informal. Given that this study aims to explore the role of parenthood for women's stigmatization experiences, a social, not purely biological, definition of parenthood was needed that was inclusive of the range of parenting arrangements. Women were thus eligible to participate if they either had given birth to a

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[2] For example, the transcription agency transcribed Lola's exclamation (in response to her sister's accusation that she wished every woman was a lesbian), "Oh, no! It's an honor to be a lesbian!" (PS01: 617) as "It's harder to be a lesbian." This was not the only notable transcription mistake. Numerous misunderstandings and omissions (i.e. sequences marked as "inaudible") revealed biases that were often illustrative of the stigmas attached to lesbianism, drug use and HIV/AIDS. In this case, Lola's distinctly positive interpretation of what it meant to be lesbian was not heard and in another case, Olga was transcribed as saying "Oh, I hate my kids. Why God gave me kids? I should have been dead before I had those kids," when the tape in fact said, "I should have been gay (not "dead") before I had those kids." (21.1: 208-9; Olga said these things in a rage to her female partner when they argued over how to raise the partner's daughter.) These transcription mistakes and omissions show how our beliefs and worldviews structure and limit our abilities to even hear each other. It would be interesting to have a third person double-check my revisions of the interview transcripts as my understanding of participants' narratives inevitably entails biases, too.

child or if they reported any kind of parenting experience with non-biological children in the present or past.

Similarly, the criteria of women's same-sex sexuality was based on a very broad definition that aimed to be inclusive of diverse forms of lived experience. The Committee on Lesbian Health Research at the Institute of Medicine recommends that researchers tailor their definition of women's same-sex sexuality to the needs of their study (Solarz, 1999). Recognizing that there is no one "right" way of defining lesbian or bisexual women, the committee notes,

> "Lesbian" should be defined to meet the needs of specific research studies, interventions or programs of care within generally accepted conceptual boundaries, with recognition of the three dimensions through which sexual orientation is most often defined: identity, attraction or desire, and behavior. (Solarz, 1999: 33)

Applying these three dimensions of sexuality to the study of women as targets of the stigma attached to women's same-sex sexuality results in a very broad possible definition of women's same-sex sexuality. Not only women who consider themselves lesbian or bisexual ("identity"), but also women who have sex with another woman ("behavior") without considering themselves lesbian or bisexual, and even women who only communicate a sexual attraction to other women ("desire"), can potentially become a target of sexual stigmatization. The stigma attached to women's same-sex sexuality may in fact stop some women from exploring same-sex sexual desires and it may prevent them from self-identifying as lesbian or bisexual due to fears of the stigma attached to these labels. However, this research study places a focus on the stigmatization experience of women with same-sex sexual experience as it aims to understand how having female sexual partners and living in lesbian family constellations affects women's social interactions and the support and services they receive. Criteria were set to include HIV positive women who reported any kind of life-time experience of same-sex sexual contact, independent of how they self-identified sexually. When speaking of "bisexual" or "lesbian" women in this text, this refers to women's sexual self-identifications, i.e. to women who consider themselves lesbian or bisexual, unless otherwise indicated.

Most participants of the screening interviews were recruited at the Lesbian AIDS Project (LAP) at a community-based HIV service provider, Gay Men's Health Crisis (GMHC). I also contacted other community based organizations and service providers that worked with HIV-positive or lesbian and bisexual women in New York City and I distributed fliers and hand cards announcing the study. In the end, twenty participants were referred through a key informant at the Lesbian AIDS Project. Four women were referred through other, non-lesbian and non-women-specific programs at GMHC, two participants saw fliers posted at another HIV organization and the Lesbian/Gay/Bisexual/Transgender (LGBT) community center, and three women entered the study through snowball referral (i.e. they learned about the study by word of mouth from other screening participants).

During recruitment conversations with interested individuals I explained the study purpose and procedures and I made a quick assessment of whether individuals met eligibility criteria. Only women who reported an HIV infection, sexual experience with women and who had biological children and/or parenting experience were invited to a screening interview.

Screening interviews followed a short, standardized questionnaire eliciting information on demographic characteristics, number of children, parenting and custody arrangements, health status and lifetime experience of same-sex sexuality, drug use and incarceration (see appendix). Participants were also asked to rate how often they experienced rejection and discrimination with regards to their race/ethnicity, same-sex sexuality, HIV infection, sex work history, criminal records, and drug use experience (on a 5-point scale from "never" to "very often"). Screening interviews lasted 25-30 minutes each and participants were compensated with $10 for their time. Written consent was sought prior to the screening interview. Most interviews took place in an office at GMHC, except for four interviews with women who were not affiliated with GMHC and who preferred to be interviewed elsewhere. One participant preferred to be interviewed in a coffee shop, another asked me to come to her home because she was too ill to leave the house, and two women were interviewed at the residences where they were temporarily housed. At the end of each screening interview, I asked participants if they were interested to participate in additional in-depth interviews and if so, I noted their contact details.

1.5 Step Three: In-depth interviews

I carefully selected nine participants for further in-depth interviewing, following grounded theory procedures for theoretical sampling. This sampling technique does not aim to represent a population, instead it is guided by concepts that are of theoretical relevance to the evolving theory (Charmaz, 2002; Strauss & Corbin, 1990). In my case, preliminary findings from the pilot study and the screening interviews suggested that differences in women's sexual self-identification, drug use experience, custody arrangements, and ethnicity affected their stigmatization experiences in significant ways. The composition of the smaller sample thus aimed to achieve greatest diversity in terms of these stigma-relevant characteristics and experiences. For example, I decided to have women with biological children in the in-depth sample as well as women who raised non-biological children. I included women who had lost custody rights as well as women who managed to maintain custody rights of their children. I selected women who identified as lesbian, but also some who identified as bisexual or as something else (e.g., “woman-loving woman”). I made sure to include self-identified butches/aggressors, as well as femmes and women who identified as neither. Most women in the screening sample had drug use experience, but I aimed to include at least one or two without a history of drug dependency. I also aimed to include an equal number of African-American and Latina women while making sure that at least one participant was White.

For ethical reasons I decided not to include women who were diagnosed with HIV recently (in the past 6 months). Newly diagnosed people often experience depression and even suicidal thoughts in the months following the receipt of their HIV diagnosis (Siegel & Lekas, 2002). I was concerned that an in-depth interview on stigmatization experiences might further increase their levels of distress. I also did not include women who had a history of drug or alcohol dependency and were actively using alcohol or drugs. I excluded these women mainly for practical reasons. During the screening phase active drug users tended to be less reliable in keeping their scheduled interview appointments compared to other participants who were not actively using alcohol or drugs. My time and financial resources were limited, so I decided to only include women who were not in active addiction.

I conducted repeated in-depth interviews with nine women and sought their written consent prior to the interviews. Two interviews were conducted per participant, each lasting about 1½ -2 hours, and they were audio-taped. All interviews took place in the homes of participants, except in the case of three participants who preferred to be interviewed at GMHC and one participant whom I asked to come to the GMHC office for the second in-depth interview. Participants were compensated with $30 for each interview.[3]

In-depth interviews combined a “problem-centered” interview format (Witzel, 1982, 1985) with a more narrative, biographical interview format (Fisher-Rosenthal & Rosenthal, 1997), in order to assess stigmatization experiences in the context of participants’ life histories. Narrative, biographical interviews usually start with a question that aims to generate a narrative in which participants describe their experiences by and large uninterrupted by the interviewer. The first interview started with the question, “Why don’t you tell me a bit about your life? Let’s start at the beginning, where were you born and how did you grow up?” The second interview started with, “Today I would like to talk more about the time since you tested positive for HIV. Would you mind telling me where and

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[3] Key informants had strongly suggested to increase the financial compensation from $20 per interview to at least $30. This amount seemed appropriate, especially since some women might have to cover child care expenses for the time of the interview. One in-depth participant explained that other research studies paid $40 per interview and more, especially biomedical studies that also collected specimen from the women or pharmaceutical studies doing market research.

why you got tested in the first place?" During both interviews, I let my interview partners lead the conversation and I only probed to clarify and deepen my understanding of what they described. I used the interview guideline (see appendix) in a flexible way, as an outline of the topics of interest, but not to determine the structure of the interviews. My questions aimed to stimulate discussions of participant's life histories including their experiences of stigmatization relating to their sexuality, HIV infection, drug use and parenting experience. Immediately after each in-depth interview, I took notes, first per hand in a field work diary and subsequently I wrote "Post-interview memos" that followed a more standardized format, similar to those used for the key informant interviews.

1.6 Data Analysis

The in-depth interviews were transcribed verbatim. Again, I double-checked the accuracy of the transcripts by reviewing and correcting them while listening to the tapes. After thus 'cleaning' the transcripts, I created case-specific memos summarizing the biographical story and interview contents for each participant on approximately 10 pages each. Subsequent procedures of coding and memo-writing are described below.

For my analysis of the interview transcripts, I used grounded theory procedures as a guideline.[4] Grounded theory aims to build theory inductively by securely grounding it in and developing it from the data (Glaser & Strauss, 1967). I applied constant comparisons, memo writing and systematic coding on two levels, "open coding" and "selective coding" (Charmaz, 2002). Open coding generates concepts as basic units of analysis. Anselm Strauss and Juliet Corbin describe coding as a fundamental analytic process representing the "operations by which data are broken down, conceptualized and put back together in new ways" (1990:57). The transcripts were read line by line and conceptual labels were assigned to events, actions and interactions discussed in the interview. Following the rule of "constant comparison," I systematically compared these concepts with one another for similarities and differences and grouped them to form categories and subcategories. I

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[4] I state that my approach was "guided" by grounded theory, because I applied its core elements of a) interrelating data collection and analysis, b) using constant comparisons, and c) applying the procedures of open coding, focused coding and memo writing (Charmaz, 2002). However, I did not apply other procedures, such as the coding paradigm, put forth by some proponents of grounded theory (Corbin & Strauss, 1990). Divergent approaches to grounded theory exist. The initial founders, Barney G. Glaser and Anselm L. Strauss (1967), each developed their own style of coding and analysis (Strauss, for example, added procedures such as the coding paradigm and dimensionalizing, while Glaser maintained that these subverted grounded theory analysis). Other researchers further modified and advanced procedures (see for example Charmaz, 2002; Emerson et al., 1995; Faas & Jaeggi, 1991). Qualitative data analysis has been described as a systematic and creative process (Patton, 1990: 432-35). Researchers are thus obliged to find analytic methods that stimulate their creative potential while adhering to standards of sound qualitative research (Maxwell, 1992). This two-folded challenge leads to combinations of different analytic strategies, modifications and methodological innovations. In my study, I used the protocol put forth by Kathy Charmaz (2002) while incorporating additional tools of analysis, such as "conceptual mapping" (Fullilove, 2002), to use visualization techniques to deepen my understanding of the data.

open coded all transcripts and then proceeded to the next level of coding. In “selective” or “focused” coding, I used those concepts and categories that held special value for answering my research question to sort and synthesize the data. Thus identifying specific interview sequences, I proceeded to conduct a second, fine-grained line by line analysis of these sequences, constantly comparing and contrasting them with each other and across interviews. The coding process was accompanied by memo-writing which helped me move from the initial open codes to more abstract categories.

I further stimulated my thinking about and understanding of the data by applying exercises of conceptual mapping. One exercise involved writing the concepts or categories into circles, starting with a core category or "fat circle" in the middle, and connecting concepts and categories with each other in a way that reflected their relationships in the data (Fullilove, 2002). I conducted this exercise with regards to the stigmas of same-sex sexuality, drug use and HIV (each treated as an individual core category), and I also applied this exercise to integrate the concepts that described different elements of women’s multiple stigmatization experience. For my analysis of the strategies of stigma management, I created a cards for each strategy and distributed, grouped and re-grouped these cards them until I had developed an understanding of how they relate to each other and to the stigmas.

Over the course of this analysis, I refined the foci of the analysis. My main research question asks how HIV-positive, lesbian and bisexual mothers experience multiple stigmatization. When I started the project, my initial focus was on how women are affected by the stigmas attached to their HIV infection and same-sex sexuality. However, I soon realized that I needed to expand this focus to include a) the stigma of drug use and b) women’s strategies of resistance to stigmatization.

I first conducted a descriptive summary of stigma-related incidences and listed women’s accounts of who stigmatized them, where and when with regards to HIV and on the basis of their same-sex sexuality. It soon became clear, that drug use-related stigmatization was an important element of HIV-related stigmatization. Some women who had a history of drug dependence even described the stigma of drug use as the most powerful grounds for devaluation and rejection in their lives. Following the basic premise of grounded theory (to develop theory from the data), I thus had to expand the focus of my analysis to include the three stigmas of HIV, same-sex sexuality and drug use.

The second refinement in focus came about when I analyzed the notes I had taken during the screening interviews. These notes include comments that participants had made on their frequency ratings of rejection and discrimination. Their comments suggest that participants interpreted the standardized question “How often do you experience the stigma of HIV/AIDS (same-sex sexuality/drug use/etc)?” to mean “How much is the stigma of HIV/AIDS (same-sex sexuality/drug use/etc) a problem for me?" When discussing their responses, participants did not usually count the number of incidences the had encountered in the past month, year or 10 years; instead, they assessed how much each form of stigmatization had "bothered" them in recent years. I noticed a similar phenomenon in the qualitative data where participants' accounts of stigmatization were always already filtered through coping efforts. I thus realized that I needed to pay attention to the ways in which women managed their stigmatization as this constituted an important element of their self-representations and accounts of stigmatization during the interview. This data-driven insight resonated with a deeply held conviction to approach research participants as active agents in their life experiences (and their recollections thereof) and it also spoke to a conceptual shortcoming of stigma theory. As described in the first chapter, much stigma theory is characterized by a conceptual flaw relating to the neglect of the modifiable and reversible nature of stigma and the power of resistance. I thus decided to make participants' strategies of managing their multiple stigmatization an explicit second focus of my analysis.

1.7 Women's "experience" as a research topic

An insight that accompanied much coding and memo-writing was that participants' accounts are not "carbon copies" of social life, but interpretations and re-constructions of current and past events, thoughts, feelings and actions. Participants' experience of stigmatization is conveyed through language and shaped by processes of remembering, interpreting and representing. As Joan Scott points out, "experience is at once always already an interpretation and in need of interpretation." (1992:37) In the context of feminist theorizing, she warns against naturalizing and essentializing the notion of women's "experience" and proposes to view it as a discursive event. This means that participants' accounts of stigmatization were necessarily constructed, "biased," partial and dependent on the context in which they were told. In other words, my interview partners did not just "report" incidents of stigmatization; their presentation and interpretation of these incidences was influenced by many factors, including the interview context in which the process of narration and meaning making took place. This understanding of women's experience as the result of interpretative efforts that require further, careful interpretation on my behalf as a researcher, has methodological consequences.

1.8 Self-reflexivity as a researcher

If women's (interpretation of their) experience is necessarily shaped by the context in which the meaning-making takes place, it is important to ask how the interviewer-participant interaction influenced their accounts. How have my question and responses, and more generally, my positioning in the field and their perceptions of me affected their self-presentations in the interview? Joan Scott calls on researchers to scrutinize their own experiences in the research process and their stake in the production of knowledge (1992: 38). In a similar vein, Donna Haraway makes a convincing argument for “situated and embodied knowledges” (1988:583), a concept that stresses the historical contingency of knowledge claims and takes into account the particular positioning and vision of those who produce them.

> I am arguing for the view from a body, always a complex, contradictory, structuring and structured body, versus the view from above, from nowhere, from simplicity. (1988: 589).

This call for situated and embodied knowledges resonates with a longstanding debate on the role and value of researcher’s subjectivity in social science research. More than thirty years ago, George Devereux argued for the “reintroduction of the observer” into the research process, “not as the source of a regrettable disturbance, but as an important and even indispensable source of relevant, supplementary behavioral science data" (1967:30). He called on researchers to reflect on their subjective patterns of cognition and behavior as additional sources of insight. Devereux considered the subjectivity of the researcher an integral element of the research process and part of the data to be studied.

Self-reflexivity has since been conceptualized in different ways in different traditions of social sciences, resulting in parallel approaches to and definitions of the concept. For example, sociologists Bourdieu & Wacquant define self-reflexivity as revealing the "social and intellectual unconscious embedded in analytic tools and operations" (1991: 36). This definition aims to uncover the effects of institutional frame, milieu-specific interests and habitus of the researcher on the research design, process and outcomes. Bourdieu & Wacquant’s understanding of self-reflexivity differs profoundly from Devereux’s psychoanalytical approach or from "confessional tales" used in ethnography, where individual researchers are asked to document their daily fieldwork experiences and emotional states in great detail. Feminists have discussed the role of researchers’ subjectivity in the production of knowledge in the context of "standpoint epistemology," a debate inspired by various lines of thinking, including critical theory (Knapp, 2000). They conceptualize self-reflexivity as a tool to unravel and use the historical and political nature of knowledge claims. As described above, by explicating and situating the specific gaze and voice of the researcher/feminist, a clearer "vision" is aimed for that lives up to a new conceptualization of objectivity (Haraway, 1988).

Researchers using qualitative social science methods have engaged in a vibrant discussion about how to define and apply self-reflexivity in their research projects (Adamson et al., 2002; Anderson, 1993; Bereswill, 2003; Boolam et al., 2003; Breuer & Roth, 2003; Finlay, 2002, Jensen & Welzer, 2003; Kong et al., 2002; Mruck & Breuer, 2003; Riley et al., 2003;). It is generally agreed that the researcher/interviewer is necessarily a “co-author” of the data and that her or his latent and explicit expectations and specific contribution to the data collection and analysis must be treated as data and be analyzed as well (Lucius-Hoene & Depperman, 2004). Reflexivity can be understood as an introspective process that aims to uncover *intra*personal dynamics (as imagined by Devereux) or it can be applied to the interaction between interviewer and participants to highlight the *inter*personal construction of subjectivity (Bereswill, 2003). Some researchers propose that researcher should subject themselves to the same level of scrutiny that they direct at their study participants, especially when studying marginalized populations where they run the risk of commodifying participants’ hardship to further their research careers (McCorkel & Myers, 2003). In one study, researchers used self-interviewing to systematically uncover the effects that their beliefs and assumptions had on the research process (Boolam et al., 2003). Jensen & Welzer (2003) suggest to use self-reflexivity as the main tool of analysis. Pointing to the communicative nature of interview-based, qualitative data, they argue that instead of analyzing only the accounts of participants, the interactions between researcher and participant must be the focus of analysis. They assume that the phenomenon of interest (i.e. the subject matter the study aims to explore) manifests itself in the interview interaction in ways that are not fundamentally different from every-day life interactions outside of the research arena. Drawing attention to the dialogue between interviewer and participant, their method of “Hermeneutische Dialoganalyse” (Jensen & Welzer, 2003) pays as much attention to the contributions of the interviewer as to those of participants. It carefully analyzes not only what is said, but *how* the subject matter is being dealt with in the interaction and misunderstandings and ruptures in the conversation are treated as sources of insight. Jensen and Welzer (2003) also argue for an inclusion of the interviewer’s questions and responses in the presentation of the data in publications.

Different conceptualizations and operationalizations of self-reflexivity exist, resulting in a variety of possible methodological applications of the concept. My understanding of self-reflexivity entails that I reflect on the ways in which my specific location, vision, and “body” affect the knowledge I produce. This requires that I explore how my situatedness in the field shaped the interaction with my interview partners, and, in extension, their accounts, and my findings.

Committing myself to self-reflexivity throughout the research process is particularly important given the highly sensitive nature of my research topic. Studying multiple stigmatization requires that I critically observe and challenge my own position and assumptions, independent of how liberal or accepting I believe myself to be, as the danger of “othering” participants is always there (Adamson et al., 2002). To encourage critical self-reflexivity on every step of the way from data collection to analysis, I decided to systematically document my subjective thoughts and feelings in the research process through memo-writing. After every encounter with participants I took notes and I developed a standardized format for post-interview memos where I rated the rapport with participants and described surprises, highlights and regrets I had about the interview. I discussed these with colleagues and project advisors which helped me become aware of assumptions that unwillingly affected my data collection and analysis.

For example, in the memos following the in-depth interviews with a participant whom I call Gloria, I noted that I was surprised about Gloria's "inconsistencies" regarding her sexual self-identification and the extent of her same-sex sexual experience. In the screening interview, she had identified as lesbian, in the in-depth interviews she described herself as "confused" and she reported different levels of sexual experience with women. My notes capture my concern about what I perceived as a lack of reliability of her accounts and I even considered excluding her from the study. In my distress, I sought the advice of one of my project advisors. In conversations with Talata Reeves I learned that Gloria's "inconsistency" is a prevalent phenomenon among female clients at the community-based HIV service provider and that it might illustrate a specific response to the stigma attached to women's same-sex sexuality. I was told that many women identify as lesbian at the (lesbian-friendly) service provider (where the screening interview with Gloria took place), but not in their home environments (where the in-depth interview with Gloria took place). I realized that I had wrongly assumed that women's sexual self-identifications would remain stable across social environments, when in fact they were much more flexible and context dependent. Gloria was one of the participants who stated that she kept her same-sex sexuality "out of the house", so when I interviewed her in her home, her mindset and self-presentation were more focused on being a mother who takes good care of her children than on her newly-found, ambivalent interest in same-sex sexuality.[5]

I also put an effort to detect my biases and assumptions during coding procedures. I was particularly looking for misunderstandings, awkward moments and expressions of surprise given that a closer look at "irritations" can often reveal insights into verbal and non-verbal expressions of subjectivity (Bereswill, 2003; Heizmann, 2003; Jensen & Welzer, 2003). Paying close attention to each word, pause and utterance recorded on the

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[5] Gloria's "inconsistencies" regarding her sexual experience with women also illustrate general difficulties in defining what counts as "sex" between women, given that "sex" is commonly associated with the involvement of a penis and penetration (Frye, 1990). I still find the variance in Gloria's accounts somewhat unsettling, but rather than dismissing her as having "cheated" and initially overstated her same-sex sexuality to get into the study, I think it is more appropriate to see what I can learn from my irritation. Gloria felt deeply conflicted about having moments when she was sexually attracted to other women. Her varying use of labels to describe her sexuality thus provided a good illustration of her contradictory feelings and discomfort with her changing sexuality.

transcripts, I detected an ethnicity-related assumption that had influenced the interview with Ana, a lesbian-identified Puerto Rican New Yorker. In our second in-depth interview, Ana told me that the mother of her first girlfriend gave the two women permission to live together. This occurred in 1980 and I probed to find out if the girlfriend's mother really accepted their relationship:

> Hella: (…) Was she okay about it?
> Ana: Uh huh. Yeah, she was okay about it.
> Hella: Was she also Hispanic?
> Ana: Yeah, she was Hispanic.
> Hella: But she was not homophobic.
> Ana: No, no, she was okay with it. She liked the way I worked and she saw that I was responsible. She used to come and see me at the job and everything. (41.2: 577-88)

I remember that I was surprised to hear that her girlfriend's mother accepted their same-sex sexual relationship so easily. Why was I so surprised? Why did I probe about the mother's ethnicity, and why did I start the probe about whether she (really) was not homophobic with a "but"? I obviously carried an assumption that Ana's chances of being accepted as a lesbian in the Hispanic community were very low, especially in the early 1980s. Key informants had described strong sexual stigma in Latino communities and this gave rise to a generalized expectation on my part that all Hispanics were homophobic.

This interview sequence also reveals that I entered the field with an eagerness to find stigma. However, this influence did not necessarily cause participants to provide socially desirable information and report stigmatization. Some participants insisted they did not experience stigmatization in specific settings, as in Ana's case, who explained that she did *not* encounter sexual stigma from her girlfriend's mother. She attributed the accepting response to the good influence that she represented in the life of the girlfriend, given that she had a regular job and was not using drugs at the time. In the eyes of her girlfriend's mother, this presented a definite advantage over the previous boyfriend who had been abusive and a drug dealer who provided her daughter with drugs. Ana thus corrected my assumption and expectation. One could ask if she downplayed the impact of sexual stigma *because* I was so eager to find homophobia in this "mother-in-law." Maybe she was concerned not to reveal negative information about members of her Puerto Rican community to limit the risk that I might over-interpret or carelessly exploit them? For the most part, Ana and other participants were very forthcoming about their sexuality-related stigmatization experiences in their families and communities. Ana for example recounted that she was stereotyped as an aggressive "corta cara" (face cutter), accused of wanting to be a man and rejected by her Puerto Rican-based family who called her same-sex sexuality "craziness." Maybe the point is not so much that she downplayed sexual stigma, but that she called attention to the stigma of drug use which outweighed any anti-lesbian sentiments there might or might not have been. This reading resonates with statements of other (Puerto Rican) participants who described the stigma of drug use as more powerful that even the stigma attached to same-sex sexuality in the Puerto Rican community in New York. Ana might have thus presented drug use as the more salient factor in the eyes of her girlfriend's mother, even if I had been more unassuming about sexual stigma.

Nevertheless, realizing that I had unconsciously reproduced negative stereotypes of Hispanic people was quite sobering. At the same time, when subjected to critical analysis, it was a tool to gain insight about Ana's accounts of stigmatization. In order to limit the potential damage *and* use the potential gain of my assumptions and expectations, I actively sought critical peer review and feedback from a diverse group of students and advisors throughout the research process. Secondly, and more generally, this sequence underlines the need to reflect on how differences between me and my interview partners, such as those along the lines of class, ethnicity or culture, operated within the study.

As a White,[6] European researcher from a middle-class background, I have class and racial privileges in the United States that most of my interview partners do not possess. Four of my key informants were also college-educated, and two key informants and one in-depth interview partner were White. The great majority of study participants, however, were low-income women of color who had dropped out of high school. How did this difference in racial and class backgrounds affect the study?

My position of privilege and power was addressed a few times, even before I met any of my interview partners. First, when I was looking for funding, an African-American researcher suggested contacting a specific foundation while noting in the same breath that the director of this agency was "actually tired of funding White researchers to study women of color." This comment clearly related to my racial privilege and illustrated a sense of frustration and resentment at the history and current status quo of research with ethnic minority populations in the United States. Predominantly White researchers have a history exploiting and even harming ethnic minority communities in the United States in the name of science (see for example the Tuskegee syphilis experiment; Jones, 1981). To this day, research projects often end up replicating negative clichés about members of ethnic minority communities or, as Loic Waquant recently pointed out, authors put forth well-intended but equally "truncated and distorted accounts of their object due to their abiding wish to articulate and even celebrate the fundamental goodness – honesty, decency, frugality – of America's urban poor" (Wacquant, 2002). Given this backdrop, the critical comment of my African-American colleague was understandable. As such it acted as a helpful reminder of the responsibility involved in studying a marginalized population, a responsibility that – I believe - all researchers face, independent of their racial and class background.

I also encountered scrutiny by my key informants. During recruitment conversations on the phone, two women of color, both advocates, thoroughly questioned my intentions and ethics as a researcher. They asked me why I was doing the study, whether I held any value judgements against drug using women and what I was planning to do with the study results. My field notes state that I felt “grilled” by them, but I also noted that I appreciated “when researchers are challenged and questioned like that” (3/7/01, blue book). I figured that their critical stance was most legitimate given the controversial history of research with marginalized communities in the US (and elsewhere) which more than once involved researchers harming study participants or simply “grabbing” their data and "running,” to be never seen or heard of again by those who participated in the research. Responding to their valid concerns, I carefully explained my motives for doing the study and my commitment to making the findings available to the HIV community upon completion of my dissertation.

One of these key informants became very warm, open and welcoming once these issues were clarified and we met in person. The other, however, maintained a level of distance and distrust throughout the interview. My post-interview notes reflect tensions in our interaction. I felt disrespected by her, and put in my place. She made me wait, repeatedly interrupted our conversation, criticized me for not paying participants enough, and by the end of the interview, she did not even remember my name. She was an advocate who repeatedly took phone calls during the interview. During one such phone conversation she made a critical remark about White, educated women who get in positions of power even though HIV-positive women of color were doing all the work. After finishing the telephone conversation, she explained that she and other women with HIV had invested time and effort in the planning of an event, but someone else, an educated White woman, was going to be the moderator of the event. This key informant was an African-American woman who did not disclose her HIV status to me but who had worked in HIV advocacy for many years. I had the impression that her critical comments about this injustice were also directed at me, suggesting I was another educated White woman who might take advantage of HIV positive women of color. My first response was outrage, but in retrospect, I understand her frustration better, and I can see some truth underneath her rudeness. As a White, educated, HIV-negative researcher, my personal gain from our interaction is undoubtedly greater than that of my interview partners, no matter how committed I am to “giving back” to the community. I aim to obtain a university degree while my study participants get a small financial compensation in return for opening up and sharing their insights and sometimes painful life experiences. They might enjoy the opportunity of talking to a friendly listener, of earning a bit of extra money and of

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[6] In acknowledgment of the fact that “White” is as much a political term as other racial and ethnic

supporting research that means to benefit the HIV community. However, participants have to lay their trust in me and they do not personally benefit from the research as much as I, the researcher, do. Analyzing my initial irritation thus drew attention to an important power differential and it reminded me that women's participation in the study constituted an act of profound generosity, especially in the case of the HIV-positive participants who, faced with a shortened life span, donated some of their precious time to this research project.

My racial privilege was also an issue during the in-depth interviews. An HIV positive, African-American participant, Stacey, for example, mentioned that her mother always wanted her to have boyfriends with a complexion as light as mine (31.1: 225). She criticized that as a Black woman she would not be served in the Italian "members only" clubs in her neighborhood whereas I would be (31.1:279-327). Another African-American participant, Wendy, mentioned that White people could always enter communities of color while Black people were not welcome in White communities. She also noted the health benefits of racial privilege referring to me as one of "y'all" white people:

> So much stuff that's happening in our population that nobody ain't properly paying no attention to. Nobody ain't caring. So it's like drugs and alcohol, all that shit. Why is that in here? Why is this all right here in our population, you know. Why is Hispanics, Blacks getting.. dying quicker than ever, than y'all? (26.2: 1878-82)

I also addressed the issue directly. As part of my debriefing at the end of the second in-depth interview, I asked participants how my European background had affected their comfort levels and if they thought it problematic that a White immigrant was doing research with mainly women of color participants. Their general response was that our racial, ethnic and cultural differences did not matter to them because they felt that I approached them with respect. Olga said she liked talking to me because I seem "like an understanding person" (21.2: 1721-22) and Wendy noted this about my German background:

> It doesn't bother me where you come from. It's the way how you present yourself, how you speak, you know, what comes out your mouth, you know. It's the way.. it's respect. And that's about it. (26.2: 1944-46).

Another in-depth participant, Vanessa, pointed out that my Whiteness and my appearance might actually work in my favor. Asked what effect she thought my being White has on a study like this, she responded:

> Doesn't have anything.. as a matter of fact, I think you're a very attractive woman, and I have to tell you that, because [NAME OF OTHER PARTICIPANT AND FRIEND OF VANESSA] said when she met you, she says, "Oh, my God! She's beautiful." I said, "Yes, she is. She's a beautiful woman." No, I think this is great. Maybe this will help somebody. I mean, somebody has to do this research. Doesn't matter whether you're Black, white, or a monkey. As long as you can get the information out there right, you know. (26.2: 1853-59)

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categories such as "Black," "Hispanic," or "Latina", I choose to spell it with a capital "W".

My different ethnic background obviously did not deter her friend who responded mainly to my gender and appearance. Vanessa herself thought that my ethnic difference did not matter as long as I "get the information right," i.e. as long as I do not misrepresent the women who are working with me. More so than skin color or ethnicity, it seemed that a commitment to the project and an ability to relate to the other person in an open and relaxed manner were crucial for the development of trust in the interview.

> Stacey: I feel good opening up with you and for some reason, like comfortable. That's a good question that you asked me because the first .. well, White lady that I did a study with, right .. I like to say Caucasian, you know .. that I did a study with... I felt uncomfortable with her. ... It was this off conscious, "Well, her shit ain't right," you know? And as we was talking, like when you started talking, I can get comfortable. Now, if you might have been snotty or maybe if you was asking me straight questions out, me and you talking and you know, like I could talk .. to me, I could talk to you like I been knowing you for a long time. Everybody I can't do that with. I don't care if they're Black, Spanish, Chinese..
>
> Hella: So, it's more like a personal thing, it's not such a color thing?
>
> Stacey: Right, right, right, right .. it's a personal thing. Because even if you was Black, and was a thing that you was kind of stuck up, like okay .. this one lady that I do .. does do a study in [NAME OF HOSPITAL], she's like a stuck up .. I be trying to joke with her and .. her name is O., she's Black .. and she's one of them stucky .. she won't even laugh. You know? You can't even ask her nothing, you know? And she just goes through what she got to say then that's it. (31.2: 2273-94)

Stacey appreciated the question and pointed out that she had encountered other "Caucasian" interviewers whose "shit ain't right," i.e. who might have conveyed prejudiced attitudes or had behaved in a prejudiced manner. However, a common race or ethnic background was no guarantee for a more trusting or open interviewer-participant relationship either. In fact, as Stacey explained, it turned out to be quite irrelevant when other factors such as class differences, attitudes (being "snotty" or "stucky") or strict adherence to standardized research protocols created social distance in the interview.

The difference in HIV status between my interview partners and me was much less talked about. I did not explicitly disclose that I was HIV-negative, but I had the impression that this was generally taken for granted. Participants had been living with an HIV diagnosis for a number of years and had talked about their HIV infection with service providers and researchers of undisclosed HIV status on a regular basis. One participant explicitly stated that social, behavioral and biomedical HIV research provided continuous opportunities for them to substitute their income (31.2: 23-110). In terms of talking about sensitive issues such as HIV-related stigmatization, I consciously expressed a critical stance towards the stigmas attached to HIV and women's same-sex sexuality when explaining the study purpose as part of informed consent procedures.

I also commonly let my interview partners know that I had same-sex sexual experience, but I did so more spontaneously. Sometimes I identified myself as a lesbian researcher when explaining the study purposes during recruitment or consent procedures, other times I told them I had a female partner or I used my own "coming out" experience as an example during the interview when probing about feelings of shame or confusion concerning their same-sex sexuality. I was aware that my experience of same-sex sexuality and sexual stigma might be completely different from theirs. However, I felt that disclosing my same-sex sexuality aided the trust-building, especially with regard to talking about women's same-sex sexuality and the stigma attached to it. A self-identified lesbian key informant for example asked me straight-out if I was a lesbian when explaining the ignorance faced by HIV positive lesbians.

> Mindy: And people think that, well lesbians, how would they get AIDS? But that doesn't have nothing to do with what we traditional think. They are people too. It's just a scourge that's been attached to that. I don't know, are you a lesbian?
> Hella: Yeah, I am. I am. But I mean, you know ..
> Mindy: So you know yourself, right? (PS09: 416-23)

Her question challenges traditional interview norms that imply a one-directional question and answer relationship between interviewer and participant. At the same time, she creates a new relationship between us by addressing me as a person who knows about being a lesbian and being the target of sexual prejudice. In the interview, this bridge opened up room to talk about more explicitly sexual matters, such as sexual disease transmission between women.

In another case, I realized only at the very end of the second in-depth interview that I had not disclosed my same-sex sexual experience. When I asked Wendy, a self-identified bisexual woman, if she was comfortable being interviewed by a lesbian researcher, Wendy noted that she had wondered about my sexual orientation. She said she had "picked it up" from the way I walked, but was afraid to ask me directly (26.2: 1991). I regretted that I had not come out to her earlier because I felt that once we established this understanding, she seemed more at ease with me. What was noteworthy about her response was that she did not pick up on the sexual *difference* that I suggested (calling myself "lesbian" as opposed to her self-identification as "bisexual"). She only responded to the *commonality* that consisted in our shared sexual experience with women. This illustrates that "difference" was a relationship that might or might not have been recognized, acted upon and bestowed with meaning in the interview. Instead of essentializing the differences between me and my interview partners, it is important that I pay close attention to when and how differences and commonalities were established and responded to within specific interactions.

The process of engaging in self-reflexivity as a researcher is an ongoing endeavor. I draw a line here, but I aim to incorporate this awareness for the significance of the interview interaction and issues of positionality into my analysis and presentation of participants' accounts of multiple stigmatization in the following chapters.

1.9 Technical notes on transcription and citation

All interviews were transcribed verbatim, following the following transcription legend:

Hella:	Interviewer
Roberta:	Interview partner/ participant (pseudonym)
YES	Words in capital letters were emphasized
[LAUGHS]	Non-verbal communication and other descriptions of situational factors in brackets
[?]	One or few words inaudible on tape
[??]	Parts of sentences inaudible on tape
[inaudible]	Whole sentence(s) inaudible on tape
[possibly?]	Inaudible, the word in brackets the best guess
..	Short pause
[PAUSE]	Longer pause
(…)	Shortened citation; removed material

The citations presented in this study are verbatim transcriptions of participants' spoken words. The grammar and syntax are thus often "incorrect" as is common in spoken language. I considered "beautifying" the language to make it more presentable in print, but have by and large decided against it to ensure better descriptive validity of the data (Maxwell, 1992). In a few instances have I strung sentences together that were uttered in the original interview (for example when participants used utterances such as "uhm"). Wherever I abbreviated longer passages and left out whole words or sentences, I indicated this in the citation as follows, (…).

The names of participants or persons mentioned in the interviews have been replaced with abbreviations or pseudonyms to ensure confidentiality.

Brackets following quotations from the interviews indicate the participant's id number followed by the line number in the interview transcript. Id numbers PS01-PS14 were given to key informants (of the Pilot Study). Quotations from transcripts of the in-depth interview partners contain a number (1 or 2) after the id number indicating whether the quotation was taken from the first or second in-depth interview (e.g. 17.2: 317 stands for line 317 in the second in-depth interview with participant #17 whom I called Alex).

2 Sample description

A total of 43 women participated in this study. Fourteen women were interviewed as key informants, 29 women participated in screening interviews, and out of these, nine were selected for repeated in-depth interviews. In this section, I describe the socio-economic status of study participants, placing a focus on the nine participants of the in-depth interview phase on whose experience the analysis is mainly based. For these nine participants, short biographical summaries are attached.

2.1 Key informants

All fourteen key informants were female. They were between 31 and 50 years old (mean age 40) and had diverse ethnic backgrounds and sexual self-identifications. Seven women identified as African American, three as Puerto Rican, one as Black Hispanic (Afro-Caribbean), two identified as White, and one as “other” (her ethnic background included part African American, part Hispanic, part American Indian and part East Indian). Seven women considered themselves lesbian, three identified as bisexual, two identified as straight/heterosexual, one referred to herself as gay, and one participant called herself a woman-loving woman.

Key informants were associated with ten different community-based HIV organizations located in four boroughs of New York City. These were mainly providers of support services to women with HIV/AIDS, including one organization that offered services specifically tailored to HIV-positive lesbians. The sample included advocates, case managers, social workers, program co-ordinators, peer educators, clients and care takers. Participants had expertise in at least one of the following areas:

- Service provision to HIV positive, lesbian and bisexual mothers, including case management, counseling, group facilitation, housing support, legal advice, permanency planning, community outreach (9)
- HIV peer counseling and education (5)
- Caring for lesbian and bisexual mothers with HIV/AIDS (5)
- Advocacy for women’s health and HIV/AIDS (5)

The numbers in brackets do not add up to 14 as most participants had more than one area of expertise. All participants were recruited as key informants and were asked to describe the situation of HIV-positive lesbian and bisexual mothers in New York City general. They were not asked to disclose their HIV status, but six key informants volunteered the information that they were HIV-positive mothers with same-sex sexual experience themselves. Their demographic profiles are as follows:

Lola[1] was a 34 year old HIV-positive lesbian-identified mother. She considered herself Black Hispanic and grew up in the Caribbean. She tested positive for HIV in the early 1990s when giving birth to her second child who was also HIV-infected. Lola worked as an HIV activist and women's health advocate and has publicly disclosed both her HIV status and sexual orientation. (PS01)

Cathy was a 32-year old African-American mother of three who self-identified as a "woman-loving woman." She tested positive for HIV when her second child, who was also HIV-positive, fell ill. Having a history of crack addiction and incarceration, she became a peer educator and currently worked as a case manager assisting HIV positive women newly released from jail or prison. (PS02)

Doreen was a 40-year old African-American outreach worker who considered herself "straight." She did not disclose her HIV status, but mentioned that she had sex work and drug use experience and currently worked as a peer educator in HIV prevention with street-walking prostitutes. (PS03)

Mildred was a 43-year old lesbian mother who identified her ethnicity as part African-American, part Hispanic, part American Indian and part East Indian. She disclosed her HIV status as negative. She had worked in HIV prevention for many years and took an active part in creating community-based support structures for bisexual and lesbian women with HIV/AIDS. (PS04)

Aurora was a 47-year old Puerto Rican case worker and therapist. She identified as lesbian and HIV-negative. She had a masters degree in social work and many years of experience in HIV advocacy and service provision. She had worked as a grievance counselor and currently assisted HIV-positive women in the area of permanency planning. (PS05)

Freda was a 31-year old White lesbian project co-ordinator. She had a university degree and had worked in HIV service provision for many years. She also worked with queer and questioning youth and disclosed her HIV status as negative. She ran support groups and one-on-one counseling with HIV-positive lesbians and conducted HIV prevention with HIV-negative lesbians. (PS06)

Nell was a 42-year old Hispanic outreach worker. She self-identified as lesbian and HIV-negative. Her main area of work was HIV prevention in Latino communities and case management with HIV positive women at a community-based social support organization. (PS07)

Molly was a 39-year old African-American residence manager at a community-based HIV organization. She was a mother and grandmother and disclosed being HIV-positive and bisexual. She had a male partner, but was in love with a woman. Having drug

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[1] All names are pseudonyms.

use and incarceration experience herself, she was very committed to her work, helping other HIV positive women find housing in New York City.

Mindy was a 50-year old African-American lesbian who provided legal assistance to marginalized communities of color. She had a university degree as a trained educator and had worked as an HIV advocate and activist since the start of the epidemic. She did not disclose her HIV status. (PS09)

Frances was a 41-year old African-American mother of three. She had sex with a woman once but had a steady male partner and considered herself heterosexual. She disclosed that she was HIV-positive and worked as a peer educator at a service provider for women with HIV/AIDS. (PS10)

Tami was a 34-year old African-American mother of four. She tested HIV-positive 6 years ago when she was in treatment for her crack addiction. She had a male partner but described herself as an “out” and proud bisexual. She knew other bisexual and lesbian mothers with HIV through her personal experience in correctional facilities, drug treatment programs and HIV support groups. (PS11)

Willa was a 37-year old White lesbian with a university degree who had worked as a social worker in an AIDS ward of a hospital. She identified as HIV-negative but was very familiar with the situation of HIV-positive lesbian mothers through extensive advocacy, professional and personal experience. (PS12)

Felicity was a 42-year old Puerto Rican who was born and raised in New York. She identified as lesbian and raised the HIV-positive daughter of her late sister. She herself was HIV-negative. (PS13)

Fame was a 43-year old African-American peer educator and mother of five. She used to be addicted to crack, and described her HIV infection as a wake-up call. She identified as bisexual and currently worked as a peer educator at an HIV service provider for women with HIV/AIDS. (PS14)

2.2 Participants of the screening interviews

A total of 29 women participated in screening interviews. They were recruited at six different HIV specific, medical and social service providers in New York City. The women were between 29 and 58 years old, with a mean age of 43. The majority identified as African-American (N=17), ten women described their ethnic background as Hispanic and two women identified as White. The majority of screening participants had not completed high school and reported a household income of less than $1,000 per month. All 29 participants had biological children and/or parenting experience with non-biological children. A great majority (N=21) reported having encountered some kind of custody-related problem as a parent, such as loosing custody rights. All women were HIV positive and 15 had an AIDS diagnosis. They had lifetime experience of sex with women and 11 women were currently in a relationship with another woman. Eleven women self-identified as lesbian, nine as bisexual, four considered themselves straight/heterosexual and five participants did not identify in terms of sexual orientation. Six participants considered themselves femme, three identified as butch, eight women called themselves aggressors and 12 women preferred not to use any of the above labels. Twenty-six women had a history of substance use or alcoholism and 21 had exchanged sex for drugs or money at some point in their lives.

2.3 In-depth interview participants - Summary

Nine women were selected for the in-depth interview phase. Like participants of the screening sample, most participants in this smaller sample were in their 40s, except for two women who were in their early thirties (see table 1).

Table 1. Overview in-depth interview sample

	Age	Ethnicity	Drug use	HIV diagnosis	Years HIV+	Sexual self-identification	Children (biol./ non-biological)
Wendy	32	Black/ African-American	Crack	1989	13	Bisexual	4 / 0
Deirdre	34	White	No	1990	12	Bisexual	0 / 1
Olga	42	Puerto Rican	Heroin/ Crack	1986	16	Lesbian (Femme)	2 / 1
Gloria	42	Black/ African-American	No	1993	9	Confused	3 / 0
Alex	43	Puerto Rican	Heroin/ Crack	1989	13	Lesbian (Butch)	2 / 0
Stacey	43	Black/ African-American	Crack	1995	7	Bisexual (Aggressor)	5 / 0
Ana	44	Puerto Rican	Heroin	1988	14	Lesbian (Aggressor)	0 / several
Roberta	47	(Black) Puerto Rican	Heroin	1987	15	Lesbian (Aggressor)	0 / several
Vanessa	49	Puerto Rican	Some cocaine, but no addiction	1995	7	Woman-loving woman	3 / several

The mean age of in-depth participants was 42 years. They were mainly women of color: five participants identified as Puerto Rican (including one Black Puerto Rican), three participants identified as Black or African American, and one as White. Their level of education was very low as only four participants had a high school diploma or an equivalent degree (GED). Participants grew up in marginalized communities and many were raised by single mothers faced with financial hardship. Six women had a history of crack or heroin dependency, but none used drugs in the year prior to the interview. Four participants had been incarcerated based on possession or selling of drugs. All participants received public benefits (e.g. DAS, SSI) at the time of the interviews. In addition, five women were employed part-time and one woman reported working hourly off the books. Their monthly income was low, and six out of nine women reported that they had insufficient money to pay for necessities in the past 12 months.

Participants of the in-depth sample had varying levels of same-sex sexual experience and differed in their sexual self-identifications. Four participants self-identified as lesbian. These women happened to have significant same-sex sexual experience and their primary partners in life had been mainly or exclusively female. Alex, Roberta and Ana identified as "butch" and "aggressor"[2], while Olga identified as "femme". Three participants self-identified as bisexual. They had some current or past same-sex sexual experience, but their primary partners in life had been mostly men. Stacey considered herself an "aggressor" in sexual terms, meaning she liked to assume an active role with her female sexual partner. Deirde and Wendy did not identify along the lines of butch/aggressor or femme. All three participants had current male partners and kept their bisexuality very private. Two participants identified neither as lesbian nor as bisexual. Until recently they considered themselves “straight” and they had just begun to gain their first same-sex sexual experience. At the time of the interviews, Vanessa was involved with a butch lover and considered herself a “woman-loving woman.” Gloria only had sex with a lesbian friend once and she described her changing sexuality as “confusing.”

At the time of the interview, participants of the in-depth sample had on average been HIV-positive for 12 years. The three women who had been diagnosed the most recently were Vanessa, Stacey and Gloria have known about their HIV infection for 7-9 years. Deirdre, Wendy and Alex have been living with the virus for 12-13 years, and Ana, Roberta and Olga have lived with their HIV diagnosis the longest, for 14-16 years.

Participants generally had an AIDS diagnosis. Olga and Wendy stated that they were not diagnosed with AIDS, but this was technically impossible as they obtained housing benefits from the Division of AIDS Services (DAS) which required eligible clients to have an AIDS diagnosis. More likely, Olga’s and Wendy’s notion that they did not have AIDS was an expression of their current well-being and health status which was free from HIV-related symptoms.[3] All participants received medical care at the time of the interviews

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[2] I first learned about the label “aggressor” from my key informants. They described this self-identification as common among queer youth and young to middle-aged women of color who had been incarcerated. The meaning of the term varied ranging from being sexually dominant, to “just another word for butch”, to being a Hispanic “macho” lesbian who pays a lot of attention to her looks and style. Participants explained that as a self-identification, the term “aggressor” did not to carry any of the negative meanings usually associated with the term “aggressive.” I discuss this label more in-depth in the second part of the findings chapter.

[3] An AIDS diagnosis is given when an HIV-positive person suffers from specific opportunistic infections and/or when her immune status is compromised (CD4 cell count below 200 cells/mL). The health status of a woman diagnosed with AIDS can improve again, for example with the help of highly active anti-retroviral medication (HAART). With her health improved and free from HIV-related symptoms she might – quite rightly - no longer perceive herself as “having AIDS.”

and the majority was taking combination therapy.[4] Most of the participants report being in good health with relatively high CD4 cell counts and low or undetectable viral loads. Only two participants were in more advanced stages of the disease and suffered from HIV related symptoms, high viral loads and low CD4 cell counts. Two women reported other, non-HIV related health concerns. Many women reported a history of visible symptoms resulting from their HIV infection or side effects of their medication, in particular lipodystrophy (fat redistribution), skin discoloration, skin rashes and weight loss.

All participants had access to HIV-related support services, including therapy and support groups. However, I noticed that the four participants who worked in the HIV field as peer educators did not currently access any HIV-related support group services.

All in-depth interview partners had parenting experience in the broadest sense of the term. Some had biological children while others cared for non-biological children, often the children of their female partners.

Six women had biological children ranging in age from 2 – 32 years. Participants described that their pregnancies had often not been planned and four participants were teenagers (18 years or younger) when they first gave birth. All biological children were conceived through heterosexual sex, either with a steady male partner, a male friend or in the context of drug-related sex work. Key informants also noted that they were unaware of any HIV positive lesbian or bisexual mother who had conceived her children through artificial insemination.

Participants raised their biological children to differing degrees. Gloria was the only participant who had maintained custody of all her children at all times. The other five biological mothers had lost or transferred custody rights for one or more of their children, at least temporarily (mainly in the context of drug use and incarceration as I will show in the next chapter). At the time of the interview, three participants lived with biological children and four women raised non-biological children in their households.

Five participants altogether, including two biological mothers, had fulfilled parenting roles for non-biological children. At the time of the interviews, Olga was co-parenting her partner's biological daughter. She did not possess any custody rights to the child and presented herself as her "godmother" in school. Vanessa cared for the biological child of her sister and had adopted the child shortly after birth. The child believed that Vanessa was her birth mother and called her "mom." Roberta had cared for a number of children over the years, mostly biological children of her "wife" of 25 years and those of other female partners. Some of these children considered her a "second mother" and

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[4] Only two participants were not on HAART. Olga was doing fine without anti-retroviral medication and Ana had developed a resistance to all available medications and was hoping to enter a drug trial for the new class of entry-blockers, T20.

referred to her as “Titi” (aunt), and two male children also called her “Papi” or “Tio” (“Papi” is an endearment for males of any sort, not limited to fathers; “Tio” is “uncle” in Spanish). Roberta also helped raise children of her wife’s immediate and extended family. Ana also cared for biological children of her female partners in the past. At the time of the interview she cared for a 4-year old child of a male friend of her ex-partner. Ana did not have any legal rights to the child who was officially in the custody of his biological father. The boy called her “Nina” (Spanish for aunt/grandmother). Whenever she needed to identify her relationship to the child to institutions such as hospitals or nursery homes, she presented herself as his “godmother.” Deirdre lived with her common-law husband and his adopted child from his first marriage. She considered herself a (common-law) “stepmother,” but this adolescent girl did not seem to accept her in that role. Overall, the diversity of formal and informal parenting arrangements in this sample was quite remarkable.

2.4 Biographical sketches of in-depth participants

Alex was a 43-year old butch-identified Puerto Rican. She was proud of her life and her apartment, and described herself as an active and resourceful “go-getter” who was “out” about being an HIV-positive lesbian mother in recovery. She shared an apartment with her female partner and her 23-year old, lesbian daughter. Alex was raised by her adoptive mother and an extended Puerto Rican family in housing projects in two neighborhoods in NYC. She called her family “crazy” (17.1:36). Violence and alcoholism were integral part of her family environment and she was taught to fight, to tolerate physical pain and to drink from a young age ("My first hangover was at the age of seven," 17.1: 53). When she found out that she was adopted at age 12, she felt angry and betrayed. She started rebelling, spent a lot of time with her cousins on the streets, joined a gang, used drugs and had girlfriends (“another way to get on their fucking nerves,” 17.1: 1162). However, Alex maintained close relationships with her family members, especially with her late mother and her cousins, throughout the years. Despite or maybe because of these close ties, Alex noted that with regards to stigmatization, “family can be the cruelest” (17.1: 1696). The religious beliefs of her family were Roman Catholic, but she stopped believing in “the God that they raised me to believe in” (17.1: 1189). Alex strongly criticized the “punishing and vengeful” concept of God in Roman Catholic teaching and has found a more “loving, understanding God” since starting her recovery from substance use (17.1: 1030-31). She was addicted to heroin and crack for 20 years and commenced her recovery from substance use four years ago. She participated in a rehabilitation and subsequent outpatient programs where she met her current HIV negative female partner. Alex tested positive for HIV in 1989 when her second child died of HIV-related complications only a few months after birth. At the time of the interviews, Alex worked as an HIV peer educator and was also going to college.

Olga was a 42 year old Puerto Rican woman who was born in New York. She moved to Puerto Rico with her family when she was 15 years old. Her mother was very strict and physically abusive. Olga married young and gave birth to two children but separated from her husband after only a few years of marriage. In her early twenties she returned to New York City with her two young children and a girlfriend. Here she started using heroin with her female partner. She moved back to Puerto Rico in an effort to settle down and control her drug use, but found herself unable to do so. She served a 5 year sentence in prison, lost custody of her children and continued using heroin. Five years ago, she entered a drug treatment program in Puerto Rico, became a peer counselor in addiction and has been clean since (except for one brief relapse). She moved back to New York City three years ago with the help of her daughter and her brother. At the time of the interviews she worked as an HIV peer educator and shared a household with her female partner (Lisa) and Lisa's daughter. Olga was generally "out" as a lesbian to her family and at work, but much more secretive about her HIV infection.

Wendy was a 32-year old Black woman who identified as bisexual. She grew up in Manhattan as the oldest child of a drug using and physically abusive mother. She never knew her father. She started smoking crack age 13, dropped out of school and was put in a youth home. When talking about her youth and interactions with authorities, Wendy described a general lack of understanding of her situation and her rights ("I didn't know what was happening") and having felt deeply "downgraded," in particular by her mother (26.1: 330). When she was 16, Wendy had her first child which she had to give up for adoption. She since had three more children, each from a different father. She tested positive for HIV 13 years ago and stopped smoking crack two years later. Since then she went back to school and has become more empowered, especially in her interactions with health care providers. At the time of the interview she lived with her three children and was involved with a male partner. Wendy described herself as very secretive about her sexual encounters with women and believed that same-sex sexuality was incompatible with (good) motherhood. She was also secretive, albeit to a lesser extent, about her HIV status and was concerned that people in her neighborhood knew that she lived in a residence for people with HIV/AIDS.

Vanessa was a 49 year old Puerto Rican woman of striking beauty. She was born in Puerto Rico and moved to New York City with her mother when she was three years old. She was the oldest of her siblings and described her childhood as "hard" (27.1:90). Her mother was a single mother working many jobs. Vanessa was regularly beaten and ran away from home repeatedly. She was placed in youth detention and in foster care. She conveyed that she was always "proper" despite the lack of motherly love and that she managed to say “no” to heroin and crack when it was offered to her. She only drank alcohol and used cocaine for many years, but mostly “dipping,” i.e. recreational use on the weekends. Vanessa told her life as a story of abuse, heterosexual relationships and breakups, while always caring for her own and other people’s children. She had three biological children and one adopted daughter who lived with her at the time of the interview. When she found out she was HIV-positive seven years ago, she “fell apart,” "It was like I exploded into a thousand and one pieces" (27.3:57-8) and to this day she said "I’m still trying to find those pieces ... I’m scattered” (27.2: 60-61). Her boyfriend at the time left her and she went into a sexual and emotional cocoon. She did not have a relationship until 10 months ago when she met her current partner, her first female lover ever. At the time of the interview she considered herself a “woman-loving woman” and wished she could be more open about her new-found happiness, but her partner asked her for discretion. Vanessa had a large support network of family and friends and worked as an HIV peer educator.

Stacey was a 43-year old Black woman who described herself as “going both ways,” i.e. bisexual. She grew up with “churchgoing parents” in the Bronx (31.1: 547-8), remembered violence and riots in the neighborhood and described her childhood and adolescence as “a little rough” (31.1: 111). Her family disapproved of her dark skin color. This triggered rebelliousness in Stacey who became fascinated with Black Nationalism and the Black Panthers in her youth (she would respond to her aunt, "The blacker the berry, the sweeter the juice.” 31.1:172). Stacey's brother died of an overdose of heroin when she was 15 years old. Around the same time she started selling and using drugs with a boyfriend. She gave birth to a total of five children, but only the first-born was raised in her family (by her mother and an aunt). The other four children were given up for adoption. Stacey noted that her drug use got out of control in her late 20s after the death of her mother. She stopped using crack three years ago when she felt a pain in her chest and thought she was going to die. She quit with the help of a harm reduction program and has not relapsed since. At the time of the interview she had a male partner and a secret girlfriend whom she saw for oral sex about once a month. She never had a regular job, described herself as a proud “hustler” (31.1: 568) and always had boyfriends who took care of her. Stacey believed that sexual stigma did not affect her because she was not “gay all the way” and because she kept her bisexuality secret. She was also very secretive about her HIV status. Even her daughter only knew about it because a medical provider once carelessly disclosed the information. Stacey came across as very self-confident and outspoken, but her main strategy for dealing with sexual and HIV-related stigma was secrecy.

Gloria was a 42 year old African-American woman. She was born and raised in a middle class family in New York City. Her father was hardly around, but she said that her (working) mother was doing a good job raising her and her siblings. Gloria got pregnant age 17 and moved in with an abusive husband. After leaving him, she had a few more relationships with men and two more children. At the time of the interview, she lived with her three adolescent and adult children in a three-bedroom apartment. She never used drugs, only alcohol. Gloria recently had sex with a lesbian friend under the influence of alcohol and described herself as "confused" about her sexuality. At the time of the interview she was single and placed priority on taking care of her house, her children and her self. Her experience of sexual stigmatization was mainly internal, she felt guilty after having sex with her friend and never did it again. She has not told anybody about her same-sex experience and her accounts of it were slightly inconsistent. She has been HIV positive for nine years, but has only started going to HIV support groups in the past 2-3 years. She experienced painful rejection and distancing from both family members and male partners. In the interview, Gloria distanced herself from other HIV-positive women (whom she described as "ghetto"), but noted that the interactions with HIV-positive peers have been very helpful in that she started to feel better about herself again.

Roberta was a 47-year old butch lesbian. She was born and raised in New York City by her Puerto Rican mother and grandmother while her father and most of her extended family stayed in Puerto Rico. She went to Catholic School, but dropped out of school after she had started using and selling heroin at the age of ten. Drug use was common in her environment (she noted that a male cousin shot up in their bathroom) but strongly disapproved of in her family. Her grandmother died when she was 17 years old and her mother committed suicide when Roberta was 23 years old. Since then one aunt in New York had been her main source of family support and a main source of stigmatization. This aunt strongly opposed Roberta's drug use and repeatedly accused her of having relapsed when Roberta said she was in fact abstinent. This aunt also opposed her same-sex sexuality and blamed her mother's suicide on Roberta's drug use and lesbianism. Roberta described her family as "dysfunctional" (35.1:1218) referring to a lack of mutual support as evidenced when this aunt refused to let her own daughter live in her house. Roberta said of herself, "I have been gay all my life" (35.2: 1488). She knew early on that she was attracted to women and had sex with a girl the first time at the age of seven. All her sexual partners in life have been female and her longest relationship with her "wife" lasted for 25 years. She never had biological children, but helped raise her lovers' children. She came across as a very caring and responsible person. Roberta used and sold drugs and had been in and out of jail for most of her life. At the time of the interview she was two years clean. Roberta had been HIV positive for 15 years and she initiated HIV peer counseling programs in jail and prison while incarcerated. She currently worked as an HIV peer educator and had ambitious plans for the future. She was hoping to open up a residential program for HIV-positive women who were newly released from jail and she was planning to write her autobiography.

Deirdre was a 34 year old White, Jewish woman who identified as bisexual. She grew up in Brooklyn and described her mother as emotionally detached, especially after her father developed schizophrenia and had a mental breakdown. Her family had limited financial resources, and her mother physically abused her. Deirdre was able to stay with her aunt for a while, finished high school and went on to work in jobs. She found out about her HIV infection 12 years ago when one of her first male partners, a hemophiliac, died of HIV related complications. Around that time she had a girlfriend for about two years, but since then all her partners have been male. However, recently when she had sex with a “free spirited” female friend. She said that her "common law husband" did not mind her bisexuality. At the time of the interviews, Deirdre had been living with her common law husband and his adoptive child for 3-4 years. She worked part-time and went to school to get a social work degree. She was close with her sister but did not seem to have many friends and she also did not attend any support groups on a regular basis. She did however frequent the Gay and Lesbian Community Center (where she saw the study flier). Deirdre struggled a lot with accepting her HIV status and was hesitant to even say the word “HIV/AIDS.” She was very secretive about her HIV status and came across as emotionally isolated and cautious.

Ana was a 44-year old lesbian-identified "Nuyorican" (i.e. a Puerto Rican New Yorker). She was born in New York City and raised in both places, traveling back and forth. She described her family as “very oriented towards” Puerto Rico (41.1:21). Her parents had marital problems and when they separated, this felt “like a war” (41.1:65). Her father had a second wife in Puerto Rico who happened to be his own cousin. The family perceived this as a violation of the incest taboo and accused him of “messing up the family name” (41.1:210). Ana became a tomboy age 13 and started hanging out with boys, as she explained, to escape her mother’s fate of suffering. When she was 15, her mother died and she dropped out of school to take care of her younger siblings. Her older brothers started selling sex for money and they lived without adult supervision for two years. When she was 17 years old, her mother’s family took her to Puerto Rico, but they sent her back the same year because they did not approve of her homosexuality. She started selling and using heroin when she was 19, but stopped again after one of her first girlfriends died of HIV-related complications. She worked in a regular job until she started selling drugs again in her 20s (which paid much better). She also started used drugs again and was addicted to heroin and crack for about 15 years. During this time, she was in and out of jail and prison for many years. In 1996, she decided to quit her drug-using lifestyle and has not relapsed since. Ana tested positive for HIV in jail 14 years ago, was put on AZT right away and later on many different drug combinations. At the time of the interview she had developed multiple drug resistance. She considered her health much better than three years ago when she almost died, but she suffered from muscle and body pains and had to use a stick for walking. She lived in the same Hispanic neighborhood where she grew up. She had just split up with her partner and was caring for the 4-year-old son of her friend. This boy, Juanito, stayed with her every other week, rotating between her and his biological father. Ana had a home attendant and a large support network of mainly Hispanic family and friends.

Chapter 3 Findings: Being a target of multiple stigmas

In this chapter I present participants' accounts of multiple stigmatization. It is the first of two findings chapters: Chapter three is dedicated to “being a target of multiple stigmas,” chapter four to “managing multiple stigmatization.” These processes are closely intertwined in social life, but the conceptual differentiation enables me to highlight different aspects of women’s stigmatization experience. The first angle focuses on participants’ descriptions of their multifaceted devaluation, the second on their active efforts at avoiding, easing and challenging this devaluation.

I commence by presenting the stigmas attached to women’s same-sex sexuality, drug use and HIV/AIDS. The three stigmas have unique connotations and applications as well as common elements of moral devaluation, notions of danger and attributions of blame. Exploring how the stigmas interact, overlap and interlock in the lives of the women, I find that “multiple stigmatization” puts participants at a distinct disadvantage, especially in the context of parenthood. Women were discouraged from becoming parents because of their HIV infection; they were dissuaded from raising their children because of their same-sex sexuality, and they often lost custody of their children due to their drug use. The three stigmas reinforced their negative effects by undermining women’s status as mothers and their rights to be parents. From the perspective of participants, multiple stigmatization presented a repeated, multi-layered attack on their sense of self-worth, and they had often internalized aspects of their own devaluation.

However, the stigmas did not simply diminish women’s self-esteem or add up to ever increasing marginalization. Women actively employed coping strategies with which they resisted their devaluation. Furthermore, each stigmatized identity offered a different niche due to collective strategies of resistance. This was most obvious with regards to the stigma attached to HIV/AIDS. Given the achievements of political AIDS activism which greatly contributed to the current status quo of public benefits and support structures for people with HIV/AIDS in New York, HIV/AIDS paradoxically opened up new doors and opportunities for participants. Their HIV/AIDS diagnosis provided access to health care, social support services and housing benefits that they did not possess before.

In the following chapter then, I explore the strategies with which participants deal with their stigmatization. A focus is placed on the strategies with which women circumvent, withstand and counteract their devaluation and its negative effects on their sense of self-worth. Stigma management strategies range from more defensive ones, such as secrecy and self-isolation, to strategies with which participants “buffer” the emotional damage that occurs as a result of multiple stigmatization, to strategies that challenge the legitimacy of the stigmas and aim to counteract stigmatization for example through education, confrontation and legal action.

The HIV-positive women with parenting and same-sex sexual experience who participated in this study have been stigmatized on various grounds and in different settings throughout their lives. As described earlier, most participants were members of marginalized communities of color. In this analysis, I focus on their experience of the stigmas of same-sex sexuality, drug use and HIV/AIDS, well-aware that they were also devalued on the basis of their gender alone, or in relation to their class status, race/ethnicity or criminal records. Racism, sexism and other forms of oppression clearly affected participants' lives and emerged as important contextual factors in their narratives. Given the specific focus of this analysis, however, these contextual factors can only be discussed to the extend that they manifested in and shaped women's experiences of the three stigmas emphasized here.

The findings presented here mainly draw on the words of the nine in-depth interview partners, but I also quote the key informants who participated in the pilot study. Key informants provided important clues for understanding multiple stigmatization. They knew a large number of HIV-positive mothers with same-sex sexual experience, they provided me with insights into the legal system, support structures and HIV-positive women's economic and social situation in New York and they had witnessed many incidents of stigmatization. Most key informants were lesbian and bisexual women of color themselves, and six were even HIV-positive mothers with same-sex sexual experience. In this chapter, I freely intersperse their personal accounts with those of my in-depth interview partners to reach a more comprehensive analysis of women's multiple stigmatization and their self-positioning and agency within these social processes.

In this chapter, I present a detailed analysis of the stigmas attached to women's same-sex sexuality, drug use and HIV/AIDS from the perspective of the women who participated in this study. However, before unfolding each stigma with its respective connotations and implications, I first explore how my interview partners used and defined the term "stigma."

1 Participants' definition of "stigma"

In the interviews, I used a variety of words to stimulate discussion of stigma related topics. I generally favored less abstract and more widely used terms such as "prejudices," "stereotypes," "discrimination," "rejection," and "negative reactions" or "bad responses" over "stigma." However, some of my interview partners used the word "stigma" in their accounts. For example Ana searched for the best word to describe the effects of the label "corta cara" (Spanish for "face cutter"), a highly derogatory term applied to lesbians in her Puerto Rican community in the Bronx during the 1970s.

> Ana: We was considered face-cutters (…). If we get disrespected, that was how we was gonna retaliate. We was gonna mark your face. (…)
> Hella: Did that ever happen? How did that come up?
> Ana: It happened. It happened at the time. But older women that were aggressors at the time, that's how they would retaliate. They would cut their lovers. A lot of them got cut up. So because of that we got.. how do you call that?
> Hella: Stereotyped?
> Ana: Yeah, it was stereotype, but uhm, it's like being HIV-positive .. stigmatized.
> Hella: Stigmatized.
> Ana: That one. It was more stigmatized than being stereotyped.
> Hella: So it had like a real negative..
> Ana: Yeah, it was a very negative..
> Hella: ..meaning?
> Ana: Yeah. (41.1: 522-51)

The label depicted lesbians as jealous, aggressive and abusive. Ana actually knew a lesbian woman (a friend of her mother) who had cut her lover's face to retaliate against her unfaithfulness, so she did not challenge the basis of this stereotype. She opposed, however, the application of the label to younger lesbians like herself.[1] For her, the term "stigma" captured the negative effects of being called "corta cara" better than the term "stereotype" that I suggested. It is interesting that Ana remembered the term in connection with HIV related stigma ("it's like being HIV-positive.."). Borrowing this term from HIV discourse she indirectly drew a comparison between HIV related and sexuality based devaluation. Later in the interview, we were discussing the stigma attached to HIV/AIDS, Ana explained in more detail what "being stigmatized" entailed for her:

> Ana: (…) When you get stigmatized .. they .. I mean you're really put aside.
> Hella: Yeah, stigmatized means that someone really puts you down..
> Ana: Yeah, yeah!
> Hella: It's like they think of you badly and then..
> Ana: And they just push you aside! Totally! Totally. I mean, all the way.. all the way to.. they open the door and put you in and close it. (41.1: 1538-47)

In our combined efforts to define the meaning of being stigmatized, Ana highlighted that it involves being confined in a label (using the metaphor of a closed door) and assigned a devalued position. In a similar vein, Alex used the word "stigma" to describe the low regard her family had of drug users:

> Alex: (…) Because an IV user, that's the lowest you can get in the family.
> Hella: Okay.

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[1] It is not clear how widely the term "corta cara" was used beyond Ana's circle of family, acquaintances and friends in her Puerto Rican community in the Bronx. None of the other participants mentioned the expression. However, several participants noted a general stereotype that depicted lesbians as abusive, dangerous and aggressive. The "corta cara" label thus constitutes only one particular version of a broader stereotypical theme.

> Alex: There was a stigma about IV use. I have a cousin that was an IV user, and like I helped him because everybody just used to treat him like shit, you know.
> Hella: What about it is so.. that people look down on it so much?
> Alex: I don't know. But I knew it was considered the lowest you could go. And knew that that wasn't worth shit. So, of course I'm going to deny being an IV user. (17.1: 1398-1411)

Alex and Ana both described stigma as a re-location from a more desirable to a less desirable position, from the center of their families or communities to the margins (being "put aside," "pushed aside"). Witnessing her cousin's treatment by family members provided Alex with a strong motivation to hide her own drug use in order to avoid becoming a target of face-to-face stigmatization herself. Another participant, Vanessa, used the word "stigma" to describe discrimination of HIV-positive people in the health care setting.

> Vanessa: There was a woman she was really sick and she had to go to the GYN clinic outside of the HIV clinic. And she said they treat you so different outside of the HIV clinic (…).
> Hella: Do you think they looked down at the woman because of her HIV status?
> Vanessa: Because of HIV, oh yeah. And these are, and this is a hospital and these are nurses, and they know what the deal is, but they still .. I guess that's stigma. And she says when she went back to the clinic, they left her for the end. They took care of all the women and she was last. And then she could hear nurses talking outside of the door "No, you gotta put on gloves! You got .. " You know, this hurts a person. (27.2: 1164-79)

When medical professionals responded to an HIV-positive person with exaggerated fear and discriminatory behavior, Vanessa called this "stigma." Her choice of words reflects a sense of injustice at the nurses' behavior. She implied that they behaved irrationally - given their medical training nurses should be more knowledgeable about the low risk of HIV transmission. It is noticeable, though, that Vanessa's example did not involve extreme behaviors or straight-out derogatory comments. Her friend was made to wait and she "only" overheard comments that were not addressed to her directly. This was a core feature of much stigmatization as described by participants of this study. Stigmatization was at times very blunt and open, for example when Vanessa's sister-in-law called her a "bitch" and a "lesbian" and told her to move out of the house (causing literal, geographical relocation); but it also occurred in more subtle and ambiguous ways, involving looks, gestures and silence.

Main agents of stigmatization were first and foremost family members, but negative responses were also encountered from partners, health care providers, friends, acquaintances, extended family of female partners, and also from strangers. However, listening to the women's stories, it became clear that stigmatization not only occurred in interaction with others. Participants also noted internal struggles with self-blame and negative feelings about their same-sex sexuality, drug use experience and HIV infection. Another agent of stigmatization were thus participants themselves. In my presentation, I aim to illuminate both aspects, their reconstruction of other's stigmatizing attitudes and behaviors towards them and their presentation of their own internal, at times contradictory meaning making. By paying close attention to how the women positioned themselves to the accusations and moral judgements inherent in the multiple stigmas, their own involvement in the culture that stigmatizes them became very clear. On the one hand participants were generally critical of the stigmas, yet – being part and product of this culture at the same time - they also shared some of its (self-) demeaning and (self-) stigmatizing views.

One of the main challenges of this analysis and representation consists in doing justice to the heterogeneity of women's experience with the multiple stigmas. The bisexual and lesbian mothers with HIV/AIDS who participated in this study were not a homogeneous group. They differed with respect to their lived experience of same-sex sexuality, drug use, HIV infection and parenthood and regarding the significance they assigned to their experiences. Great differences also existed with regards to the extent that they encountered stigmatization in face-to-face interactions. Keeping these fundamental differences in mind, my aim in this chapter is to outline some of the main stigma related themes that emerged across interviews while paying attention to the uniqueness of each woman's account and the diversity of their views and experiences.

2 The stigma of same-sex sexuality

The stigma attached to women's same-sex sexuality involves various components.[2] Participants described violating gender norms and being threatened with physical assault. They noted that their families felt ashamed and tried to convert them to heterosexuality. They also described a search for a cause of their same-sex sexuality and one participant discussed the religious condemnation of women's same-sex sexuality. Participants described visible indicators of same-sex desire that triggered hostile responses. They also pointed out that sexual stigmatization came in subtle forms of belittling, silence and denial. In the realm of parenthood, sexual stigma unfolded as beliefs that same-sex sexuality and motherhood were irreconcilable and that women who loved other women constituted a threat to the well-being of children.

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[2] For purposes of better legibility of the text, I abbreviate the precise but lengthy term "stigma attached to women's same-sex sexuality" at times with "stigma *of* women's same-sex sexuality ," or - following Herek & Capitanio's notion of "sexual prejudice" (1999) - simply with "sexual stigma."

2.1 "You think you're a man?" – Gender role violations and physical assault

Three in depth participants encountered sexual stigma long before they became parents. Roberta, Ana and Alex started exploring their same-sex sexuality as teenagers, much to the chagrin of their families. Alex described that she feared a violent response from her uncle when her family found out about her love relationship with another young woman.

> We got in the car. All of a sudden, he's driving and we had to stop at a red light. And he turns around: "What the fuck. Do you think you're a man?" And he started grabbing me, you know. And I said, oh, man, I'm dead. And this is the whole thing. This is why growing up with them was so confusing. I thought I was going to get my ass kicked. When we got to his house, he parks. He sends everybody upstairs. He tells me, "No, you stay down here with me." (…) He takes me to the liquor store, buys a fifth, and sits down with me to drink. Okay? So, talking about being confused?! .. [LAUGHS] (17.1: 355-63)

Her uncle's angry question "Do you think you're a man?" illustrates a central tenet of the stigma attached to women's same-sex sexuality in the cultural context of hetero-normativity. In mainstream American culture as well as in Alex's Puerto Rican community, dominant heterosexual norms link sexuality to a gender system (men and women have to be distinguished in order to be paired). In this context, women who desire other women are seen as breaking gender rules. Their love for women is interpreted as a masculine. Within the dichotomous gender system they are seen as quasi-male as they assume a role that is reserved for men. In this sense, women's same-sex sexuality entails a challenge to the gender system and to male privilege. This triggers violent responses. The accusation of wanting to be a man was mainly encountered by participants who had a more butch appearance and comportment, but threats of physical assault were also experienced by more feminine-looking women when they were perceived as the initiators of same-sex sexual intimacy, i.e. when they behaved in ways that were thought to come "natural" only to men.

Alex was not assaulted by her uncle, at least not in this instant (she was physically abused by family members on other occasions, not directly linked to her sexuality). Instead, the conflict was temporarily resolved with alcohol which left Alex thoroughly confused. Ambivalence characterized much of her family's response to her same-sex sexuality. Alex was never outright rejected, but her same-sex sexuality was not fully embraced either. The people closest to her showed what I would call *strategic tolerance*. Alex said her mother was "accepting" (17.1:387) in that she was allowed to bring girlfriends home, but this was mainly a bargaining strategy to keep her close.

> Hella: In your own family, was there anyone gay or lesbian?
> Alex: No. (…)
> Hella: So, how come your mom was accepting? I find this really interesting.
> Alex: I think that basically it was the manipulate..the manipulative nature that my mother had. My mother would do anything to keep me in the

> house, and to keep me by her side (…) and to have some kind of control over me. And, to tell you the truth, until the day she died, she did. [LAUGHS] (17.1: 1226-43)

Her mother and other family members tried to separate Alex and her girlfriend, but when their attempts failed, they "put up" with her same-sex sexuality for the sake of maintaining close family relationships. There was always a threat of violence in the air, though, as exemplified by her mother's typical comment, "Don't let your uncle catch you!" (17.1: 389)

Participants also encountered physically violent responses to their same-sex sexuality outside of family environments. Ana, for example, barely escaped being gay-bashed on the street when she and her girlfriend left a public hang-out of young lesbians in the Bronx. A group of men pulled up in a car, verbally harassed her ("Oh, you think you're a man? .. You ain't nothing but a whore!" 41.1: 571-72) and threatened her with a gun. She managed to talk herself out of the situation, but the incident "opened" her "up" to the dangers of sexual stigma:

> Yeah! That was scary. I walked away with her and I'm like, I told her "See, this is what we're gonna go through. Are you sure you want to go through..?" Cause I was her first lover. (…) That was the first incident that really .. opened me up to "Oh, I gotta find out what's going on. I gotta find out why people .. why people see me like this!" (41.1: 588-595)

Encountering stark opposition from their families and hostile attacks from non-family members, participants explained that loving women came with a price. Overall, most participants believed that women's same-sex sexuality has become more visible in American mainstream culture since the 1970s, but they also pointed out that sexual stigma still existed and that to this day lesbian women continued to be attacked and even killed.[3]

2.2 "Shaming the family" – Disappointing cultural expectations

Discussing her family's lack of acceptance of her same-sex sexuality, Roberta mentioned two sources of stigma, the portrayal of homosexuality as a mental illness in the media, and culturally specific notions of embarrassment.

> Society plays a big part in that, too. Because you know, I remember years ago, hearing it on TV on the radio, if you had .. if you were gay or if you was a lesbian, there was something really psych.. something wrong with you, mentally, you know what I'm saying? And I guess, for our cultures, the embarrassment, you know? Cause to them a man is supposed to be with a woman and a woman with a man. They are supposed to bear children and have a life and you know you do whatever your man says. And I'm sorry that's just not the way I am. (35.1: 920-927)

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[3] One of my key informants, Mildred, pointed to the murder of Juanita Hernandez who was killed in NYC by the son of her female partner on 1/23/01. Another participant, Wendy, mentioned news reports of a violent attack on a lesbian in New Jersey. Since conducting the in-depth interviews, another killing of a young lesbian took place in New Jersey in May 2003. Sakia Gunn was stabbed to death at a bus stop when she rebuffed the "sexual innuendoes" of young men and identified herself as lesbian (Gay City News, 11/27-12/3/2003, p.9-10).

The first issue that Roberta raised was the view of homosexuality as a mental illness. This was common medical and therapeutic practice when Roberta was growing up as homosexuality was considered a psychiatric disorder until 1973, when Roberta was 18 years old.

The second source of sexual stigma, embarrassment, has culturally specific connotations for her. Given that Roberta self-identified as Puerto Rican, her reference to "for our cultures" can be read as a reference to Puerto Rican culture. Her use of the plural "culture<u>s</u>" might indicate that she perceived embarrassment as characteristic of various Latino/Hispanic cultures (i.e. Puerto Rican, South American, Mexican, etc.) or it could be a reference to her bi/multicultural roots in relation to me.[4] Embarrassment describes an emotional state of disconcertment and discomfort. According to Roberta, by not fulfilling traditional gender role expectations (having children and "doing what your man says"), lesbians trigger such state of discomfort in their families. In a similar vein, a key informant explained that many Latino families viewed women's same sex sexuality as a source of shame. Nell spoke from her personal experience as a butch Puerto Rican and as a provider who worked with HIV-positive women from various Spanish-speaking cultures.

> As far as being a lesbian in the Latina culture, you just fucked up all the way around, you know, because you're supposed to have pride. You're raised with a lot of pride, and you should be better than this. (…) You've brought shame to the family, especially if you're a dyke, you know, meaning butch. It's disgusting. Most of the.. a good seventy percent of the time, you are disinherited from the family. That's why so many lesbians go into drugs. Drugs, all kinds of situations. (…) Let's say you're fourteen, fifteen, sixteen, and your family finally realizes that it's not a phase, okay. (…) This is who, you know, you really want to be. You want to be a woman sleeping with another woman. And they disinherit you. They throw you out of the house. They don't want you anywhere near the family because you've brought this shame and disgrace. And you find yourself getting into crowds and little crews and gangs, you know, hungering, okay, for that family, looking for that loving. Because in the Hispanic culture, when you're born, you know, to.. till you leave your home, even after, you know, it's like you're always Mommy's baby. Because you could be ninety years old, you're Mommy's baby, you know. And, so, throughout all these years, you know, you've had that closeness and all that loving and all this stuff, and all of a sudden, you find like they threw you off the roof, you know. You find yourself alone, without nobody, no one to call. There's times when you're in the streets with no place to live, okay, because you're a young kid. You get into all sorts of situations when looking for love in all the wrong places. (PS07: 487-524)

In this narrative, Nell reconstructed what she perceived as a typical story of a young Latina lesbian who ends up in the streets because she is rejected by her family. Nell

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[4] Throughout the interviews Roberta repeatedly self-identified as Puerto-Rican. When I specifically inquired about her ethnic background, she explained: "My mother is Puerto Rican, my father is Puerto Rican, part Black and part Indian (…) I'm what they call mixed mutt." (35.1: 161-66) Roberta grew up in New York and only sporadically visited her family in Puerto Rico. "For our cultures"

identified both the notion of “shame and disgrace” and close family ties as characteristic of Hispanic culture. Same-sex attracted women are viewed as not only personally fallen from grace, they “brought shame to the family.” Women’s sexuality is not a matter of the individual, it is a family affair and closely related to concepts of shame and family honor. When women’s same-sex sexuality is interpreted along these lines, Nell explained, the tightness of family bonds can backfire. Women-loving women are excluded from family networks that sustained them up to this point, which sends them “looking for that loving” in “all the wrong places.” In this sense, Nell implied that sexual stigma leads to drug use and to abusive relationships with men. This connection between expulsion from close family networks and self-destructive behaviors was also described by Lola, a Black Hispanic lesbian mother with HIV/AIDS. Looking back at her life she summarized,

> I was destroying myself, because my God, every time you try to live and express who you are, you're being told it's bad, it's horrible, it's nasty, it's causing problems, your family is falling apart. You're shaming your family. So I went on this rampage to get rid of me. And to get rid of me was my drug use. (…) I was living a very promiscuous life. I was having, I mean, sex with multiple men. What was that about? I hated me. I hated this lesbian. (PS01: 584-92)

Lola was born and raised in the Caribbean and her family strongly opposed same-sex sexuality. Barely an adult, Lola left her country of origin and moved to the United States. In the interview, Lola drew a clear connection from sexual stigma (being told, “You’re shaming the family”) to self hate and to drug use. Not all participants attributed women’s drug use to sexual stigma in their families, but accounts of other participants mirrored the emotional distress caused by sexual stigmatization in their families.[5] Both Ana and Roberta were cast aside by their families in their late teens/early twenties shortly after their mothers had passed. Their cases provide clear examples of painful expulsion from previously close Latino family networks due (at least in large parts) to sexual stigma.

Alex’s story on the other hand provides an example of a Puerto Rican family that worked out a compromise *because* family ties were so close. Alex was good friends with several cousins and her mother in particular seemed to have been a key figure who did not allow for distancing to occur. They established an arrangement I called ‘strategic tolerance.’ This points to the importance of the role of a family member, in this case the mother, who, at least in some families, keeps lesbian women integrated in family networks

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could thus refer to her cultural background as both American and Puerto Rican given that I am German/European.

[5] Most examples of “shaming the family” derive from my Latina interview partners. I did not find similar descriptions of this theme in the accounts of Black or White participants. This might indicate a cultural difference or it could be due to sample bias - most of my Black and White interview partners were not as committed to their same-sex sexual partners and had not revealed their love for women to their families to the same degree as Latina participants. Cathy, an HIV-positive African American key informant, was also called a “dyke” and stigmatized by several family

despite existing tensions. Given that Alex had biological children while Ana and Roberta did not, one could also ask whether having children reduced the risk of being expelled from family networks. Maybe by fulfilling at least part of the gender role expectations, biological mothers have a bargaining chip at their hands and shared child care responsibilities create lasting bonds with other family members? In Alex's case, her family raised her daughter (in part to prevent her from becoming a lesbian as well) but they did not stop Alex from seeing her child. Her relationship to her daughter, however fragmented it might have been, thus linked her to the family network.

2.3 Conversion attempts by family members

Not all participants in this study had let their families and friends know about their liking for women. However, those who had, commonly described that their families tried to discourage their same-sex sexuality and attempted to convert them to heterosexuality. For example Ana' s Puerto Rican based family strongly opposed her love for women when she stayed with them as an adolescent after her mother's death.

> Ana: I got to Puerto Rico and I was with my mother's family. (…) And then I started doing the things that I was doing here, and in Puerto Rico that's a no-no.
> Hella: What things?
> Ana: With the girls. And they found out and they were like, I don't know, "We're not gonna have that!" And they sent me from uncle to uncle .. and ..
> Hella: What does that mean, from uncle to uncle?
> Ana: To go and live .. they didn't want part of my craziness, that's what they called it. (41.1: 1087-1099)

Ana's expression that she was sent "from uncle to uncle" carries connotations of a patriarchal family structure. It might also indicate that uncles played a significant role in the conversion attempts. Elsewhere in the interview Ana explained that her family perceived her supposed "craziness" as a result of the loss of her mother who died when Ana was 15 years old. However, it is noteworthy that they did not arrange for a mother substitute (for example by sending her 'from aunt to aunt'). Instead, they hoped that male authority figures would bring about the desired change.[6] When her family realized that they could not change Ana's sexuality, they sent her back to New York City in the same year where she lived on her own.

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members, but her family was not as close-knit and she did not indicate that there was a sense of tainted "family honor."

[6] Earlier in the interview, Ana explained that her mother's family was outraged that her father had taken his own cousin as a second wife long before her mother died. By openly admitting to this second marriage and by having children with his own cousin, he not only disrespected Ana's mother, he also violated the incest taboo and "messed up the family name" (41.1:210). This might be another reason why the family on her mother's side believed that Ana was in need of the corrective influence of a 'proper' male authority figure.

Two HIV-positive key informants also had family members who intervened when their same-sex sexuality first became known. Cathy, an African American woman who “came out” as a woman-loving woman later in life, was taken to a heterosexual sex resort by her sister. Lola was taken to a traditional healer in her Caribbean country of origin. Lola described her mother’s intervention as follows:

> At thirteen, that's when I told my mother how I am feeling towards women. What was done was that I got thrown in a closet. My parents, my mother.. I won't say my parents, because my dad.. my dad never knew of me being this.. you know, same-gender-loving person until I think it must have been two years after my diagnosis, and I got diagnosed in 1990. But my mother made me swore to her, “You're never, ever going to say this!” Because my daddy's Hispanic. He's a very machismo man, and what my mother choosed to do.. in the Caribbean, you know, they have this thing, you know, voodoo. But they call it obeah .. What my mother choosed to do, she took me to this obeah priest, and she told the man that someone threw a voodoo in her house and I caught it, and I'm saying all these weird things. So every Friday, I used to.. my mother used to take me to this man. This man literally was sticking his hand down my throat and giving me these horrible things to drink, telling my mother he's taking the demons out. And I had to deal with that from the age of thirteen up until I was sixteen. I attempted suicide twice, and I survived. The last time I attempted suicide, I almost died. And that's what..you know, that's what made me come to the U.S. My mom said she just didn't want to deal with it anymore, she wouldn't have to deal with me anymore, and I came out here. (PS01: 560-78)

The traditional healer that her mother made her see subjected her to highly invasive, utterly ineffective procedures. Lola clearly expressed feeling violated by this obeah priest and her subsequent mention of suicide attempts indicate how troubled she was while trying to comply with her mother’s wishes. In her experience, being stigmatized for her sexuality fostered self-destructive behaviors as she was unable to accept herself in an environment that deeply disapproved of her love and desires for women. Very similar to Ana, her final move to New York represented both an escape from hurtful stigmatization as well as a painful rejection by her family.

The strategies family members applied in their supposed ‘cleansing’ or conversion attempts varied, depending on their cultural background and respective interpretation of the causes of women’s same-sex sexuality. What remained a stable feature across cultures and families, was the tremendous pressure on participants to change and suppress their love for women. When the desired change did not occur, many participants described painful experiences of rejection often combined with lengthy periods of estrangement from their families.

2.4 “Who you gonna blame now?” - The search for a cause

When Alex’s same-sex sexuality became known, members of her family asked themselves what they had done wrong. She remembered that her mother blamed herself

"Where did I go wrong?" and her male cousins wondered if they had "turned her that way" by being physically rough (17.1: 386, 480). These responses indicate that her family thought someone or something was to blame for what they considered a mal-development. Alex described this pattern again when she discussed her family's stance toward her daughter's sexuality. Alex had been discouraged by her family from raising her child, not only because of her drug use, but also because of her same-sex sexuality.

> Everybody used to say, "Oh, you shouldn't raise your daughter, because she's going to come out a lesbian, like you." So everybody else practically raised my daughter except for me, and she still came out a lesbian. So what the fuck? .. [LAUGHS] .. you know. Who you blame.. who you gonna blame now? (17.2: 867-71)

I will discuss the fact that she was discouraged from raising her daughter shortly. But first, I would like to explore the argument that someone or something must be responsible when women express love and desire for other women.

Olga's family thought that she turned to women because she was abused by her husband. Vanessa's therapist believed that she got involved with a woman only because she was infected with HIV by a man. Ana's family thought she was "acting out" after the death of her mother. Interestingly, while Olga and Vanessa disagreed with their family's/therapist's interpretations and attempts to identify a "cause" of their same-sex attraction, Ana provided her own explanation. She related the beginning of her same-sex sexuality to the marital problems of her parents and to witnessing her mother being hurt by her unfaithful father.

> I started hanging out with the boys and I started hanging out with my brother's friends .. and I started playing basketball. And I guess it .. it had a lot to do with not wanting to get hurt. With what was going around. Cause I felt that females .. that I was gonna get hurt. That I was gonna go through more or less what my mother was going through. That's what I kept in my mind. She is going through this with this man. How am I gonna find somebody to have..? If my mother is not happy, I'm not gonna be happy. You know, you feel like it's a curse. [LAUGHS] (…) I wanted to be hard in a sense that I didn't want to show no pain. Or you can do whatever you want to me and I wasn't gonna show you that it hurt, so .. my only way of escaping that was .. I saw the boys as being tough, you know, being part of the gang, hanging out with each other. They would stick together so that they would .. so nothing would hurt them. And I thought if I do that then I'm not .. you know if I stick with my brother, my brother is gonna protect me. So I became part of a .. part of his little crew. (…) It turned out pretty good, because you know .. I mean in a sense that I kept away from guys, that was a loss for me in that sense, because I didn't experience that fairy tale thing that thing that you look for, that girls look for, you know that first love with a guy .. or .. or .. I experienced it with a woman instead of with a guy because of .. I didn't want to get hurt by guys. So I put myself in that, in that.. and I hung out more with women. Cause I was like a boy, so they wanted to hang out with me, too. (41.1: 388-424)

In retrospect, Ana expressed a sense of loss over not having experienced "that fairytale thing … with a guy". This is remarkable as she was otherwise very positive about her same-sex sexuality.[7] It indicates that she is well-aware of standing outside of a cultural "master narrative" (Andrews, 2002) that entails an idealized version of (heterosexual) first love. In this interview sequence, her involvement with women sounds almost coincidental, as if it was only a by-product of her assuming a more male gender role to escape a woman's (her mother's) "curse" of suffering. By telling her story this way, Ana presented her sexuality as not predetermined, but as the result of life circumstances that involved parental problems and fostered a specific need for self-protection in her. She thus implicitly suggests that life could have also taken another turn and thereby normalized her sexual development.

Arguing that her mother's suffering was an environmental influence on her socio-sexual development, Ana, too, provided an circumstantial explanation for the start of her same-sex orientation. Her explanation differed from that of her family in that she described it as a consequence of a survival strategy while her family perceived her same-sex sexuality as a rebellion and temporary confusion ("craziness") following the trauma of her mother's death. However, both explanations have in common that they viewed some problem at the root of her same-sex sexuality.

Most 'explanations' of causes of women's same-sex sexuality - independent of whether they represent participants' beliefs or were re-constructions of their families' convictions - attributed responsibility and blame not directly to participants, but to some other person or circumstance. Women's sexual development was generally viewed as not fully under their control. As I will show in the next section, this stands in stark contrast to the stigma of drug use which places blame directly on the women because their drug use is considered a willful choice.

Participants might not have been blamed for their own same-sex sexuality, but they were blamed for "turning" others "gay" (21.2: 852). Olga for example was threatened and harassed by members of her partner's family in law who held her responsible for seducing her partner Lisa. Alex, quoted above, pointed out that she could not be blamed for her daughter's same-sex sexuality, but she was convinced that blame would have been attributed to her had she been her daughter's main care taker.

2.5 "My pastor says it's a sin" – Religious condemnation

Participants explained that sexual relationships between people of the same sex were often considered unnatural and sinful. When describing (experienced or anticipated) negative responses from family members, participants sometimes mentioned religious

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[7] Ana described relationships and sex with women as simply more satisfying. For her, sex with women often involved "one of those deep feelings" while sex with men was fast, less emotionally involved and unsatisfying (41.2: 875-79). In the past 20 years she has had only female partners and described herself as an "out" and "proud" lesbian to friends, family and in her neighborhood.

beliefs as an explanation for someone's opposing stance towards same-sex sexuality. Alex mentioned that her family raised her as a Roman Catholic and that the Roman Catholic church remains a main agent of stigmatization (17.1: 1736-37). When she first realized that she was attracted to girls she said, "I knew that it wasn't right," (17.1: 1169), but she rebelled against her (adoptive) family and their religious beliefs and did not experience an internal conflict between religious beliefs and her sexuality. Since starting her recovery from substance use she found a more "loving, understanding God" (17.1: 1029) and her current spiritual beliefs to not conflict with her same-sex sexuality.

One of my key informants seemed more torn in this respect. Frances was an HIV-positive mother with same-sex sexual experience. She described her sexual orientation as "male only, (…) straight" (PS10: 469-71) and was generally very secretive about the one time she had sex with another woman. She was friends with an openly bisexual mother, though, and she knew of women who had female partners at her HIV service provider. When asked whether she thought being a lesbian is "still considered something bad," she responded:

> Yeah, because they say that in God's eye ..God made man and God made woman. He didn't make..you know, he made them, but he didn't make man and man together and woman and woman together. He made man and he made woman. So that's like a sin. (…) Well, people think it's a sin. My pastor says it's a sin. (PS10: 439-446)

When asked whether she agreed with the teachings of her pastor and personally thought relationships between women were sinful, she replied:

> No, well, everything is not all right, but it is in the Bible. But I say people are people, no matter what they are, you know. That's their preference, that's not for me to judge. That's only for God to judge, Jesus Christ to judge. I am not judging anyone. If they're nice with me, I'm nice with them, and I'm pretty much nice with everybody, so it doesn't matter to me. I have no problem with nobody being lesbian and bisexual .. to each his own. That's what I believe. It's to each his own. I have no problem. (PS10: 532-40)

Frances seemed to struggle with her pastor's homophobic interpretation of biblical texts on the one hand and a desire to get along with women of different sexual orientations in her HIV support network on the other. She reconciled this contradiction by refusing to personally pass moral judgment and decided to tolerate women's same-sex sexual preference as long as they were "nice" and kept to "their own." From her point of view, bisexual and lesbian women were not stigmatized at her HIV service provider ("They are considered as human. Everybody doesn't push them away … everybody is family." PS10: 486-88). Another key informant, Fame, however, who happened to attend the same provider in the same function as client and peer educator, described a very different scenario. She explained that she kept her bisexuality secret from other women at this HIV service provider.

> Because most of my friends, I hear them make certain statements about people that's bisexual or gay, and I listen to them, but I don't like half the things that they say. For instance (...) we had group yesterday, and there was this girl (...) and she was speaking about how she was tired of men, and she's ready to do, you know, the female thing. She doesn't want to be bothered with men anymore. (...) And the girls were saying, well, "Bye, you can go ahead .. but don't come over here with me like that! Don't do .." I mean, they was like..they really kind of pissed me off, you know. I mean, everybody is whatever they are. You know, you just don't judge people that way, because that's not your preference, that don't mean you have to down anyone else for being like that or wanting to do that. That's what they want to do. And they're always talking about it like that was the lowest thing to do. (PS14: 538-68)

Fame described an atmosphere where women's same-sex sexuality is disproved of and where expressions of same-sex sexual desires or intentions are met with homophobia ("don't come over here with me like that!"). She agreed with Frances that the HIV-positive women at the provider were generally very supportive of each other and she, too, felt like part of a family, but she was much more aware of the sexual stigma that occurred in this setting. Contrary to Frances who partially embraced beliefs that homosexuality was a sin ("it's in the bible"), Fame believed that homosexuality was acceptable ("everybody is whatever they are"). She had more same-sex sexual experience, interpreted it differently and positioned herself differently to it. For Frances it was "just an experience" that she would not repeat again, while Fame had had a "relationship" with another woman, considered herself bisexual and did not rule out that she might have a female partner again. Neither of them spoke about their same-sex sexual experience at the HIV service provider, but their assessment of how legitimate and prevalent sexual stigma is differed fundamentally.

2.6 Endorsing (self-) stigmatizing views

Most participants, both key informants and in-depth interview partners, made statements that strongly opposed sexual stigma. They pointed out that women's same-sex sexuality was as "natural" and "normal" as heterosexuality and several participants described themselves as "out" and "proud" about their love for women. However, in a number of cases it became clear that women endorsed aspects of sexual stigma in specific situations. For example Wendy stated that she was not ashamed of her sexual experiences with women ("I didn't feel ashamed or anything;" 26.1: 1605), but when she discussed telling her boyfriend about these experiences, it became clear that she quickly promised not to do it again.

> He's looking at me like I was stupid. He was like "You're not doing that." I was like, "I know that. I don't do that anymore." (26.2: 829-30).

She also expressed her reservation against lesbian co-parenting which clearly indicated that she harbored negative views of lesbian women's ability to be good mothers (quoted below). Other women mentioned doubts and fears when they first had sex with a woman ("I was trembling underneath her", 27.1: 1012) or feelings of guilt and regret in the aftermath (Gloria told the woman she had sex with, ""That wasn't right what we did last night." 32.1: 469-70).

Even some participants who expressed very accepting and positive attitudes towards their same-sex sexuality described moments when they struggled with self-stigmatization. Roberta provided a prime example. She has been aware of the stigma attached to same-sex sexuality since she was a child (she admired a lesbian couple that was "out" in her neighborhood and "didn't care" what people thought; 35.1:129). She described herself as having been "gay all my life" (35.2: 1488) and stated that she was never ashamed of her same-sex sexuality. The concept of shame and guilt only entered her views of her sexuality when an aunt accused her of having caused her mother's suicide.

> When my mom committed suicide, my aunt went to my family and stated that my mom killed herself because I was a drug addict. My mother killed herself because I was a lesbian. She started saying that me and my wife used to hit my mother. I mean she invented so much shit. (…) And you know with all the shit she said, she really made me start believe in it after a while. She actually had me feeling guilty because I was a lesbian thinking that my mother killed herself because of that. (35.1: 1154-57; 1194-97)

The tragic loss of her mother placed Roberta in a position where she was vulnerable to self-doubt and self-loathing and she described internalizing her aunt's attributions of blame. I will discuss the intersection of sexual and drug use stigma later in this chapter. At this point, I would like to point out two things, a) the power of stigma to convince even women who were very comfortable with their sexuality of its supposed inherent moral flaw; and b) the situational nature of stigma (and self-stigmatization) that is revealed in this Roberta's account. Stigmatizing beliefs could be endorsed in one moment, but not in another. Far from being stable and consistent, they depended on the context in which they were raised and the function they served. Roberta was deeply hurt by her mother's suicide and she was looking for answers why her mother had taken her life. In a way, blaming herself based on the stigmas attached to her same-sex sexuality and drug use seemed to provide an answer. Today Roberta contended that her mother's suicide was not her fault. She admitted that her mother did not approve of her drug use, but she stressed that her mother had come to a greater acceptance of her lesbian lifestyle before she took her life. This provided Roberta with some peace of mind, but I will show in the second part of this findings chapter how pertinacious these elements of self-stigmatization could be, causing participants a tremendous amount of emotional pain despite decisive efforts to overcome them.

2.7 Butch looks and other triggers of sexual stigmatization

For face-to-face stigmatization to occur, women's sexual difference had to be known about, proclaimed or recognized. Participants described varying levels of "visibility" of their same-sex sexuality. Roberta believed that her same-sex sexuality has been visible since she was very young. People in her neighborhood "knew" by inferring it from the way she looked and behaved (e.g. she never had a boyfriend or feminine looks). Alex described a very similar situation ("what you see is what you get" 17.2: 1567-68). When asked whether people in her HIV clinic knew that she was a lesbian, she replied "Yeah," and responded to my probing "Yeah?" with laughter and, "Phew, you think not?" (17.2: 1054-58). She explained that she was "very bold," frequently mentioning her female partner to her health care professionals, bringing her to social events and introducing her as her "partner" (and not as a "friend"). Most importantly, she believed that her looks gave her same-sex sexuality away with her short hair, loose clothing and distinctly butch comportment. Merely showing up at ("straight") *Narcotics Anonymous* meetings meant making a statement of sexual difference (which she described as "crashing straight meetings"; 17.1:1633*).*[8]

Olga who self-identified as "femme" wore long hair and a much more feminine attire (e.g. long fingernails and tight clothes) than Roberta and Alex who both identified as "butch." Olga's gender conform appearance did not indicate her same-sex sexual preference, but she reckoned it could be inferred from her behaviors, for example in her neighborhood where she and her lover were always together. She also pointed out that her lover's family started noticing their relationship when they saw how much Olga cared for Lisa and how she used to "act" when she was "near her" (21.2: 494). Associating with other lesbians functioned as another indicator of women's same-sex attraction. Ana reckoned that friends of her mother "knew something was up" because they had seen her "hang out with the gay girls at school" (41.1: 758; 779-80).

All of these indicators of women's same-sex sexuality - butch looks, showing affection, associating with other lesbians - served as triggers of face-to-face stigmatization. However, such indicators were at times misleading or ambiguous and the relationship between "visibility" of same-sex sexuality and stigmatization was not linear. Participants who described their looks as butch or non-feminine recollected stark opposition to their same-sex sexuality, not only from their families, but also from strangers. They were easily identified as lesbian, stood accused of wanting to be men and

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[8] Alex explained that some *Narcotics Anonymous* meetings are specifically for gays and lesbians, such as those in the LGBT community center in Manhattan. Meetings that are not listed as "gay and lesbian" are automatically considered "straight." When Alex attends such meetings, she feels that her sexual difference is immediately recognized. She goes "dressed up in style" and has encountered tensions, looks and raised eyebrows, but was never verbally attacked or stigmatized in a blatant way. (17.1: 16333-67)

they were perceived as the ones who induced other women to engage in sexual intimacies with them. Their gender non-conform looks made them prime targets of sexual stigma. However, the in-depth interviews also revealed that women with feminine appearance and even women without same-sex sexual experience experienced severe sexual stigmatization. For example, Vanessa was called a lesbian and stigmatized when she still considered herself heterosexual and long before she engaged in any same-sex sexual relationship: She merely happened to have a lesbian friend who was attracted to her. But when her sister-in-law found love letters from this friend, she called Vanessa a lesbian and told her and her children to move out of the house. Similarly Olga who self-identified as femme and had very feminine looks was threatened with physical violence by her partner's family because they blamed her for "turning" Lisa gay. Butch looks thus triggered stigmatization more easily, but femme looks by no means provided fool-proof protection when other signs indicated women's (real or perceived) same-sex sexual preference.

2.8 "It doesn't sink in" – Belittling, silence and denial

Participants described a range of stigmatizing behaviors, including verbal harassment and threats of violence, name-calling, sexualized language, and explicit attempts to discourage their same-sex sexuality. But not all responses were confrontational and blunt. Participants also described that some people belittled their same-sex sexuality, for example by calling it a "fantasy" or a "phase" (26.2: 1595-1604). Participants also encountered silence and denial. Alex, for example, described herself as very forthright about being lesbian, but her doctor seemed to repeatedly "forget" that she was in a committed relationship with a woman.

> Alex: (…) I've been going to the same freaking doctor for close to four years.. and the other day, I went for a follow-up and she looked at me and she goes, "Do you need any condoms?" And I looked at her like, "What the fuck is wrong with you?" you know. "Excuse me, do you have any damn dental dams?" .. [LAUGHS] .. "Oh, I keep forgetting!"
> Hella: That's your primary care physician?
> Alex: Yeah! And I'm like.. how can you forget? I mean, I make it very obvious. So, I mean, you know ..
> Hella: How do you make it obvious? Do you talk about it?
> Alex: I talk about my partner. I've brought her to the clinic with me.
> Hella: Yeah.
> Alex: So, I mean, what the hell is wrong with you, you know? What the fuck am I going to use a condom for? And it's like, you know, it doesn't.. I guess it doesn't sink in, or she's forgetful or she's getting old or something, you know. But it happens every time I go for my follow-up. (17.1:762-786)

Alex was very offended that her doctor continuously assumed she had sex with men (thus the offer of condoms) while ignoring her lesbian relationship and her need for HIV prevention methods for sex with women (such as "dental dams"). She noted that her health care providers generally “don’t ask many questions” about her same-sex sexuality which implies a lack of interest and possible discomfort talking about and acknowledging her same-sex sexuality (17.2:1097). Her health care providers knew about her HIV-negative female partner, but they never informed her of the risks of sexual HIV transmission from woman to woman. They never failed to assume she had sex with men, though. This presumed heterosexuality was particularly upsetting for Alex who self-identified as butch, but it also brought Lola, an HIV-positive self-identified femme, to tears. In her case, a nurse falsely presumed that Lola’s history of recurrent pelvic inflammatory disease (PID) indicated ongoing sexual conduct with men and advised her – in a rather patronizing manner - to stop having unprotected sex with men. Lola was outraged given that she attributed the recurrent PID to past sexual abuse experiences and at the time of the nurse’s comment she had been in committed lesbian relationships for the past 10 years.

Women’s medical HIV care was clearly affected by provider’s unwillingness to see and acknowledge their same-sex sexuality. Female partners were not involved in treatment and care and appropriate counseling regarding HIV transmission risks and permanency planning was not provided. Willa, a key informant who worked as a social worker in a hospital setting, was highly critical of the discrimination of HIV-positive lesbian patients by medical staff.

> [Heterosexual] families would be included in making medical decisions, making social work decisions. It was just sort of an understood. "Where is your wife? Let me call her." "Where is your husband? Let me call him." But when lesbians came in, and they were very out lesbians. "Do you have a husband?" "No." "Do you have a wife?" "Well, yes, kind of, I'm a lesbian." You know, and they'd write it in the chart and..and they just wouldn't make an effort to like, "Well, can I call your girlfriend? What's her phone number?" "Do you have a living will?" "Do you need some legal help with that?" "Do you have any children?" "Are you domestic partners?" "Who's going to make these decisions for you?" You know, they were just very unsophisticated. And not just unsophisticated, sort of blatantly ignorant. (PS12: 344-54)

Willa described a number of social service needs that were not met by providers, even when patients stated they had female partners. These specific needs included legal help with writing a living will, recognition of the partnership as a “domestic partnership,” permanency planning to arrange custody of the children, and writing a health care proxy so that the female partner had a right to be involved in medical decision making in a case of an emergency. All of these were important precautions in a social context where same-sex relationships lacked official recognition. Without these precautions, female partners for example had no rights to be informed of their partner’s health by medical providers. Should anything happen to the HIV-positive woman, only her biological family members were entitled to medical information, custody of children, and women’s possession under the current legal system. Given that lesbian and bisexual women were often estranged from their biological families due to sexual stigma, failing to help same-sex couples take legal precautions could cause great problems and grief for members of the lesbian family.

In Willa's description, providers were not blunt in their anti-lesbian prejudice, they "merely" put less effort and neglected aspects related to their patients' same-sex sexuality. These more subtle forms of sexual stigma were not necessarily less harmful. On the contrary, Lola, a key informant and HIV-positive lesbian mother, described the every-day battle against hetero-normative assumptions as very stressful. She criticized heterosexist bias in provider's intake forms and in eligibility criteria for family support services. The burden to disrupt these assumptions and gain recognition of her reality as a "same-gender loving woman" who has children and a female partner was always on her. This constituted an extra strain for her as a client/patient who was interested in establishing good rapport with providers on whom she was dependent for her treatment and care.

2.9 "I don't want that around my daughter" – The perceived threat to children

Participants described that their same-sex sexuality was at times perceived as a threat to the welfare of children. For example a woman "grabbed her child" in a doctor's waiting room when Deirde was holding her girlfriend's hand.

> The woman grabbed her child, like she didn't want, you know, to be a part of it, you know. So, it was a little extreme what she did, but because we weren't really doing much. We were just holding hands. And she was like, you know, I mean, she was like really, you know, scared for her child. (36.2: 74-78)

Other participants, too, were treated as if they posed a threat to children. Wherein exactly lay the perceived danger of women's same-sex sexuality? Participants described an element of fear of contagion. People were literally afraid that women's same-sex sexuality might "rub off" on their children, as in Alex's case where her family discouraged her from raising her child because they were concerned that her daughter would also become a lesbian.

Participants also mentioned beliefs that exposing children to homosexuality might harm their psycho-social development. This notion was expressed by one of the participants who explained that she would never raise her children with another woman as a lesbian family unit. Wendy anticipated that her children would not understand such an arrangement and was concerned that this would "mess them up."

> They never saw nothing like that. They don't see people like that. They see you like they see on TV, mother and father. For you to bring a woman in your house to live with you .. and they are used to mother and father, it will mess them up. (26.2: 1687-1690)

To prove her point, Wendy provided an example of a friend whose children rebelled against her lesbian relationship; the adolescent son started "smoking weed" and "he don't want to listen" (26.2: 1698). Wendy thought her friend should not have integrated her female lover into the family in the first place.

> If you didn't bring it home, it would have been alright. But once you bring it home, it's a whole different concept. (26.2: 1701-2)

Wendy believed mothers should not engage in committed, open relationships with other women. From her point of view, secret sexual affairs with women were acceptable, but cohabiting or even lesbian co-parenting was not. She believed this would confuse the children who were primed to heterosexual norms by society. She was adamant that *because* she was a mother she would keep her (sporadic) same-sex sexual encounters separate from her children ("Whatever I do, I don't do it at home. I do it out of the house." 26.2: 1675).

Similarly, Vanessa perceived a contradiction between being a (good) mother and exploring her same-sex sexuality. In contrast to Wendy she was an outspoken proponent of lesbian parenting and believed that same-sex couples cared as well for their children as other parents. However, in her personal life, she felt slightly more conflicted about the subject matter. For example she chose a location far removed from her children when she first had sex with a woman. She was at an HIV related conference and described her response to a roommate who tried to discourage her from having sex with a woman:

> She says to me, "You ain't no damn lesbian, girlfriend, you better not even go there." And I says, "No, I'm not. But you know what? I'm not even near my kids, I'm not nowhere, so you know what? If this is gonna happen it will happen. I don't care. (27.2: 452-55)

She did have sex on that occasion and when this one-night stand evolved into a more serious relationship, she kept it secret from her children, especially from her adolescent daughter whom she perceived as particularly vulnerable.

> Linda is an attention deficit disorder child. She's on Ridolin, I don't know if she could handle certain things (…). I would tell her in due time, but I have to make sure this is definitely where I'm gonna stay. I am not gonna screw this kid's mind .. I'm taking her to therapy because of her hyperactivity and stuff. My older daughters, they're on their own, they can handle it, they do their own shit. But this one .. (27.2: 612-18)

She once tested the waters asking the girl how she would feel if she and her partner were a couple, and Vanessa remembered that Linda responded with repulsion and disgust, "Ma, that's not supposed to happen," (27.1: 1097) and, "That's not normal, yuck!" (27.2: 620)

After a couple of months, Vanessa told her two adult daughters about her female lover. When recollecting the interaction with her oldest daughter, she remembered affirming her identity as a mother in the same breath, "Regardless of what you're thinking or feeling, I'm your mother. I will always be your mother" (27.1: 780-81). Her oldest daughter responded negatively to the news. She told Vanessa, “You can do better,” and announced she did not want “that” around her daughter.

> She says, “Ma, you could do better.” (…) She means that I shouldn’t settle for just a woman. That I should settle for a man to make me happy. (…) And I guess my daughter would want, you know, typical grandma. I’m a grandmother. Then she told me, “I don’t want that around my daughter.” I says, “whatever that means.” I mean, when she does come here or I’m with her, I’m not all over her, and neither is she.. (27.1: 1034-45).

What did Vanessa’s daughter mean when she said she did not want “that” around her child? Was she referring to the relationship in general? Did she not want the child to meet Vanessa’s partner? Or was “that” referring to something more specific? Vanessa interpreted her daughter’s comment to mean the sexual aspect of their relationship, thus her statement that she and her partner were not overtly sexual with each other in the presence of others (“I’m not all over her, and neither is she”). This illustrates a point previously raised by one of my key informants, Lola, who explained that lesbian and gay relationships were often reduced to their sexual aspects. Highlighting the sexual can foster strong emotional responses such as titillation, fear or repulsion. Negative emotions such as fear or disgust can then in turn contribute to increased levels of stigmatization.

In sum, women’s same sex relationship are perceived as a dangerous influence on children due to the inherent challenge to existing gender norms as well as the sexual connotations which are considered inappropriate for mothers (and grandmothers alike). Children are thought to suffer in their psycho-social and sexual development from the mere presence of lesbian mothers, but one participant was also accused of abusing a child (an unfounded accusation as it turned out). This occurred in the context of a court case where he drug use was also an issue, so it is a prime example of when the two stigmas attached to same-sex sexuality and drug use interlocked and will be discussed further below.

2.10 Lesbian mother – “What an oxymoron!”

Key informants pointed out that assumed heterosexuality was particularly persistent when women were known to have children. As mothers, women were automatically assumed to be heterosexual and women who were known as lesbian were automatically assumed to be child-less. Mildred explained,

> Many people don't expect a mother to be a lesbian. (…) I was talking to a young man who's in the ball scene, and I think I said something about my son, and he went, "You're a mother?" And he was amazed. And he kept on like, "You're a mother?" They don't expect you to be a mother. People will.. they know you're a lesbian, "You're a mother? Really?" Then there's the butches aren't supposed to be mothers. And a lot of butches will hide it. (PS04: 864-72)

Mildred’s experience was mirrored by other participants who described that being a lesbian and being a mother were perceived as contradictions in terms, “What an oxymoron. Lesbian mother!” (PS12:837) Given the stigmatization of lesbians as aggressive (“corta cara”), masculine/gender-confused (“you want to be a man”), sinful, and dangerous to children, it is hardly surprising that “lesbian” and “mother” were not thought of together. In fact, same-sex sexuality and motherhood were perceived as irreconcilable contradictions in two ways: Motherhood was viewed as contra-indicative of lesbianism and lesbianism was viewed as undermining (good) motherhood.

Mildred’s notion that “butches aren’t supposed to be mothers” and “will hide it” furthermore emphasized that butch women’s gender non-conformity reinforced these perceived contradictions and that some lesbian mothers also perceived their motherhood in conflict with their sexual identity. The only self-identified butch and biological mother in my sample, Alex, did not explicitly state that she felt conflicted about being a mother. She indicated that she became pregnant primarily to please her mother, but she expressed great love for her daughter in the interviews. However, she also mentioned that she found it difficult to reconcile her "macho ego" as a butch/aggressor (17.2:2384) with having engaged in sex work in the past to finance her drug use. Only with difficulties could she integrate the fact that she had sex with men into her self-positioning as a butch/aggressor. In extension, motherhood might also be a conflicted topic as both of her children were conceived through heterosexual sex.

Other participants, who neither self-identified as butch nor as lesbian, felt conflicted about another aspect of the motherhood/same-sex sexuality combination. These were women who identified strongly as a mother and not so strongly with their same-sex sexuality (e.g. Wendy and Vanessa). These women perceived their same-sex sexuality in conflict with good motherhood because of its challenge to the gender norms and its sexual connotations as mentioned above. For them, their same-sex sexuality conflicted with their main identity as mothers while in case of Alex, the heterosexual aspect of motherhood conflicted with her sexual identity as a butch/aggressor. The focus of these perceived contradictions varied depending on how participants identified more strongly, as first and foremost mothers or butches.[9] This illustrates that the “oxymoron”

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[9] Of course, these observations are based on women’s identifications *in the interviews.* They might assign different levels of significance to these aspects of their lives in other social and situational contexts. However, in the interviews, women who had raised their children identified more strongly with their parent-role. I compared the timing of participants’ first mention of their children assuming that this might serve as an additional indication of how important their children were to their self-presentation in the interview. I found that the first mention of their children by and large reflected my previous assessment of how strongly they identified with their parent-role: Alex only talked about her daughter more than 60 min into the interview (and when prompted) while Vanessa and Wendy mentioned their children in the first 5-15 minutes of the interviews. Other self-identified butches/aggressors, such as Roberta and Ana, also mentioned the non-biological children whom they had raised quite early in the interviews. They identified strongly as caretakers, but their non-

phenomenon also took place internally, creating conflicts for participants' own positioning as both mothers and women who loved women.

3 The stigma of drug use

Participants' accounts of drug use related stigmatization were in many ways similar to their experiences of sexual stigma: they experienced devaluation and rejection and were viewed as a threat to the welfare of children. However, there were distinct differences, too. First, some participants felt that drug use was more severely stigmatized than their same-sex sexuality. Second, blame was placed directly on participants as using drugs was believed to be their choice. Third, given that the consumption of drugs such as crack-cocaine and heroin is criminalized in the United States, participants encountered more severe sanctions and interventions not only from family members, but also from public authorities which resulted in mandated treatment programs, incarceration and the loss of custody of their children.[10]

3.1 Notions of responsibility and blame

Alex, a former heroin and crack user of many years, explained that in her family, intravenous drug use (IV use) was more severely stigmatized than homosexuality.

> Alex: It was considered the lowest you could go. (…)
> Hella: Did you tell anyone else in your family?
> Alex: No. No. Not even my cousins, because they grew up believing in that stigma, and I would never would have told them that. I had told one of my cousins recently, you know. She didn't say much, but, you know, either you take me or you don't. I don't give a shit, myself. And.. but IV use, oh no.
> Hella: That's even worse than homosexuality?
> Alex: An IV user? Yeah. Because, in our family, it was considered worse.. an IV user, you would either go into homosexuality in order to get your drugs, because one of my cousins did that.
> Hella: What did he do?
> Alex: He actually.. he used to go into the city and have sex with men, so he could get money so he could shoot up.
> Hella: And the family knew about it?
> Alex: Yeah. So, you know, homosexuality was more like something that.. to them it was like something.. there's a reason for it, okay. And it's either over drug use or, you know, somebody taught it to you, okay. But, you know, and it wasn't your fault. Now, if you were an IV user,

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biological parenthood did not entail associations with heterosexual sex as in Alex's case and thus did not conflict with their sexual self-identification as butches or aggressors.

[10] As shown in the first chapter, the majority of lesbian and bisexual women with HIV/AIDS in the US have drug use experience. However, in this study, three in-depth participants did not have a history of drug dependency (Deirdre, Gloria and Vanessa). Of the six participants who had been addicted to crack-cocaine and/or heroin, five had been incarcerated at least once. Four women lost custody of biological children and two women were stopped from caring for non-biological children due to their drug use. None of the participants were incarcerated or used drugs at the time of the interviews.

> "What the hell do you think you're doing?" It was like, you know, we're the dirtiest of the dirt. (17.1: 1409-1437)

In Alex's experience, intravenous heroin use was more heavily stigmatized because it was considered more of a choice than homosexuality. Injection drug users were held responsible for what was considered their decision to use drugs. People who engaged in same-sex sexuality on the other hand were viewed as victims of circumstances, they were pressurized, mislead or otherwise compelled to have sex with members of the same sex, but their same-sex sexuality was not considered their own "fault" to the same degree. Alex did not discuss whether she shared her family's beliefs; she presented both her drug use and her same-sex sexuality as facts of life without providing an explanation or justification for it. However, later in the second interview she called drug addiction an illness. When discussing punitive laws against drug using mothers, she argued, "A person shouldn't be arrested for having a disease, and addiction is just that." (17.2: 2416-17)

Framing drug addiction in medical terms as a disease shifts some of the blame from the shoulders of drug users. 'Suffering from a disease' involves less agency on behalf of the woman. From this point of view, drug using women were not to blame for character flaws, their environment had exposed them to the disease. Their difficulties in quitting and relapses into using drugs were not due to supposedly weak personalities, but to the stronghold a chemical dependency had over their minds and bodies.

Such negotiation of women's responsibility and blame for their drug use was characteristic of the accounts of participants with drug use experience. Most women acknowledged that they had been curious to try new and exiting substances at the time, but many also pointed to abuse and neglect experiences in their families. Olga for example was physically abused by her mother and never received the affection or support she was hoping for. In retrospect she attributed her drug use (and in extension, her HIV infection) almost exclusively to her mother's lack of love 21.1:387-90). In a similar vein, Wendy, who grew up with a crack-using mother, explained, "When you don't have that attention around you, you find something else to maintain that part which you're missing." (26.1: 130-31) Roberta, a recovering heroin user described her drug use as both, a personal choice and a result of environmental factors. She stated with regards to her former drug using lifestyle which involved repeated periods of incarceration,

> Cause I say, you make your bed and you lay in it. Maybe if I would have had family support and a little bit more guidance .. not that my mom wasn't doing what she had to do, she did the best she could, you know, because it was my choice to get bad friends and do all the bad things. (35.1: 1392-96)

On the one hand, Roberta assumed responsibility for her decision to get involved with drugs ("it was my choice"), but she also mentioned a lack of family support which shifts some of the blame for her "bad choices" to her environment. Roberta started using and selling drugs at the age of ten. She described that in her inner-city environment, drug use was not only common and highly visible, it also constituted an economic realm with its own pulls and enticements.

> Well, actually, the bottom line is, Hella, that in our neighborhood, here, to get you started on drugs, anybody will give it to you. Anybody will introduce you to it. Once you are introduced to it and you want more, now you ain't got the money, now you gotta work for what you want. So anybody will give you drugs. And at that time .. everybody trusted everybody back then. You know and these were friends from the neighborhood, so they introduced me to something new. Uhm, it happened to be that the lady upstairs, that used to live upstairs, uhm, her sons were drug addicts and she used to have everybody selling for her. So her son took me upstairs and you know told her 'Ma, you know S. [ROBERTA'S NICK NAME] this and this and that.' And before I knew it, I was selling drugs for her. (35.1: 189-99)

Roberta described a drug market that recruited young people like herself. Again, presenting herself as an innocent, trusting child by stressing how "everybody trusted everybody back then "points to the need of alleviating some of the blame. The economic aspects of the drug market which provided a rare opportunity to make a decent living in women's marginalized inner-city communities of color, was also mentioned by other participants such as Ana who first started selling drugs before she actually began using them herself. In sum, the accounts of participants with drug use experience illustrate their attempts to address their own responsibility for past actions while placing it in the context of family influences and community structures, thereby negotiating the blame that has been placed entirely on their shoulders by the stigma attached to drug use.

3.2 "If you're a crackhead, you're a liar, a cheat, and you will steal"

Participants explained that drug users, especially users of street drugs such as crack and heroin, were stigmatized as reckless, unreliable persons who could not be trusted. One of my key informants, an African American HIV-positive mother who used to smoke crack, was suspected of lying and stealing by her family.

> Hella: When you were smoking, did you ever get the feeling that other people were looking down on you?
> Fame: Oh yeah.
> Hella: Yeah?
> Fame: Oh yes. Everyone. My family. They don't want to be walking with me. And they say, "I don't want that crackhead in my house."
> Hella: How did it feel at that time? Did you..did you care a lot about it, or did you.. were you hurt?
> Fame: Mainly.. yes, I was. I was hurt, yes. I was hurt.
> Hella: And why do you think.. why do you think they said that?
> Fame: Because they.. I guess they think that all crackheads are .. [?] .. They have this thing, if you're a crackhead, you are a liar, a cheat, or you will steal, okay, and I was not like that, because really if I did not get my own drugs, I did not do them. And I always had money, so I always got high, and it was always my money. So I never stole. I never went in nobody's house and I never stole nothing from them. I never tried to run off with nobody's money .. you understand? .. And they would like..they wasn't trying to hear that. They was just saying,

> "You get high. You are going to steal." That's how .. the category they dumped me in. So I never went to their house. (PS14: 727-752)

In her recollection of the strained relationship, Fame pointed out that her family unjustly assumed that she would engage in theft to finance her drug use. The defensiveness with which she repeatedly denied this assumption only reveals the power of the accusation. Other participants pointed out that this prejudice lingered even after they stopped using drugs. For example an HIV-positive key informant, Tami, noticed that her new employers would not let her in the office by herself anymore after she told them about her past drug use. Stacey described a similar experience with acquaintances. Being in recovery thus did not fully re-instate participant's status as a trustworthy person. In the eyes of others, their morals and character were still under suspicion.

3.3 Criminalization of drug use and loss of custody

Given the criminalization of drug use in the United States, most participants with a history of crack cocaine and/or heroin dependency had been arrested and incarcerated. In New York State, prison sentences for the possession and selling of drugs tend to be quite harsh.[11] Even for minor offenses, women spent years in correctional facilities (in Roberta's words: "They give you more time for drug cases than for murder." 35.1: 1422). Women's reintegration into the community after their release from prison was usually clustered with obstacles. More often than not, participants ended up continuing the same lifestyle that led to their arrest in the first place resulting in frequent re-incarcerations. Participants eventually managed to break the cycle with the help of treatment programs and job opportunities in HIV education and service provision. One participant tried to get a 'regular' job outside of the HIV and drug treatment sector, and she described being haunted by stigma. When applying for employment, Stacey was asked to disclose any criminal records, and when answering truthfully, she was not offered the position. Having a criminal record is stigmatized per se, but in the case of women who have been incarcerated for drug related offenses, having to explain a history of incarceration involves disclosing drug use experiences. Criminal records thus amplified the stigma of drug use, making it harder to find employment and to be trusted and accepted by friends, family members, employers and colleagues.

The current legal situation also resulted in the frequent loss of custody rights of children. In the case of a woman's arrest, the city agency, Administration of Children's Services (ACS), is notified and the children are placed in foster care, except when a family

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[11] New York's sentencing laws for drug offenders, commonly called the Rockefeller drug laws, have been in place for about thirty years. These laws mandate prison sentences for almost all drug offenses, including low level offenses such as retail street sales or being a courier. The drug law enforcement in New York has had a stark racial impact: ninety-four percent of people sentenced

member is present who agrees to take care of them. In some cases, ACS is notified even without prior arrest of the mother. For example, certain service providers and social workers (including some of my key informants) are mandated to report clients who use drugs and who have children in their care. Notification is not limited to providers, though. Anyone can report a suspected case of child neglect to ACS. The agency's official mission entails safeguarding the welfare of children which is thought to be at risk when the mother or caretaker uses illicit drugs.

3.4 Accused of neglecting and abusing their children

To understand the portrayal of drug using mothers as a threat to the welfare of their children, we first have to backtrack and explore the stigmatization of drug using women. Participants explained that the stigma of drug use affects women differently from men. One of my key informants, Mildred, pointed out that drug use in women triggers more of a moral outcry than drug use in men:

> Women that are drug users .. when they're using, people kind of see them.. you see a man and you're like, [FLAT TONE OF VOICE] "Oh, there's a drug user." You see a woman and you're like, [OUTRAGED TONE OF VOICE] "Oh, she's a drug user!".. that is (…) .. they have no respect for themselves. They're just let themselves go down. (…) They're going to bed with everybody. They don't care. And even so, now, like if I see a woman drug abuser, it's kind of, "How could she!" (PS04: 761-72)

Mildred described the stereotype of drug using women as lacking in self-respect, self-control and sexual decency. This view of drug using women stands in stark contrast to traditional gender norms which expect women to be decent guardians of conservative mores and values. Because of this conflict with traditional gender norms, drug use in women is met with particularly strong dismay. If drug using women are also mothers, the gap between normative expectations and perceived reality becomes even wider. Drug using women are thought to be everything a mother is not supposed to be: undignified, unreliable, non-caring, and promiscuous. Thought to be fully consumed by their drug use, they are considered unable and unfit to care for children. The crack epidemic pushed this stereotype even further and crack-using women were depicted as not only negligent of their children, but outright abusive. Mildred provided a "story" that circulated in her network of peers and friends who were involved in HIV prevention work with crack users:

> There was a story, this girl, she would be great for you to interview. She was like a drug runner. And they.. the drug dealer gives you the drugs, and somebody puts the money over there, and you run over here and get this person the drugs. And one day she went to a drug den where people get high and stuff. And there was a woman there. And the woman sold her five year old daughter to the drug dealer to have sex with right then and there so that she could get drugs. And my friend told the drug dealer, "No,

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under the drug laws have been Black or Hispanic, even though White people use illicit drugs at approximately the same rates as ethnic minorities (Human Rights Watch, 2000).

> you can't do that." And he put the gun to her head and said, "Yes I can, and you're going to watch." And did. (…) And a lot of that goes on. And that was just one of the little stories. But a lot of that goes on. (PS04: 1021-34)

Mildred called this anecdote quite aptly a "story." It is a shocking description of a archetypical 'non- mother,' a woman who sacrificed her own young child for her drug use. It is not to say that this never happened; participants were very frank that their addiction often brought out the worst in them. However, none of them used their children in such a way. On the contrary, they generally made sure that their children were looked after by someone else when they were getting high. For the most part, they had very different stories to tell about motherhood and parenting on drugs. Stories about women who struggle to find a compromise between caring for children and using drugs, however, are much less sensational and much less likely to circulate. It is the shocking, extreme stories, like the one provided by Mildred, that are being told and retold and that end up dominating the view of drug using mothers.

A number of women in my study lost custody of their children due to drug use. Stacey for example voluntarily transferred custody of her first child to family members, and the four subsequent children were taken into foster care and given up for adoption more or less against her will. In one case she was "running" from the system in an attempt to keep her child:

> They took my son from my ex-boyfriend. When I got home, they claim .. they said he was hollering for help. My son couldn't even talk. But I couldn't get him back because the judge knew me. (…) He was like, "Oh, hell no." They were looking for me for two years. Because my second daughter was born with drugs in her system and they took her from me. But my son wasn't. But they were trying to find me. They were slipping letters under the door and I was running with my son for 2 years. (31.2: 1562-71)

Stacey was using crack for a number of years. When she gave birth to her second child, the hospital detected traces of cocaine in her daughter's blood and the child was directly placed in the foster care system and given up for adoption. With her third child, the son mentioned in the quotation above, she managed to reduce her drug intake during pregnancy and since no traces of cocaine were found in the child's body at birth, she was allowed to take him home. Given her record of drug use in the past, though, ACS workers tried to follow up with her to make sure that her son was cared for well. Stacey, however, was so afraid of the agency by that time, she thought they were trying to take her son away. Consequently, she never answered any of the letters they slipped under her door and avoided contact with the social workers by any means. This, of course, reflected badly on her case at ACS and when they were called to investigate the neighbor's claims that the child was being neglected, they quickly made a decision to take him away. At the time of the interview, Stacey voiced regret over having lost her children in the context of using drugs.

> If I had a chance to do it all over again, I would have been a better mother. I wouldn't have used the drugs, you know. Crack is a very addictive thing that you can't control, and I was out there. All I could do if I ever see them again, is tell them, "I was an addict. I loved you, though." But I preferred just to give them up, than to have them out there and sell 'em, whatever .. you understand? (…) This is something I have to live with. I suffers .. every day I wonder how my children look. If they pass me by right now, I probably wouldn't even know them, you know? (31.2: 1625-36)

This sense of loss and deep regret was described by many participants who lost their children to the foster care system. In retrospect, Stacey felt that giving them up for adoption was probably in their best interest, voicing a concern that she might have been tempted to abuse them to satisfy her crack addiction. She thus revealed a highly critical view of herself during active addiction.

Olga lost custody of her two biological children as a consequence of her heroin use and incarceration. In the interview, she expressed a general belief that active addiction obstructs women's ability to properly care for a child ("A woman that uses on a daily basis cannot take care of her baby correctly … because when you're high you're very unresponsible." 21.2: 1205-10). However, she did not consider herself a "bad mother."

> Hella: Did anyone ever call you like a bad mother?
> Olga: [CLEARS HER THROAT] Yeah, my mother. [CLEARS HER THROAT] She used to say I was a bad mother.
> Hella: Why did she say that?
> Olga: I don't know. Maybe because I used to use drugs. Or maybe because I didn't take care of them right. Or maybe because my mother's been, she was always, always getting on me, always.
> Hella: Mhm. Did you ever feel that, that you, yourself, weren't happy with how you were as a mother? How did you feel about the whole thing?
> Olga: No, I felt that I was a good mother, because I used to take care of my kids and have them dressed up nice. Everywhere I would go I would take them with me, before I started with drug use, of course. After I started the drug use, then I was out of control, but before I got heavy on drugs, I was always taking care of my kids. So I don't feel that I was a bad mother. I wasn't a perfect one either, because I guess there is not a perfect one. But I tried to be the best I can. (21.2: 1133-52)

Olga has always had a strained relationship with her mother who physically abused her as a child and strongly stigmatized her for leaving her husband, using drugs and loving women as an adult. Being called a "bad mother" by her own mother thus had a unique twist for Olga. It not only brought up feelings of guilt over having used drugs and not taken care of her children "right," it also reinforced old feelings of inadequacy and anger at her mother (she pointed out, "she was always, always getting on me"). When I turned the question around and asked whether she herself ever felt like a bad mother, Olga denied this and presented herself as a "good mother," instead. It is quite telling, though, that she considered herself a "mother" only until she started using drugs. She did not discuss the time when she used heroin and still had custody of her children. The topic was very sensitive and her tone of voice and the clearing of her throat indicated discomfort. Maybe Olga did not discuss her parenting during active addiction because she would rather forget those days when she was “out of control;” or maybe she simply wanted to avoid being re-stigmatized as a “bad mother” in the interview.

Most women felt conflicted about having used drug while caring for children. Cathy, one of my HIV-positive key informants, pointed out that women who used drugs or alcohol were not alert enough to care for young children (“I think that any person who is putting a mood- or mind-altering drug in their body is not fully there.” PS02: 1127-9). She arranged a guardianship with her daughter’s aunt when she went to jail and concluded that this arrangement worked out well for all involved. At the time of the interview she felt stable in her recovery, job and living situation and had come “to a place when it’s time to be a mother.” (PS02: 611). Distinguishing between having children and being a mother, she said that earlier in her life, she did not feel ready for this responsibility. However, she was also critical of society’s normative expectations of mothers and of the blaming of women who did not meet these standards:

> They don't give you a fucking handbook when you have a baby. They don't say, "This is how you do it." But when you make a mistake, they're looking at you like, "You're not a good mother." What is a good mother? So, society has defined what a mother should be, and most women don't meet up to society's expectations. So then we have a problem with who you are. You're not a mother per se, you're an unfit mother, or you're less of a mother, or you're this..you know, you're not a mother. And women strive to be good mothers in the best way they know how. (PS02: 1092-99)

Cathy described the difficulty of meeting high expectations with only limited support and guidance. In her narrative, she mounts a defense of mothers like herself who made mistakes but who tried to care for their children as best as they could. Like several other participants, she perceived her drug use as an (additional) obstacle to good parenting (besides other obstacles such as poverty, violence and lack of support), but she described taking precautions to safeguard the well-being of her children to the point of giving up her custody rights.

3.5 Visibility of drug use

Again, for stigmatization to occur in face-to-face situations, the stigmatized attribute had to be visible, suspected or known about. How did participants discuss the visibility of drug use? Alex suggested that drug use was more visible than active users tend to think.

> Addicts go into real deep shit denial, because we swear that people can't tell and people don't see the difference, and it's all b.s. [bullshit, HU], okay? Ever since I've been in recovery, I've noticed that. Because I can tell when someone is out there ready to cop [buy drugs, HU], all right? (…) You

> haven't slept for days. Who knows when you've last changed your clothes. You aren't.. do you really think somebody's not going to notice that? (17.2: 267-73)

She explained that during times of extreme crack use, she lost weight, wore inappropriate clothing (e.g. summer shorts in winter) and neglected her personal hygiene. However, these indicators may be unmistakable signs for insiders and ex-users like her, but people who are less familiar with drug use might not be able to read these signs as clearly. Roberta mentioned that her intravenous drug use left visible marks on her hands and arms which repeatedly triggered stigmatization from health care providers and strangers, but Alex was able to hide her IV use for the most part, for example by wearing long-sleeved shirts and by avoiding situations that exposed her body (including health care visits even when she required medical care). Crack use does not create injection marks on the body, but Alex's mother found out about her crack use when she found a pipe in her clothing. Drug use was thus visible as far as it could be deciphered from signs (at least by insiders), but it could also be concealed, especially from people who did not know the trade and did not have access to women's bodies where the use of certain drugs could leave noticeable marks.

3.6 "To me it's degrading" – The view from recovery

As mentioned earlier, none of the in-depth participants currently used drugs. From their current point of view as recovering addicts, they often expressed critical views of their past drug use. Roberta described an internal transformation which was part of the reason why she stopped using drugs during periods of incarceration.

> Roberta: To me it [using drugs in jail, HU] is degrading because I can't see a grown woman getting high in jail. I can't see it. I mean I used to do it. I think the last time I got high in jail was back in the '90s. And I was, don't get me wrong, I was already .. old. But I, once you go into recovery, it's not the same thing. It's not the same thing.
> Hella: What's different about recovery?
> Roberta: The guilt. The guilt. It makes you feel guilty. (35.2: 857-864)

From her current point of view as a recovering addict, Roberta expressed the belief that drug use was a sign of immaturity (it was "degrading" to get high in jail as a "grown woman") and she embraced the feeling of guilt as helpful for abstaining from drugs. This indicates that she endorsed some elements of the stigma attached to drug use. Similarly, Alex described having been "ashamed" of herself when she decided to go into rehabilitation. She also stated that the prospect of feeling embarrassed in the case of relapse helped her maintain her recovery at the time of the interview (17.1: 621). However, asked if she felt remorse over her drug addiction, she explained that she has learned to accept her drug related actions and experiences.

> Alex: Sometimes I can't even believe that.. the shit that I did and I'm still here. I mean, you know, I must have had more lives than a cat.

> Hella: When you look back, do you feel like lots of regret or remorse over things that you've done?
>
> Alex: You know, I used to, but I can't see it that way anymore, because of all that I had been through and experienced, that's what made me the person I am today, okay. The go-getter, and striving, and, you know, wanting to do things. Everything that I did in addiction, I kind of reversed it. Instead of doing it for the cause of addiction, I do it differently and for other causes. (17.1: 1578-1588)

Alex was critical of some of her past actions during addiction (for example she mentioned that her addiction destroyed the love relationship with her first girlfriend and generally fostered abuse), but she clearly aimed to strike a balance between being critical and avoiding self-blame and regret.

Participants' take on the stigma of drug use differed from their perspective on the stigmas attached to same-sex sexuality and HIV in that they were situated differently in relation to the stigmatized attribute. None of the participants actively used illicit drugs at the time of the interviews. They were either in recovery or never had a drug dependency in the first place. In their accounts, they interpreted their drug use in various ways, as a bad choice, a form of rebellion, as a consequence of circumstances, as a sign of immaturity, and an obstacle to loving and caring, and so on. Most of these meanings were rather critical and reflected the distance participants created towards their addiction from their current standpoint of recovery. However, being in recovery did not mean that they fully endorsed all aspects of the stigma attached to drug use. They acknowledged the (self-) destructive aspects of their addiction in their lives, while maintaining that the negative stereotyping and blaming of drug using women was inappropriate and harmful. They also criticized that ceasing their drug use did not relieve them of being a target of the stigma. By abstaining from substance use, participants managed to reduce the level of stigma from “active addict” to “recovering addict,” but they were still excluded from full moral reinstatement. They described that even in recovery, their trustworthiness and character remained tainted and suspect in the eyes of others.

4 The stigma of HIV/AIDS

One of the most apparent characteristic of the stigma of HIV/AIDS was its link to the stigma of drug use. Intravenous drug use constitutes one of the main routes of HIV transmission to women in the United States, and participants described that women with HIV/AIDS were generally suspected to be either drug users or sex workers (or both). Given the stigmas attached to drug use and prostitution, HIV-positive women were treated as if they deserved their illness, except if they clarified that they had been infected by a steady male partner. In this case, they were considered “innocent.” A main difference between stigma of HIV/AIDS and the stigmas of drug use and same-sex sexuality lies in the fact that HIV is a communicable, possibly lethal disease. This triggered fears of transmission in their environments, which participants described as a main driving force of HIV related stigma, as well as pity and sympathy. A second main difference relates to the shock that an HIV diagnosis generally bestows on those who test positive for HIV. For most participants, it was a devastating surprise and the struggle to accept their HIV status affected the ways in which women viewed and handled the stigma attached to it. With regards to parenthood, HIV-positive women stood accused of risking to transmit HIV to their children and of failing to fulfill their care-taking responsibilities.

4.1 "You must have done some dirty thing" – Associations with drug use and prostitution

Key informants explained that HIV-positive women were suspected of having committed some wrongdoing to acquire HIV. Nell described what she perceived as a prevalent attitude in Latino communities:

> This is what they think, "You have AIDS," because it doesn't even go through "HIV", you've just got AIDS, you know. "You must have been drugging, you know, you must have been prostituting, doing some dirty thing in order to end up here." (PS07: 552-55)

By noting "it doesn't even go through, HIV", Nell pointed out that some people fail to distinguish between HIV and AIDS. This means they do not acknowledge that people can be infected with the virus and still be symptom-free for many years before they might reach the more progressed, symptomatic stage of the disease (AIDS). Treating HIV and AIDS as one and lumping it into the latter category, stresses the more advanced stage where people fall ill (and die). This view of HIV as AIDS fosters fears, and with fears, stigma. Second, Nell pointed out that HIV-positive women are usually assumed to have acquired HIV through drug use or sex work, both of which classify as "some dirty thing." This resonates with the accounts of other, HIV-positive participants. Vanessa for example described encountering nurses who looked "down their noses" at her. When asked what might go on in the nurses' minds when doing so, Vanessa described what she perceived as their preconceptions about people with HIV/AIDS:

> That we're no good. Whether we're drug users, prostitutes or people on welfare, or .. what I would call, uhm, society's rejects. (27.2: 1211-12)

When HIV-positive women are viewed as drug users, prostitutes and welfare recipients, they are subjected to the stigmas attached to these identities. As shown in the previous section, drug using women are stereotyped as untrustworthy, immoral and 'out of control.' Poor people, and especially people who receive public assistance, are often suspected of being lazy and "taking advantage" of the benefits system. Prostitutes are also stereotyped in a very negative way. Frances pointed out that sex workers are called names such as "sluts" and "whores" and are judged for the way they earned their money (PS10: 1347-48).

Another key informant and former sex worker, Doreen, described a dehumanizing view of street-working prostitutes:

> A sex worker is not a human being.(…) The sex workers I deal with they are like ghosts to people (…) most people don't see them. (…) Some men look at them as a tool, just like you would look at a shoe street look for the shoe." (PS03: 646-57)

In her experience, prostitutes are robbed of their humanity both by the objectifying gaze of male clients and by the disdainful ignorance of other women who pretend they do not exist. Participants also explained that prostitutes stand accused of spreading diseases. Sex workers are blamed for putting men at risk for HIV (and other sexually transmitted diseases), even though it is generally the male client who refuses to use protection. An HIV service provider recollected a group discussion during which sex workers were even blamed for the HIV infections of the women in the group whose men visited prostitutes. Freda recounted the discussion as follows:

> One of the lesbians was talking about doing sex work, and the straight women in the group, who have husbands who infected them, were blaming the sex workers for infecting them. Like that indirectly they infected.. which is like .. please .. [LAUGHS] .. Chances are your husband infected other le.. other sex workers as opposed to the sex workers infecting him. (PS06: 1053-57)

The attribution of blame to the sex worker is based on a rather twisted logic: she was accused of immoral behavior towards other women via their husbands. The husbands on the other hand were acquitted of all responsibility for not using condoms with a prostitute in the first place, for failing to inform their wives and for not using HIV protection with their wives after having engaged in risky extramarital behavior.[12] Such blaming of sex workers was in no way restricted to group discussions among HIV-positive women. Participants described that prostitutes were generally stigmatized in this way. By suspecting HIV-positive women to be prostitutes, then, they are in extension stereotyped as immoral women who use their bodies in undignified and endangering ways. However, some participants with HIV/AIDS never worked as prostitutes and did not use drugs, and they explained that as soon as they clarify this information, they are perceived in a very different light.

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[12] Freda's comment that it is more likely that the husbands infected prostitutes as opposed to the other way around refers to the physiological phenomenon that HIV is transmitted more easily from the man to the woman during heterosexual sex than from the woman to the man, at least in the United States. Women have a greater risk of becoming infected due to the substantial mucosal exposure to seminal fluids. In other parts of the world, however, such as in some African countries, men seem to be as likely as women to become infected through unprotected heterosexual intercourse, probably related to the fact that male circumcision (which reduces men's mucosal exposure to vaginal fluids) is less prevalent in these countries than in the US (National Institute of Allergy and Infectious Diseases, 2004).

4.2 Blame according to route of transmission

A recurrent theme across interviews related to the differential attribution of blame according to the route through which women (most likely) got infected with HIV. Vanessa related her overwhelmingly positive experiences with health care professionals to the fact that she acquired her HIV infection through heterosexual sex with a steady male partner, and not through sex work or drug use.

> I remember going to the clinic, not the HIV clinic, but another clinic, and the doctor would see me and he asked me “How were you infected?” And I told him, “Heterosexual.” And he said, “Oh, I’m so sorry.” But I have friends who have been infected through drugs who have told the doctor and they were treated so totally different. It depends on you .. the way you got infected, how you get treated also. But you know what? It doesn’t matter how you got infected, we’re all human beings. And, but they do. Stigma is there, too. In other words, there’s a girl at the place that I go to and she says “I was married 25 years. How could my husband do this to me? I wasn’t a whore, I wasn’t a junky, I don’t deserve this!” So I said to her, “So what you’re saying is that whores and junkies deserve this?” I says, “No, nobody deserves this.” (27.2: 1303-14)

Vanessa described the common distinction between people with HIV/AIDS who have “done wrong” and supposedly “deserve” their HIV infection, and those who do not (i.e. the “innocent victims”). She belonged to the group that escaped the attribution of blame, but she criticized the underlying moral argument that other people justly or rightly earned their HIV infection. The literature shows that most lesbian and bisexual women with HIV/AIDS have engaged in drug use or sex work. What does the attribution of blame mean to them and how do they perceive the significance of their transmission route? Does the way they acquired their HIV infection affect how they experience and deal with HIV related stigma?

Four of the nine participants of the in-depth sample mentioned injection drug use as one of their HIV transmission risks. Three women identified unprotected sex with a steady male partner as the most likely route of their HIV transmission. And two women thought they acquired HIV either from a steady male partner or when exchanging sex for drugs or money (Wendy said, “I know I got it sexually, but I don’t know from who;” 26.2: 518-19).

Alex said she acquired her HIV infection through sharing needles with a friend who later died of AIDS. She also engaged in sex work to finance her drug use, and her second pregnancy indicates that this involved unprotected sex with men, but she did not mention this as an HIV risk and possible source of her HIV infection. Elsewhere in the interview, she explained that as a self-identified butch/aggressor with a “macho ego” (17.2: 2384) she found it generally difficult to admit to having had sex with men during her addiction. In some ways, having had sex with men was more shameful for her than injection drug use. She thus only mentioned injection drug use and not unprotected sex with men as her main HIV risk and transmission route.

Roberta first identified her “wife” as the most likely source of her HIV infection. She said her female partner of 25 years who was also an IV drug user and HIV-positive once “tempered” with her “works,” i.e. she used her syringes before Roberta did without telling her (35.2: 130). Roberta stated that she never willingly shared needles but that she shared other utensils to prepare heroin for injection. Later in the interview, she summarized her HIV risks as follows:

> I was an IV drug user. I was using paraphernalia that other people had used which was a mixture of blood. I was raped. I was having sex with bisexual women. So .. who is to say how I got infected? (35.2: 428-31)

She mentioned injection drug use first, then having been raped by a man and lastly having had sex with women. Her notion that she had sex with “bisexual women” indicates that she perceived bisexual - but not lesbian - women as possible sources of infection. This resonates with a theme already mentioned in the key informants’ interviews. Several key informants had described that self-identified lesbians are often convinced that women could not transmit HIV sexually to one another and that “real lesbians” did not have HIV (PS01, PS04, PS06). The latter belief implies that only women who never had sex with men, who never injected drugs and who were never raped qualify as “real lesbians.” Key informants pointed out that most lesbian women do not fit this idealized profile of a “real lesbian,” but the myth of lesbian invulnerability to HIV/AIDS still prevails. Against this backdrop, bisexual women come to personify many negative aspects associated with sex with men: diseases (including HIV), smells, being dirty, and they were viewed as opportunist or confused fence-sitters and traitors. A number of lesbian-identified in-depth participants also expressed beliefs that HIV was unlikely to be sexually transmitted between women and they, too, as illustrated in the quote of Roberta above, entertained notions that bisexual women were carriers of disease.[13]

Pointing to her multiple HIV risks, Roberta questioned the feasibility of singling out one factor as the most likely route of HIV transmission. Roberta said “in a way” her HIV infection “was to be expected” given her a drug using lifestyle (35.2: 75-81). This stands in stark contrast to Gloria's take on her HIV infection. Gloria was one of the three women in the in depth sample who reported having been infected by a steady male partner. Her comments illustrate that she still had problems accepting her HIV infection.

> If I was that type of woman that was in the street ripping and running, you know, or if I was out there, you know, messing with the drugs, then I might have not, you know, felt so bad. But then, I was like, damn, I've always been faithful, and I was never that type of woman that went out there, you know, to explore other people. (32.1: 355-59)

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[13] At the time of the interviews, scientific evidence for sexual HIV transmission from woman to woman was still lacking. A number of studies suggested that it was possible, but a definite proof was only found recently when an HIV genotype test showed that the strains of one woman’s HIV virus closely matched the HIV virus of her female sexual partner (Kwakwa & Ghobrial, 2003).

She presented herself as a faithful woman as opposed to “that type of woman” who was in the streets, “messing with the drugs” and “exploring other people.” She recreated the dichotomy between the “innocent” (herself) and the “guilty” (“that type of woman” who is supposedly more deserving of an HIV infection) and she remained notably silent on those aspects of her life that do not fit this self-presentation as a virtuous woman. For example, elsewhere in the interviews she stated that she had *serial* monogamous relationships and also exchanged sex for money and food in the past.

These reconstructions of women’s accounts of their HIV risks clearly show that the way women experience HIV related stigma affects the way they re-construct their HIV transmission route. Alex only noted injection drug use as a transmission risk because sex with men was more shameful than drug use (at least in the interaction with me). Roberta questioned the whole enterprise of determining transmission routes because it was so closely tied to attributions of blame (for example, she thought that the debate about sexual transmission from woman-to-woman attributed blame to lesbians: “When they started saying “Woman to woman transmission” then it was the lesbian’s fault;” 35.2: 2003-04). Gloria, distancing herself from other women with HIV/AIDS, reinforced HIV stigma and portrayed herself and her HIV risk in a purified light. And Stacey, too, responded to the stigmas of HIV and prostitution when she chose not to discuss her drug related sex work that led to various pregnancies and only identified her steady male partner as the source of her HIV infection.

4.3 Fear of contagion

Participants identified people’s fears of acquiring a debilitating and possibly fatal disease as a driving force behind HIV related stigma. Almost all HIV-positive participants recounted household and family members who were afraid of acquiring HIV from them. For example Roberta's aunt was preoccupied with cleaning and disinfecting everything that Roberta had touched.

> The wiping with the chlorox, my own spoon, my own fork, “Don’t do this, don’t touch that!” You know, sleeping in the kitchen, she put me through a whole lot of stuff. (35.1: 1252-54)

It is very unlikely for HIV to be transmitted during household contact, but her aunt was clearly afraid of it. This aunt was her only living relative in New York at the time and Roberta was dependent on her for housing. Being treated as if she would contaminate things through mere touching caused Roberta great distress. When asked how her aunt’s behavior made her feel, she responded, “Like shit. Made me feel like she wasn’t even family.” (35.1: 1275)

Gloria, an African American participant with close family ties, also noticed a change in her sister’s and her mother’s behavior after she disclosed her HIV status to them. Her mother stopped giving her hugs and her sister disposed of dishes that Gloria had used.

> When I told her [her sister, HU] I had the virus, her daughter says to me, "Auntie, don't eat at my mother's house no more." And I was like, "Why not?" She was like, "Because she throws the plates and stuff, you know, the plates and the glasses and spoons that you eat, she throws them in the garbage." And I'm like, "What?" And it was rejection, you know. (32.1: 298-302)

These examples illustrate family member's (unfounded) fears of HIV transmission during casual contact. This fear was not restricted to lay people. Health care providers were also reported to have avoided physical contact and to have put on gloves and masks in situations where there was no considerable risk of HIV transmission. Stacey noted that doctors avoided treating her when she went to the emergency room for asthma related reasons.

> And I seen them pick up my chart and so it says "HIV positive," and that doctor will put it down, and walk off and call somebody else. I have watched three doctors pick up my chart and put it down until one doctor finally took me. (31.2: 1696-98)

Overall, participants felt that unfounded fears of "contagion" (i.e. fears of transmission through casual contact such as hugging, touching or using the same dishes) have decreased over the last decade due to HIV education efforts. Gloria also pointed out that HIV related stigma decreased since more and more people have come out as HIV-positive in the media and due to protests and HIV activism. Other participants critically noted that HIV stigma might have decreased, but that despite improvements, "The stigma is still there. It is." (27.2: 1273)

4.4 Feeling diseased

Sexual relations entail a higher risk of transmitting HIV and some of my interview partners had been rejected by sexual partners when disclosing their HIV status.[14] Vanessa said the most hurtful experience with HIV related rejection happened shortly after she received her positive test results. Her male lover at the time ended their relationship and she was so "devastated" that she "went into a shell." (27.1: 926) For a number of years, she did not engage in any intimate or sexual relationships until she recently fell in love with a woman. Gloria was left by her husband after she received her positive HIV test results and she was recently rejected again, when an HIV-positive boyfriend told her he did not want to have sex with her because he was afraid she was

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[14] It is interesting that while some sexual partners rejected them, others, both male and female, chose not to practice safer sex even if they had been told about participants' positive HIV status. At times concerns about transmission risk seemed rather misplaced as in the case of Deirdre's boyfriend who refused to use condoms with her but forbid her to use the same razor ("He was cautious that I didn't use the same razor (…) you know, to shave my legs and I had to remember that" 36.1: 683-85).

going to “give him something.” (32.2: 1690). This left Gloria very upset and she had difficulties comprehending how a man who was infected with HIV himself would treat her like she was more ‘diseased’.

To my surprise, participants did not report similar negative or stigmatizing reactions from any of their female sexual partners following the disclosure of their HIV status. One participant mentioned that her former female partner had difficulties dealing with her acute illness when she developed incapacitating symptoms, but female partners were generally described as very supportive following disclosure and during the asymptomatic phase of women’s HIV infection. That is, when they had a chance to show support. Some participants did not disclose their HIV status to female sexual partners for fear of rejection. However, whenever they did, they tended to encounter positive, supportive responses.

How to explain the gap between stigmatizing responses from male sexual partners (who made participants feel "diseased") and the absence of similar rejection from female sexual partners? One clue to understanding this discrepancy might lie in the different levels of HIV transmission risk involved in heterosexual sex versus sex among women. It is widely known that women can transmit HIV to their male sexual partners, while the risk of sexual transmission from woman to woman is considered lower and has been much less publicized. Five participants had used protection with female partners, but the majority believed that the actual risk of sexual HIV transmission between women was rather small. They mentioned that conclusive research on the topic was lacking,[15] and at times they also showed traces of denial. For example when probed repeatedly about the risk of transmitting HIV during unprotected sex with her HIV-negative partner, Olga stated,

> Maybe .. like when I’m really really wet, I could get her sick. Maybe when she’s eating me, but I haven’t thought about it. I don’t wanna think about it. (21.2: 246-7)

Olga felt visibly uncomfortable being scrutinized on the subject. She acknowledged a potential risk of passing HIV to her female partner, but she did not want to discuss it in more detail. Her partner was aware of her HIV infection, but neither of them wanted to use barrier methods such as dental dams or saran wrap for oral sex. However, they decided not to have sex during Olga’s menstrual periods as they believed that menstrual blood could indeed transmit the virus. Other participants changed their sexual practices slightly to reduce the risk of transmitting or acquiring communicable diseases, but only a few women described consistently using barrier methods during sex with female partners.

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[15] As mentioned above, scientific proof of female-to-female sexual transmission of HIV through genotype testing was only recently established, after the data collection for this study was completed. Kwakwa and Ghobrial (2003) provide evidence for sexual transmission, but the specifics of how it occurred is still up for debate. The authors suggest that the “traumatic” use of (shared) sex toys might have led to an exchange of blood-tinged vaginal fluids. However, the two women also practiced oral sex, which might be another possible route of transmission.

Main motivations to practice safer sex included protecting one's partner, but also protecting oneself from acquiring additional diseases which can cause significant health problems given women's already compromised immune status.

Independent of their use of protection, participants generally (and quite accurately) perceived the risk of transmitting HIV during sex to a woman to be lower compared to the risk immanent in unprotected heterosexual sex. Given that fears of transmission were described as a strong driving force behind stigma, the lower level of perceived transmission risk might actually protect women's same-sex relations from higher levels of HIV stigma.

However, HIV stigma did affect lesbian relationships beyond fears of transmission. This was evident when Ana described the break-up with her ex-partner which happened when she was very ill (this break-up will be discussed in more detail below). Participants also struggled with internalized stigma and fears of their own illness and death. Shortly after testing positive, Roberta met a female lover in jail who was also HIV-positive but whose infection was more advanced. On their release, Roberta relapsed into using drugs and so did the girlfriend, but when this lover was hospitalized for HIV related complications, Roberta refused to see her.

> Roberta: I was mad at her (…). I said "I'm not gonna go see her."
> Hella: Why were you mad at her?
> Roberta: Because she had started getting high all over again. And if you tell me you have six months to live, why would you get back to getting high and stickin' needles in your arm? (35.2: 649-57)

Roberta blamed her lover for using drugs again despite the advanced state of her illness and the prospect of near death. When this lover passed, Roberta described that she went on a "suicide mission," using excessive amounts of drugs and trying to provoke someone into killing her.

> And it was crazy because, maybe it was the fact that when she first went into the hospital, I wasn't there. Maybe it was my own guilt that was making me go through that, you know? (35.2: 696-98)

Roberta noted that she felt guilty for not having supported her female partner until the end. Her example illustrates the challenges involved when being in a relationship with another woman who was also HIV-positive (and using drugs). Any difficulties the other experienced served as a reminder of one's own vulnerability. By not going and visiting her in the hospital, Roberta avoided being reminded of her own HIV infection and its frightening prospect of illness, death and dying.

4.5 Visibility of women's HIV infection

Participants encountered most HIV related stigmatization from family members, sexual partners and health care providers. These were the people who knew about their HIV status. In general, women's HIV infection was not visible as it often remained asymptomatic for many years. During this phase, only signifiers such as medical charts or HIV medication gave away women's HIV status. Participants noted that living in a building that is known as a residence for people with HIV/AIDS and accessing HIV related services could also indirectly disclose their HIV status to people in the neighborhood.

Olga repeatedly mentioned that she was glad that she did not have any physical signs of her HIV infection ("There's nothing that could show that I have it." 21.1:1237) but a number of women noted that they have had HIV related symptoms or side-effects of HIV medication that were visible to others. Visible symptoms of the more progressed state of the disease (AIDS) and side-effects of the medication included lipodystrophy (fat redistribution), wasting, and skin discoloration. Ana for example described having been so sick three years prior to the interviews, she could hardly walk. She remembered encountering pity and distancing from people on the streets and in waiting rooms, “because you could tell by looking at me that I wasn’t well.” (41.2:196-7) This is the exception, though. Most women were not visibly ill and encountered HIV related stigma first and foremost from family members, partners and providers who had insider knowledge about their HIV status.

4.6 Racial connotations of HIV related stigma

As mentioned previously, most participants were low-income African American and Latina women who lived in predominantly Black and Latino inner-city communities. They mainly discussed stigmatization in the context of their every-day lives in their families and communities of color. At times they made explicit references to this context, as when Roberta explained the recruitment into the drug economy in her neighborhood to me, a White European outsider. Participants also described ethnic/racial tensions between ethnic minorities to me. For example Nell explained that her Latina clients do not want to mix with Black clients at the HIV service provider and Stacey recollected family feuds and riots between Puerto Ricans and Blacks in the Bronx. Racial difference also emerged as a topic in discussions of HIV related stigma. For example Olga, a Puerto Rican participant who has been in a 3-year relationship with an African American woman (Lisa) explained why she keeps her HIV infection secret from Lisa’s family.

> Hella: Does her family know about your HIV status?
> Olga: No. And I don’t want them to know either.
> Hella: Why not?
> Olga: For what? So they can start talking shit, tell her to leave me? “Uh, she’s gonna get you sick.. the baby!” No. They don’t need to know. I don’t want them to know anything. I don’t even want it to go through their mind. Cause, I don’t want them to start talking shit, you know? So I don’t want them to know anything. And she promised me she’s not gonna tell them anything.
> Hella: Do you think they would talk badly?

> Olga: .. Yeah. You know, how Black people are about HIV and AIDS, “Huh, this woman’s got AIDS!” I could just imagine it. (21.2: 565-80)

Olga feared that Lisa’s family would be concerned about possible HIV transmission to Lisa and Lisa’s daughter and would encourage Lisa to leave her. She anticipated being perceived as having AIDS (not HIV) and that they would gossip and disclose her HIV status to others. This, she thought, was typical of Black people’s response to HIV/AIDS. She did not explain why she perceived Black people in this way, but she discussed the racial difference between her and her lover a number of times during the interviews. For example, she said she was surprised that she fell in love with a Black woman because she used to think all Blacks were abusive “troublemakers” (21.2: 1732). She felt that Lisa was “lucky” to have a Puerto Rican girlfriend and her descriptions of Lisa’s family were very critical (she described Lisa’s sisters as loud, gossipy and lacking Spanish hospitality). Olga was not alone in her negative remarks on Black people. Vanessa stopped going to an “all Black” support group because she thought the women were too loud, “every other word as a curse” and they were “very aggressive” (27.2: 1901-3) and Ana felt that Latina, more so than Black women, were “proper” women with manners (41.1:1001).

Two African-American participants were also critical of other Black people. During the screening interview, Stacey pointed out that “lots of Black people are very ignorant about HIV” and Gloria distinguished herself from other Black women at her HIV service provider whom she called “ghetto” thus pointing to class and milieu differences. Stacey and Gloria were both very hurt by their (African American) family’s prejudice against people with HIV/AIDS, but participants' personal experience did not fully explain their critical references to Black people. Participants' critical remarks about Black people might describe social realities (i.e. HIV-stigma might be particularly strong among some African American communities) or they could illustrate race- and class related stereotyping. The latter reading would suggest that HIV/AIDS related stigma not only revived negative stereotypes of drug users, gay men and prostitutes, but also prejudice against Black people.

Comparing participants’ references to ethnicity and race across stigmas, it was noticeable that some participants perceived Latino communities as particularly homophobic and Black communities as prone to HIV related prejudice. Overall, African American culture was not referenced as much during discussions of sexuality related stigma, nor was Latino or Puerto Rican culture mentioned as often in descriptions of HIV related stigma.

4.7 “Actually, I don't think it's really the devil” – Reconsidering (self-) stigmatizing views

Earlier I showed that HIV/AIDS in women was commonly associated with having done “some dirty thing,” namely drug use or prostitution. Since the start of the epidemic there have been voices in public discourse who claimed that HIV was a punishment from God for sinful behaviors. Religious beliefs were used to blame HIV-infected people. In participants’ accounts of HIV related stigma, however, references to religion were surprisingly seldom made. This might be due to a lack of questions on my behalf. I asked only one key informant specifically about the topic, and she willingly described religious constructions of HIV as a “devil’s spirit.”

> Frances: (...) People still think that you can catch it by talking to them and sitting on the toilet, you know. Some people is very ignorant to the disease.
>
> Hella: Do you think some people still think, or think this is also a sin? Do they..do you think they think along those lines there?
>
> Frances: Is it a sin? Well, it's a devil spirit. It's a devil spirit. It's a devil's advocate thing. It's.. you know, I guess because in this world, it's the good and the bad. And this is a part of the bad, you know. This is not a.. God didn't put this here for us to get. You know, God didn't, you know, plant this here because he said, you know, in the Bible it says .. [?] .. So he's going to heal everybody. He's not trying to kill and destroy everything or no one. So yeah, I think that that's a devil's thing, yeah.
>
> Hella: So, what does that mean for the people who've got it?
>
> Frances: That don't mean they're going to hell. No, no. No. And.. but what to me, myself, it's just that, you know, life..your life that you live is sometimes..sometimes.. what's the word I'm looking for? Sometimes your life that you live can go good or bad. Like some people have did sex and drugs and, you know, God has blessed them and they haven't got it, or they haven't been detected. And some people that hasn't did as much of the sex or drugs, whatever, and it's just the type of things you come across that.. and it can happen to anybody actually. Actually it doesn't..you know, it doesn't really have to be a drug user or sex worker. It can be, you know, some..something innocent and, you know, blood. It could be something innocent. No, I don't..actually I don't think it's really the devil, because, well, it can happen to anyone, you know. It can happen to anyone. You know, things happen. It's a part of life. I don't know how it got here and I don't know why it's here, but it's a part of life now. So you've just got to be safe. Use your precautions. You've got to get educated. (PS10: 898-928)

At the beginning of this interview sequence, Frances mentioned concerns that people in her environment might reject her based on fears of HIV transmission. When I probed whether HIV was also associated with religious sin, she first stated that it was considered a “devil’s spirit,” a part of “the bad” in the world. Interestingly, though, as her argument progressed, she reconsidered this statement: “Actually, I don’t think it’s a devil’s thing”. Her change of heart came about when I asked her what the view of HIV as a “devil’s thing” meant for people with HIV. She had constructed this view from a more detached position, but now she had to apply it to her own life given that she was HIV-positive as well. This is reflected in her narrative when she went from saying “*they*’re not going to hell” to talking about “*me, myself.*” She noted that not everyone was blessed to have been spared. As if remembering her HIV peer educator training, she mentioned that HIV not only affected drug users and prostitutes, but also people who got infected through contaminated blood products ("it can be … something innocent"). She then revised her previous statement and concluded that HIV was neither good nor bad, it was simply "part of life," and fully assumed the position of a peer educator by saying, "it can happen to anyone" and giving out good advice, "Use your precautions! You've got to get educated."

The way Frances interpreted and re-interpreted the meaning of HIV/AIDS in this interview sequence shows that women living with HIV/AIDS can hold conflicting views on the issue of stigma. Other participants, too, expressed self-stigmatizing views as well as de-stigmatizing positions. Participants seemed to have a two-fold perspective on HIV stigma. On the one hand it was seen as something that other (uneducated) people were struggling with (as with fear of casual transmission). But at the same time participants also shared moral beliefs that fostered self-blame and self-devaluation. Ana for example described having felt ashamed and guilty of her HIV status in the past ("I thought it was my fault" 41.2: 269). Olga stated that she did not disclose her HIV status to her lover Lisa at first for fear of being rejected. She thought the prospect of death and dying would deter Lisa and she was still surprised at the time of the interview that an HIV-negative woman such as Lisa would want to be with her despite her HIV status.

4.8 HIV forfeits motherhood

Most participants expressed ambivalent feelings about their HIV infection. They were all shocked when they first received the diagnosis, and had recovered from this shock to differing degrees. Vanessa was diagnosed seven years ago and she described a life-shattering event from which she had not yet fully recuperated, "I exploded into 1001 pieces (…) and I'm telling you, I am still trying to find those pieces." (27.2: 60-64) At the time, she interpreted her HIV test result as a death sentence and felt that her life expectations came crumbling down.

> I couldn't stop crying, I was a mess. I walked on the streets, crying. Crying. Crying. I go to sleep, I wake up crying, "I'm gonna die. I'm gonna die." This is what I was thinking "I'm gonna die. I'm not gonna see my kids grow up, I'm not gonna see my grandkids." (27.2: 250-53)

The fear that she would not be able to be a mother and a grandmother to her children and grandchildren was one of her main concerns. HIV/AIDS disrupted the expected sequence of events: Infected children could die before their mothers and mothers could die before their children were grown, which Vanessa found "really scary." She remembered the group discussions in one of her first HIV support groups,

> I remember women coming in and talking about their children being born with HIV and dying, dying before the mother died. I says I couldn't deal with that. (...) I would never have another child, knowing .. but that's my own personal belief .. that if a woman is positive .. I'm sure she can have a baby and the baby will be fine, but then .. what's gonna happen to the baby

> when you're gone? And that scares me so .. I would never have another child anyway. (...) Yesterday I was at [NAME OF HOSPITAL] there was a woman there, she had a baby and she looked horrible. Hella, she looks horrible. I sat there, I got so anxious I got sick, just watching her. She was in a lot of pain. She has the most beautiful 2-year old boy. And I remember seeing her a lot when the baby was small and I held him a few times. She looks real bad and she was in a lot of pain. (…) She says she's been in the hospital for the past couple of months, they don't know what's wrong with her. (...) You know she looks like she's not doing so good. So what's going to happen to the little boy? See, that's what I mean. It's scary, it's really scary. (27.2: 266-89)

Vanessa described vividly how HIV/AIDS could incapacitate a woman and shorten her life-span thus rendering her unable to provide and care for her children. Because of this risk, Vanessa questioned the moral right of HIV-infected women to pregnancy and motherhood. She said, "that's my own personal belief," but she posed the chilling question to HIV-positive women in general, "What's gonna happen to your baby when you're gone?" Her concerns illustrate a moral dilemma that many HIV-positive women face: How to balance a desire to have children with the desire to protect them from harm? As a peer educator, Vanessa was aware that HIV-positive mothers can give birth to healthy, HIV-negative children.[16] However, another participant noted that she was accused of putting the life of her child at risk by becoming pregnant as an HIV-positive woman, "I've had people telling me when I was expecting my son, "'How could you do this?'" (PS08: 779). In her case, the concern was not only that she might not live long enough to raise the child, but that she might pass her HIV infection to her child. Knowingly exposing a child to a possibly fatal illness made her seem like a heartless and selfish person; she was viewed as jeopardizing the health and life of her unborn child. The stigma attached to HIV/AIDS thus presented HIV-positive mothers as a two-fold threat to the well-being of their children: as a potential source of infection (and death) and as a handicapped caretaker who might not be able to fulfill parenting responsibilities.

5 Multiple Stigmatization

According to participants of this study, the stigmas attached to women's same-sex sexuality, drug use and HIV/AIDS triggered devaluation and self-devaluation, constructions of blame, and notions of danger, especially with regards to children. The stigmas differed in that the stigmatized attributes were considered alterable to differing degrees. HIV was understood to be an irreversible medical condition, but drug use and

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[16] The risk of transmitting HIV from mother to baby is generally less than 30% and can be further minimized to below 2% when mother and baby are treated with anti-retroviral medication, when the child is delivered by caesarian section and exclusively bottle-fed (National Institute of Allergy and Infectious Diseases, 2004).

same-sex sexuality spurred many attempts at conversion and change. A second difference between the stigmas relates to the attribution of blame. Participants’ drug use was considered a willful choice and thus their fault while their same-sex sexuality was usually attributed to some sub-optimal circumstance in their environment. Attributions of blame for HIV/AIDS depended on the route of transmission. Drug using women and sex workers were thought to “deserve” their HIV infection, while women who got infected from a steady male partner were viewed as "innocent." This distinction clearly builds on the pre-existing stigmas attached to behaviors associated with transmitting the disease. Drug use and prostitution (or promiscuity in women in general) were strongly condemned while monogamous heterosexual relations were considered acceptable. It is important to bear in mind that most HIV-positive lesbian and bisexual women have experience of drug use and drug related sex work, so they are more likely to be blamed for their HIV infection.

Participants also mentioned non-stigmatizing, positive responses to their HIV infection independent of their route of transmission. Some participants who were rejected by family members when their drug use and same-sex sexuality became known, received a different reaction when they disclosed their HIV status. When Roberta told her aunt about her HIV infection, this aunt verbally reaffirmed the family bond and offered love and support. Roberta was later disappointed when the aunt displayed strong fears of HIV transmission during household contact, but the initial response was positive. Olga stated that her HIV infection has strengthened relationships with some family members, such as her brother and her children ("it got us closer" 21.2:648-9). Ana noted that she encountered sexual prejudice from her family, but not HIV stigma, "I was being stigmatized (...) not for being positive, but for being gay." (41.1: 1559-60) These examples illustrate that as a medical condition HIV could foster pity and sympathy. However, as a communicable disease with possibly fatal consequences HIV also triggered immense and often unfounded fears of transmission – especially on close contact - which at times undermined initial pledges of support and resulted in high levels of subsequent stigmatization. Participants were thus faced with ambivalent responses and they themselves often held conflicting beliefs and ambivalent feelings towards their HIV infection, as well as towards their same-sex sexuality and (in the cases of the recovering addicts) their past drug use.

5.1 Interlocking stigmas

How did participants describe the multiplicity of their stigmatization experience? Overall it was noticeable that the different aspects of their lives, related identities and stigmatization experiences were discussed separately. This means most often, women discussed issues relating to sexual stigma *or* HIV/AIDS *or* drug use. However, on a number of occasions it became clear that the stigmas interlocked. Several participants described being devalued as drug using lesbians. For example Olga remembered, "My mother used to tell me, "'Damn, you're a fucking junkie, then a fucking lesbian, too?'" (21.2:782-3). Having two stigmatized statuses instead of only one "makes it worse" (21.2: 786). Similarly, Roberta attributed the severe rejection she experienced from her family to both drug use and lesbianism.

> In our culture, once you start using drugs and you are a lesbian, family tend to put you to the side. You know what I'm saying? And that's what my family did. You know, my mother was gone and my aunt was the one that was there. And my aunt wanted no part of the drugs. She was embarrassed that I was a lesbian, you know, it was like, my whole family isolated me. (35.1:838-43)

These accounts illustrate that the stigmas attached to same-sex sexuality and drug use were experienced as interlocking in a sense that their negative effects added up to greater devaluation. Roberta also provided an example where all three stigmas combined caused an intense strain. The aunt mentioned above was her only living relative in New York when she tested positive for HIV and she thus asked her for help. The aunt's first response was supportive ("Don't worry, you're my niece, I love you, it doesn't matter if you're positive" 35.1: 1251-2) indicating that HIV did not reinforce the two existing stigmas, but triggered pity and sympathy instead. Her aunt's display of support might have also been influenced by the fact that Roberta was trying to overcome her drug addiction at this time. In any case, when Roberta subsequently lived with her, this aunt showed strong fears of HIV transmission. She continued to disapprove of Roberta's same-sex relations, she suspected her to relapse into drug use at any moment and now she also subjected Roberta to decontamination and disinfection procedures which made Roberta feel "like I had nobody in the world" (35.1: 1281). At this point the three stigmas interlocked resulting in even greater rejection and isolation for Roberta.

5.2 Loosing custody and other challenges to parenthood

The three stigmas also reinforced their negative effects in the realm of parenthood. Seven out of nine parents in the in-depth sample experienced struggles over child custody rights. The main reason for loosing or transferring custody was clearly women's drug use, but sexual stigma also played a role. For example when Roberta was charged with child neglect, the stigma of same-sex sexuality seems to have led to additional charges of child sexual abuse. Roberta's account of these unfounded accusations is very insightful, so I quote it here in some length:

> It was me and my aunt taking care of the baby. (…) I remember having sleepless nights with the baby because she was teething. (…) And I was all messed up. I remember being in Metropolitan Hospital (…) getting off the bus cause I missed my stop and I asked this lady, this Black lady "Excuse me, can you tell me which bus I could take back, going back to 8th Ave?"

> Cause I was on 1st. And it was wintertime, and I had just, and I had just done a robbery, so I had gotten some money. The baby was fully dressed, we were dressed alike. And the only thing that had lookeded bad was that I had tracks on my hand (...) from shooting up. But the baby was fully clothed. New Carriage, new everything. So I asked this lady how to get back. And she said “Okay, I’ll tell you in a minute!” (…) And all of a sudden I see two security guards coming out. And I didn’t think it’s for me cause I didn’t do nothing wrong. So the first thing they did was snatch the carriage. And I broke, I went crazy “Why are you taking my daughter?” And I got into a fight with them, and the cops came and everything. I must have gone into some type of a rage that I guess I went into a seizure. And they took me to the hospital, and when I woke up, I woke up cause I heard the doctor say “She ain’t got no veins, we have to go into her neck.” Cause all my veins were messed up. So when I woke up the first thing I said was “Where is my daughter?” (…) So this Puerto Rican guy, this security guard told me “Your baby is in the back, she is alright, now calm down!” You know, so, another guy came out and said “Is that your daughter?” “No,” I said, “it’s my lover’s daughter.” He said “You need to know that right now”, he says, “this lady put this complaint that you were dragging the baby, we can’t give you the baby. Only the mother can come and get the baby.” And I was like “Oh, God” I don’t even know where my wife was right about then. (…) By the time she came the social worker said “That’s it, the baby is going into foster care ‘til we go to court.” Come to find out that when we went to court they had put [?] negligence, they put, like I had molested the baby. That I had endangered the baby’s life and that I had dragged it through the street. (…) I don’t know where all of these charges came from. (…) So the lawyer told the judge (…) "We’ll bring the baby in and we’ll see how she reacts around her.” (...) So when they brought the baby in the court, she would haywire when she seen me. She wouldn’t even recognize her mom, cause she was always with me. So the judge spoke to me, he said “Listen, the charges are gonna be dropped against you." (…) Yeah, my drug use was also an issue. Because you know we had this baby, and both of us were active, you know? So I said, I was going into a rehab, but I didn’t. Right after that, after the case got dropped, I said to my wife “Listen, the way things are going, I think it’s best if you give custody to your mom.” (…) So I convinced her. She signed the temporary custody papers. Her mom came, picked up the baby and that was that. (35.1: 334-440)

Roberta’s parent-status was questioned by strangers, hospital personnel, court prosecutors and by herself (when she decided to transfer custody to the child’s grandmother). How come the stranger got the impression that Roberta was not supposed to have the baby in the first place? Roberta described herself as “messed up” and sleepy on that day, but she said she and the baby were well dressed and only the track marks on her hands might have given away that she was using drugs. During the screening interview Roberta also mentioned that the child was light-skinned (while she was a dark-skinned Black Hispanic), so race or skin color issues might have also contributed to this woman’s impression that the baby was not rightfully with Roberta. I am not sure how to explain the woman’s accusation that Roberta “dragged” the baby “through the streets,” but it seems that she implied from Roberta’s disorientation and injection marks that the baby was in danger. Once legal proceedings were initiated, the charges of child neglect were expanded to include accusations of child sexual abuse (“molestation”). These accusations evolved when it became known that the baby was raised by a lesbian couple. During the screening interview Roberta noted that a hotel manager where she and her female partner rented a room had been quoted in court claiming that they had been naked in bed with the child. In the in-depth interview she simply stated to affirm her innocence, "I don't know where all of the charges came from." It is clear, though, that these charges were brought up *after* it became known that Roberta and the birthmother were lovers. The stigma attached to lesbianism might thus have played a part in the formulation of these charges. The hotel manager's comment drew attention to the couple's sexuality. And as noted earlier, highlighting the sexual can act as a powerful tool to trigger negative emotional responses. In the presence of children any display of sexuality can be considered inappropriate, and a display of supposedly unnatural or sinful same-sex sexuality even more so. Given the stigmatization of drug using women as immoral and “out of control”, it might have seemed likely to court prosecutors that serious harm was being done to the child and the combination of sexual and drug use stigma contributed to the accusation of child molestation.

Women’s same sex sexuality was never the sole or most important reason why participants were considered unfit mothers, but it was a contributing factor. Most of these situations were slightly ambiguous. Ana was stopped from seeing a child she had raised with her girlfriend (the biological mother) when this girlfriend died. Ana thought the grandmother’s main concern was that the child would start using drugs. However, Ana had been the first girlfriend of the child’s biological mother and it is possible that Ana’s same-sex sexuality was also part of the grandmother’s concern. Ana explains that her influence was perceived as dangerous and the child was prohibited from seeing her. The argument that Ana was not biological family was also of central importance, “She wanted to stay with me. And the grandmother was like, “’No, she is not your family!’” (41.2: 637-38) In Puerto Rican culture, Ana explained, “blood is thicker than water,” (41.2: 1485-86) a saying that illustrates the great significance placed on blood related family ties. In this view, non-blood related ties are secondary and less important. Female partners who help raise non-biological children thus never have the same rights to the child as the father or biological family members.

At the time of the interview, Ana described being in parental borderland as a caretaker of another non-biological child. This boy (Juanito) was so dear to her heart that she described him as “therapy” and only “reason to get up” when her HIV related sickness weighed her down. Ana explained that members of her family questioned why she cared for Juanito so much given that he was not even related to her.

> Ana: Because he is nothing to me, why do I go out of my way like that, they think.
> Hella: Nothing to you meaning..?

> Ana: He is not blood related.
> Hella: Aha. I was gonna ask you about that, cause sometimes in some families that's really important, right?
> Ana: Yeah. Especially with us.. with us Hispanics. To them blood is thicker than water, all the way. (41.2: 1475-86)

Ana's status to the child was also questioned by non-family members, for example when she wanted to take him to a day care programs. She also remembered being afraid when an social worker from the Administration of Children's Services (ACS) had to determine her and her ex-partner's ability to care for the child during daytime when the father was at work. This occurred during the initial court proceedings when Juanito's father claimed custody from the birthmother. Ana was worried that her and her female partner's HIV status and same-sex sexuality would disqualify them from being Juanito's guardians.

> I was so scared. I was like, not only that we was positive, but you know we was also gay! And she [the social worker, HU] was like "No, there's a lot of gay parents around. (41.2: 1320-22)

To Ana's surprise, neither their same-sex sexuality nor their HIV status constituted a problem. In general, I noticed that none of the other participants described their HIV status as a (potential) drawback in situations where their custody rights were at stake. Their HIV infection was not mentioned at all in the context of struggles for parenting rights of their children. This might be in part due to the fact that most women lost custody in the context of their drug use, i.e. they lost custody prior to testing positive for HIV, or court decisions were dominated by drug use related concerns. For example when Roberta was falsely accused of child neglect and abuse, she had not yet been tested for HIV. We can only speculate how a positive HIV status would have affected her case.[17]

However, women's HIV infection seemed to limit their prospects for becoming a mother. As described earlier, HIV related stigma undermined women's moral right to pregnancy as it fostered fears that an HIV-positive woman will transmit HIV to the child or might not live long enough to raise the child. Deirdre said she would like to have a biological child, but her male partner refused to father a child with her because he was concerned that Deirdre might die of HIV/AIDS before the child was grown. In summary, HIV stigma forfeited women's right to pregnancy, sexual stigma challenged their standing as good parents, and the stigma attached to drug use portrayed them as the greatest threat to children's well-being and constituted the main reason for loosing custody rights.

Despite these multiple challenges to their status as parents, many participants managed to raise their children, at least some of the time, and felt that they did so well.

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[17] The effect of women's HIV diagnosis on court proceedings was not always clear-cut. On the one hand, an HIV infection could have given rise to HIV related stigma and it could have been perceived as yet another source of possible harm to the child. On the other hand, HIV/AIDS was reported to add an element of compassion to legal considerations. Women were able to use their HIV status to negotiate shorter jail and prison sentences and Stacey noted that she might be able to obtain visiting rights of her children precisely *because* she was suffering from HIV/AIDS.

Participants not only found joy and strength but also acceptance from others through caring for children. Roberta for example noted that her wife's family accepted them as a lesbian and drug using couple "as long as the kids were taken care of" (35.1: 878). She described herself as a good care-taker and expressed great love and concern for the children she helped raise. During her active addiction, she tried to protect the children from the negative effects of her drug use. For example, she had a rule never to inject drugs or "nod out" in front of them and she also prevented them from seeing their biological mothers in this state (35.1: 906-8). She described a particularly good and close relationship to a son whom she raised with her "wife" of 25 years (his biological mother). She expressed pride of his achievements in life, as he graduated from school, had a professional career, never used drugs and had recently started his own family.

Olga reckoned that family members of her female partner were worried that the child they were raising together might "come out as a lesbian" (21.2: 544), but she believed that the child's good grades in school were proof of their beneficial influence on the child. In sum, participants' standing as mothers and parents were clearly undermined by the stigmas of HIV, drug use and same-sex sexuality, but their parenting skills were at times able to counteract some of the negative effects of the multiple stigmas. Also, as noted earlier, when women had biological children whom they raised or who were raised by family members, this could keep the women integrated in their families despite existing tensions over their drug use, HIV infection or same-sex sexuality. In this sense, parenthood had a paradoxical effect in the context of women's stigmatization experience – on the one hand it increased their vulnerability to being stigmatized, on the other it provided protection or a counterbalance to stigmatizing views in their families.

5.3 Different stigmas dominated in different settings

Participants encountered the stigmas of same-sex sexuality, drug use and HIV/AIDS to differing degrees in different settings. For example, jails and prisons were described as environments where same-sex sexuality was less stigmatized, but HIV/AIDS related stigma was frequently experienced. HIV related gossip and ostracization were rampant among inmates and the institution deprived HIV-positive inmates of confidentiality and good quality HIV counseling, treatment and care in the prison health care system.

In health care settings outside of correctional facilities, significant differences were perceived between HIV specialist and non-specialist care providers. The former were described as very supportive, well-trained and accepting of women's HIV infection, while non-HIV specialists were very often described as more prejudiced and fearful of HIV transmission. Drug use and sexual stigmatization, however, was encountered from health care professionals across the board. Participants were often assumed to be heterosexual, especially when they were known to be mothers. But even those who were visibly butch or who came out as lesbian had providers who chose to ignore their same-sex sexuality. As a result, their specific needs as women who partnered with women were not met: their female partners were not included in treatment and care; they often did not receive assistance to take legal precautions to provide female partners with rights to medical information or child custody in the case of emergency or death; they were not counseled on the risks of sexual HIV transmission between women; and they did not receive HIV prevention tools to reduce this risk.

Similarly, HIV peer support structures provided an accepting space regarding women's HIV infection, but their same-sex sexuality and active drug use were often highly stigmatized. The Lesbian AIDS Project was described as one of the few places where HIV-positive lesbian and bisexual women received the information and support they needed. Also, at gay and lesbian *Narcotics Anonymous* meetings women felt accepted with their history of drug use, their HIV infection and same-sex sexuality.

Family settings were most often talked about and the most severe forms of multiple stigmatization, or to be more precise, the most hurtful experiences with stigmatization based on women's drug use, HIV infection and same sex sexuality were experienced from family members. Some participants did not encounter stigmatization in their families, for example Cathy and Vanessa said their family have been very supportive with regards to their HIV infection, and Ana described current family relations as very accepting and supportive of her HIV infection and same-sex sexuality, but these constituted the exceptions to the rule. Most participants reported that they had been hurt and rejected by members of their family based on the stigmas attached to HIV/AIDS, same-sex sexuality, drug use or a combination thereof.

5.4 Disconnected from lesbian communities

Participants described that very few lesbian-friendly HIV support structures existed. They also mentioned a notable absence of HIV related support for HIV-positive lesbian and bisexual mothers in the larger lesbian community in New York City. The lesbian/ gay/ bisexual/ transgender community center in Manhattan offered HIV related support groups for gay men, but there was no such service for lesbian or bisexual women with HIV. When discussing the topic with key informants, they described a disconnect between lesbian and bisexual mothers with HIV/AIDS on the one hand and lesbian communities outside of HIV support structures in New York on the other. Their HIV prevention and outreach experience had taught them that many self-identified lesbians did not accept HIV-positive lesbian and bisexual women. Key informants explained that self-identified lesbians commonly associated HIV/AIDS with drug use, prostitution and sex with men, all of which were considered unacceptable behaviors. HIV stigma was amplified in lesbian communities by the disapproval of any sexual relations with men. Being a birth mother, having children and identifying as bisexual further reinforced associations with heterosexual sex and led to even greater rejection. One key informant, Nell, illustrated the stigmatization of HIV-positive lesbian mothers by lesbian peers from her own experience of having rejected a friend in the past:

> I always thought that butches were like me .. I've never been with a man. .. And one day she comes to my house and she's pregnant. I was really naive. I thought that lesbians just didn't sleep with men. .. She said, "I need to tell you that I've gotten into crack." I said, "Crack?" She said "You know, that stuff that people are smoking .. and money's gotten very tight so I've been turning tricks." "Tricks?" "I'm on the stroll, I'm prostituting." None of these words were making sense to me. And at that moment I got so angry at her, I mean, so angry, because I felt like people were going to think that maybe I was the same way. .. I told her, "Get away from me, I don't want you around me!" And I just went berserk on her. "Get out! Get out of my house." And she left. And we didn't see each other for a couple of years. And when I saw her again, she had had her son and she was still into the same stuff. And then she tells me she's HIV positive. (PS07: 675-703)

This account illuminates Nell's disappointed assumptions (of what it meant to be butch), her lack of understanding (she was unfamiliar with drugs and addiction) and her fears of being associated with the friend's stigmatized behaviors (she was worried "people were going to think that maybe I was the same way"). From Nell's perspective as a butch lesbian who was a target of sexual stigma herself, the stigmas of drug use and prostitution posed an additional threat to her already damaged social standing and this triggered an extreme response of anger, rejection and distancing. From the perspective of her friend, however, Nell might have been one of the few people who accepted her as a butch lesbian but then turned her back when she disclosed her drug use, sex work and pregnancy. Only years later, after Nell had gained some life experience and her friend had turned out to be HIV-positive, did they re-establish their friendship. In the interview, Nell mentioned this experience and their friendship as one of her main motivations to become involved in HIV related work.

Another key informant who lived with HIV noted that her lesbian identity was repeatedly questioned by other self-identified lesbians. She was repeatedly accused of being bisexual, not lesbian.[18] As noted earlier, the label "bisexual" had many negative associations for lesbians, such as "traitor," "fence-sitter" and "disease carrier." By devaluing HIV-positive self-identified lesbians, by challenging their lesbian identity and by

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[18] Lola clarified in the first two minutes of the interview, "I am a lesbian. (…) I'm definitely not bisexual." (PS01: 45-49) She has very feminine looks and described that she encountered disbelief regarding her lesbian identity from people in general given stereotypical expectations that lesbian women were masculine or butch. Other lesbians, however, tend to challenge her lesbian identity

demonizing bisexual women, HIV-negative or untested lesbians externalize their fears of HIV and other STDs. For HIV-positive lesbian and bisexual women, these mechanisms constitute a barrier to finding acceptance and support in the larger lesbian communities (outside of HIV and drug treatment structures).

Key informants pointed out that the lack of connection between HIV-positive lesbian and bisexual mothers and larger lesbian communities was not only due to the stigmas attached to HIV/AIDS, drug use, bisexuality and sex with men. The disconnect also occurs in the context of racism and class differences. Most HIV-positive lesbians are lower-income women of color who live in relatively segregated communities in New York City. Many lesbian organizations, places and events on the other hand are organized by White, middle class lesbians, and class and race differences (and prejudices) creates social distance. Furthermore, participants explained that some HIV-positive lesbian and bisexual mothers choose not to participate in the lesbian bar and club culture (where they could meet other lesbian and bisexual women) as to not jeopardize their recovery from alcoholism and substance use. Key informants stressed the need for a drug and alcohol-free space where HIV-positive lesbian and bisexual mothers can socialize without being obliged to access services, participate in groups, pay entrance or drink alcohol. Such a space would allow them to step out of their social isolation that was often experienced as a result of multiple stigmatization.

5.5 “Too much to deal with” – the toll on intimate relationships

Multiple stigmas also had adverse effects on women’s intimate relationships. As noted earlier, Roberta described refusing to visit an HIV-positive girlfriend in hospital because she was angry that she had relapsed into using drugs. After this girlfriend died of AIDS, Roberta struggled with intense feelings of guilt. I argued that her anger and refusal to see this girlfriend functioned as a mechanism to avoid being confronted with her own HIV infection and its frightening prospects of sickness, death and dying. Similar struggles, only from the perspective of someone who was rejected by her partner, were noted by Ana. Until recently, she was in a relationship with a woman who was also a recovering addict and HIV-positive. She described that her ex-partner had great difficulties accepting her own HIV infection and that she “could not deal” with Ana’s sickness (41.2: 1344-5). When Ana fell so ill that she was unable to walk or be touched and she could not "provide sexually" anymore, this ex-partner started an affair with a man, relapsed into using drugs and ended the relationship with Ana. At the time of the interview Ana was still very hurt by their break-up. Ana described that she has had many girlfriends who had difficulties accepting their same-sex sexual desires (she described that they enjoyed the sex and

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not because of her femme looks, but because of her past sexual experiences with men, her HIV emotional intimacy but could not deal with the social implications of having a same-sex lover). Her last partner was no exception. Ana was also her first female lover and their relationship was burdened in many ways, including by sexual stigma and HIV related stigma. Ana's sickness then amplified her ex-partner's general fear of loss and death and – given that she was also HIV-positive – it might have also raised fears of her own HIV infection. Ana's descriptions of the break-up are very brief and she avoids harsh words or criticism, but it appears that her ex-partner was overwhelmed by the multiplicity of challenges and unable to deal with sexual stigma, HIV stigma and acute illness all at once. For Ana, her ex-partner's behavior could not have come at a worse time. Worried about her own health and life, she was in excruciating pain, she still managed to maintain her recovery, but she could not care for the boy, Juanito, as well as before and when her partner relapsed and started an affair with a man, Ana felt deeply hurt and betrayed at a time when she needed support most.

5.6 Stigmatization as interpretation

Women's accounts of their stigmatization experiences constituted recollections and reinterpretations of past experiences. The way they interpreted their encounters with face-to-face stigmatization was a process that hinged on many factors. Ana described that realizing that she was a target of stigma in itself was a learning process. She said, "I didn't know that I was being stigmatized 'til I started putting two and two together." (41.1: 1534-35). In conversations with other lesbians and HIV-positive women she learned to notice certain actions (and inactions). She learned to read their meanings and to figure out what they were attributable to ("put two and two together"). The attributing process often entailed a level of ambiguity, especially when stigmatizing behaviors were more subtle. What cause certain behaviors were attributed to (e.g. to one stigma and not the other, as when Ana said she was stopped from seeing the child because of her drug use, not sexual stigma) and whether they were interpreted as stigmatization depended on many factors, including participant's relationship to the person who had displayed the behavior. Participants' interpretations were also influenced by the relationship they *wanted* to have to that person, as well as by concerns to do with the presentation of self and other in the interview context. For example, Vanessa evaluated the reaction of her oldest daughter to her coming out as a woman-loving woman rather mildly in the interview. This daughter told her she "could do better" and behaved in ways that I would clearly classify as sexual stigmatization. However, Vanessa did not call these behaviors prejudiced or stigmatizing. Her soft stance might have had to do with Vanessa not wanting to admit to rifts in the

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infection and her status as a mother of biological children.

mother-daughter relationship or it might have been the result of a desire to protect her daughter in front of a stranger.

Listening to women's stigmatization experiences in the context of their life histories revealed some very painful experiences (many of which were acknowledged as such), as well as strong capacities for avoiding, denying and counteracting stigmatization. Presenting and analyzing their accounts of multiple stigmatization is incomplete without paying attention to participants' strategies of resistance to stigma as these were part of their experience and a crucial factor in their interpretation and presentation of events.

Chapter 4 Findings: Managing multiple stigmatization

In this chapter, I present my analysis of how participants managed their multiple stigmatization. Their strategies are grouped into three main categories: 1) strategies with which women avoided becoming the target of stigmatization such as secrecy or self-isolation; 2) strategies that "buffered" the emotional impact of stigma for example by denying, ignoring or re-appraising stigmatization experiences and 3) strategies such as education, confrontation and advocacy that challenged the legitimacy of the stigmas and aimed to change perceptions, norms and beliefs that caused stigmatization in the first place.

1 Avoiding Stigmatization

1.1 Secrecy

The three stigmatized attributes - same-sex sexuality, drug use and HIV/AIDS - were in principle concealable, at least for some women, some of the time. Participants described that visible indicators existed, including butch looks, injection marks or HIV-related physical symptoms, but not all women displayed such signifiers at all times. At the time of the interview, only one in-depth participant had HIV-related physical symptoms. Most women were relatively free of symptoms and had no visible side-effects from their medication. Similarly, none of the participants had been using drugs in recent months so they did not display bodily signs or behavior associated with active addiction. With regards to their same-sex sexuality, three participants had a distinctly butch appearance and stated that people could often tell they were attracted to women just by looking at them. However, one of them mentioned that clothing and hair styles were changing and she felt that her looks no longer necessarily gave her same-sex attraction away. Most of these indicators of same-sex sexuality, drug use and HIV/AIDS required that others recognized and interpreted them correctly, and this was not always the case (e.g. HIV-related physical symptoms could be attributed to another illness and butch women described passing as men). Most participants had thus some leeway to engage in what Goffman termed "information management;" they could conceal their stigmatized attributes and withhold or manage information to protect themselves from stigmatization.

A poignant example of HIV-related secrecy was provided by Olga who kept her HIV infection secret from everyone except her female partner, closest family members and medical providers. She was acutely aware of the stigma attached to HIV/AIDS and described denying her HIV status when she anticipated that the information would be used to her disadvantage.

> And I have bumped into people that have asked me "Olga, somebody told me that you have AIDS!" And I said "Who told you that lie? Are you crazy?

> (…) I don't have it." Because I feel that's none of their business and if there is someone who wants to know because they want to help me, I don't mind. But a lot of other people they want to know 'cause they want to gossip and talk and hurt my feelings. And for that I don't tell nobody. (21.2: 734-42)

Olga was particularly adamant about keeping her HIV infection secret from people who had previously behaved negatively towards her, such as the former in-laws of her female partner Lisa. When she saw an acquaintance of these in-laws at the Division of AIDS Services (DAS), a city agency for people with AIDS, Olga staged a whole scenario to distract from the fact that she was at the agency to claim benefits for herself.

> At DAS there was a lady there, that works there, that she is the best friend of one of her sister in law. And that's the sister in law that jumped me with her family. When I saw her there I said "Lisa, look who's there: Caroline!" And Lisa said "So?" And I said "No, they are gonna start talking about me." (…) And you know what we did? We saw this guy there and I told this guy "Come over here. Stay with me like I'm with you, like I'm helping you, like you don't know any English and you need someone to translate for you!" (…) When his case worker came, we made it look like we was with him. So then, my lover, when we went back to the block, she told her sister in law "Oh, me and Olga went to DAS because Olga's uncle came out of jail and Olga took him to DAS." She told her that, just in case her friend says she saw us. I cover myself a lot, because I'm afraid of people going "Oh, that girl's got AIDS!" You know, to avoid all that, I try to tell people the less I can about my status. (21.2: 697-712)

To avoid indirect disclosure of her HIV infection, Olga created the impression that she was at the agency not for herself, but to help someone else. Such efforts at "covering herself," as she called it, were costly to her, not only emotionally, but also on a practical level. Maintaining a secret takes time and energy. Olga for example never had a chance to talk to her case manager about her own service needs at the agency that day. Even after the incident, Olga invested in the cover-up by asking Lisa to tell a preventive lie. Olga felt compelled to go to such lengths because of previous negative experiences with Lisa's former in-laws who had opposed their relationship and attempted to physically attack ("jump") her. Based on this experience, Olga expected an equally non-accepting and hostile response were they to find out about her stigmatized illness.

A similar pattern was described by Stacey who kept her HIV status secret from members of her family who had previously rejected her when she was using drugs. She since stopped using drugs and once attempted to disclose her HIV status to them, but their initial responses were so negative that she backtracked from her intention.

> Stacey: (…) The reason why I didn't tell my nieces, they don't know, one day I came in with the flyers, (…) I said, "They was giving these out," you know, to see what they were going to say. And they reading. I said, "Yeah, you all need to read this," because I didn't want to tell them. And honey, they all three, sitting in my house, telling me, right here, "Oh, no. I don't give a fuck what this paper say. I think you can catch it from smoking or eating behind somebody. If I found out a per.. oh, God, I wouldn't fuck with nobody with HIV." Let me tell you,

> that shit hurt me so bad, that I wanted to tell them, "You know what .. the three of you just got to leave my house. (…) I'm HIV positive. Now get the fuck out." But I didn't, you know.
>
> Hella: Why didn't you?
>
> Stacey: Because I knowed that I would never see them again, you know. I mean, I know how my family is. Because when I was cracked up, they didn't want me. No, they didn't fuck with me at all. Shit. I used to knock on the door, ask her for something, she'd slam the door in my face and shit. No. When I had TB, my aunt would give me a plate, a plastic plate and a plastic spoon. You know, so you can imagine me telling them I'm HIV positive. Hell no. (31.1: 1539-59)

Stacey described her nieces' misinformation about HIV transmission risks. They did not want to believe the information on the flyers and thought that HIV could be transmitted by sharing a cigarette or using the same dishes ("eating behind someone"). Her nieces' remark that they "wouldn't fuck with nobody with HIV" was probably not limited to the literal sense. It also meant they would not socially interact with people whom they knew to be infected with HIV. Her family ostracized her when she was using crack and they were afraid when she had tuberculosis. They created social distance ("slammed" the door in her face) and Stacey feared they would respond similarly if she told them about her HIV status. Her previous negative experiences of being stigmatized on the grounds of other conditions thus fostered greater secrecy with regards to her HIV status.

Another example of extreme HIV-related secrecy was provided by Deirdre who described that she was still struggling to accept her HIV status and found it "hard" to even say the words HIV or AIDS. In those rare instances when she disclosed her HIV status, she usually made the person she was talking to guess what illness she had. In some instances, she disclosed partially, saying she had "health problems," at other times she called it another, less stigmatized illness, such as cancer. In most cases, though, as with her adolescent step daughter, she kept her condition completely hidden (she expected that a disclosure would only further complicate an already difficult relationship, "She hates me as it is .. [LAUGHS] .. She'll hate me more." 36.1: 1377).

Secrecy was not limited to HIV stigma, some participants also kept their same-sex sexuality hidden at the time of the interviews. Four in-depth participants described concealing their same-sex desires from almost everyone except their female sexual partners. However, as with HIV there were different degrees of secrecy, ranging from actively denying their same-sex sexual desires to simply going along with people's heterosexist assumptions. Some participants described engaging in a "Don't ask, Don't tell" strategy. For example, Alex received housing services from a Catholic charity. Having been raised Roman Catholic, she was aware that some Catholics strongly oppose homosexuality, but she found a way of avoiding conflict with the staff of her charity:

> Like when I deal with Catholic Charities (…) we have this thing: They don't bother me. I don't bother them. (17.2: 34-39)

She believed that her sexual orientation was obvious from her (butch) looks and comportment (“I think they pretty much knew that as soon as I walked in.” 17.2: 122) and she stated she “never tried to hide it” (17.2: 127). Alex attributed the fact that she never encountered problems with this charity to her manners and personality. She treated the social workers with respect and did not “take advantage” of their services, that is why “they just leave me alone” (17.2: 168). Staff members of the charity knew that she was living in the apartment with her female partner (and her daughter), but they neither explicitly acknowledged nor objected to their lesbian family unit. There thus seemed to be an unspoken agreement to tolerate each other's beliefs without ever making the topic of possible disagreement, Alex’s homosexuality, an issue. Alex also used this strategy to avoid stigmatization and harassment in her neighborhood. She summarized her and her female partner’s survival mantra, “Basically, nobody bothers us, and we don’t bother nobody” (17.2: 1846).

In a similar vein, Olga walked a fine line between being and letting be in a potentially hostile environment when dealing with the teachers of the eight-year old child of her female partner. In school she was known as the child’s “godmother.”

> Hella: So, people at school, do they know that you two are lovers and together?
>
> Olga: No. ‘Cause yesterday I told the baby, she had to write a story. I said “Okay, write the story: Me, my mother and my godmother were driving the car and we were going to the mountains!” She did the story, she wrote ‘Me, my mother and my father went to a trip’, she didn’t write ‘godmother’. I didn’t ask her to, neither. Cause I figured that she was probably afraid that the teacher might ask her about the story “Why is it your mother and your godmother? Why isn’t it your mother and your father?” So I figured that’s why. But in school .. I don’t know. The teacher, last year we went with her when they sent to get the kids. Every year in school they do it two times a year (...) the kids come out half the day and you gotta go in the afternoon to talk to your teacher. The teacher tells you about your kid, how they are doing, if they are doing good, the next year, whatever. We always go to the after school parent thing.
>
> Hella: You go with her?
>
> Olga: I go with her, yeah. And last time it was a male teacher. He didn’t ask anything, we didn’t tell him anything. (21.2: 289-309)

This “Don’t ask, don’t tell” approach was widely discussed in public discourse when it was established as the main way of (not) dealing with homosexuality in the American Armed Forces under the Clinton administration. Participants adopted the expression to describe their way of avoiding overt sexual stigmatization without denying their same-sex sexuality. This approach required both sides not to address the issue. Participants refrained from openly displaying their sexuality and received tolerance in return. Participants seemed to use this strategy more frequently when they felt less of a need to show affection or to have their intimate relationships explicitly acknowledged, for example in interactions with strangers and authorities. “Don’t ask, don’t tell” entailed a lower level of renouncement than other forms of secrecy, but it nevertheless constituted an attempt to avoid sexual stigmatization by keeping certain things concealed and unsaid.

Secrecy was also used to avoid drug use related stigmatization. Participants described hiding their heroin and crack-cocaine use during active addiction, especially from family members. At the time of the interviews, however, all six women with drug dependencies had stopped using drugs and the majority described themselves as rather forthcoming about their recovery. Drug treatment programs had encouraged them to be open about their past drug use, and most of them did not hide their identity as recovering addicts. On the contrary, they described that they preferred being open and honest and that shedding the burden of secrecy provided a sense of relief (see p.174).

Participants felt that in many social situations, not mentioning their HIV infection, same-sex sexuality and history of drug use was perfectly reasonable, especially when it did not entail any costs. However, in situations where maintaining a secret involved effort or where it conflicted with their needs for greater openness or support, it constituted a problem. Secrecy helped participants avoid becoming the target of stigmatization, but it was often socially and emotionally costly, and it took a toll on their sense of self-worth. When Stacey remained silent in the face of her niece’s prejudice, this clearly went against her sense of self-respect. However, given her experience of stigmatization, she knew the stakes of disclosure were high and she did not want to be rejected by her family once again. Similarly, participants could not afford loosing housing services and they did not want to risk a conflict with their children's teachers. The fact that they had to manage more than one stigmatized attribute seemed to increase the use of secrecy, in particular when they had had negative experiences in the past. Furthermore, when making decisions about secrecy and disclosure, women not only considered their own needs, they often also considered the potential risks and benefits for their children whom they wanted to protect from stigmatization as well. In these cases, parenthood increased women's vulnerability to stigmatization and further encouraged the use of secrecy.

1.2 Limiting behaviors that carry a stigma

Some participants tried to avoid stigmatization by limiting behavior that carried a stigma. In the first part of this chapter, I noted that families put pressure on participants to abandon their same-sex relationships and to convert to heterosexuality. Here, I show that in some cases, participants themselves tried to suppress or limit their desire for women, often to prevent their families from finding out about their same-sex sexuality. Stacey, for example, not only kept her female lover hidden, she also restricted her investment in this relationship.

> I keep it like on a [down note/down low], too, because my family wouldn't understand it. Oh, Lord no. If I told them that I liked women, that would be

> it! You understand what I'm saying? I know that. So I keep that on a down note, but I try not to let that bother me, because I'm not really out or in it like that. You understand what I'm saying? Like I see a woman sometime. If I was all the way gay, maybe .. I think it would probably bother me .. if I didn't go both ways, you know. But as long as I keep a couple .. [here] .. like I got with this man, then I don't have no problem, you know. (31.1: 1462-69)

Stacey kept her same-sex sexuality on a “down note,” meaning she did not tell her family about her female lover and she kept her relationship to this woman limited. She explained as long as she only saw her lover for sex “sometime” and kept a man as her main partner, she avoided problems with her family. Limiting their same-sex sexuality to sex only (no emotional involvement), to certain times and locations (e.g. “out of the house” and away from the children), and assigning it a secondary place behind heterosexual relationships was also described by other participants. These women self-censored their love for women before it came to the attention of their families and communities. Three participants described using this strategy. It was not considered possible or even desirable by other participants who had often unsuccessfully attempted to suppress their same-sex desires in the past and had often suffered family-induced conversion attempts.

Participants could not limit or change their HIV status, so this strategy could not be used to avoid HIV-related stigmatization. In respect to women’s drug use, however, this strategy of restricting the stigmatized behavior was widely used and whole-heartedly endorsed. All six women with drug addictions managed to cease their drug use and reduced their stigmatized status from being an “addict” to being a “recovering addict.” It should be noted, though, that they provided a range of explanations for ceasing their drug use. For example, Wendy said she wanted to be able to raise her children, Ana felt she was too old to spend so much time in jail, Roberta was afraid she would die of HIV/AIDS-related complications and Alex was burned out as a result of many years of extreme poly-substance use. They all described seeing the down side of their addiction more clearly and the toll it took on their well-being, bodies, relationships, and life opportunities. A desire to avoid being stigmatized, incarcerated and deprived of custody rights over their children constituted a contributing factor in some women’s decision to quit their substance use. However, it was one among many factors and participants pointed out that sympathetic and instrumental support, rather than stigmatization, proved to be the most important factor in helping them cease their drug addiction.

Like secrecy, this strategy of attempting to limit stigmatized behavior involved a high level of complicity with the stigmas. The strategy enabled women to avoid face to face stigmatization, but the effort came at a cost, especially in the case of women’s attempts to suppress their feelings for other women. Participants repressed their desires and their potential to love and they had to deal with the psychological consequences of self-stigmatization, in particular feelings of shame, guilt and fear. In the case of their recovery from substance use, on the other hand, women expressed that they gained self-respect and self-esteem in the process of limiting the stigmatized behavior. This was explained by the fact that drug use had been a (self-) destructive behavior. Women had come to view their drug addiction as a harmful form of escapism and denial. Their same-sex sexuality, on the other hand, never equaled self-destruction and only jeopardized their well-being in so far as society attached a stigma to it. Attempts to repress their desires for women were often shame-driven, unsuccessful and accompanied by secrecy. Recovering from their drug addiction on the other hand had a positive meaning beyond avoiding stigmatization and constituted a commitment to self-care, honesty and openness. In this sense, being less of a target for stigmatization as a recovering addict was more a beneficial side-effect rather than the driving force behind women's decision to discontinue substance use. Consequently, the psychological implications of this change were very different from participants' efforts at suppressing and restricting their same-sex sexuality to avoid stigmatization.

1.3 Self-Isolation

Participants described a third strategy with which they avoided becoming the target of stigmatization, but this strategy, self-isolation, was mainly used with regards to the stigma attached to HIV/AIDS. Vanessa mentioned going into an emotional and sexual "shell" after she was rejected by her male lover following her HIV diagnosis (27.1: 926). For a number of years she did not engage in any intimate relations, and she suffered from depression and suicidal thoughts. Gloria also described isolating herself following painful experiences of rejection by her husband and her family ("… and me going through that with my family, I didn't want nobody else to hurt me, so I stayed away from everybody." 32.1: 302-3). Other women, such as Wendy, described that her HIV infection reinforced the notion that she could only rely on herself in difficult times. When Wendy tested positive, she did not fully comprehend the diagnosis and she had no one to talk to. She stated, "I kept that shit under wraps for a long time" (26.2: 505). In the interview, she expressed a sense of pride at her self-reliance, "I learned how to solve my problems, but in my mind, I never talk about them" (26.1:208-9). Yet, at the same time, she realized that this attitude also caused her problems:

> When I went to go see the doctor, he said, "Take the hunch off your shoulders. We are not here to hurt you." And I was like, "What?" I had attitude. Because the attitude was, I got to face this alone. I have to do this alone. I have to deal with this problem for the rest of my life. I was like okay, okay, okay. I had to take the hunch off my shoulder. Because then everybody started giving me their attitude, because I was giving them mine. I started keeping my shit I was throwing out there to other people that didn't even need it. And I had to go see the therapist in there. And that happened too. (26.2: 594-601)

Not being able to trust others, Wendy was distant when interacting with patients or staff at the service provider. Her “attitude” in turn caused negative responses from others and reinforced her feelings of dejection and isolation. By accessing HIV-related health care services, Wendy had made the first step out of her self-isolation, but to overcome the isolation she experienced on an emotional level still required further effort.

Deirdre seemed the most isolated (and self-isolating) of all participants at the time of the interviews. She did not participate in an HIV support group on a regular basis and had no HIV-positive friends or family members in her support network. In fact, she did not seem to have many friends in general and relied for support mainly on a common law husband and her sister. In the interview, she was very tense and cautious. It took time to establish some trust between us. In the second in-depth interview, Deirdre mentioned that after 12 years of living with an HIV diagnosis, she still found it difficult to accept her HIV status. She also hinted at suffering from internalized HIV stigma. She said she preferred not to disclose her HIV status to others because she felt “that they have a stigma against me,” and she added, “maybe I have it subconsciously, too, that I feel like “Oh, no!” (36.2: 323-26). With these few words, Deirdre provided a glimpse into an internal world that is dominated by fears and tensions concerning her HIV infection. Deirdre mentioned being in therapy for anxiety-related mental health problems. Many more participants noted that they had suffered from depression following their HIV diagnosis and this was often accompanied by disengagement from relationships and self-seclusion.

Self-isolation was not described in the context of drug use or sexual stigma. It was mainly a response to HIV related stigma. In part caused by experienced and anticipated rejection based on their HIV status, self-isolation also seemed directly linked to being diagnosed with a life-threatening illness. The news of their positive HIV test results was generally described as a devastating shock. Women’s subsequent self-isolation might thus not only have been a conscious “strategy” to avoid stigmatization, but also a subconscious response to their diagnosis. Being told about their HIV infection raised fears of illness, death and dying, and created high levels of uncertainty regarding when and how the illness might manifest itself in acute symptoms. Their HIV diagnosis threatened their social standing *and* their very lives. These fears and uncertainties were the cause of immense psychological distress and more than one participant mentioned having had thoughts of suicide during the initial phase of self-isolation and despair following their HIV diagnosis.

At the time of the interviews most women had ceased to isolate themselves. Withdrawing from friends, lovers and families had been an initial, often desperate attempt to protect themselves, but it had also reinforced feelings of hurt, fear and self-devaluation by depriving them of opportunities to find support, acceptance and meaningful connections with others. From their current point of view as partakers in supportive HIV communities, participants considered prolonged phases of self-seclusion harmful to their mental and physical well-being, especially in the longer-term.

1.4 Distancing

Seeking geographical, social or emotional distance was part of self-imposed isolation, but it was also used selectively to stay away from specific people who behaved in a judgmental fashion. Alex described "ignorance" as being at the root of much (HIV and drug related) stigmatization and when realizing that she could not change a person's ignorant beliefs, ceasing contact was at times the only possible solution.

> Some of them they don't want to know, either because of spiritual beliefs, you know, or culture. So, you know, I mean, you can't tell people not to believe in whatever they believe, you know. You could try to give the information, and then, you know, if it.. you know, if it don't work out, just remove yourself. That's the way I feel about it. (17.1: 1706-1711)

She stopped going to the house of her daughter's grandmother who was worried about HIV transmission during household contact. Alex also described refusing to talk to a social worker at her HIV service provider who had displayed a "holier than thou attitude" towards her and other women with a history of drug use (17.2: 1606). One of my HIV-positive key informants, Lola, mentioned that she ceased contact with male friends and acquaintances if they made disrespectful comments about her female partner or their lesbian relationship. On a larger scale, Lola left her Caribbean home country in part due to her family's conversion attempts and their stigmatizing beliefs about women's same-sex sexuality. Olga, Roberta and Ana also mentioned seeking geographical distance from Puerto Rican based family members who were non-accepting of their same-sex sexuality. In the family context, distancing was often described as extremely painful and participants used this measure mostly temporarily and as a last resort. It was often triggered or complemented by rejection on the part of the family members involved. With non-family members however, distancing seemed to constitute a more voluntary and less taxing strategy of avoiding people who were known to be a source of stigmatization and distress.

1.5 Choosing friends and care providers carefully

Another strategy of reducing one's chances of becoming a target of stigmatization involved seeking out people who were more supportive and accepting. These people were carefully recruited into one's support network. Alex for example described how she surrounded herself with a "whole new group of people," most of whom were in recovery and HIV-positive (17.2: 942). Roberta found herself a gay substitute family during adolescence when her own blood-related family members were non-accepting of her same-sex sexuality and drug use:

> I remember meeting this lady called B. that I made her my gay mother. She was gay, her oldest daughter was gay and it was like her house was the hangout for everybody gay in the neighborhood. (…) And I met this other girl in my neighborhood, she was an aggressor, which I made her like she is my gay son. (35.1:529-45)

By building a gay family network around her, Roberta created a more self-affirming environment while staying away from her less accepting biological family. Participants also mentioned being selective about their service providers. Wendy repeatedly changed health care providers when she was not happy with the way they treated her. She mentioned health care providers made her feel “stupid” (26.2: 1035) and less important than male patients, and they did not take her concerns about medication side effects seriously. She had therefore changed her HIV care providers six times in the past few years, each time accompanied by a disruption of her treatment regimen. In the realm of health care this strategy of seeking new, more supportive and accepting providers can thus have serious adverse effects on participants’ health status. Discontinuing treatment and interruptions of anti-retroviral medication fosters viral resistance to the medications and this can threaten participants’ health and limit their options for medically treating and managing their disease in the future.

The strategies presented above - secrecy, limiting stigmatized behaviors, self-isolation, distancing, and carefully creating one’s support network - represented efforts with which participants aimed to avoid becoming a target of stigmatization. These strategies tended to be individual in focus and they could involve high psychological, physical and social costs for the women. In order to prevent rejection, participants isolated themselves, they missed opportunities for support and had to endure the negative psychological consequences of maintaining a secret, such as fear of accidental disclosure and unresolved resentment. Avoiding face to face stigmatization often shifted stigma-induced conflicts and challenges from the interpersonal to the intra-psychic realm were participants suffered from self-devaluation and shame. Overall, these strategies constituted more defensive ways of managing stigma by avoiding face to face stigmatization. Next, I show participants’ strategies of easing the emotional pain once they had already been stigmatized and thirdly I summarize their ways of counteracting stigma and challenging its legitimacy.

2. Buffering the emotional impact of stigma

This second group of strategies includes mechanisms with which participants aimed to shield themselves from the negative emotional effects of stigmatization. Most of these strategies were applied after stigmatization had taken place. Participants denied being hurt, they minimized their experience of victimization and chose not to talk about it when they feared that the memories would evoke too much pain or discomfort. One participant seemed to counterbalance her stigma-induced devaluation by stigmatizing other lesbian women with HIV/AIDS. However, most participants described less divisive ways of easing the emotional damage resulting from being a target of stigma. They adapted to multiple stigmatization by learning to ignore hostile gestures, accepting rejection and "moving on." They also mentioned that coming together with other women with the same stigmatized attributes helped them mend their sense of self-worth and they described processing stigma-induced hurt in psychotherapy and support groups.

2.1 “It don’t bother me, but..” – Denying the pain

When describing their stigmatization experience, most participants mentioned that it made them feel sad, hurt and angry. Some participants, however, downplayed or denied being emotionally affected by face to face stigmatization. For example, one of the younger participants, Wendy, described feeling stigmatized based on her HIV status and she expressed feelings of hurt, worry and distress, yet at the same time she claimed that she was not “bothered” by HIV-related stigmatization. Wendy told me that she kept her HIV status secret from her (HIV-negative) children because she was afraid they would “tell the whole world” and become secondary targets of stigmatization (a phenomenon Goffman called “courtesy stigma”). Recently, a friend disclosed her HIV status to someone else without her consent and she expressed concern that someone might eventually tell her children that they were living in a residence for parents with HIV/AIDS.

> Wendy: Some people will tell them what's wrong with them and that pisses me off. Just get.. it's a bad thing to do for kids at a young age because it sticks with them. “Your mother's HIV positive.” They don't need to know that (…), but some people do it and this building is already labeled as the AIDS parent. So, it doesn't really bother me.
>
> Hella: So who treats you different? Like ..
>
> Wendy: Well, nobody actually. Everybody in here is HIV positive, so they don't really bother me. What I'm talking about is the outside. Like you've got the projects over there, and then you've got the co-op over here, you know.
>
> Hella: A lot of people hanging out on the street?
>
> Wendy: Uh huh.
>
> Hella: And they make ..
>
> Wendy: They say, you know when you walk past somebody and they got to whisper all the time. But they wasn't whispering before you got there. That's all it is .. [?] .. It don't really bother me if anybody knows that I'm HIV positive, as long as you approach me in the right way and I say I don't disrespect myself. No way I'll low grade myself for you to say anything out your mouth that.. so I don't really have nothing to worry about. And some people's just take it beyond the point because they have a tendency just to say things out their mouth and then they're, "Oh, well, I'm sorry. Was it okay for me to say this?".. Because some people they just don't care.
>
> Hella: So.. who will just say it and then ask you afterwards, who's that? Is

> that your cousin or aunt or something?
> Wendy: No, my friend.
> Hella: And whom did she tell?
> Wendy: Oh, one of her friends. (...) It don't bother me, but why didn't you ask before you said anything, you know? And it didn't work like that. But it's okay. I learned to accept that I'm HIV positive (…). (26.1: 1233-74)

She was clearly worried that someone would disclose her HIV status to her children (her oldest son was nine years old). She expressed this fear ("that pisses me off"), but a few sentences later she said, “So, it doesn’t really bother me.” The same contradictory pattern characterized her response to the perceived "whispering" in her neighborhood ("It don't really bother me if anybody knows that I'm HIV-positive") and to her friend's disclosure of her HIV status ("It don't bother me, but why didn't you ask before you said anything?"). Wendy acknowledged these stigma-related problems, but by saying it did not “bother” her, she denied being emotionally affected and presented herself as tough and invulnerable to HIV-related stigmatization instead. This illustrates a survival mechanism she described earlier – having grown up with an absent father and a drug-using mother in a low-income inner-city neighborhood, she had learned to keep her emotions “under wraps.” She generally did not discuss her problems or worries with others. Following this established pattern, the partial denial of her stigma-related distress illustrates a desire to create a self-image that remained unspoiled by the harm done to her. It constituted an attempt to convince herself (and me) that she was able to handle difficulties without being emotionally affected.

At the same time, her acknowledgment of some of the problems she encountered illustrates that she was at least partially willing to discuss these issues. Throughout the interview, Wendy carefully considered how much information she wanted to reveal. At the very end of the second in-depth interview, she mentioned that she revealed one secret to me (referring to her same-sex sexuality), but that she still kept other secrets. She said about her interview experience:

> It was very interesting, because I didn't think nobody would ever ask me (…) about it, because I always keep certain, like these things, they are secrets in your life. I just unfolded one. And I don't feel bad about it, you know. I know I've got little other secrets, but I never thought I would sit down and talk about them the way I did and, you know, the things that came out for these interviews. It's real good. It was real good, and I liked it. (26.2: 1912-21)

This comment draws attention to the issues of trust and self-protection in the interview interaction which affected Wendy’s willingness to “let me in” on her emotional life. Discussing aspects of her life she usually kept secret constituted a novelty for Wendy. By expressing surprise at how good she felt talking with me about them in the interviews, she indirectly revealed that she did not expect to have such positive experience. As a researcher, I represented a professional to her, not unlike the social workers and medical professional she encountered at her HIV service providers. These people suggested that she change her reserved “attitude” and encouraged her to start therapy. Wendy complied, but she hardly ever stayed longer than a few months at the same provider. Developing a trusting relationship to professionals was not an easy task for her. Wendy has had a number of negative experiences with health care professionals ranging from early experiences of loosing her first-born child against her will (the child was taken away and given up for adoption immediately after birth) to more recent experiences of being treated in a condescending manner by HIV specialists. Yet she has also come to realize that working together with social service and health care professionals can have beneficial effects. At the time of the interviews, she was in the process of changing the way she interacted with professionals. Agreeing to being interviewed illustrated her new willingness to relate and engage while she also remained cautious and concerned about self-protection. She trusted me enough to discuss some secrets while keeping others. In a similar vein, she communicated that stigmatization constituted a problem for her while simultaneously minimizing the emotional damage it entailed which illustrates her old pattern of self-preservation by maintaining an image of strength and invulnerability.

2.1 Minimizing personal victimization

Wendy downplayed the emotional impact of the stigmatization she encountered. In other cases, women downplayed or denied having been stigmatized in the first place. It is important to acknowledge the possibility that women do not encounter stigmatization in specific settings or relationships. However, some interviews show a certain variability regarding women’s self-reports of having been a target of stigmatization. Specifically, participants denied or minimized stigma-related problems that they had described as bothersome in a previous interview.

For example, in the first in-depth interview Olga was clearly upset. The same day, she has had an argument with her partner over her right to discipline the partner’s biological child. Olga indicated a lack of respect from the child towards her and attributed this in part to the fact that they were not a heterosexual household (“When you're raising a child and you're straight .. the child has more respect when there's a man in the house;” 21.1: 1128-30). She also mentioned that the child pretended in school that her mother and father were still together. The child experienced general difficulties in accepting her parents’ break-up and the replacement of the father, and these problems were exacerbated by the stigma attached to women’s same-sex sexuality. Interestingly, when asked in the second in-depth interview whether the eight-year old girl had a problem accepting their lesbian relationship, Olga denied this entirely.

> Hella: How do you think the, the daughter .. does she have a problem with you two being together?

> Olga: No. The only thing she doesn't want us is to argue. That's what she has said. But she doesn't have any problems .. she would like her mother to be feminine. (21.2: 334-39)

The difference between Olga's presentation of the child's stance towards her in the first and second interviews is striking. It draws attention to the interpretative nature of narrative accounts. In particular, it highlights the significance of situational context and motivations of the narrator when she is constructing an account of stigmatization. In the first interview, Olga discussed her problems with the child in detail since she just had an argument with her lover over how to raise the child together. The problem was acute, it was being discussed in another context as well (between Olga and her partner Lisa) and Olga was interested in gaining support for her position that she was entitled to certain co-parenting rights. In the second interview, however, the argument between Olga and her partner had been resolved, the problem was not as acute and Olga was not motivated to discuss any stigma-related difficulties that might exist between her and the child. She denied the child's lack of acceptance of her as a lesbian co-mother and new partner of the mother and drew attention instead to the child's support of their relationship and to a problem in the relationship between the child and its biological mother. She did not consider the child's problem with the mother's lack of femininity as very serious. Instead, her reference to it seemed to mainly serve the purpose of changing the topic to deflect from any criticism the child might have of her. As if to compensate for the revelations of stigma-related vulnerabilities in the first interview, Olga's self-presentations in the second interview mainly focused on her as part of a functioning family unit. She repeatedly stressed the good relationship she had with her partner (calling her a "good, decent woman;" 21.2: 166, 187, 255) and the child ("And she loves me a lot. And I love her a lot. I'm gonna baptize her." 21.2: 412-13). In this context, she was not inclined to discuss stigma-related difficulties and she probably considered these less relevant or significant compared to the first interview.

This example highlights the importance of situational narrative aims. Participants were generally forthcoming with accounts of their experiences of prejudice and discrimination. However, this case illustrates that problems could be denied or downplayed when participants intended to produce a more positive impression of themselves, the other person or their relationship with the other person. Presenting oneself as lacking appreciation, control or acceptance (in the interview or elsewhere) is not a very pleasant experience. As the previous example of Wendy showed, it requires a level of trust in the conversation partner, and as this example with Olga shows, it also requires a motivation on the part of the participant to reveal such undesirable information. Simply being asked by an interested interviewer is not always sufficient, especially not when the participant strives to create an unspoiled impression of herself or her relationships.

Participants often acknowledged the general existence of stigmas attached to HIV/AIDS, same-sex sexuality and drug use on a societal level, but they did not always report having experienced face to face stigmatization. It is possible that individual participants were never personally or explicitly devalued in specific social interactions (e.g. when their environment was accepting or when they successfully avoided becoming a target of stigmatization by applying the strategies described in the previous category). However, this phenomenon also draws attention to the many factors that influence whether or not an event is reported as stigmatization in an interview.

Ana described recognizing that one is a target of stigmatization as a learning experience. She explained she did not realize that she was stigmatized on the grounds of her HIV infection until she started talking to other HIV-positive women who had similar negative experiences. These other women discussed their experiences in the broader context of prevalent attitudes towards HIV/AIDS and attributed their personal experiences to people's HIV-related fears and prejudices. Their explanations provided Ana with a new framework to interpret her own negative experiences as stigmatization. However, as the example of Olga showed, the process of re-interpretation in retrospect can also take another turn; problems can be minimized. Unpleasant experiences can be disregarded or forgotten. In the interview interaction, there is not only the question of "recall," i.e. how adequately certain experiences are remembered, there is also the question of interpretation.

When I as the interviewer probe, how does my question affect the response? How does my wording affect a participant's understanding of and answer to my question? For example, when asked colloquially whether anyone ever "gave her attitude" in hospital settings, Roberta described subtle signs of disapproval which she called "the stigma look" (35.2: 1271). Nurses communicated nonverbally that they disapproved of Roberta and her female lover (who was also a drug user and HIV-positive) and Roberta described how she and her wife responded to these looks with proud bravado and "bold" statements. However, when I asked if she was ever "treated badly" by doctors or nurses, she denied this a few moments later (35:2:1295). The phrasing of the second question implied a higher level of victimization and a different degree of concreteness than the first question. The term "attitude" allows more space for ambiguous situations or signs and it also implies that one can respond in kind and "give attitude back." Being "treated badly," on the other hand, can be understood as asking about specific behaviors that are less subtle or ambiguous, and the term implies a different self-positioning: one is the object of maltreatment in a hierarchical relationship. The first question inspired Roberta to talk about confronting HIV related and sexual prejudice in these hospital settings and beyond.

Having presented a very active, empowered self, her subsequent denial of mistreatment by doctors and nurses can be read as a refusal to assume the role of a victim. This clearly points to the influence of choice of words as well as the context of the conversation on participants' answers and self-presentations. This also became obvious when Roberta described her career as an HIV peer educator. She had just told me that she started to educate herself in prison and that she was officially trained and certified after her release, when I asked about sexual prejudice from other women with HIV/AIDS. In this case, she even denied having encountered "attitude."

> Hella: When you started in jail and when you then came out and became a peer educator, a certified peer counselor, did you ever come across, you know, attitude from other women with HIV that you were a lesbian?
> Roberta: No.
> Hella: No?
> Roberta: I have this uhm knack that people will get along with me, they feel comfortable talking to me. I never had that problem. Unless it's another aggressor that thinks I'm trying to take her girl. That's the only time I run into a problem. But as far as other women .. being positive .. and giving me attitude ..
> Hella: Did you ever feel that, 'cause sometimes I get the impression that when I go around and there is like conferences on women and AIDS, right, ..
> Roberta: Yeah.
> Hella: .. there is not a word said on bisexual and lesbian women. [ROBERTA COUGHS] And I feel like, "Okay ..?" I mean I'm trying to understand..
> Roberta: Right.
> Hella: I'm asking you here, what is your impression? You've been around the block quite a bit ..
> Roberta: Mhm.
> Hella: Do you feel there is lots of homophobia among ..
> Roberta: There is. There is. There is lots of homophobia. You know, it .. our society, our society is so funny, man, to this day, we are in 2002, I can step into a place, be dressed like I was dressed yesterday [IN A MEN'S SUIT AND SHIRT, HU] and a lot of them might mistake me for a man. As soon as I take off my jacket and they see I'm a woman, you know there goes the barriers up all over the place. You know, society is funny. They're still stuck on the piece where a man is supposed to be made for a man, you know, for a woman, and a woman for a man. And it's not like that. You know, you have your own life. You choose.. your sexual preference is your sexual preference.
> Hella: Mhm.
> Roberta: But there is lots of homophobia, still, out there. You know in the same way there is ignorance about HIV and AIDS. (35.2: 364-407)

Roberta denied having encountered sexual prejudice from other women with HIV/AIDS and explained this, following my expression of doubt or surprise ("No?"), with her personal talent and social skills. Given that Roberta worked as a peer counselor in prisons where – according to participants with incarceration experience – women's same-sex sexual behaviors are more common and less stigmatized, this might be an accurate description of her work experience in this specific setting and sub-culture. However, it is also noticeable that the previous topic of our conversation framed her understanding of and response to my question. In her response, she was referring not so much to other women's attitudes, she was talking about herself and her skills as a peer educator. She made a point that her work was not hampered by her sexuality (she only ever "had a problem" when other lesbians misinterpreted her behavior and became jealous). When I framed the question differently, i.e. when I placed it in the context of *my* experience of conferences on women with HIV/AIDS, when I called on her expertise ("you've been around the block") and when I asked about homophobia in general, she readily acknowledged the problem on a general level and even provided a personal example of when "the barriers go up." However, she did not tie this back in with her work as a peer educator with other women with HIV/AIDS. Instead, she discussed homophobia in society in general and then moved the conversation to the stigma attached to HIV/AIDS.

Why did she not discuss sexual stigma among women with HIV/AIDS? Other participants had described this as a pertinent problem, not only in their HIV support groups at community based providers, but also inside correctional facilities. Several possible explanations exist. It could simply be that Roberta was never personally or explicitly devalued as a lesbian by other women with HIV/AIDS. Alternatively, she might not recollect such experience. Or she might not deem it relevant in the context of a conversation where she was presenting herself as a successful peer educator. It is important to note that talking about multiple stigmas constitutes an act of managing multiple stigmas during the interview. Minimizing their stigmatization experiences, re-interpreting them in a more positive light, assigning them a different meaning or considering them not important or relevant for answering specific questions were tools with which participants reduced the negative effects of multiple stigmas on their social standing and sense of self.

2.3 Not talking about painful memories

In some cases, participants acknowledged that they were stigmatized and also that this caused them pain, but they limited both the extent to which and the detail in which they wanted to discuss these issues. When telling me about her aunt's accusation that she was to blame for her mother's suicide, Roberta revealed that it unsettled her tremendously. She described that she started to feel guilty and that only years of therapy helped her overcome the feeling that that her mother's suicide was her fault (35.1: 1201). After discussing for a while how she was blamed and rejected by her family following her mother's death, Roberta reached a point in the interview where she said:

> That's a real touchy subject for me when it comes to my mom's. (...) I don't want to bring up the past and old memories .. cause it'll make me depressed. And I am not the type of person to be depressed. Too many

> things in my life that I wanna do, you know what I'm saying? She's dead. May she rest in peace. (35.1: 1300-07)

Roberta's words clearly express that recollecting past experiences can re-open old wounds. In order to limit the pain associated with memories of her mother's death and her family's attribution of blame, Roberta brings the topic to an end ("May she rest in peace"). She trusted me enough to talk about this "touchy" topic in the first place, but she actively managed the degree to which she wanted to explore it. This form of self-protection points to the emotional risks involved in talking about negative and painful experiences.

Other participants simply did not talk about sensitive topics at all in order to avoid feeling sad, ashamed or guilty. For example, earlier I showed that Olga avoided discussing her parenting skills during the time she was using heroin. Olga was generally critical of women's ability to take care of children during active addiction. Had she discussed her own parenting while on drugs, she would have probably had to face (self-) criticism and feelings of inadequacy and guilt as a mother. Ana provided another example. She only briefly discussed the break-up with her last female partner which was in part related to the stigmas attached to HIV/AIDS and same-sex sexuality. Ana mentioned that she perceived her ex-partner's unfaithfulness as particularly "disrespectful" (41.2: 1124) because it had been with a man, but she chose not to discuss their relationship or the break-up in more detail, despite my probing. This strategy of limiting the emotional pain associated with memories by regulating the extent to which they talked about those memories was the most subtle and the most difficult to detect. Only rarely did participants spell it out as clearly as Roberta. Most often this strategy could be found in the silences, in the things that were not said and in those moments when I sensed participant's pain and noticed a resistance to discussing a topic more in-depth. By limiting the topics of conversation, participants managed the distress evoked by particularly hurtful memories related to stigmatization and loss.

2.4 Stigmatizing others

One participant buffered the emotional and social costs of being a target of stigmatization by stigmatizing others in the interview. Especially in the second in-depth interview, Gloria was very critical of peers at her HIV service provider and she clearly set herself apart.

> They had a lot of women that you know was on drugs and they would talk about the things they did, how they caught HIV. And at first I started getting mad, because I was like, I shouldn't have caught it, because I wasn't out there like that. (32.2: 337-41)

Gloria used the stigmatizing distinction between the guilty and the innocent to clarify that she did not deserve her HIV infection as much as other women who had been "out there" using drugs. In a sense she stigmatized others to communicate that she did not deserve to be stigmatized herself. She was also highly critical of HIV-positive mothers who lost custody of their children.

> A lot of the women that come to the group, not only did they have like drug habits, but a lot of them got their children taken away from them, you know. And I would sit there and listen to like, you know, like they.. "How did you let you kids get taken away?" (32.2: 788-92)

She blamed the women for *letting* their children be taken away and for "choosing the high over the kids" (32.2: 693). In contrast, she presented herself as a good mother. She also mentioned that other women at her provider were lacking sexual morals, describing them as unfaithful, uncaring and dishonest, for example by not disclosing their HIV infection to sexual partners. She struggled with women's open acknowledgement of their same-sex sexuality, "a lot of them was hard rock gay women" (32.2: 510-11), and she felt intimidated by what she perceived as their 'wildness' or vulgarity.

> That was mostly the type that they were wild women .. [LAUGHS] .. Excuse me. They was like real - no disrespect – ghetto, alright? And I always carried myself with a lot of respect. (32.2: 469-72)

Her constructions of contrast and social distance are apparent. Other women were "ghetto," an expression denoting class/milieu differences and implying that those women lacked her manners, morals and self-respect.[1] Gloria further described other women as "trouble makers" (32.2: 542) and "loony tunes" (32.2: 652). All in all, she drew a horrendous picture of HIV-positive women at her support group in these interview sequences. Elsewhere, she also mentioned very positive aspects of interacting with these women (see below), but here she criticized them so as to present herself in a more positive light.

Gloria experienced severe HIV-related stigmatization, especially from male partners and family members. She felt guilty about the one time that she had sex with a woman and described her new-found same-sex desires as "confusing." Using downwards comparisons and re-enacting stigma against "other" women with HIV/AIDS provided a means of distancing herself from these women as well as from aspects of her own life that were hard for her to accept (e.g. living in the "ghetto," being HIV-positive and having same-sex desires). Stigmatizing others served to elevate her self-image based on the notion that she was not as "bad" or as "deserving of stigmatization" as others. In this

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[1] I argue that Gloria's stigmatizing remarks about other women at her HIV provider were in part a measure to elevate her self-esteem and repair her standing in the interview which was damaged by her own stigmatized status. However, calling others "ghetto" entailed more than that. With this expression Gloria positioned herself in a larger and more complex discourse. The expression is widely used by African-Americans and others to (stereotypically) describe people belonging to impoverished inner-city communities of color. Equivalent terms for poor White people would be "redneck" or "white trash" and these expressions, too, have derogatory connotations. By calling others "ghetto," Gloria indicated existing class and lifestyle differences between her and other women who used illicit drugs, were repeatedly incarcerated and had a different style of communication and self-presentation.

sense, she was using a strategy to reduce self-stigmatization and to avoid being stigmatized by me, the listener, in the interview interaction. Her use of this strategy showed that people who were targets of stigmatization themselves were not only able to stigmatize others, but might even do so precisely *because* they were stigmatized or because they were *afraid* of being stigmatized. However, it should be noted that Gloria was the only participant who used this strategy in the interviews. Other participants did not present themselves as ‘better than others.’ On the contrary, they often explicitly opposed such distinctions between “us” and “them” as misguided tenets of stigmatization (see for example Vanessa's critique of the distinction between women who "deserved" their HIV infection and those who did not, p. 128).

2.5 Learning to adapt: "Letting things fall off my back"

The degree to which participants seemed aware of using the strategies previously described in this category (i.e. denying the pain, minimizing victimization experiences, not talking about painful memories and stigmatizing others) varied. I now present several psychological mechanisms that they explicitly described as their ways of “adapting” to multiple stigmatization. Women mentioned benefiting from focusing on the positive, accepting rejection as part of life, ignoring less significant hostilities and concentrating on their own priorities as opposed to other people's value judgements. These strategies were mainly described by participants who had extensive stigmatization experience with all three stigmas.

Alex described a conscious decision not to “care” about stigmatization too much when it happened. Her frame of reference for dealing with HIV-related stigma and rejection were her life experience as someone who had been taught to tolerate physical and emotional pain as a child and who later learned to “adapt” to prison life and the discredited status of being “property of the state” (17.2: 450; 498). She used the same expression (“adapting”) when describing her response to being stigmatized on the grounds of her HIV infection.

> I used to hang out with some of the fellows in the projects, and when my HIV status got around, they stopped hanging out with me. They wouldn't drink with me no more. We used to always have these barbecues and parties in the park. I wasn't a part of it anymore. But, I made up for it, because, even though they didn't want to be a part of my life, there were other people that still did. (…) You've got to understand what you.. when this hand rejects you, you've still got this hand. So, you know, you learn to adapt. (17.2: 755-73)

For Alex, “learning to adapt” to stigmatization meant focusing on the positive, i.e. instead of mourning the loss of acquaintances who withdrew from her, she chose to appreciate people who still wanted to be close to her. She also explained that she learned to accept that “rejection is part of life” and that the resulting emotional pain diminishes over time.

> [In] my transformation from drugs to recovery also, I had to make a real tough decision, which was that I had to stay away from my cousins that I grew up with, okay? And if I could do that, then why should I give a shit about things about who would think what about my HIV status, you know. So, I mean, damn, you know, you don't pay my rent, you don't give me shit. It might hurt, because I might want to be your friend, but if that's the way you want it, the hell with you! You know. Because, you know, rejection is a part of life. Nobody likes it. But see, when you feel rejected you get hurt. Hurt stays there for a while. It's a feeling. You get over it. (17.2: 739-47)

Similarly, Roberta described putting experiences of stigmatization in perspective. She argued that she has encountered so many negative responses from others in her life that she has had to learn to ignore those that seem less important. When encountering stares (what she referred to as the “stigma look”) with her “wife” in the hospital (who was also an HIV-positive drug user), she chose to disregard the nurses’ condescending looks.

> I really didn’t let it bother me. I really didn’t. Because .. as many things .. if I let bother me in life .. I’ve learned to let things fall off my back. (35.2: 1277-78)

Similarly, Olga noted that she has become much less concerned about what people thought of her same-sex sexuality. Like Roberta, she consciously decided not to let disapproving gestures or comments affect her emotionally:

> I don’t let it bother me. You know, I can’t. Cause if I let it bother me I’ll be messed up all the time thinking about it. (21.2: 1803-5)

Olga and Roberta both described ignoring negative responses that would otherwise be a cause of distress. Having encountered plenty of hostile reactions in the past, they developed a “thick skin,” an ability not to be emotionally affected by signs of disapproval. Their state of emotional detachment was not impermeable, but it shielded them at least partially from feelings of pain and self-devaluation. This was especially the case in interactions with strangers and acquaintances, i.e. people who were less important as they were not part of their immediate network of family and friends.

These strategies of adaptation differed from denial in that they involved an active intervention on the side of participants to not *let* signs of disapproval bother them by accepting them, by viewing them as the problem of the other person and by refusing to assign significance to them. Participants described having learned to accept a level of opposition and rejection in life. They chose not to respond emotionally to stigmatizing gestures from people who were less important in their lives while admitting when they were hurt by people closer to their hearts (Alex for example said with respect to stigmatization in general, “family can be the cruelest.” 17.1: 1694) In this sense, adapting to stigma seemed a mature and psychologically effective strategy of buffering the negative effects of multiple stigmatization.

2.6 Support groups and therapy

The strategies described so far were mainly individual attempts to reduce the emotional impact of stigmatization. Participants also described more collective, communal ways of buffering the pain. All participants for example had participated in peer support groups. Gloria described how going to HIV support groups has made her feel better about herself.

> When I started coming down here, then sitting around in group, you know what I'm saying, and listening to people, that's, you know, I realized I started opening up more. You know, not to be afraid that you'd say.. I think, you know, like my sister telling my family and then my family, everybody being negative you know what I'm saying? I think it made me close up more to like, "Oh, man, if somebody touched me, they're going.. they feel that I'm going to give them something." So it put me on a serious depression, you know what I'm saying? That when I started coming down here, it was alright to have HIV, because I was around everybody that had it. And then people was like really hugging me and saying, "Girl, it's going to be all right." (32.2: 953-65)

Hearing from others that it was "alright to have HIV" provided Gloria with immense relief. Similarly, Wendy described the company of other people with HIV as "soothing" (26.2: 538). Being around others with the same stigmatized attributes normalized their condition and provided a space to find acceptance and comfort.

For participants with a history of drug addiction, entering drug treatment programs and going to self-help groups such as *Narcotics Anonymous* (*NA*) or *Alcoholics Anonymous* (*AA*) was of crucial importance. They not only found support in dealing with their addiction and the stigma attached to drug use, in many cases it also opened doors for dealing with their HIV infection, their same-sex sexuality and the associated stigmas. Alex, for example, had a drug treatment therapist who told her about gay and lesbian *NA* meetings at the Lesbian, Gay, Bisexual and Transgender (LGBT) Community Center in Manhattan. Here, she learned about the other support services specifically for lesbian women with HIV/AIDS that she subsequently joined. Before starting her recovery, she did not receive any HIV-related treatment or care and most of the lesbians she knew were also active drug users. At the time of the interviews, however, she had a well-developed support system that included other HIV-positive lesbians in recovery. Her "sponsor" (i.e. a more senior member of *NA* who provided mentoring in her recovery from substance use) was also an "aggressor" and she regularly went to *NA* meetings at the LGBT community center. She explained the psychological benefits of talking to others in a similar situation:

> When you're in an environment where you have so many things in common with people, it makes it easier to let all that baggage out, you know. (…) NA is.. you know, you're not supposed to be judgmental and what-not, [but] being judgmental is a human thing. No matter how much you try not to be, it's still going to come up, you know. It's just where you take it afterwards. So, you know, you have to find a place where you could release all that

> and be comfortable or else you're going to be keep carrying shit all around.
> (17.2: 2351-59)

Going to support groups allowed Alex to “share” her experience and “release” emotional "baggage." She found a place where she was comfortable dealing with her feelings of shame, regret and self-stigmatization. For example she mentioned that it was a relief to hear that she was not the only butch or aggressor who had engaged in sex work to finance her drug addiction.

Individual psychotherapy was also mentioned as an important tool and opportunity for addressing wounds inflicted on them by stigmatization. Most participants were from socially marginalized, ethnic minority backgrounds and therapy was a new experience that was part of (often mandated) drug treatment programs or it was suggested to them in the context of HIV/AIDS treatment and care. They commonly described an initial hesitation but came to find psychotherapy helpful for becoming more aware and changing self-destructive patterns and dealing with problematic situations differently. Support groups and therapy were important places for participants to face unsettling questions, to address their feelings of shame and hurt while learning that they were not alone and that other women faced very similar problems and experiences. Psychosocial support from sympathetic peers and mental health professionals helped them feel accepted and regain a sense of self-worth after it had been shattered by multiple stigmatization.

3 Challenging stigmatization

The previous two categories contained strategies with which participants avoided and buffered stigmatization. Most of those efforts were responsive and evasive in their relationship to the stigmas. This third category on the other hand entails strategies with which participants contested their stigmatization and challenged the legitimacy of the stigmas.

3.1 Educating oneself, educating others

Virtually all women in the sample mentioned that they started to educate themselves about HIV/AIDS after receiving an HIV-positive test result. Some described this as a very empowering experience. It is important to note that many study participants had discontinued their school education as adolescents, often in the context of drug use. Wendy for example dropped out of school after commencing to use crack at the age of thirteen. When she tested positive in her early twenties, she started to educate herself and studied the information on HIV/AIDS prevention, treatment and care that she received at the doctor’s office.

> And there was always something new so I would snatch it and read it. And I'd be like "Damn!" As I am reading, I'm learning something new. (…) Then I went to the class. I got a certificate for that. (26.2: 28-33).

The information they gathered helped participants address some of the fears that fueled their own self-stigmatization and virtually all participants started passing information on to others. Information played a crucial role in addressing the stigma attached to HIV/AIDS. Participants educated themselves, their friends and family members about HIV/AIDS, treatment options and transmission risks. The process of educating self and others was transformative. By learning how HIV was transmitted and how it was not transmitted, women could assess the level of risk more appropriately, they felt less "diseased" in casual daily contacts and were able to address fears of transmission in others. Learning that "everybody" who engaged in unprotected sex "could get HIV" decreased their levels of internalized stigma and helped them convince others that the distinction of "us" versus "them" created a false sense of security. And finally, learning about treatment options helped them realize that an HIV diagnosis was not a death sentence, thus reducing fears of death and dying. Education as a tool of (self-) empowerment and deconstruction of stigma was mainly described with regards to HIV, but it was also used to address the stigma attached to women's same-sex sexuality. Alex for example encouraged her health care professionals to overcome their heterosexist assumptions. She was always offered condoms, i.e. HIV prevention tools for sex with men, but never dental dams, the equivalent tool for safer sex among women. Having access to dental dams through another HIV service provider (the Lesbian AIDS Project), Alex decided to distribute "pussy packs" (small containers of HIV protection tools for women who have sex with women) at her clinic. In the second in-depth interview she proudly informed me that her educational initiative had born fruit.

> Alex: They always ask you, "Do you want condoms? (…) Do you need any condoms?" "Uh, no. You got any dental dams?" Well, you see, this last time she had them.
> Hella: She had them?
> Alex: Yeah.
> Hella: And you.. and she gave them to you?
> Alex: Yeah. (...) Well, you know what I did. You know the Pussy Packs, that the Lesbian AIDS Project gives out?
> Hella: Yeah.
> Alex: I brought them a whole bunch of them over and started handing it to all the care providers .. [LAUGHS] (17.2: 1098-1130)

Their efforts at educating others about HIV/AIDS, same-sex sexuality and drug use were not always as successful as in this incident described by Alex, but processes of information gathering were described as empowering and efforts to pass this knowledge on constituted a significant way of responding to stigmatization.

3.1 Early disclosure

As shown above, secrecy was widely used to avoid stigmatization. However, some participants who had used this strategy (at times extensively) in the past explained that they had ceased to do so. For example Alex said that she now preferred to be open and honest about her (past) drug use, even if that meant that she had to deal with negative responses. She explained,

> You lie so much during your drug addiction that actually it's a relief, you know, because you don't have to hide one lie on top of .. to hide the other one, and, you know, keep covering your tracks. You say it. That's it. If it's accepted, it's accepted. If not, you deal with it and you move on, you know. It'll hurt? Maybe, you know. It hurt for a while. Well, move on, you know. But, you know, it actually becomes a relief. (17.1: 1473-78)

For Alex, keeping her heroin and crack use secret had required an immense effort. “Covering her tracks” had meant hiding her addiction, lying and inventing new lies to maintain old ones. Since starting her recovery, she became more open about her drug use history. This entailed a higher degree of exposure to possible stigmatization (as recovering addicts are still stigmatized), but from her current point of view, the psychological benefits of being honest provided her with a sense of personal integrity and relief which outweighed the pain caused by rejection. In a very similar vein, Roberta described being up-front about her HIV status when she met her last girlfriend in jail:

> She said “Tell me a little something about yourself!” I said “Well, I’ve been gay all my life, I’m Puerto Rican and I’m HIV positive.” And she looked at me and said “That’s nothing.” So when she said “That’s nothing.” I put two and two together and I figured she was positive, too. I said “Well, you know what? That’s good to know that you said it’s nothing, because you know what? It really doesn’t bother me if you think it IS something or not. Because your loss is my gain. I don’t worry about people that think, you know, all those things about HIV or AIDS.” (35.2: 1487-94)

Roberta took a risk when she revealed this information at the very beginning of their relationship. She was aware that HIV/AIDS was heavily stigmatized in correctional facilities, and she still disclosed her HIV status early on. Her self-description not only communicated an acceptance of herself, but also the central importance of her same-sex sexuality, Puerto Rican cultural background and HIV infection to her self-concept. It is interesting that she related the response, “that’s nothing,” only to her HIV status (and not the other two identities she had claimed) and that she (correctly) interpreted it to mean that the other woman was HIV positive, too. However, the difference in how the two women disclosed their HIV status to each other is striking. Roberta raised the issue and explicitly self-identified as HIV-positive. The other woman used this “outing” to express acceptance which indirectly revealed her HIV status. Roberta further expressed a defiant and proactive approach towards the stigma attached to HIV/AIDS by presenting herself as fearless and unconcerned about potential stigmatization.

Early disclosure is tied to having accepted the stigmatized aspects of one’s self.

Ana expressed such self-identification with several stigmatized characteristics with humor. She said with respect to her HIV status,

> I came to terms with it, with that and just about everything else. Because being lesbian and having the virus is like, no, it’s not two, it’s .. like I’m Hispanic, and I’m lesbian, I have the virus, I have Hepatitis, I have this, and I have that, so there is a lot of .. Xs, I call them exes. You know, every time you fill something out, I got this and I got this and I got that [BOTH LAUGH]. It’s like testing positive for just about everything. (41.2: 298-306)

Later in the interview, she critically discussed the various labels for woman-loving women and made the following remarks about self-acceptance, disclosure and its effects on herself and her conversation partners.

> I’m just living to live. How do they say? Striving to survive. Cause I have the virus, I’m gay, so I’m trying to understand myself more, I’m trying to be comfortable in my way. And I’m trying to be as comfortable with myself so that you can be comfortable, anybody that sits with me can be comfortable. Don’t be afraid to come to my house because I’m alone. Because we’re gay, so you gotta be careful. Because now you know I’m gay, now you know I have the virus, so now are you cautious? Are you wary? So where do I, what category am I in now? I’m just a gay, happy person. [LAUGHS] Right? (41.2: 1889-97)

This is one of the few interview sequences where a participant made a direct reference to the risk of being stigmatized in the interview interaction by me, the interviewer. She pointed out that disclosing her same-sex sexuality and her HIV status as part of the interview protocol could trigger fear in me. Interestingly, she explained that even though disclosure entails this risk, it is also a prerequisite to resolving the tension – as acceptance and openness about her stigmatized attributes is crucial for her to be comfortable with herself, she believed that this in turn fostered comfort in others and eased potentially awkward interactions. Ana, like Roberta, thus often preferred to manage the risk of stigmatization by being open about her HIV infection, same-sex sexuality and past drug use and disclosing it early. Alex added that she tells potential female partners about her HIV infection early on to reduce the pain that a subsequent rejection might cause her.

> I find it easier that if I know that there might be any possibility of me having any kind of contact with a woman, I'd rather get it over and done with and say straight out that I'm HIV positive, you know. That way, she has the choice, and it won't hurt as bad as I wait and then I get too involved and I get rejected. So, to me, that's playing it safe both ways. So, that's the way I like to do it. (17.2: 1302-06)

To sum up, the emphasis of some of the older participants on honesty and early disclosure served several purposes. It enabled them to maintain a level of personal integrity that secrecy did not allow. Secondly, it communicated self-acceptance that was at once normalizing and defiant of stigma. Thirdly, it forced other people to take a stance on the subject early on and thereby limited the pain of rejection by preventing participants from getting too involved with people who held stigmatizing beliefs.

3.3 Addressing stigma in interactions

Some participants reported that they explicitly confronted stigmatization when they encountered it. Olga for example told her partner's ex-husband to stop harassing them on the phone. Roberta described confronting nurses who displayed HIV-related and sexual prejudice.

> Roberta: I wasn't having them giving me attitude actually [CHUCKLES].
> Hella: How did you stop them from giving you attitude?
> Roberta: Actually, cause I would tell them straight up "How do you know what you've got? At least I know. I took the test. Do you know what you've got?" Especially the females, "How many niggers have you slept with? Get real." And I throw shit at them that they gotta stop and think. (…) L. [ROBERTA'S EX-WIFE] was real bold, too. You know you'd give her a dirty look and she'd say "What the fuck! You never seen two women together? And I bet you my wife treats me better than your man do! I know, when my wife goes out, at least I know she's selling drugs on the corner. When your man goes out, you know where he's at? Between whose legs he's at?" She was bold like that. (35.2: 1253-76)

Roberta challenged HIV stigma by questioning people's perceived sense of security and their constructions of HIV-positive people as "the other." She used her knowledge about HIV/AIDS, e.g. about HIV risks and undetected, asymptomatic HIV infections, to make people "stop and think" (35.2: 1261) when they behaved in a stigmatizing fashion. Her ex-wife took it even further. By asking, "You never seen two women together?" she put the stigmatizer on the spot and implied that they were inexperienced and uneducated in their prejudice. She challenged the assumption that heterosexual relationships were necessarily better than same-sex relations and questioned if the nurses' male partners were equally faithful and trustworthy as her female partner. Her question, "You know ... between whose legs he's at?" also carried the connotation implied by Roberta earlier that the nurses would be well-advised to consider their own HIV risk. Roberta called this style of verbally exposing and refuting people's stigmatizing beliefs being "bold."

Participants also described more diplomatic styles of confronting stigma. Alex for example addressed sexual stigma at her HIV service provider when a male client had made sexist and sexualizing remarks about her. Alex did not criticize his behavior when it happened, but she addressed the issue later on. She called him up in private and calmly set boundaries which allowed the other person to "keep face" (17.2: 1969-75). Thus resolving the conflict successfully, she prevented a recurrence of his offensive behavior. By dealing with conflicts in this way, she managed to turn her local HIV service provider into a "safe haven" for herself (17.2: 2014).

Participants also described using charm and humor to weaken negative attitudes and transform stigma into sympathy or at least more respectful tolerance. Roberta who at times responded to disdainful looks with boldness generally advocated less confrontational ways of dealing with stigmatizing attitudes, especially from social service and health care providers. She believed that humorous and respectful ways helped minimize stigmatization. She applied this strategy to deescalate a potential conflict with a male African case worker at the welfare office. When they first met, he mistook her gender and thought she was a man. When she corrected this misperception, he was upset and she subsequently had the impression that he was going to give her “a hard time.” However, she described that she managed to break the ice and establish common ground with a joke about both of them being lovers of women. She has since developed a much better relationship with him and on occasion he even makes exceptions from the rules to accommodate her. Based on her personal experience, Roberta encourages other women to use a less confrontational style in difficult situations with social and health care providers. As a peer educator, she gives the advice, “Don’t get, don’t get angry and yell and scream! Kill ‘em with kindness and believe me, you’ll get what you want!” (35.2: 2223-4) Similarly, Ana stressed that interactions with service providers can be eased with politeness and friendly conversation. She believed, “it depends on how you approach them” (41.2: 242), even though she admitted that it is not always easy to remain calm and friendly when one is being discriminated, as in her experience with some DAS workers.

> They automatically know that you are there for benefits because you are positive. That’s automatic. So before you even sit, they already have an opinion of you. “Oh, this one is gay and she is all this or all that”, they already got you written down. That’s how I felt. But then again it’s the way you carry yourself. Because if you carry yourself proper, you don’t get that then. But if you go to them with an attitude, you’ll get an attitude back. They are already on the defensive side. So it has a lot to do with how you carry yourself. (41.2: 370-76)

Ana believed that her own politeness and respectful demeanor would foster politeness in others and reduce stigma and hostility. Other participants described that this strategy reduced their own stress levels in the long term. Vanessa mentioned that she tended to stay calm in conflict situations with health care providers and tried “not to let anybody take me out of my character” (27.2: 1617-18). Responding in kind, i.e. saying “nasty stuff, too,” would only make her “look bad” (27.2: 620). One should note, though, that participants were not always able or in the mood to be charming in the face of prejudice. This strategy was possible when they were doing well, but it was much more difficult to practice when they suffered pain or physical symptoms or when they had passed a threshold of frustration with service providers who simply did not seem to care.

3.4 (Not) Taking legal action

In a few instances participants used the legal system to fight their stigmatization when this could be classified as discrimination or harassment. Olga and her female partner, Lisa, for example went to court to get an order of protection when they were harassed by Lisa’s ex-husband. The harassment was clearly related to their lesbian relationship. The ex-husband could not fathom that Lisa had left him for a woman, threatened them and called them names using sexualized language. Given his history of physically abusing Lisa, the courts did not hesitate to issue an order of protection. They also did not hold Lisa and Olga's lesbian relationship against Lisa or the fact that that they were raising Lisa's eight-year old child together. This very much surprised Olga who was afraid to mention the nature of their relationship in court and who expected to be scrutinized by the Administration of Children's Services if they did.

Two participants considered filing formal complaints or suing medical providers for malpractice with regards to their HIV status, but both decided against it. Stacey, whose doctor had carelessly disclosed her HIV status in public, felt “my one complaint ain’t gonna help” (31.2: 1748). Ana did not realize until much later that she could have sued the nurse who gave her the positive HIV test results in jail without any explanation, counseling or confidentiality.

Overall, participants did not put much trust in the legal system. Historically, the majority of participants had experienced conflict with legal authorities, mainly in the context of using drugs. They were often skeptical (to say the least) that city and state authorities would do anything for their benefit such as protecting them from HIV-related or sexuality-based discrimination. Furthermore, hardly any participant ever voluntarily sought legal advice or representation. In their drug-related court cases, participants had utilized 18-B lawyers, i.e. pro-bono lawyers provided by the courts to defend persons with limited financial resources who could not afford to hire their own lawyers. These lawyers did not usually have the time or commitment to really represent the interests of their clients. As Cathy put it, for them "it’s about getting a conviction and moving this case along" (PS02: 819-20) which further diminished participants' trust in the justice system. Only rarely were participants as lucky as Roberta whose lawyer actually did some research on her behalf and put an effort in to acquit her of unsubstantiated charges of child neglect and child abuse (see p. 141).

Overall, the strategy of challenging stigma by taking legal action was rarely utilized. When it was used, this occurred in the context of fighting the stigmas attached to same-sex sexuality or HIV/AIDS, but not drug use. The criminalization of drug use in the United States constitutes an institutionalization of the stigma attached to drug use. Consequently, there are fewer opportunities to fight this particular stigma through the legal system.

HIV support structures seemed to facilitate participants’ use of existing legal aid and protection. Participants repeatedly reported that other HIV-positive peers had informed them of their rights and had encouraged them to make use of the legal system.

Community-based HIV providers offered legal support and HIV activists had successfully used the legal system to push for anti-discrimination laws. In fact, participants often found that their HIV status proved to be an advantage in legal proceedings. For example, they were able to use it as a leverage point in court to negotiate shorter drug-related prison sentences. They were released from prison prematurely when their health had deteriorated and Stacey even hoped that she might be able to gain visiting rights for her children who were given up for adoption during her crack addiction. In this sense, their HIV status could prove a legal advantage. Overall, community-based HIV support structures provided crucial support in dealing with the legal system and in particular when using it to fight against HIV-related discrimination.

3.5 Building communities, creating support structures

Another strategy of challenging the stigmas attached to same-sex sexuality and HIV/AIDS involved collective activities such as Gay Pride marches or the annual Walk for Life (a local fundraiser for HIV/AIDS organizations). These events aimed to publicly denounce stigmatization and to foster higher levels of acceptance and support. They were organized by people in the lesbian/gay/bisexual/transgender (LGBT) and HIV communities and those women who had participated felt it created a sense of belonging to a community.

Building communities and creating support structures was described as an important strategy with respect to all three stigmas. Roberta was quoted earlier, explaining how she created a gay substitute family. Ana described how she and other lesbian and gay friends met informally to discuss anti-gay violence in the late 1970s. These informal groups also provided her with support and information when she lost her partner to AIDS in the early 1980s.

> I started going to groups and stuff like that. I started meeting all these people and getting educated on a lot of stuff. (…) Now it's called support groups, (...) but it was a combination of everything group. We talked about being gay, a virus that we didn't understand. We talked about family stuff. But mostly about the virus. (41.1: 1369-78)

Later in her life when she was in jail, she found out about her own HIV infection and joined an HIV support group that Roberta had started. This peer support helped her understand information about the disease that medical professionals failed to explain in simple enough terms.

> I understood more in jail than I did when I was outside, about being positive. Because it's.. you would ask .. even the doctors .. you would ask, "Can you explain this?" and even with the written information in front of them they weren't able to make me understand. All these words. They kept using big words. And I started realizing .. what .. stigmatized me in the late '80s .. because of what was happening to me.. I didn't know that I was

> being stigmatized ‘til I started putting two and two together. And I was like “Wait a minute, this is what this means..” (41.1: 1536-42)

Talking to other women with HIV helped her not only understand medical aspects of the disease, but also to recognize HIV stigma. During her last prison stay, after many years of drug use and repeated incarceration, Ana decided to stop using drugs. She joined a substance use treatment program and here, again, coming together with other women in a similar situation changed the way she perceived herself in the world. The community of recovering addicts and the treatment program also helped her deal with the stigma attached to HIV/AIDS in a new way. It changed the way she felt about herself and about other people’s opinions.

> I learned a lot about myself, I learned how to be with myself, cause I couldn’t be by myself WITH me. I learned how to do that. I learned how to not worry about other people, what other people think of me. I didn’t mind being positive .. some people aren’t comfortable with other people being positive. If they are not comfortable with me then “Move on!” Cause I wasn’t gonna get into any arguments or fights over it any more and I wasn’t gonna hide anymore. (41.1: 1448-53)

Ana described becoming more comfortable with her HIV status and less willing to accommodate other people’s negative responses to it. Similar to Alex and Roberta, she came to the conclusion that the psychological benefits of being more open and less secretive outweighed the risk of being stigmatized. Substance use treatment communities and *NA* meetings and networks were described as a significant source of support for those women who had a history of drug dependence. They found instrumental support, friends and partners in these communities. And once they had stopped their substance use and had entered drug treatment programs, they usually also became more involved in the HIV community.

At the time of the interviews, four in-depth participants worked in the HIV field as peer counselors. All in-depth participants accessed HIV-related support services and four women were connected to lesbian-specific HIV/AIDS support services. The creation of support structures specifically for lesbian and bisexual women with HIV/AIDS in New York City deserves special attention. One of my key informants, Willa, an HIV-negative self-identified lesbian, was involved in starting an initiative when she worked as a social worker in a hospital. In the early 1990s, she noticed an increasing number of lesbian patients with HIV/AIDS and decided to start a support group for HIV-positive lesbians at the clinic. This was met with resistance from the hospital administration.

> Generally, support groups that started in the social work department, you know, were supported generously (…) by the administration, "Great idea! Do that. Sure, you want to do a medication support group. Great idea! You want to do a family support group? Great idea. You want to start a .. what?? A lesbian AIDS support group? For what? Well, write us, write down a brief description." .. "Yes, we got your description. We're not really quite sure how it fits in. Could you write up another?" Whatever. It was all

> kinds of administrative red tape. Probably six months later, I was allowed - allowed, quote, unquote - to start a Lesbian AIDS Support Group, (…) and I did it with one of the full nurse practitioners (…) And this support group was great. It was well-attended. It was finally supported by administration. And out of that, I felt like there was a need to do more, not just at [NAME OF HOSPITAL], but at all the other Bronx-based clinics and hospitals, to really bring together staff who were working in other places to think about lesbians and AIDS in their particular field. (…) "Now that you have lesbians, you know, what are their needs? What are their issues? And how are you addressing them? (…) How can we support?" So it was a great task force. I got people from interdisciplinary, you know, doctors, nurses, social workers, advocates, all of us, to really come together to think about lesbian AIDS issues in the Bronx. It was terrific. (PS12: 366-98)

The local support group led to a larger network of health care professionals and advocates that were dedicated to the needs of lesbian patients in HIV health care. The Lesbian AIDS Task Force in the Bronx eventually ceased to exist due to limited resources. However, around the same time, another support structure and advocacy organization opened up in Manhattan. The Lesbian AIDS Project was created at the Gay Men’s Health Crisis (GMHC) in 1992. It was initiated by a group of lesbian and bisexual women who were working in the HIV field, some of whom were HIV-positive themselves. These women had noticed a lack of information and services for HIV-positive women in general, and for women who partnered with women in particular. The Lesbian AIDS Project was the first community-based HIV program in New York City that specifically targeted women who had female sexual partners. It provided support services, group discussions and individual counseling to HIV-positive lesbian and bisexual women and it also conducted outreach and HIV prevention to the lesbian communities in New York City. The Lesbian AIDS Project worked with “peers,” mostly HIV-positive lesbian and bisexual women working part-time in outreach, HIV prevention efforts and peer counseling. Three of my in-depth interview partners worked as peers at the Lesbian AIDS Project or had done so in the past. Since its inception, the program has expanded from its mainly African-American client base to also include more Latina women with HIV/AIDS. At the time of the data collection for this study, the program celebrated its tenth anniversary with a gala honoring women who made outstanding contributions to helping lesbians in the HIV community.

In 1997, another group was initiated to support HIV-positive lesbian and bisexual women, the House of Moshood. It was named after a Harlem-based African designer who let members of the house wear his clothes to the balls.[2] Mildred, current self-appointed mother of the House of Moshood, described the idea behind the creation:

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[2] The concept of a "house" was created by queer homeless youth of color as a way to emulate family life. Although house members do not always cohabit, they often form close bonds. Houses tend to be named after fashion designers and are run by a "mother" or "father" (usually of a non-traditional gender). Houses host "balls" at various venues where people “walk” in categories and compete for cash prizes and trophies. Houses first received widespread attention in the 1991 documentary film *Paris is Burning,* but they have been in existence for longer than that (POZ,

> The House of Moshood was started by this woman named [NAME OF FOUNDER] who was an out HIV positive woman (…). She grew up going to bars and clubs to meet women .. that was the only safe space .. And she felt that women work in HIV for the same reason. So she wanted a space where women could come and hang out, learn about HIV, and help other women that were positive. (PS04: 130-137)

The House of Moshood organized balls and HIV-prevention outreach to lesbian bars and clubs and it provided an opportunity for HIV-positive lesbian and bisexual women to form a support network. These examples of lesbian-specific HIV support structures in New York City provided important spaces for women to come together in an environment that was affirmative of their same-sex sexuality, recovery and HIV infection and relatively free from the sexism that characterized so many gay male dominated HIV support structures. Besides providing affirmation and support to HIV-positive women with same-sex sexual partners, these structures also fostered advocacy efforts. Since the 1990s, HIV-positive women, often in collaboration with HIV-negative lesbians, started to take an outspoken stance against the multiple stigmas that negatively affected their lives.

3.6 Advocacy

One of my key informants, Lola, was a lesbian mother with HIV/AIDS who worked as a professional HIV advocate/activist. She had joined the activist movement in the early 1990s when *ACT UP* (AIDS Coalition To Unleash Power) organized a class action suit against the exclusion of women from HIV treatment trials. She described her joy when she first found her way into the movement:

> My case manager actually told me about this group called Act Up New York. And I was so .. [LAUGHS] .. oh, my God!, inspired when I just heard about these people and what they were doing. And what happened, what really enticed me was that I heard that they had this lesbian coalition, and they were actually working on filing a class action suit against the Food and Drug Administration (...) because women were not being allowed to participate in clinical trials. (...) And I went there one night and, you know, when the floor was opened for questions, I just got up and I said, you know, "I'm a lesbian, and I'm living with AIDS, and I have a child that's po.." And I just, I really just started just talking out of my head. And everyone was like: "Wow! We can't find a lesbian who is willing to come forward and talk!" And, you know, it's like I have never done any kind of public speaking before ever in my life. And I said, you know what .. So, a lot of people actually really, you know, embraced me that same night. I made a lot of friends. And I actually went down and demonstrated and was part of a coalition of women that actually filed this class action suit against the Food and Drug Administration. (PS01: 168-89)

From this initial, very positive experience, Lola developed a whole career as an HIV activist and advocate. She joined groups of treatment activists, worked on committees and served on community advisory boards of clinical trials. Here, she discovered that gay male

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treatment activists were at times not very supportive of lesbian issues in HIV/AIDS.

> I joined this committee, and I can tell you, in fact, it was one of the most intimidating atmosphere that I really got, you know, cast right into, because it was a lot of the self-opinionated, you know, gay white guys, very smart, very, very intelligent. They had a lot of upper-hand, know how to talk the lingo, understood the research. (...) They were getting the studies approved, and (...) I just saw more and more where the women's issues were not being addressed. There were times that I actually had, you know, a gay white guy, infected guy, telling me.. you know, "Talking about lesbians, this is not the place." "Why is it not the place? I'm here and I've got AIDS, so this is the place," you know. So we were like, a lot of my energy was just, you know, spent toward fighting against my peers, you know, but these were male peers, you know. (PS01: 217-230)

Lola found the hostility with which some gay men challenged the legitimacy of lesbian AIDS issues upsetting and she described the resulting arguments as exhausting. However, she did not give in and successfully started to make her voice heard.

> So I was beginning now to get invited to meetings where you normally would not once see a woman, a woman of color, a lesbian, you know. So I pretty much really started out..I started really building networks, you know, within different entities, and really actually got.. started getting some attention, you know, from large decision-making bodies, and so I really just went, you know, from the researchers right into policy. (PS01: 239-44)

On her path, Lola encountered opposition, from policy makers as well as from gay male activists and other HIV-positive women. Some of these obstacles turned out to be insurmountable. The stigma attached to women's same-sex sexuality constituted one such obstacle during her work on the community advisory board (CAB) of a large study of HIV-positive women where she tried to advocate for the inclusion of questions on women's same-sex sexuality.

> They wanted to have a lesbian on the CAB, and they wanted a person who was verbal and who was outspoken. I got into CAB, and when I looked at the criteria.. in fact, at the concept of this whole research, I says, "My God, there is nothing in here that addresses (...) the issues that lesbians are dealing with. (...) So I would bring this to the board, and I said, look, we need to develop these criterias. "Lola, why do you want to turn this into a lesbian study?" “Excuse me, no! I'm not trying to turn this into.. we need to have these areas so when a lesbian sits before the interviewers, at least she knows there's an opportunity for her to say this is who I am and this is how I'm living.” (...) I compared it to a male study that had been having going on since 1985 called The MAP Study. And MAP addressed everything, addressed for gay, heterosexual, men who were infected, men who were affected. And they had a whole, I mean, a complete package. So I compared the both studies, and (...) you know, they threw me off the national CAB because I did that. (...) They said that I was trying to monopolize the study. I was jeopardizing women's research. (...) These were my own peers. These were infected women that also, too, went against me. Infected women got up and they said, "No, we don't want you on this CAB." And they voted, and then I stepped down, and I did it with honor because I said, you know what, I don't have to be on this CAB to get lesbian health issues addressed within this AIDS epidemic right now. I don't have to be on here. There are other podiums and there are other

> entities, and I'm not..I'm going to speak even more about the dis-justice that's been going on now with lesbians. Because when you're a lesbian with AIDS (...) you get ostracized. You know, I think women with AIDS get ostracized, but you know as a lesbian, it's so much..you know, it's just so.. it's overwhelming. You know, they have no kind of respect, no kind of consideration. (PS01: 678-726)

Lola expressed her frustration very clearly. When she attempted to change the research protocol to address women's same-sex sexuality in the same detail as heterosexual arrangements, her efforts were boycotted. Other HIV-positive women felt threatened by her call for an equal treatment of women's same-sex sexuality and ostracized her from the project. For Lola, the multiple stigmatization as an HIV-positive *and* lesbian woman was simply "overwhelming."

Lola not only worked on research projects and policy making, she also advocated against the stigmatization of lesbian couples and families in HIV service provision. At her own service provider she raised the issue proactively.

> My family is me, my partner, and my two kids. (…) And they have this (…) camp program, it's a family camp (…) and they kept talking about, you know, husband and wife. Or you could bring your boyfriend. I said, "I have a question, is there an issue if there are same-gender-loving families?" And the guy was like, "What do you mean by same gender?" I said, "I'm a lesbian, and my partner, I need to know if she would be .." And everyone, "Lola! You don't have to ask .." I said, "Yes, I have to ask that question, because if I want [NAME OF FEMALE PARTNER] to come to that camp, when she goes with me, I want no one looking at us as if we both just stepped out of a flying saucer when she gets there." .. [LAUGHS] .. (PS01:1153-73)

The service provider and the other HIV-positive clients reassured Lola that they would accept her lesbian family just like any other family unit. Nevertheless Lola insisted that it was important to raise the issue because sexual stigma and hetero-normative conceptions of what constitutes a family so often went unscrutinized in HIV service provision. Other participants also pointed out that more advocacy was needed as lesbian couples and families often did not receive the same HIV-related services as their heterosexual counterparts. For example, lesbian couples and families were not entitled to many family-based support services, such as family therapy, food assistance programs or emergency overnight housing.

3.7 Finding positive meaning in stigmatized attributes

The last strategy in this category has been a crucial element of most of the other strategies described above. Participants were only able to challenge and undermine stigmatization when they had found positive meaning in their self-identification with their stigmatized attributes. This was the case with being HIV-positive as well as being a recovering addict, but it was most obvious regarding sexual stigma. A number of study participants conveyed a sense of pride in their love for women and their lesbian self-identification. For example, Lola mentioned that her sister once accused her of wishing every woman was a lesbian, to which she responded, "Oh, no! It's an honor to be a lesbian!" (PS01: 617) For Lola, identifying as lesbian and living in a committed relationship with a female partner today was synonymous with recovering from the self-hate that had been induced by sexual stigmatization earlier in life and had surfaced in the form of substance use and promiscuous heterosexual relationships. Loving women and considering herself lesbian today entailed very positive meaning and was associated with self-love and self-respect.

Some participants' self-identification as "aggressor" constituted another interesting example of how positive meaning was assigned to a stigmatized attribute. As shown in the first part of this chapter, the stigma attached to women's same-sex sexuality entailed the stereotyping of lesbians as aggressive and abusive. Given this backdrop, it might seem surprising that some women voluntarily self-identified as "aggressors." One of my key informants, Mildred, explained the label as follows:

> Mildred: Dyke, butch, or aggressor, they're all kind of lumped in together. And if I say femme, then it's a totally different ..
>
> Hella: Yeah? What do you consider yourself?
>
> Mildred: I consider myself a femme. (...) My wife considers herself an aggressor, and it's funny because like we crack this joke. You have a dyke, a butch and an aggressor. You get up in the morning, and the dyke is like, okay, .. gets herself fixed up in five minutes [SNAPS HER FINGERS]. The butch is like, okay, ten minutes .. and an aggressor is like thirty minutes, fixing their hair .. and then the aggressor is supposed to be more butch than anybody else [LAUGHS].
>
> Hella: (...) Where does this word "aggressor" come from?
>
> Mildred: It's really kind of more a Hispanic term for Hispanic girls. It's that they're really.. they consider themselves really tough and they act real tough. They.. I mean, they usually bodybuild, and they lift stuff, but they really dress themselves like down .. They've got to look perfect. (...) Their clothes have to be perfectly fit, perfectly ironed, perfectly sown (...) Their hair has to be perfect. And they usually look.. they look kind of feminine. They look like boys, little younger boys. And they are really into that, but they really like, “This is my woman. I will open the door..” It's funny, it’s kind of like the Hispanic machismo .. (PS04: 425-61)

According to Mildred, the label was used by Hispanic lesbians who behaved in a gentleman-like or macho-like fashion and paid more attention to style and appearance than regular “butches” or “dykes”. Other participants had other definitions of the term. Stacey, a bisexual African American in-depth participant, self-identified as an aggressor in the screening interview to signify that she assumed a sexually active role with her female lover. Some of my Puerto Rican lesbian interview partners who identified as "aggressors" simply regarded it as another, more up-to-date word for "butch", the more masculine role in the butch-femme dyad. Most participants said they learned about the term in prison.

Ana: I believe that that came from jail, from the system. Aggressor is a

> woman .. to me, an aggressor, they look at me like that as an aggressive woman. It's a more a woman with a.. with a stronger attitude towards things or .. a different attitude, a different frame of mind in that sense. Not an aggressor as being the one that's gonna lash out. Because there's so many different ways to look at an aggressor.
>
> Hella: It is someone who's gonna lash out or not?
>
> Ana: No, it isn't.
>
> Hella: Why would you call her aggressor?
>
> Ana: Because it's supposed to be the boy. That came from the system. Because we were just considered butches, butches at one time. And then .. it's like being a dyke. What's the difference? It's all lesbians. (…)
>
> Hella: I was wondering, cause the name "aggressor" sounds negative to me, right, because being aggressive is something negative, right?
>
> Ana: That's what I think. That's what I think.
>
> Hella: So who would come up..?
>
> Ana: Yeah, so what kind of woman is that then? Is it a woman with a bad attitude? A troublemaker? [LAUGHS] (41.2: 1799 -1833)

Ana described being considered an "aggressor" by other inmates in prison. The term was just another label for lesbian, but she acknowledged that other women might assign a different meaning to it ("there is so many different ways to look at an aggressor"). For her, the term carried connotations of having a "stronger attitude towards things," possibly indicating a more traditional value system or a more outspoken personality. Ana pointed out, though, that the term did *not* mean that an aggressor was abusive or violent. When I probed about the apparent contradiction in meaning between the ordinary, negative use of the term "aggressive" and the self-identification as an "aggressor", Ana agreed. Based on the usual negative connotations of the term, it could be deduced that self-identified aggressors were "troublemakers" or women with a "bad attitude." However, she stated very clearly that this was not how the term was used by women in the prison system. It seems that a re-appropriation of the term has taken place. Lesbian women collectively assigned it a new meaning. Based on a new, positive evaluation of the stigmatized attribute (women's same-sex sexuality), the same word ("aggressive") that was previously used to stereotype and downgrade same-sex loving women was now used to convey a different, affirmative meaning. Another example of the re-appropriation of stigmatizing language, is the previously derogatory term "cachapera" which has been reclaimed by Puerto Rican women to describe their positive self-identification as lesbians (PS05: 642-57). This phenomenon illustrates a shift in meaning that is a crucial underpinning of all strategies used to challenge and deconstruct stigmatization processes.

Overall, participants tended to manage their multiple stigmatization by selecting or combining strategies from all three categories. For example, Alex avoided stigmatization by choosing her friends and providers carefully and by not making her HIV status and same-sex sexuality explicit in certain non-accepting environments. She buffered the emotional impact of being the target of multiple stigmatization by learning to adapt and by participating in support groups and therapy. She also challenged the stigmas attached to her same-sex sexuality, HIV infection and (past) drug use through education, early disclosure and diplomatic confrontation in specific interactions. Her ways of managing the multiple stigmas have changed over time – she used to rely more heavily on secrecy and distancing while she now challenged the stigmas more often, actively constructing a support network and educating others. For Alex, her decision to stop using drugs constituted a crucial turning point. Since starting her recovery from substance use she received additional medical, therapeutical, emotional and instrumental support. A significant amount of time, skills and energies that were previously taken up by her drug addiction were now available for alternative use. Being in recovery changed her self-concept and sense of self. She communicated pride in her achievements, and the encouragement and acceptance from her peers and providers affected all aspects of her life. While she was never afraid of sexual stigma (that is, once her family knew about and tolerated her same-sex sexuality), she now also became more open and less secretive about her HIV status and drug use history. Coping strategies previously used with regards to one stigma (e.g. early disclosure and confrontation of sexual stigmatization) were now applied to other stigmatized attributes as well (i.e. drug use and HIV/AIDS). Multiple stigmatization thus not only fostered greater secrecy, as described by other participants, it could also result in greater use of strategies that challenged the stigmas.

In conclusion, managing stigmatization often involved a combination of strategies that changed over time. The fact that *multiple* stigmas had to be managed, had different effects. For some, experiences of rejection on the grounds of one stigmatized attribute fostered fears of further stigmatization on the grounds of another and led to greater efforts at avoiding becoming a target of face to face stigmatization. As a result, women were more secretive, they tried to limit stigmatized behavior and one participant even stigmatized others in response to her own stigmatization. For other participants, however, having to deal with multiple stigmas did not lead to greater secrecy and complicity with the stigmas, but to an increased level of openness and resistance. Given the right circumstances, in particular the existence of an accepting support network and an increased level of self-acceptance, strategies to combat one form of stigmatization were applied to the other stigmas as well. For example, women learned to use education and advocacy in the context of HIV/AIDS, but they often also applied these strategies to challenge the stigmas attached to same-sex sexuality and drug use. Finding positive meaning in the stigmatized aspects of one’s self and integrating these into a coherent sense of self seemed a crucial prerequisite to being able to challenge one’s stigmatization and the cultural construction of the stigmas attached to HIV/AIDS, same-sex sexuality and drug use more generally.

A second aspect of managing *multiple* stigmatization entailed the use of a strategy described as “learning to adapt.” For some women, being the target of multiple stigmas involved dealing with a myriad of negative experiences. As a consequence of repeated stigmatization experience, they developed an ability to distinguish between important and unimportant encounters with stigmatization and to ignore signs of disapproval from people that were considered less important, such as strangers or acquaintances. This ”thick skin” can be viewed as a cognitive and behavioral achievement of women who survived repeated exposure to multiple stigmatization. However, this achievement clearly came at a cost and it is important to note its limitation. Most women who described such an ability to ignore disapproving and hostile gestures also had – to use the same metaphor - very sensitive areas where their skin was broken and worn as a result of repeated stigmatization from people who *were* important to them, such as sexual partners or family members.

Chapter 5 Discussion

Findings from this study are in line with existing research showing that women's HIV infection, drug use and same-sex sexuality have stigmatizing effects (Bradford et al., 1997; DiPlacido, 1998; Greene, 1997; Hackl et al., 1997; Herek et al., 1999; Hidalgo et al., 1976; Hunter, 1990; Inciardi et al., 1993; Mays & Cochran, 2001; Moneyham et al., 1996; Murphy & Rosenbaum, 1999; Rosenbaum, 1981). The specific contribution of this study is to highlight how the stigmas intersect in the lives of HIV positive, lesbian and bisexual women who are also parents. I first discuss how the stigmas converge with respect to attributions of blame. I then interpret the findings on women's perceptions of sexual and HIV related stigma in their ethnic minority communities. Next, the role of emotions in the stigmatization process is discussed, in particular the target's emotional vulnerability to stigmatization which has received inadequate attention in stigma research and theory to date. One of the research questions of the current study asks about the meaning of parenthood in the context of women's multiple stigmatization and I comment on the ambivalent role of parenthood that has been described by participants of this study. Negative consequences of the multiple stigmas with regard to social support and service provision are discussed, as well as women's individual and collective strategies of stigma management. Finally, I highlight the methodological implications that can be drawn from this in-depth analysis of women's narrative accounts of stigmatization.

1 Intersecting stigmas

Initially, a focus was placed on the stigmas attached to women's HIV infection and same-sex sexuality. However, the interviews revealed that participants' experience of multiple stigmatization cannot be understood without taking the stigma of drug use into account. This is due to the high prevalence of drug use experience among HIV positive, lesbian and bisexual women, the strong stigma attached to drug use, its role in HIV transmission and the associated attributions of blame.

1.1 Attributions of responsibility and blame

Attributions of responsibility and blame are a core feature of stigmatization processes and they are based on perceptions of what caused the attribute that carries the stigma. Participants explained that others tended to search for causes of all three attributes, their same-sex sexuality, HIV infection and – in the case of women with drug use experience – their drug use. Social psychologists note that causal attributions are usually made when something out of the ordinary happens, i.e. when an event or evidence calls into question a person's understanding of reality (Weary & Reich, 2000). Participants explained that their same-sex sexuality, drug use and HIV infection constituted a surprise to most people in their environment. All three attributes conflicted with normative expectations. Family members, friends and service providers (and sometimes the women themselves) tried to find explanations for these differences, differences that posed a challenge to their world views.

As explained in the first chapter, social psychological theories on attribution distinguish between internal and external attributions (Heider, 1958). Internal (or personal) attributions assign responsibility for an event or behavior to the person, while external (or situational) attributions assign responsibility to situational factors or circumstances. Observers generally tend to attribute causes more readily to people than to situations, a bias referred to as the "fundamental attribution error" (Bordens & Horowitz, 2002: 82ff) or “correspondence bias” (Gilbert & Malone, 1995).[1] This bias is thought to derive in part from cultural values of control and responsibility and the related belief that individuals are largely in control of their fate and behavior. A second contributing factor to the "correspondence bias" is thought to lie in cognitive processes that highlight the person or actor over environmental factors. Perceptual psychology explains that from the perspective of the perceiver, the actor becomes the "figure" (i.e. the focus in the foreground) and the situation, the "ground," i.e. the backdrop against which the figure stands out and demands our attention (Bordens & Horowitz, 2002: 85). The perceiver tends to be "engulfed by the behavior" (Heider, 1958) and connects it with the person only. External factors that might have brought on the behavior are not as visible or easily accessible, so they are disregarded and the perceiver falls into the correspondence bias.

This pattern of attributing the cause of a stigmatizing attribute or behavior to the person displaying it, is a central element of stigmatization processes. The individual is thought to be responsible for the attribute that carries the stigma and blame is assigned to them. In the case of substance use, study participants described that their addiction was perceived as a personal weakness and character flaw. Their drug use was considered

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[1] The terminology “correspondence bias” refers to the tendency of observers to conclude that a behavior was exhibited because the person was predisposed to do so – i.e. that the person's behavior *corresponds* to her or his unique dispositions (Gilbert & Malone, 1995). I prefer to use this term over “fundamental attribution error,” because the latter term implies that it is possible to clearly distinguish “right” from “wrong” attributions (i.e. “errors”) and because the term “fundamental” is controversial. Cultural differences in attributional practices have been observed, e.g. between members of individualist cultures, such as the US, and those of more collective cultures, such as Asian cultures (where situational attributions are more prevalent), differences that seem to imply that the bias might be less “fundamental” than previously thought (Weary & Reich, 2000). On the other hand, recent studies suggest that observed differences are due to situational factors that affect subsequent steps of attributional processes, but that the basic tendency to first attribute outcomes to an actor's disposition is a cognitive bias that can be found across cultures (Aronson et al., 2004:132-38).

their choice, their "fault," and this contributed to the strong stigma attached to it. Participants, on the other hand, emphasized the environmental factors that contributed to their use of drugs. They mentioned having being neglected or abused by their parents, they stressed physiological aspects of their dependency and pointed to the influence of peers and drug markets in their neighborhoods. As the actors, their point of view revealed a number of background factors that contributed to their drug use. In attribution theory, the different perspective and attribution patterns of actors have been described as the “actor-observer bias” (Weary & Reich, 2000). Unlike observers who tend to attribute actions and outcomes to stable personal dispositions of the actor (i.e. the “correspondence bias”), actors tend to stress the significance of situational cues and circumstances (Kelley & Michela, 1980; Weary & Reich, 2000). This is thought to be partially due to motivational factors. Actors generally try to avoid blame for negative outcomes. Studies find that actors prefer to attribute socially redeemable, positive outcomes of their behavior to their disposition while they use more situational attributions for behavior that is considered negative (Kelley & Michela, 1980). However, it has also been pointed out that actors tend to have more accurate information about events that are affecting them and are more aware of the cross-situational variability of their behavior, so they may make more accurate attributions (Kelley & Michela, 1980).

In the current study, participants did not attribute their drug use entirely to external factors. They usually described a combination of factors and circumstances that contributed to their addiction. In talking about the subject matter, they made a fine distinction between blame and responsibility. Especially women who had undergone drug treatment programs explicitly claimed (shared) “responsibility” for their drug use (and, by extension, their HIV infection). They stated that their drug use was in part their own doing and their choice. This constituted an act of agency and self-empowerment and was regarded as a constructive element of recovering from drug use. However, they objected to being blamed and also avoided self-blame. Blame involved an undifferentiated assignment of full responsibility and moral failure which elicited negative feelings of regret and guilt that were perceived as not helpful to the process of overcoming their addiction. Attributing their drug use to both external and internal factors allowed participants to shift the blame while portraying themselves as active agents in their own lives.

Participants also described being held responsible for their HIV infection, especially when they acquired HIV/AIDS in the context of using drugs. The differential attribution of blame - based on the distinction between those who supposedly "deserve" their HIV infection (i.e. substance users and sex workers) and the "innocent victims" (i.e. recipients of blood products and wives of infected men) - has been a characteristic of HIV related stigma since the start of the epidemic (Gorna, 1996; Treichler, 1999). This is usually explained by reference to existing negative societal views of women's drug use and prostitution. Attribution theory allows us to go one step further and connect the blaming to the perceived controllability of the behavior which results in personal attributions. Blame is attributed when the women are thought to be personally responsible for their HIV infection because substance use and sex work are considered voluntary behavior choices that indicate women's supposed lack of morals and strength of character. Women are not blamed for their HIV infection, however, when external forces clearly outside of their control, such as tainted blood products or unfaithful husbands, are held responsible for their HIV infection. This illustrates the central role that beliefs about the controllability of a condition play in the construction of stigma (Jones et al., 1984).

As described in the first chapter, most lesbian and bisexual women acquire their HIV infection through injection drug use (or drug related sex with men). This was also the case for most women in this study and participants explained that managing HIV related stigma was closely intertwined with managing the stigma attached to their drug use experience. Disclosing their HIV status commonly incited questions about the source of their HIV infection. The imperative to explain the source of their infection has been described for HIV positive women in general (Lawless et al. 1996; Moneyham et al., 1996), but it might be particularly strong in the case of lesbian women with HIV/AIDS. Lesbian women are commonly believed to be unaffected by HIV/AIDS due to the "myth of lesbian immunity to HIV" (Goldstein, 1997: 86; Hollibaugh, 1993; Vasquez, 1994). It is assumed that women cannot transmit HIV sexually to one another, that self-identified lesbians only have (had) sex with women (and not men) and that they never injected drugs. These assumptions stand in stark contrast to research evidence showing that HIV can be transmitted sexually between women (Kwakwa & Ghobrial, 2003), that a majority of self-identified lesbians have had sex with a man at some point in their lives (Diamant et al., 1999; Laumann et al., 1994; Skinner et al., 1996), and that some self-identified lesbians are indeed active drug users (Deren et al., 1996; Ehrhardt et al., 1995; Friedman et al., 2003; Young et al., 2000). However, based on the misperceptions mentioned above, lesbian women are thought to be safe from HIV infection. When lesbian women disclose an HIV diagnosis, this can incite questions how they can possibly be lesbian *and* HIV positive. As a consequence, disclosure of HIV induces disclosure of their drug use experience. Participants describe the stigma attached to drug use as particularly virulent and this is confirmed in findings from other studies of drug using women in the United States (Inciardi et al., 1993; Murphy & Rosenbaum, 1999; Rosenbaum, 1991). Having to disclose past or present drug use thus leads to being rejected, distrusted and devalued as (active or recovering) drug users. In the context of women's HIV infection, the intersection of the two stigmas results in higher levels of HIV related stigma, as women who acquire

HIV through drug use are more likely to be viewed as deserving of their HIV infection (Gorna, 1996). The intersection of women's same-sex sexuality, drug use and HIV/AIDS may thus create particularly high levels of blame and HIV related stigma for lesbian women with HIV/AIDS.

Given the common association of bisexuality with promiscuity and disease transmission (Herek, 2002b; Rust, 1995), bisexual women might not encounter the same imperative to explain their HIV infection (because their bisexuality is assumed to be the route of infection). Bisexual women do not necessarily encounter less blame, but they might not be as pressured (as self-identified lesbians) to explain their HIV infection and disclose their drug use experience. This possible difference in the experience of HIV related stigmatization of bisexual women requires further investigation. Most participants who identified as bisexual in this study happened to be very secretive about their bisexuality and they did not discuss the experience of disclosing their HIV infection to people who knew about their bisexuality.

Participants described that others also tried to identify causes of their same-sex sexuality. Interestingly, in most cases, these were family members who tended to apply external rather than internal attributions. This exception from the correspondence bias may derive from family members' hesitance to identify dispositional causes for women's same-sex sexuality, such as genetic factors, that might indirectly reflect badly on their own family background. A second possible reason may be found in people's beliefs about women's sexuality in general. Women were not considered to be fully in control of their sexuality. Other, external factors such as traumatic events, being cursed or having experienced maltreatment from a man were thought to exert more influence on women's sexual development. This may illustrate a view of women as passive "victims," so to speak, of their own sexuality. Alternatively, it may be interpreted as a strategic approach: given that external factors might be changed more easily than internal, dispositional factors, family members might have a particular investment in identifying external factors which could serve as an indication as to how women's same-sex sexuality could be changed or "healed."

1.2 The context of social marginalization

Women's multiple stigmatization does not occur in a social vacuum. Their stigmatization as HIV-positive, lesbian or bisexual drug users intersects with their social situatedness in terms of race, class and gender. The HIV positive lesbian and bisexual women who participated in this study had limited educational and financial resources and lived in communities adversely affected by racism, lack of employment, violence and drug use. In this respect, their socio-economic situation was characteristic of HIV positive women in the United States in general (Barkan et al., 1999; Campbell, 1999; Farmer et al., 1996; Ward, 1996) and HIV positive women with same-sex sexual experience in particular (Kennedy et al., 1998; Moore et al., 1996). This backdrop of social marginalization framed and shaped their experience of multiple stigmatization: it affected the significance they assigned to stigma related problems and it shaped the setting in which their stigmatization experience took place.

In accordance with other studies of HIV positive women (Hackl et al., 1997; Ingram & Hutchinson, 1999; Lawless et al., 1996; Moneyham et al., 1996), participants described HIV related stigma and fear of stigmatization as serious concerns. Most had encountered rejection and distancing due to exaggerated fears of transmission (including unfounded fears of ‘contagion’ in household contact) and they were made to feel like morally inferior “rejects of society” who had brought their infection on themselves by engaging in “some dirty thing” such as drug use, promiscuous sex with men or prostitution. Those with experience of drug use explained that the moral taint of drug addiction remained even after they stopped using drugs (as recovering addicts their trustworthiness was still in doubt). The stigma attached to their same-sex sexuality was also described as harmful, especially in the context of family networks, social support and service provision. However, given the multiplicity of problems they encountered as low-income women of color who raised children in marginalized inner-city environments while managing a complicated disease, other concerns (e.g. about housing, violence, their children, medication or illicit drugs) at times seemed more urgent than issues to do with stigmatization. A similar phenomenon has been noted for HIV positive women who describe a long list of challenges resulting from their socially marginalized position that often take priority over concerns to do with their HIV infection (Ciambrone, 2001; Mizuno et al., 2003; Smith et al., 2001; Ward, 1996). While multiple stigmatization did not constitute the only problem in the lives of the women who participated in this study, it was still described as a serious strain that exacerbated other problematic aspects of their lives.

1.3 Perceptions of HIV related stigma in ethnic minority communities

The majority of participants in this study were women of color who lived in predominantly ethnic minority communities and mainly encountered multiple stigmatization in this context. They also described being stigmatized in other environments, such as in health care settings, jails or HIV support networks which involved interactions with White people, but the stigmatization which was experienced as most upsetting usually took place within participants’ family networks and ethnic minority communities. Participants usually did not discuss these incidents with reference to race or ethnicity, as it was first and foremost the closeness of the bonds that made these encounters with stigmatization so hurtful. However, some participants made explicit references to racial/ethnic groups when discussing experienced and anticipated stigmatization. Critical remarks were made either about their own ethnic minority group or about another ethnic minority group. These remarks merit special attention as they seem to suggest – on first sight - that the stigmas attached to HIV and same-sex sexuality are particularly strong in ethnic minority communities.

A Latina in-depth participant who had an African-American female partner explained that she kept her HIV status secret from her lover's family, because she anticipated a very negative response. She regarded Black people as having strong prejudices against people with HIV/AIDS. This participant expressed subtle forms of anti-Black attitudes at different points in the interview, so one could interpret her comment as racial prejudice. This would illustrate once again that being a target of stigma does not preclude one from stigmatizing others (in fact, being stigmatized might actually foster the stigmatization of others as a defense mechanism). However, an African American participant also suggested that HIV is strongly stigmatized in her community when she stated that, "a lot of Black people are very ignorant about HIV."

Research on the topic has produced mixed results. It finds that people with HIV/AIDS are indeed strongly stigmatized in African-American communities (Fullilove & Fullilove, 1999). Yet, a national survey showed that stigmatizing attitudes towards people with HIV are common *across* racial and ethnic groups: HIV related stigma has decreased since the first decade of the epidemic, but it still persists with very few differences between racial or ethnic subgroups (Herek et al., 2002a). Differences between ethnic groups were detected only on specific sub-scales of HIV related stigma. Black participants reported higher levels of misinformation about the likelihood of HIV transmission during casual social contact than White participants (Herek & Capitanio, 1993). For example, more Black people thought it was possible to acquire HIV by drinking from the same glass or using public toilets. They were also more likely to say they would avoid people with HIV/AIDS under various circumstances (e.g. they would avoid a close friend or a neighborhood grocer if they knew this person was infected with HIV) and they were more in favor of coercive public policy measures (e.g. putting HIV-positive people in quarantine or publishing their names).

From this perspective, the women's comments about the severity of HIV related stigma in the Black community might refer to a particular element of HIV related stigma, namely fears of transmission. These were described as a driving force of HIV related stigmatization by all participants. Since misinformation about the risks of HIV transmission during casual social contact seem to be particularly prevalent in ethnic minority communities (Herek & Capitanio, 1993; Herek & Capitanio, 1999; Kaiser Family

Foundation, 2004) this might translate into greater fears of transmission and higher levels of fearful and distancing behavior toward women with HIV/AIDS.

Black participants in the current study reported strong fears of transmission during casual contact especially on the part of family members, friends and people whom they shared a household with, but so did some of the Latinas and the White participant. Stigmatizing responses due to (unfounded) fears of transmission were neither unique to Black participants, nor an inevitable response. Two Black participants reported strong fears of transmission and stigmatizing responses in their environments, but another HIV-positive African-American participant described that she received nothing but support and understanding from her predominantly African American circle of family and friends. The diversity of participants' experiences must thus be noted as well as the heterogeneity of Black communities. Furthermore, while documenting higher levels of misinformation about HIV transmission risks among Black participants, the survey of stigmatizing attitudes mentioned above actually found lower levels of negative emotions towards people with HIV/AIDS (Herek & Capitanio, 1993). Black respondents were less likely than White respondents to express negative feelings towards people with HIV/AIDS (i.e. fewer Blacks said they felt angry at people with HIV/AIDS, disgusted by them or afraid of them) and they were also less likely to assign blame (i.e. less Black people subscribed to the view that "people who got HIV through sex or drugs have gotten what they deserve"). When all variables were combined to compute an overall index of stigmatizing beliefs and attitudes towards people with HIV/AIDS, no significant differences were found between Black and White respondents.

So how can the comments suggesting that HIV stigma was particularly strong in the Black community be explained? For one, as explained above, it could serve as an indication that one aspect of HIV related stigma, namely fears of transmission, are particularly prevalent in the women's communities. Other possible explanations emerge when these comments are viewed in the context of the conversational interaction in the interview. In the case of the Latina participant, her comment could have served as an excuse for her desire to keep her HIV status hidden from her lover's family. She was generally very secretive about her HIV status and also mentioned other situations, for example with members of the Puerto Rican community, where she had denied her HIV infection for fear of stigmatization in the form of negative gossip. The comment from the Black woman about her own community, could be viewed in a similar light – she, too, was very secretive about her HIV status and might use the reference to Black people as a justification of her actions. Her fear, however, was based on previous negative experience: she had tried to disclose her HIV status to family members who had responded to this attempt in a highly prejudiced manner. Her comment, made in the very first interview, could also be interpreted as an attempt to explain her situation (as an African-American woman in her ethnic minority community) to a White interviewer, i.e. an outsider. This interpretation rightfully acknowledges the possible influence of the interview interaction and of participants' narrative aims on the construction of their accounts of stigmatization. However, it is noteworthy that this phenomenon did not only occur with regard to descriptions of HIV related stigma in African-American communities, Puerto Rican participants made similar remarks about the stigmatization of women's same-sex sexuality in Latino communities.

1.4 Sexual stigmatization in Latino communities

Not unlike the Black participant's comment about HIV related stigma in her ethnic community, some Latina participants made references to their communities and culture when discussing the stigma attached to women's same-sex sexuality. They mentioned the "machismo" phenomenon and suggested that shame, embarrassment and a sense of tainted family honor were common family responses to women's same-sex sexuality in Hispanic cultures. These themes accord with social science and cultural studies literature on the experience of same-sex loving Latinas in their ethnic minority communities in the United States (Chávez-Leyva, 1998; Greene, 1997; Hidalgo & Hidalgo Christensen, 1976/77; Torres & Pertusa, 2003).

One of the first studies on the topic revealed that the most prevalent attitudes towards lesbian women among members of the Puerto Rican community were rejection and punishment (Hidalgo & Hidalgo Christensen, 1976/77). Virtually all (98%) members of the Puerto Rican community included in this survey reported they would feel ashamed and uncomfortable if they knew their sister was gay and that they would want to change her sexuality through psychiatric treatment and family pressure. These attitudes are extremely non-accepting, but it should be noted that this was not unusual for the time. The General Social Survey from 1976 reveals that the overwhelming majority of Americans surveyed (more than 75%) thought homosexuality was wrong and only 15% were accepting of same-sex sexual relations (National Opinion Research Center, 1998). Unfortunately, the limited sample size of the General Social Survey does not allow claims to be made about the possible differences in anti-gay attitudes between Hispanic individuals and members of other racial/ethnic groups.[2]

The same study that detected strong anti-lesbian sentiments among Puerto Rican Americans also included interviews with Puerto Rican lesbians residing in continental

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[2] In 2002, when the percentage of those who thought homosexuality was always wrong had declined to 52%, the sample included only 122 Black and 23 Hispanic individuals among a total of 919 respondents (National Opinion Research Center, 2003).

Puerto Rican communities (Hidalgo & Hidalgo Christensen, 1976/77). These women described two main responses from their families: “silent tolerance,” i.e. their families knew of, or suspected, their lesbianism without openly acknowledging it, and “double messages,” i.e. women received praise for not being “boy crazy” and were criticized for not being married at the same time (e.g. they were teased, “tú vas a quedar jamona,” meaning, “you are going to be an old maid;” Hidalgo & Hidalgo Christensen, 1976/77: 115-116). Most lesbian women who were interviewed in the study kept their same-sex sexuality secret from members of their families and from the larger Puerto Rican community. Some described living a “double life,” they were married to men while having secret love relationships with women on the side, in order to avoid stigmatization and rejection from their family and community (Hidalgo & Hidalgo Christensen, 1976/77:116).

Qualitative studies observe that ethnic minority lesbians, both Black and Latina, often perceive their own communities as particularly stigmatizing and anti-lesbian (Espin, 1997; Greene, 1997; Mays et al., 1993). Several possible explanations exist. First, sexual norms and values might indeed vary across ethnic groups, leading to different levels of sexual stigmatization. As reviewed in the background chapter, some African-American authors suggest heterosexism might be particularly strong in African American communities due to the history of racism which has fostered a strong group interest in claiming sexual normality (Betsch-Cole & Sheftal, 2003). Latino communities might enforce conservative sexual norms and values as part of their specific cultural heritage and current situatedness as migrant ethnic minority communities in the United States (Espin, 1997; Greene, 1997).

However, independent of whether or not there are measurable differences in the stigmatizing attitudes and practices between ethnic groups, findings from this study suggest that, from the perspective of the targets of stigma, devaluation experienced “close to home” is more painful and carries more significance than stigmatization by people who are not part of one’s immediate network of family and friends. As one participant put it, “sometimes, the family can be the cruelest.” This implies that family members can be particularly mean or open in their disapproval, and/or that rejection and devaluation from family members is experienced as particularly devastating because it comes from someone the woman cares about and depends on. This was a prevalent theme across the three stigmas - stigmatizing responses from women’s immediate circle of family and friends (i.e. their Latino or Black community) were described as most significant (and most painful).

Furthermore, in order to understand the claim that one’s own community is particularly prejudiced, one also has to bear in mind that individuals generally know their own communities better than other communities. Participants of this study tended to interact more with people of the same racial/ethnic background than with people of other ethnic groups. They were thus more familiar with stigmatizing attitudes in their own communities and were better able to read the more subtle or ambiguous facets of stigma. These factors - the often very painful experiences of devaluation and rejection from family members and friends, the greater emotional vulnerability towards negative responses from family and friends and the greater familiarity with one’s own community - may in part explain why some women perceive HIV related and sexual stigma as particularly strong within their own communities of color.

1.5 Emotional vulnerability to being stigmatized

This study reveals that more attention must be paid to the role of emotions in creating a vulnerability to being stigmatized and to developing self-stigmatizing views. Goffman limited the conceptual frame of stigma to persons who shared dominant norms and endorsed (self-)stigmatizing views and he took an emotional vulnerability to being stigmatized on the part of persons with stigmatizing attributes for granted. Findings from this study challenge such monolithic assumptions. Participants’ experience suggest a more complex picture. Not all encounters with stigmatization resulted in lowered self-esteem and feelings of guilt and shame. Participants expressed a range of attitudes and feelings toward their stigmatized attributes, including very positive ones, and they often refused to accept people’s stigmatizing views of their HIV infection and their same-sex sexuality. Furthermore, some participants described adapting to their stigmatized status by ignoring and disregarding signs of stigmatization or by appraising them as not important. In their accounts, participants often challenged the legitimacy of the stigmas and they found ways of protecting their sense of self from the damaging effects of being stigmatized. However, they also described encounters with stigmatization that affected them and their sense of self very much. These were mainly incidents that occurred in interactions with people whom they cared for and/or depended upon (such as family members, partners or providers) and at times when they felt emotionally vulnerable. When participants who seemed generally untouched by people’s stigmatizing views of them described moments of self-doubt following encounters with devaluation and blame, this pointed to the central role of their situation-specific emotional state for the process and outcome of their experience of being stigmatized. This aspect that has not yet been adequately addressed in the literature.

Social psychology has advanced our understanding of the cognitive processes that influence the target’s experience of stigmatization, such as beliefs about the controllability of the stigmatizing condition, the target’s perception of situational cues, their group identification, and their motivations for claiming or minimizing discrimination (e.g. initiating social change vs. avoiding psychological and social costs) (Crocker et al., 1998; Major et al., 2002). However, the role of emotions in the processes of stigmatization has received very little attention. Social psychologists have studied “stigma sensitivity,” but this concept refers only to individuals’ beliefs and attitudes (i.e. their “stigma consciousness”), not their emotional state when experiencing or reporting stigmatization (Major et al., 2002). For example, scales assess whether individuals who are targets of stigmatization generally believe that their behavior is interpreted in terms of their group identity (Pinel, 1999), or how prevalent they think stigmatization is and how much they are bothered by it (Stangor et al., 2001). By asking very broad and general questions about perceptions and expectations, these scales fail to assess the individual’s emotional state during specific encounters with stigmatization or when claiming to have been stigmatized.

Fear is the only emotion that has received some attention from social psychologists, as perceived danger has been identified as one of the six dimensions along which stigmas differ (Jones et al., 1984; Crocker et al., 1998). But even with regard to this emotion, the majority of research and theory has focused on its role in the construction of stigma from the point of view of the stigmatizer, and much less attention has been paid to the influence of fear on the target’s experience of stigmatization. Findings from this study suggest, however, that fear is a crucial factor in women’s experience of HIV related stigmatization. Fears of illness, death and disease transmission contributed greatly to their view of themselves, their illness and what they represent to society. For most participants in this study, receiving an HIV diagnosis triggered immense fears of death and dying that were accompanied by self-stigmatizing views and fears of HIV related stigmatization. They described how, over the years, they realized that their HIV diagnosis did not constitute a death sentence, but that the illness could be managed with the help of medical treatment, and they learned to assess the risk of HIV transmission more accurately. Over the course of this process, they became less afraid and more accepting of their HIV status and this also affected how they dealt with the stigma attached to it. The women described becoming more open about their HIV infection, less afraid of negative responses and how they consciously surrounded themselves with people who expressed more accepting views of their HIV status. For these women, being less afraid of their illness was connected with fewer fears of HIV related stigma and more self-confident forms of stigma management.

It has been noted that the biophysical state of an HIV infected person affects their experience of the “stigma trajectory” (Alonzo & Reynolds, 1995). As reviewed in the background chapter, four phases of this stigma trajectory were identified: 1) pre-diagnosis “worried well,” 2) diagnosis, 3) latent, asymptomatic phase, and 4) the phase where AIDS becomes manifest in physical symptoms. Given recent treatment advances that have changed the course and character of the illness, I suggested adding a fifth phase of chronic infection, where an HIV infected person receives highly active anti-retroviral treatment (HAART), which might improve their health and well-being but which might also include visible side-effects of the medication. Findings from this study suggest that not only the course of the HIV infection and onset or treatment of physical symptoms affects the stigma trajectory, but also an HIV positive person's emotional well-being. It has been shown that infected individuals experience particularly high levels of emotional distress shortly after diagnosis, when HIV related symptoms first appear, in the later stages of the disease and when suffering multiple AIDS related losses (Siegel & Lekas, 2002). These might be times when HIV infected persons are particularly vulnerable to stigmatizing responses.

Participants' emotional state also constituted an important factor in their experience of stigmatization based on their same-sex sexuality. It was shown that one participant who generally expressed a very positive, accepting view of her same-sex sexuality, described becoming emotionally very vulnerable to stigmatizing accusations from family members after the suicide of her mother. She explained that she had never felt bad abour or ashamed of her same-sex sexuality, but then she started to believe her family's claims that she was to blame for her mother's death because of her drug use and her same-sex sexuality. Her account of this incident illustrates the long-term effects of being stigmatized by people in one's close network of family and friends at a time when one is emotionally vulnerable. Research shows that being the target of stigmatization can elicit strong emotions such as anger or frustration (Mays et al., 1993; Moneyham et al., 1996; Swim et al., 2001), but the role of emotions during the process of experiencing stigmatization is much less well understood. Findings from this study suggest that not only emotionally charged relationships (such as sexually intimate or family relationships), but also emotionally troubled times, such as those following the loss of a loved one, can increase the target's vulnerability to being harmed by stigmatization and can facilitate the endorsement of self-stigmatizing views. Future research must take this factor, i.e. the situational emotional state of the person that affects her or his perception and interpretation of events, into account in order to come to a comprehensive understanding of the target's experience of stigmatization.

1.6 The parenthood paradox: a socially redeemable identity and amplifier of stigma

This study showed that the topic of parenthood was highly charged with meaning. On the one hand, it was an area of great investment and significance for most women and it constituted an identity (or an aspect of their lives) that was highly valued, not only by themselves, but also by their families, their communities and society at large. In this sense, their identities as mothers or care-takers were often one of the few socially redeemable identities they possessed. In some cases, it even constituted a counter-balance to the stigmas, and women felt more accepted by family members because of their children and/or because they managed their care-taking responsibilities well (e.g. one participant noted her family in law accepted her and her wife's relationship and tolerated their drug use "as long as the children were taken care of").

On the other hand, their parenthood was also an avenue of criticism and attack. Women's drug use, same-sex sexuality and HIV were viewed as threats to children's welfare. Women's same-sex sexuality was perceived as a threat to the psychosexual development of the children, their HIV infection was considered a risk to children's health and life, and their drug use was thought to lead to neglect and abuse. As a consequence, women's status as care takers of children was challenged by friends, family and the authorities. In this sense, having children made women more vulnerable to stigma and amplified their stigmatization.

Two possible explanations exist for this observation. First, perceived danger is known to add to the construction of stigma (Jones et al., 1984; Crocker et al., 1998). The perceived threat to children adds fuel to the condemnation of women's drug use, same-sex sexuality and HIV status. Secondly, Erving Goffman noted the relational nature of stigma. He defined stigma as an undesired difference from what we had anticipated, i.e. as a negative deviation from a norm (1963). When normative expectations are particularly high, and expectations of "mothers" in this culture certainly are, greater stigmatization emerges when these expectations are not met. In other words, because "mothers" are put on a pedestal, and they can fall much deeper in social esteem.

Lesbian and bisexual mothers with HIV contradict several normative expectations. In many ways they combine not only stigmatized but also supposedly contradictory elements and they have to integrate identities that are perceived as mutually exclusive. For example, people usually do not think that lesbians can be HIV-positive or that HIV-positive women could be lesbians (Hollibaugh, 1993). Similarly, participants described an "oxymoron effect" with regard to lesbian mothers, i.e. "lesbianism" and "motherhood" were perceived as being two incompatible terms. This perceived oxymoron has also been noted in the literature. Cherríe Moraga (1997) points to a host of factors that contribute to this phenomenon, including the physiological fact that women cannot impregnate each other during sex, and socio-cultural beliefs that lesbians are not "real women" who give birth to children. As a butch-identified lesbian, Moraga admits to having held this self-limiting belief herself for many years.[3] Findings from the current study mirror this insight that societal beliefs and stereotypes are taken on board by the women themselves. Women were affected by and entangled in the norms of society and the dominant beliefs in their communities, even if they disagreed with them. As a consequence, they often expressed that their struggle to be a good mother or parent was accompanied by feelings of guilt and regret as well as by a desire to challenge normative expectations of mothers and the negative stereotypes associated with their same-sex sexuality, drug use and HIV infection.

Different forms of parenthood (i.e. with and without biological ties to the child) were described by participants in this study. These differences have consequences for women's self-concept as mothers or caretakers and they also influence how women are treated by others. Biological mothers are often recognized as parents. This recognition may help reconcile relationships previously strained by stigma, in part because the lesbian mother is now perceived as more similar to heterosexual persons and may herself feel she has more in common with heterosexual society (Lewin, 1994; Oswald, 2002). Birthmothers can easily pass as heterosexual while the parenthood of the non-biological co-mother entails special challenges. Co-mothers, for example, have to provide an explanation for their relationship to the child which creates an imperative to disclose their same-sex sexual relationship or to provide an alternative explanation (Oswald, 2002). Women in this study often called themselves godmothers of non-biological children, a term that legitimizes their relationship while avoiding the stigma that might be provoked by calling herself co-mother, step-mother or the mother's partner.

For the women who participated in this study, the greatest source of concrete legal challenges to their status as mothers or parents derived from factors to do with their drug use and the stigmatization and criminalization thereof. However, the stigmas attached to their HIV status and their same-sex sexuality also undermined their moral right to parenthood and their standing as mothers. Their accounts confirm other studies on the stigmatization of mothers who use drugs (Murphy & Rosenbaum, 1999), who have female sexual partners (Falk, 1993; Oswald, 2002) or who are HIV-positive (Ingram & Hutchinson, 1999). For women who have to manage all three stigmas at once, the status

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[3] In her book, “Waiting in the wings: Portrait of a queer motherhood,” Cherríe Moraga (1997) describes how her self-concept as a butch lesbian excluded the option of becoming a biological mother for many years. Upon deciding to get pregnant at the age of forty, she notes self-critically, “(…) buried deep inside me, regardless of empirical evidence to the contrary, I had maintained the rigid conviction that lesbians (that is, those of us on the more masculine side of the spectrum) weren’t really women. We were women-lovers, a kind of third sex, and most certainly not men. Having babies was something “real” women did – not butches, not girls who knew they were queer since grade school. We were the *defenders* of women and children, children we could never fully call our own.” (1997: 20; italics in the original)

of parenthood is continuously challenged. The experiences of women who participated in this study, however, show that while parenthood is a battlefield and amplifies stigmatization processes, it also acts as a source of strength for the women and as avenue to increased acceptance, thus undoing some of the negative effects of multiple stigmatization.

2 The negative impact of stigmatization

Findings from this study suggest that multiple stigmatization has adverse effects on the health and well-being of HIV-positive mothers who have female sexual partners. The adverse mental health consequences of stigmatization have been described in the literature (Garnets et al., 1993; Dovidio et al., 2000; Mays et al., 2001; Meyer, 2003; Smith & Ingram, 2004). Women who participated in the current study described feeling lonely and depressed and some mentioned self-destructive behavior, such as drug use and suicide attempts, in response to stigma related rejection and blame, especially from family members.

2.1 Strained relationships and difficulties finding support

In the experience of most study participants, being the target of multiple stigmas translated into repeated stigmatization experience. A special aspect of HIV related, sexual and drug-use stigma is that these stigmatization experiences often take place *within* one's network of family and friends. As a result, relationships with family and friends were often strained. Being stigmatized by members of one's family and community at times resulted in estrangement from the networks that fulfill important functions, such as providing support, a sense of belonging and protection from other forms of adversity (e.g. racism or low socioeconomic status) (Greene, 1997).

This study suggests that some lesbian and bisexual mothers with HIV face a difficult task finding acceptance and support. Many were rejected by their biological families. In the HIV community, they find support relating to their HIV infection, but their same-sex sexuality is by and large ignored and stigmatized. Lesbian communities on the other hand disapprove of their HIV infection, history of sex with men and/or drug use. Members of lesbian communities often view bisexual women with suspicion and hostility (Rust, 1995). Some participants of this study explained that their HIV status acted as a code word for “bisexual” in mainstream lesbian communities, even if they self-identified as lesbian. Race and class boundaries further contribute to the segregation and exclusion of HIV-positive lesbian and bisexual mothers from mainstream, predominantly White and middle-class lesbian communities. Social isolation and lack of support thus seem to be a crucial problem faced by many HIV-positive lesbian and bisexual parents. This has previously been noted by other lesbian-identified women with HIV/AIDS (People with AIDS Coalition of New York, 1996). A similar situation has been described for drug using women with female partners (Young et al., 2000). The problem of lack of support is likely to be worse outside of metropolitan areas where even fewer places exist that offer support to HIV-positive lesbian and bisexual mothers with drug use histories.

2.2 Scars on women's self-concept

Multiple stigmatization not only affects women's social networks, but also their self-concept. Participants did not generally convey a damaged sense of self or low self-esteem, but they tended to have a host of painful memories that marked their self-image. Experiences of stigmatization, especially from loved ones, such as members of one's family, took a toll on women's sense of self-worth, even in participants who approached stigmatizing encounters with self-confidence and “bravado” (Goffman, 1963: 17) and who avoided portraying themselves as victims.

Repeated in-depth interviews revealed the careful efforts with which painful experiences were managed. The women attempted to interpret their memories of devaluation and rejection in ways that did not undermine their current needs and aspirations, that did not interfere with their struggle for survival, and that did not impair their self-presentation in the interview. However, when probed, most participants expressed having had moments of self-doubt and self-stigmatizing thoughts. This speaks to the well-documented power of stigma to convince its targets of their own inferiority (Allport, 1954; Goffman, 1963).

At the same time, their accounts also illustrate that the effects of stigmatization on the self are not linear. Social psychological research finds that members of stigmatized groups do not necessarily suffer from low self-esteem and points to the power of stigmatized groups and individuals to resist their stigmatization (Camp et al., 2002; Crocker & Major, 1989; Crocker et al., 1998). For example, a qualitative study of women with severe mental illness showed that these women only partially accepted stigmatizing labels of their mental illness (Camp et al., 2002). They rejected unrealistic and negative stereotypes of people with mental illness and did not consider society's unfavorable representations of them valid. The present study produced very similar findings. Most participants conveyed a critical stance towards the stigmas attached to HIV/AIDS, same-sex sexuality and (to a lesser degree) women's drug use. They often expressed positive, or at least more differentiated attitudes towards their stigmatized attributes. At the same time they were undeniably marked by demeaning and hurtful responses, especially from individuals whom they (had) cared about deeply (e.g. family members) or whom they depended upon (e.g. service providers). Having been stigmatized left scars, sensitivities, anger and resentment. Those who managed to avoid face-to-face stigmatization by being extremely secretive did not necessarily suffer less. On the contrary, their struggle was often internal, and self-stigmatization and fears of stigmatization caused high levels of distress. Overall, participants expressed mixed emotions including fears of future rejection and remorse for past actions, as well as pride in their achievements despite the odds. The various stigmatized statuses amounted to a repeated and ongoing attack on women's social standing and sense of self, but individual and collective strategies of resistance offered a degree of protection and affirmation that alleviated some of the damage resulting from their multiply stigmatized status.

2.3 Deficits in HIV service provision

An important finding of this study relates to the intersection of the stigma attached to their same-sex sexuality with HIV related stigma in the area of service provision and HIV support networks. Stigmatizing attitudes and practices towards people with HIV/AIDS have been documented among medical providers (Fliszar & Clopton, 1995; Kegeles et al., 1989; Silverman, 1993). Participants in this study described that medical providers in New York City have become more accepting and less afraid of HIV transmission in recent years. Participants said they still encounter HIV related prejudice and fears in health care settings, but less so than 10 or 15 years ago, especially from HIV specialists. Most participants have “shopped around” until they found a medical provider who was not only knowledgeable about HIV infection and treatment options, but also respectful towards their patients. These HIV specialists provided a refuge from HIV related stigma, but they tended to provide sub-optimal care with regard to women’s same-sex sexuality. Participants described that they were assumed to be heterosexual or sexually active with men. Provider’s heteronormative assumptions not only caused emotional distress for participants, they also resulted in deficits in the provision of information, counseling and care. Even women who disclosed their same-sex sexuality to their providers were not counseled on the risks of female to female transmission of HIV and other sexually transmitted diseases (STDs). They had difficulties obtaining safer sex tools, such as dental dams, and their female partners were not generally included in their treatment and care. Discrimination was also encountered in family-based support services, such as family therapy, overnight housing or food programs. Here, lesbian couples and families were not eligible for the same services as their heterosexual counterparts.

Opportunities for support were also missed in peer networks in the HIV community. Sexual prejudice against women-loving women were described as prevalent, and especially the women who identified as bisexual and who did not utilize services at the lesbian specific program at GMHC chose to keep their bisexuality secret. Accounts of personal growth by some key informants, who succeeded in addressing their own homophobia and managed to overcome stigmatizing attitudes, is encouraging in this respect. However, the persistent stigmatization of women's same-sex sexuality within HIV support networks clearly contributes to the secrecy exhibited by some lesbian and bisexual women. This might create a hesitance to be associated with people or programs that are clearly related to the stigmatized label “lesbian” and thus in part explain why so many HIV positive lesbian and bisexual women do not utilize the few existing services for HIV-positive women who partner with women (Fitzsimmons, 2000).

With the exception of social support services such as the Lesbian AIDS Project in Manhattan, most HIV related services are not designed to meet the needs of HIV-positive lesbian and bisexual women. The lack of health providers' awareness for women's same-sex sexuality is particularly worrisome as opportunities to support these women and their partners are missed with potentially life-threatening consequences. Recently, a case of woman-to-woman transmission of HIV was reported which could have been prevented had health professionals provided their patients with information on HIV prevention during same-sex sexual contact (Kwakwa & Ghobrial, 2003). Both the woman who had newly acquired an HIV infection as well as her HIV-positive female partner had informed their medical providers of their sexual relationship and had followed their doctors’ advice, for example not to share a toothbrush. However, neither of them had been informed of the risks of sexual HIV transmission from woman to woman and they were not encouraged to use any barrier methods during sex. Several months into their relationship, the younger, previously HIV-negative lesbian tested positive for HIV with viral strains that matched those of her female partner. This case clearly illustrates the need to train medical health professionals to provide adequate information on the risks of sexual HIV transmission between women.[4]

The call for more research and provider training must be expanded beyond transmission risks of HIV to include a range of sexually transmitted diseases (STDs). Historically, the epidemiology of STDs among lesbian and bisexual women and the risks of female-to-female transmission of STDs have been neglected. However, a number of recent studies document considerable prevalence rates of sexually transmitted diseases (STDs) in self-identified lesbians and other women who have sex with women (WSW),

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[4] Such training of health care providers should include basic communication skills, e.g. how to ask HIV positive female patients about possible same-sex sexual experience in a respectful way. As findings from this study show, HIV positive women who have children and/or male partners may very well have sexual experience with women, even though some women will only reveal this information when they can be certain that they will not be stigmatized. An accepting, non-judgmental atmosphere must thus first be created. Providers also have to learn to take full sexual histories with women who self-identify as lesbian without offending these patients by implying that they necessarily have current or past sexual experience with men.

thus showing that the risks of STDs including HIV are clearly beyond "negligible" (Bauer et al., 2001; Fethers et al., 2000; Marrazzo, 2000; Marrazzo et al., 2001; Scheer et al., 2002; Skinner et al., 1996). A study of self-identified lesbians presenting at a genitourinary clinic in London finds that their rates of genital infections are as high as those of self-identified heterosexual women (an infection is diagnosed in 65% of lesbian women and 62% of women in the heterosexual control group) (Skinner et al., 1996). The most common diagnosis is bacterial vaginosis, a condition associated with pelvic inflammatory disease. Bacterial vaginosis is diagnosed in 33% of lesbian, but only 13% of heterosexual women, and the authors do not preclude the possibility of female-to-female sexual transmission. Smaller numbers of lesbians were also diagnosed with trichomoniasis or herpes, again including cases of possible female-to-female sexual transmission. Given the comparable rates of infections between lesbian and heterosexual women and the diversity of diagnosis, the authors recommend offering full STD screens to lesbian women (Skinner et al., 1996). Other studies of women reporting same-sex sexual contact come to similar conclusions (Bailey et al., 2004; Fethers et al., 2000; Marrazzo et al., 2001).[5] A large study in Sydney finds that women who had sex with women have higher rates of bacterial vaginosis, hepatitis B and C than matched heterosexual controls (Fethers et al., 2000). Less common is a history of genital warts, and equally prevalent are gonorrhoea, chlamydia, HIV and Papanicolaou smear evidence of squamous epithelial lesions (SIL). An American study shows that certain types of the human papillomavirus (HPV) are common among women who have sex with women; these types of HPV are associated with genital warts and cervical cancer and can be transmitted sexually between women (Marrazzo, 2000). For HIV positive women who are sexually active with women, information on transmission risks of sexually transmitted diseases (STDs) are important for two reasons. First, being able to correctly assess the risk of sexual transmission allows them to take precautions to prevent transmission to their female sexual partners, and second, it allows them to protect themselves. For HIV infected women who already have a

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[5] Comparisons of STD rates across studies are hampered by the fact that studies vary in their definitions of women's same-sex sexuality – some are based on women's sexual self-identifications (such as the London-based study where 90% of self-identified lesbians had a history of sex with men), others apply behavioral definitions (i.e. WSW) and vary in the time frame during which same-sex sexual behavior are assessed. One study shows that women who have had sex with both men and women (in the preceding two months) have higher rates of STDs compared to women who only have had sex with women (Marrazzo et al., 2001). However, women in the latter group were equally likely to have bacterial vaginosis and some were diagnosed with chlamydia, syphilis, trichomoniasis or vulvovaginal candidiasis. This study shows a worrying discrepancy between screening rates which illustrates the common misperception that lesbian women and other women who disclose having female sexual partners are not at risk for STD: women who reported exclusive same-sex contact were screened at significantly lower rates for a range of infections compared to women who have had sex with both men and women and women who only had sex with men (Marrazzo et al., 2001).

weakened immune system, acquiring a co-infection with an STD can present a serious health threat. Regular screening for STDs, information on the risks of female-to-female sexual transmission and counseling on how to prevent such disease transmission are thus important health service needs of women who have sex with women in general, and HIV positive women in particular.

The current study also suggests that same-sex couples and lesbian families are discriminated in other areas of social service and health care provision. For example family support services and partner benefits should be made available to non-heterosexual couples and families. HIV-positive women, their female partners and their children must be informed on how to prepare their families for possible illness and death, and they need assistance with establishing living wills, granting power of attorney and making arrangements for the long term care of their children (permanency plans). These important needs of same-sex couples and families are often neglected by providers working with HIV-positive women.

In the provision of services to gay men with HIV/AIDS, the issues of heteronormativity and sexual stigma have been addressed, but they are still prevalent obstacles in service provision to HIV-positive lesbian and bisexual women and their families. Sexual transmission between women does not involve the same high risks as sex between men, and the group of lesbian and bisexual women with HIV is not as large in numbers as the group of HIV-positive men who have sex with men. However, as detailed in the first chapter, same-sex sexual experience is common among HIV-positive women. Large cohort studies show that approximately one in five women (19%) have had sex with a woman at some point in their life and one in ten (11-12%) consider themselves bisexual or lesbian (Barkan et al., 1998; Zierler et al., 1999). These women’s needs with regard to sexual disease transmission, social support and integration of their partners into treatment and care must be acknowledged. Their social support needs tie into a broader development that calls for an expansion of the notion of family. The heterosexual nuclear family model no longer reflects the structure of a significant number of North American families (Mays et al., 1998; Mellins et al., 1996). Social and health care services - in general as well as with regard to HIV specifically - have to be based on new, more diverse conceptualizations of family that include same-sex partners and a variety of chosen family members or “selective kin” (Mellins et al., 1996).

Findings from the current study suggest that it is necessary to train medical and social service providers, educate HIV positive peers and change institutional arrangements to overcome the sexual stigmatization of this group. Lesbian and bisexual women with HIV/AIDS need more and better information on the risks of HIV transmission to female sexual partners. Safer sex tools for use during sex with another woman must be made widely available. Female partners should have the same the option to be involved in HIV positive women's treatment and care as male partners and institutional arrangements must be based on a revised family concept that is more inclusive of diverse family constellations.

3 Managing multiple stigmatization

As noted in the first chapter, it is necessary to conceptualize HIV positive lesbian and bisexual women as more than "victims" of stigmatization and to view them as active agents within conditions not of their own choosing. A special focus is thus placed on women's strategies of managing their multiple stigmatization.

3.1 Stigma management strategies

Participants' strategies of stigma management were grouped into three main categories. The first category involved the strategies with which the women attempted to avoid becoming the target of stigmatization. These included secrecy, distancing, trying to limit stigmatized behavior and self-isolation. Secrecy and selective distancing were described as often helpful and appropriate strategies, for example when dealing with individuals who were known to be prejudiced. However, participants also mentioned that secrecy involved high psychological costs, especially when it was not entirely voluntary, i.e. when they would have preferred to be more open but decided against it out of fear. Secrecy also hindered support. Given that women had to manage multiple stigmas, their options were further limited by having to guard more than one secret. At times they avoided disclosing one stigmatized attribute in order to be able to keep another hidden. As described earlier, disclosure of one's HIV infection could create an imperative to explain the route of infection which would involve revealing other secrets such as unsafe sexual behavior or drug use. As a result, participants often chose to reveal as little as possible. This in turn restricted their opportunities of finding support when dealing with their HIV infection, same-sex relationships or drug use.

Secrecy and fear of stigmatization constituted an obstacle to accessing health care and social services. A butch-identified participant, for example, went without HIV related treatment or support for many years. She kept her HIV status a well-kept secret, even from closest family members. The relationship to her family was already strained by the stigma attached to her same-sex sexuality which she openly acknowledged. This participant was determined to hide her drug use, because she was afraid of further rejection by her family. It would have been difficult for her to disclose her HIV status without disclosing her drug use or sex work experience. Being so secretive reduced the likelihood of encountering face-to-face stigmatization, but this protection came at a price.

It took a toll on her mental and physical health and she expressed feeling relieved, since having started her recovery from substance use, that she was now able to deal with her drug use experience and HIV infection more openly. The costs of secrecy for those who feel they *have* to maintain a secret has been documented in other studies (Cortina & Mogley, 2003; Smart & Wegner, 2000). Stigma related secrecy was shown to cause psychological strain, including, in its most extreme form, intrusive thoughts and obsessive worrying (Smart & Wegner, 2000). Furthermore, a large study on victimization experiences in the workplace showed that silence and self-silencing in the face of persistent injustice can hamper not only the victims' psychological, but also their physical well-being (Cortina & Mogley, 2003).

The second category entailed strategies that "buffered" the negative impact of stigmatization. Some of these strategies were described as involving less personal harm compared to the strategies in the first category. This was especially true for seeking support and “adapting” by selectively ignoring stigmatization, prioritizing supportive relationships and focussing on the present and future instead of the past (e.g., "letting things fall of my back," focusing on the positive and "moving on"). One strategy in this category, however, also seemed costly, namely elevating one’s self-esteem by stigmatizing other women with HIV/AIDS and same-sex sexual and drug use experience. This strategy was highly divisive in nature. It required the downgrading of other women with the same stigmatized attributes and undermined the solidarity that other participants described as a helpful element of their support structure and group identity.

The distinction of “us” versus “them” constitutes a crucial element of stigmatization processes (Devine et al., 1999; Gilmore & Somerville, 1994; Link & Phelan, 2001). The current study suggests that it is not only applied by stigmatizers to the targets of stigma, but it can also be applied by targets against others as a tool for self-elevation and defense against one’s own stigmatization. This concords with findings from other studies. For example Michele Crossley documents divisions among people living with HIV/AIDS (1997). She finds that some long-term survivors distance themselves from other people with HIV/AIDS whom they conceive as “unhealthy others.” She notes that their specific definitions of “healthy” and “unhealthy” vary profoundly depending on how they explain their health and prolonged survival (some are convinced that *not* taking antiretroviral medication and continuing life as usual constitutes the reason for their health while others stress their close collaboration with medical doctors). Viewing themselves as healthy and others as unhealthy protects the individual from the sense of vulnerability imposed by the disease. However, Crossley notes that this defense mechanism comes at a cost. The scapegoating results in social distancing from people who could otherwise serve as sources of support and the construction of the “healthy self” can backfire at the onset of physical symptoms. Having to come to terms with an illness that is not entirely under their control, the construction of "healthy self" and "unhealthy other" can collapse into self-blame.

The third category entailed strategies with which participants challenged their stigmatization and attempted to contravene it. Women educated themselves and others, for example, to reduce the fears of transmission involved in HIV stigma and to dismantle negative stereotypes. They spoke up about the injustice of their devaluation and confronted prejudice in face-to-face interactions in diplomatic, bold and humorous ways. Participants described that disclosing their same-sex sexuality, HIV infection and former drug use exposed them to rejection, gossip and vicious attacks, but some participants had come to the conclusion that the benefits of personal integrity, self-respect and political involvement outweighed the risks involved. Participants wholeheartedly appreciated the support structures available to HIV-positive lesbian and bisexual mothers in New York City. Communal spaces, such as support groups, transformed their ways of dealing with the stigmas. One participant mentioned costs in the form of risking indirect disclosure by accessing these services, but by and large, participants were very positive about the benefits gained from these structures. These spaces were not free from stigmatization, but the process of coming together with other women helped them re-evaluate their situation, understand stigmatization and gave them an opportunity to find affirmation and support. Some participants not only accessed support structures, they took an active role in creating them. Building communities facilitated the process of finding positive meaning and fostered individual and collective efforts that challenged the legitimacy of the multiple stigmas.

Participants' strategies of managing their multiple stigmatization closely resemble those strategies identified by Karolynn Siegel and colleagues in their study of ethnic minority bisexual and gay men with HIV/AIDS (1998). The authors described a continuum from "reactive" to "proactive" strategies based on the extent to which the strategies implicitly accepted or challenged the social norms and values that underlie the stigmatization of HIV/AIDS. In my analysis, however, I did not apply the classification of Siegel and colleagues, for a number of reasons. First of all, I believe that those strategies classified as "reactive" are mislabeled. These strategies, described as "defensive attempts to avoid or mitigate the impact of stigma;" (Siegel et al., 1998: 3) are "defensive" with regard to the values and beliefs that aid the construction of stigma, but nevertheless they are very proactive ways of dealing with possible stigmatization. Secrecy is used to *prevent* stigmatization and it can involve high levels of active effort. Second, the continuum runs the risk of implying a hierarchy. "Reactive" strategies might come across as more passive while the term "proactive" carries connotations of positive action that aims to achieve praiseworthy, long-term goals. Such a hierarchy does not do justice to women's reality. Secrecy and partial concealment for example are often very effective ways of avoiding additional conflict in every-day life situations. Furthermore, women with care-taking responsibilities tend to also consider the possible repercussions of stigma and "courtesy stigma" (Goffman, 1963) for their children, partners and families. It thus seems more appropriate to classify stigma management strategies according to the function they entail from the perspective of the women themselves.

3.2 Collective strategies of resistance and social creativity

Most women used strategies from all three categories. Some described a trend that they had become less secretive about their HIV infection, drug use history and same-sex sexuality over time. At the same time, they had become more selective about the members of their support networks. They noted that this process of change had been greatly helped by the support they received from drug treatment programs and women's HIV support groups.

These programs and groups not only provide individual women with emotional, instrumental and social support, they are also part of a larger community structure that exerts influence on policy makers and educates the public in an attempt to change the norms and values that lead to the construction of stigma in the first place. Such collective strategies of resistance and advocacy have proven immensely effective in initiating social change. In the United States, AIDS activists successfully advocated for the right to health care for all people with HIV/AIDS. As a result, an HIV-positive status opens up access to health and social services for lesbian and bisexual women with HIV that are not available to other low-income, sexual and ethnic minority mothers without HIV/AIDS. In this sense, women's HIV status and drug use experience balances out previous class related disadvantages, at least in the state of New York where programs such as the AIDS Drug Assistance Program and a host of community-based organizations provide health care and social support for people living with HIV and AIDS and those with drug use experience. Because of the achievements of these collective strategies of resistance, women's various stigmatized statuses do not simply "add up" to ever increasing social marginalization.

However, the study also showed that the inclusion of lesbian and bisexual women with HIV/AIDS in existing HIV support service and advocacy structures has not always been a smooth enterprise. As discussed above, the stigma attached to women's same-sex sexuality prevails in the HIV community, paradoxically, even though male homosexuality is widely accepted. A number of factors hamper the inclusion of HIV-positive, lesbian and bisexual women as recipients of care and as advocates/activists.

Racism, sexism, the stigmas attached to women's same-sex sexuality and drug use and competition over scarce resources constitute obstacles to their inclusion (Ward, 2004).[6] Furthermore, women's socially marginalized status has meant limited access to education which puts them at a distinct disadvantage compared to more privileged White gay male advocates (Treichler, 1998). Multiple life demands as parents and caretakers further restrict their ability to dedicate themselves to full-time advocacy work.

Nevertheless, HIV positive lesbian and bisexual women have managed to create supportive community structures in New York City and some participants of this study worked as advocates and peer counselors. Furthermore, they described subtle, but profound ways of resisting their stigmatization within the communities they created. The individual and collective strategy of managing their multiple stigmatization by finding positive meaning in their stigmatized attributes merits closer attention.

The tension between the dominant norms in society and the resistance of the targets of stigma has been noted in the literature. In his theory on intergroup relations, Henri Tajfel (1981) explains that members of minority groups tend to incorporate negative evaluations of their group into their self image due to the power of the majority to define the norms and the values on which social comparisons and, in extension, the definition of minority group membership are based. However, Tajfel also notes that some minority groups withdraw from the larger society and its system of norms, values, prescriptions and achievements, and create their own values and basis of comparisons. Minority groups whose members mainly interact with each other in such separate, affirmative environments might be able to "protect the self-respect of their members from the cold winds of disapproval blowing from the outside." (1981: 327) In a display of "social creativity" (1981: 338), minority groups re-evaluate the existing group characteristics which carry an unfavorable connotation and create new group characteristics that are endowed with positive values. Tajfel cites the African American civil rights and Black Nationalist movements as examples (e.g. the slogan "Black is beautiful"). Traces of such "social creativity" also emerged in the current study with regard to women's HIV status and same-sex sexuality.

Women resisted their devaluation by finding positive meaning in these stigmatized attributes, at times in surprising and unusual ways. Some participants for example used the term "aggressor" as a sexual self-identification and stated that this term (which was

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[6] Jane Ward (2004) describes Latina lesbian women's struggle with sexism in an HIV organization in Los Angelos. She eloquently shows how multiple stigmatization creates limited options for these women. Latina lesbians who are working at community-based HIV service providers are caught in a trap – homophobia, ethnic and class-based prejudices keep them from seeking employment or support elsewhere, but they are not accepted in the Latino gay HIV organization, either, because of

coined in the prison system) does not carry the usual negative meanings associated with “aggressive.” In mainstream American and their ethnic minority communities, lesbian women were often negatively stereotyped as aggressive and abusive, but the label “aggressor” - when used voluntarily by the women to describe themselves - conveys a different, more positive meaning. Participants associated various meanings with it, including being sexually dominant, being butch, paying attention to style and appearance and having strong moral convictions. As a self-identification, this term is the product of a collective strategy of resistance that involves a radical reframing of the meaning of the same word. Similar phenomena have taken place when members of lesbian, gay, bisexual and transgender communities gave the term "queer" a new meaning and, more recently, when Latina lesbians started to re-appropriate Spanish terms such as “tortillera” that were commonly used in a derogatory fashion (Torres & Pertusa, 2003).

The skill and creativity of resisting one’s devaluation by finding positive meaning in the very attributes that carry a social stigma have also been documented for women’s same-sex sexuality (Faderman, 1991; Lewin, 1996) and with regard to HIV/AIDS (Barroso, 1997; Barroso & Powell-Cope, 2000; Siegel & Schrimshaw, 2000; Williamson, 2003). With alternative interpretations at hand, stigmatized groups and individuals can find positive meaning in their difference. As a consequence, they are able to distance themselves from the negative images of themselves and can protect their sense of self-worth to some degree.

3.3 Minimizing personal victimization

Participants generally acknowledged that HIV/AIDS, women’s same-sex sexuality and drug use carried a social stigma, but their reports of having personally experienced face-to-face stigmatization varied. Study participants generally reported at least one incident of HIV related stigmatization and the majority had also encountered stigmatization based on their same-sex sexuality. All participants with experience of drug use had been devalued as active drug users or recovering addicts. Some women, however, reported no or very little personal experience with one or more of the stigmas. These reports can be interpreted in three ways: a) as reflections of the heterogeneity of women’s stigmatization in social life; and/or b) as the result of coping mechanisms that affect women’s perceptions and interpretations of their experience; and/or c) as a matter of (self-) presentation in the interview context.

The phenomenon that people perceive their group but not themselves as targets of stigma or discrimination has been noted in the literature for a range of disadvantaged

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the sexism within this niche and the perceived lack of HIV related needs of their lesbian and groups (Crosby, 1984; Kobrynowicz & Branscombe, 1997; Mays et al, 1993; Taylor et al., 1990). Most authors, when describing this personal/group discrimination discrepancy, presume that members of stigmatized groups do not view themselves as victims of stigmatization when in fact they are. They are thought to downplay their personal discrimination because of the psychological and social costs entailed in perceiving and presenting oneself as a victim of stigmatization or discrimination (Crocker et al., 1998; Kaiser & Miller, 2001; Kobrynowicz & Branscombe, 1997; Major et al., 2003; Taylor et al., 1990). Other researchers point out that some members of stigmatized groups indeed escape stigmatizing or discriminatory face-to-face encounters. Mays and colleagues (1993) note that most of their African American lesbian study participants managed to escape face-to-face encounters with sexual prejudice through secrecy and other efforts of avoiding people and situations, thus reducing their risk of becoming a target of stigmatization.

In the context of the current study, a number of participants managed to prevent or reduce the level of stigmatization in social interactions through secrecy and other preventive strategies. Furthermore, their accounts illustrate that stigma is not a fixed, omnipresent feature of social life – it varies between settings, situations and over time. Participants explained that they used to experience more stigmatization one or two decades ago when prejudiced views of their HIV infection and same-sex sexuality were more pervasive and when they had not yet created an accepting support network around them. They also described that settings differed in their social norms and the degree to which these were enforced, which affected the level and kind of stigmatization encountered in the setting. As mentioned earlier, HIV medical care specialists were reported to be very accepting of women's HIV infection, but not of their same-sex sexuality. Jails and prisons, on the other hand, were described as environments where women's same-sex sexuality was less stigmatized, but HIV related stigmatization was rampant. Depending on the setting and situation, women thus encountered varying degrees of stigmatization. The visibility of their stigmatized behavior or attributes also influenced the frequency with which they encountered face-to-face stigmatization. Women who looked butch, for example, were more likely to encounter sexual stigmatization, especially in interactions with strangers, peers, providers and acquaintances, than women whose appearance or comportment could not be interpreted as a sign of same-sex sexuality. Factors such as these affected the degree to which women encountered face-to-face stigmatization. From this point of view, reports of no or low levels of personal stigmatization can be an accurate description of the lower end of the spectrum of

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bisexual Latina clients.

experience of stigmatization. A group as heterogeneous as this is likely to encounter varying levels of face-to-face stigmatization in the social world.

A second, possible perspective on women's reports of no or low levels of personal stigmatization relates to the way in which women's coping efforts may affect their perception and interpretation of stigmatization experience. Some participants in this study, especially those who had suffered from repeated and severe stigmatization based on their same-sex sexuality, drug use experience and HIV infection, described having learned to adapt and to "let things fall off their backs." They sometimes purposefully ignored signs of disapproval, especially when displayed by people who were not part of their immediate network of family and friends. They assigned very little significance to such incidents and explained that given the multitude of adversity in their lives, *not* developing such self-protective measures would be costly as they would be "messed up all the time thinking about it."

It has been suggested that avoidance, denial and minimization are effective coping mechanisms for stressors that lie outside of a person's realm of control (Aldwin & Brustrom, 1997). Stigma constitutes such a stressor. HIV-positive, lesbian and bisexual women might be able to reduce the amount of stigma related hostility they encounter by carefully choosing supportive care providers and friends, but they are unable to fully control and completely avoid all stigma related stressors in their lives. Ignoring that stigmatization happened to them, denying the pain it might have caused and refusing to assign much significance to encounters with stigmatizing beliefs or behavior thus constitute important aspects of coping with stigma. The limited significance assigned to some of their experience with stigmatization might thus not only be due to the multiplicity of problems in the context of their social marginalization, it might also be in part a product of their efforts to minimize the effects of stigma in their lives.

A third possible explanation exists, besides differences in the degree to which women encounter face-to-face stigmatization in their social worlds and coping efforts that affect the process of appraising stigmatizing events. The third perspective draws attention to the influence of the interview interaction and situational context factors on women's narrative accounts. At least in two cases, participants denied experience of face-to-face stigmatization in specific settings when they previously had described stigmatizing incidents. One participant mentioned subtle signs of prejudice from nurses (i.e. "attitude" which she called the "stigma look") but claimed shortly after that she was not "treated badly" in the health care setting. In between these somewhat conflicting statements she had presented herself as a self-confident, empowered person who confronts prejudice and tries to educate people by making them "stop and think." Her subsequent denial of mistreatment from doctors and nurses can thus be interpreted as a refusal to assume a victim role. Another participant first described a lack of respect from her female partner's daughter and indicated that the child's lack of respect was in part due to the stigma attached to women's same-sex sexuality. In a subsequent interview, however, she denied that the child had any problems accepting their lesbian relationship and stressed only the positive aspects of her relationships to the child and her female partner. The main difference between the two interviews lay in situational context factors. On the day of the first interview, the participant had just had an argument with her female partner over how to raise the child together. By the time of the second interview, they had made up and resolved the conflict. In the second interview, the participant thus stressed the positive, functioning aspects of their family unit, almost as if to undo the criticism she had expressed in the first interview. Both examples highlight the interpretative nature of "experience" and the influence of situational context and women's narrative aims on the construction of narrative accounts. In these cases, participants minimized their experience of victimization to convey a positive image of themselves and their relationship to others. However, the communicative nature of interview-based data is an important aspect that affects the construction of accounts of experiences of stigmatization more generally. The implications of this insight for stigma research in general are discussed below.

4 Methodological considerations

4.1 Implications of working with narrative accounts of stigmatization

This study found that most participants had been hurt by stigmatization based on their HIV status, same-sex sexuality and - if they used drugs - the stigma attached to drug use. How much of this hurt they are willing to share in an interview, however, is a different question. The many factors that influence participants' presentation of their experiences of stigmatization in narrative interviews merit closer attention.

Lucius-Hoene & Depperman (2004) list a number of factors that shape the creation of narrative accounts in general. First of all, the communicative nature of interview data must be acknowledged. Data on stigmatization is collected in conversation and the rules that govern this conversation affect the accounts that are being constructed. These include, for example, narrative conventions such as the expectation of creating a coherent and consistent account. Secondly, the institutional frame of the conversation, in this case the interview format, gives the conversation a specific purpose and determines the specific roles of the conversation partners. Third, the data collected in this conversation is largely based on retrospective accounts. This raises questions about remembering as well as how participants choose to talk about their memories today (Lucius-Hoene & Deppermann, 2004: 29). It has been pointed out that remembering is a selective, constructive and active process of accessing information about an event; information that are already selectively coded, partially forgotten and transformed in various ways (Lucius-Hoene & Deppermann, 2004: 30; Welzer, 2002). Memories are not static, they are formed by the current situation in which they are recollected. The methods used in an interview can have a tremendous influence on what is being remembered. For example, a study of the victimization experiences of lesbian, gay and bisexual adults in California found that many participants reported no victimization experience during a first, short screening interview, but recollected some type of victimization experience during a second, more in-depth interview (Herek et al., 2002b). The authors explain the discrepancy between first and second interviews with the proliferation of memory cues provided in the second interview.

When working with autobiographical data, four levels are distinguished: 1) *events* that took place in the past; 2) participant's *responses* to these events at the time; 3) how participants *remember* these events and their initial responses *today*; and 4) how they *choose to talk* about it today (Lucius-Hoene & Depperman, 2004: 29). In retrospective interview data, the fourth level affects the remaining three in significant ways. Past events and responses are always recounted from one's current point of view and participants' memories are only accessible through their verbal reconstructions and presentations thereof in the interview. Findings from the current study imply that a fifth important level might be added to the list, namely the history of talking about an event or experience. Many of the women reconstructed their life stories using certain phrases and narrative elements that they had used before. In other words, a history of storytelling had been formed and the interview conversation further contributed to this history. For example, some women had participated in drug treatment programs and used the interview as another opportunity to tell their story as they previously told it in an *Narcotics Anonymous* or *Alcoholics Anonymous* meeting. Similarly, most women participated in HIV support groups and individual psychotherapy where they talked about some of the same issues. Between the time that an event took place and the time of the interview when it is being recollected, a communicative process has taken place that has shaped the memory and interpretation of the event. For example, one participant recalled group discussions with other HIV positive women that made her aware of HIV related stigma and helped her put her own experience into words and understand it in new ways. As described in the first chapter, at the core of interpreting an event as discrimination lies an evaluative process that assesses whether a negative event was a) related to one's group identity or stigmatized attribute and b) whether it was unjust (Major et al., 2002). Such an assessment implies a knowledge of the norms that have been violated and of the additional stereotypes and prejudices that are inferred. Goffman notes that stigmatizers "tend to impute a wide range of imperfections on the basis of the original one" (1963: 5). Talking to other women with HIV/AIDS helped participants gain such knowledge and it also provided an opportunity to articulate their criticism of the injustice inherent in the stigmatization they experienced. This history of talking about stigmatization thus shaped the presentation of stigmatizing events in the interview and the interview itself also becomes part of this history. Participants often mentioned having thought about the topics of conversation between the interviews and some even stated during the interview that the conversation made them see past events in a different light. The interviews thus added to the history of reconstructing, remembering and interpreting past events.

Talking about stigmatization documents past events, creates a personal history and serves to establish the narrator's status and self-image in the current context. As such, it is affected by the narrator's self-presentational aims and motivations. Participants' efforts to present a successful, undamaged self was at times responsible for minimizing their experience (or, more precisely, for minimizing the presentation of their experience) of stigmatization in the interview. Similarly, when they wished to present the stigmatizers (e.g. members of their family) or the relationships they had to these persons in a positive light, this caused them to downplay the extent or significance of the stigma related problems they might have encountered in these relationships. At other times, the same participants freely shared their victimization experience. This was the case when participants wanted to document specific problems (in order to criticize with the intention of changing them), or when they were seeking confirmation and support. Participants also noted that it was helpful to talk to a sympathetic listener who was a professional outsider, as this provided them with an opportunity to analyze their own situation under quasi-anonymous conditions and gain momentary relief from having to keep a secret. However, fears of being stigmatized in the interview, lack of trust, and a desire to avoid emotional distress connected with reliving a painful experience were among the factors that seemed to discourage the sharing of stigmatization experience. Depending on which interests and factors were most salient at each moment in time, this shaped women's presentation of their experience.

Narrative accounts are influenced by the institutional characteristics of the situation in which they take place, by narrative conventions and the communicative goals of the narrator, and also by the audience who is the co-author of the narrative (Lucius-Hoene & Depperman, 2004:33). Harald Welzer points out that one should not conclude that certain topics have subjective meaning to the participant simply because they were discussed in an interview (2002: 206-7). Participants will often go to great length to fulfill the (perceived and stated) expectations of the interviewer. It is thus indispensable to identify the influence of the interviewer and the research context on the interview interaction and the construction of narrative data it entailed.

Given the research aims of the current study, interviewer questions tended to focus on women's multiple stigmatization, and not on situations when their stigmatized attributes were of no importance. However, the influence of the interviewer as co-author was far from straightforward. Participants often disagreed and provided different information from what was expected. They painted a complex picture of their stigmatization experience and clearly distinguished situations when one or more of their stigmatized attributes caused stigmatization from situations when these attributes were of no importance and/or did not lead to stigmatization. For example, one participant pointed out that not using drugs and working in a regular job counterbalanced her stigmatized status as a lesbian in the relationship to her girlfriend's mother when the interviewer expected to hear that sexual stigmatization negatively affected the relationship.

The interaction between participants and interviewer shaped the narrative beyond the interviewer's exerted influence in the form of questions, gestures and responses. Participants' perceptions and expectations of the interviewer influenced their accounts. This was most obvious when participants made reference to existing differences between us. For example when explaining the stigmatization of women's same-sex sexuality in their communities, some Puerto Rican participants referred to "our culture." When, as discussed earlier, an African-American participant emphasized HIV related ignorance among *Black* people, this might have been an effort of communicating to me, a White interviewer, that Black people are prejudiced, too. Differences between interviewer and participants (e.g. with regard to HIV status, class background and cultural/ethnic background) and similarities (e.g. regarding my same-sex sexuality and migration experience) were at times significant. Perceived similarities seemed to aid the development of trust. For example, whenever I had not disclosed my same-sex sexuality or self-identification, participants usually inquired at some point during the interview (e.g., one woman asked point blank, "Are you a lesbian, too?"). When the anticipated similarity was confirmed, this seemed to increase comfort levels for subsequent discussions of issues related to participants' same-sex sexuality and the stigma attached to it. Perceived differences, however, for example those along the lines of race/ethnicity, did not always constitute an obstacle to communication. On the contrary, it could be argued that the need to explain their life to a complete stranger or outsider fostered detailed descriptions that participants might not have provided had they assumed the interviewer was more familiar with the subject matter or their environment. The meaning and effects of the differences and similarities (in the social positioning and experience) between interviewer and participant thus varied and had to be determined for each specific interview interaction.

The findings from this study illustrate that stigmatization was not only a topic of conversation, but also a concern of the women when they were being interviewed. Talking about stigmatization involved managing their stigmatized status and the concern (or lack of concern) about possible stigmatization during the interview influenced the interview interaction and the collaborative construction of women's stigmatization accounts. However, just as participants dealt with (experienced and anticipated) stigmatization outside of the interview context in diverse ways, so was there no one particular way in which this concern shaped the women's accounts. Some participants were defensive or cautious while others seemed comfortable or unconcerned about sharing potentially discrediting information. Overall, it is important to acknowledge the various factors that affect women's accounts of their experience of stigmatization. These include the institutional and situational context, the methods used, the narrative aims of participants (e.g. their interest to elicit sympathy, to avoid stigmatization and/or to present a strong, invulnerable self), participants' emotional state, their rapport with the interviewer and their assessment of the psychological and social costs and benefits of claiming to have been stigmatized. How these factors influence the interview interaction and participants' recollection and interpretation of their experience of stigmatization must be determined for each specific interaction. Doing so not only promises a better understanding of the influence of the interviewer and contextual factors on the data, but also of the subject matter, in this case stigmatization processes, itself. As Devereux (1967) pointed out more than 30 years ago, when treated as data, and not as a bias or regrettable disturbance in the research process, these "influences" become highly valuable avenues to insight.

4.2 Study limitations

This study used an exploratory, inductive approach to investigate a new research topic. As a qualitative study, its strength lies in the sensitivity and flexibility of the research tools which allowed to explore a highly complex subject matter (in this case the subjective experience of multiple stigmatization) in some depth. At the same time, limitations exist. The small scale and recruitment procedures of this study have created specific limitations that need to be acknowledged. First, the experience of African American mothers with HIV who self-identify as lesbian is not reflected in this study. All African American participants self-identified as bisexual or described themselves as "confused" about their sexuality and were very secretive about their same-sex sexual experience. All findings must be confirmed in future studies, but the findings on sexual stigma in ethnic minority communities in particular will have to be confirmed in future studies with HIV positive African-American women who are equally "out" about their same-sex sexuality as the Latina women who participated in this study. Furthermore, participants were part of HIV services networks and they had been living with HIV for many years, so the positive effects of having had access to an HIV support system left a mark on their narratives. In this sense, they constitute the better supported and more successful end of the spectrum of women suffering from this constellation of multiple stigmas. Participants often mentioned other women who also lived with HIV/AIDS and who had female partners and children but who have not made it as far, i.e. who had died or were still wound up in a drug-using life style. Lastly, active drug users were excluded from the in-depth interview phase. All in-depth participants were either in recovery from drug use or had never been dependent on illicit drugs. They were thus either never targeted by drug use stigma (only via their HIV infection) or had managed to reduce their stigmatized status from drug user to recovering addict by the time of the interview. HIV positive lesbian and bisexual mothers who are active drug users might experience the combination of stigmas differently.

5 Conclusions

In conclusion, this study contributes to the existing knowledge base in three ways. First, it sheds light on the specific situation of this particular group of HIV positive women who have female sexual partners and are also parents. It shows that many of these women experience multiple stigmatization as a problem even though they have learned to manage and resist their stigmatization with considerable success. Findings from this study suggest that the stigmas attached to same-sex sexuality, drug use and HIV/AIDS amount to a multi-layered attack on the social standing and sense of self of participants. The multiple stigmas result in particularly high levels of blame, rejection and isolation and cause deficits in HIV service provision.

Secondly, this study makes a contribution to stigma research and theory more generally. It shows that the multiple stigmas can have additive effects, as when women were rejected more harshly by their families for being not only lesbian, but also drug users and HIV-positive, or when participants felt even more compelled to be secretive because they had more than one secret to keep. On the other hand, the diversity of women's experience of stigmatization demands caution regarding generalizing claims about the effects of multiple stigmatization. Furthermore, their use of individual and collective strategies of resistance helped attenuate many of the negative effects described above. How participants were affected by stigmatizing responses from others depended on many factors. This study suggests that participants' emotional state constitutes one such factor that has been neglected in stigma research and theory to date. The role of the target's emotional vulnerability to processes of stigmatization and self-stigmatization merits greater attention.

Thirdly, this study contributes to the methodological debate in that it clearly shows that stigmatization experiences must be understood as a product of interpretation. It cannot be assumed that individuals who are targets of stigmatization will remember and interpret their experiences in the same way. Target’s self-reports of their experience of stigmatization are always influenced by the interview context, the methods used, the questions asked, the interaction with the interviewer, the situational context and the specific narrative aims or self-presentational goals. With regard to stigmatization research, researchers must bear in mind that stigmatization is not only a topic of conversation but a force that structures the conversation itself. Stigmatization is a way of relating. By making the stigmatized aspects of participants’ selves salient through the choice of the interview topic and the questions asked, the risk of stigmatization during the interview context becomes acute. This dilemma cannot be solved or avoided, it can only be taken into account and used as a resource to learn more about stigmatization processes within and outside of the research setting. Self-reflexivity on the part of the researcher/scientist is an indispensable element of the research process. It was practiced in the current study and enriched the analytic process, but methods that place an even stronger, systematic focus of analysis on the interaction between interviewer and participant, such as those put forth by Jenkins and Welzer (2003), offer great promise, in particular for future research on processes of stigmatization.

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Appendix

Pilot study on stigma and sexuality in HIV-positive mothers with same-sex experience

Consent form

Interviews with key informants

Purpose of study
You are being asked to participate in a research study on HIV-positive lesbian and bisexual mothers in New York City. The purpose of this study is to collect information from key informants about prejudices, discrimination and sexuality as experienced by HIV-positive mothers who have sex with women.

Study procedures
You are being interviewed as a key informant. Key informants are people who are familiar with a number of HIV-positive mothers with same-sex experience, either through work, volunteer or activism experience. The interview will last 1 ½-2 hours. If you are an HIV-positive, lesbian or bisexual mother yourself, the focus will be on women with these characteristics as a group, not on your individual experiences. At the end of this interview you will be asked to comment on preliminary findings. If you agree, you will be contacted in 2-3 months from now. The collection of your feedback can take between 5 - 60 min. A decision not to review material will not have any negative effects. Independent of your decision you will be offered a summary of final study findings.

Audiotaping
Audiotaping of this interview is required for purposes of data analysis. Tapes will be transcribed. Tapes and transcripts will be kept for 5 years in the office of the Principal Investigator (PI) and only the PI will have access to them. You may stop or interrupt the recording at any time. You may also ask to erase the tape at any time during or after the interview. However erasing a tape before it is transcribed will make an interview incomplete and no part of the interview will be used in the analysis.

Compensation
As a compensation for your participation in this study you will receive $20.00 in cash after completion of this interview. There will be no compensation if the interview is incomplete.

Alternative to study participation
As an alternative to participating in this study you may choose not to be interviewed. This would not have any negative consequences for you or your organization.

Benefits
This study is not designed for your personal benefit. However, a desired outcome of this study is to help improve service provision to HIV-positive mothers with same-sex experience.

Risks
Participation in this study involves a minimal risk regarding the protection of your personal identity. A well informed audience might be able to identify you based on unique knowledge and skills which you have as a key informant. Precautions to minimize this risk include measures to keep personal information confidential.

Research Standards and Rights of Participants
Participation in this study is voluntary. You can refuse to participate or discontinue this interview without effecting your employment situation or your standing in the community.

Confidentiality

Confidentiality will be protected by the following measures: Written and audiotaped research records will be kept in locked files in the office of the principal investigator. Data in computers will be password-protected and only the investigator will have access to these files. Names will substituted by aliases and erased from transcripts and reports. Written, audiotaped and computerized research records will be identified by numbers only. Findings will be presented in aggregate form wherever possible in order to protect the identity of key informants.

There are legal advocacy organizations that have the authority under state law to access otherwise confidential subject records, but they cannot re-disclose this information without your consent. Personnel from State or Institutional Review Committees may review the research records as part of routine checks. All records will be kept confidential to the extent permitted by law.

All my questions regarding this study and my participation have been answered by the principal investigator. If I have questions in the future I can contact Hella von Unger who can be reached at (212) 543 5207.

The New York State Psychiatric Institute – Columbia University Department of Psychiatry Institutional Review Board has approved the recruitment of subjects for this study. If I have any questions about my rights as a research subject or any complaints, I might call the IRB at (212) 543 5758 during office hours.

I received a copy of this consent form and I agree to participate.

____
Date

______________________________ ______________________________
Participant Name (please print) Participant Signature

______________ ________________ ______________________________
Interviewer Name (please print) Interviewer Signature

Guideline for interviews with key informants

Date __ / __ / __

ID # ______

1 Demographics of key informant

Gender female ☐ male ☐ other ____________________

Age ____________ Ethnicity ____________________

Education ____________ Sexual orientation ________________

Currently employed? Yes ☐ No ☐ Position ____________________

Organization ____

2 Participant’s expertise

How have you been in contact with HIV-positive women who have sex with women and who are also parents?

- since when/for how long
- how, where, under what circumstances
- with which organization
- in what role/ with what responsibilities
- with what motivation

Tell me about your experiences of working with the women!

- What are your roles and responsibilities?
- What was the most challenging situation while working with the women and what the most rewarding?
- If you have stopped working with them, how come?

Has your perspective changed while working with them? If so, how?

3 Describing the population

Please describe the HIV-positive women that you have been in contact with, in terms of

- Ages
- Ethnicity
- Education
- Employment status
- Relationship status
- Drug use
- Prison experience
- Health status (physical and mental)
- Custody arrangements
- Living arrangements
- Insurance status/ access to health care
- Service providers

How would you describe the main differences and commonalities between the women?

(Imagine all of these women in one room and they had to build groups of people who are in a similar situation. What kinds of subgroups do you think they would build? Do they find common ground along the lines of ethnicity or drug use vs. no drug use experience or maybe having children vs. not having their child(ren) live with them?)

What are some of the greatest achievements/ accomplishments of these women?

What would you describe as the greatest problems they are facing?

What could be done to help and support them? Do existing services work? How could their needs be met better?

4 Social Context

What are the main social factors that impact on the lives of these women?
- Structural forces such as racial discrimination and social marginalization
- Specific laws or regulations here in NYC (for example regarding housing, custody, drug laws, etc)

5 Ethnicity

What role does ethnic or cultural background play in terms of
- Living with HIV
- Sexuality/ being openly bi/lesbian
- Expectations of women/ mothers
- Family relations and support

How many of the women are first generation immigrants? Are there any special issues related to being undocumented or especially dependent on family/ husbands / jobs?

6 Stigma / Prejudices / Discrimination

How would you describe the main prejudices these women are facing? Please have a look at the model (STIGMA CIRCLES; see p.7) and describe
- the worst or more subtle incidences that you have experienced or witnessed for each label;
- Are there additional stigmatized labels that could be added to the vacant circle (for example incarceration)?
- What happens in the intersections, i.e. when labels/stigmatized statuses overlap and interact?
- Who are the actors/agents of stigmatization (family, friends, partners, media)?

How do the women deal with the prejudices?

Do you generally get the impression that the women receive support? If so, how and from who?

Do you think discrimination experiences vary greatly depending on women’s ethnicity or drug use behaviors?

Are there differences in how the women themselves use the labels to identify and describe themselves?

7 Sexuality

How would you describe the sexual diversity of these women (in terms of sexual behaviors and identities)?

How many HIV-positive women you know are in a relationship with a woman? What kinds of relationships?

Do you think there are differences in sexuality, relationship status or “being out” along the lines of ethnicity?

Tell me about the women’s experiences of sex with men. How many of the women that you know probably have (had) sex with men and under what circumstances? Have you ever discussed it with them?

What would you say is the impact of stigmatization on sexuality and vice versa?

Are sexual abuse or domestic violence experiences the women talk about?

Would you say most of the women have a hard or an easy time talking about sex?

8 Drug use

How are drug use and sexuality related?

What kinds of drugs are being used?

How much does the drug habit dominate their lives?

9 Prison/ Incarceration

How many of the women have been in jail or prison? On what charges (mainly drug related?)

What are the effects and consequences?

10 Living with HIV/AIDS & health care

How would you say women are coping with HIV? Is it a major concern or just one more item on the list?

Are there any problems regarding accessing health care for these women? If so how and how could that be helped?

Do you think most health care providers are aware that these women have sex with women?

11 Motherhood

Please describe the forms of parenthood, i.e. the number and ages of children, the pathways to parenthood and the current living, custody and parenting arrangements.

How much do their children know about their mothers sexuality, HIV status or drug use? Other disclosure/ secrecy issues (jail, etc)

How many of their children are also HIV positive?

How would you describe the most important concerns and service needs of these women related to being a parent? What could be done to help them?

What distinguishes the service needs of HIV-positive WSW with children from those of heterosexual mothers with HIV/AIDS?

What might be service needs of their children or their partners, are these needs being addressed?

Would you say that motherhood makes women more or less vulnerable to prejudices? Do you think that some women are more cautious and secretive in order to protect their children from discrimination? Do fears of loosing custody rights exist and if so with what effects?

How would you describe the impact of motherhood on the sexuality of these women?

Do you think custody arrangements have any impact on sexuality, relationship status or “being out”?

12 Future work

What issue or questions would you like to see covered in a future study with the population?

How many HIV-positive mothers with same sex experience do you know? Would you help me get in touch with them?

Do you know of any other places that provide services to women who meet these criteria? How would you advise me to approach the women and conduct recruitment?

Would you be interested to be involved in the data analysis, i.e. would you like to review material and give feedback?

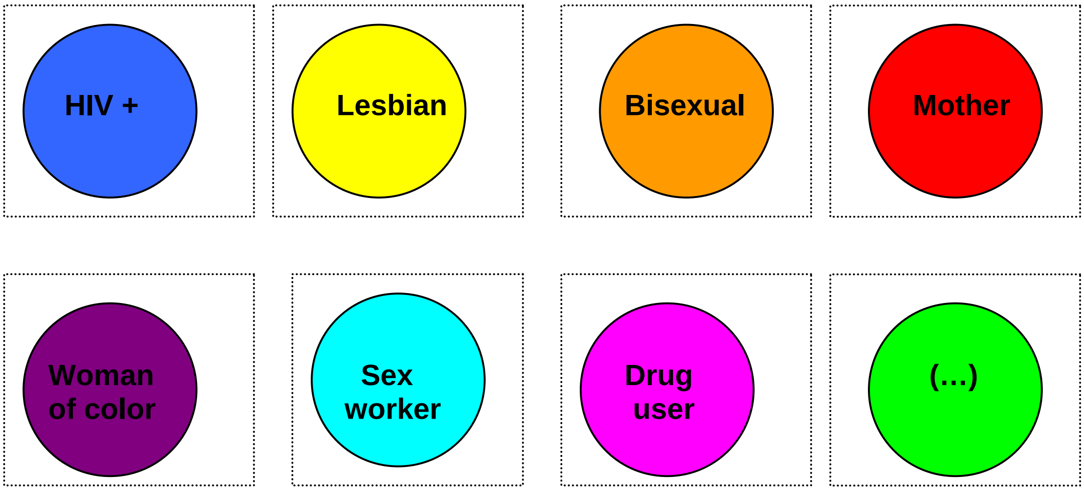
Is there anything you would like to ask or add?

Stigma Circles

Data collection tool used in key informant interviews

Description:

To facilitate the discussion of multiple stigmatization processes in the pilot study, a model consisting of several pieces of transparencies was created. Each square, slightly smaller than a post card, contained a circle in a different color. Each circle contained a label representing a stigmatized status such as “HIV-positive”, “lesbian”, “bisexual”, “mother”, “woman of color”, “sex worker”, or “drug user.” Additional circles were left blank.



Procedure:

Squares were distributed on a white sheet of paper and handed to the participant who was asked to describe meanings and prejudices or expectations associated with each label. Participants were then asked to recount incidences of stereotyping and discrimination that they experienced or witnessed in relation to the labels. Participants were probed for additional labels, i.e. additional characteristics that play a significant role in women’s experience of multiple stigmatization, and these were written into vacant circles (e.g. “butch” or “criminal records”). As a last step participants were asked to comment on the co-occurence of stigmatized statuses. Since circles were printed on transparencies, new colors emerged where labels overlapped. Participants were asked to discuss these intersections, i.e. how labels and prejudices interact in the lives of women who are for example lesbian *and* HIV-positive *and* mothers. Overall, participants could pick and choose which label or label combinations they wanted to discuss. They were thus able to focus on those that seemed most salient to them.

HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute

Project Title: Multiple stigmatization of HIV-positive mothers who have female partners

Principal Investigator: Hella von Unger, M.S.

Consent form

Screening Interview

Purpose of study
You are being asked to participate in a research study of HIV-positive mothers who have female partners. The purpose of this study is to collect information on experiences with discrimination and prejudices and how these affect self-esteem, social support and service provision.

Study procedures
You are being asked to participate in this study because you are a woman who has been living with an HIV diagnosis for longer than 6 months. You have had sex with at least one woman in your lifetime and you are also a parent. In this screening interview, you will be asked questions relating to your health, sexuality, children and custody arrangements, drug use, incarceration and discrimination experiences. This interview will last 30 minutes. At the end of this interview you will be asked whether you would like to participate in further interviews if you qualify based on the information provided in this screening interview. Those two additional interviews would last 1½ hours each and would be more in-depth about your life and how you cope with challenging situations. A decision not to participate in those further in-depth interviews will not have any negative consequences for the benefits you are otherwise entitled to or social and health care services provided to you.

Benefits
This study is not designed for your personal benefit. However, a desired outcome of this study is to help improve service provision to HIV-positive women including mothers who have female partners.

Risks
Participation in this study involves a risk relative to the protection of your privacy. Precautions to minimize this risk include measures to keep personal information confidential (see confidentiality section below). If you experience emotional distress as a result of this interview, you can ask for a break or to discontinue the interview and community based organizations that provide counseling or support services will be suggested to you.

Research Standards and Rights of Participants
Participation in this study is voluntary. You can refuse to participate or discontinue this interview at any time and this will not have any negative effects on benefits you are otherwise entitled to or services provided to you.

Confidentiality
Your privacy will be protected by the following measures: Your name will not appear on the questionnaire or any other research record. Written and computerized research records will be identified by code numbers only. Research records will be kept in locked files in the office of the principal investigator. Data in computers will be password-

protected. Records will only be available to research staff and Institutional regulatory personnel (who may review records as part of routine audits). Findings will be presented in summarized, aggregate form wherever possible in order to further protect your privacy. This research is covered by a Certificate of Confidentiality issued by the Department of Health and Human Services (DHHS). With this Certificate, the researchers cannot be forced to release any research data in which you are identified, even under a court order or subpoena, without your written consent. The principal investigator has obtained the Certificate to protect your privacy and to resist any demands for information that would identify you, except as explained below.

The Certificate of Confidentiality does not prevent the researchers from reporting suspected or known sexual or physical abuse of a child, or threatened violence to self or others. Such information must be reported to the appropriate authorities.

Compensation
As a compensation for your participation in this screening interview you will receive $10 in cash after completion of this interview. There will be no compensation if the interview is incomplete.

The researcher doing this study will answer any questions you may have. If you have questions in the future you can contact Hella von Unger at (212) 543 5207.

You will be given a copy of this consent form to keep.

The New York State Psychiatric Institute – Columbia University Department of Psychiatry Institutional Review Board (IRB) has approved the recruitment of subjects for this study. If you have any questions about your rights as a research subject or any complaints, you might call the IRB at (212) 543 5758 during office hours.

I voluntarily agree to participate in this research study described above. I may choose not to participate, or to discontinue my participation at any time, without penalty or loss of benefits to which I am otherwise entitled.

___ ___ / ___ ___ / ___ ___
Date

______________________________	______________________________
Name of Participant *(Print)*	Participant Signature

I have discussed the proposed research with this participant, and, in my opinion, this participant understands the benefits, risks and alternatives (including non-participation) and is capable of freely consenting to participate in this research.

___ ___ / ___ ___ / ___ ___
Date

______________________________	______________________________
Name of Interviewer *(Print)*	Interviewer Signature

Screening Questionnaire

ID [__ __ __] {id}

Date of Interview [__ __ / __ __ / __ __] {intdate}

Site of interview ____ **[__ __]** {site}

1. How old are you? **[__ __]** {age}

2. Were you born in the US? [1] Yes *(skip to 3)* [0] No **[___]** {usborn}

2a) If "No", where were you born? ____________________________

2b) How long have you been living in the US? ____________________________

3. Is English your mother tongue? [1] Yes *(skip to 4)* [0] No **[___]** {english}

3a. What other languages do you speak?

______________________________________ **[___]** {language}

4. When accessing social or health care services how often does language pose a problem?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {langprob}

5. What is the highest year of school that you completed?

[1] Elementary school (8th Grade)
[2] High school (12th Grade)
[3] GED certificate
[4] Some college or technical school
[5] Completed college/ technical school
[6] Other _________________________________ **[___]** {education}

6. Are you currently employed? [1] Yes [0] No *(skip to 7)* **[___]** {employed}

6a. What do you do? ____

____

7. In the past 12 months, what has been your main source of income?

[1] Welfare, DAS, SSI, other benefits
[2] Job salary, Employment
[3] Other *(specify)* ____ **[___]** {monsourc}

8. In the past 12 months, have you had sufficient money to pay for necessities?

[1] Yes [0] No **[___]** {monsufi}

9. In the past 12 months, how high was your average monthly household income?

[1] less than $1,000 [2] 1,000- 2,000 [3] more than 2,000 **[___]** {moninco}

10. Who lives in your household? *(specify number for each category in brackets, if N/A code "0")*

12a. Child(ren) **[___]** {livechil} 12d. Friend/Roommate **[___]** {livefrie}

12b. Female Partner **[___]** {livefp} 12e. Other *(specify)* ________________ **[___]** {liveoth1}

12c. Male Partner **[___]** {livemp} 12f. Other *(specify)* ________________ **[___]** {liveoth2}

11. How would you describe your current living situation?

[1] Apartment (rent/own) [2] Supervised Residence

[3] Scatter Site [4] Single Room Occupancy (SRO)

[5] Shelter [6] Other ____________________________ **[___]** {living}

12. In what borough of New York do you live?

[1] Manhattan [2] Bronx [3] Brooklyn

[4] Queens [5] Staten Island **[___]** {borough}

13. Do you have any children? [1] Yes [0] No **[___]** {children}

Specify number. of children and form of parenthood (biological, adoptive, etc)

____

____

If no biological children and no other form of parenthood, discontinue the interview

14. How old are your children? *Code age of children in years* **1. [__ __]**{child1} **2. [__ __]**{child2}

______________________________ **3. [__ __]**{child3} **4. [__ __]**{child4}

______________________________ **5. [__ __]**{child5} **6. [__ __]**{child6}

15. Who was/is involved in raising your children? ____________________________

____

16. Have you ever lost or transferred custody rights for your children?

[1] Yes [0] No **[___]** {custody}

Specify ____

____

17. How often do you see your children?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {seechild}

18. How would you describe your ethnic background?

[1]	African American	[2]	Afro-Caribbean
[3]	African	[4]	Latina/Hispanic
[5]	White	[6]	Asian/Pacific Islander

[7] Other (*specify*)________________________________ **[___]** {ethnicit}

19. How often do you experience rejection or discrimination because of your ethnic background?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {ethndisc}

20. When did you first test positive for HIV? __________ *code years since diagnosis* **[__ __]** {HIVyears}

If first HIV diagnosis in previous 6 months, discontinue the interview

21. Do you have an AIDS diagnosis? [1] Yes [0] No [2] Don't know **[___]** {aidsdx}

22. What is your most recent CD4 cell count? ______________________ **[__ __ __ __]** {cd4cells}

(specify date of test) ______________________

23. What is your most recent viral load? __________________ **[__ __ __ __ __ __]** {viraload}

(specify date of test) __________________

24. Are you currently taking anti-retroviral medications? [1] Yes *(skip to 29)* [0] No **[___]** {ARVcurr}

(specify type of medication) ____

____

25. Did you ever take anti-retroviral medication (in the past)**?** [1] Yes [0] No **[___]** {ARVpast}

26. Have you ever had visible HIV-related symptoms or side effects of medication (such as wasting, lipodystrophy or Kaposi Sarcoma)**?** [1] Yes [0] No **[___] {SXvisi}**

Specify ____

27. How often do you experience HIV-related rejection or discrimination?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {HIVdiscr}

28. Do you consider yourself to be …

[1] Lesbian [3] Straight/ heterosexual

[2] Bisexual [4] Other *(specify)* ______________________ **[___]** {identity1}

29. Have you ever had sex with a woman? [1] Yes [0] No **[___]** {wsw}

30. Throughout your life, have you had sex …

[1] … with women only
[2] … predominantly with women
[3] … with both women and men at equal shares
[4] … predominantly with men
[5] … with men only **[___]** {sexscale}

If no same-sex sexual experience, discontinue the interview

31. When was the last time you had sex with a woman? ________________ **[___]** {WSWlast}

32. Are you currently involved in a relationship with a woman?

[1] Yes *(skip to 38)* [0] No [2] Other ____________________ **[___]** {relawom}

33. When did you last have a significant relationship with a woman? ________________

34. For how long have you been together? ________________________________

35. Do you have any lesbian, bisexual or gay friends? [1] Yes [0] No **[___] {lefriends}**

36. How often do you go to lesbian bars or clubs?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {leclubs}

37. Would you use any of the following labels to describe yourself?

[1] Femme [3] Aggressor [0] No, wouldn't use these labels
[2] Butch [4] Other ________________________________ **[___]** {identity2}

38. Do you think some people can tell that you are attracted to women just by looking at you?

[1] Yes [0] No [2] Other ________________________ **[___]** {lezlooks}

39. Has anyone ever mistaken your gender and thought you were male? [1] Yes [0] No

43a. If yes, how often does this happen to you?

[0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {gendercx}

40. Do your health care providers know about your sexual experience with women?

Primary Care Physician [1] Yes [0] No [2] Maybe **[___]** {outMD}

Nurse [1] Yes [0] No [2] Maybe **[___]** {outnurse}
Gynecologist [1] Yes [0] No [2] Maybe **[___]** {outgyn}

Other (specify) ____________________ [1] Yes [0] No [2] Maybe **[___]** {outoth}

41. How often do you experience rejection or discrimination related to your homo/bisexuality?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {sexdiscr}

42. To what degree do you currently feel sexually attracted to women as compared to men?

(Show card #2) Rate on a scale from 0 (not attracted at all) to 100 (exclusively attracted to women or men):

Women	100	90	80	70	60	50	40	30	20	10	0
Men	0	10	20	30	40	50	60	70	80	90	100

[Thanks to Neil McConaghy's Sex-Linked Behaviors Questionnaire for inspiration; Davis et al 1998:402] **[** __ __ __ **]** {attrawom} **[** __ __ __ **]** {attramen}

43. When was the last time you had sex with a man? ________________ **[** ___ **]** {datewsm}

44. Are you currently involved in a relationship with a man?

[1] Yes [0] No [2] Other ____________________________ **[** ___ **]** {relamen}

45. What is your marital status? [1] Never married [2] Married [3] Divorced

[4] Separated [5] Widowed **[** ___ **]** {marital}

46. Did a man ever force you or threatened you with physical force to have sex with him?

[1] Yes [0] No **[** ___ **]** {fsexman}

47. Did a woman ever force you or threatened you with physical force to have sex with her?

[1] Yes [0] No **[** ___ **]** {fsexwom}

48. Have you ever exchanged sex for drugs or money? [1] Yes [0] No *(skip to 50)* **[** ___ **]** **{sexwork}**

49. How often do you experience rejection or discrimination because of you sex work experience?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[** ___ **]** {sexwdisc}

50. Have you ever used any of the following substances on a regular basis...

Crack	[1] Yes	[0] No	**[** ___ **]**{crack}
Cocaine	[1] Yes	[0] No	**[** ___ **]**{cocaine}
Heroin	[1] Yes	[0] No	**[** ___ **]**{heroin}
Alcohol	[1] Yes	[0] No	**[** ___ **]**{alcohol}
Other __________________	[1] Yes	[0] No	**[** ___ **]**{othdrug}

51. When was the last time you used any of the substances mentioned above?

____ **[** ___ **]**{dactive}

52. How often do you experience rejection or discrimination related to your drug use experience?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {drugdisc}

53. Have you ever attended a drug treatment program? [1] Yes [0] No **[___]** {drugtp}

54. Have you ever received mental health counseling or therapy? [1] Yes [0] No **[___]** {counsel}

55. Have you ever participated in a support group? [1] Yes [0] No **[___]** {group}

Specify ____

56. Were you ever convicted of a crime? [1] Yes [0] No *(skip to 62)* **[___]** {excon}

57. Did you ever serve time in jail or prison? [1] Yes [0] No **[___]** {jail}

58. How often do you experience rejection or discrimination related to your criminal records or incarceration experience?

(show card#1) [0] Never [1] Rarely [2] Sometimes [3] Often [4] Very often **[___]** {incdiscr}

59. Who can count on most when you have a problem and you need help?

____

____

Thank you. We are at the end of our interview.

Some women who complete this interview can participate in two more interviews. They will be selected based on their answers to these questions. Those two additional interviews will last about 1½ hours each and will be more about your life history and how you've dealt with challenging situations. Everything said in those interviews will be treated strictly confidential. If you would qualify, would you be interested to participate in two more interviews?

[1] Yes [0] No [2] Maybe **[___] {interest}**

Notes

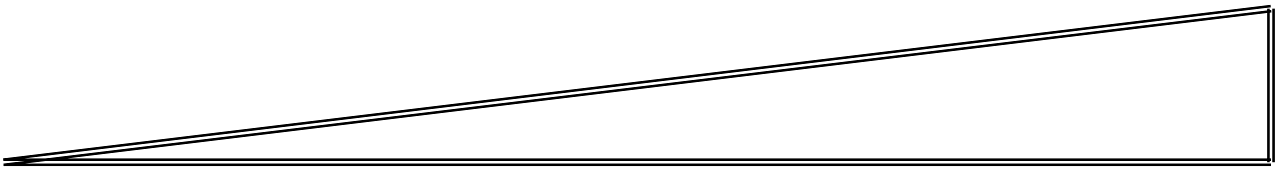
____

____

____

____

CARD #1



[0]	**[1]**	**[2]**	**[3]**	**[4]**
Never	**Rarely**	**Sometimes**	**Often**	**Very**
often				

CARD #2

How much are you currently attracted to women as compared to men?

Women	**100**	**90**	**80**	**70**	**60**	**50**	**40**	**30**	**20**	**10**	**0**
Men	**0**	**10**	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**

0 = not attracted at all

100 = exclusively attracted to women or men

HIV Center for Clinical and Behavioral Studies, New York State Psychiatric Institute

Project Title: Multiple stigmatization of HIV-positive mothers who have female partners

Principal Investigator: Hella von Unger, M.S.

Consent form

In-depth Interviews

Purpose of study

You are being asked to participate in a research study of HIV-positive mothers who have female partners. The purpose of this study is to collect information on experiences with discrimination and prejudices and how these affect self-esteem, social support and service provision.

Study procedures

You are being interviewed because you are a woman who has been living with an HIV diagnosis for longer than 6 months. You have had sex with at least one woman in your lifetime and you are also a parent. You will be interviewed twice. Each interview will last 1½ hours. You will be asked questions relating to your life history including your sexual relationships, HIV infection, children and parenting issues, and, if applicable, about your drug use and incarceration experience. A focus will be on how you have coped with challenging situations throughout your life. The style of both interviews will be conversational and you will not be forced to talk about topics you are uncomfortable with. A decision not to participate in these in-depth interviews will not have any negative consequences for the benefits you are otherwise entitled to or social and health care services provided to you.

Audiotaping

Audiotaping of both interviews is required for purposes of data analysis. Tapes will be transcribed. Tapes and transcripts will be kept for 10 years in the office of the Principal Investigator (PI) before they will be destroyed. Only researchers will have access to the tapes. You may stop or interrupt the recording at any time. You may also ask to erase the tape at any time during or after the interview. However, erasing a tape before it is transcribed will make an interview incomplete and no part of the interview will be used in the analysis.

Benefits

This study is not designed for your personal benefit. However, a desired outcome of this study is to help improve service provision to HIV-positive women, including mothers who have female partners.

Risks

Participation in this study involves a risk relative to the protection of your privacy. Precautions to minimize this risk include measures to keep personal information confidential (see confidentiality section below). If you experience emotional distress as a result of this interview, you can ask for a break or to discontinue the interview and community based organizations that provide counseling or support services will be suggested to you.

Research Standards and Rights of Participants

Participation in this study is voluntary. You can refuse to participate or discontinue this interview at any time and this will not have any negative effects on benefits you are otherwise entitled to or services provided to you.

Compensation
As a compensation for your participation in this study you will receive $30 in cash after completion of each of the two in-depth interviews. If you complete both interviews you will thus receive a total of $60 in compensation. There will be no compensation if an interview is incomplete.

Confidentiality
Your privacy will be protected by the following measures: Your name will not appear on any other research record. Written and computerized research records will be identified by code numbers only. Research records will be kept in locked files in the office of the principal investigator. Data in computers will be password-protected. Records will only be available to research staff and Institutional regulatory personnel (who may review records as part of routine audits). Findings will be presented in summarized, aggregate form wherever possible in order to further protect your privacy.

This research is covered by a Certificate of Confidentiality issued by the Department of Health and Human Services (DHHS). With this Certificate, the researchers cannot be forced to release any research data in which you are identified, even under a court order or subpoena, without your written consent. The principal investigator has obtained the Certificate to protect your privacy and to resist any demands for information that would identify you. However, the Certificate of Confidentiality does not prevent the researchers from reporting suspected or known sexual or physical abuse of a child, or threatened violence to yourself or others. Such information must be reported to the appropriate authorities.

The researchers doing this study will answer any questions you may have. If you have questions in the future you can contact Hella von Unger at (212) 543 5207.

You will be given a copy of this consent form to keep.

The New York State Psychiatric Institute – Columbia University Department of Psychiatry Institutional Review Board (IRB) has approved the recruitment of subjects for this study. If you have any questions about your rights as a research subject or any complaints, you might call the IRB at (212) 543 5758 during office hours.

I voluntarily agree to participate in this research study described above. I may choose not to participate, or to discontinue my participation at any time, without penalty or loss of benefits to which I am otherwise entitled.

___ ___ / ___ ___ / ___ ___
Date

______________________________	______________________________
Name of Participant *(Print)*	Participant Signature

I have discussed the proposed research with this participant, and, in my opinion, this participant understands the benefits, risks and alternatives (including non-participation) and is capable of freely consenting to participate in this research.

___ ___ / ___ ___ / ___ ___
Date

______________________________	______________________________
Name of Interviewer *(Print)*	Interviewer Signature

In-depth Interview Guideline

Interview 1

Today's interview will be about the different stages in your life, how you grew up to become the person you are today. Why don't we start with your childhood and go from there – how was growing up like for you?

Childhood & Adolescence

- Where and when were you born?
- Do you have any brothers or sisters?
- Who raised you? Who else lived in the household?
- How did your parents (and/or the people who raised you) make a living? How did you get along with them?
- Were there any events or changes during your childhood that you found particularly challenging or upsetting?
- How was school? How long did you stay in school? If you dropped out – why?
- What was the neighborhood like that you grew up in?

Migration

- If there was a change in environment, moving to another city/neighborhood or a migration experience across cultural boarders – what prompted this change and how did you feel about it?
- How did you adapt to the new environment, what was that like for you?

Sexual History

Sexual socialization

- Would you describe your family/environment as open minded or more conservative when it comes to sexuality? Where there any tensions about your sexuality?
- Has anyone ever called you a tomboy when you grew up?
- When you grew up, was there someone gay or lesbian among your friends or family members? What did you think of them and how were they regarded and treated by others?

Sexual relationships with women

- Can you remember the first time that you felt attracted to a girl or woman? How did you feel about it? Did you tell anyone at the time?
- When was the first time you had sex with a woman? What was it like?
- Tell me about your first girlfriend!
- Tell me about other significant relationships with women, if you had any!
- How open are you about your attraction to women today?
- Did you ever go out with someone who had problems accepting the fact that she was attracted to women?
- Did you find that your environment was supportive of your relationships with women?
- Are you in a relationship now? For how long and how is it going? How did you meet?

Sexual relationships with men

- Have you ever been sexually attracted to men?
- If you ever had sex with men - what was it like?
- If you have had relationships with men, how would you describe them?
- How were the relationships with women different or similar to those with men?

Sexual abuse	- Have you ever experienced physical or sexual abuse? If so, how did you cope? Was there anyone you could talk to about it? - Did you ever experience physical, emotional or sexual abuse in a relationship? How did you handle it? - Have you ever abused any of your partners? How do you feel about that today?
Sex work	- Did you ever exchange sex for drugs or money? - How did you feel about it at the time and how do you feel about it now? - Has someone ever put you down or thought less of you because you were prostituting? - Who knows about your sex work experience? - If people who are close to you don't know about it, what is your main reason for keeping it a secret?
Drug use	- Have you ever used drugs? What drugs did you use and for how long? - What was happening in your life when you started using? How did you get introduced to drugs? - Describe your drug-using lifestyle: how much did the habit dominate your life? - How did you feel about your drug use at the time and how do you feel about it now? - Were you able to take care of your children when you were using?
Recovery	- What made you decide to stop using? - When and how did you attempt to quit? Did you ever go to a treatment program? - Who and what has been helpful for maintaining your recovery? - Where are you in your recovery today?
Stigma of drug use	- Has anyone ever looked down on you because of your (history of) drug use? Please give me an example and tell me how you dealt with it. - Has anyone who knew about your drug use experience ever questioned whether you are trustworthy? If so, how did you respond to that lack of trust? - How do you explain that people have negative preconceptions of someone who has a history of drug use? - Are you worried your children might start using drugs some day? How would you feel about that and what would you do? - Have you heard about the case in South Carolina where a hospital called the police to arrest pregnant women who were using drugs? What do you think of that? - Do you share any of the negative views people have about drug users?

How was it like to be interviewed today? Is there anything you would like to add or ask?

Interview 2

In our last interview we talked about your childhood and growing up and about your relationships. Today we will focus more on the time since you tested positive for HIV.

HIV/AIDS

HIV Infection	- **When and why did you get tested for HIV?** - How did you feel about your results? - Who were the first persons you told about your HIV diagnosis and how did they respond? - Has anything changed about how you feel about your HIV infection today? - Have you since had any symptoms or HIV-related hospitalizations? - Are you taking any medications? How do they work?
Stigma of HIV	- How did your family/partners respond when you told them you were HIV-positive? - Do your children know about your HIV infection? - Have you ever encountered HIV related prejudices or discrimination? - Have you ever been accused of putting someone else at risk? - If you knew about your HIV infection when you were pregnant, how did you feel? Did anyone suggest you should not have the baby? - Overall, do you think people are becoming less prejudiced in US society when it comes to people with HIV/AIDS? - Have you ever heard someone say something negative about a person who was living with HIV/AIDS?
HIV and sex life	- How does HIV impact on your sexual life? - Do you enjoy sex? - How do you and your sexual partners deal with the risk of sexual transmission? - Do you usually tell new sex partners about your HIV infection? - If you use protection with men and/or with women, how do you address the issue? - Has safer sex ever been a problem for you or for any of your partners? - Have you ever worried about infecting a sexual partner?
HIV support	- Do you attend an HIV support group or do you have friends who are HIV-positive? - Do your HIV-positive peers know about your attraction to women? If not, why do you keep that private? If yes, how did they respond? - Do your HIV-positive peers know about your drug use experience?
Accessing services	- Have you ever applied for benefits from DAS (Division of AIDS Services, now called HIV/AIDS Service Administration)? - How did DAS staff treat you? Did you ever encounter someone with an attitude problem? - Medical services – who provides your care? - Do you feel you are getting the information and care that you need? - Did you ever feel disrespected or mistreated by medical professionals?

- Do your medical providers know about your sexual relationships with women?
- Social services / family based services – have you ever had any problems accessing them as a lesbian woman, lesbian couple or lesbian family?

Incarceration

- Were you ever sentenced to serve time in jail or prison? Please tell me about the circumstances of your arrest and the charges that were brought against you.
- How much time did you spend in jail or prison?
- Did you have a romantic or sexual relationship with a woman while you were in jail/prison?
- How was your release and the step back into the community?
- If you've been going in and out of prison, how do you manage to stay out now?

Stigma of delinquency

- Did you get visits from anyone when you were serving time?
- Do you feel discriminated against as an ex-convict, for example did anyone ever treat you differently after they learned that you have been convicted of a crime?
- Did you ever see that someone else was put down because of her incarceration experience?
- When you compare yourself with other women who have been released from jail or prison, would you say you all faced the same difficult situation?
- What do you think about the laws that require some providers to report to parole offices when women who are on parole relapse?
- Do you think people in general are prejudiced against women who have served time in jail or prison?

Custody/ Motherhood

- Have you ever lost or transferred custody rights for your children?
- If you have tried to get custody rights back, was this easy or difficult? Please describe the details of going to court, social workers, family, etc
- How do you feel about having lost or transferred custody rights?
- Has anyone ever questioned whether you were a good mother?
- Some people say there is a difference between 'having children' and 'being a mother' – what do you think about that?
- Do you think women who use drugs can take good care of their children?
- Do your children know about your relationships with/ attraction to women?
- How do your female partners get along with your children?
- Are you sharing parenting roles and responsibilities?
- What does your family think about the fact that you are raising your child(ren) with another woman?

Sexual identity

- How open are you about your sexual attraction to women? Do your family members know? Do people at work and people in your support group know?
- Do you have friends who are gay or lesbian?
- Do you feel part of a gay/lesbian/bisexual/transgender community?
- Would you use any of the following labels to describe yourself: "lesbian", "dyke", "butch", "femme", "aggressor" or "bisexual"?

Stigma of same-sex sexuality	- Did anyone ever use any of those labels in a derogative manner, i.e. to put you down? - Has anyone who you've come out to as lesbian/bi/attracted to women ever reacted negatively? - Do you think your looks give your sexual orientation away? - Have you ever experienced hassle on the streets? - Have you ever wondered whether someone was rude to you because of your sexual orientation or because of something else? - Would you say New York City is a safe and tolerant place to be out as gay, lesbian or bisexual?
Money /Poverty	- Have you ever had a time in your life when you were struggling financially? How did you manage? - Has anyone ever looked down on you because you were poor or unemployed? - How are you doing financially now? Do you have enough money to pay for necessities?
Ethnicity	- Do you feel part of a [Black or Latino] community? - Do you have friends of other ethnic backgrounds? If so, have you ever talked about racism or skin color? - Was skin color ever an issue at school or at work? How do you feel about it and how did people respond to you? - Did you ever experience discrimination based on your skin color, race or ethnicity? - Ambiguity: Were you ever not sure whether someone's behavior was in response to your race or skin color or not? - What about daily hassles - the little ways how people show disrespect? Does it happen to you? How does it make you feel and how do you respond? - Have you ever dated/gone out with someone from a different ethnic background than your own? How did that go? And how did people respond? - Do you think that racism is overall on the decrease in US society?
Coping	- In these past few months, what has been the most stressful problem in your life? How did you deal with it? Was there anyone you could ask for help? - How do you usually respond when people are rude to you? - How do you respond when your social service and medical providers treat you in a disrespectful manner? - What keeps you going and what cheers you up when you are down? - What is your greatest wish for the future?

How was it like to be interviewed today?

How do you feel about me being a White interviewer from Europe? Do you think it makes a difference?

Is there anything you would like to add or ask?

Thank you very much.