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Does Family Matter to HIV-Positive Men Who Have Sex With Men?

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Abstract

Most studies have indicated that friends or families of choice provide more support to HIV-positive men who have sex with men (MSM) than members of the family of origin. The creation of families of choice by MSM has been viewed as a means of creating a support system in the absence of traditional family. The purpose of this study is to explore if HIV-positive MSM believe family of origin are important. Data was drawn from a qualitative study of HIV disclosure to family. Responses to the question “How important is family to you?” are explored. Results suggest that for many HIV-positive MSM relationships with family of origin are very important. While not definitive, data to be presented are provocative and challenge notions of the significance of family of origin to marginalized populations.

Keywords

Family; HIV; MSM; qualitative methods

Introduction

Under the most restrictive conditions family can be defined as being “of origin” or those persons to whom, through blood, adoption, or marriage, someone is related. In marginalized communities whose members have depended on friends or family “of choice” for support and affection this restrictive definition draws ire. Weston (1991) suggested that gay men and lesbians may create and maintain families of choice not only due to experiences of rejection from their biological families, but also because of perceptions of exclusion from traditional societal definitions of family. Men who have sex with men (MSM)¹ have a justified argument for seeking inclusivity of others into the family designation. Researchers investigating the role of social support in the lives of MSM have focused on the vital role that friends play in their lives possibly replacing or usurping the role of biological family. Traditional family surrogacy may be due to perceptions developed over time in the gay

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¹Not all men in our study self-identify as gay but they did acknowledge having sex with other men. Therefore, the terms *gay*, *gay male* or *gay men* are not appropriate descriptors of our sample. Much of the existing literature is based on studies of gay men and in these circumstances we correctly refer to the population as gay men.

community that family of origin are not only unhelpful but harsh, rejecting and condescending. This perception, not otherwise documented in the literature, is problematic because HIV-positive MSM in particular need increased support from family to alleviate the numerous burdens HIV imposes. Despite the defensible position that MSM may not view family as important it is reasonable to invite the question whether family of origin is significant in the lives of HIV-positive MSM.

There can be benefits of receiving social support from family of origin related to HIV disease management such as increased medication adherence (Murphy, Roberts, Marelich, & Hoffman, 2000). However, receiving health related assistance requires disclosing one's HIV-status (Huber, 1993). Studies of HIV-positive women suggest that those who disclose their HIV-status to family and friends do so because they want to preserve honesty in the relationship, to gain social support, and to avoid the anxieties of concealing their HIV-status (Simoni, Mason, Marks, Ruiz, Reed, & Richardson, 1995). These results were later supported in another study finding that HIV-positive adults who disclose their HIV-status to family and friends experience greater social support from those relationships (Kalichman et al., 2003). Although results are somewhat equivocal (see Chidwick & Borrill, 1996; Kimberly & Serovich, 1999; McCann & Wadsworth, 1992), most studies have indicated that friends provide more support to HIV-positive MSM than family members (Friedland, Renwick, & McColl, 1996; Hays, Catania, McKusick & Coates, 1990; Hays, Chauncey, & Tobey, 1990; Hays, Magee, & Chauncey, 1994; Johnston, Stall, & Smith, 1995; Namir, Alumbaugh, Fawzy, & Wolcott, 1989; Schwarzer, Dunkel-Schetter, & Kemeny, 1994).

It is important to note a number of difficulties or plausible oversights to these studies. For example, it is probable that family represent a small proportion of the total number of people in the social network of HIV-positive persons. In these instances, friends may be both more plentiful and available to provide assistance. Support for this position comes from Barbee and colleagues (1998), who found the more siblings a HIV-positive person had, the fewer supportive behaviors they experienced from friends. Further, few studies of social support explicitly report disclosure of HIV status. It is easier to request and receive disease specific support from family and friends who are knowledgeable about the HIV-positive person's condition than from those who are unaware. Serovich, Esbensen, and Mason, (2007) reported that while friends are told of an HIV-positive status more quickly, over time there are no significant differences between rates of disclosure to friends or family when numbers of friends and family are controlled. Moreover, findings which suggest that family support is not as abundant as friend support should not be construed as meaning family involvement is not desired or meaningful.

Research regarding the role of family of origin in the lives of MSM primarily approaches the subject from a deficit-based model. The assumptions about the importance of families have been rooted in anecdotal and clinical reports of homophobia, rejection, misunderstanding, stigma, and shame (Beeler & DiProvo, 1999; Weston, 1991). However, while researchers have argued that families of origin are a vital source of social support to MSM with HIV (Kimberly & Serovich, 1999; McDowell & Serovich, 2007), there has been little qualitative examination of the relationships that these men have with their families outside of the caregiving realm. The purpose of this paper is to answer the question of whether family is important in the lives of HIV-positive MSM. Based on previous research interactions with HIV-positive MSM, as well as our experience as couple and family therapists, we believe that familial bonds will have a salient role in the lives of these men. Moreover, we assume that the relationships these men have with their families of origin will be varied, reflecting both direct and indirect themes of social support.

Methods

Recruitment and Participants

Participants for this study came from a larger study of HIV disclosure and were recruited in two ways. The first method was through advertising at local AIDS service organizations (ASOs). Caseworkers were informed of the study and provided with information about the project that they could distribute via flyers or through newsletters. Second, recruitment materials were made available at various HIV-related venues and forums (e.g., AIDS Walk and Gay Pride festivities) held in the community. Recruitment efforts resulted in 48 HIV-positive, adult MSM from a large Midwestern city who were eligible to participate in the study. For this study, men who exclusively had sex with women, could not speak and understand English, and those under the age of eighteen were excluded. Data from all eligible participants from the larger study were included in this analysis.

Participants were primarily unemployed (70%), men of color (55%) between the ages of 18 and 78 ($M = 43.5$ years, $SD = 9.6$). At entry into the study, participants had been diagnosed with HIV for periods ranging from 1 month to 35 years ($M = 124$ months, $SD = 101.37$). Thirty-five percent of participants had some college education and 14% holding a bachelor's degree.

Eligible participants were grouped according to categories of disclosure. These categories included "told none/few," "told some," and "told most/all." Categorizing participants in this fashion ensured that the total spectrum of disclosure was investigated. If the level of participant disclosiveness was not accounted for, it was plausible that only men who were highly disclosive by nature would be interviewed, thereby skewing the sample and results. For this study "family" was defined as anyone related by blood, marriage, or adoption. To assess the degree to which disclosure had occurred participants were asked "What percentage of your family members have you told you are HIV-positive?"

Participants who had "told most/all" of their family were defined as those who self-reported disclosing to roughly 80% or more of their family members. Participants who had "told some" of their family were defined as those who self-reported disclosing to roughly 20–80% of their family members. Those who had "told none/few" family were defined as those who self-reported disclosing to roughly less than 20% of their family members. Interviews were conducted with a total of 48 MSM; 13 qualified as "told none/few," 26 who had "told some," and 9 who had "told most/all." Participants that "told some" were purposefully oversampled because it was thought that they may have developed more complex reasoning patterns regarding the decision to disclose or not disclose.

Procedures

Data collection methods reflected an inductive approach to studying disclosure practices (Charmaz, 2000). Therefore, extensive, semi-structured interviews were used to understand the experience and composition of disclosure and the importance of family from the participant perspective (Fontana & Frey, 2000; Sayer, 1992). Graduate students experienced with qualitative inquiry conducted the interviews. All interviewers received training during two, two-hour sessions. Training sessions included instruction on issues related to sex and HIV research (e.g., confidentiality, data safety and protection issues), clinical and ethical issues involved with interviewing, and expectations of the interview. Interviewers practiced their training during a series of mock interviews in which more experienced interviewers would offer suggestions for improvement, particularly focusing on questioning techniques. Both male and female interviewers were trained and available. The decision to include male and female interviewers was based on the desire to have participants choose an interviewer

with whom they would feel comfortable given the sensitive nature of the information elicited. Approximately two-thirds ($n = 30$) of the interviews were conducted by men.

Interviews lasted from one to two hours. Interviewers were provided an interview protocol that contained both questions to be asked and areas where extra probing was appropriate. Participants were compensated \$40 for their time. Each interview was audio-taped and transcribed by project personnel. The original interviewer later reviewed the transcript for accuracy. After reviewing the transcript, the data were then analyzed and organized into increasingly specific codes. When analysis revealed that codes began to repeat and new information was not being revealed, we determined data saturation had occurred and ceased recruiting participants.

Data Analysis

For this project, both the participants' responses to specific questions about whether family was important to them as well as the importance of specific relationships (e.g., Mom) were of interest. How participants conveyed the importance or non-importance of family in more implicit ways was also explored. This was done by exploring how participants talked about family members, including their reactions and reasons why they chose to disclose or not disclose to them. Utilizing a process Miles and Huberman (1994) describe as data reduction, we selected particular aspects of data and focused analysis by deploying both inductive and deductive approaches. A constant comparative method was used to contrast responses, situations and concepts within and across interviews. This approach to data analysis is borrowed and modified from the grounded theory qualitative literature (Glasser & Strauss, 1967; Charmaz, 2000). For example, if a theme emerged it was coded and the transcript was re-analyzed for evidence of that theme. Likewise, subsequent interviews were reviewed for evidence of that theme. Results were not limited to include only concepts that were shared across all interviews because doing so would devalue the unique perspectives of each participant. The initial analysis was informed by the research question: "Is family important?" which included responses to the question: *In general, how important is family to you?* As we began to explore this question in the data it was apparent that there was more depth to the answer than what emerged from looking only at participant responses to one particular question. Therefore the analysis was expanded by exploring how participants talked about particular family members and how relationship dynamics affected these men.

Results

Overwhelmingly, participants described their family or particular family relationships as important. In fact, family was described as being important to all of the nine men who had disclosed to *most/all* of their family. A 39 year old Caucasian stated family was "very, very important, absolutely." A 44 year old African American described his family as "extremely important."

Of the men that had told *some* of their family members ($n = 26$), 24 of them described family as important and two participants described family as somewhat important. Responses such as, "Oh, my family is very important to me" (28 year old, African American) and "very, very important" (43 year old Caucasian) were common. Another participant, a 35 year old African American man described his family as significant to him by stating, "It's like the most important, most important relationship." One of the participants that described family as somewhat important indicated that the importance of family to him was a five on a one to ten scale. He went on to explain,

They've never really been there for me most of my life so. I mean, I'm trying to get family oriented now and I'm just like, I've done some family things here in the last

few months, you know. Hell I almost died 3 months ago so that kinda brought us close together. (36 year old, Caucasian)

The other participant spoke of desiring his family to play a more active role in his life. “[Family] is reasonably important to me. I wish it was in a little better construction to be honest. You know, I wish we had more interaction and closeness with us” (38 year old, Caucasian). In this case importance appears to be equated with the degree of emotional involvement.

It is significant that 12 of the 13 men who told *none/few* of their family members also described family as important. This is surprising because it could be assumed that disclosure has not occurred because of negative relationships or potentially negative reactions. This, however, proved untrue. For example, a 43 year old Caucasian man stated, “I think my family is important.” Another participant stated that family as a group was not important, yet certain family members were. This 50 year old African American man expressed feeling disconnected from his sisters and estranged from his brothers: “They’re not important to me actually. I’m more like the black sheep so I don’t hang out with them, like they do with one another.” While this suggests that importance may be strongly associated with acceptance; he later described his relationship with his mom who had passed away the previous year as very important to him. His mother was the only family member who he directly disclosed his HIV status to and when asked about his relationship with her he stated, “That was my heart. Yeah. Very important. And I miss her very much.”

This data suggests that men have relationships with family members that are disparate and not conducive to a group assessment. Men frequently shared that particular family members were more important to them than others. For example, a 48 year old African American participant who had told *some* of his family described the differences in relationships.

Family members, my mom and my sister, in my mind and in my heart are the only ones that need to know. Because the rest of them, I wouldn’t say I have any love for. We argue too much and they’re very vindictive.

Finally, the importance of family served as a double-edged sword with respect to disclosure of serostatus to family. Some disclosed to maintain family ties while others chose to not disclose for the same reason. For this same man, the importance and closeness of his family contributed to his desire to disclose his serostatus to his family: “Because if we wasn’t [as close] I wouldn’t have been as eager or as apt to tell them. I would have just kept on, kept on, putting it off.” Alternately, a 39 year old Caucasian man had chosen to not disclose because he feels, “very compelled not to tell them” and later stated, “I guess you could say there’s a little bit of paranoia and a little bit of fear in there that, you know, I don’t want to change the relationships drastically.” For him, his family was important despite the fact they held different views on certain issues:

You know I love my family dearly. And I was joking with them earlier this week that I think I was placed in the wrong family at birth, that there is another child out there with another family that’s got like two gay parents or something like that and he’s this staunch Republican. He’s just going, why God, why did you do this to me? But I love my parents and I love my family. Um... we don’t see eye to eye on a lot of stuff and you know, we may not always be in each other’s company, but I know they care about me and I care about them as well.

Factors associated with family importance

Emotional closeness—Several factors emerged that contribute to how and why family is important to these men. One factor was that of pre-existing emotional closeness between

family members. Participants often described the loving and tight knit nature of their family. As one 54 year old, Caucasian man who had told *none/few* of his family stated, “We are very, very close and we love and care for each other and do just about anything for each other”. A 41 year old African American participant that had disclosed to *some* of his family highlighted the emotional connectedness and reliance on one another that is often present in families: “Family is very, very important because being HIV-positive, you know you go through so many changes mentally and down the road, physically and you really need that support of your family- that love and togetherness.” In this case, being HIV-positive emphasized the importance of relying on family for emotional and physical support.

Others described how the presence of family closeness was a factor in deciding to disclose their serostatus to their family. For example participants noted that emotional intimacy was so profound that disclosure was almost mandatory. “I just had to, I mean, cause we’re all open and close, so it was not even a question really...we were close” (39 year old, Caucasian, *some*) and “We’re all very very close. Very close, you know? Just a little tight unit” (45 year old African American, *some*) were common statements. These examples demonstrate that when a family’s relational and communication dynamics are perceived as close-knit, HIV-positive men may feel compelled to disclose.

Family as a unique relationship—There is evidence that suggests that biological ties are significant in how these men defined the importance of individuals in their lives. It was not uncommon for men to report that friendships were less important than family relationships. For example, a 54 year old African American who had told *most/all* of his family stated, “To me it’s [family] my world. I mean you have as far as your family or other people outside of your family, maybe acquaintances and stuff, but the only people that really care about you is your family.” Another participant also reported that family relationships were sometimes seen as unique as compared to other types of relationships MSM may have: “I think that it’s a good idea that [family] know especially if they are a part of your everyday circle. You know because they’re gonna support you more than pretty much anybody else” (28 year old, African American, *some*).

Contact and Proximity—While men may have more consistent and daily contact with friends and live in closer proximity with them, it does not preclude them from maintaining positive family relationships. In fact, men stated that family is important to them despite the amount of distance between them or frequency of contact. According to a 60 year old Caucasian man who had told *most/all* of his family “Even though we are somewhat distant [physically], they’re important.” Another participant expressed how his relationship with his mother is important even though he is no longer living in the same area:

We have a close relationship and we, you know, even if I’m not, even now I’m not living in (City) and I talk to my mom almost every day, if I feel like calling her, or if I don’t have anything else going on in my life. (28 year old, African American, *some*)

Another 18 year old African American who has told *some* of his family discussed the importance of family despite his family member’s unwillingness to have contact:

Family is important to me, even though we don’t like to socialize or do anything together. I try to make contact with them to check up on them and even though they don’t call or try to catch up with me, I try to stay in contact with them.

Family of Creation—Twenty five percent of the MSM ($n = 12$) had been involved in forming a family of creation. For these men, the family of procreation was equally, if not in some cases more, important than the family of origin. A 54 year old Caucasian who had told

none/few of his family was careful to make sure he included the importance of his family of origin and family of creation in his response: “My family is very important to me; my brothers and sisters and my son and my grandchildren.”

Inclusion of family of creation in the discussion was not unusual. Men discussed family of creation in relation to either a positive or negative family of origin experience. For example, a 32 year old African American who had told *most/all* of his family stated, “Family is important to me... and that’s why I want my own children to be very close and to have a bond that me and my family didn’t have.” Another participant described how over time he has distanced himself from his family of origin and places more value on his family of creation:

Being that I was fortunate enough to have two children, that part of family is really, really important to me. My mom and dad, my brothers and sisters, every year I get older, this sounds horrible, but they are less and less important. I care about them; I care about what happens to them, that sort of thing. But, there’s just been too much stuff that’s happened over the years they just don’t have a lot of importance anymore. (46 years old, Caucasian, *most/all*)

Discussion

The results of this study should be considered a call to the professionals in the fields of couple and family therapy, HIV research, and family science to address what appears to be a bias in our work due to neglect of an important population. The literature base on HIV and the family is replete with studies of the impact of HIV and mechanisms for intervening and assisting families cope with having a positive family member. A closer look, however, reveals that a preponderance of the data is derived from and applicable to only to women and children. Men, let alone MSM, are rarely included in family focused research and clinical guidelines. A recent book edited by Pequegnat and Szapocznik (2000) describes numerous programs for assisting families living with HIV; however none focus on MSM despite the fact the highest proportion of reported cases of HIV infection is among MSM. Approximately 71% of all adolescent/adult AIDS cases are men and 48% of these cases can be traced to MSM (CDC, 2008).

Inclusion of MSM in family related research is especially important given that the results of this study suggest that HIV-positive MSM hold very positive attitudes towards family of origin. Positive feelings were evident across participant age, race, physical proximity, and disclosure. These results suggest that a deep emotional connection to family is present for many MSM that transcends sexual orientation, distance and disease. A recent study by McDowell and Serovich (2007) investigating social support and mental health for HIV-positive gay men, women, and straight and bisexual men suggests that for many MSM family provides valuable social support that significantly affects mental health symptoms such as depression. Taken together, these findings suggest that family is not only important for many MSM, but that family also provides support that has direct positive effects on these men’s lives.

A family resilience approach (McCubbin & McCubbin, 1988) may be one appropriate mechanism of examining the role and importance of families for sexual minorities because despite the difficulties these families face, they continue to “exist, endure, and even thrive” (Oswald, 2000, p. 375). One commonly held assumption is that the revelation of homosexuality or HIV status serves to destroy or severely damage family relationships. The compounding stigmatization of being gay and HIV-positive (Kalichman & Nachimson, 1999) may significantly influence familial relationships. However, the direction of this influence may not always be negative. For example, Zea and colleagues (2004) reported that

HIV-positive Latino gay men who had disclosed their sexual orientation to family members were also more likely to disclose their HIV status to their families. The authors speculated that men who had “experienced accepting or neutral responses to that disclosure may well feel able to reveal their positive serostatus without fear of rejection” (p. 114). A complementary explanation may be that dual disclosures of sexual orientation and HIV status are more likely to occur in resilient families due to the presence of characteristics such as positive outlook, flexibility, open communication, spirituality and cohesion (Black & Lobo, 2008). These qualities not only create a family environment that is more conducive to emotional sharing, but also aid the family in handling future stressors. Though this explanation is largely speculative, the resiliency model coupled with the results of this study suggest that scholars and clinicians are challenged to find ways to strengthen families so that relationships are strong before issues such as homosexuality, HIV, or addictions emerge. Scholars should further investigate ways of enhancing family relationships for people who feel disenfranchised or marginalized from their families.

Family was depicted as multidimensional for these men and encompassed both family of origin and creation. One interesting result which emerged from this study is that men expressed a desire to extend the meaning and importance of family to their own children. They reported seeking close relationships with sons and daughters and found these connections to be meaningful. Therapists and future researchers should consider these varied relationships in their work. Several questions meriting exploration must be considered. Is the importance or support provided by family of origin and creation substantially different and if so, how? Are any differences mirrored in other populations? Does the importance of family change over time? Answer to these questions could lead to a second generation of questions including how are family members impacted by their relationships with their HIV-positive gay sons, brother, fathers or other relatives? Assuming that not all families are equally accepting and inclusive of all members, what is the impact of relationship disruption on gay men and how are their family members coping? Does the presence of sexual minority family members change the political, religious, or social views held by other members?

Results from this study should be especially encouraging to clinicians and therapists who work with MSM in medical and therapeutic settings as they suggest that the family could be considered a resource for HIV-positive MSM. While friends may be more plentiful and available this should not be construed to mean that family are not consequential. Family can be and should be considered a valuable support mechanism for many MSM. In fact, friends and family may provide differing types of support to HIV-positive MSM; therefore, men should be encouraged to discuss which relationships might provide the most fundamental support and be the most beneficial to the maintenance of their health.

There are limitations to this study. First, data came from an investigation of HIV disclosure to family and did not explicitly focus on issues regarding the importance of family. Therefore, it is likely that other factors related to the consequential nature of the family to MSM were not evidenced in the data and should be explored. Further, the men in our study are all located in the Midwest. Coastal men or men who deliberately locate to larger cities may have a different experience with family of origin. It should be noted that much of the research on men affected by HIV has focused on men living in Coastal areas, such as San Francisco, New York, and Miami. Our study is unique in examining the importance of family for men living in the Midwest. In addition, data for this study came from HIV-positive MSM but suggests that we should be exploring the importance and role of family of origin for other sexual minorities (gay, lesbian, transsexuals, or bisexual). Family researchers and clinicians should welcome diverse family forms and adopt an inclusive definition of family while not inadvertently diminishing the meaning of family of origin.

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