



Participatory Methods for Stigma Reduction with HIV-Affected Families

Sally Mason, Ph.D.

Professor of Clinical Social Work in Psychiatry

Institute for Juvenile Research

University of Illinois at Chicago

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Abstract

HIV stigma contributes to risks for poor health; these risks are exacerbated by additional stigmas of race, gender, sexual orientation, and substance abuse history. As women continue to be infected by HIV and as people with HIV are living longer, their children, most of whom are not HIV infected, are *affected* by their parent's HIV status. Children may feel stigma as acutely as their HIV-positive (HIV+) parents, contributing to the children's vulnerability. Children of HIV+ mothers have more emotional problems, disrupted relationships, and poor school outcomes than those whose mothers are not living with HIV.

As we learn about stigma's impact beyond the individual, we are compelled to respond systemically within families to reduce future generations' vulnerability to HIV and other risks. Based on a line of inquiry with HIV-affected teens about their stigma experiences, our multidisciplinary team discovered stigma's impact on our ability, not only to study stigma, but to engage parents and especially their children in services and research. We draw on these findings and the literature on community-based participation to contend that participatory methods have value, not only for research and program development, but in reducing the impact of stigma with our HIV-affected partners. The participatory *process* is as important to stigma reduction as knowledge and service development outcomes. Participatory methods can expand our potential for breaking the cycle of intergenerational vulnerability by strengthening family skills and capacity and enhancing self-worth so those affected by HIV are empowered to overcome stigma's impact.

Introduction

HIV stigma has been linked to disparities in access to health care, low medication adherence, and decreased impact of HIV-prevention strategies. These risks for poor health are exacerbated by additional stigmas of race, gender, sexual orientation, and substance abuse history. The majority of women (e.g., mothers) living with HIV are African American or Latina, low-income, single parents living in urban neighborhoods characterized by violence and poverty. As women continue to be infected by HIV and as people with HIV are living longer, their children, most of whom are not HIV infected, are *affected* by their parent's HIV status.

Stigma moves out in waves from the person living with HIV to their loved ones. Children may feel stigma as acutely as their HIV+ parents, because of their close connection and because children cannot easily distance themselves from the stigmatized parent, as a friend or extended family member might. Stigma contributes to the vulnerability of HIV-affected children. Children of HIV+ parents have more emotional distress, thought or attention problems, substance use, and sexual risk than those whose parents are not living with HIV.

As we learn about stigma's impact beyond the individual, we are compelled to respond systemically within families to reduce future generations' vulnerability to HIV and other risks. Based on a line of inquiry with HIV-affected teens about their stigma experiences, our multidisciplinary team discovered stigma's impact on our ability, not only to study stigma, but to engage parents and especially their children in services and research. Drawing on our findings and the literature on participatory methods, we contend that these methods have value, not only for research and program development, but for reducing the impact of stigma with our HIV-affected partners.

Background

Parents Living With HIV in Chicago

Initially in the US, HIV disease was identified in men who have sex with men (MSM) and, soon after, in injected drug users, as they shared blood through unclean needles. Although MSM were parents, concerns about parents living with HIV became a major concern when the number of women infected, whether through sexual transmission or injected drug use, increased. In the late 1980s, the rising number of infants and children infected perinatally (through birth) raised awareness of HIV infection rates in women. Since more babies were being born HIV positive, it followed that women must be HIV infected. However, women were blamed for their HIV status, considered deviant, a junkie, or a prostitute and a vector of transmission to children and to men (Sandelowski, Lambe, & Barroso, 2004) rather than recognized as people living with HIV with specific needs of their own. Women were not likely to get tested for HIV and, when they did, testing or diagnosis often came too late in the disease process for treatment to be effective. In fact, until the 1993 revision, the Centers for Disease Control's definition of AIDS did not include many of the manifestations of HIV that were commonly seen in women, such as recurrent vaginal yeast infections, severe pelvic inflammatory disease (PID), and an increased risk of precancerous changes in the cervix. With the change in definition, women were finally recognized as having HIV. Programming and research focused on women's needs, including helping mothers make plans for their children's custody in case of the parent's death (Mason & Vazquez, 2009).

In the mid 1990s, highly active antiretroviral therapy (ART) became available in the US and other high-resource countries. These medications were much more effective in managing HIV than previous medication regimens. With access to ART, the longevity of people living with

HIV increased substantially, with many able to manage symptoms of the disease and plan for long, productive lives (Mascolini, 2016). Consequently, programs for parents shifted to supporting them in the role of mother or father as they raise their children to adulthood (Mason & Vazquez, 2009).

Most parents living with HIV are single, women, African American or Latina, and living in low-income urban areas where violence and drugs are constant threats (Schuster, Kanouse, Morton, Bozzette, Miu, Scott, & Shapiro, 2000; Centers for Disease Control, 2003). In 2016 in Chicago, non-Hispanic Blacks represented the highest percentage of HIV-positive diagnoses (58.5%); Hispanics represented 23% of new HIV diagnoses (Chicago Department of Public Health, 2017). Women represented a smaller percentage of those newly diagnosed with HIV (16.8%) than men (81.2%) (AIDSvu, n.d.). However, Black females living in Chicago had an 11.5 times higher rate of HIV infection than white females; Hispanic/Latina females had a 3.3 times higher rate than white females (AIDSvu, n.d.). Of the five Chicago community areas with the highest average rates of HIV diagnoses in 2015–2016, two were considered to be areas of high economic hardship (Chicago Department of Public Health, 2017).

Data on the impact of ART and initiatives to increase access to medical care are encouraging. Early in the epidemic, children were at risk for transmission of HIV perinatally from mothers who were positive. Men and women of reproductive age have always been the age group most at risk (Chicago Department of Public Health, 2017) with 67% of perinatal transmission (children born with HIV) occurring with non-Hispanic Black women and 10% with Hispanic women since 2009. Increasingly, however, perinatal transmission decreased through the use of ART and other interventions with pregnant women. In 1993, 43 children were born

with HIV in Illinois; in 2013, six children were born perinatally infected (Illinois Department of Public Health, 2014).

Nevertheless, children who are not HIV positive are affected by a family member's HIV status. A parent's chronic illness and the potential loss of that parent are stressors that can contribute to adverse outcomes (e.g., emotional distress, thought problems for adolescents, etc.) (Pederson & Revenson, 2005). Women with HIV experience high rates of depression (Brackis-Cott, Mellins, Dolezal, & Spiegel, 2007; Do et al., 2014; Miles, Holditch-Davis, Pedersen, Eron, & Schwartz, 2007; Simoni & Ng, 2000) and substance use (Centers for Disease Control, 2003). In some studies, mental health and substance abuse are highly correlated for parents living with HIV and their affected children (Bauman, Camacho, Silver, Hudis, & Draimin, 2002; Lee, Lester, & Rotheram-Borus, 2002). Adolescents of infected parents may also be at high risk for behaviorally transmitted HIV infection, other STDs, and early pregnancy (Chabon, Futterman, & Hoffman, 2001; May, Lester, Ilardi, Rotheram-Borus, 2006; Mellins et al., 2009).

HIV Stigma

HIV disease is one of the most stigmatized illnesses in modern history (Mahajan et al., 2008). Associated with death, contagion, debilitating illness, drug use, and sexuality, a person with HIV may internalize the negative messages resulting in a “spoiled identity” (Goffman, 1963) or self-stigma—internalized stigma leading to depression, anxiety, or anger (Larson & Corrigan, 2008).

Family members of people with HIV, including their children, may experience courtesy stigma or stigma by association with their loved one (Goffman, 1963; Neuberg, Smith, & Hoffman, 1994). Due to proximity and relationship, children of HIV-positive parents or HIV-affected children fear that they will be rejected if others find out their parent has HIV (Brackis-

Cott, Mellins, & Block, 2003; Woodring, Canceli, Ponterotto, & Keitel, 2005). Although potentially important to the family's safety, being asked to keep the secret can reinforce the child's shame, giving the message that stigma is deserved. Some children feel increased stigma as they defend their mothers from stigma (Murphy, Robert, & Hoffman, 2002). In fact, children may feel stigma as acutely as their HIV-positive parents, because of their close connection and because children cannot easily distance themselves from the stigmatized parent, as a friend or extended family member might (Cree, Kay, Tisdall, & Wallace, 2004; Goffman, 1963). Two small studies have found that the mother's level of stigma is positively associated with the child's level of stigma by association (Fair & Brackett, 2008; Mason, 2011). Multiple studies across cultures and countries substantiate that children experience stigma by association with their HIV+ parent and that stigma by association is associated with negative outcomes, including emotional problems, disrupted peer and adult relationships, and poor school outcomes (Mason & Sultzman, 2019).

Interventions for Stigma Reduction

Heijnders and Van Der Meij (2006) conclude that stigma reduction for people affected by a condition must occur not only at the community and individual levels but also at the intrapersonal level or within the person's support networks (e.g., family) where stigma is often most noticeable. They recommend that those affected assist in the development and implementation of stigma-reduction programs, not only to ensure that the programs are effective, but to empower those living with the stigma. However, the majority of HIV-stigma interventions have targeted populations who might stigmatize people living with HIV (e.g., healthcare workers, community members, teachers) in order to reduce public stigma (Sengupta, Banks, Jonas, Shandor Miles, & Corbie Smith, 2011; Stangl, Lloyd, Brady, Holland, & Baral, 2013).

Few studies focused on reducing stigma experienced by those living with HIV or by their family members. Interventions using people living with HIV as educators have been effective in reducing stigma in those receiving the education (Markham et al., 2000); no studies have been conducted with those who are living with HIV and providing the intervention to determine if they experience reduced stigma due to their participation.

Methodology

Our research team came together over common interests in family, HIV, stigma, and health quality of life. We were well aware that people with HIV experience stigma and, through three small studies, began to explore the concept of stigma by association (SBA) as experienced by children of mothers who are HIV positive. In the first study, we addressed the need for a comprehensive and valid measure of SBA for use with HIV-affected adolescents, following a multistage process beginning with scale construction and a content analysis by the authors—experts in HIV, stigma, adolescents, families, and measure development. In the second stage, nine African American HIV-affected teens participated in cognitive interviews to assess comprehension and relevance as well as content validity; scale modifications were made based on their responses. The last stage was data analytic with 27 African American HIV-affected teens resulting in further refinement of the measure and the establishment of initial psychometric properties on reliability (Mason, Berger, Ferrans, Sultzman, & Fendrich, 2010).

The second set of results came from a broader study of HIV-affected adolescent risk. Twenty-seven non-infected African American adolescents, living with an HIV-positive mother and knowing her HIV status, responded to four open-ended questions. The teens ranged in age from 13–18 years; 48% were female. Analysis was an inductive and iterative process. Using ATLAS.ti, two researchers independently coded all transcripts and met after each level of

analysis to scrutinize and clarify codes or, at higher levels of analysis, coding schemes until a consensus emerged. Coding schemes and processes were also examined and discussed regularly by the full research team—experts on HIV, stigma, adolescents, family systems, and mental health (for details see Mason, Sultzman, & Berger, 2014).

In the third study, nine HIV-affected teens, their HIV-positive mothers, and six service providers to HIV-affected families participated in separate focus groups. Each group was asked to define stigma and talk about either their experiences of stigma by association (teens) or how they thought or had heard that affected teens experienced SBA (mothers and service providers). Teen, mothers, and service providers were also asked about the teens' stigma-management strategies and services or programs that had been helpful or could be helpful with stigma reduction in the future. Teens were asked about the potential barriers to program usage and how those barriers could be overcome. The academic research team did an initial analysis of the results and then worked with a group of teens, mothers, and service providers to refine the results.

Results

Teens' Experience of Stigma

Over the course of three studies, teens told us that they experienced rare instances of direct stigma, as few had told anyone, even a best friend, the mother's HIV status. Mothers living with HIV often ask their children to keep the mother's status a secret for fear of stigma. However, teens experienced indirect stigma, usually in silence, when friends made fun of people with HIV or AIDS or used it as an insult. If the teen had told a peer, the information was sometimes used against the teen. Anticipating a range of reactions from friends if their mother's status became known—sadness, fear, understanding, shame, anger—teens adapted their behavior

to avoid stigma through vigilance and silence within the family and without. One teen living with her HIV-positive mother described the stigma as “like being in a cage” (Mason, Sultzman, & Berger, 2014).

Stigma-management strategies generally strained or reduced peer interactions and reinforced the mother-teen connection, a combination at odds with the peer relationships and independence fundamental to adolescent development. Teens were the “wise” for their parents—“intimately privy to the information and sympathetic with the stigmatized person” (Goffman, 1963, p. 28). At the same time, teens were looking for their “own”—those “who know this particular stigma from experience and with whom one can feel at ease, accepted” (Goffman, 1963, p.20). Teens cited infrequent camps or retreats with other affected families as a place of safety, even if HIV was not discussed. Mothers, on the other hand, were often not aware that the teens experienced or managed stigma. In fact, many mothers and teens did not know what the word meant; yet, when defined, they readily described their experiences with and concerns about stigma.

Studying Stigma With HIV-Affected Families

As clinicians, we recognized the impact of stigma on people with HIV but had not considered how stigma affects the conduct of research (and, ironically, research on stigma). For example, we knew that recruitment materials could not include the term *HIV* as many people with HIV, due to stigma, hide their status—carrying a flyer with those words or taking it home might open them up to questions from family, friends, or neighbors. However, this concern was just the tip of the iceberg when engaging family members, and specifically children, in interviews about their mother’s status.

To begin with, this population—children not infected but affected—was hard to reach because they were once removed from the “recruitment” process and because they protected themselves from stigma. There were few programs or gathering places for affected children and teens so engagement occurred through parents living with HIV who sometimes were reluctant to have researchers speak to their children about a sensitive subject or, in some instances, had not told their children their HIV status. Often parents choose not to tell their children in order to protect the children from the burden of their illness and from the potential stigma. When parents have told their children, in some cases the adolescents are reluctant to talk about their parent’s illness, being protective of mother and the secret. In other instances, the parent may think the child knows or the parent reports having told the child, but the child does not endorse the parent’s status; the child indeed may not know, or the child may be reluctant to divulge the secret, even with the parent’s permission. Cree, Kay, Tisdall, and Wallace (2004) also describe difficulties engaging HIV-affected children for their study of the impact of having a mother with HIV and attribute the challenges, at least in part, to HIV stigma.

With our pilot studies of mom and teens, we carefully adapted a set of questions (Murphy et al., 2002) to discover whether the teen knew the parent’s HIV status and, if so, was willing to tell us, without us disclosing the parent’s status. With 31 mom-teen dyads, in which mother reported having told the teen at a specific time and reported using the words HIV or AIDS to tell the child, four of the teens in a private solo interview did not endorse mother’s status. We are not clear if they knew and were not willing to talk with us about it or if, contrary to mother’s report, the teen did not know. In at least two instances, however, the teen reported knowing someone with HIV but when asked to identify their relationship to that person, the teen refused to say.

As clinicians and researchers, we struggled with our responsibility to the affected teens. The majority of teens had not told anyone about their mother's status; the teens used silence as a form of protection from stigma. If we asked them to open up to us, to be less vigilant for an hour or two in a research interview, first, how could we reduce (and not reproduce) stigma for them in the research process and, second, what was our responsibility to give them a safe place to talk in the future? We used participatory methods for a few aspects of our studies. Our findings—the teens' silence and vigilance while wanting to find “like” or safe others—coupled with our concern about reproducing stigma for children and parents and our intention to alleviate the impact of stigma led to the conclusion that consumer participation (i.e. engagement in decision making and implementation should be the approach of choice when conducting research and program development regarding HIV-affected children and their families).

Discussion

Developing Knowledge and Interventions With Stigmatized Families

The methods used in participatory research are diverse but share a “core philosophy of inclusivity and of recognizing the value of engaging in the process those who are intended to be the beneficiaries, users, and stakeholders of the research” (Cargo & Mercer, 2008, p. 326). In our work, the participants included HIV-positive mothers, their non-positive children, and service providers to HIV-affected families. In participatory research, the traditional research “subject” is an active participant at multiple points in the process, including defining the research questions, helping with “recruitment” (i.e., identifying and engaging participants, assisting with data collection, and contributing to analysis). Participants are experts alongside researchers, sharing power by involvement in all phases of the work. Participation by potential users and stakeholders increases the relevance of the findings contributing to the likelihood that they will be useful,

used, and sustainable. Notably, participatory research is especially valuable in “work with marginalized communities that experience a disproportionate burden of environment, health, and other problems and that typically have not been included in deciding what types of research and interventions are most appropriate for and likely to be most effective in their communities” (Israel et al., 2005, p. 1471).

These reasons alone are powerful enough to support the use of a participatory approach with HIV-affected children and families, as the majority of these families are low-income, African American or Latina, single women raising children in the inner city. Based on our pilot work, we believe that participatory methods have added value for developing knowledge and services with children and families experiencing HIV stigma, as stigma can exacerbate the vulnerability, silence, and disenfranchisement already experienced by low-income families and racial or gender minorities. Participatory methods can enhance the relevance and usefulness of outcomes but, just as importantly, the participatory process may be less likely than traditional methods to reproduce stigma and may potentially reduce stigma.

1) Participatory methods can mitigate the silence perpetuated by stigma. Through active involvement in the research process, parents living with HIV and their children give voice to those needs suppressed and silenced by secrets and stigma. Most teens never talked about their mother’s status, honoring their mother’s request to keep the secret while protecting mother and themselves from stigma. Through dialogue with women living with HIV and their children, researchers become the “wise,” gaining an understanding of those living with stigma and overcoming the distrust of children and parents who have traditionally been research “subjects” and, in this instance, may have additional concerns about lack of safety due to stigma. Participatory methods reach out to this hidden population of children and teens who would

appear to benefit from intervention but who are harder to engage because they are not in the HIV+ service system and because of stigma. We bring them into the process so they can lend their voices to knowledge development, encouraging the exploration and raised awareness which are key to reducing stigma's impact on, not only with the parent or primary stigma target, but also their loved ones (Larson & Corrigan, 2008).

2) The participatory process has the potential for reducing the impact of stigma on children and families. A “spoiled identity” cannot be repaired or redefined in isolation; stigma, by definition, exists in relation to others, so stigma reduction may be especially effective in relation to others, whether “like” others or within family relationships. Groups have a strong history in the HIV epidemic (Paudel & Baral, 2015), not only because of the mutual support provided, but also because people with HIV or their loved ones benefit from contact with others like themselves—in Goffman’s words, the “own” or those who can be trusted and understand. Participatory research brings people together in a group process—in this case, people who may be socially excluded due to stigma. In our pilot work, some mothers and teens did not know the meaning of the word *stigma* but shared compelling and distressing stigma experiences. The group process of developing a stigma definition named the experience while developing a sense of community and inclusion among the mothers, teens, and service providers.

3) The participatory process increases self-efficacy, which can be eroded by stigma. Self-stigma is the acceptance or internalization of feelings of shame and guilt. Self-stigma, in this case “by association,” is associated with low or negative self-efficacy (Larson & Corrigan, 2008; Corrigan, Watson, & Barr, 2006). A growing body of evidence supports improved self-efficacy through participatory methods, “particularly for those at risk for social exclusion” (Wallerstein & Duran, 2006, p. 318). Positive self-efficacy has been linked to reduced vulnerability and fewer

problem behaviors, such as depression, delinquency, risky sexual behavior, violence, drug use and HIV risk in adolescents (Jagers, Sydnor, Mouttapa, & Flay, 2007; Muris, Schmidt, Lambrichs, & Meesters, 2001; Jemmott & Jemmott, 2002). As equal and empowered partners in the process, parents and youth acquire knowledge and skills, foster relationships, and become agents of change. As children are raised and live within the context of family, that context can be essential to supporting their management of stigma. If parents increase their self-efficacy, they can help their children manage stigma and continue to coach the children as they develop.

Our studies were limited by small convenience samples. The samples represented parents connected with services and willing for researchers to speak to their children about a sensitive topic and teens who were willing to participate. The focus on African American adolescents living with HIV+ mothers is relevant to a large percentage of HIV-affected teens, but these findings may not generalize to other races or ethnicities, younger children, or children living with other caregivers. Some analyses outside the scope of the studies (e.g., comparison of genders) would be beneficial in the future. As with any analysis, our expectations of the data may have influenced our analysis. However, the extensive iterative analytic process between multiple researchers and, in the last study, the inclusion of consumers in the analysis strengthen the validity of the findings.

Future Directions

Our contention that participatory methods can reduce stigma for participants has not been tested. As many have noted, participatory methods take time and skills which are not always supported or understood by funding sources or institutional structures. Families also may not be familiar with this form of engagement with, rather than “recruitment” by, providers or

researchers. Participatory methods require commitment to a long-term process and, for many of us, new skills and different approaches to our work (Israel et al. 2003).

As participatory methods become more prevalent, we have the opportunity to develop measurable definitions of “participation” in research and program development and to measure how participation impacts, not only the research or programming outcomes, but also the participant. Institutional review boards, which oversee participatory research, will need reviewers (including consumers) with skills and experience in participatory methods. Funders who value participation will have to support training for and implementation of participatory methods, including the assessment of participation. Funders often require or encourage consumer participation in research and programming. Inclusion and participation of those affected, however, cannot be tokenism (Oliveras, Cluver, Bernays, & Armstrong, 2018). True inclusion will require training *and* field experience for researchers, students/future researchers, agency program directors, and consumers with appropriate curricula. Our experience is that, with community engagement, boundaries between community members and academics blur so researchers become more involved with the stigma situations that people living with HIV encounter every day (Mason, 2017). Training will require not just “methods” but a new way of thinking about relationships with team members.

Children’s experience of stigma by association with parents living with HIV has been identified and studied around the globe, including in South Africa, China, Scotland, Rwanda, and the US (Mason & Sultzman, 2019). Skills taught to students can have a global impact. We also have the opportunity to collaborate with researchers from other countries and cultural contexts to refine measures, delineate the practices of participation, and identify commonalities as well as unique contextual aspects of participation and its impact.

Implied in the use of these methods is the creation of an environment free of judgment about having HIV or a family member's HIV status and protected from disclosure of that status to outsiders. As researchers, educators, and service providers, we accept the honor of being allowed into the families' lives and secrets—being the “wise.” As we strive to become experts *with* parents living with HIV and their children or any stigmatized population, we still have much to learn from the parents and their children about what will engage them and how or whether they want to be engaged.

Conclusion

People living with HIV experience multiple stigmas related to race, gender, socioeconomic status, chronic illness, and substance abuse history and thus multiple vulnerabilities. Stigma increases vulnerability to HIV and can reduce one's sense of self-efficacy. Stigma affects not only the person with the stigmatizing condition; it moves out in waves to others who are connected to that person. Thus stigma contributes to the vulnerability, not just of those with HIV, but to those in their care and who care for them. Stigma also makes service provision and research difficult. How do we develop relevant services and develop knowledge if we cannot engage families socially excluded by stigma? How do we ensure that we are not reproducing stigma? Participatory methods have the potential to engage through collaboration while, at least, not reproducing stigma and, at most, reducing stigma's impact.

Participatory methods level the historical power differential between researchers, service providers, and families, a difference which may be exacerbated by stigma, bringing the parents' and children's voices in authenticity while potentially empowering families. In the age of ART, an activist phrase from early in the epidemic—silence equals death—has new meaning. Originally *death* was literal in its meaning. Increasingly, positive people are living longer lives,

but they and their loved ones may experience psychological, social, and spiritual death if silenced and kept in their place, seen as abnormal or less than others. Freire reinforces that the “the oppressed must be their own example in the struggle for their redemption” (1970/1993, p. 36) along *with* those in solidarity but not *by* those in solidarity. Liberation comes from praxis or inclusion in the process, rather than exclusion (Deegan, 2013; Freire, 1970/1993).

The participatory process is as important as the outcome and facilitates the ultimate outcome of reducing the intergenerational impact of stigma. If our goal as educators, researchers, and service providers is to move beyond simply not reproducing stigma to reducing stigma, then all of our actions must reflect that goal, and a participatory approach is essential. In the vein of feminist pragmatism, we put into action the principles implemented at Chicago Hull House over a hundred years ago, emphasizing “education and democracy while retaining the importance of home, family, and community” (Deegan, 2013, p. 31). Participatory methods can expand our potential for breaking the cycle of intergenerational vulnerability by strengthening family skills and capacity and enhancing self-worth so those affected by HIV are empowered to overcome stigma’s impact. In partnership with families, we apply methods which open the doors to engagement and empowerment while reducing intergenerational risk for adverse outcomes.

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