Perceived Family Member Reaction to Women’s Disclosure of HIV-positive Information

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Disclosing one’s HIV status to family members is a difficult process, particularly if the anticipated reaction of the recipient is negative. The purpose of this study was to expand the understanding of reactions experienced by women who disclosed their HIV-positive status to family members. One hundred and seventy-three reactions were extracted from 97 disclosive episodes during ethnographic interviews with 13 adult HIV-positive women. Using constant comparison methods, reactions were placed in 31 topologies and 6 categories. Each of these categories are described and implications for therapists and future researchers are discussed.

Researchers have documented that people tend to disclose information when they feel distressed and may obtain some benefit(s) by doing so (Derlega, Metts, Petronio, & Margulis, 1993; Greenberg & Stone, 1992; Pennebaker & Beall, 1986; Stiles, 1987). Individuals with HIV who disclose disease-related information visit physicians less frequently, demonstrate normal immune functioning, and exhibit autonomic nervous system regularities to greater degrees than their nondisclosing counterparts (Pennebaker, Colder, & Sharp, 1990). Researchers have also demonstrated that suppressing thoughts or communication about difficult experiences can increase the likelihood of stress-related problems (Greenberg & Stone, 1992). Disclosure of some disease-related information, such as an HIV-positive diagnosis can, however, be more stress inducing than relieving.

Telling others of HIV-infection is a complex phenomenon and researchers have indicated that decisions surrounding disclosure of one’s status to family members may be especially difficult (Kimberly, Serovich, & Greene, 1995; Yep, 1993). Kimberly and colleagues’ (1995) theory of disclosure of HIV information was developed from interviews with HIV-positive women, and the theory consists of six steps which might experience as they navigate the disclosure process. The steps include: (1) adjusting to the diagnosis, (2) evaluating personal disclosure skills, (3) taking inventory of whom to tell, (4) evaluating potential recipients’ circumstances, (5) anticipating reactions of the recipient, and (6) having a motivation for disclosing.

According to this model, events could transpire at each stage of the disclosure process which would inhibit disclosure. For example, an important factor in the disclosure process for these women was anticipating the reaction of the potential recipient of this information. Before disclosure occurred, women reported attempting to anticipate how the potential recipient would respond to her HIV-positive status. Anticipated reactions took three forms: supportive, hostile, and ambivalent. This process of anticipating reactions was important because women who felt that the potential recipient would react negatively or ambivalently did not disclose diagnosis information, whereas women who anticipated that individuals would be understanding did disclose this information. Although anticipated reactions may be barriers to disclosure, actual reactions of family members were of interest in this study.

Background

There have been few studies examining the reactions of family members to an HIV-positive diagnosis. Two studies have been identified. In their study of HIV-positive women, Simoni, et al. (1995), directed participants to place the reactions of family members into one of three categories: (1) provided emotional support, (2) became angry, or (3) withdrew from you. These women reported mothers, fathers, and friends reacted by providing emotional support and rarely responded by becoming angry or withdrawing. Interestingly, lovers reacted with emotional support in most cases, however, they were also the most likely to become angry or withdraw. In their study of men with HIV/AIDS, Mansergh, Marks, and Simoni (1995) used the same three categories of reactions and found that their results mirrored those of the Simoni et al. study.

Given the spectrum of human emotions and functioning, using three categories to describe reactions to receiving HIV diagnosis information is restrictive. In fact, forcing responses into pre-set categories is problematic because the participant is constrained to the researcher’s context and is not allowed his or her own “voice.” Using a naturalistic approach in which there are no predetermined constraints on the outcomes, however, would allow for a more varied universe of reactions to emerge. Since the research to date has not allowed for this openness, the validity of these studies is questionable. Clearly, a qualitative approach is needed.

Purpose

The purpose of this study was to examine the reactions experienced by HIV-positive women to the disclosure of their status to family members in order to expand the understanding of the nature of disclosure. This area of research is important for a number of reasons. First, it is important to understand what experiences are unique versus what experiences are common to HIV-positive persons as they negotiate the disclosure process. Learning what reasonable expectations for disclosure may be can be therapeutically beneficial to HIV-positive individuals by giving him/her an illustration of the issues and dilemmas that may be encountered when disclosing. Since one reason for disclosure may be to obtain social support, anticipation of others’ reactions may be important to ensure that disclosure is indeed stress-reducing rather than stress-inducing. Likewise, this information may help an individual make the decision to delay disclosure to

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some individuals. In these instances, HIV-positive persons may need time to develop a plan for disclosure, adjust to the diagnosis himself/herself, and make decisions regarding who should and should not be provided this information.

Given the lack of research examining the reactions of family members receiving HIV-diagnosis information and the importance of these reactions for HIV-positive persons, the following research question was posed: What reactions do HIV-positive persons experience upon disclosing their HIV-positive status to family members?

Methods

Due to the lack of understanding and uncertainty as to the nature of women's experiences upon disclosing their HIV-positive diagnosis to family members, a qualitative approach was used. Specifically, a grounded theoretical approach was adopted for this study. According to Strauss and Corbin (1990), grounded theory is:

...inductively derived from the study of the phenomenon it represents. That is, it is discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to the phenomenon. Therefore, data collection, analysis, and theory stand in reciprocal relationship with each other. One does not begin with a theory and prove it. Rather one begins with an area of study and what is relevant in that area is allowed to emerge. (p. 23)

Sample

One hundred and seventy-three reactions were extracted from 97 disclosive episodes shared by 13 HIV-positive women. Women were recruited for this study using maximum variation sampling procedures. Maximum variation sampling is a purposeful sampling technique designed to "document unique variations that have emerged in adapting to different conditions" (Lincoln & Guba, 1985, p. 102). This procedure was selected because, according to Lincoln and Guba (1985), it is preferable to sample a population based on dissimilarity of backgrounds when a researcher is interested in understanding a phenomenon in "all of its various ramifications and constructions" (p. 201). Hence, the women in this study were chosen based on divergence of ethnicity (African-American [n = 3], Hispanic [n = 3], White [n = 7]), age (Range: 20-59, M = 33.46; SD = 5.78), mode of HIV contraction (risky sex with infected partner [n = 7], sex workers [n = 2], injection drug use [n = 2], unknown [n = 2]), and desire to participate.

The Director of Support Services at a nonprofit community agency that serves HIV-positive persons in two medium-sized communities located in the southwestern United States assisted in recruitment to ensure the anonymity of participants. The director identified and contacted potential participants based on achieving maximum diversity in accordance with the strata outlined. The only exclusion criteria employed by the director were health status and disease progression. That is, women who were too ill or who demonstrated signs of dementia were not contacted by the director for participation. The director did not maintain a rejection rate, however, of the 13 women scheduled, only one woman did not show for her interview and she was replaced by a woman of the same race and similar age.

Procedures

Semi-structured interviews were conducted in April 1993 and March 1995 in either a clinical setting or in an office in the nonprofit community-based agency. Each interview lasted between 45 and 90 minutes and was conducted by the first author. Participants were informed, prior to consent, that the study was examining how HIV-positive individuals decided to disclose or not disclose their HIV status and that the interviewer was there as a researcher interested in their disclosure process. The data for this study were from a larger project involving the understanding of the general disclosure process of HIV-positive individuals, therefore, questions were developed to stimulate conversations around to whom individuals disclosed they were HIV-positive. Questions such as, "Who did you tell you were HIV-positive? When? Where? Why was that person chosen to receive this information? What was his/her reaction(s)?" served as the basis for the interviews. Each participant was paid $25.

Data analysis

Data analysis was conducted in several steps. First, the interviews were transcribed verbatim, checked for accuracy, and then edited for identifying information. Accuracy checks included having a second transcriptionist simultaneously listen to the tape and read the text, making corrections as she/he went along.

Coding. After each interview was re-checked and edited, it was read independently by three undergraduate coders who were trained by the principal investigators. Coders were trained in one, two-hour individual session in which the principal investigators described how to access and save the data files, how to identify reactions, and how to mark the transcripts when a reaction was identified. These coders were directed to extract from the text what they considered to be reactions of family members. The term "reaction" was defined as any response, both verbal and nonverbal, to being told the participant's HIV-positive diagnosis. Particularly important in this phase of the analysis was thoroughness in extracting reactions from the entirety of the interviews. Agreement between all three coders of family member reactions occurred at an acceptable level (75%; n = 73). When agreement between coders about a reaction was not present (1 coder disagreed = 19%, n = 18; all 3 coders disagreed = 6%, n = 6), one of the principal investigators reviewed the transcripts and made a decision regarding the inclusion or exclusion of the material to increase assurance that all "reactions," in whatever form, were included for subsequent analyses. Utilizing this method of identification, each HIV-positive woman described the reactions of approximately six family members (M = 6.5; Range = 2-16). The family members women disclosed to were: boyfriends/husbands/ex-husbands (n = 14), fathers (n = 2), mothers (n = 10), step-mothers (n = 1), sisters (n = 13), brothers (n = 8), daughters (n = 7), sons (n = 16), in-laws (n = 12), aunts (n = 5), uncles (n = 1), cousins (n = 2), nieces/nephews (n = 2), and grandparents (n = 4). In total, the reactions of 97 persons were extracted and provided the data for this study.

Constant Comparison. Reactions were analyzed using the constant comparison method. The constant comparison method is a mechanism for deriving theory in addition to processing data (Glaser & Strauss, 1967). Four stages of this method are: (1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory (Glaser & Strauss, 1967, p. 105). For this
study, utilization of this method involved comparing each reaction to every other reaction and identifying their similarities and differences. During this comparison effort, categories began to emerge. Reactions were then placed under categorical headings. Categories were continuously rearranged, properties redefined, and "rules" for inclusion and exclusion constantly challenged. Utilizing this method, family member reactions were grouped into six categories which will be discussed in more detail later.

**Contextual Analysis.** After all the coding was completed, a contextual analysis was conducted. Since naturalistic inquiry is based on the notion that human activity is not context-free, the context in which these activities occur must be examined. As such, contextual analyses involve the examination of the "location of events or incidents pertaining to a phenomenon... the particular set of conditions within which the action/interaction was managed, handled, carried out, and/or responded to" (Strauss & Corbin, 1990, p. 101). In this instance, the interviews were reassembled and reread many times, paying particular attention to each woman's disclosive story and the environment in which disclosure to family members occurred. In the contextual analysis conducted here, trying to honor each woman's point of view, method of explanation, and interpretation of her family members' reactions as her responses were grouped was adopted. Next, a method for a contextual analysis of the data collected within each category was devised so that the woman's own meaning and experiences could emerge. When one of the women's expressions (whether an idea or actual words) was thought to characterize one of the six categories derived from the constant comparison, the quotation was copied verbatim under that category heading. The very process of recopying the women's words and remembering their voices, tones, and inflections when the words were first spoken, helped to place the reactions described in the context of the woman's whole story. Using this technique, it was possible to record how unique each woman's perspective was even though she was expressing a similar category of reaction.

**Results**

Thirty-one types of reactions were placed into six categories (see Table 1). Each of the categories are described below.

**Intellectual/Cognitive/Information Based**

There were three forms of intellectual or cognitive reactions: information seeking, giving advice or instructions, and giving personal meaning. If the individual took the disclosure and wanted more information, he or she typically reacted with an inquiry, which was the most common reaction (25 incidents). For example, the family member might have asked, "How long have you been infected?" "Who infected you?" or "Are you OK?" When a family member took the information and made some determination about the implications of the information for the HIV-positive family member, resulting reactions were usually in the form of advice or instruction. Typical instructions included, "Don't tell anyone else," or advising the woman to be careful about personal behaviors, such as drinking alcohol. Finally, some individuals reacted by personalizing the information and internalizing it. For example, one son said, "It's not going to happen to me. I'm going to be careful when I have sex."

<table>
<thead>
<tr>
<th>Type of Reaction</th>
<th>Dimensions</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual</td>
<td>Information gathering</td>
<td>25</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Advise/instruct</td>
<td>6</td>
<td></td>
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<td></td>
<td>Personal meaning</td>
<td>1</td>
<td></td>
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<tr>
<td>Physical</td>
<td>Hugs</td>
<td>4</td>
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<td></td>
<td>Crying/no crying</td>
<td>12</td>
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<td></td>
<td>Violent</td>
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<td>Upset</td>
<td>1</td>
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<td></td>
<td>Deep breathing</td>
<td>1</td>
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<tr>
<td>Spiritual</td>
<td>Prayer</td>
<td>4</td>
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<td></td>
<td>Instruction</td>
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<tr>
<td></td>
<td>Question</td>
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<tr>
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<td>Question relationship</td>
<td>12</td>
<td></td>
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<tr>
<td></td>
<td>Confirm relationship</td>
<td>4</td>
<td></td>
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<tr>
<td>Instrumental</td>
<td>Offer help/assistance</td>
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<td></td>
<td>Tell others</td>
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<tr>
<td>Emotional</td>
<td>Blame</td>
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<tr>
<td></td>
<td>Reassurance/support/comfort</td>
<td>14</td>
<td></td>
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<td></td>
<td>Fear of contagion</td>
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<tr>
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<td>Shunned/reject</td>
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<td></td>
<td>Disbelief/denial (about infection)</td>
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<tr>
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<td>Anger</td>
<td>7</td>
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<tr>
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<td>Hope for a cure</td>
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<tr>
<td></td>
<td>Embarrassed</td>
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<td></td>
<td>Shock/stunned</td>
<td>8</td>
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<td>Pity</td>
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<tr>
<td></td>
<td>Worry</td>
<td>5</td>
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<tr>
<td></td>
<td>Sorrow</td>
<td>8</td>
<td></td>
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<tr>
<td></td>
<td>Don't talk about it</td>
<td>10</td>
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Example

- "Is it HIV or AIDS?"
- "Don't tell your father."
- "I'm going to be careful when I have sex."
- "He kinda looked at me, and came up to me and he hugged me."
- "She just went to crying."
- "She busts a window and stormed out of the house."
- "She was near a heart attack."
- "She took deep breaths and kept repeating my name."
- "He went to church and prayed."
- "You need to get right with God."
- "Why did God do this to us?"
- "Why did you wait so long to tell me?"
- "It didn't change his way of thinking about me."
- "What can we do?"
- "Momma told my sister."
- "It's your own fault."
- "Talk with me about it."
- "They don't want to touch me."
- "They don't want me nowhere around."
- "You don't look sick to me."
- "She is angry at her dad for giving it to me."
- "Medicine will slow it down."
- "My daughter's embarrassed to tell her husband."
- "She screamed and dropped the phone."
- "Poor them, there's nothing the doctors can do."
- "Is my baby going to be OK?"
- "It was like he wanted to cry."
- "He doesn't like to talk about it."

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Physical

Physical reactions were ones in which the family member responded in a nonverbal manner and accounted for 11% of the reactions. The most common physical reactions were hugging the HIV-positive individual and crying. Others reacted idiosyncratically. For example, one woman reported her younger sister put her fist through a window and “stormed out of the house.” Another woman reported her sister screamed and dropped the phone. These women were surprised when anticipated physical reactions were not realized. In particular, several women noted when a family member did not cry. This may suggest that unanticipated reactions may be more noteworthy or have more impact than realized anticipated reactions.

Spiritual

Spiritual reactions were ones in which the individual responded either by praying, instructing the HIV-positive woman religiously, or blaming their God. For example, one brother-in-law’s reaction was to go to church and start praying for the woman. A sister reacted by telling her sister to “Get right with God” and one teenage son asked his mother, “Why did God do this to us?” Spiritual reactions were uncommon, accounting for only 2% of the reactions, which may be a reflection of the fact that a spiritual reaction may not be shared between the reactor and the HIV-positive person. Praying is frequently a silent activity, therefore, it may not be easily detected as an initial reaction. It is also possible that spiritual reactions simply did not occur.

Relational

Relational reactions were identified as ones in which the family member responded by either questioning the relationship or by confirming the quality of the relationship; this reaction occurred relatively infrequently (7%). Family members who questioned the state of the relationship typically reacted to the timing of the disclosure and took this as a sign of relationship deterioration. For example, a number of sisters and mothers reacted by asking, “Why didn’t you tell me sooner?” or “Why did you take so long to tell me?” These questions were interpreted by the HIV-positive woman as another way of saying, “Don’t you trust me?”

Conversely, other family members, usually males, saw this as an opportunity to confirm or strengthen the relationship; one brother stated, “How could I think bad about my little sister?” These women were most likely to report that their boyfriends did not think about them differently or had voiced a desire to maintain the relationship. Overall, female family members were inclined to question the relationship while male family members generally confirmed the relationship.

Instrumental

Instrumental reactions were those in which family members responded by offering assistance or by sharing the burden of disclosing to others. These responses accounted for 10% of the reactions and were typically expressed by women. The offering of help or assistance was usually a generic offer such as, “What can I do?” It is plausible that these family members were expressing a desire to support and be closer to the HIV-positive woman. Equally possible is that the socialization of women is such that their training, upbringing, and role expectations to be helpers and/or care providers may also influence how they express their willingness to help. The exception to this were reports of female family members, typically mothers or maternal figures, taking on the task of, or encouraging, disclosure to others. These HIV-positive women also noted that the nature of the relationship with the family member was predictive of an instrumental response; those having a positive relationship with a family member were offered help more often than those in arduous relationships.

Emotional

As might be expected, emotional reactions were the most common (51%) and the most varied. There were 12 types of emotional reactions, including: blame, reassurance/comfort, fear, shunning/rejecting, disbelief/denial, anger, hope, embarrassment, shock/stunned, pity, worry, sorrow, and silence.

Blaming. Family members who reacted with blame did so by blaming either the HIV-positive woman or the person they believed to be the infector. An example of blaming the HIV-positive woman was one mother who said, “With your lifestyle it’s amazing you didn’t get [HIV/AIDS] sooner.” An example of blaming the infector was one son of an African-American woman who asked, “Did you get it from that man? I know I didn’t like him for some reason.” Overall, blaming was uncommon and when directed at the HIV-positive woman, blaming occurred in the context of an otherwise poor relationship.

Reassurance/comfort. A number of family members reacted to the disclosure by attempting to console the HIV-positive woman. Reassurances ranged from encouraging the HIV-positive woman to talk with them about HIV/AIDS, to messages such as “You still have a lot of chance to live long if it doesn’t develop to AIDS,” and “Don’t cry, don’t cry, mom—it’s going to be okay.”

Fear. The fear expressed by family members was typically of becoming infected themselves. Women reported family members distanced themselves physically, were afraid of being in the woman’s home, or were afraid of being touched by the woman. For example, one Hispanic woman reported,

“They’re scared. They’re scared ‘cause they think that just by talking to them or just touching them, they think they’re going to get [HIV]. I told them they can’t get it like that and they say they know, but you don’t see them coming to my house.”

Clearly, confounding issues which may have led to this reaction were a lack of knowledge about HIV/AIDS transmission and/or prejudice on the part of the family member.

Shunned/rejection. Although rarely reported, some family members reacted by ostracizing the HIV-positive woman. For example, statements like, “She (sister) turned her back on me” and “He (son) wants nothing to do with me,” were expressed. Other rejecting reactions appeared to be a manifestation of an anticipated burden that the HIV-positive woman might become. For instance, one sister responded with, “I don’t have time for this,” while a mother wondered, “What do you want from me?” Contextual analysis revealed, however, that for each of these reactions the relationship between the HIV-positive woman and the family members was either poor or strained.

Disbelief/denial. Disbelief or denial by family members was reported by some of these women. Typical comments were,
"Why you?" "You don't look sick to me," or "It can't be true." One Caucasian woman reported her mother's reaction was, "No! Not my favorite. Not this. It can't be." Such reactions usually occurred under two conditions: (1) the family members were unaware of the HIV-positive woman's lifestyle that may have placed her at risk or, (2) the woman contracted HIV from her husband, and family members were unaware of his risky behaviors. Therefore, reactions of disbelief/denial typically transpired under the condition of double disclosure, where the woman was telling of her HIV-infection and also revealing other information about herself or her spouse/partner.

Anger. Family members expressing anger did so at either the suspected infector or the messenger. Anger toward the suspected infector was expressed by a friend of one Hispanic woman who, after being told the woman contracted from her husband, stated, "Oh I just want to go out there and strangle him. I can't believe what your husband just did. Was he not thinking about you?" Anger at the messenger was expressed by one mother of a Caucasian woman who directed her reaction to the doctor who told them both of her diagnosis. The HIV-positive woman related "I was numb but my mother came out of her chair. I really thought she was going to hit him." Somewhat striking is that these women characterized the expression of anger towards themselves as blame. For instance, condescension in the form of, "Why weren't you more careful," were common. None of the women described instances in which others became physically violent toward them.

Hope. The expression of hope was specifically for a cure. Here, family members made such statements as, "Medicine will slow it down," and, "I wish I had the money to find a cure." One Hispanic woman related that her children are "always looking at the television to see if there is a cure that might come out for AIDS. They're always looking for some good news."

Embarrassed. There were two instances where adult children of infected women reported being embarrassed by the fact their mother was HIV-positive; one daughter was embarrassed to tell her husband and one son was embarrassed to tell his wife. Possibly, some younger children were also embarrassed by their mothers' status but may have manifested it in different ways or didn't express their embarrassment directly to her. Interestingly, these women did not report other family members such as mothers or brothers being embarrassed.

Stunned. For many family members, being told of the woman's HIV-infection was shocking. Instances of this reaction included one sister who "never said a word for a minute. For a few minutes she stayed QUIET." Another sister's reaction was, "All I heard was a yell across the phone, a scream, crying, dropping the phone and picking it back up to say, 'How long have you known?'

Pity. Reacting to being told of the woman's HIV-positive status with pity was rare but reported in a few instances. Statements such as, "poor them [HIV-positive woman and her spouse], there's nothing the doctors can do" were reported. Pity was typically reported by extended family members versus immediate family. This may indicate that extended family members are concerned about the HIV-positive family member, but due to distance from the situation or individual, extended family members may not elicit the intensity or scope of reactions expressed by more intimate others.

Worry. Worry was expressed in two forms; either family members worried about how the diagnosis would impact their lives or they worried about how the diagnosis would affect another family member. For example, a son worried about how his mother's HIV infection was going to affect his going to college. A sister worried about the health of her baby who received daycare provided by the infected woman. Worry reactions were frequently the result of incomplete information either about the disease or uncertainty about repercussions from being sick or dying.

Sorrow. Reactions of sorrow were common and expressed by several family members. HIV-positive women reported family members "being all sad and everything" or "she just got sad about it." One African-American woman reporting on her brother's reaction stated, "He was all sad and he looked like he wanted to cry."

"I don't want to talk about it." Women reported that many family members, typically men, did not want to talk about her being HIV-positive. Statements such as, "My husband doesn’t like to talk about it," or "My son doesn’t like to talk about AIDS" were expressed. Interpreting this reaction is difficult because of the multiple possible meanings. For instance, silence may be a reaction of disbelief, denial, or a time of personal reflection. This reaction is included as a separate category because several women noted this response by family members even though these women did not clarify the interpretation of this reaction. Clearly, not talking about the diagnosis is a noted reaction.

Discussion

There are a number of interesting issues raised in this study for therapists and researchers, as well as for HIV-positive individuals. This study expands the research about what is known of family member reactions to HIV-disclosure in a number of ways. For example, reactions failed to fall neatly into the broad categorizations used by other researchers. Instead, family member reactions were multidimensional, complex, and not mutually exclusive.

Like the studies conducted by Simoni et al. (1995) and Mansergh et al. (1995), the results from this study indicate the reactions of anger, withdrawal, and emotional support were experienced by several of these women, however, other single reactions and combinations of reactions were more often expressed. In fact, family members typically expressed a number of different reactions, not just a solitary response. One mother's reaction that is illustrative of the multiplicity of these reactions is:

She was quiet. Never a word for a minute (Stunned). I could just see it...it sort of rippled through her. Then she was just like, "OK. How?" (Intellectual) I go, "Don't worry about how. It's in me and that's it. I'm asking for support." She was like, "OK, I can give you that (Reassurance/comfort), but why didn't you tell me sooner? Is this why you changed all of a sudden? Is this why you lost weight? You should have told me sooner (Relational). You probably wouldn't have fallen into a depression." Then later in the conversation she said, "Well, they're going to find cures" (Hope).

In addition to the number of reactions, family member reactions tended to hinge on such factors as the nature of the relationship, having known others with HIV/AIDS, lack of knowledge
about HIV/AIDS transmission, or prejudice. Other studies have demonstrated that, in the general public, lack of knowledge about HIV transmission is positively related to negative perceptions of HIV-positive individuals (Herlitz & Brorsson, 1990). Researchers have also found that knowing someone who is homosexual has been demonstrated to influence attitudes about homosexuals in general (Larsen, Cate, & Reed, 1983; Larsen, Reed, & Hoffman, 1980). Although lack of knowledge, prejudice, or even knowing someone with HIV/AIDS may have a different influence on reactions than they may have on attitudes about persons with HIV/AIDS, it is likely that actually attempting to predict a particular reaction would be confounded by such issues and circumstances. Future research would benefit from examining these as mediating or moderating variables.

Implications for Practitioners

The categorization of reactions presented here give both future researchers and clinicians an indication of the reactions persons may encounter upon disclosure of an HIV-positive diagnosis. Clearly, therapists should counsel HIV-positive women to closely examine many moderating factors before proceeding with the disclosure in order to more accurately predict a family member's reaction. For example, therapists may inquire as to whether or not the person already knows someone with HIV and discuss how that HIV-positive individual disclosed his or her diagnosis to others, what reactions she/he experienced, and what she/he may have learned or can learn from that person. Likewise, therapists might examine the nature of the relationship between the HIV-positive individual and the potential recipient of the information, discussing or role-playing possible interactions. Specifically, therapists can explore with clients how relationships could worsen in the event of disclosure, even though data in this study suggests this is unlikely. For example, discussion of the possibility of physical violence, rejection, or withdrawal of emotional and/or material support may be helpful. If these reactions became reality, identifying auxiliary sources of support may be necessary.

A discussion of positive effects of disclosure on relationships would also be appropriate. For instance, family bonds may become stronger or family members may decide to put aside previous feelings to rally support around the woman. Finally, it may be helpful for therapists simply to discuss the possibility that disclosure of an HIV-positive diagnosis will probably not change the overall nature of the relationship. That is, negative relationships with family members will likely remain negative and positive relationships with family members will likely remain positive.

Adding to the complexity of these reactions is that at first glance, it might seem as though family members reacted negatively more often than they reacted positively. In actuality, although there were a wider variety of negative reactions, positive reactions were just as common but tended to be described with less variability. This is contrary to previous research studies which have suggested negative reactions such as anger and withdrawal were dramatically less common than positive reactions such as providing emotional support (Mansergh et al., 1995; Simoni et al., 1995). One explanation for this may be that the women in this study anticipated relatively favorable reactions to disclosure and, therefore, were surprised by their family members' negative responses. Another plausible explanation may be that, given the methodology employed with this study, participants were not constrained in reporting the perceived reactions of family members and, thus, provided a more detailed description. Given this, therapists can be prepared for clients to report a variety of negative reactions which may be anxiety-provoking for their clients. It is likely that a few negative reactions may over shadow more positive reactions. Therapists then may find themselves working to mediate the impact of negative reactions by maintaining a balance or putting into perspective the totality of family members reactions.

Other studies have also suggested that when a negative reaction was anticipated, disclosure was not likely to occur (Kimberly et al., 1995). Since each woman interviewed had disclosed her status to at least one family member, these women may have felt obligated to tell other family members, regardless of the anticipated reaction. If this was the case, this result would be congruent with previous findings which suggest a sense of duty to tell family members negates the anticipated reaction (Kimberly et al., 1995). Therapists might help the HIV-positive individual explore his/her reasons or desires for disclosing to those persons with whom they have a poor relationship or a negative reaction is anticipated. Also noteworthy was that negative reactions primarily occurred within the context of a poor relationship. In these situations, women were not surprised or even terribly bothered by the negative reaction as the anticipated reactions were realized. Therefore, it may be valuable for therapists to explore how the HIV-positive client would feel if the anticipated negative reactions were expressed. If, as in this study, the HIV-infected individual would not be bothered, the benefits of telling (e.g., obligation) may outweigh any anticipated negative reactions that might result from the self-disclosure.

Future Research

Several issues impacting future research arise from this study. First, some reactions were more difficult than others to clarify. For example, love and compassion were reactions that were expressed by many of the women but were impossible to extract as a separate category because they tended to be embedded in many reactions. In fact, no reaction from a family member was referred to as "love," but the understanding was that most reactions of sorrow, for example, originated out of love and compassion for the woman. Except for extreme reactions (e.g., punching a wall, blaming, or shunning), the expressions of love and compassion permeated most situations. Future researchers may examine reactions or emotions that may enable or underscore other reactions.

Second, the congruence of perceived reactions by the HIV-positive individual with the actual reactions of family members deserves further exploration. One possible weakness of this study is that the reactions identified and labeled by these HIV-positive women may be different from those actually experienced by family members. In other words, persons might label someone's reaction as "shocked" when the individual who experienced the disclosure might label it as "sorrow." On the surface, if misrepresentation of reactions were consistently true and these women were unable to accurately identify responses, this study might be severely compromised. Nonetheless, the accurate appraisal of another's reaction may be less important than what individuals interpret as the reaction. This distinction is important because it is the perceived or anticipated reaction that is feared by HIV-positive persons, not what the recipient of the information ac-
tually experiences. Actual reactions of family members are important and should be investigated, however, these were beyond the scope of this study. Future researchers should examine the intention behind family members' reactions to elicit whether or not there is congruence between the intention and the perception.

Next, it was difficult to describe the divergent levels of intensity of the emotions expressed. In fact, it was difficult to remain true to these women's contexts when divergent levels of expressed emotional intensity were placed in the same category. In other words, it may be a shortcoming to place a reaction that was expressed by a family member with a great deal of emotion and one that was expressed nonchalantly or devoid of affect into the same category. Intensity may be important especially for the individual deciding to disclose. If the HIV-positive person anticipates an extremely negative reaction, or for a family member to be overly emotional, she/he may choose to either delay disclosure so that a more suitable response can be ensured or choose to not disclose. Future researchers might attempt to integrate or examine intensity of reactions in subsequent studies as it may be that a few intense reactions are more detrimental to the HIV-positive individual or his/her disclosure process than mild reactions.

Like intensity, the duration of reactions may need to be investigated in future studies. The women of this study reported initial reactions as well as reactions that were long term in nature; however, this distinction was not scrutinized in this study. Studies examining the relationship between duration of reactions and the well-being of an HIV-positive individual would be valuable. Closely related to duration of reactions is the need for an examination of when reactions were expressed (immediate versus years later). This was not of interest for this study but would remain important for future researchers, especially when addressing whether or not reactions of family members change over time. An important question for further investigation is whether change in reaction is an indicator of adjustment.

Juxtaposed to the context of family member reactions is the outcome of these reactions. That is, further research which examines the long term consequences of disclosure is necessary. Questions such as, “What are the benefits or costs of disclosure to family members?” “Which reactions lead to adaptive or maladaptive outcomes for the HIV-positive individual and family member?” and “Does disclosure to greater numbers of family members result in greater benefits for the HIV-positive family member?” are more important. Exploring relational consequences are an important next step for researchers.

Finally, although the data for this study come from women who are HIV-positive, these results could be generalized to the experiences of any woman faced with the task of disclosing HIV status information to other family members. For example, reactions expressed to a mother disclosing the HIV status of her son should theoretically be similar to reactions expressed to an HIV-positive mother disclosing her own status to a family member. Therefore, professionals who counsel women who bear the burden of disclosing family HIV information may need to prepare these women to expect or anticipate similar reactions to those presented here. It should be noted, however, men's interpretations of family members' reactions to HIV-infection information may be different from women's interpretations. Consequently, researchers and clinicians should exercise caution when generalizing the results of this study to populations other than adult, heterosexual women. Clearly, comprehensive studies with male populations are necessary. Furthermore, while the content of the information in this study is an HIV-positive diagnosis, this work could be extrapolated to the disclosure of other types of equally stigmatizing or difficult information such as rape, sexual abuse, or abortion.

**Conclusion**

Unquestionably, family member reactions to HIV-positive diagnosis information are multifaceted, complex, and diverse. This study was an initial attempt to disentangle some of these dimensions of reactions to better understand their impact on HIV-positive individuals. Although this study raises a multitude of questions concerning family member reactions to HIV-positive diagnosis information, it is sensitive to the context in which these reactions occurred and the myriad of reactions that are possible. Ideally, therapists and clinicians working with HIV-positive individuals making decisions regarding disclosure can utilize this study as a tool for empowering clients with the experiences of others that have faced similar dilemmas.

**References**


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