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PSYCHOLOGICAL DIFFERENCES BETWEEN HIV-POSITIVE MOTHERS WHO DISCLOSE TO ALL, SOME, OR NONE OF THEIR BIOLOGICAL CHILDREN

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Abstract

This study explored the psychological differences between HIV-positive women who disclosed their serostatus to all, some, or none of their biological children. Data from this project come from a larger, longitudinal investigation of the disclosure process of HIV-infected women. Data were obtained regarding the disclosure processes and the psychological adjustment of women with children ($n = 90$) based on measures of depression, anxiety, and stress. Results suggest that women who disclose to all, some, or none of their children are not significantly different with regard to emotional well-being. Implications for marriage and family therapists are provided.

INTRODUCTION

The number of people living with AIDS has drastically increased in recent years. According to the Centers for Disease Control and Prevention (2003), there are 929,985 reported cases of AIDS in the United States. Previously a disease that occurred among gay men, the rates of heterosexual transmission have changed the demographics of the pandemic (Semple et al., 1997). An increasing number of HIV infections are being diagnosed in women (Centers for Disease Control and Prevention, 2003) and women have become the fastest-growing population living with AIDS in the United States (Kirshenbaum & Nevid, 2002).

In 1985, women accounted for only 7% of adults and adolescents living with AIDS; currently, however, 18% of all diagnosed AIDS cases and 30.7% of all new HIV infections are diagnosed in women (Centers for Disease Control and Prevention, 2003). In 1999, HIV/AIDS was the fifth leading cause of death for women aged between 25 and 44 years in the United States and the third leading cause of death among African American women in the same age group (Centers for Disease Control and Prevention, 2002). Of the 87,940 female adults and adolescents currently living with HIV/AIDS, 73% were exposed through heterosexual contact and 25% were exposed through injection drug use (Centers for Disease Control and Prevention, 2003). Approximately 80% of women with AIDS are within their prime reproductive years (Siegel & Schrimshaw, 2001).

Many HIV-positive women in the United States are mothers. The parental role brings with it stressors and concerns which are exacerbated once a woman is diagnosed with a life-threatening illness for which there is no cure. These effects are clearly evident in the literature. For example, mothers who are HIV-positive are more likely to be clinically depressed than mothers who are HIV-negative (Johnson & Lobo, 2001). HIV-positive mothers also face a unique set of stressors in coping with their diagnosis and deciding whether or not to disclose their serostatus to their children.

Disclosure of one's HIV status is very stressful due to numerous issues such as possible rejection and other negative reactions. The decision to disclose seems to be very calculated, based on weighing the risks and the benefits of disclosure (Black & Miles, 2002; Semple et al., 1997; Serovich, Mason, Lim, & Ostrom, 2004). Many women are particularly concerned about the consequences of disclosing their HIV status to children. Problem behavior and more negative family episodes have been reported in adolescents who have been told of their parents' serostatus (Lee & Rotheram-Borus, 2002; Shaffer, Jones, Kotchick, Forehand, and The Family Health Project Research Group, 2001). Mothers have reported wanting their children to have a carefree childhood as much as possible, not wanting their children to worry about them, not wanting to scare their children, and not wanting to burden their children (Armistead, Morse, Forehand, Morse, & Clark, 1999; Ostrom, Serovich, Lim, & Mason, 2006; Sowell, Seals, Phillips, & Julious, 2003).

Maintaining secrets may be one antecedent of women's poor mental health. Individuals who have experienced a traumatic event are more prone to a variety of illnesses when they have not talked about the trauma (Pennebaker, Colder, & Sharp, 1990). Concomitantly, disclosure of troubling information has been shown to have beneficial effects on one's health (Pennebaker et al., 1990). Disclosure is believed to decrease stress and eventually lead to better psychological health (Pennebaker et al., 1990). When dealing with the traumatic experience of being diagnosed as HIV-positive, research has demonstrated that people living with HIV/AIDS enjoy greater social support when they disclose their HIV status to family and friends. Social support may act as a buffer for the emotional distress that comes with living with HIV (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). Researchers have demonstrated the benefits of disclosure, such as decreased depression and anxiety due to the resultant helpfulness of significant others (Hays et al., 1993).

The relationship between disclosure to children and the mother's mental well-being has received little attention in the literature. Theoretically, if disclosure is therapeutic, women who have disclosed to all of their children should demonstrate less depression, anxiety, and stress than those women who have told some or none of their children. There are numerous reasons for anticipating elevated mental health. First, mothers who tell *all* of their children may be less concerned about the child's ability to keep the secret from other siblings. Second, children who are aware of a mother's HIV status may be able to provide some instrumental support in terms of assistance with household chores. In addition, adult children may provide emotional support in the form of comfort and the mother will not feel so alone with her diagnosis. Studies have found that women have higher disclosure rates to older children (Simoni, Davis, Drossman, & Weinberg, 2000), seeming to enhance the chances that the child will cope more successfully (Shaffer et al., 2001). Women are also more inclined to disclose to their daughters than to their sons (Shaffer et al., 2001). Daughters often assume more household responsibilities when a mother is ill when compared with times prior to the illness (Grant & Compas, 1995). Therefore, mothers who disclose to older daughters may reap more benefits than those who chose not to disclose.

Theoretically, mothers who have told *some* but not all of their children will be very concerned about the child's ability to keep the secret. A family secret is created by telling some and not

all of the children. Family secrets tend to be related to unhealthy communication and problematic adjustment (Wright, Garrison, Wright, & Stimmel, 1991), which can negatively impact the mother's mental health. The mother may worry that the child will tell his or her siblings before she is ready for them to know. Although this child may be able to provide some support and comfort for the mother, it is hypothesized that this group will be less psychologically healthy than women who have told all, but they will be better off than those who have told none.

In contrast, women who have disclosed their HIV status to *none* of their children may worry that their children are suspicious of issues surrounding their health and will have the stress in maintaining the secret. They will also not be able to benefit from any of the comfort and support that may come with disclosure. As a result, women who have told none of their children will most likely be the most depressed, the most anxious, and the most stressed of the three groups. It is hypothesized that women who have told all of their children will experience reduced amounts of depression, stress, and anxiety as compared with women who have disclosed to some or none of their children.

METHODS

Sample

Data for this project comes from a larger, longitudinal investigation of the disclosure process of HIV-infected women. Eligibility requirements were minimal. Participants were women aged 18 years or older who are HIV-positive or have AIDS. For this investigation women must have at least one biological child. Data collected from 90 eligible HIV-positive women who completed Phase 1 of the seven-phase project are included. Women ranged in age from 19 to 63 years ($M = 39.77$ years, $SD = 8.47$) and were primarily African American (71%), with the remainder endorsing Caucasian (22%), Hispanic/Latina (4%), or Other (2%) as their race. More than 17% of the participants were employed and the median monthly income was \$1298. Almost half (49%) of the women were married, partnered, or dating, 32% of the women were single, and 19% of the women were divorced or widowed. These women were reasonably educated; 54% completed high school, 38% were either in college or had some college credit, and 8% had at least a college degree.

Procedure

The Institutional Review Board of The Ohio State University approved all research procedures and instrumentation. Women were identified by personnel at AIDS Service Organizations located in a midwestern state and scheduled an appointment to be interviewed and to complete a questionnaire. Interviews were conducted by trained doctoral-level research associates. All interviewers completed 4–6 hr of training by the Principal Investigator or Postdoctoral Fellow and were supervised weekly. Participation in Phase 1 lasted approximately 3 hr and women were paid \$35 for their time.

Instruments

Disclosure was measured with a social network screening questionnaire. This screening ascertained the extent of the available social network and the actual number of those in the social network to whom they had disclosed. An adaptation of the Barrera (1981) Arizona Social Support Interview Schedule (ASSIS) was used for this purpose. The ASSIS consisted of a series of questions tapping seven dimensions of social support. For example, participants were asked whom they would talk to about things which are personal and private. After the administration of the ASSIS, demographic information on each social support network member was obtained. This included gender, age, race, relationship with the participant, length of relationship, physical proximity, if this person knows they are HIV-positive, and, if so, who

disclosed to them. Data provided on biological sons and daughters between the ages of 5 and 46 years were used.

Depression was measured with the Depressed Mood Scale (CES-D; Radloff, 1977). The CES-D is a 20-item, 4-point Likert-type scale and was chosen because of its brevity, good internal consistency, and excellent reported validity (Radloff, 1977). For this study, Cronbach's alpha = .92.

Anxiety was measured with the Costello-Comrey Anxiety Scale (CCAS; Costello & Comrey, 1967). The CCAS is a 9-item scale developed to measure anxious affective states. The CCAS has good split-half (.70) and test-retest (.72) reliability. In this study, Cronbach's alpha = .84.

Stress was measured with an adapted version of the Stress-Arousal Checklist (SACL; Mackay, Cox, Burrows, & Lazzarini, 1978). The SACL is a list of 30 adjectives commonly used to describe psychological stress. Examples of descriptor adjectives include tense, relaxed, uneasy, pleasant, calm, and stimulated. Participants indicated on a 5-point Likert-type scale the extent to which each characteristic is currently experienced. In this study, Cronbach's alpha = .63.

RESULTS

A one-way multiple analysis of covariance (MANCOVA) was carried out in order to identify possible differences in psychological well-being (i.e., depression, anxiety, and stress) according to women's disclosure groups. The women were categorized as women who disclosed to all children ($n = 46$), women who disclosed to some children ($n = 17$), and women who disclosed to none of their children ($n = 27$).

Before the main analysis, demographic information was examined. Families tended to be rather large, with 32% having four or more children. In total, these women reported having 221 children: 98 sons and 123 daughters. Children included in the study were biological children ages 5 to 46 years ($M = 19$ years, $SD = 9.4$) and 118 (53%) of the children were between the ages of 5 and 18 years. Information regarding child HIV status was not garnered for this study. One hundred forty-four children knew of their mother's diagnosis (77%) and 129 of those children were disclosed to their mothers and 15 children were disclosed to someone else. In addition, 45% ($n = 99$) of the children resided with their mothers in the same household, with an additional 28% residing within the same city limits as the mother. Only 13% lived outside the state. Time since disclosure ranged from 1 month to 14.6 years ($M = 68$ months, $SD = 39$). Furthermore, a chi-squared analysis was conducted to determine the relation between the children's residence and the women's disclosure categories. The results showed that children whose mothers disclosed to none and some were significantly more likely to reside with their mothers compared with children whose mothers disclosed to all ($\chi^2 = 13.17$ with $df = 2$, $p = .001$).

Multivariate Analysis of Covariance

To determine the comparability of the groups, a one-way MANCOVA was performed with scores of depression, anxiety, and stress as the dependent variables after controlling the variance accounted for by the degree of perceived family social support and perceived friends social support. The scores of depression, anxiety, and stress were correlated with each other, ranging from .60 to .75.

In contrast to the hypothesis, the result of a one-way MANCOVA did not reveal differences among disclosure categories regarding their psychological well-being (depression, anxiety, and stress) at the 5% level of significance (based on Wilks's Lambda) [$F(6, 164) = 1.70$, *ns.*]. On the other hand, the controlling variables showed significant effects. That is, the family

social support covariate effects [$F(3, 81) = 7.23, p < .001$] and friends social support covariate effects [$F(3, 81) = 5.63, p = .001$] were significant.

Subsequent univariate analyses showed that the degree of perceived family social support was significantly covaried with the depression scores of these women, while the degree of perceived friends social support was significantly covaried with all three psychological well-being indicators including depression, stress, and anxiety. That is, these women were more likely to report much lower depressive symptoms as they perceived more family social support. Furthermore, as these women perceived more friends social support, they also experienced significantly lower depressive symptoms, stress, and anxiety.

DISCUSSION

The results of this study suggest that HIV-positive women do not experience divergent levels of psychological well-being based on whether they have disclosed their serostatus to all, some, or none of their biological children. This information is important for therapists working with families with a mother who is HIV-positive. Possible explanations include the wide age range of children and varying levels of maturity. Adult children may understand a mother's situation or be able to give instrumental/emotional support. Younger children may not be able to understand their mother's situation realistically and therefore show negative reactions, such as fear, worry, or anger. Some children may be relatively supportive; however, other children may show internalized or externalized problems after disclosure. When comparing their children before and after disclosure, mothers have reported a significant increase in behavior problems in their children as well as a decline in their relationship with that child (Shaffer et al., 2001). Mothers may worry that the negative reactions of children would add more stress rather than improve their psychological adjustment.

The results did show a difference in the disclosure patterns of women based on where their children resided. There were a greater number of mothers who disclosed to some or none of their children when the children resided with their mothers. The concern that family secrets tend to be related to unhealthy communication and problematic adjustment (Wright et al., 1991) makes this finding even more relevant for women who are HIV-positive and whose children reside with them.

This suggests that therapists should be cautious in encouraging women to fully explore disclosure issues, but they do need to be respectful of the individual decisions women make. Many women have made decisions regarding disclosure to their children on a child-by-child basis (Simoni et al., 2000) based solely on their personal appraisals of their children and their own emotions and intuition (Sowell et al., 2003). Based on the lack of difference between disclosure groups, it seems that women are making their decisions based on what is best for them and for their family members. Family therapists should be aware of the fact that there is no one right answer for all women; their situations are all unique to them and their families. In addition, marriage and family therapists who counsel these women should be advised that while mothers disclosing to children may initially feel cathartic and beneficial, there appear to be no substantial gains in decreasing depression, anxiety, or stress. Keeping anticipated emotional benefits realistic may serve to reduce any later residual feelings of being let down. Furthermore, while the benefit of disclosure to children was not investigated in this study, if both women and children do not benefit from disclosure, caution should be taken in promoting its benefits. Results from this study suggest that women are probably making good decisions about their disclosure decisions, which might explain a lack of substantial variation in well-being.

The results of this study provide evidence that with increased family social support there was decreased depression and that with increased friend social support there was decreased depression, stress, and anxiety. Therapeutic goals of helping women who are HIV-positive to assess the possibilities of people in their lives being able to give this support, and to be able to ask for support once they have disclosed, could be beneficial for women. In addition to helping women, family therapy would be a very beneficial platform for discussing the benefits of family social support.

It is plausible that there are other benefits to mothers for disclosing that were not directly addressed in this study. These might include such variables as reduced worry about children, parental self-efficacy, and improved parent-child dyadic relationships. In addition, no child variables were assessed to determine if the children benefited from disclosure. Moreover, child outcomes, such as academic achievement, pro-social behaviors, sexual risk taking, or substance use, were not investigated. Future researchers might consider these variables in their work.

Finally, although an HIV diagnosis has unique variables when compared with other illnesses, such as stigma, discomfort in discussing how the parent was infected, and possible parental guilt over transmission of the illness to the child, it may share some commonalities with disclosure experiences of other parental illnesses. Future researchers should consider the possible mental health benefits of parents disclosing other illnesses to their children.

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