IMPACT OF DISCLOSURE OF HIV/AIDS
DIAGNOSIS ON PERCEIVED
FAMILY RELATIONSHIPS

By

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The first case of Acquired Immune Deficiency Syndrome (AIDS) was diagnosed in the United States in 1981 (Centers for Disease Control, 1988). By 1988, over 55,000 Americans had died of AIDS and 400 new cases were being diagnosed each week. In 1989, "the number of cases reported quietly passed the 100,000 mark," with more Americans lost to AIDS than were killed in the Viet Nam war (Friedman, 1989). The Centers for Disease Control (CDC) identified 501,310 cases of AIDS reported in the United States as of October 31, 1995, with 295,473 confirmed AIDS related deaths through June,1995. Current CDC reports estimate one million Americans are infected with HIV (Centers for Disease Control, 1995).

Kubler-Ross (1989) suggests that AIDS has become the major sociopolitical issue of our time. There is little argument that the HIV/AIDS epidemic is a crisis that demands a clear and continual nationwide response. Preparation for the "next wave" calls for evaluation of HIV/AIDS services to assess appropriateness and effectiveness. Ongoing evaluation must take into account the increased chronicity of AIDS and issues specific to long-term survivors. Psychosocial interventions must be adaptable to newly infected groups and populations. Issues specific to sub-groups such as individuals with AIDS-related dementia must be addressed as the number of persons infected continues to rise. Preventive maintenance for overtaxed community and personal resources is critical as the epidemic's lifespan lengthens and the impact broadens (Buckingham, 1994).

The psychological impact of the disease is clearly and graphically defined in the lives of individuals and their families. The "stories" of those living and dying with HIV/AIDS are reminders that the disease is a juncture at which internal and external scars meet in a profound and devastating way. To listen and hear is to acknowledge that "The face of AIDS is no longer the face of a stranger" (Clinton, 1993). Persons living with HIV/AIDS are found in virtually every segment of the population, with women, children, and people of color currently the fastest growing groups infected (Buckingham, 1994; Centers for Disease Control, 1995; Land, 1994).

An eighteen year old honor student whose hopes of a military career came to an end when her mandatory AIDS test came back positive tells us that "AIDS also kills dreams" (Beachy, 1992, p.46). HIV/AIDS invades the lives of the uninfected as they struggle to cope with the disease in partners, lovers, parents, and children. Death brings an end to coping for the infected. The uninfected are left to cope with continued loss. The New York City Department of Health predicts AIDS will leave as many as 40,000 children orphaned in the next decade (Principi et al., 1992). Hope, age 20, recalls opening the letter from a Santa Monica hospital that contained the news that her mother had tested positive for

AIDS. She tells of her final moments with her mother when she stopped "being strong." "She laid down beside her, put her arms around her and rested her head on her mother's chest. 'I knew I'd never have a chance to feel that again,' Hope says," (Harmon, 1991, p.22).

In a memoir of grief for her dead brother, Ascher (1993) writes that for the last ten years of her brother's life, even when they had contact, Bobby was "our Addressee Unknown." "Now I experience the worst of all pains: The knowledge that it is too late to remedy failed love." Following her brother's death Ascher writes,

> "Don't be fooled by the statistics you read: Grief doesn't read timetables. One morning, three weeks after Bobby died, I arose feeling happy and energetic. Well now, I thought, I guess we've taken care of that. Wrong. The next morning I was awakened by a wail I thought was coming from the storm outside until I realized it was coming from me," (p.92).

Just as a cure for the physical debilitation of HIV/AIDS has eluded us, the psychological and emotional wounds created by HIV/AIDS are difficult to heal.

Walker (1988) writes about the broadening scope of therapeutic interventions in response to the overwhelming context of HIV/AIDS. In 1988, the "families" of persons with HIV/AIDS are being included in treatment not only for the benefit of the HIV/AIDS individual but because the family members are seen as "victims" as well. By 1989 HIV/AIDS related problems are a part of the daily work schedule for some family therapists (Bor, Perry, & Miller, 1989). Although family therapists have seen an increase in AIDS related issues in the therapy room, little has been published in their professional journals in the last 5 years. The need for a clearer definition and understanding of the complex effect of HIV/AIDS on individuals and their families is necessary in order to intervene at this critical point of impact (Green & Bobele, 1994). Clinical experience is valuable in defining and understanding HIV/AIDS. Research that identifies the ways in which the disease impacts individuals and families is necessary for assessment and intervention.

Purpose

This study uses systems theory as a conceptual framework to explore changes that occur in relationships between individuals and their families of origin following disclosure of an HIV diagnosis. An integrated research format of quantitative and qualitative measures is used to identify families in terms of cohesion, adaptability, and affect. This format is used to explore the relationship between the identified family types and the perceived presence, level, and type of support given in response to an HIV/AIDS diagnosis. The study attempts to evaluate needs specific to HIV/AIDS families. Information from this systemic study will provide a meta-view of the psychosocial impact of HIV/AIDS while identifying the diversity of experience and unique characteristics that blend together in each family's response to the disease.

Research on the reality of human experience is limited in that the description of the reality to be studied is based on human perception. The validity of such research is further impacted by the limitations of language. For the systemic researcher however, perception may become the difference that makes a difference. Integrating quantitative and qualitative research with a systemic framework provides a context that defines the "perceived" limitations of the human story as a critical and desirable element in understanding and responding to reality. An integrated design provides a structure for "discovery-oriented" research that includes formal elements (Moon, Dillon, & Sprenkle, 1990). Exploring the experience of HIV/AIDS is the catalyst for a responsible and compassionate response. Disclosure is a critical element in the experience of HIV/AIDS that may involve more than an individual's HIV positive status (i.e. choice of lifestyle, method of contraction). Whether a person determines that his/her HIV positive status should be made public or kept private, disclosure is at the core of the perceived reality of HIV/AIDS. Mental health professionals working with HIV/AIDS report that disclosure of the disease often occurs in stages (Jue, 1994) that are not applicable to other life threatening illnesses (Bok, 1994). Researchers and clinicians must explore the impact of disclosure of an HIV/AIDS diagnosis on families for the response to this crisis to be timely and appropriate. The intent of this exploratory study is to report what HIV individuals identify as critical issues related to family functioning in response to and in the context of HIV/AIDS. The identified issues include implications for intervention and questions calling for future research.

Problem Statement

How does disclosure of an HIV/AIDS diagnosis in an individual impact perceived interaction and affect within the family of origin?

Objectives

1. To identify changes in support given to individuals by their family of origin following disclosure of an HIV positive diagnosis as perceived by the individual.

2. To identify differences between perceptions of support needed and support given by the family of origin of HIV/AIDS individuals following disclosure.

3. To identify the impact of positive and negative affect present within the family on the presence of perceived support before and after an HIV/AIDS disclosure.

4. To identify the relationship between cohesion and adaptability within the family and their style of coping in the context of HIV/AIDS.

Conceptual Framework

Systems Theory. A systemic conceptual framework is more a way of thinking than a standardized theory. The framework is perhaps best known for the descriptor the whole is greater than the sum of all its parts. A systemic frame of reference focuses on the interrelatedness of persons. Systemic therapists look for the process in addition to the content of family interaction. Emphasis is given to the mutual but not always equal influence of family members on each other. This framework identifies levels of systems. Some theorists view the individual as a system as well as the family, community, and organizations with which the family interacts. In this study on relationship changes in families of origin with an HIV/AIDS family member, the individuals, family, and outside resources are all viewed as interacting systems. Mutual but not always equal influence is present among the components within and across the identified systems.

Examining the impact of HIV/AIDS from a systemic frame of reference is critical for three reasons. First, Systems Theory provides a structure for research and practice that observes persons within their life context. A systemic perspective embraces the complexity of relationships rather than attempting to simplify family interaction (Moon et al., 1990). Individual psychology was the foundation for early interventions with HIV/AIDS infected persons. Therapists approached those diagnosed as though they lived and died in a vacuum. A psychosocial response to HIV/AIDS that focuses on the individual as a separate entity limits intervention by ignoring our inherent interconnectedness and reciprocal impact. Whether embraced or alienated, the HIV/AIDS individual does not live or die in psychological or emotional isolation. The impact of the presence or absence of support is felt and calls for a response.

Second, a systemic point of view reminds the researcher and clinician that family members of those diagnosed with HIV/AIDS are not mere spectators but key participants in the drama. Systems Theory facilitates research from the perspective of the participant rather than the researcher (Moon et al.,1990). Recognizing that the disease affects the entire family is the beginning of interventions that are sensitive to each family's cultural and socioeconomic history. The complexity of the disease demands that the family address multiple issues simultaneously. Members may be forced to reconsider their basic values while in transition from a theoretical stance to practical, daily coping. The disease often confronts families with a level of intimacy or "knowing" among members that is in opposition to previous patterns of interaction. The family's most private moments may be open to public view. Whether this invasion of privacy comes in the form of positive resources or negative scrutiny and judgment, the loss is significant. This intrusion leaves families feeling they have no private place and little control over their own destiny. Effective coping with HIV/AIDS requires the use of resources that have often been overtaxed or depleted by the combined effect of other family stressors. Just as the disease immobilizes the physical immune system, the psychosocial threats of HIV/AIDS often seem to weaken or overwhelm traditional methods of emotional coping. Models based on stages of grieving are inadequate in the context of multiple, overlapping losses and prolonged grief (Schwartzberg as cited in Jue, 1994).

Third, a systemic response to HIV/AIDS acknowledges that reactions to the epidemic have the potential of changing the very nature of human social life (Bateson & Goldsby, 1988). HIV/AIDS raises questions about our individual and collective response to human need. These questions force us to examine and clarify the basic societal values we claim to hold. Therapists working in the context of HIV/AIDS must face their clients and themselves with honesty based on self-reflection (Green & Bobele, 1994).

In a review of Kidder's Old Friends, Gates (1993) reminds us that in a culture that holds health and vigor as an ideal we struggle with what to make of a diminished thing," (Frost, 1969, p. 120). Kidder (1993) suggests that life is of incalculable value even in the last days and that if we fail to see that value "we, too, are diminished," (p. 75). He writes, "moral life doesn't have to end with youth or public life, or even with confinement in a nursing home." Kidder eulogizes one of his characters stating, "his life had expanded . . . He'd made himself as useful as he could. He had entered a little society founded merely on illness, and, . . . realizing it was all there was for him, he joined it and improved it," (p.75).

Kidder's words are true of persons living with HIV/AIDS who must find within a "society founded on illness" a way to expand and improve their quality of life. If we turn away from them, refusing to see the value in their lives, we too are diminished. Walker (1988) presents the challenge of HIV/AIDS. "Our choice as a society -- we can treat people with AIDS as the bad, the 'other' and take away their rights, or we can treat this disease as if it belongs to all of us," (p. 51).

Literature Review

Psychosocial research and clinical intervention regarding HIV/AIDS have followed a track that parallels the perception and response of society to the discovery and growth of the disease. In the early stages of the epidemic, many perceived HIV/AIDS as a disease isolated to a specific, minority population; homosexual males. The moral stigma attached by many to homosexuality was woven into society's response to those diagnosed with HIV/AIDS. Research suggests that the integration of morality and discomfort with sexuality in general has led many therapists to avoid involvement in research and publication related to HIV/AIDS (Green & Bobele, 1994). Studies have slowly evolved from addressing intervention with the HIV/AIDS individual (Morin, Charles, & Malyon, 1984) to intervention with families experiencing anticipatory mourning regarding the pending death of an HIV/AIDS family member (Dane, 1991). In addition, studies have begun to identify and respond to the needs of parents coping with pediatric AIDS. With advances in treatment, HIV/AIDS has transitioned from a terminal disease to one increasingly chronic in nature. Other studies have acknowledged the applicability of literature on childhood chronic illnesses while calling for exploration of HIV/AIDS specific characteristics and interventions (Boyd-Franklin, Steiner, & Boland, 1995). With the shift to chronic status, researchers have begun to examine issues specific to long term survivors who must cope with unexpected longevity as opposed to premature death (Jue, 1994). HIV/AIDS is currently impacting families at every level of interaction. The ripple effect of an HIV/AIDS diagnosis opens a Pandora's Box of internal and external trauma involving medical, mental health, and often legal transactions.

The initial response to the HIV/AIDS epidemic in this country came from a small percentage of the medical community. They focused their attention on defining and understanding a virus that seemed to defy clear definition due to an ability to restructure and mask its identity (Macklin, 1988). A similar challenge faces researchers and mental health professionals as they attempt to define and respond to a disease that impacts the family system in a devastating and pervasive manner. The proposed study is a positive step toward research and intervention that identifies HIV/AIDS as a disease that invades families, threatening their structure and function.

<u>Early Psychosocial Intervention</u>. Morin et al., (1984) were the first to publish a response to the psychological

crisis brought on by HIV/AIDS (Macklin, 1988; Cleveland, Walters, Skeen, & Robinson, 1988). The article's individualistic focus on assessment and intervention is representative of the mindset during the early years of the epidemic (Cleveland et al., 1988; Macklin, 1988). In spite of the delay of psychosocial studies and the narrow focus that mirrored the belief that AIDS was a gay men's disease, Morin et al. (1984) brought public attention to two important facts. First, HIV/AIDS is a "profound psychological issue," (p. 1288). Secondly, the support group is a vital part of therapy for persons with HIV/AIDS suggesting a move toward systemic intervention.

Kinnier (1986) addresses the need for psychosocial research and interventions related to HIV/AIDS. The publication expanded the psychological focus on HIV/AIDS, emphasizing the suffering brought on by the "extreme rejection and aloneness" (p. 472) experienced by persons with the disease. Though still tied to the medical arena and individualistic in nature, Kinnier (1986) represents movement toward a broader view of intervention that called for further research on effective social support systems. This strong and important article offers (a) a broader definition of those suffering with HIV/AIDS that ranges from the worried well to those in the advanced stages of the disease, and (b) an effort to heighten public and professional awareness of the epidemic nature of HIV/AIDS by relating the disease to historical epidemics such as smallpox and the black plague.

Families and HIV/AIDS. Macklin (1988) writes on the implications of HIV/AIDS for families, stating that "only recently have family professionals become sensitized to the profound impact of these realities on families and their members as well as on the communities within which they live" (p. 141). Macklin provides a transitional bridge in her writing from a medical focus to a family focus that ties HIV/AIDS to people who experience multi-dimensional suffering and to the families who share their pain. She represents a trend among mental health professionals to consider the broad range of psychosocial issues facing persons with HIV/AIDS and the family systems that provide their care.

Persons with HIV/AIDS and their families must face a broad and often ambiguous range of issues, that is social stigma and isolation, fear of contagion, fear of abandonment and/or rejection, guilt, anger, grief, and economic hardship (Macklin, 1988; Rolland, 1990; Brown & Powell-Cope, 1991). Shanfield, Benjamin, and Swain (cited in Cleveland et al.,1988) point out that AIDS has brought parents face to face with one of the most distressing causes of grief, the death of an adult child.

The well-being of family members, caregivers, and persons with HIV/AIDS takes on an added weight when children are involved. "In New York City, at least 10,000 children have already lost one or both parents to AIDS; some have lost as many as thirteen or fourteen relatives" (Ryan, 1991, p.3). A child with AIDS may face helplessness and vulnerability at the very time s/he is attempting to "master tasks of autonomy, initiative, and industry" (Urwin, 1988, p. 154). Parents may experience bereavement overload as they deal with the struggle of simultaneously hanging on and letting go of their child, as well as grieving for their own losses. Parents often find themselves unable to offer appropriate disclosure to their child about diagnosis and prognosis. They may find themselves in an adversarial role with medical staff who believe the child should be allowed to receive appropriate information as a part of the process of living and dying with AIDS (Lipson, 1993). HIV/AIDS magnifies the importance of effective communication and interaction within and outside the family system.

A systemic frame of reference is important as parents are encouraged to think of disclosure to their HIV/AIDS child as a process that can be gradual rather than traumatic (Lipson, 1993). An understanding of systems is critical in families where siblings suffer psychologically due to the time required to care for a child with HIV/AIDS. These "forgotten children" often experience anger exhibited through acting out behaviors (Boyd-Franklin et al.,1995). Children who must "parent" a parent dying of AIDS are in danger of emotional overload (Urwin, 1988; Evans, Chen, Shidlo, & Caprariis,1994). The stress caused by HIV/AIDS can be devastating to families. If intervention is to fit the need, then intervention related to HIV/AIDS must be aware of and involved with the family system as well as the individual who is HIV positive. Perhaps the greatest danger of HIV/AIDS in the family system is the tendency to make boundaries more rigid. Families responding in this manner may accept isolation at the very time when boundaries need to be permeable, allowing for expansion of resources (Serovich, Freene, & Parrott, 1992). Literature regarding HIV/AIDS has begun to call for a multidisciplinary and multidimensional approach to intervention and support for infected individuals (Williams & Stafford, 1991; Stuntzner-Gibson, 1991; Cates, Graham, Boeglin, & Tielker, 1990; Kelly & Sykes, 1989; Tiblier, Walker, & Rolland, 1989).

Issues surrounding HIV/AIDS touch both public and private spheres. Testing sparks debates over a person's right to privacy versus public health (Macklin, 1988). The dual demands of the protection of public health and the protection of infected individuals has forced closer scrutiny of the U.S. Constitution in general and the fourteenth amendment in particular. Miller and Carlton (1988) address societal debates such as attribution of responsibility for HIV infants abandoned in neonatal units and potential assignment of criminal status to anyone "willfully and knowingly exposing another to the AIDS virus" (p. 555). AIDS, though a relatively recent epidemic, now holds the status of the most litigated disease in U.S. history (American Bar Association AIDS Coordinating Committee, 1988; Burris, S., Dalton, J. L., Miller, J. L., & Yale AIDS Law Project, 1993).

The added dimensions of ethnicity, religion, and social class play a role as defining components of a family. These "criteria" suggest which members are responsible for caregiving, and the role of extended family during crisis times (Tiblier et al. cited in Pierret, 1992). These same factors determine how each family will experience AIDS. Pierret (1992) highlights the diversity of HIV/AIDS stating that though there are commonalities, psychosocial needs will differ with varying categories of persons infected with HIV/AIDS. In addition to gay males, intravenous drug users, and hemophiliacs (Tiblier, et al., 1989; Pierrot, 1992), professionals have identified women (Macklin, 1988; Stuntzner-Gibson, 1991), minor children (Miller & Carlton, 1988; Urwin, 1988; Lockhart & Wodarski, 1989), and adult children (Cleveland et al., 1988; Dane, 1991) as persons living with HIV/AIDS. If attempts to understand and intervene are to be successful, we must consider the ethnic diversity of those affected by HIV/AIDS.

The diversity of persons with HIV/AIDS and the diversity of experience related to the disease have been established (Brown & Powell-Cope, 1991). Mental health professionals have acknowledged the contextual impact of individual circumstances and personal characteristics on decision making and coping responses related to HIV/AIDS. A correlation exists between unique psychosocial stressors within caregiver subgroups and individual characteristics of the person with HIV/AIDS (Brown & Powell-cope, 1991). Diversity in the context of HIV/AIDS is even reflected in the dual classification of the disease as both chronic and terminal (McDonnell, Abell, and Miller, 1991). The presence of HIV/AIDS requires that individuals and families blend the certainty of death with the uncertainty of life. Families must come to terms with the unresolved relational conflicts brought to the surface by the daily stress of the disease (Aranda-Naranjo, 1993).

Systemic Perspectives. If therapeutic intervention is to be effective, the diversity found in persons and families living with HIV/AIDS must be accepted and encouraged as therapists identify family support (Macklin, 1988; Bourne, 1989) and social support and resources (Tiblier et al., 1989; Turner, Hayes, & Coates, 1993). As understanding of the psychosocial implications of HIV/AIDS has grown, helping professionals have increased the use of systemic terms in describing the interaction of individuals and families with the disease, that is defining disclosure of an HIV/AIDS diagnosis as a process that occurs in stages rather than a single event (Cates et al., 1990; Dane, 1991; Brown & Powell-Cope, 1991; Pierret, 1992; Lipson, 1993; Jue, 1994). The emphasis on the benefits of group therapy in helping persons to accept and cope with the HIV diagnosis (Morin et al., 1984; Kinnier, 1986; Rounds, Galinsky, & Stevens, 1991; Getzel,1991) has been broadened to include HIV/AIDS families (Tiblier et al., 1989; Kelly & Sykes, 1989; Williams & Stafford, 1991; Dane 1991), and caregivers (Brown & Powell-Cope, 1991; McDonnell et al., 1991). The inclusion of families in support groups has resulted in a broader picture of who suffers when HIV/AIDS is diagnosed within a family. HIV/AIDS family support groups, though incorporating aspects of other bereavement groups, are unique in that each family may be coping with a different stage of living with HIV or with an AIDS death. Membership falls along a broad continuum of age, often spanning three generations. Members' diversity of lifestyle, socioeconomics, and ethnicity reflect the diversity of the population infected (Anderson & Shaw, 1994).

HIV/AIDS is a relationship problem that magnifies our physical and emotional interactions. The shift from an individualistic focus to a relational one has included an awareness of the reciprocal impact of persons living with HIV/AIDS and those with whom they interact. There is increased awareness of the need to provide care for family and friends who serve as informal caregivers. These caregivers face multiple stressors as they care for those infected in the midst of ongoing responsibilities to career and uninfected family members (Wardlaw, 1994). The psychological transition from cure to management (Rolland, 1990; Pierret, 1992) requires that all involved accept truth that changes from day to day (Zerwekh, 1994). Acceptance that "the condition of a dying person is everchanging," (p. 32) is important if the HIV/AIDS individual and the family members are to make the shift from the hope for physical healing to a healing of the mind and heart found in day to day living. Each loss of function is a signal of changing truth about what is to come (Zervekh, 1994). Persons with HIV/AIDS may respond to these changes with a sense of urgency about life goals. Facing the possibility of a shortened life span may lead to an attempt to reconnect with the family of origin. The person with HIV/AIDS may experience increased support from talking about AIDS concerns with family (Turner et al., (1993). Family members who are faced with stress and fear surrounding the disease may react with full, unconditional support or total rejection (Mortelli, Peltz, & Messina, cited by McDonnell et al., 1991). HIV/AIDS related issues disclosed and/or discussed at the point of death may do more harm than good by leaving families under the weight of unresolved issues (Rolland, 1990). A systemic perspective which shifts the focus of life from an event frame of reference to one of process appears to help families and HIV/AIDS family members to live with a life expectancy "measured in months rather than years" (Zerwekh, 1994, p.32).

Systemic Interventions. Macklin (1988) calls for a team approach as essential to prevent burnout when working with families and HIV/AIDS members. Systemic intervention in the context of HIV/AIDS requires multiple systems interacting for effective caregiving. Coordinated systems of care must identify needs and design programs based on the perceptions of families living with HIV/AIDS (Aranda-Naranjo,1993). Models for therapeutic intervention with HIV/AIDS which incorporate a systemic focus include assessment of family members' willingness to give care for persons with HIV/AIDS (McDonell et al., 1991). This model assesses the strengths within a system, external resources available, and potential obstacles to effective caregiving. The Theory of AIDS Family Caregiving (Brown et al.,1991) focuses on transitional intervention addressing the multiple stages of uncertainty through which caregivers and persons with HIV/AIDS must progress. Rolland (1990) has developed the Family Systems-Illness Model which focuses on grief and loss as encompassing the duration of the illness in addition to the point of death and beyond. The model aims to help the family understand the experience of anticipatory loss. Dane (1991) proposed a conceptual framework designed to deal with tasks specific to the anticipatory mourning of middle aged parents of adult children with HIV/AIDS. The Double ABCX Model (McCubbin & Patterson, 1983) offers a method to identify stressors present within the family system which lead to what is describe as pile-up. The authors define pile-up as the accumulated affect of normative changes, strains and hardships, and/or catastrophe. The ambiguity often associated with these stressors also contributes to the pile-up (Figley & McCubbin, 1983).

Macklin (1988) calls for additional study on families as a unit of care in the context of HIV/AIDS. If mental health professionals are to offer effective intervention to HIV/AIDS families, existing correlations between changes in family interactional patterns and the disclosure of an HIV/AIDS diagnosis into the family system must be identified. Lubkin (cited by McDonell et al., 1991) states that the potential caregiver's willingness to take on the task of caretaking will be affected by the historical patterns of family interaction. Horowitz & Shindelman (McDonell et al., 1991) add that reciprocity and affection serve as motivational determinants for caregivers. The positive and negative feelings of family members toward each other influence the decision to disclose an HIV/AIDS diagnosis. Family members' willingness and effectiveness as caregivers and their use of external resources, that is therapy, extended family, friends, and the family of choice of the HIV/AIDS family member are also influenced by family affect. The coping mechanisms of HIV/AIDS families must be assessed through studies on emotional bonding, recognition of individual autonomy, and the family's adaptability. Data related to the impact of an HIV/AIDS diagnosis on family relationships and interaction will provide information and impetus for appropriate intervention. Family therapists can benefit from knowing how disclosure of an HIV/AIDS diagnosis affects relationship changes within the individual's family.

Effective intervention with HIV/AIDS families depends on a solid base of knowledge that includes both descriptive and empirical studies. Current research related to the psychosocial aspects of HIV/AIDS in families is largely descriptive. The research data is from anecdote and clinical observation. There is a need for ongoing research that examines the family as a unit, focusing on how subsystem interaction is affected by the process of disclosing an HIV/AIDS diagnosis. Information is also needed on how family interaction with other systems changes in the presence of HIV/AIDS (Boyd-Franklin et al., 1995). Empirical research provides the facts that identify the critical need for development of HIV/AIDS specific interventions. Descriptive studies become the heart of intervention, allowing HIV/AIDS families themselves to identify their needs. The complex nature of HIV/AIDS requires research that utilizes both empirical and descriptive methods. Research containing both quantitative and qualitative aspects provides a viable structure through which to gather and report data reflective of the diverse populations and family configurations affected by HIV/AIDS. Though there are some commonalities shared by those infected with HIV, there are contexts, issues, and symptoms specific to each group (i.e. physiological symptoms related to the reproductive system in women, developmental issues in children). Research designs must be structured to support valid data collection while providing the flexibility necessary to accommodate to the unexpected and sometimes rapid changes that occur in the HIV/AIDS environment. Interventions must be innovative and adaptable to meet the unique needs of each context and set of issues while acknowledging that each context is interconnected with other contexts to create a complex whole.

Method

This research study examines perceived systemic changes that occur in relationships of HIV/AIDS individuals and their families following disclosure of an HIV positive diagnosis as operationally defined with four areas of focus: cohesion, adaptability, affect, and support. The research design combines quantitative and qualitative methods to explore the impact of disclosure on families.

Participants

The purposive sample for this study includes six individuals, 18 years of age or older from the Southwest region who have tested positive for HIV. Participants include 5 males and 1 female with ages ranging from 36 to 54 years (M = 43, S.D. = 7). The length of time participants have been HIV positive ranges from thirteen months to seven years, four months (M = 3.7 years, S.D. = 2.5). Four of the six participants reported a current diagnosis of AIDS. One participant reported the presence of HIV without a diagnosis of AIDS. Another participant reported an HIV positive status verbally, but declined to respond regarding HIV/AIDS status on the pencil and paper background form. Due to the vulnerable population, significant attention was given to protect the participant's confidentiality. The study was conducted with sensitivity to emotional and physical fatigue factors while administering the measurements. Participants were debriefed following the study to reduce the risk of negative emotional impact.

Materials

Personal History Questionnaire. (Appendix D). The personal history questionnaire contains demographic information such as gender, race, sexual orientation, date tested positive for HIV, socioeconomic background, and religious preference.

Family Adaptability / Cohesion Evaluation Scales, (Olson, 1979). (Appendix D). FACES III is a 20-item self report scale designed to measure emotional bonding (cohesion), ability to change (adaptability), and communication within a family system. The inventory has a projected time requirement of 10-15 minutes. This inventory was administered twice, once to measure the individual's perceived reality of the family system on these three dimensions prior to disclosure of HIV status and once in terms of the perceived reality at present. The Circumplex Model (Maynard & Olson, 1987) was used to analyze results from FACES III, identifying family types and plotting distance between the participant's scores on perceived family functioning before and after disclosure of an HIV diagnosis, (Appendix C, Figure 1. & Table 2).

A summary evaluation of FACES III as found in Olson (1979) describes the inventory as a theory based scale with both reliability and validity. The evaluation identified cohesion with a test $r = .77$ and test/retest $r = .83$, adaptability $r = .62$ and test/retest $r = .80$, and total $r = .68$. FACES III is an established and well developed standardized inventory and is generalizable to multiple family types and configurations.

Inventory of Family Feelings, (Lowman, 1974). (Appendix D). The Inventory of Family Family Feelings (IFF), Form 3, is a 38-item inventory which may be used as an interview or self report. The inventory has a projected time requirement of 10 to 15 minutes for completion. Participants respond to questions concerning: (a) positive and negative feelings toward individual family members, and (b) members' perceived feelings toward the participant. The IFF was administered twice in a self-report format. Participants responded to the first administration regarding perceived family feelings in the family of origin prior to disclosure of an HIV diagnosis. The second administration provides data on perceived family feelings in the family of origin at present.

Reliability for Form 3 with factor analytic scales shows coefficients of .96 for the Actual Affect and .95 for Perceived Affect. Lowman cautions that the IFF is not a "fully developed and standardized psychometric instrument" warning researchers of the danger of interpreting data as "having more generalizability and scientific merit than is appropriate at this time," (Lowman, 1974).

Support for validity comes from two studies. A family field study was conducted with pathological and nonpathological families (Loman, 1974), and Fineberg and Lowman (1975) conducted a study of marital adjustment. In the field study, pathological families algebraic sum scores were significantly lower than those of non-pathological families. Relationships involving the identified patient in the pathological families were significantly less positive than the corresponding relationships in non-pathological families. In the marital adjustment study, positive feeling scores for all subjects correlated .64 with positive affect scores.

HIV/AIDS Semi-Structured Interview. (Appendix D). The HIV/AIDS Semi-Structured Interview (HSSI) is a 45-60 minute face to face interview developed by the researcher for the purpose of this study. The HSSI uses open-ended questions (i.e. "How did you find out you had HIV?" and "Who was the first person you told?") to explore family structure, the experience of disclosure, and the individual's perception of support. An audio recording was made of each interview to aid in transcription. Only first names were used during the interview and are available only to the researcher conducting the interviews. Transcripts were coded with an identification number for purposes of confidentiality.

Procedure

The researcher identified HIV/AIDS related agencies and programs in the region and established a prospective research network through contact by phone and mail. A summary of the research purpose and procedure, prospective participant abstract, and informed consent forms were submitted to those agencies expressing an interest in being involved with the study. (See Appendix A for research summary and participant abstract, Appendix B for informed consent form). Personnel at cooperating sites made participant abstracts available to clients. Prospective participants called a designated, confidential phone number to report their interest. The researcher then scheduled a data collection appointment with each participant.

Prior to data collection the researcher reviewed the purpose and structure of the study and the informed consent. Participants were given the opportunity to ask questions prior to signing the consent form. Data collection began with participant response to the Personal History Questionnaire. The researcher then administered the Family Adaptability and Cohesion Evaluation Scales and the Inventory of Family Feelings respectively to record the participant's perception of family closeness, adaptability, and affect prior to disclosure of HIV. The audio-taped HIV/AIDS Semi-Structured Interview followed, during which the participant reported on the experience and perceived impact of disclosure. Participants were then asked to respond to a second administration of the FACES and IFF inventories based on their perception of current family cohesion, adaptability, and affect. The researcher gave each participant an opportunity to debrief following data collection. Debriefing included participant questions and feedback, as well as researcher/participant dialogue.

Each participant was assigned an identification number to protect confidentiality. Assigned numbers were recorded on all paper and pencil inventories. The semi-structured interviews were transcribed from audio-tape. The participant's identification number was recorded on the audio-tape and transcriptions prior to analysis. The data summary and report are available to participants and cooperating agencies upon request.

Analyses

Descriptive statistics were used to analyze data. Data obtained through the Personal History Questionnaire was reviewed and presented in written and tabular form to indicate the demographic context of the study, to provide data for future research, and to identify gaps in data that suggest where additional and/or broadened exploration is needed. The Family Adaptability and Cohesion Evaluation Scales were scored and plotted on the Circumplex Model Profile, identifying movement within and across family types as indicated by changes in cohesion and adaptability scores before and after the identified point of disclosure of HIV. The Inventory of Family Feelings was scored for individual scores to identify the respondent's positive/negative rating of each family member. Individual responses were scored from three perspectives: total affect score, perceived and actual affect scores, and positive/negative/neutral response scores. Written, graphic, and tabular displays were used for presentation of results. Analysis of the HIV/AIDS Semi-Structured Interview was issue focused and generalized. Inductive analysis and constant comparative method (Weiss,

1994) were employed as results were coded, sorted, and integrated. Common themes across participant reports were identified for generalization to individuals and families living with HIV.

Results

Demographic information obtained from The Personal History Questionnaire provides limited information to support the fact that HIV/AIDS is not confined to a single sector of the population, but cuts across gender, ethic, and socioeconomic lines (Appendix C, table 1). Analysis of the questionnaire suggests important topics for future research which are addressed in the implication section of this paper.

Analysis of FACES indicates perceived movement in all respondent's families ranging from minimal movement within a family type to significant movement across family types. Changes occurred in both cohesion and adaptability, with adaptability showing the greatest increase (Appendix D, Figure 1). FACES places families in one of four identified levels of cohesion: (a) disengaged, (b) separated, (c) connected, (d) enmeshed. The mid-range levels are noted to be more balanced than the outer levels (Olson, 1979). Scores for perceived cohesion prior to disclosure ranged from 10-33 ($M = 20.8$, $SD = 8.7$), identifying all participants' families as falling within the disengaged range of 10 to 34. Scores for post-disclosure perceptions on cohesion indicated a more narrow range of 11 to 29 ($M = 24$, $SD = 7$). All six participants indicated minimal changes in cohesion, still within the disengaged range. The four levels of adaptability range from: (a) rigid, (b) structured, (c) flexible, (d) chaotic. Mid-range levels of adaptability are hypothesized to be most suitable for healthy family functioning (Olson, 1979). Pre-disclosure perceptions of family adaptability ranged from 15 to 24 (M = 19, SD = 3.3), with three families in the rigid category (10 to 19) and three families in the structured category (20 to 24). Post-disclosure adaptability scores fell along a broader range from 15 to 38 (M = 25, SD = 8.9). Changes in adaptability reflected greater diversity than those in cohesion, with two participants remaining in the rigid sector, while two participants reported a shift to the flexible family type (25 to 28), and two to chaotic (29 to 50).

Analysis of IFF indicated a positive increase in perceived total family affect in five participants, ranging from 2.2 to 8.7 points (M = 5.5, S.D. = 2.79) compared to a perceived reduction in total affect of 1.25 points in one participant's score. Composite scoring indicated the six participants perceived an increase in positive affect toward fourteen of twenty-three family members, a decrease in positive affect toward two members, and no change in positive affect regarding one family member. Increase in negative affect was noted in only one family member. Table 3 (Appendix C), identifies participant scores for positive, negative, and neutral responses. A mean of differences t-test (alpha = .05, df = 5, t = 2.015) was completed on the difference between participants positive and negative scores from pre-disclosure to post-disclosure. Results indicated a significant increase in participants' perception of current positive family affect from perceived positive affect prior to disclosure.

Responses were also scored for actual and perceived affect. Twenty-three of the 38 inventory questions tested actual affect, with fifteen questions related to perceived affect. Figures 2.1 - 2.6 (Appendix C) represent the comparison of pre-disclosure and post-disclosure actual/perceived score for each family member by family unit. Table 4 (Appendix C) identifies the directional and numerical breakdown of actual/perceived scores for participant responses to twenty-three (23) family members. The highest number of responses were reported regarding simultaneous positive increases in actual and perceived scores for ten (10) family members. Results also indicated three (3) scores in which participants' actual feelings toward a family member decreased while the same family member's feelings toward the participant were perceived as having increased. Actual scores on 23 family members reflected a pre-disclosure mean of 11.52 (SD = 7.44) compared to a post-disclosure mean of 14.39 (SD = 7.92). Actual positive affect response scores indicated an increase in actual positive affect toward fifteen (15) family members, a decrease toward four (4) members, and no change toward four (4) members from pre-disclosure to post-disclosure. Perceived scores on 23 family members had a pre-disclosure mean of 6.52 (SD = 5.03) and a post-disclosure mean of 8.04 (SD = 5.17). Perceived positive affect scores reflected an increase regarding fifteen (15) family members, a decrease from two (2) members, and no change regarding six (6) members from pre-disclosure to post-disclosure.

Analysis of interview data identified three issues significant to individuals and families living with HIV: (a) disclosure, (b) support, and (c) integration. Identifiable sub-categories were present in each issue with one sub-category shared by both support and integration. Responses from participants support the three stated categories as related to the individual experience of living with HIV. The data also suggests a reciprocal, if not equal, experience between families and the member diagnosed as HIV positive.

Disclosure

Disclosure is descriptive of the complexity of HIV. Respondents reported that being told of their HIV status and the initial disclosure to others has characteristics of a marker event occuring at a single point in time. However, the issue of disclosure quickly shifts from a single experience in time to a process punctuated by multiple experiences of telling others and continually acknowledging the reality of the diagnosis to oneself.

As an event, disclosure may trigger traumatic experiences that become a part of the process. One participant described the experience of disclosing his HIV status to his boss, anticipating a response of warmth and support based on friendship. He was surprised and hurt to find her afraid and distant, a response that continued until he quit his job. Another participant described the devastation of having the decision to disclose taken out of her hands as test results were erroneously mailed to a family member's place of business where a secretary opened the results and told others about the individual's HIV diagnosis. The participant stated that she was virtually the last person in her family to find out she had tested positive for HIV. These same participants however, described the process of disclosure as having elements of self-discovery that have a positive effect on the HIV individual and others.

Support

When asked about the issue of support, participants described a practice of accessing two sectors: the private sector of the family, and the public sector which included friends, professionals, and the AIDS community. Those interviewed reported utilizing family support for help with financial issues both in terms of monetary support and estate planning. Participants tended to identify one or more siblings who served in a blended role meeting both emotional and practical needs. Most participants were in agreement that placing parents in a primary role could be problematic. They identified parents as having the tendency to become overinvolved emotionally, leading to difficulty dealing with the realities of the disease without disempowering and controlling their HIV positive adult child. Participants perceived siblings as better able to offer emotional support with objectivity which allows the HIV individual to maintain appropriate independence and a sense of dignity.

Education was reported as a significant factor in familial support. Participants identified increased education on HIV/AIDS as the pivotal issue affecting change in family members' response from negative and/or detached to one of positive support. Family members who refused opportunities for increased information on the physical and psychological aspects of HIV/AIDS tended to display their fear by continued detachment from the individual diagnosed. Participants reported the presence of some degree of detachment with these family members prior to disclosure, with an increase in negative affect and detachment following disclosure. Participants also reported that increased education has a direct effect on family members' ability to offer positive and appropriate support.

In terms of the public sector, support takes on the practical aspects of networking with professionals to gain access to health care, legal advice, and psychosocial support. Support drawn from the AIDS community is critical for the subjective understanding of those who share a common experience. Support from friends outside the AIDS community helps persons living with HIV/AIDS to interact in a context other than that of the disease itself. Participants expressed the desire to be a part of relationships and activities that allowed them to focus on something other than their HIV status.

Integration

Two sub-categories related to integration emerged particularly as participants talked about the experience of living with HIV and the process of weaving that experience into the fabric of their lives. The sub-category of education was shared between the categories of support and integration. Participants followed a pattern identified by those working with HIV positive individuals as they reported a focus on HIV/AIDS education as one of their first responses to the diagnosis (Bor, Miller, Salt, & Scher (1990). Increased knowledge about the disease appeared to have allowed the persons diagnosed to maintain some sense of control over their own lives. Knowledge also helped the interviewees to focus on the task of living with HIV rather than being overwhelmed by fears and anxieties related to the uncertainty and complexity of the disease.

The two sub-categories specific to integration appear divergent. Participants tended to talk about them simultaneously however, suggesting that a deeper look might reveal a common thread or connection between the two. Participants reported a significant need to attribute meaning and purpose to their experience with HIV. Most described an active search to find or creat the positive, the hopeful, in the midst of a heightened awareness of their own mortality.

One interviewee stated, "As crazy as it sounds, AIDS saved my life." Another reported wanting to send the message that the experience of living with HIV is "not all bad." One participant asked to be "understood, not pitied." Five of the six participants were actively involved in support groups, volunteerism, social and/or political activism. Some described their involvement as a way to give back some of what others had given to them. One reported a need to give, knowing that the time would come when she would need others to give to her. Another person living with HIV painted an eloquent word picture of his experience as a long-term survivor reaching out to those "just coming," and carrying those who "have gone before."

In the midst of a search for purpose and meaning that involves high levels of activity and interaction with others, participants gave a clear and contrasting message that isolation is a significant aspect of living with HIV. Some described the isolation that comes with loss, stating "As soon as you make a friend, they die." Others described isolation related to previewing your own death over and over again in the death of friends and acquaintances. One interviewee described his fear that he was in the early stages of dementia. He reported his feelings of isolation related not only to losing others, but to progressively losing himself.

Discussion

The blending of quantitative and qualitative research methods in this study produced a research experience that became a microscopic, somewhat symbolic reflection of the experience being reported. The ABA design of reporting pre-disclosure perceptions through pencil and paper inventories, "disclosing" to the researcher in a face to face interview, and reporting post-disclosure perceptions through the same written questionnaires duplicates the cycle of internal processing and external disclosing that is central to the experience of living with HIV/AIDS. Four of the six respondents reported that participation in the study had afforded them personal benefit in addition to the satisfaction of helping to further HIV/AIDS research.

Participants' statements reflecting the personal therapeutic value of the research experience suggests that population vulnerability in research with human subjects can become a positive rather than negative research component. The replication of human experience as a process blending therapeutic and research techniques may be of particular value to HIV/AIDS participants in light of their reported search for meaning and purpose in the midst of isolation and disenfranchisement. A participant confirmed the value of the research experience in processing his life experience as a long-term survivor of HIV/AIDS as he commented on ways in which both inventory and interview questions made him stop and think about things related to his family that he had not thought about in a long time. Another participant identified concluding the research appointment with the realizationi the context of AIDS as well as the challenge of therapeutic intervention as she writes, "The very notion of AIDS and the family is paradoxical. I believe we want to keep family in the AIDS picture, recognizing both its usefulness and its vulnerability; yet circumstances compel us to redefine the AIDS family in such a way that it no longer lends itself easily to conventional family therapy." (p. xi). Therapists may be challenged to step outside their established, predictable, and comfortable patterns of client interaction. Systemic therapists must avoid abandoning a systems approach for one that focuses on the diagnosed individual as operating apart from the family (Taylor-Brown & Garcia). HIV/AIDS calls for the willingness to be innovative in helping persons cope with the disease.

Family Affect

Results indicating that a diagnosis and disclosure of HIV may be a pivotal juncture in family interaction is critical to the development and implementation of appropriate interventions. Participant reports of significant reconnection in families having experienced clear cutoffs suggests disclosure of HIV as a teachable moment for therapeutic intervention with individuals and families. Whether the desired outcome is a literal connection with one's family or the connection that comes from internal resolution of family of origin issues, the moment(s) and process of disclosure become both point of entry and catalyst for therapeutic work on family relationships. The mixture of positive, negative, and neutral affect toward each family member supports the ambivalence in relationships that is exacerbated in the context of HIV/AIDS. The presence and identification of perceived and actual affect supports the importance of systemic intervention that recognizes the reciprocal impact of family members' perceptions on family functioning and interaction.

Disclosure

Interview results support the historical view that disclosure is a significant and often traumatic event. Therapeutic work with families immediately surrounding the point of disclosure must be prepared to respond to multiple losses and overwhelming grief. One participant reported the belief that if he was ever diagnosed with HIV, he would commit suicide to spare himself and his family the pain of watching him die with AIDS. Literature supports the participant's experience, raising the importance of timely intervention to a critical level (Cote, Biggar, & Dannenberg, 1992; Mancoske, R. J., Wadsworth, C. M., Dugas, D. S., & Hasney, J. A., 1995).

Strong evidence is woven throughout participants' stories that disclosure is also a daily process that occurs in stages. Daily issues include the repeated decision of whether or not to disclose to persons coming and going from the HIV individual's sphere of interaction. This moment by moment decision taps the fear of rejection and ostracization. One participant reported a sense of obligation to disclose that is related to beliefs about honesty and truth to oneself. There is a need for therapy that is sensitive to the constancy of this issue. Therapeutic processing can validate the individual's feelings and explore realistic actions and expectations related to disclosure.

Support

The greatest impact from participant reports regarding support in the context of HIV/AIDS may be in the opportunity for therapists and other professionals to help families identify and access their own internal support systems, matching capabilities and willingness to the identified needs of the HIV individual. Families can also benefit from professionals who use their area of expertise and resources to educate families on what resources are available, suggesting that families have more viable options than they may be able to see.

Therapists with a systemic theoretical foundation can offer families the opportunity to redefine what may be a perspective of one-way support in which family members are perpetually "giving" to the HIV member. Families can reduce their own risk of burnout or compassion fatigue and offer respect and dignity to HIV members by shifting to a perspective of two-way support allowing all family members to give and take interactively as in the description by one participant of the need for reciprocal patience between HIV individuals and those not infected. Therapeutic work with families to improve communication is necessary to clarify messages and expectations related to family members' needs and the willingness and capability of other members to meet the stated needs.

Integration

Participant reports in regard to finding meaning and purpose in the midst of HIV suggest the importance of opportunities to think aloud with those who empathize with and those who share the experience of life with HIV. Responses to the reported study verify the value of telling one's story. The fact that someone else hears, and to some degree, experiences another person's history communicates to the teller that her history matters. The fact that the teller hears, and to some degree, reexperiences her history allows for the continued weaving of life events into life's fabric. Both elements mentioned are important avenues to a sense that one's life has meaning and purpose in the midst of uncertainty and loss.

In terms of isolation, this study cautions against interpretation of activity and involvement in persons with HIV as clear signs of effective coping. Participant reports of commitment to activism and volunteerism may indeed identify an effective coping mechanism. Those same reports however, clearly call for recognition of and response to the inherent and pervasive isolation felt by HIV individuals, and to some degree by their families. Identifying the need for autonomy and privacy must be balanced with a recognition of the feeling of being alone that is inherent in the experience of HIV. The ability to separate the beneficial aspects of the aloneness present in human experience from the detrimental isolation of rejection or self-imposed exile is a critical therapeutic issue.

Limitations

Researcher bias must be acknowledged in studies involving human subjects. The potential for bias increases when researching toxic and/or emotional issues. HIV/AIDS is recognized as a disease and experience that produces a wide range of responses, many of which are based on emotion. Researcher bias may include an emotional response related to the presence of HIV/AIDS and the impact of the disease on people's lives. The strength of such a bias is in the energy and commitment brought to the research. Using pencil and paper inventories developed by others to assess general family characteristics of cohesion, adaptability, and affect offer moderate protection against a study skewed by the researcher's bias. Additional steps were taken to reduce the impact of bias by using a uniform semi-structured outline for all interviews. Transcripts of interviews were transcribed verbatim to reduce the risk of substituting researcher interpretation as fact.

The flexibility required to access a sample in a vulnerable population such as persons with HIV/AIDS often involves collecting data in less than controlled circumstances. Adhering to a uniform administration of the research design helps reduce the risk of results skewed by environmental factors. The advantage of helping participants feel at ease by conducting research in familiar surroundings outweighs the loss of environmental control. There is much to be gained by observing the participant in the context of their home environment. Study results also suggest that participant anxiety regarding confidentiality may be reduced by the researcher's willingness to meet in the participant's home. This reduction in anxiety may allow participants to offer a clearer picture of themselves and their experience. This study demonstrated the range and fluctuation of physical and mental capacity in HIV individuals and the potential impact on collecting data. The fact that a major portion of the data collected pertained to the individual's perception of life experience and related feelings and responses rather than the reporting of factual information such as times and dates reduces the risk of erroneous data and/or skewed test results.

An adequate sample is critical to the generalizability of research. When researching a vulnerable population the risk of a small sample is increased. Though the sample of six is a limitation in the current study, the limited research regarding disclosure and family coping suggests the importance of exploratory studies in this area.

Implications

Aspects of living with HIV/AIDS identified and discussed in this study suggest the need for developing and implementing innovative and flexible therapeutic strategies.

Continued research is necessary to collect data from a larger sample in order to verify patterns of response and coping infered by a smaller sample. An increase in demographic diversity is necessary for generalization to a larger population.

Due to the breadth and complexity of HIV/AIDS, ongoing research is called for to identify, understand, and intervene in the diversity of stages and experiences that are a part of the disease. The blending of exploratory and empathic connection in the current study suggest the importance of research that is sensitive to the people and the experience of living with HIV/AIDS. The aggressive nature of the disease calls for recognition of the urgency of timely intervention. The significance of the disease's impact raises the challenge of conducting and translating research into intervention simultaneously. Future research must include the entire family system of persons with HIV/AIDS. Participants in the current study, though few in number, have given a clear message, both verbal and written, that their experience with HIV/AIDS has magnified the experience of being a part of a family. The participants also identified the importance of clear but permeable boundaries in accessing family resources. Valuable information has been gained from the diagnosed person's perspective. Consensus is needed however to more accurately assess changes in cohesion and adaptability in the context of HIV. The perspective of multiple family members is important in determining changes that occur in family structure and functioning following the death of a family member due to HIV/AIDS. Data is needed that is inclusive of families falling in the flexibly connected and chaotically enmeshed typologies to assess whether more connected and flexible families shift toward a more disengaged structure while maintaining and/or increasing flexibility.

Identifying disclosure as a critical point of intervention with HIV/AIDS suggests the need to utilize counseling just prior to testing for HIV as well as when post-test results are reported. These identified times of vulnerability are important opportunities to connect individuals and families with therapeutic resources. Results from the current study identify the importance of helping families identify inherent strengths as well as ways in which they can become more adaptable. Reports from study participants suggest that families attempt a shift toward greater flexibility that may be facilitated through therapy.

Helping families identify boundaries and changes that are necessary to maintain a sense of autonomy for the person living with AIDS while being permeable enough to allow for appropriate familial and extra-familial support is an important therapeutic aspect. The ongoing issue of disclosure as related to other family members and society in general must be identified and addressed in therapeutic encounters with HIV/AIDS families. Helping families cope and adapt to the physical and emotional changes that are a part of the diseases symptomology are critical in helping families find the balance in holding on and letting go. The need persons living with HIV/AIDS have for a compassionate response is important. The current study also suggests that many individuals and families in the context of HIV/AIDS have gained a depth of wisdom about the meaning of life and death that we can benefit from. A participant, also a long-term survivor of AIDS, reflected on the paradoxical experience of being young chronologically, with the hopes and dreams of young adulthood; and being aged physically, with the debilitation one might expect near the end of a long life. His words caution us against the delusion that time is on our side.

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APPENDICES

IMPACT OF DISCLOSURE OF HIV/AIDS DIAGNOSIS ON PERCEIVED FAMILY RELATIONSHIPS

Appendix A

Information for Cooperating Sites

Prospective Participant Abstract

HIV/AIDS Psychosocial Research

Researchers: Paulann Condray Canty and Dr. Kathleen Briggs, Department of Family Relations and Child Development, Oklahoma State University.

Proposed Study: Impact of Disclosure of HIV/AIDS Diagnosis on Perceived Family Relationships

Background and Purpose of Research:

Research has produced significant evidence that the presence of HIV/AIDS in an individual impacts those within that individual's sphere of relationships, affecting such arenas as family, extended family, family of choice, workplace, community, and support groups. Research has been limited however, in regard to the degree and manner in which each of these arenas is impacted. Although evidence suggests that support plays a key role in helping the persons cope with HIV/AIDS, research has not identified the role of familial support and which persons are recipients of this support. Moreover, there is a need to look at change in familial support over time from pre-disclosure to post-disclosure.

The purpose of the proposed research is to explore the impact of disclosure of an HIV/AIDS diagnosis on perceived changes in closeness, adaptability, and support within the family of origin.

Respondents:

The respondents will consist of individuals 18 years of age or older who have tested positive for HIV/AIDS. The intent of the researchers is to recruit a sample diverse in gender, sexual orientation, and ethnicity.

The sample will be recruited from hospitals, support groups, and outpatient facilities in the Southwest region. The person with HIV/AIDS will initially be made aware of the opportunity to participate in the study through personnel at the cooperating sites.

A brief written summary of the study will be given to the respondent. Individuals interested in participating in this important study may contact the researchers by phone or mail at the Center for Family Services, 103 Human Environmental Sciences West, Stillwater, OK 74078, (405) 744-5058. A time will then be scheduled to complete inventories and an interview. The respondent will be given a copy of the informed consent form at the interview appointment. The researchers will explain the purpose of the study and the potential positive and negative effects to the participant. Opportunity will be given to ask questions regarding the study and/or the participant's involvement. When questions have been answered to the participant's satisfaction the researcher will request that the informed consent form be signed by the participant.

Study Measures:

Measures for the current study are both quantitative (paper and pencil questionnaires) and qualitative (interview with open-ended questions). The following is a list of the measures to be used.

1. **Inventory of Family Feelings (IFF), Form 3** -- This 38 item instrument will be taken twice, once in response to current feelings and once in response to feelings prior to disclosure of diagnosis.
2. **Family Adaptability/Cohesion Evaluation Scales III (FACES)** -- This 20-item measure will be taken twice, once to describe the present and once to describe pre-disclosure perceptions of family closeness and flexibility.
3. **Personal History Questionnaire** -- This questionnaire records demographic information.
4. **HIV/AIDS Semi-Structured Interview** -- The semi-structured interview will ask open ended questions concerning perceived changes in family relationships from pre-disclosure to post-disclosure of an HIV/AIDS diagnosis. The interviews will last approximately 45 minutes and will be audiotaped. Names will not be used on the tapes to protect confidentiality.

Copies of the instruments are available upon request.

Potential Risks of Study:

There appear to be three possible risks for this proposed project. These risks include fatigue, psychological discomfort in answering questions, and breech of confidentiality of data and records. These risks are outlined below with the accompanying precautions to be taken.

First, participation may result in fatigue due to the length of the questionnaires. The researchers believe the questionnaires selected provide a balance between brevity and gathering necessary information. To help alleviate possible fatigue, the participant will be allowed to take breaks as needed. In addition, the interviewer will be available to answer any questions the participant may have to prevent the task from taking any longer than necessary.

Second, it is possible that the participant may experience some psychological discomfort by the questions asked. The participants are vulnerable, nevertheless this risk is seen as present regardless of the research project. A trained therapist will conduct the semi-structured interview to alleviate further risk. The interviewer will be available to answer any questions the participant may have and to assess and process any emotional or psychological discomfort experienced. The interviewer will end the interview if it appears there is undue stress for the participant. Moreover, the interviewer will remind the individual that participation is voluntary and may be stopped at any time without consequence.

Third, confidentiality will be maintained to protect the participant's rights in the following ways:

a. Questionnaires will be coded with an identification number. Only the researchers will have access to the numerical code.
b. Participants' names will not appear on the questionnaires or audiotapes.
c. Informed consent forms will be kept separate from the

questionnaires and interview tapes.

d. All consent forms, questionnaires, and audio tapes will be kept in a locked filing cabinet.

f. All personnel will be trained in confidentiality.

Participants will be informed of this procedure and will be told that the results of the study may be published but no names will be revealed. Any potential breach of confidentiality will be minimized through constant vigilance.

Benefit to Participants:

One benefit to participation in the study comes from greater awareness of resources and support available to the participant from within the family of origin and from external sources. The possible benefits to society will include the ability to identify ways in which disclosure of an HIV/AIDS diagnosis impacts families. This information will facilitate development of better support and interventions for families and individuals living with HIV/AIDS.

Benefit to Society:

Participants in this study will have the opportunity to increase societal awareness and deepen understanding of the impact of HIV/AIDS on individuals and families. HIV/AIDS statistics tell us that "something must be done." Statistical information from this study will provide a broadened database to aid in further research and development of interventions. The personal story of living with HIV/AIDS tells me that "I must do something." The stories from this study will remind us that HIV/AIDS impacts each of us and will teach us how to respond with compassion to the individuals and families who live with this disease.

Additional Contact Information:

Prospective participants and/or cooperating sites may also contact Paulann Condray Canty at her home phone number which is within the OKC calling area. The number is (405) 273-8129.

Participant Abstract For HIV/AIDS Research

Researchers: Paulann Condray Canty and Dr. Kathleen Briggs, Department of Family Relations and Child Development, Oklahoma State University.

Proposed Study: Impact of Disclosure of HIV/AIDS Diagnosis on Perceived Family Relationships

Background and Purpose of Research:

Research has been limited in regard to the degree and manner in which relationships are affected by an HIV/AIDS diagnosis. Research has not identified the role of familial support and which persons are recipients of this support. Moreover, there is a need to look at change in familial support over time from pre-disclosure to post-disclosure.

The purpose of the proposed research is to explore the impact of disclosure of an HIV/AIDS diagnosis on perceived changes in closeness, adaptability, and support within the family of origin.

Who can participate?

- Individuals 18 years of age or older who have tested positive for HIV/AIDS.

How can I participate?

- Contact the researchers at **The Center for Family Services, 103 Environmental Sciences West, Stillwater, OK 74078, (405) 744-5058.** All contacts at the Center for Family Services are confidential.
- The researchers will contact those interested to schedule an appointment.

What will happen during the research appointment?

- An informed consent form will be provided and the purpose of the study explained.
- Opportunity will be given to ask questions regarding the study.
- Those willing to participate will be asked to sign the informed consent form and complete a personal personal history questionnaire.
- Participants will respond to two inventories and a series of open ended questions about changes in family relationships before and after disclosure of an HIV/AIDS diagnosis. The interview will be audiotaped. Names will not be used on the tapes to protect confidentiality.

How will potential risks be minimized?

- To help alleviate fatigue, the participant will be allowed to take breaks as needed.
- A trained therapist will conduct the semi-structured interview and will be available to assess and process any emotional or psychological discomfort experienced. The interviewer will end the interview if it appears there is undue stress for the participant.
- Confidentiality will be protected in the following ways:

Responses will be coded with an identification number.
Only the researchers will have access to the numerical code.
Participants' names will not appear on the questionnaires or audiotapes.

Informed consent forms will be kept separate from the questionnaires and tapes.
All consent forms, questionnaires, and audio tapes will be kept in a locked filing cabinet.
Names will be withheld from any published results of the study.

How will my participation make a difference?

You will have the opportunity to increase awareness and deepen understanding of the impact of HIV/AIDS on individuals and families. Information from this study will help in further research and development of interventions. This study will remind us that HIV/AIDS affects each of us. Your story can teach us how to respond with compassion to the individuals and families who live with this disease.

Appendix B

Consent Form

The Impact Of An HIV/AIDS Diagnosis On Perceived Family Relationships

Paulann Condray Canty and Dr. Kathleen Briggs of the Department of Family Relations and Child Development, Oklahoma State University, request your participation in a research study. The purpose of this study is to explore the impact of an HIV/AIDS diagnosis on perceived family relationships. Your participation will include completing three questionnaires about personal history; family closeness, flexibility, and communication; and feelings of family members toward each other. You will also participate in a semi-structured interview about the ways in which HIV/AIDS has affected your family relationships. The interview will be conducted by the researchers who are trained in marriage and family therapy. The interview will be audiotaped. All audiotapes will be confidential and stored in a locked filing cabinet. The only individuals who will have access to the tapes will be the Program Co-directors and their research assistant.

One benefit of participation in this study is greater awareness of resources and support available to the participant from within the family of origin and from external sources. The possible benefits to society from your participation will include the ability to identify ways in which an HIV/AIDS diagnosis impacts families. This information will facilitate development of better support for families and individuals living with HIV/AIDS. The only potential negative effect from participation in this study could be psychological discomfort and fatigue due to the length of the questionnaires.

At no time will pressure be placed on you to participate in this study. You may withdraw from the study at any time without consequences. The results of the study will be published, but no names or other identifying information will be revealed. To maintain confidentiality, all data collected will be labeled with a numerical code. No names will be on the information. Paulann Condray Canty and Dr. Kathleen Briggs, program co-directors, will be the only persons who will have access to the numerical code.

If you have any questions about your rights, or feel you have been placed at risk, you can contact University Research Services, 001 Life Sciences East, Oklahoma State University, Stillwater, OK 74078; (405) 744-5700. Any questions about the study or your participation should be directed to the program co-directors at (405) 744-8354 or (405) 744-5058.

Informed Consent for Participants

I agree to participate in the research. The name of the study and the positive and negative effects have been explained to me. I understand the risks involved and that I can withdraw from participating in the study at any time without consequence. In signing this form I am not waiving any legal rights. I understand this form and it has been completely explained to me. A copy of this form will be given to me.

Date: ____

Participant's Name (Please Print)

____

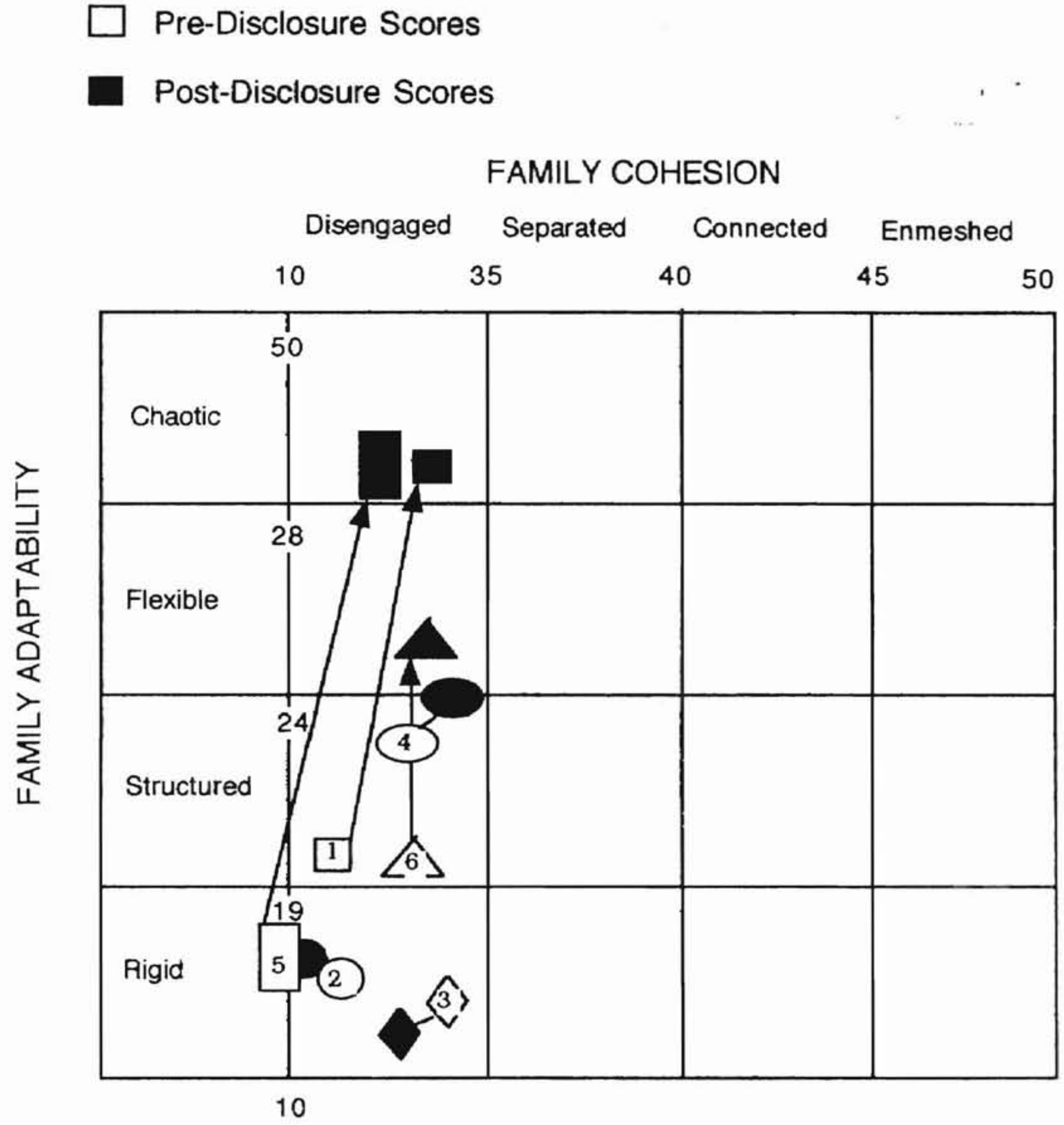
Participant's Signature

____

Witness

Appendix C

Tables and Figures



<u>Figure 1.</u> Pre-disclosure and post-disclosure participant perceptions of family cohesion and adaptability. Family unit positions are plotted in specific locations to reflect actual scores.

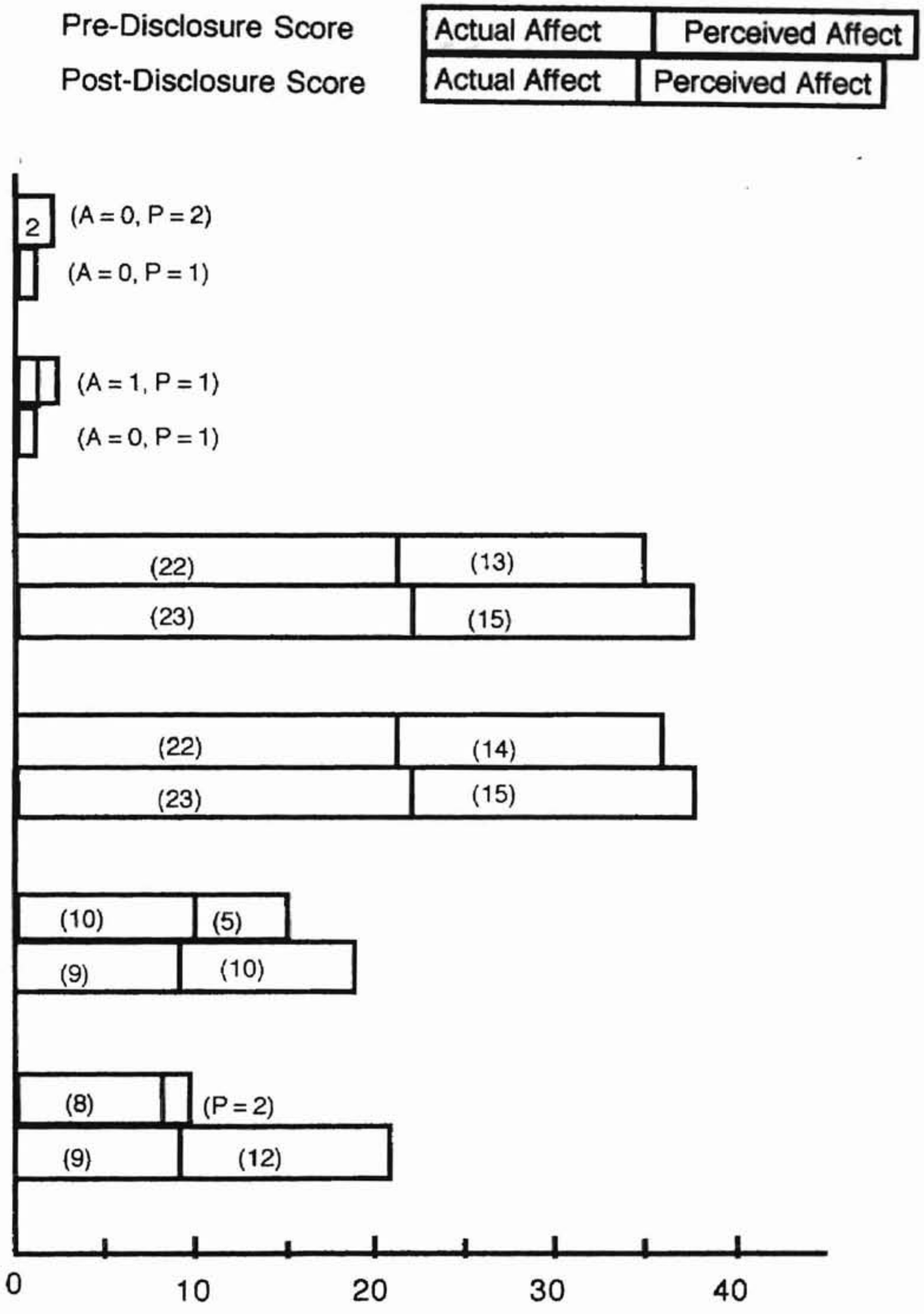


Figure 2.1. Participant #01, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

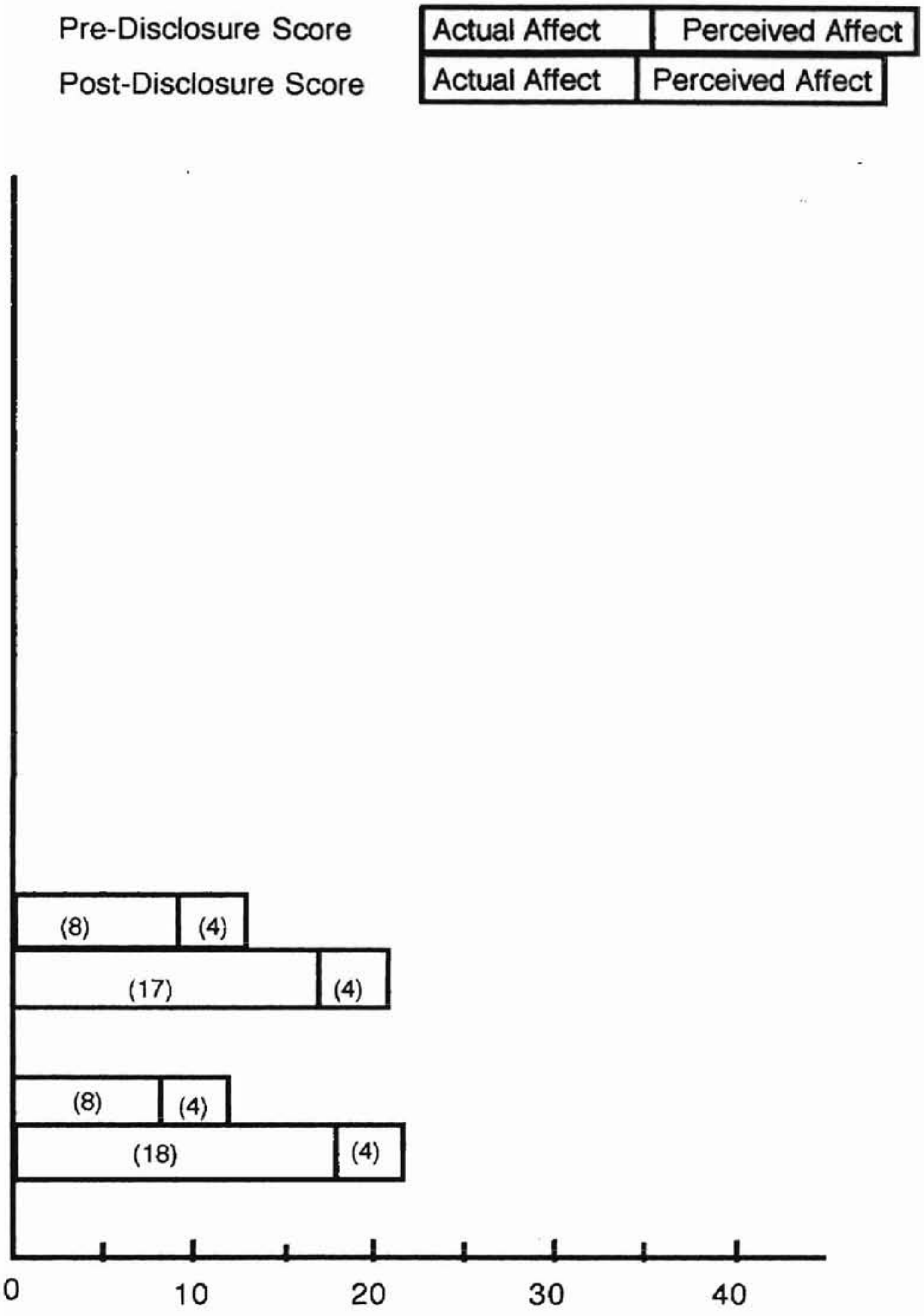


Figure 2.2. Participant #02, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

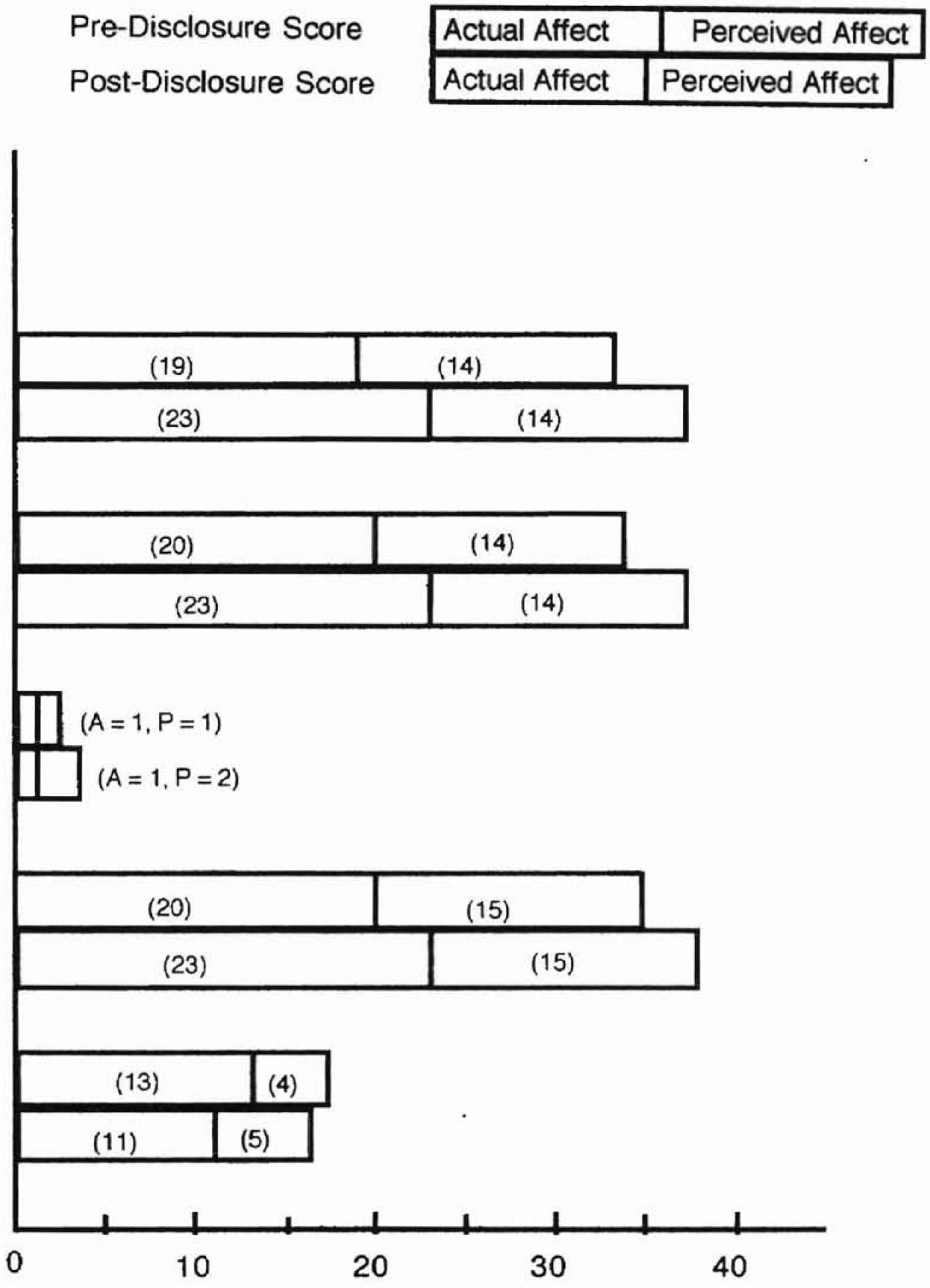


Figure 2.3. Participant #03, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

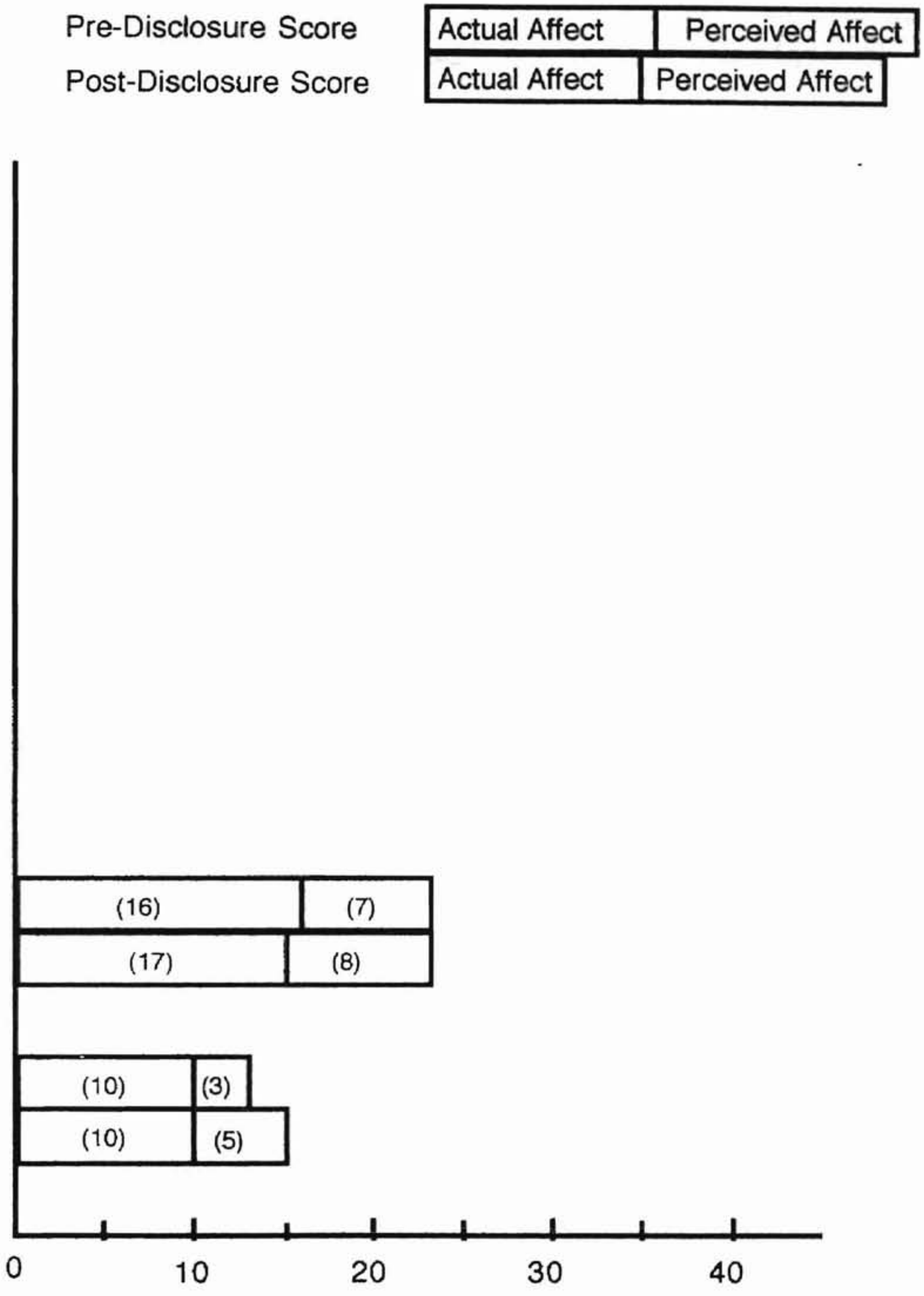


Figure 2.4. Participant #04, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

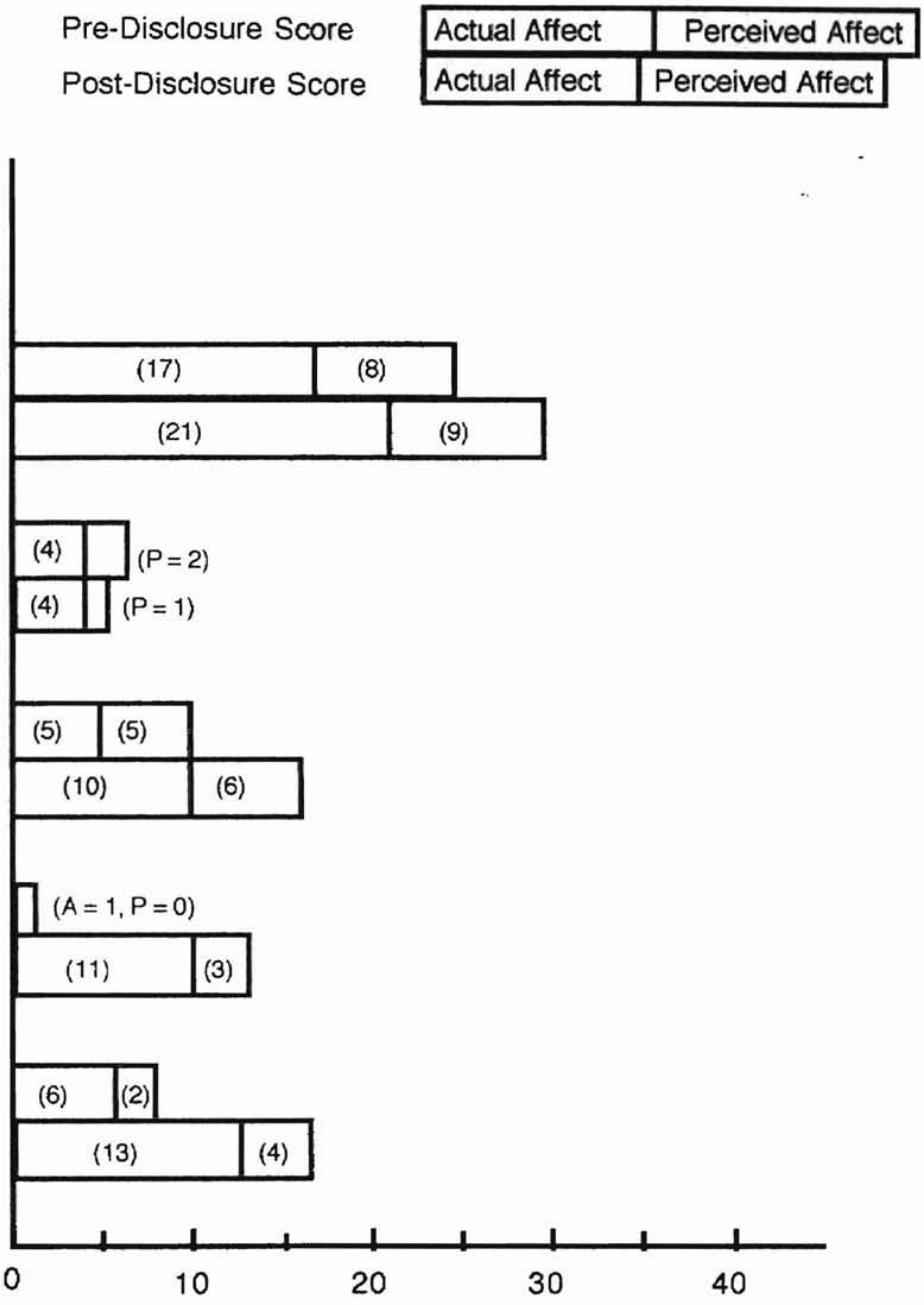


Figure 2.5. Participant #05, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

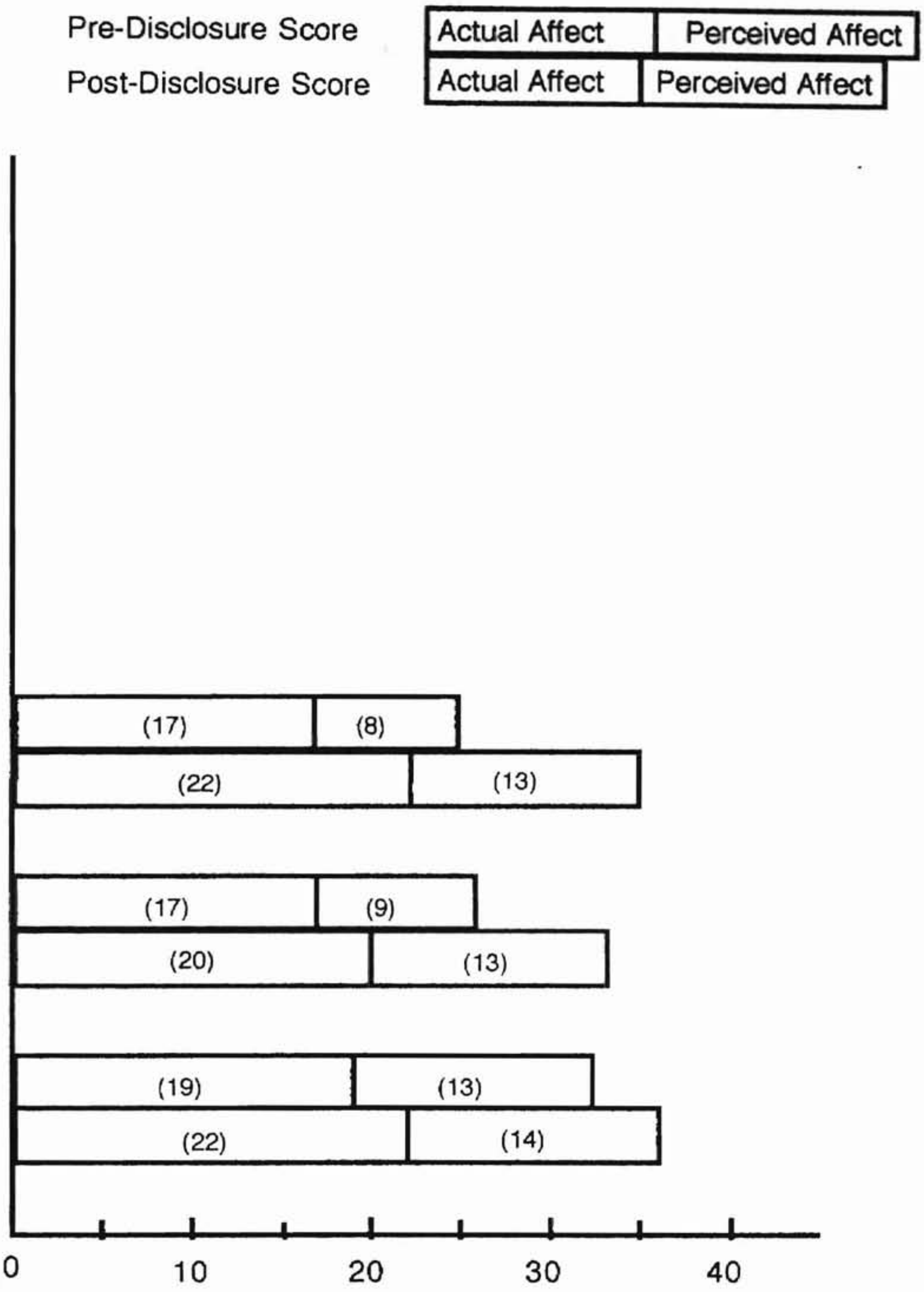


Figure 2.6. Participant #06, Pre-disclosure and post-disclosure affect scores for each family member. Numerical scores for actual and perceived affect noted.

Table 1

Numerical and percentage Representation of Personal History Questionnaire Data

Category	Number = 6	% of Participants
Bisexual/Diverse	4	66.7
Heterosexual	1	16.7
Homosexual	1	16.7
		100.01
Race		
African American	1	16.7
Asian	0	00.0
Caucasian	5	83.3
Hispanic	0	00.0
Native American	0	00.0
		100.0
Education		
Less than grade 12	1	16.7
High school/ equivalency test	0	00.0
Vocational or technical school	2	33.3
1-4 years of college, not graduate	3	50.0
Bachelor's degree	0	00.0

(Table 1 continued)

Master's or post graduate degree	0	00.0
Doctoral degree	0	00.0
		100.0
Employment Status		
Retired	1	16.7
Unemployed; not looking	3	50.0
Unemployed; looking	0	00.0
Employed part-time	2	33.3
Employed full-time	0	00.0
		100.0
Income		
$9,999 or less	2	33.3
$10,000 - 19,999	1	16.7
$20,000 - 29,999	1	16.7
$30,000 - 39,999	1	16.7
$40,000 - 49,999	0	00.0
$50,000 - or more	0	00.0
		83.9
Current Marital Status		
Married	0	00.0
Divorced	3	50.0
Widowed	0	00.0
Remarried	0	00.0
Engaged	0	00.0

(Table 1 continued)

Married, but separated	1	16.7
Never married	2	33.3
Living together (not married)	0	00.0
		100.0
Method of Contraction		
Blood Transfusion	0	00.0
Hemophilia	0	00.0
IV Drug Use	1	16.7
Sexual Contact	3	50.0
Unknown	2	33.3
		100.0
Resources Used		
Individual Therapy	5	83.3
Couple Therapy	0	00.0
Family Therapy	1	16.7
Group Therapy	4	66.6
Support Groups	4	66.6
Hospice	0	00.0
Crises Center	2	33.3
Hotline	0	00.0
Nutrition Center	2	33.3
Hospital	3	50.0
Government Agency	2	33.3
Legal Aid	3	50.0
Home Health Care	0	00.0

Table 2

Participant Pre-Disclosure and Post-Disclosure Cohesion and Adaptability Scores

	Cohesion	
Participant	Pre-Disclosure	Post-Disclosure
1	21	26
2	13	11
3	33	29
4	20	21
5	10	28
6	28	29
	Adaptability	
	Pre-Disclosure	Post-Disclosure
1	21	38
2	17	18
3	15	13
4	24	25
5	17	31
6	20	25

Table 3

Sum of positive and negative responses, and the number of neutral responses given for each family member

PRE	POST	PRE	POST	PRE	POST
10	21	18	16	0	14
-19	-14	-7	-2	-23	-3
-9	7	11	14	-23	11
Neut =9	Neut = 3	Neut = 13	Neut = 20	Neut = 15	Neut = 21
15	19	35	38	10	16
-9	-7	-3	0	-9	-4
6	12	32	38	1	12
Neut =14	Neut = 12	Neut =0	Neut =0	Neut =19	Neut =18
36	38	2	3	6	5
-1	0	-19	-27	-16	-14
35	38	-17	-24	-10	-9
Neut =1	Neut =0	Neut =17	Neut =8	Neut =16	Neut =19
35	38	33	37	25	30
-3	0	-4	-1	-3	-2
32	38	29	36	22	28
Neut =0	Neut =0	Neut =1	Neut =0	Neut =10	Neut =6
2	1	33	37	25	30
-33	-37	-4	-1	-3	-2
-31	-36	29	36	22	28
Neut =3	Neut =0	Neut =1	Neut =0	Neut =10	Neut =6
2	1	13	15	26	33
-7	-6	-4	-3	-5	-2
-5	-5	9	12	21	31
Neut =29	Neut =31	Neut =21	Neut =20	Neut =7	Neut =3
13	22	23	23	32	36
-9	-7	-3	-2	-6	-2
4	15	20	21	26	34
neut =16	Neut =9	Neut =12	Neut =13	Neut =0	Neut =0
12	20	8	17		
-8	-8	-18	-3		
4	12	-10	14		
Neut =18	Neut =10	Neut =12	Neut =18		

Table 4.

Frequency and Configuration of Actual/Perceived Affect Scores

Actual Affect	Perceived Affect	Frequency
Increase	Increase	10
Decrease	Increase	3
Increase	Decrease	0
Decrease	No Change	1
Increase	No Change	5
No Change	Decrease	2
No Change	Increase	2
Total		23

Appendix D

Questionnaires

Appendix D

Questionnaires

List of Contents

ID#: ____________

Date: ____________

Personal History Questionnaire

Participant:

1. Male _______ Female _______

2. Your current age: __________

4. Sexual Orientation:

Bi-sexual _______
Heterosexual _______
Homosexual _______
Lesbian _______

5. Race/Ethnic Group (check one of the following):

_______ 1. Asian
_______ 2. Black
_______ 3. Caucasian
_______ 4. Hispanic
_______ 5. Native American
_______ 6. Other (Please explain)

6. Religious preference (check one of the following):

_______ 1. Protestant
_______ 2. Catholic
_______ 3. Jewish
_______ 4. None
_______ 5. Other (Please explain)

5. Highest grade completed (check one of the following):

_______ 1. Less than high school (grade 12)
_______ 2. High school or passed equivalency test
_______ 3. Vocational or technical school
_______ 4. One to four years of College, but did not graduate
_______ 5. Bachelor's degree (e.g., B.A., B.S.)
_______ 6. Master's or post graduate degree (e.g., M.A., M.S., M.S.W.)
_______ 7. Doctoral degree (e.g., Ph.D., D.D.S., M.D., Ed.D.)

6. Employment status (check one of the following):

_______ 1. Retired
_______ 2. Unemployed; not looking for work
_______ 3. Unemployed; looking for work
_______ 4. Employed part-time
_______ 5. Employed full-time
_______ 6. Other (Please explain)

7. If unemployed, for how long? ______________________

8. Household's total income before taxes (check one of the following):

_______ 1. $9,999 or less
_______ 2. $10,000-19,999
_______ 3. $20,000-29,999
_______ 4. $30,000-39,999
_______ 5. $40,000-49,999
_______ 6. $50,000-or more

9. Current martial status (check one of the following):

_______ 1. Married
_______ 2. Divorced
_______ 3. Widowed
_______ 4. Remarried
_______ 5. Engaged
_______ 6. Married but separated
_______ 7. Never married
_______ 8. Living together (not married)
_______ 9. Other (Please explain)

10. If currently married, for how long? ______________________

11. Have you ever been divorced?

_______ 1. Yes
_______ 2. No

12. Number of children you have? _____________

13. Date Tested HIV positive _____________

14. Method of Contraction of HIV:

Blood Transfusion _______
Hemophilia _______
IV Drug Use _______
Sexual Contact _______
Other _______, Please explain:
Unknown _______, Please explain:

15. Have you been diagnosed with AIDS? ________, if so, when? ________

16. Do you have medical insurance? ______, If so, does insurance cover medical costs related to your HIV/AIDS diagnoses? ________________________________

17. Resources you have used related to diagnoses, check all that apply:

1._____Individual Therapy
2._____Couple Therapy
3._____Family Therapy
4._____Group Therapy
5._____Support Groups
6._____Hospice
7._____Crises Center
8.____Hotline
9.____Nutrition Center
10.____Hospital
11.____Government Agency
12.____Legal Aid
13.____Home Health Care
14.____Other (Please explain)

18. Family: (List age, gender and your relationship of all members of your birth family, whether or not the family member is still living, if deceased give age at death.) **Do not list any names.**

Age	Gender (Male/Female)	Relationship to you (e.g., father, sister, etc.)	Living Yes/No	Age at death

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______

ID# ____________

FACES III

David H. Olson, Joyce Portner, and Yoav Lavee

1	2	3	4	5
ALMOST NEVER	ONCE IN A WHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR FAMILY BEFORE DISCLOSURE:

_____1. Family members asked each other for help.

_____2. In solving problems, the children's suggestion were followed.

_____3. We approved of each other's friends.

_____4. Children had a say in their discipline.

_____5. We liked to do things with just our immediate family.

_____6. Different persons acted as leaders in our family.

_____7. Family members felt closer to other family members than to people outside the family.

_____8. Our family changed its way of handling tasks.

_____9. Family members liked to spend free time with each other.

_____10. Parent(s) and children discussed punishment together.

_____11. Family members felt very close to each other.

_____12. The children made the decisions in our family.

_____13. When out family got together for activities, everbody is present.

_____14. Rules changed in our family.

_____15. We could easily think of things to do together as a family.

_____16. We shifted household responsibilities from person to person.

_____17. Family members consulted other family members on their decisions.

_____18. It was hard to identify the leader(s) in our family.

_____19. Family togetherness was very important.

_____20. It was hard to tell who does which household chores

INVENTORY OF FAMILY FEELINGS

Today's Date________________________ ID #________________________

Instructions

Members of a family feel many different ways toward other members at different times. This Inventory is trying to see how you were feeling about the other members of your family before disclosure.

On the following pages are listed 38 statements of how one member of a family might feel toward another member. Beside the statements are six columns. In each are written the letters A--N--D, The "A" stands for Agree, the "N" stands for Neutral, and the "D" stands for Disagree.

1. Please write the name of one of the other members of your family in the space above each of the columns, using as many columns as necessary. You should have a column for each person in your family other than yourself, with any remaining columns left blank.

2. Then, read each item carefully and decide if you mostly felt the same way as the item toward the family member above the first column. If you did, draw a dircle around the "A" to show you Agree with the statement. If you did not, draw a circle around "D" to show you mosrly Disagree with it. If you did not feel one way or another towards this person, or if you feelt both ways to an equal degree, circle the "N" to show you are Neutral.

3. After marking the first column, go on to the second column and circle "A", "N", or "D", depending on how you felt toward this person. Then go on to the third column and mark it, and so on.

4. After you finish marking all the items on the first page, go on to the next page. Please write the names of your family members in the same order above the columns on every page.

5. There are no right or wrong answers. Try to answer in terms of how you were feeling toward each person before disclosure. It is usually best to give your first impressioin rather than thinking about each item a great deal before answering.

Please mark all the items. It is very important that you answer every item. Please check when you have finished to see that you haven't missed any pages. They sometimes stick together. After you have finished, secure the seal on the bottom of the Inventory and fold it over the top. This is to keep your answers private.

Example

(1.) I felt close to this family member . . . . ____ A--N--D ____ A--N--D ____ A--N--D ____ A--N--D

If you Agree with this statement (if you did feel close to your Dad), circle the "A" in the first column. If you Disagree with this statement (if you did not feel close to your Mother), circle the "D" in the second column. If you didn't really feel really close to you brother, but didn't feel distant from him either, circle the "N" in the third column.

INVENTORY OF FAMILY FEELINGS

Write the names of your family members in as many of these spaces as are needed.

(1) I felt close to this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(2) I admired a lot of the things about this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(3) I felt a lot of love for this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(4) I felt this family member liked me very much	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(5) I liked a lot of the things this family member did.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(6) This family didn't pay a lot of attention to me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(7) I felt a lot of affection for this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(8) I didn't enjoy being with this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(9) I felt wanted by this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(10) I am not very thankful to have had this person in my family	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(11) This family member was usually generous to me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(12) This person had a hard time showing love for me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(13) This family member made me feel very secure	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(14) This person rarely encouraged me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(15) I felt like this family member sometimes uses me to get what he (she) wants	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(16) I usually felt kindly toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

Page 2

(17) I couldn't get along all right without this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(18) I didn't feel very loyal toward this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(19) I felt this person didn't appreciate the things I did for him (her)	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(20) I valued this person highly	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(21) This family member didn't show alot of consideration toward me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(22) I felt this person had alot of love for me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(23) I didn't enjoy talking with this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(24) I didn't enjoy listening when this family member was talking	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(25) I missed this person alot when I didn't see him or her as much as usual	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(26) I usually felt very generous toward this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(27) This person didn't have many qualities I would have liked to have.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(28) This person was not usually kind to me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(29) I didn't have a great deal of respect for this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(30) I seldom felt very friendly toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

	________	________	________	________	________	________
(31) I felt this person often acted in a selfish way toward me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(32) I didn't feel this person was willing to help me in any way he (she) could.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(33) I was seldom proud of this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(34) I often felt very cold toward this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(35) I very seldom felt joy when I was with this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(36) I felt very warm toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(37) This person didn't do a lot to make me happy. . .	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(38) I was very fond of this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

Please check to be sure you answered every item on every page. When you have finished checking, seal your Inventory. You are welcome to write any reactions or observations you had about this Inventory in the space below.

HIV Semi-Structured Interview Outline

1) Tell me a little bit about what it was like to grow up in your family?

2) How did you find out you had HIV?

3) Who was the first person you told?

4) How long before you told someone else?

5) Who told the rest of the family?

6) How did you feel about decisions other family members made?

7) Who do you feel most supported by at this point?

8) Have you talked with family about your death?

9) What would you most like to give your family at that point?

10) Have you asked for support that you did not get?

11) Have you received support that you may not have even know to ask for?

12) What kind of response do you get when you go back to ask for support?

13) Who do you feel the least supported by?

14) Is there anything you would change about the responses

you have received?

15) Would you look to your family for a caregiver? If so, who?

16) Are there any members who have said they want to be the caregiver?

17) What qualities would you look for in a caregiver?

18) What do you worry about most in your situation?

19) Do you ever get afraid? Of what?

20) If you were giving a word of advice to families about the best way to help a member with HIV, what would you say?

21) Is there anything else you would like for me to know?

22) If I was your student, what would be the one thing you would want to teach me about living with HIV?

ID# ________________

FACES III

David H. Olson, Joyce Portner, and Yoav Lavee

1	2	3	4	5
ALMOST NEVER	ONCE IN A WHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR FAMILY NOW:

_______1. Family members ask each other for help.

_______2. In solving problems, the children's suggestions are followed.

_______3. We approve of each other's friends.

_______4. Children have a say in their discipline.

_______5. We like to do things with just our immediate family.

_______6. Different persons act as leaders in our family.

_______7. Family members feel closer to other family members than to people outside the family.

_______8. Our family changes its way of handling tasks.

_______9. Family members like to spend free time with each other.

_______10. Parent(s) and Children discuss punishment together.

_______11. Family members feel very close to each other.

_______12. The Children make the decisions in our family.

_______13. When our family gets together for activities, everybody is present.

_______14. Rules change in our family.

_______15. We can easily think of things to do together as a family.

_______16. We shift household responsibilities from person to person.

_______17. Family members consult other family members on their decisions.

_______18. It is hard to identify the leader(s) in our family.

_______19. Family togetherness is very important.

_______20. It is hard to tell who does which household chores.

INVENTORY OF FAMILY FEELINGS

Today's Date______________________ ID #______________________

Instructions

Members of a family feel many different ways toward other members at different times. This Inventory is trying to see how you are feeling about the other members of your family right now.

On the following pages are listed 38 statements of how one member of a family might feel toward another member. Beside the statements are six columns. In each are written the letters A--N--D, The "A" stands for Agree, the "N" stands for Neutral, and the "D" stands for Disagree.

1. Please write the name of one of the other members of your family in the space above each of the columns, using as many columns as necessary. You should have a column for each person in your family other than yourself, with any remaining columns left blank.

2. Then, read each item carefully and decide if you mostly feel the same way as the item toward the family member above the first column. If you do, draw a dircle around the "A" to show you Agree with the statement. If you do not, draw a circle around "D" to show you mosrly Disagree with it. If you do not feel one way or another towards this person, or if you feel both ways to an equal degree, circle the "N" to show you are Neutral.

3. After marking the first column, go on to the second column and circle "A", "N", or "D", depending on how you feel toward this person. Then go on to the third column and mark it, and so on.

4. After you finish marking all the items on the first page, go on to the next page. Please write the names of your family members in the same order above the columns on every page.

5. There are no right or wrong answers. Try to answer in terms of how you are feeling toward each person right now. It is usually best to give your first impressioin rather than thinking about each item a great deal before answering.

Please mark all the items. It is very important that you answer every item. Please check when you have finished to see that you haven't missed any pages. They sometimes stick together. After you have finished, secure the seal on the bottom of the Inventory and fold it over the top. This is to keep your answers private.

Example

(1.) I feel close to this family member . . . . ____ A--N--D ____ A--N--D ____ A--N--D ____ A--N--D

If you Agree with this statement (If you do feel close to your Dad), circle the "A" in the first column. If you Disagree with this statement (If you do not feel close to your Mother), circle the "D" in the second column. If you don't really feel really close to you brother, but don't feel distant from him either, circle the "N" in the third column.

INVENTORY OF FAMILY FEELINGS

Write the names of your family members in as many of these spaces as are needed.

(1) I feel close to this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(2) I admire a lot of the things about this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(3) I feel a lot of love for this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(4) I feel this family member likes me very much	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(5) I like a lot of the things this family member does.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(6) This family doesn't pay a lot of attention to me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(7) I feel a lot of affection for this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(8) I don't enjoy being with this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(9) I feel wanted by this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(10) I am not very thankful to have this person in my family.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(11) This family member is usually generous to me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(12) This person has a hard time showing love for me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(13) This family member makes me feel very secure	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(14) This person rarely encourages me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(15) I feel like this family member sometimes uses me to get what he (she) wants	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(16) I usually feel kindly toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

(17) I could get along all right without this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(18) I don't feel very loyal toward this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(19) I feel this person doesn't appreciate the things I do for him (her)	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(20) I value this person highly	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(21) This family member doesn't show alot of consideration toward me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(22) I feel this person has alot of love for me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(23) I don't enjoy talking with this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(24) I don't enjoy listening when this family member is talking	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(25) I miss this person alot when I don't see him or her as much as usual	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(26) I usually feel very generous toward this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(27) This person doesn't have many qualities I would like to have.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(28) This person is not usually kind to me.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(29) I don't have a great deal of respect for this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(30) I seldom feel very friendly toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

(31) I feel this person often acts in a selfish way toward me	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(32) I don't feel this person is willing to help me in any way he (she) can.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(33) I am seldom proud of this person	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(34) I often feel very cold toward this family member.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(35) I very seldom feel joy when I'm with this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(36) I feel very warm toward this family member	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(37) This person doesn't do a lot to make me happy. . .	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D
(38) I am very fond of this person.	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D	A--N--D

Please check to be sure you answered every item on every page. When you have finished checking, seal your Inventory. You are welcome to write any reactions or observations you had about this Inventory in the space below.

VITA 2

Paulann Condray Canty

Candidate for the Degree of

Master of Science

Thesis: IMPACT OF DISCLOSURE OF HIV/AIDS DIGNOSIS ON PERCEIVED FAMILY RELATIONSHIPS

Major: Field: Family Relations and Child Development

Biographical:

Education: Graduated from Will Rogers High School, Tulsa, Oklahoma in May 1967; received Bachelor of Church Music degree, a Bachelor of Arts degree in Art, and a Bachelor of Arts degree in Family Psychology from Oklahoma Baptist University, Shawnee, Oklahoma in May 1971, May 1988, and May 1993, respectively. Completed the Requirements for the Master of Science degree with a major in Family Relations and Child Development, Marriage and Family Therapy Specialization at Oklahoma State University in May, 1996.

Work Experience: Employed as a youth minister to work with adolescents; employed as a child care worker, attendant care worker, and student intern with mental health agencies. Employed by Oak Crest Hospital as intern therapist and therapist from 1994 to present.

Honors: AAMFT 1994 Minority Fellowship
1994-95 Scruggs Research Fellowship
Kappa Omicron Nu Honor Society
President's Honor Roll, 12 Semesters
Who's Who Among Students in American Colleges and Universities
Kappa Pi, National Art Fraternity

Conference Presentations: Identification and treatment of psychosocial issues surrounding AIDS: AIDS victims reconciled and rejected. (1994, April) Presentation at Oklahoma Council on Family Relations Annual Meeting, Edmond, OK.

Co-author of grant proposal for a study on

Relationship Changes of Persons Living with HIV/AIDS and Their Families of Origin from Pre-Diagnosis to Post-Diagnosis. Submitted to the Streisand Foundation, December 1, 1994.

Relationship Changes of Persons Living with HIV/AIDS and Their Families of Origin from Pre-Diagnosis to Post-Diagnosis. (1995, March) Poster presentation at Oklahoma Association for Marriage and Family Therapists Annual Meeting, Oklahoma City, OK.

Professional Organizations: Student Member of American Association for Marriage and Family Therapists and Oklahoma Association for Marriage and Family Therapists
Student Representative, Oklahoma Association for Marriage and Family Therapists Board
Student Member of Society for the Psycological Study of Social Issues
Student Member of the National Council on Family Relations

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 12-06-94 **IRB#:** HE-95-009

Proposal Title: RELATIONSHIP CHANGES OF PERSONS LIVING WITH HIV/AIDS AND THEIR FAMILY OF ORIGIN FROM PRE-DIAGNOSIS TO POST-DIAGNOSIS

Principal Investigator(s): Kathleen Briggs

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

APPROVAL STATUS SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Provisions received and approved.

Signature: Date: January 30, 1995

Chair of Institutional Review Board

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
HUMAN SUBJECTS REVIEW

Date: 12-06-94 **IRB#:** HE-95-009A

Proposal Title: RELATIONSHIP CHANGES OF PERSONS LIVING WITH HIV/AIDS AND THEIR FAMILY OF ORIGIN FROM PRE-DIAGNOSIS TO POST-DIAGNOSIS.

Principal Investigator(s): Paulann C. Canty

Reviewed and Processed as: Continuation

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL.
ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Request for continuation received and approved.

Signature: John H.

Chair of Institutional Review Board

Date: December 6, 1995