Bearing Witness to Suffering in AIDS: The Testing of a Substantive Theory

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AIDS volunteerism, as a response by those affected by loss associated with HIV/AIDS, has been described as an act of bearing witness. The theory “bearing witness to suffering in HIV/AIDS,” proposes that AIDS volunteerism assists individuals affected by loss to increase their levels of hope, self-esteem, social support, and develop a sense of purpose in life (PIL). The purpose of this descriptive research was to determine if AIDS volunteerism, hope, self-esteem, and social support were predictive of PIL among individuals affected by loss from HIV/AIDS. Path analysis was used to analyze data. Hope, social support, and self-esteem were found to have significant positive effects on PIL and accounted for 66% of the total variance. The results from this study will be used to further develop the theory of bearing witness; this theory may be useful to develop and test interventions to relieve the suffering experienced by individuals affected by HIV/AIDS.

Key words: bearing witness, AIDS volunteerism, hope, social support, self-esteem, purpose in life

Throughout recorded history, suffering and human responses to suffering have been explored by philosophers, theologians, and health care professionals (Pollock & Sands, 1997; Rodgers & Cowles, 1997). Responding to human suffering is a significant aspect of nursing and health care. Despite the importance of suffering to health care professionals, a paucity of research on the topic exists. Suffering is often discussed indirectly and is frequently associated with the experience of pain. However, work on the conceptualization of suffering indicates that the experience of suffering extends well beyond physical pain and involves psychosocial and spiritual dimensions (Frankl, 1992; Kahn & Steeves, 1986). Frankl (1992) described suffering as an inevitable component of human existence. Kahn and Steeves (1995) conceptualized suffering not only as individual and intrapersonal but also as interpersonal in nature: Individuals who observe or come into contact with the sufferer are inevitably drawn into the suffering experience. Most important, suffering is conceptualized as resulting from the perception of threat or potential threat and involves a profound sense of loss (Kahn & Steeves, 1986; Rodgers & Cowles, 1997).

The complexity of loss associated with suffering in HIV/AIDS is congruent with the broader conceptualizations of suffering noted above (Frankl, 1992; Kahn & Steeves, 1986; Rodgers & Cowles, 1997). The loss of family, partners, or friends is readily apparent in the body of research on loss in HIV/AIDS. Yet other types of loss also exist that exacerbate the experience of suffering. Common types of loss described in this AIDS research include the loss of supportive relationships, personal freedom, dreams of the future, self, and purpose and meaning in life (Brown & Powell-Cope, 1993; Gaskins & Brown, 1992; Gregory & Longman, 1992; Powell-Cope, 1995; Reynolds & Alonzo, 1998).

Despite the negative impact of suffering and loss in HIV/AIDS, it has also been conceptualized as an experience that can actualize the potential purpose and meaning in an individual’s life (Frankl, 1992). Morse and Carter (1996) proposed that finding meaning in...
suffering could actually empower an individual. This proposal by Morse and Carter suggests that suffering can be transformational in nature and potentially healing.

The identification of responses to suffering that promote transformation and healing is essential but has received little attention (Rodgers & Cowles, 1997). One response that has been identified as potentially healing for the suffering involved in HIV/AIDS is AIDS volunteerism. Kayal (1993) described AIDS volunteerism as an act of bearing witness that assists individuals affected by HIV/AIDS to find meaning as they face the ravages of the disease. Chambre (1991) identified AIDS volunteerism as a transformative process, one that can positively affect individuals for the rest of their lives.

The substantive theory, “bearing witness to suffering in HIV/AIDS” (V. P. Hall, 2001), proposes that AIDS volunteerism is one response to suffering in HIV/AIDS that can assist individuals to transform and heal through the construction of meaning from their loss. The theory also proposes that AIDS volunteerism assists individuals affected by loss from HIV/AIDS to increase their sense of hope, their sense of self-esteem, and their level of social support, the effects of which can ultimately lead to the development of a new sense of purpose in life. However, further testing of the substantive theory is needed if it is to be useful in guiding nursing research and practice. Therefore, the purpose of this research was to test if AIDS volunteerism, hope, self-esteem, and social support are predictive of purpose in life as Hall’s theory suggests.

**Background**

Suffering for individuals affected by HIV/AIDS extends well beyond the experience of physical pain; it is complex and involves loss in the physical, financial, psychosocial, and spiritual dimensions of life. In the physical dimension, HIV is recognized as a chronic illness where a wide range of life-threatening conditions can occur, leading to the loss of physical integrity and functioning (Flaskerud & Ungvarski, 1999). The debilitating physical effects of HIV/AIDS and the costs associated with treatment can also lead to the loss of valued careers, financial resources, personal freedom, and lifestyle (Bechtel, 1994; Crystal & Kersting, 1998). Furthermore, the physical and financial toll of AIDS on individuals affected by the disease can lead to a sense of despair, fatalism, and loss of hope (Carson, Soeken, Shanty, & Terry, 1990; V. P. Hall, 2001; Sowell et al., 1997).

In the psychosocial dimension, the loss of interpersonal relationships through isolation and the death of loved ones are a continual threat in HIV/AIDS. Gay men affected by HIV/AIDS have faced a density of bereavement related to the deaths of large numbers of friends, acquaintances, and former lovers (Bigelow & Hollinger, 1996; Mallinson, 1999b). In turn, AIDS family caregivers, whether parents, close friends, or lovers, have not escaped the pervasiveness of loss and dying (Brown & Powell-Cope, 1993; Stajduhar, 1997). Moreover, HIV/AIDS has become a disease of families, where the increasing incidence among women and children is expected to further amplify the experience of premature loss in parent and surrogate parent caregivers (Brown & Powell-Cope, 1993; Klirsfeld, 1998). The stigma and secrecy that continues to surround HIV/AIDS complicates loss and bereavement and fosters isolation. Family, friends, or partners who serve as caregivers may experience loss of their loved ones invisibly, without the traditional acknowledgment and support that can be helpful in the bereavement process (Mallinson, 1999a; Reynolds & Alonzo, 1998; Siegl & Morse, 1994). In addition, stigma alone can make individuals affected by HIV/AIDS lose a sense of psychological well-being and produce feelings of guilt, self-hatred, unworthiness, and rejection (Bechtel, 1994; Gaskins & Brown, 1992). The loss of interpersonal relationships and the effect of stigma can have a significant negative impact on social support and self-esteem (Carson et al., 1990; V. P. Hall, 2001; J. Lewis, 1999; Stokes & Peterson, 1998).

Spiritually, individuals affected by HIV/AIDS may face certain existential dilemmas (Brown & Powell-Cope, 1993; B. A. Hall, 1998; Siegel & Meyer, 1999). These dilemmas stem from issues of death and mortality and involve the loss of future dreams and life direction, the loss of a sense of fulfillment in life, the loss of a sense of power or control, and the loss of a sense of self (Carson et al., 1990; V. P. Hall, 2001; Mallinson, 1999b; Sherman & Kirton, 1998). These dilemmas can
lead individuals to question the meaning of HIV/AIDS as well as the purpose and meaning of their own existence (Siegel & Meyer, 1999).

The cumulative nature of this suffering and loss among the physical, financial, psychosocial, and spiritual dimensions and its ultimate negative effect on factors of hope, social support, self-esteem, and purpose in life is significant. Previous research has shown that these factors are associated with better physical, psychosocial, and spiritual health and increased survival from life-threatening illness.

Hope is considered to be an important response to diseases such as cancer or HIV, and a sense of hopefulness may assist individuals with HIV/AIDS to manage their disease more effectively (Carson et al., 1990). A sense of hope has been found to assist individuals in adhering to treatment regimens (Bruhn, 1984), and there is some evidence that hope may slow disease progression in cancer (Post-White et al., 1996). Hopelessness has also been found to predict increased levels of depression in men with HIV (Johnson et al., 2001).

Social support and its relationship to health has been examined in diverse age groups, populations, and conditions such as cancer, heart disease, depression, and HIV/AIDS. Research to date suggests that social support may promote positive physical and psychological health outcomes during serious illness and even reduce mortality in adults (Kadushin, 1996). In populations with HIV, greater satisfaction with social support has been associated with better psychological adjustment (Turner-Cobb et al., 2002) and the development of healthier coping strategies or styles (Nannis, Patterson, & Semple, 1997). In contrast, limited perceived social support has been found to be a significant predictor of emotional distress in HIV-positive women (Hudson, Lee, Miramontes, & Portillo, 2001). The lack of social support may also accelerate the course of HIV disease progression (Lesserman et al., 1999).

Self-esteem is described as an important personal resource that has been related to the maintenance of healthy self-care behaviors after life-threatening illnesses (Nyamathi & Stein, 1997). In HIV, positive self-esteem has been associated with decreased risk behavior in individuals at high risk for contracting the virus (Harris, Bausell, Scott, Hetherington, & Kavanagh, 1998; Nyamathi & Stein, 1997). For individuals already infected with HIV, positive self-esteem has been found to influence a greater sense of well-being and satisfaction with life (Anderson, 1995) and be an important resource for adapting to the disease (Anderson, 2000).

The search for purpose as well as meaning in life as a response to loss is well documented (Taylor, 1993). Frankl (1992) described the need for purpose and meaning in life as innate and universal. Significant research has focused on purpose and meaning in life in cancer and HIV/AIDS populations. F. M. Lewis (1989) found a clear sense of meaning was positively associated with a sense of personal control and predicts low anxiety and healthy self-concept in cancer patients. A clear sense of purpose and meaning in patients with cancer was also associated with adjustment to illness (Taylor, 1993). Kemeny, Taylor, and Fahey (1998) found that bereaved HIV-positive men who found meaning after an AIDS-related loss showed less rapid declines in CD4 T-cell levels and lower rates of AIDS-related mortality. Research also indicates that finding purpose and meaning in life is an important process for individuals affected by HIV/AIDS that can assist them to develop a sense of self-worth (Coward, 1994), a sense of mental well-being (Coward & Lewis, 1993), and a positive meaning regarding the disease (Carlisle, 2000; B. A. Hall, 1998).

**Conceptual Model**

Concepts within the theory “bearing witness to suffering in HIV/AIDS” (V. P. Hall, 2001) formed the conceptual model for this study. This substantive theory, developed through grounded theory methodology, describes one positive response to suffering and loss (i.e., AIDS volunteerism) that assists individuals affected by HIV/AIDS to transform and heal through the development of purpose in life and the construction of meaning from loss. This research tested several of the predictive relationships proposed by Hall’s theory. Hall proposed that AIDS volunteerism increases levels of hope, social support, and self-esteem. The effect of AIDS volunteerism, as well as the effects of increased levels of hope, social support, and self-esteem, increases a sense of purpose in life in those individuals affected by the suffering and loss in HIV/
AIDS. Figure 1 represents the conceptual model that was tested.

**Method**

The data reported herein were collected as part of a larger study that examined differences between HIV-positive and HIV-negative AIDS volunteers and non-volunteers and factors that acted as motivators and barriers to AIDS volunteerism. The study took place primarily within two community-based AIDS Service Organizations (ASOs). Both ASO sites were located in southern cities, one in North Carolina and one in South Carolina. These ASOs provided client services such as case management and benefits advocacy, as well as outreach education programs that focused on prevention. Each ASO had a volunteer program. Volunteers, many of whom have HIV/AIDS themselves, served as caregivers and peer counselors to others who have HIV/AIDS (i.e., through the provision of information, transportation, household chores, and basic physical and emotional support) and also as educators and advocates for the HIV/AIDS community through outreach programs. Data were also collected from individuals who attended a large weekend retreat held at an Episcopal conference center in North Carolina. The purpose of the retreat was to provide support and respite for persons infected by HIV and HIV/AIDS caregivers. The study and all procedures involving participants were approved by the sponsoring university’s Institutional Review Board for the Protection of Human Subjects prior to the initiation of the research.

**Sample**

A voluntary convenience sample was drawn from volunteer and client populations of the two community-based ASOs as well as the Episcopal retreat. The sample consisted of individuals who were HIV positive and HIV negative and who had been affected by the loss associated with HIV/AIDS. These losses included the loss of physical ability, the loss of jobs or financial stability, or the loss of partners or friends for those individuals who were HIV positive. Losses for those individuals who were HIV negative included the loss of relatives, friends, spouses, or partners. In addition, individuals had to be 18 years of age or older and be able to speak and write in English. Participants who met study criteria were assigned to one of four groups that were equal in number (n = 30). One group consisted of individuals who reported a history of AIDS volunteerism and were HIV positive. The second group consisted of individuals who reported a history of AIDS volunteerism and were HIV negative. The third group consisted of individuals who reported no history of AIDS volunteerism and were HIV positive, and the fourth group consisted of individuals who reported no history of AIDS volunteerism and were HIV negative. The four groups were monitored as they were being formed in an attempt to ensure no wide disparity existed in age and socioeconomic status between group members.

The total sample size was 120. The sample consisted of 76 men (64%) and 43 women (36%). The mean age of the sample was 42.32 years (SD = 12.25), and the mean years of education was 13.75 (SD = 2.39). In regard to income, 36.7% (n = 44) of the sample had incomes less than $10,000, 31.7% (n = 38) had incomes between $10,000 and $19,999, and 13.3% (n = 16) had incomes between $20,000 and $29,000. The remaining 18.3% (n = 22) of the sample had incomes greater than $30,000.

**Procedures**

Data were collected using a self-administered questionnaire packet. This packet contained (a) a cover
letter that briefly described the study along with instructions for completion and return of the instruments, (b) an informed consent form, (c) five instruments that included a demographic questionnaire, and (d) two envelopes. One envelope was stamped and self-addressed to the researcher for return of the instruments. Individuals were offered a small monetary amount for participating in the study; therefore, the other envelope was addressed by the participant and returned so that the researcher could mail the money to the participant at a desired location. The participant was instructed by the cover letter that they could address the envelope in any manner that they felt protected their anonymity (e.g., by using their initials, an alias, or by using an address other than their own).

Case managers and volunteer coordinators at each ASO recruited subjects. Case managers distributed pamphlets to clients—who may or may not have been volunteers—during office or home visits; these pamphlets described the study and provided instructions on how to become involved. During home visits, pamphlets were also offered to the client’s partner or family members; this procedure assisted in recruiting other individuals affected by loss from HIV/AIDS who also may or may not have volunteered. Volunteers at each ASO were recruited in a similar manner. The volunteer coordinator at volunteer functions or volunteer support groups distributed pamphlets describing the study. A flyer advertising the study was also posted in prominent areas of each ASO with instructions to contact their case manager, volunteer coordinator, or the researcher if they were interested in participating.

To recruit participants at the Episcopal retreat, the researcher sought and gained permission from the retreat organizers. The researcher was introduced to the participants at the opening session of the retreat and was allowed to explain the nature and purpose of the research and how to enlist in the study if they so desired.

The self-administered questionnaire packet allowed participants to complete the questionnaires at their leisure and in privacy. The self-administered questionnaires took approximately 30 to 40 minutes to complete. Participants who returned the questionnaire packets and met eligibility requirements were placed into one of the four groups previously described. Data collection took place over a period of 6 months.

**Instruments**

Five instruments were used to collect data for the study: (a) a demographic questionnaire, (b) the Herth Hope Index (Herth, 1992), (c) the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991), (d) the Rosenberg Self-Esteem Scale (Rosenberg, 1979), and (e) the Existential Well-Being Scale (Paloutzian & Ellison, 1982). The demographic questionnaire was developed by the researcher and collected data on variables such as age, gender, education, and HIV status. Other questions asked for a report on types of losses the participant might have experienced that were associated with HIV/AIDS. In addition, participants were asked if they had performed some type of AIDS volunteerism in the past, as well as reasons for their participation or nonparticipation in volunteer activities.

The Herth Hope Index (HHI) is an abbreviated and self-administered 12-item scale that was adapted from the Herth Hope Scale and is intended to measure hope in adult populations (Herth, 1992). The HHI consists of four items in each of the three subscales. These subscales mirror the three dimensions of hope conceptualized by Herth as (a) temporality and future, (b) positive readiness and expectancy, and (c) interconnectedness. The HHI uses a Likert-type response, and each item is scored on an ordinal scale from 1 (strongly disagree) to 4 (strongly agree), with a total range of scores from 12 to 48. Higher scores on the HHI indicate higher levels of hope. Cronbach’s alpha reliabilities have ranged from .81 to .95 (K. Herth, personal communication, July 6, 1999). Concurrent criterion-related validity has been assessed by calculating the correlation of the HHI to the Hope Herth Scale ($r = .92$) and the Nowotny Hope Scale ($r = .81$); divergent validity was assessed by calculating the correlation of the HHI to the Hopelessness Scale ($r = −.73$) (Herth, 1992).

The Medical Outcomes Study Social Support Survey (MOS SSS) is a 19-item self-administered questionnaire that consists of four subscales to assess the functional dimensions of social support: (a) emotional/informational, (b) affectionate, (c) tangible, and (d) positive social interaction (Sherbourne & Stewart, 1991). The questionnaire emphasizes the perceived availability of support if needed and assesses the types of support, but not the sources of support. The MOS
SSS uses a Likert-type response, and each item is scored on a scale from ranging from 1 (none of the time) to 5 (all of the time), with a total range of scores from 19 to 95. Higher scores on the MOS SSS indicate higher levels of social support. Cronbach’s alpha reliability for the overall instrument was .97. The 1-year stability coefficient for the overall instrument was reported to be .78. The items included in the four subscales of the MOS SSS reflect the types of functional support available in a community-based ASO.

The Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1979) measures basic feelings of self-worth and self-acceptance. The RSE consists of a 10-item Likert-type scale, with items answered on a 4-point scale ranging from 4 (strongly agree) to 1 (strongly disagree). Possible scores range from 10 to 40. The RSE is worded such that a high score indicates high self-esteem and a low score indicates low self-esteem. Test-retest reliability has been reported at above .85 after 1, 4, and 10 weeks; internal consistency using coefficient alpha was reported at .78 (Bufford, Paloutzian, & Ellison, 1991).

Table 1. Means, Standard Deviations (Reliability Estimates), and Intercorrelations for Variables in the Conceptual Model (N = 120)

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hope</td>
<td>39.30</td>
<td>7.09</td>
<td>.53</td>
<td>.92</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Social support</td>
<td>57.07</td>
<td>19.02</td>
<td>.66</td>
<td>.97</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Self-esteem</td>
<td>30.94</td>
<td>5.95</td>
<td>.57</td>
<td>.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Purpose in life</td>
<td>45.36</td>
<td>10.85</td>
<td>.68</td>
<td>.76</td>
<td>.93</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: AIDS volunteerism was measured at the nominal level. Coefficient alpha reliability estimates of instruments are reported in parentheses. p < .001.

Table 2. Goodness-of-Fit Indices for Various Models Testing the Effect of AIDS Volunteerism, Hope, Social Support, and Self-Esteem on Purpose in Life (N = 120)

<table>
<thead>
<tr>
<th>Model</th>
<th>( \chi^2 )</th>
<th>df</th>
<th>p</th>
<th>NFI</th>
<th>NNFI</th>
<th>CFI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Null model</td>
<td>266.02</td>
<td>10</td>
<td>.001</td>
<td>0.000</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Initial model</td>
<td>103.98</td>
<td>3</td>
<td>.001</td>
<td>.609</td>
<td>-.315</td>
<td>.606</td>
</tr>
<tr>
<td>Revised Model 1</td>
<td>6.59</td>
<td>2</td>
<td>.04</td>
<td>.975</td>
<td>.910</td>
<td>.982</td>
</tr>
<tr>
<td>Revised Model 1a</td>
<td>4.64</td>
<td>2</td>
<td>.10</td>
<td>.982</td>
<td>.95</td>
<td>.989</td>
</tr>
<tr>
<td>Revised Model 1b</td>
<td>1.26</td>
<td>2</td>
<td>.53</td>
<td>.995</td>
<td>1.01</td>
<td>1.00</td>
</tr>
</tbody>
</table>

NOTE: NFI = normed fit index; NNFI = nonnormed fit index; CFI = comparative fit index.

Testing of the Conceptual Model

To test the conceptual model (see Figure 1), data from the four groups were combined, and path analysis was performed using the SAS System’s CALIS procedure (Hatcher, 1994); this analysis used the maximum likelihood method of parameter estimation. Path analysis enables the researcher to establish whether the proposed conceptual model effectively accounts for the actual relationships observed in the sample data. In doing path analysis, the researcher tests the “fit” between the conceptual model and the data: The better the fit, the stronger the support for the theory (Hatcher). Table 1 presents the means, standard deviations, and intercorrelations for the variables in the conceptual model. Table 2 presents goodness-of-fit indices used to test the fit of the conceptual model: (a) the chi-square statistic, (b) the normed fit index (NFI) (Bentler & Bonnett, 1980), (c) the nonnormed fit index (NNFI) (Bentler & Bonnett, 1980), and (d) the comparative fit index (CFI) (Hu & Bentler, 1995). Values
greater than .9 on the NFI, NNFI, and CFI denote an acceptable fit between the conceptual model and the data; the NNFI and CFI have been shown to be less biased in small samples (Bentler, 1989).

The conceptual model presented in Figure 1 was the initial model reflected in Table 2. Analysis of the initial model produced a significant $\chi^2$ value, $(3, N = 120) = 103.98, p = .001$. In addition, values for the NFI, NNFI, and CFI were all below .9, indicating a poor fit between the conceptual model and the data. Hatcher (1994) noted that the testing of an initial conceptual model rarely produces a good fit; the model must then be modified so that it can better account for the observed relationships between the variables. Therefore, the study’s conceptual model was rejected, and modifications were made in an attempt to improve the model’s fit.

In an effort to improve the model’s fit, the path coefficients of the initial model were reviewed. The $t$ values for all the path coefficients were statistically significant ($p < .01$) except for the direct path between AIDS volunteerism and purpose in life. In addition, the Wald test (Hatcher, 1994) for the path between AIDS volunteerism and purpose in life indicated that the path could be dropped without any significant increase in $\chi^2$, $(1, N = 120) = .073, p < .786$. Thus, the path between AIDS volunteerism and purpose in life was eliminated from the model. Furthermore, a Lagrange multiplier test (Bentler, 1989) suggested that the model could be improved by adding paths between hope and self-esteem and social support and self-esteem; these paths were added and the resulting model, termed Revised Model 1, was then reanalyzed.

The goodness-of-fit indices for Revised Model 1 are reflected in Table 2. The chi-square statistic for Revised Model 1 was compared to the chi-square statistic for the initial model by performing a chi-square difference test. This test was computed as $103.98 - 6.59 = 97.39$. The chi-square difference statistic of 97.39 with $df = 1$ was significant ($p < .001$) and indicated that Revised Model 1 was a better fit to the data.

The path coefficients for Revised Model 1 are presented in Figure 2. All the $t$ value coefficients were significant at $p = .05$ or lower except for the path between AIDS volunteerism and self-esteem. $R^2$ values were .07 for hope, .45 for self-esteem, .35 for social support, and .66 for purpose in life. Hope, self-esteem, and social support explained 66% of the variance in purpose in life.

Although the goodness-of-fit indices for Revised Model 1 were all above .9, the model remained statistically significant ($p = .04$) (see Table 2). Moreover, the path between AIDS volunteerism and self-esteem was not significant, and the Wald test (Hatcher, 1994) indicated that the path could be dropped without any significant increase in $\chi^2$, $(1, N = 120) = 3.52, p < .06$. The Lagrange multiplier test (Bentler, 1989) also suggested that a path could be added from social support to hope. The path from AIDS volunteerism to self-esteem was dropped, a path was added from social support to hope, and the model was reanalyzed. This new model was called Revised Model 1a.

Table 2 indicates that Revised Model 1a provided a good fit for the data. The model chi-square statistic was not significant, $\chi^2(2, N = 120) = 4.64, p = .10$, and the NFI, NNFI, and the CFI were all at .95 or beyond. Figure 3 presents the standard path coefficients for Revised Model 1a. All the path coefficients in the model were meaningful in absolute magnitude (each coefficient was >.05), and $t$ tests were significant at $p < .05$ or lower. $R^2$ values were .24 for hope, .42 for self-esteem, .31 for social support, and .66 for purpose in life. Hope, self-esteem, and social support explained 66% of the total variance for purpose in life. However, the path leading from self-esteem to social support...
could not be justified based on theory or prior research. Therefore, the path from self-esteem to social support was reversed and the model, termed Revised Model 1b, was analyzed again.

Results

Table 2 indicates that Model 1b provided a better fit for the data. The model chi-square statistic was not significant, $\chi^2 (2, N = 120) = 1.26, p = .54$, and the NFI, NNFI, and the CFI were at .99 or beyond. Figure 4 presents the standard path coefficients for the final model. All the path coefficients in the model were meaningful in absolute magnitude (each coefficient was $> .05$), and $t$ tests were significant at $p < .05$ or lower. $R^2$ values were .29 for hope, .50 for self-esteem, .11 for social support, and .66 for purpose in life. Hope, self-esteem, and social support explained 66% of the total variance for purpose in life. Therefore, Model 1b was chosen as the final and “best” model.

In addition to the best fit for the data, the relationships in the final model (see Figure 4) are supported by findings from other studies involving populations affected by HIV/AIDS or other chronic illnesses. Hope has been positively correlated with a sense of purpose and spiritual well-being (Carson et al., 1990; Fehring, Miller, & Shaw, 1997) and self-esteem (Frieson & Frieson, 1996). A positive relationship may also exist between self-esteem and a sense of purpose in life (Anderson, 1995). As noted earlier, research has indicated that a greater sense of perceived social support is related to a greater sense of self-esteem (Linn et al., 1993), whereas in turn, a sense of social isolation and rejection is related to poor self-esteem (Fife & Wright, 2000). Moreover, poor levels of social support among individuals with AIDS has been associated with higher levels of hopelessness (Sarna, van Servellen, & Padilla, 1996; Swindells et al., 1999). The research of B. A. Hall (1994) and Siegel and Meyer (1999) also suggest that hope can be maintained or increased by the activation of social support. Although the final model demonstrated no direct effects for AIDS volunteerism on self-esteem or purpose in life, other relationships posed by V. P. Hall’s (2001) theory were supported. Hope, self-esteem, and social support did have positive effects on a sense of purpose in life.

Discussion

In examining the final model (see Figure 4), interpretation of AIDS volunteerism’s direct effect on hope and social support is somewhat limited because of measurement issues (i.e., AIDS volunteerism was measured at the nominal level). Nevertheless, it can be inferred from the model that individuals affected by loss from HIV/AIDS and who do not perform AIDS volunteerism have associated lower levels of hope and
social support. In contrast, the relationships between hope, self-esteem, and social support infer more direct influence on one another and purpose in life. Hope accounted for 29% of the variance in self-esteem and purpose in life and had a relatively strong direct influence on purpose in life and an even stronger direct effect on self-esteem. Self-esteem accounted for 50% of the variance in purpose in life and had the strongest direct effect on purpose in life as compared to hope and social support. Social support accounted for 11% of the variance in self-esteem, hope, and purpose in life and had a relatively moderate direct effect on purpose in life, but social support had a strong direct effect on self-esteem and an even stronger direct effect on hope.

The fact that AIDS volunteerism demonstrated no effects on self-esteem or purpose in life might be attributable to the lack of a sensitive measure of AIDS volunteerism. In the absence of a sensitive measure, a larger sample size might have been needed to discover the true effect of AIDS volunteerism on self-esteem and purpose in life. Alternatively, the HIV-positive AIDS volunteer group as well as the HIV-positive and HIV-negative nonvolunteer groups had lower mean scores on measures of self-esteem and purpose in life. AIDS volunteerism in itself may not be able to exert a strong enough influence to overcome the possible effects of stigma and multiple and complicated loss on self-esteem and purpose, albeit previous research has indicated that volunteerism can increase feelings of self-worth, importance, and general satisfaction with oneself (Gaskins & Brown, 1997; Snyder, Omoto, & Crain, 1999).

Of interest in the final model (see Figure 4) was the significance of self-esteem. As described earlier, self-esteem accounted for 50% of the variance and had a stronger direct effect on purpose in life than did hope or social support. HIV-positive volunteer and HIV-positive and HIV-negative nonvolunteer groups had lower mean scores on the measure for self-esteem than the HIV-negative volunteer group did. In addition, respondents in the HIV-positive volunteer group and the nonvolunteer groups qualitatively reported greater physical, financial, and social losses. The nonvolunteer groups also reported feelings of isolation and stigma. These physical, financial, and social losses in addition to stigma may have a negative effect on the individual’s identity, self-worth, and self-esteem (Bechtel, 1994; Carson et al., 1990; Fife & Wright, 2000; Gaskins & Brown, 1992; J. Lewis, 1999; Stokes & Peterson, 1998). Although V. P. Hall’s (2001) theory supports the relationship between self-esteem and purpose in life, the strength of the relationship was not expected. The results of this study indicate that self-esteem, in relationship to the other variables of hope and social support, may play a greater role in the development of purpose in life for those affected by loss from HIV/AIDS. In other words, individuals affected by loss from HIV/AIDS and who do not possess a strong sense of self-esteem may not be able to transform their loss and therefore may be unable to construct new purpose in their life. Other research has found that self-esteem may be related to purpose in life (Anderson, 1995) or may be predictive of a sense of satisfaction with life and purpose in life in persons infected with HIV (Anderson, 2000).

Implications for Research and Practice

This study made no attempt to examine specific factors related to loss such as the time since loss, the intensity or type of loss, and cumulative loss; these factors may have some effect on hope, self-esteem, social support, and, in particular, the development of purpose in life. For example, many of the HIV-positive participants reported physical loss or poor physical health as a consequence of having HIV/AIDS. Multiple health problems and poor functional health have been associated with feelings of powerlessness in populations with HIV/AIDS and cancer (Fife & Wright, 2000). Other research has indicated that in populations with cancer, finding purpose and meaning in life was negatively affected if a component of their loss was poorer physical functioning (Thompson & Pitts, 1993). Poor physical health may too play a role in the ability to find purpose in life among individuals with HIV/AIDS; further research examining these issues is warranted.

The development and testing of nursing interventions that enhance self-esteem seem of particular importance. Harris et al. (1998) used a 16-week peer counseling and leadership training program as an intervention to increase self-esteem, decrease high-risk sexual behavior often associated with poor self-esteem, and increase community-based AIDS prevention education activities among a group of drug-dependent African American women. The goal of the intervention was to help the women take greater
responsibility and control over their lives. Longitudinally, the women’s self-esteem scores improved, and they reported less risky sexual behavior and more frequent involvement in AIDS prevention education activities in their community. Harris and colleagues (1998) designed the intervention to be culturally congruent with their sample population. However, a culturally modified peer counseling and leadership intervention might be appropriate for other populations with HIV; this intervention might prove useful to increase self-esteem and initiate involvement in AIDS volunteerism as it relates to prevention education or other types of volunteerism. Interventions that focus on the development of leadership abilities, empowerment, or the mastery of other desired skills might also be helpful.

Although the final model explained a significant portion of the variance for purpose in life, the endogenous variables in the model had relatively high-error terms. These high-error terms suggest that other variables not specified in the model contributed to the variance in purpose in life among individuals affected by loss from HIV/AIDS. Demographic variables such as income may provide further explanation. For example, a significant number of HIV-negative nonvolunteers reported the loss of spouses to AIDS and the loss of their own jobs due to caregiving responsibilities to a loved one with AIDS. The loss of spouses (i.e., who may have been a source of income) and jobs were much more frequently reported among HIV-negative nonvolunteers than HIV-negative volunteers who more frequently reported the loss of sons. The loss of sons probably did not have a significant impact on the incomes of HIV-negative volunteers as the loss of spouses did among the HIV-negative nonvolunteers. In past research, the financial strain that AIDS produces has been found to negatively affect a sense of control over life (Fife & Wright, 2000) and purpose in life (Bechtel, 1994).

The final conceptual model (see Figure 4) suggests that social support is particularly helpful in increasing a sense of hope and self-esteem. Nurses can encourage individuals to take part in forms of AIDS volunteerism that promote social interaction and support. Forms of AIDS volunteerism that promote social interaction and support include buddy support teams and peer counseling. Furthermore, the final model suggests that hope and, in particular, self-esteem are fruitful targets for nursing interventions to enhance purpose in life among individuals affected by loss from HIV/AIDS.

Results of this study should be interpreted with some caution. The study’s design was descriptive in nature and did not use random sampling techniques. Participants volunteered for the study, and the risk of selection bias exists. As a result, the study’s population may differ in some way from individuals who chose not to participate in the study. In addition, data tested for the model were cross-sectional and thus lacked the strength longitudinal data could provide.

Although multi-item measures with established reliability and validity are desirable (Carmines & Zeller, 1979), no scales were available to measure AIDS volunteerism. Thus, AIDS volunteerism was measured at the nominal level. The use of nominal-level data in path analysis (i.e., when dummy coded) is acceptable when the variable is considered exogenous (Hatcher, 1994), as was the case in this study’s conceptual model (see Figure 2). However, the measurement of AIDS volunteerism at the nominal level somewhat limits the interpretation of AIDS volunteerism’s effect on other variables in the conceptual model. Future research should focus on the development of a more sensitive instrument to measure AIDS volunteerism. Despite these limitations, this study is important to provide further understanding of AIDS volunteerism’s effect on an individual’s sense of hope, self-esteem, social support, and purpose in life.

References


