

# **Loss and Bereavement: HIV/AIDS Family Caregiving Experiences**

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Le but de cette étude théorique fondée sur une recherche empirique était de décrire l'expérience des soins prodigués en milieu familial aux personnes atteintes du VIH-sida lors de la phase palliative. Sept entrevues en profondeur ont été réalisées et analysées à l'aide d'une méthode comparative constante. L'analyse a mené à une conceptualisation des soins donnés en milieu familial. Le présent article décrit le « travail personnel » des personnes prodiguant des soins à un proche atteint du VIH-sida, à savoir l'acceptation de la mort prochaine de l'être cher, la prise de décisions critiques et le lâcher prise. La nature du soutien reçu pour effectuer ce travail est soulignée ici en mettant l'accent sur son influence sur le deuil des personnes soignant un proche atteint du VIH-sida. Les conclusions de cette étude fournissent un début de compréhension de l'expérience vécue par ces personnes et révèlent l'existence d'un besoin significatif pour des interventions visant à les aider à enclencher les mécanismes de résolution du deuil. Il est essentiel de créer et de fournir des réseaux de soutien aux personnes chargées de soigner un proche vivant avec le VIH-sida, et davantage de recherches sont nécessaires pour clarifier et explorer plus avant la question de l'impact du support social sur le deuil. Grâce à ce savoir, les professionnels de la santé seront mieux préparés pour anticiper les difficultés auxquelles font face les personnes soignant un proche atteint du VIH-sida, planifier des interventions répondant à ces difficultés, prévenir les problèmes futurs et mettre sur pied des soins fondés sur la théorie et la recherche.

The purpose of this grounded theory study was to describe the experience of HIV/AIDS family caregiving in the palliative phase. Seven in-depth interviews were conducted and analyzed using the constant comparative method. The analysis resulted in a conceptualization of HIV/AIDS family caregiving. This paper describes the "personal work" of caregivers, including reconciling that a loved one would die, making life-and-death decisions, and letting go. The nature of support received to attend to this work is highlighted, with attention to its influences on HIV/AIDS caregiver bereavement. The findings of this study provide some insights into the HIV/AIDS family caregiver experience and reveal a significant need for interventions designed to support caregivers in establishing the mechanisms required for bereavement resolution. The need for the creation of supportive networks for HIV/AIDS caregivers cannot be overstated. Further research is required to help clarify and expand on how social support might have an effect on HIV/AIDS family caregiver bereavement. With this knowledge, health-care providers will be better prepared to anticipate difficulties faced by caregivers, plan appropriate interventions to address these difficulties, prevent future problems, and plan care based on theory and research.

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My partner of seven years, Christopher Esposito, was rushed to the hospital in a coma. "AIDS," they said. "Six months," they said. I clasped my hands over my ears, but the message penetrated through. Death. Destruction. Gloom. Doom. I screamed the loudest scream I ever heard in my life. It emerged from my gut and built up momentum as it raced to my heart, to the lump in my throat, to my mouth. But no sound passed my lips as the scream echoes through my brain. (Hitchens, 1992, p. 13)

## **Introduction**

The concept of death instills fear in and seriously affects family members in a society that generally denies or does not accept death (Macklin, 1989).

The physical and emotional devastation of HIV/AIDS poses extraordinary challenges to the health-care system and to family members who frequently care for persons living with (PLW) HIV/AIDS (PLWHIV/AIDS) during the chronic and palliative phases of life (Hitchens, 1992; McShane, Bumbalo, & Patsdaugher, 1994). Caregivers attending a national HIV/AIDS family caregiver (e.g., any person whom the PLWHIV/AIDS identified as significant to him or her, regardless of kinship ties, marital relationship, or whether they shared a residence) conference identified the death of their loved one as one of the major difficulties they faced (Health & Welfare Canada, 1990). Such caregivers experience multiple loss: the loss of partners and friends, financial status, health, independence, intimacy, and freedom of sexual expression (Barouh, 1992; Grief & Porembski, 1988; Powell-Cope, 1995; Powell-Cope & Brown, 1992). This multiple loss is compounded by unique challenges such as the fact that they might be infected with HIV themselves and the deterioration and death they have witnessed could be their own fate as well (Dick, 1992; Shilts, 1987). HIV/AIDS family caregivers are usually young to middle-aged and thus might not have acquired the perspectives on death and loss that can accompany middle to old age (Brown & Powell-Cope, 1993; Folkman, Chesney, Cooke, Boccellari, & Collette, 1994). The multiplicity of societal taboos associated with HIV/AIDS can be overwhelming for caregivers (Takigiku, Brubaker, & Hennon, 1993). HIV/AIDS-related stigma can lead them to attribute the illness or death of their loved one to other causes such as cancer (Barbo, 1987; Worden, 1991). Moreover, many of the family relationships within the HIV/AIDS community are not legally acknowledged or formalized in a socially acceptable way, which can serve to accentuate the stigma.

A search of the literature reveals that caring for a person with a life-threatening illness can cause tremendous uncertainty (Brown & Powell-Cope, 1991). It can place a financial burden on family members and put them at risk for chronic fatigue and physical and emotional exhaustion (Folkman, Chesney, & Christopher-Richards, 1994; Pearlin, Semple, & Turner, 1988; Smith & Rapkin, 1996). While studies have focused on families caring for persons with cancer (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Brown, Davies, & Martens, 1990; Hull, 1989; Martens & Davies, 1990) and for the frail elderly (Horowitz, 1985; Knight, Lutzky, & Macofsky-Urban, 1993; Lindgren, 1993; Rabins, Fitting, Eastham, & Fetting, 1990), there is little information on the experiences of HIV/AIDS family caregivers, even though the majority of home-based HIV/AIDS care is provided by family caregivers (Pearlin, Mullan, Aneshensel, Wardlaw, & Harrington, 1994; Raveis & Siegel, 1990).

To address this dearth of information, an exploration and description of HIV/AIDS family caregiving in the palliative phase was conducted. The complete results are presented elsewhere (Stajduhar, 1995). This paper will focus on the consequences to those in the HIV/AIDS caregiving role and the effects that these consequences have had on caregiver bereavement.

### **Methods**

This study focused on developing an inductively derived description and theoretical explanation of family caregiving in the palliative phase. Grounded theory (Glaser, 1978; Strauss & Corbin, 1990) was used to examine the processes through which caregivers tended their dying loved one in the context of the home setting. This method was selected because it is particularly amenable to researching topics that have been subjected to little formal inquiry (Burns & Grove, 1987; Chenitz & Swanson, 1986).

### **Sample**

Participants were recruited through various AIDS service organizations, home health-care providers, and community newsletters. Theoretical sampling (Morse, 1991a) was used to deliberately select participants according to the theoretical needs of the study. A total of seven family caregivers, ranging in age from 31 to 65 years, agreed to participate. All but one caregiver had lost their loved one to HIV/AIDS within a year of the study taking place. Four of the participants were partners in a gay relationship, two were mothers, and one was a sister.

Two of the participants relocated from their permanent residence to provide care, and all seven shared the household with their loved one throughout the caregiving period. More than half of the sample had received some post-secondary education. At the time of caregiving, two participants were employed full-time and one was employed part-time outside the home. Two participants were unemployed and receiving income assistance, one was unemployed and not receiving income assistance, and one was retired.

### *Data Collection*

Data were collected through unstructured, face-to-face interviews in the home where caregiving took place. The open-ended interview format allowed for probing and clarification of participant responses. As a result, there was considerable variance in the time it took to complete each interview, which ranged from two and a half to four hours. Observational fieldnotes (Boyd, 1990; Lincoln & Guba, 1985) and theoretical memos and diagrams (Corbin & Strauss, 1990) were recorded immediately after each interview to maximize richness and depth of the data. Concurrently, newspaper clippings and videotapes pertaining to HIV/AIDS family caregiving were collected, reviewed, and analyzed to ensure a broad perspective throughout the research process. Because the interviews could be emotionally charged and draining, the researcher kept a personal journal and debriefed with colleagues as a way of reflecting on various aspects of the research and to explore and examine the researcher's own assumptions throughout the research process. As Hutchinson (1986) points out, "only through self-awareness of mind-set can the researcher begin to search out and understand another's world" (p. 115).

### *Analysis*

Tape-recorded and transcribed interviews and fieldnotes were analyzed using the constant-comparative method. Analysis proceeded with examination of the data line by line, important passages and themes being highlighted. Each theme involved open substantive codes. *The Ethnograph* computer program (Seidel, 1988) was used to facilitate coding and to sort and manage code files. Following open coding, codes were condensed, conceptually labelled, and categorized. The categories were tested, revised, and modified throughout the process of data collection and analysis. After repeated analysis, a core category emerged, which linked to other categories and explained most of the variation in

the data. The final analysis resulted in a conceptualization of HIV/AIDS family caregiving (Stajduhar, 1995).

Several strategies were used to reduce threats to validity and reliability (Lincoln & Guba, 1985; Sandelowski, 1986). Credibility and fittingness were achieved by triangulating data sources and data-collection procedures to ensure congruence. Follow-up telephone interviews were conducted with two participants. All participants were given a summary of the analysis and asked to comment on its accuracy. The results in their entirety were presented at a national HIV/AIDS conference and to HIV/AIDS family caregivers who had not participated in the study. These steps were taken to ensure "trustworthiness" of the research (Lincoln & Guba).

## **Results**

This study resulted in a conceptualization of HIV/AIDS family caregiving in the palliative phase. While the conceptualization has several components, only data related to loss and bereavement will be presented here.

### *Personal Work*

Caregivers of PLWHIV/AIDS engaged in "personal work" while caring for their dying loved one at home. Personal work comprised three distinct processes. First, *reconciling* that a loved one would die began when family members noticed a decline in their physical condition. Then they perceived that their loved one was dying rather than getting better. Caregivers often characterized reconciling as a series of stages or transitions. One mother compared it to the process of discovering her son was gay:

I think you go through stages. It's the same when you find out your child is gay. You can't believe it. Go and get checked out is the first thing. Then you get over it and after a while you accept it. It's the same thing with this... knowing that he's dying.

Reconciling was difficult because the caregiver had little control over the situation, which resulted in feelings of helplessness:

You are going through hell. I mean, you're standing every day at the side of the bed of someone you love who is dying and you can't change it. There is nothing you can do. You can't sell your soul. They are dying, that's it. And you have to watch that and accept it.

Reconciling was easier when the caregiver and the loved one were able to reminisce about the good times they had shared:

We were talking about this profound love that we had for one another and the commitment that we shared. We had never had those discussions before... It became easier for me to accept he was going as long as I knew how he loved me.

*Making decisions* related to cessation of treatment and *letting go* were two other dimensions of personal work. In many cases caregivers struggled with wanting their loved one to live while at the same time knowing they were dying:

I knew that he was terminal, but even if he could just stay sick that was okay. Just don't die on me... that was what I was hoping for. Stay sick. I'll take care of you. We can bandage this and bandage that but just stay sick. Don't die on me.

Making decisions, particularly related to cessation of treatment, made things complicated:

He was sick and he [the doctor] said you've got to make a decision... I didn't want to make the decision... it's 100% responsibility... I literally had control over his life. I said I think we should let nature take its course. That was the most difficult decision I've ever had to make in my life.

Reconciling that a loved one was going to die and letting go were profound and difficult processes. This experience was less complicated when the caregivers were able to reflect on and discuss their life with the loved one, when they were aware of the wishes of their loved one, and when the loved one could participate in decision-making:

I knew what he wanted. We had talked about it long before he got sick. So when the time came there wasn't any problem. We were very open and honest with each other. I held his hand and ran my fingers through his hair and I'd tell him, it's okay, you don't have to fight this. It's acceptable for you to let go. So it was easier because I knew what he wanted.

### *Approaches to Dealing with Impending Death*

Family caregivers developed and took various approaches to dealing with the impending death of their loved one. *Being with* helped them accept the fact that their loved one was going to die, and they used it as an opportunity for reconciliation:



Every minute is important because you know what the end result is... it [being with] helps in the long run. The time I spent with him ... made it okay.

*Seeking support* through both formal and informal mechanisms helped caregivers with personal work. Formal systems such as organized support groups and AIDS service organizations, and informal supports such as friends and family members, helped caregivers face the inevitability of death:

I think it's really great [the support group], because they set a box of Kleenex in the middle of the table and we can all tell our stories ... it's just good to have other people ... those who are going through the same thing...it helps to deal with what's to come.

When caregivers *worked as part of a team*, with nurses, social workers, physicians, and volunteers, they felt supported in their personal work. It enabled them to be acknowledged and recognized for their role. Central to the success of working as part of a team was the reciprocal trust and respect that developed between the HIV/AIDS caregiver and other members of the team:

His doctor was someone who believed in participating in care. This was a team effort...it was the three of us sitting down and saying, here are the options, what do you think? — actually listening to me as if I was a reasonably intelligent being...that my opinion mattered.

*Planning for death* was a final approach taken by family caregivers to deal with the impending death of their loved one. This approach helped them identify their loved one's "last wishes." Knowing these wishes gave caregivers confidence:

We talked about it right from the very beginning ... so I knew what he wanted and I could carry that out.

Planning for death also helped circumvent potential problems with other family members. More than half of the participants in the study were not related by blood to their loved one. These caregivers saw the possibility of interference and disagreement on the part of the family of origin. One partner caring for his lover said that planning for death helped him to avoid a potentially difficult situation:

I told him ... I want you to tell your mother ... I want it to come out of your mouth. I don't want her to think that I concocted this [planned memorial service]. She has got to know what you want, because we've had problems before.

Some family caregivers failed to plan for death, citing their difficulty accepting the inevitability of the death of their loved one.

### *The Nature of Support*

HIV/AIDS family caregivers sought support in dealing with their loss and grief, but the nature of that support was a critical factor for them. One caregiver said that life would have been unmanageable without good counselling:

I don't know what we would have done without them [the social workers]. They were our backbone... they were the best support we got. It kept us upright.

When asked to explain how this support was helpful, the caregiver elaborated:

She told me the lovers tend to be forgotten. And her focus was, if you fall apart, what the hell's going to happen? ... She saw an integral part of her job as keeping the partners reasonably healthy. We get supported so that we can continue to look after our lovers at home.

Support from the family of origin was a factor as well. Some caregivers were estranged from both their own family and the family of their loved one, and in some cases they received no family support at all. Other families were able to overcome their homophobic feelings, leaving the caregivers surprised and appreciative:

I think one of the biggest recognitions I got was from my parents, particularly my mother. She said, "You've gone through something I hope I never have to ... you are remarkable." Coming from my mother, whoa ... that was real good. It was the full acknowledgement of what I did and of our relationship, that our relationship was as significant as any straight couple's relationship.

Caregivers experienced emotional pain, feeling rejected and isolated when support was not forthcoming:

...his family was not there. It was really disappointing ... I phoned his mother and she said she would come, but she never did ... she was really removed. That hurt a lot. How could a mother not come to see her own son?

I had very little contact with my family. In fact there were no flowers or no card or anything saying we're sorry for your loss ... you know, there are phone lines between the provinces, and airplanes, but there was never any offer of coming out, so I was disappointed by that.

Unsupportive interactions most often involved people with whom the caregivers came in frequent contact — physicians, nurses, social workers, and in some cases volunteers. They repeatedly reported encounters with health-care providers that left them feeling angry, bitter, isolated, and disillusioned. The caregivers had assumed that



health-care providers would be supportive, but their expectations were not always met:

We went to see a social worker ... I felt really good about this because we really needed help dealing with this, but this woman was hopeless. She does not belong ... with AIDS patients at all. She has no understanding. She's very good at shuffling papers, but as far as dealing with people on an emotional level she is pathetic ... we were looking for a little bit more nurturing but that was never forthcoming ... it never came ... I had no one. I was at my wit's end.

Some caregivers had their hopes dashed when they sought help from community health services:

This woman [a volunteer] from the hospice called me to see how I was doing. I said, I'm not doing that well today. Today is my birthday and birthdays were really big for G. and I. She triggered something inside me and I started to cry. As soon as she heard me crying she said, well, I'll let you go now. You take care of yourself. Take care of myself? Why did you call? What did she expect? I told her I was profoundly lonely and she hung up on me ... she literally hung up on me.

One of the caregivers, a nurse caring for his partner, experienced difficulties when he sought support from nurses in a palliative-care unit:

I think health professionals providing support to health professionals forget that we are family — that we are there just to be there. I think there is an assumption that those of us who are health-care professionals can bear the weight a bit more. So they tended not to attend to me as much, which they really needed to do.

HIV/AIDS caregivers tried to understand these unsupportive incidents, citing heavy workloads and staff stress. They believed that professional caregivers were unable to be supportive because they were not supported themselves:

Unfortunately, the majority of nurses are terribly overworked and they don't have the time to spend with patients ... I feel sad about watching the level of burnout because there are not enough of them [nurses]. They are exhausted. None of them are debriefed after someone dies. That process isn't there. They are burnt.

### *Consequences of Caring for a Dying Loved One with HIV/AIDS*

The approaches family caregivers took in dealing with the impending death of their loved one ultimately affected their bereavement. When caregivers were able to build supportive networks they were better able to find meaning in their loss and come away with a renewed sense of self:

It was a learning experience... when you come through that whole experience you develop a certain profound sense of something. I know I definitely came out a different person. I came out with a different sense of life.

This renewed sense of self helped them to make constructive changes in their lives and acknowledge the love and commitment they had shared with their loved one:

I'm fortunate in a sense that I was loved and I was able to love so profoundly... I was there to say goodbye to him and hold him when he died.

On the other hand, caregivers who were unable to obtain support faced difficulties with their bereavement and were challenged to find meaning in their experience. Feelings of cynicism, anger, and disillusionment permeated their lives:

...rose-coloured glasses no longer exist... you know, you try and smell the roses but you realize after this that the shit that goes on is really evident. The people you have to deal with, it's just such a problem, so I don't expect that support to be there any more.

Caregivers seemed stuck in their grief and resentment:

It just replays in my mind... like that emergency room guy that I'd like to run over with a truck... it's going to be a long time until I deal with that anger, never mind my own stuff about his death.

## **Discussion**

The findings of this study lend support to the notion that loss and grief are central to HIV/AIDS caregiving both before and following the death of the loved one. How caregivers dealt with the impending death, and what imprint was left in their minds following the death, was found to be highly dependent on the nature of the support they received. While some studies acknowledge that loss is a central theme for HIV/AIDS caregivers (Brown & Powell-Cope, 1993; Folkman, Chesney, & Christopher-Richards, 1994; Powell-Cope, 1995), the relationship between social support and caregiver bereavement remains relatively unexplored in the HIV/AIDS literature. Social support appears to be a necessary component of bereavement resolution (Broadhead et al., 1983; Vachon et al., 1982). However, in HIV/AIDS caregiving the process of family coping with bereavement is severely compromised by societal stigma (Rolland, 1990), a lack of the traditional acknowledgement that can be helpful in bereavement (Geis, Fuller, & Rush, 1986; Murphy & Perry, 1988), and inappropriate support from

health-care providers (Ferrell & Boyle, 1992; Lennon, Martin, & Dean, 1990). The results of this study demonstrate that supportive networks are essential, contributing to caregivers' ability to make sense of their loss and re-emerge to face life without their loved one.

These findings reflect a significant need for interventions designed to support caregivers in establishing the mechanisms necessary for bereavement resolution. Nurses play a pivotal role in supporting family caregivers (Alexander, 1994) and are in a primary position to influence the bereavement outcomes of high-risk grievers (Ferrell & Boyle, 1992). Creating and sharing supportive relationships with nurses and others may help caregivers continue their lives with a renewed sense of self. Relationships must be built on reciprocity — making patients and caregivers equal partners on the health-care team (Morse, 1991b; Thorne & Robinson, 1988). Nurses and other health-care providers must also be aware of the potential relationship between social support and the ability of caregivers to find meaning in their loss. Only through this awareness can health-care providers begin to reflect on their actions, behaviours, and potential impact on caregivers.

Health-care workers must be comfortable caring for those infected and affected by HIV/AIDS. Unsupportive or stigmatized care will only serve to further alienate and isolate those who require care. Nurse administrators can contribute by ensuring that supportive work environments and appropriate staff education are available. For support and genuine caring to be shared, nurses must be given the opportunity to learn and to feel just as accepted, respected, and honoured as unique individuals as they profess to feel about patients and patients' families (Neil, 1994). Open discussion and commitment to creating such an environment are essential to the promotion of self-knowledge and growth.

The importance of creating supportive networks for HIV/AIDS caregivers cannot be overstated. Research is required to clarify and expand on the effect of social support on HIV/AIDS family caregiver bereavement. As well, research on effective care and support strategies for HIV/AIDS caregivers is urgently required if we are to better understand how to intervene in helping caregivers to face life without their loved one.

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