

## Chapter Two

### LITERATURE REVIEW

#### Traditional Caregiving and Bereavement Literature

##### Caregiving

##### The Primary Caregiver

When care for an individual is provided in the home, one person is usually faced with the majority of caregiving tasks (Baum & Page, 1991; Brody, 1985). This individual is often called the “primary caregiver.” Studies have traditionally shown that in caregiving for an older adult, the primary caregiver is often a spouse if the older adult is married. In the absence of a spouse or in the event that the spouse is unable to provide care, adult children will usually assume the primary caregiving role (Cantor, 1983; Mace & Rabins, 1981). It is also noted that women account for the overwhelming majority of primary caregivers (Stone, Cafferata, & Sangl, 1987). The adult daughter or daughter-in-law has been cited as the typical primary caregiver. This daughter/daughter-in-law phenomenon has been deemed the “woman in the middle” phenomenon. They are “in the middle” not only because they are often the middle generation in the family, but also because they are often torn between the demands of the caregiver role and the demands of the mother, spousal, and worker roles (Brody; Stone et al.).

The primary caregiver is presumed to experience many adverse effects related to the provision of care. These effects are often referred to as “caregiver stress,” “caregiver

strain,” or “caregiver burden.” Unfortunately, these concepts are often used interchangeably and various meanings are attached by a wide range of disciplines. Many have cited these discrepancies among concepts as problematic in understanding the nature of the caregiving experience and its impact on caregivers (Braithwaite, 1992; Kramer & Kipnis, 1995; Poulshock & Deimling, 1984; Shultz, 1990; Vitaliano, Russo, Young, Becker, & Maiuro, 1991a). Although discrepancies exist, caregiver “burden” appears as the most widely used term in the caregiving literature.

### Burden, Stress, and Strain

Many attempts have been made to measure the concepts of burden, stress, and strain among caregivers. The overwhelming majority of these studies have assessed caregivers of those afflicted with Alzheimer’s Disease and related dementias (Greene, Smith, Gardiner, & Timbury, 1982; Kinney & Stephens, 1989; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Novak & Guest, 1989; Rabins, Mace, & Lucas, 1982; Vitaliano, Young, & Russo, 1991b). Others have assessed the well being of persons providing care to loved ones with more general physical impairments (Montgomery, Gonyea, & Hooymann, 1985; Poulshock & Deimling, 1984; Robinson, 1983).

Despite discrepancies, some commonly agreed upon definitions and contributors to the negative impact of caregiving do exist. A common, and the most broad, definition of “burden” characterizes it as a set of “physical, psychological or emotional, social, and financial problems...” (George & Gwyther, 1986, p. 253). Some also differentiate between subjective and objective aspects of burden (Kinney & Stephens, 1989;

Montgomery et al., 1985; Poulshock & Deimling, 1984). Objective burden often entails a change or disruption of roles, family life, or social activities (Kinney & Stevens; Montgomery et al.). Subjective burden entails feelings, emotional responses, and perceptions. These feelings may include overload, entrapment, and resentment (Montgomery et al.; Poulshock & Deimling; Zarit, Reever, & Bach-Peterson, 1980).

In general, the contributors to caregiver burden include the level of impairment and frequency of disruptive behaviors of the care-receiver, level of social support, decreased finances, physical strain, isolation, shared residence with the care-receiver, and health problems of the caregiver (Kinney & Stephens, 1989; Kosberg, Cairl, & Kellor, 1990; Poulshock & Deimling, 1984; Zarit et al., 1980). Each piece of the literature will confirm or rebut one or more of the above mentioned contributors and may add a few new contributors as well.

Caregiver “stress,” although not used as frequently in the literature, is often conceptualized as the impact (mostly negative) of the caregiving experience (Poulshock & Deimling, 1984; Robinson, 1983; Zarit et al., 1986). Stress involves interrelated variables such as caregiver characteristics, available support, and roles performed. Caregiver “strain,” as conceptualized in the literature, is sometimes considered part of the stress process or interchangeable with a stressor (Cantor, 1983; Robinson; Shultz, Visintainer, & Williamson, 1990). Strain is also often tied to roles, involving personal and relationship sacrifices, and often equated with burden (Cantor). Contributors to strain have included care-receiver characteristics, subjective perceptions and emotional health of the caregiver, physical and financial stressors, disruption of family equilibrium,

and impaired relationships (Cantor; Mui, 1992; Mui & Morrow-Howell, 1993; Robinson).

### Impact of Caregiving

In addition to the contributors to caregiver burden/stress/strain, outcomes of this negative impact have also been studied. Clinical studies have examined the physical and psychiatric “morbidity” which often results from the impact of caregiving. Physical and psychiatric morbidity deal specifically with the detrimental effects on caregivers’ mental and physical health (Shultz et al., 1990). Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Sprecher (1987) found caregivers for those afflicted with Alzheimer’s Disease had poorer immune functioning than non-caregiving peers. The caregivers also reported more distress, indicating stress-related immunologic changes resulting from the caregiving situation.

Studies including self-reports of health by caregivers also point to caregiving effects on caregiver physical health. Twenty-one percent of the caregivers in Chenoweth and Spencer’s (1986) study reported poor health as a reason for institutionalizing their loved ones. Health conditions noted included heart attacks, ulcers, “nervous breakdowns,” fractures, and exhaustion-related illnesses. A large-scale study by Stone, Cafferata, and Sangl (1987) showed that caregivers perceive themselves as being in poorer health than non-caregiving peers. Haley, Levine, Brown, Berry, and Hughes (1987) also found caregivers to report poorer health and even more prescription drug use than non-caregiving peers.

Research also suggests a link between the impact of caregiving and mental health problems. Psychiatric morbidity includes mental health problems such as depression and anxiety. Haley et al.'s (1987) sample of forty-four caregivers for persons with dementia reported higher levels of depression and lower overall life satisfaction than controls. Kiecolt et al.'s (1987) sample of thirty-four caregivers also reported higher levels of depression and lower levels of life satisfaction than their thirty-four non-caregiving peers.

There is evidence suggesting that the impact of care and other negative effects of caregiving are lessened or "buffered" by social support (Cantor, 1983; George & Gwyther, 1986; Montgomery et al., 1985; Pearlin, Mullan, Semple, & Skaff, 1990; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993; Zarit et al., 1980). Social support, just as caregiver burden/stress/strain, has been diversely defined in the caregiving literature. Thompson et al. (1993) note that some studies define social support in terms of the number of persons within a network in which the caregiver can access in times of need, while others define it in terms of functional assistance provided with caregiving tasks. Others also define social support in terms of emotional (advice giving and listening) and instrumental support (assistance with physical tasks) (Pearlin et al.). Thompson et al. (1993) found that social support involving social interaction in fun activities to be the most important form of social support in buffering caregiver burden. Caregivers experienced increased burden when social opportunities were restricted.

Despite the aversive effects of caregiving, the majority of caregivers sustain the burden and are committed to providing care at home (Carter & Golant, 1994). Many provide care out of love and concern for the loved one. The caregiver may also value

positive aspects of the situation, such as the fact that the loved one is happy to be in the home environment, that the caregiver is providing good care to their loved one, and they have the opportunity to “give back” to the care receiver and to fulfill a family obligation (Farran et al., 1991; National Alliance for Caregiving and American Association of Retired Persons, 1997). Many caregivers are clearly committed to avoiding the institutionalization of their loved one (Chenoweth & Spencer, 1986; Colerick & George, 1986).

#### Caregiving Among Older Couples

The traditional caregiving literature provides some insight into the experiences of older couples. Only a few studies have made distinctions between spousal caregiving and caregiving by other relatives and friends (Fengler & Goodrich, 1979; Johnson, 1983; O'Conner, 1995; Pruchno & Resch, 1989; Robinson, 1983; Ross, 1991; Spaid & Barusch, 1994; Thompson et al., 1993; Zarit et al., 1980; Zarit et al., 1986). Robinson (1983) and Zarit et al. (1980) both found no significant differences between the negative impacts experienced by spousal and adult child caregivers. Cantor (1983) and George and Gwyther (1986), however, found spousal caregivers to be at an increased risk for the adverse effects of caregiving. Most spousal caregivers are old themselves and in poor health as well (Cantor). George and Gwyther also found that spousal caregivers showed lower levels of well-being, as indicated by more stress symptoms, more use of psychotropic medications, and lower levels of life satisfaction. Additionally, older caregivers have experienced less social support in the form of assistance with physical

tasks, advice and feedback, and emotional support (Thompson et al.). Spousal caregivers may be at further risk as it has been suggested that despite their vulnerability in the caregiving situation, they are less likely to utilize formal services for assistance (Gonyea & Silverman, 1991; Gwyther, 1990; Johnson).

Distinctions have also been made between husbands and wives in caregiving. In comparing husbands and wives, studies have found wives to be more depressed, to experience more burden, and to provide more hands-on care (Horowitz, 1985; Pruchno & Resch, 1989). Pruchno and Resch also found that husbands were more likely to have assistance in providing hands-on care but wives were more likely to have a confidant while providing care.

### Loss and Bereavement

Although the duration of care can last several years, a chronic illness can eventually take the life of a loved one. This loss is felt very deeply by and has a tremendous impact on the lives of the survivors. The concepts of bereavement, grief, and mourning are often associated with loss and will be discussed in this section.

Bereavement is the state or fact of having experienced a loss. This state is often experienced when persons who were close die (Kastenbaum, 1995). When someone close dies, one typically responds both mentally and physically to this loss. Grief is the individual's response to this state of bereavement (Kastenbaum; Sanders, 1999). These responses may include anger, guilt, despair, sorrow, and somatic complaints and

symptoms (Sanders). Grief is also described as an internal condition of mental and physical pain that can result from the loss of a loved one (Stephenson, 1985).

Bereavement is often not a solitary experience, as those who are bereaved seek support and understanding from persons in their lives. Through mourning, individuals seek validation for their loss from others. Mourning, then, is the social and external expression of grief (Stephenson, 1985). Each society will hold certain beliefs and establish particular rules for this expression (Stephenson; Sanders, 1999). In this culture, funerals serve as social rituals for individuals to mourn the loss of a loved one (Stephenson).

It has been suggested that survivors must go through a process of dealing with their loss. This process is often conceptualized in stages of normal grief. These stages often begin with an initial period of shock and denial, followed by a period of mourning, and finally, a period of "restitution." Following the death of a loved one, an individual is often in shock, denial and disbelief that their loved one is really gone. This initial stage may last a few hours or a few weeks. This period of shock may be followed by a period of mourning, which may last for several months. During this time the loss is acknowledged and the individual experiences emotional distress as a result. The bereaved may also isolate themselves socially during this time. This period of mourning is followed by a period of restitution, where the individual feels that he/she has grieved and is ready to move on in life, work, and relationships (Schuchter & Zisook, 1993)

These stages are not thought to be discrete but are often overlapping. In some cases, the grief process may be complicated or even left unresolved. These complications may



occur when there is insufficient social support, pre-existing depression, or financial difficulties or when the relationship was dependent or unstable, when other life events conflict, or when the loss was sudden (Schuchter & Zisook, 1993). Stigmatized deaths, such as those from suicide and HIV/AIDS may further complicate grief reactions (Sanders, 1993).

Although stages are mentioned, grief is a process that is not the same for every person. Some advocate that grief is not linear, as in stages, but must be examined in terms of its “diverse, multidimensional perspectives” (Schuchter & Zisook, 1993, p.43). These perspectives include affective and cognitive states, coping strategies, the continuing relationship with the deceased, changes in relationships, and alterations of identity. The development of these perspectives was based upon a Zisook, Mulvihill, and Schuchter study of 350 widows and widowers (as cited in Schuchter & Zisook, 1993)

According to Schuchter and Zisook (1993), the emotional and cognitive responses to a loss may include such reactions as shock, a sense of loss, anger, guilt, regret, anxiety and fear, and loneliness. Coping with a loss may involve disbelief, suppression, rationalization, faith, involvement with others, and expression. In bereavement, changes may also occur in mental and physical health, social and occupational functioning as well as in relationships with others. As a result, the widow(er) may need increased levels of emotional support from family and friends during this time (Schuchter & Zisook).

Widowers may also be faced with the challenge of beginning a new romantic relationship. Re-engaging in romantic relationships can be especially complicated for widows(ers). Changes are also made in identity, as those that experience loss will often

view themselves and the outside world differently (Schuchter & Zisook, 1993). In addition, the process of grief often facilitates personal growth and understanding, can help individuals realize their strengths and capabilities, and can foster increased sensitivity to others (Attic, 1991; Schuchter & Zisook). In this way, grief can be considered “life enhancing” (Attic).

Not only is bereavement an individualized process, but it is also viewed as an “active coping process” (Attic, 1991, p.385). In this sense, the coping process is separate from the emotion of grief. Bereavement is not strictly a course of emotion, in which one is passively experiencing the loss. Instead, it is a process that presents challenges to be actively worked through. These challenges include accepting the death and its ramifications, working through the emotional upset, and moving on and re-engaging meaningfully in the world without a loved one (Attic; Worden, 1982). In addition, there are several paths that can be chosen by the individual in this process and in meeting these challenges (Attic).

A few researchers have looked specifically at spousal bereavement (Caserta & Lund, 1992; Hegge & Fischer, 2000; Lund, 1989; Lund, Caserta, & Dimond, 1993; Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991; Zisook & Schuchter, 1991). According to Lund et al. (1993), loneliness is the most persistent and serious problem among bereaved spouses. Even if a widowed spouse has the constant support of family and friends, he/she will often feel alone without his/her spouse. Other areas of concern in spousal bereavement include problems with personal identity, family and

friends, depression, and physical ailments. Despite these problems, spouses have also proven to be very resilient in adapting to bereavement (Caserta & Lund, 1992).

Gender differences have also been found in spousal bereavement (Benedict & Zhang, 1999; Bierhals, Prigerson, Fasiczka, Frank, & Miller, 1995; Lund et al., 1993; Zisook & Schuchter, 1991). Women tend to feel more helpless following the death of a spouse and often view the deceased as “watching over” or protecting them. Men “show less acceptance of the death, become involved sooner in romantic relationships, express themselves less, and drink more” after losing a spouse (Schuchter & Zisook, 1993, p.42). Older spouses were also found to have deficiencies in particular skills in widowhood. Widowers have been found to have difficulty with domestic chores such as cooking and cleaning. Widows, on the other hand, have been found to have difficulty with home maintenance and repair and handling legal and financial affairs (Lund et al., 1993). According to Martin and Doka (2000), gender differences in bereavement may be influenced, but not determined, by gender role socialization.

Very few studies have examined bereavement experiences of caregivers for older adults. In addition, the bereavement and caregiving segments of the literature have existed as two very separate research areas (Schulz, Newsom, Fleissner, Decamp, & Nieboer, 1997). Although bereaved caregivers often experience a deep sense of loss following the death of a care-recipient, many positive outcomes have also been identified. In existing studies, caregivers experienced positive effects, including reduced stress, improved health and quality of life, and increased leisure time and social interaction (Gold, Reis, Markiewicz, & Andres, 1995; Seltzer & Li, 2000). Caregivers have also

experienced an increased sense of personal mastery and lower levels of overload in bereavement (Mullan, 1992; Skaff, Pearlin, & Mullan, 1996). Some caregivers also found that the death of the care-recipient came as a relief after prolonged suffering (Jones & Martinson, 1992).

According to research in this area, a few factors may contribute to bereavement outcomes for caregivers. As some studies have found, caregivers that experience tremendous strain during caregiving are more likely to experience greater difficulty adjusting to the death of the care-receiver (Bass & Bowman, 1990). In addition, strong social support (during caregiving and bereavement) can positively impact bereavement for caregivers (Bass, Bowman, & Noelker, 1991; Sankar, 1991). In fact, Schulz et al. (1997) suggest that in the case of a strong, pre-existing support system, “when a death occurs, the support system is already in place and roles for individual members are defined and ready to be implemented” (p.279).

## Gay and Lesbian Caregiving and Bereavement Literature

### Caregiving

#### Gay and Lesbian Caregiving

To date, Frederikson (1999) exists as one of the only researchers to reveal gay men and lesbians as participants in family caregiving. Based upon her survey of 1,466 gay men and lesbians, she describes the prevalence and characteristics of gay men and lesbians caring for children, friends, partners, and parents. About one-third of the study sample was providing some kind of care for an adult or child and 27% of the sample were

caring for an adult. Of those caring for adults, most (61%) were caring for friends and 13% were caring for same-sex partners.

Most of those who provided care to adults reported receiving support from at least some biological family members in regards to their life as a gay man or lesbian. Only 7% reported receiving no support from any family members. Despite this support from family, 82% reported experiencing (mostly verbal) harassment because of being gay or lesbian. Many also reported that they were “out” to all of their coworkers (56%) and health care providers (62%). Only 7% were completely closeted at work and 8% were not out to any health care providers (Frederikson, 1999).

Frederikson (1999) also found differences between gay men and lesbians caregivers. Among those caring for an adult, lesbians were more likely to be caring for persons 65 and older and were more likely to be partnered. Gay men, on the other hand, were more likely to be providing care for “working age” adults. These working-age care-receivers were often afflicted with HIV/AIDS. A smaller study by Frederikson (as cited in Frederikson, 1999) suggests differences between the caregiving experiences of gay men and lesbians and those in heterosexual relationships. Gay and lesbian caregivers were found to provide more hours of care and higher levels of care than their heterosexual counterparts. In addition, they experienced higher levels of role strain and were more likely to quit their jobs because of their caregiving responsibilities.

Tully’s (1989) survey of 73 midlife lesbians also sheds light on caregiving in the gay and lesbian community. Specifically, their utilization of formal and informal caregiving services and those services they deemed necessary were examined. These women tended

to seek out and receive the most caregiving support from family members, friends, and partners. Of those who were involved with the “social welfare” system, the majority of their involvement was with health care professionals as opposed to the use of housing, transportation and other services. In general, formal support services were not well utilized when respondents were in need of caregiving services and respondents did not expect to get much support from this sector in the future. Almost 60% thought professionals were generally not accepting of their being a lesbian. Many also believed professionals did not understand their special relationships or needs.

In terms of future care, many respondents in Tully’s (1989) study mentioned emotional support and personal care as the two most important needs they would have if they became ill. Seventy-seven per cent of the sample believed that they would have adequate support if caregiving were needed in the future and some named a female friend or partner who could serve as a caregiver. In addition, the respondents were asked about the types of caregiving services that were most needed by aging lesbians. The majority said “that first and foremost they wanted women friends to whom they could turn for love, acceptance and interpersonal communication” (p. 99).

Organizations such as the National Gay and Lesbian Task Force, Pride Senior Network and Senior Action in a Gay Environment (SAGE) have also investigated the issues related to caregiving in the gay and lesbian community. Information collected from a series of focus groups conducted with older adults in New York in 2000 by the National Gay and Lesbian Task Force and Pride Senior Network, suggests that older gay men and lesbians may actually have a greater burden related to caregiving. This may be

due to the assumption of their heterosexual siblings that because they are not “married” or do not have children, they are the most likely and most appropriate caregivers when their parents become ill and are in need of care (as cited in Cahill, 2000).

Cahill et al. (2000) also proposes that older gay men and lesbians may have fewer supports available when they are in need of care. They base this concern on the fact that studies have found a high percentage of older gay men and lesbians live alone and they have fewer children who could provide care (see Brookdale Center on Aging, 1999; Rosenfeld, 1999). In addition, HIV/AIDS has taken the lives of millions of gay men who could have otherwise served as supports (Cahill).

To add to this concern, Pride Senior Network also conducted a survey in 1999 related to the caregiving resources of older GLBT (gay/lesbian/bisexual/transgender) adults. The information was collected from 98 participants at a gay and lesbian health fair in New York City. Sixty-four per cent of those under 50 said that they would have a caregiver available to them. Interestingly, 68% of those over 50 could not name a person who could provide care if they were in need (Karpiak, Cantor, Chernesky, Ensig-Brodsky, & South, 2000). As a result of these findings and concerns, Cahill et al. (2000) believe a crucial and urgent question is, “Who will care for GLBT seniors?” (p.41).

### HIV/AIDS Caregiving

The HIV/AIDS caregiving literature also adds to knowledge in the area of gay and lesbian caregiving. Although seemingly very different from traditional caregivers, studies of caregivers for persons with HIV/AIDS have shown some of the same

contributors to the negative impact of caregiving. As with caregiving for older adults, the HIV/AIDS epidemic has also brought with it increased informal caregiving. Also similar to traditional caregiving, caregiving for PWAs has involved other victims, namely the caregivers (Turner et al., 1994).

There are many noted similarities between traditional and HIV/AIDS caregiving. Turner et al. (1994) found that HIV/AIDS caregivers had many of the same concerns as traditional caregivers, including avoidance of institutionalization, increasing financial problems, need for social supports, and negative impact on personal relationships. Turner and Catina (1997) also found that, like traditional caregiving, HIV/AIDS caregiving is increasing due to the advancement in treatments and increasing institutional health care costs, as well as the psychosocial benefits provided to the PWA. Caregivers for PWAs, like traditional caregivers, also experience adverse effects of providing care (Turner et al.). Like traditional caregivers, caregivers for persons with HIV/AIDS also note positive aspects of the experience, including increased emotional closeness and a gain of personal confidence and strength (Wardlaw, 1994).

The most obvious difference between traditional and HIV/AIDS caregiving is the unique characteristics of the caregiver and the care-receiver. With regard to the care-receiver, gay and bisexual men continue to make up the largest proportion of HIV/AIDS victims in the United States. Many of these men are cared for by gay or bisexual men (Turner et al., 1994). As it is estimated that between 30-40% of these HIV/AIDS-afflicted men are in committed relationships, a great proportion of caregivers are likely to be same-sex partners (Folkman et al., 1994).



In some respects, HIV/AIDS caregiving may be differentiated and considered a non-normative experience. A non-normative life experience is one that is off-sync with expected life events. Normative experiences, on the other hand, are those that are expected given a certain age or time of life (Hayslip & Panek, 1989). As Turner et al. (1994) found, 74% of their national sample was under forty years of age. This contrasts with the traditional caregiver for older adults as well as with Brody's (1985) picture of parent care as a normative family stress. Turner et al. suggest that caregiving for persons with HIV/AIDS is a non-normative experience due to the age and gender of the caregiver and fulfilling of non-traditional sex roles with regard to caregiving tasks. This experience may be particularly stressful, as life-span scholars state that normative (developmentally expected, or on-time) life experiences are less stressful than non-normative experiences. Turner et al. also suggest that gay male caregivers, in particular, may have the additional stress of being HIV positive themselves and may have the psychological distress of experiencing repeated loss of friends who die from HIV/AIDS.

As noted HIV/AIDS caregiving also appears to involve non-traditional sex-roles in task performance. Male HIV/AIDS caregivers report great involvement in domestic and personal care activities, whereas in traditional caregiving, males provide more assistance with bill paying, transportation, and appointment making. Women, in traditional caregiving, are more likely to take on the tasks of personal care and household chores (Miller & Cafasso, 1992).

Few researchers have looked specifically at the impact of caregiving on caregivers who care for partners with HIV/AIDS. In the Folkman et al.'s (1994) study of gay men

as caregivers for partners with HIV/AIDS, 84% reported assisting with housekeeping, meal preparation, and grocery shopping. Most also worked full-time. Many also experienced dysphoria. This dysphoria was reported as being due to the partner's illness and its unpredictable path, increasing responsibilities and decision making, changes in the relationship, fatigue, role conflict, feelings of helplessness, one's own HIV status, and fears related to the future loss of the partner. For these men, role conflict involved multiple demands including working outside the home as well as serving as the primary caregiver. Caregiving caused financial strain as well, as some men had to reduce work hours to provide care. With regard to their own HIV status, some worried about who would take care of them when their partner died. It was also found that families were often not available to provide respite care. Many families were either physically distant or not accepting of the relationship (Folkman et al.).

Although families may not be available to provide respite care, many gay men with HIV/AIDS have relied on their network of friends for care and support. According to Bonuck (1993), HIV/AIDS caregiving has impinged and challenged "our traditionally held notions of who and what is family" (p.86). This network of friends may also "fill the void of formal (paid services) and familial support" (Delgado & Rose, 1994, p.12).

HIV/AIDS caregiving contradicts the support systems of traditional care-receiving populations, which have included heterosexual spouses and adult children as the primary sources of support. Instead, the support networks of PWAs may be largely made up of friends as well as other persons with HIV/AIDS (Delgado & Rose, 1994; Hayes, Chauncey, & Tobey, 1990). Many of these persons are also gay or lesbian (Turner &

Catania, 1997). Caregivers may be assisting more than one person with HIV/AIDS and one PWA's caregiving network could consist of a team of several caregivers (Delgado & Rose; Wardlaw, 1994). This team of caregivers challenges the traditional "primary caregiver" image of traditional caregiving studies (Delgado & Rose). Similar to caregivers in the traditional literature, though, persons in these caregiving networks provide a variety of tasks, including personal care, legal and financial assistance, and emotional support (Delgado & Rose; Wardlaw).

#### Gay and Lesbian Bereavement

Few researchers have also investigated the bereavement experiences of gay men and lesbians. Studies and theories that do exist suggest that the bereavement process can be very different for persons who survive same-sex partners (Doka, 1987; Shernoff, 1997). Shernoff, in his collection of essays of gay men who have lost partners, describes gay widowhood as "a completely unique societal situation" (p.xvi). This situation is unique in that it lacks social status and recognition as well as visible and available role models. To add to this difficulty, the men who share their stories with Shernoff, struggled with developing a new identity in the face of this loss and a new identity as a gay widower. They also faced the challenge of moving on with their lives and, in some cases, establishing new romantic relationships. Many of these men, however, found comfort in connecting with others who had also gone through the loss of a same-sex partner.

Although not focusing exclusively on gay men and lesbians, Doka (1987) contends that bereavement can be even more difficult for those in "nontraditional" relationships.

These relationships include persons involved in extramarital affairs, cohabitating couples, as well as same-sex couples. One difficult aspect of this experience is that a nontraditional partner may not be permitted to visit their loved one when they are dying, as hospital visitation may be restricted to immediate family only. When the partner dies, they may also be excluded from plans related to the burial and funeral or may not receive recognition at a funeral. Following the death of a nontraditional partner, an individual may also have to battle relatives over inheritance and property. The partner may also receive very little social support if the relationship was closeted or was not accepted by family members. According to Doka, these added stressors can hinder the grief process for the nontraditional partner.

Those in nontraditional relationships, including gay men and lesbians, can experience what Doka (1989a) calls “disenfranchised grief.” This type of grief is experienced when a loss that is not “recognized or validated by others” (p.xv). Further, this loss cannot be “openly acknowledged, publicly mourned, or socially supported” (p.4). These widows(ers) do not fit in with the “grieving rules” of society. These rules establish “who, when, how, how long, and for whom people should grieve” (p.4). These rules may be covert or may be formalized through policy. As a result, these persons may not be able to take time off from work after a partner dies and may not be able to verbally express their loss to others. In effect, when grief is disenfranchised, the relationship, the loss and the griever are all not recognized (Doka, 1989b). Furthermore, if the nature of the relationship had been kept a secret, the death of a same-sex partner may go completely unrecognized by family members or coworkers (Dane & Miller, 1992).

HIV/AIDS also presents a bereavement experience that often exists in nontraditional relationships as well as existing as a death that is very stigmatized (Dane & Miller, 1992; Doka, 1989b; Martin, 1988). HIV/AIDS has also facilitated multiple and reoccurring losses for members of the gay community (Dane & Miller; Dworkin & Kaufer, 1995; Martin & Dean, 1993). In fact, Dworkin & Kaufer have called this experience a “chronic state of mourning” in which individuals experience the loss of partners and friends and often these periods of mourning overlap (p.42). Compounding this loss for partners are feelings of survivor guilt as well as a fear about one’s own HIV status (Dane & Miller; Martin & Dean). This type of bereavement may also involve higher degrees of psychological distress (including depression, anxiety, and suicidal ideation) and possibly higher levels of substance use among survivors (Martin & Dean).

### Gay and Lesbian Aging

Taken together, the traditional and the HIV/AIDS caregiving and bereavement literature may begin to provide a partial picture of the experiences of midlife and older gay men and lesbians caring for partners. Unfortunately, this picture is still incomplete. Although no study to date has dealt specifically with the experiences of midlife and older gay men and lesbians caring for partners, several studies have examined the unique issues gay men and lesbians face in aging, older adulthood, and midlife.

### Aging and Older Adulthood

#### Diversity and Strengths

Older gay men and lesbians, as a group, are considered to be very diverse (Friend, 1991; Herdt, Beeler, & Rawls, 1997; Kimmel, 1978). The major unifying characteristics of this population appears to be that its members have developed some type of homosexual identity and that they have grown up in a similar time period (Friend). Older gay men and lesbians of today have lived through a similar historical period and often describe the majority of this period as involving a generally hostile and oppressive attitude toward homosexuality (Adelman, 1991; Kimmel). Also common is the stigma and stereotypes often faced by this population throughout their lives.

A common belief is that this group is isolated from family as well as the gay community. They are also believed to be depressed, over-sexed and seeking sexual experiences with children and becoming increasingly feminine with age (in the case of gay men), and becoming increasingly cold and bitter (in the case of lesbians) (Berger, 1984; Berger & Kelly, 1986; Friend, 1991; Kelly, 1977). In reality, research has shown that the vast majority of older gay men and lesbians are self-described as psychologically healthy and as having high levels of self-acceptance (Berger, 1996; Deevey, 1990; Dorfman, Walters, Burke, Hardin, & Karanik, 1995; Kehoe, 1986a; Kimmel, 1978; Quam & Whitford, 1992). Additionally, Dorfman et al. found no differences between the levels and sources of social support between gay and lesbian elders and those in the general population, although gay men and lesbians had less support from families of origin but more from friends.

With regard to their adjustment to aging, older gay men and lesbians have been found to have similar concerns as heterosexuals in old age, including the fears of poor health, physical limitations, mortality, and adequate finances (Berger, 1984; Kehoe, 1988; Quam & Whitford, 1992). Many also contend that older gay men and lesbians may have advantages over heterosexuals in adapting to old age and may experience more “successful aging.” One of these advantages is that, for some, the process of “coming out” (or revealing a homosexual identity to self and others) and the associated stigma earlier in life may cause an individual to better deal with the later stigma and trauma of “old age” (Berger, 1996; Francher & Henkin, 1973). Gay men and lesbians may also have the advantage of not taking for granted the support of a family of origin, as they may be estranged. As a result, they may learn self-reliance at an earlier age (Berger & Kelly, 1986). Gender role flexibility may also add to more successful aging as they may develop skills not developed by their heterosexual peers (Francher & Henkin; Friend, 1980). For example, an older lesbian may be informed about and in control over her own finances, while her heterosexual peer may have relied upon her now deceased husband to handle the finances. It is also noted that older lesbians may be more successful in that they do not feel the pressure to uphold physical beauty and youthfulness as do their heterosexual counterparts (Laner, 1997). Older lesbians, then, may be better able to cope with wrinkles and other physical signs of aging.

The families and support networks of older gay men and lesbians are also noted as a unique feature of this older adult population. Not only are older gay men and lesbians as individuals very diverse, but their families are diverse as well (Fullmer, 1995). Kimmel

(1992) notes three types of older adult families. These include long-term relationships or companionships, social networks of friends, and special roles within their families of origin. Berger and Kelly (1986) found that the majority of older gay men did not live alone and many maintained contacts with friendship networks. Although few studies have examined the living arrangement of older lesbians, Kehoe (1988) found that almost half of her sample was involved in a relationship. Gay men and lesbians also have a variety of kinds of relationships, including closed couples, open couples, serial monogamy, lovers who live in separate homes, lovers who turn into roommates, and roommates who turn into lovers (Berger & Kelly). Most, though, couple with similar aged peers and many maintain extended, monogamous relationships (Berger & Kelly; Kehoe).

Gay men and lesbians often form strong social support networks that may serve traditional family functions such as emotional support, nurturance, and acceptance (Francher & Henkin, 1973). This is often called a “family of choice” and may include gay as well as straight friends and even former partners (Weston, 1991). Still, others may be almost completely isolated from the gay community (Fullmer, 1995).

Family of choice appears to be a strong source of support for many older gay men and lesbians. In Beeler, Rawls, Herdt, and Cohler’s (1999) study of 160 gay men and lesbians ages 45 to 90, almost 70% reported having a family of choice with whom they could socialize with and spend holidays. Despite the fact that many could rely upon the support of friends, participants in one of the study’s focus groups revealed the need for “increased social interaction” and more opportunities to meet other gay men and lesbians.



Grossman, D'Augelli, and Hershberger's (2000) study of 416 gay men, lesbians and bisexuals over 60 found an average of 6.3 people in their social support networks. In this particular sample, single respondents had significantly smaller support networks than those who were partnered. Close friends were the most frequently noted sources of support, followed by partners and then family members. Two-thirds of these support persons were homosexual or bisexual. Almost 90% of the support persons "definitely knew" the sexual orientation of the individual. Interestingly, the most important contributor to the respondents' satisfaction with the support they received was the degree to which support persons knew about their sexual orientation.

With regard to children in the family, some "lateblossoming" gay men and lesbians may have married prior to coming out and may have had children as well (Kehoe, 1988). Some may have positive relationships with family members while others may be estranged from their families of origin or even from their children. Some older gay men and lesbians, then, may not have traditional family supports and may rely more heavily upon their "family of choice" (Berger & Kelly, 1986; Weston, 1991).

### Challenges Faced by Older Gay Men and Lesbians

Older gay men and lesbians also experience unique difficulties in old age. A challenge faced by gay men and lesbians may include an acceptance of homosexual identity in old age (if the individual had not come to terms with this identity earlier in life) (Berger, 1996). Even if they have successfully integrated their sexual orientation into their lives, older gay men and lesbians may feel the need to conceal their homosexual identity.

Older persons with HIV/AIDS reported a reluctance to share homosexual identity with health care workers and family (Emlet, 1996). Concealment of homosexual identity, or “passing,” is often problematic and can cause great anxiety (Berger & Kelly, 1986). Many older adults have needed to play the heterosexual role to avoid scrutiny and sometimes harassment from society (Berger, 1982). Some may be struggling with and may have internalized society’s negative attitudes toward their non-traditional relationships (Mellor, 1996).

As previously mentioned, older gay men and lesbians may also experience difficulties with policies. For example, legal difficulties may arise if a will is not drafted and the deceased’s family inherits an estate, instead of the long-term partner (Berger, 1982). Additionally, housing organizations may ban cohabitation between unrelated adults and hospitals may limit visiting to “immediate family members” (Ettlebrick, 1996; Fullmer, 1995). Nursing homes, while allowing heterosexual spouses to have conjugal visits and to share rooms, are not required to extend the same privilege to same-sex couples (Ettlebrick). In terms of widowhood and retirement, Social Security benefits are also not extended to same-sex partners (Cahill et al., 2000).

Lastly, older gay men and lesbians have special issues regarding abuse and neglect. In terms of neglect, health care professionals may be reluctant to provide care to known “homosexuals” (Raphael, 1997). Additionally, older gay men and lesbians are sometimes the victims of domestic violence. Same-sex partners can threaten the “outing” of an individual if they seek help from adult protective services or domestic violence services (Elliott, 1996). Not only the threat of outing by their partner, but also the fear of

encountering homophobia and negative attitudes from professionals, may prevent victims from seeking help, especially if they are “closeted.” Legal barriers prevent help-seeking as well, when a partner has no rights to shared or individual income and may be economically dependent on their abusive or neglectful partner. Additionally, the older gay man or lesbian may have learned a sense of independence that may prevent them from being dependent and seeking help (Cook-Daniels, 1997).

#### Utilization of Support Services

Berger (1996) contends that although older gay men and lesbians undoubtedly use traditional informal support services, these services do not recognize and are not prepared to deal with their special needs. In fact, a few studies suggest that older gay men and lesbians may be apprehensive about using formal support services. Kehoe (1988) found that the majority of older lesbians she surveyed avoided traditional senior centers. In fact, only five of the 100 women she surveyed attended these programs “regularly.” Many were also averse to nursing homes. Additionally, only 21%, if ill, wanted to be cared for by a professional or social health agency.

Jacobs, Rasmussen, and Hohman’s (1999) study of 71 gay men and lesbians ages 50-80 in San Diego also uncovered interesting findings with regards to service usage. In general, respondents reported little participation in senior center programs, HIV/AIDS services, and support groups outside of the gay community. Respondents were also more likely to attend support groups and social groups in the gay community.

A study of gay men and lesbians and area agencies on aging (AAAs) also points to this possible under-utilization of formal services. Gay men and lesbians over 60 (N=121) were surveyed regarding their knowledge of and involvement with their local AAA. Although three-quarters of those surveyed reported that they were aware of local AAA services, over 70% were “tentative” about using the services. In effect, many did not trust the staff and doubted that they would be understood. Only 19% reported any involvement with their local senior center. In addition, almost half of the 24 AAAs that were interviewed reported that gay men and lesbians would not be welcome at a senior center if others were aware of their sexual orientation. It is not surprising, then, that 96% did not provide special services for or conduct special outreach efforts to older gay men and lesbians in their community. Almost 90%, though, were willing to provide training to staff regarding sexual orientation issues (Behney, 1994).

### Midlife for Gay Men and Lesbians

Although several studies have focused attention on the issues facing gay men and lesbians in older adulthood, very few researchers have sought out the experiences of gay men and lesbians in midlife. As a result, very little is known about midlife for this population. Interestingly, most of the literature in this area is segregated by gender.

### Lesbians in Midlife

Some researchers have specifically looked at the challenges and opportunities that lesbians face in midlife (Donaldson, 2000; Gurevitch, 2000; Kimmel & Sang, 1995;

Kirkpatrick, 1989; Mitchell, 2000; Raphael & Meyer, 2000; Rose & Zand, 2000; Sang et al., 1991; Sang, 1992; Tully, 1989; Weinstock, 2000). Similar to the studies of older adulthood, midlife has proven to be a wonderfully rich time for many lesbians.

In Sang's (1991) sample of 110 lesbian women between the ages of 40 and 59, 76% stated that midlife was the best period in their life. Many also felt that they "developed a stronger sense of self" as a result of fighting an oppressive society all of their lives (p.208). Despite this strength, many wanted to be less work and achievement-oriented and wanted to spend more time on creative and personal pursuits. Forty-six percent were also experiencing a sort of "midlife crisis." This crisis involved either an "illness, loss a relationship, or an awareness of one's limitations" (p.209).

According to Sang (1991), both work and personal relationships have been a very central part of the lives of midlife lesbians. Their heterosexual counterparts (both male and female) have tended to neglect one of these two aspects until midlife. Many had also worked continuously throughout their lives as opposed to heterosexual women who may have taken time off after childbirth. Some midlife lesbians may also be in nontraditionally female occupations and may have always known that they would need to be self-supportive in terms of income (Sang).

Bradford and Ryan's (1991) National Lesbian Health Care Study found that lesbians at this stage of their lives were more likely to experience worry and more likely to have their functioning affected by this worry than women in the general population. Midlife lesbians were also five times more likely to have financial problems than their heterosexual counterparts. Bradford and Ryan also found that the income of many

women in their sample was not comparable to their level of education or experience. Despite their level of education, many were “economically vulnerable.” It is suggested that this may be due to their desire to be “more comfortable” and “outside the mainstream in jobs that do not pay well.” Despite these challenges, according to Sang (1991), lesbians in midlife may be more accepting of the physical changes of aging than midlife heterosexual women.

Over half of the women in Sang’s (1991) study were involved in partner relationships. Even if they were partnered, these respondents were almost twice as likely to be living alone as heterosexual women. Bradford and Ryan (1991) suggest that even if a midlife lesbian has a partner she may not wish to uproot and move in with another women, as she may have done so many times in the past. This may also be because these midlife women have not wanted to live openly as lesbians or they did not wish to “disrupt” the “balance” they had developed in their lives (Coss, 1991).

Midlife lesbians receive support from family and friends and especially from female friends in their support networks (Bradford & Ryan, 1991; Sang, 1991; Tully, 1989; Weinstock, 2000). Some have been previously married and are dealing with coming out issues in midlife. If dealing with coming out issues they may fear that their adolescent children will not approve of their lesbianism (Kirkpatrick, 1989). Some also provide care to their older parents (Warshow, 1991).

### Gay Men in Midlife

Even fewer researchers have looked specifically at gay men in midlife (Cornett & Hudson, 1987; Kimmel & Sang, 1995). Instead, many middle-aged gay men have often

been included in studies of older gay men (Berger, 1996; Gray & Dressel, 1985). In addition, the bulk of the literature in this area is based purely upon theory.

Based on his practice as a therapist, Kooden (1997) proposes twelve developmental tasks that the midlife gay man must complete in order to age successfully. To age successfully, the midlife gay male must have resolved internalized homophobia and attained a positive image of his sexual orientation. He must also find a role model for successful aging and have a positive body image despite physical changes. He should secure positive relations with a family of choice and strike a balance between work and leisure activities. To age successfully, the midlife gay man must also take charge of his life and develop a positive outlook on the future. He may also need to forgive family members for past actions. He also accepts middle age and his own mortality and looks for meaning in life. His inability to successfully arrive into middle age may result from his internalized ageism or his inability to complete the above mentioned tasks.

Kimmel and Sang (1995) have also theorized about the special midlife issues faced by gay men. They speculate that because they may not have children, gay men in midlife may place more importance on their worklife and may not retire as early as heterosexual counterparts. They have also noted that little is known about how gay men in midlife balance work and a commitment to a partner.

Kimmel and Sang (1995) have also suggested that the midlife crisis may be heightened in gay men. This may be because of his distress over his own mortality or that the family line will end with him. Additionally, the gay man may be afraid of becoming ill or losing his sexual attractiveness at this time in his life. He may have

already lost several friends to HIV/AIDS. Another factor that may relate to a heightened crisis may include his “search for meaning or wholeness in life within a heterosexist society” (p. 207). On the other hand, the gay man in midlife may be better able to deal with midlife crisis because he has experienced past crises, including coming out.

### Professionals’ Attitudes and Behaviors Toward Gay Men and Lesbians

#### Attitudes and Behaviors of Health and Human Service Professionals

Another related body of literature, which can provide clues to the experiences of midlife and older gay men and lesbians, is the literature concerning professional attitudes and behaviors. Negative attitudes regarding gay men and lesbians (both young and old) have been examined in numerous studies. In many accounts, negative attitudes have been documented among physicians, nurses, social workers, and counselors (Berkman & Zinberg, 1997; Douglas, Kalman, & Kalman, 1985; Garfinkle & Morin, 1978; Graham, Rawlings, Halpern, & Hermes, 1984; Gramick, 1983; Harris, Nightengale, & Owen, 1995; Kelly, St. Lawrence, Smith, & Cook, 1987; Rudolph, 1988a; Rudolph, 1988b; Scherer, Wu, & Haughey, 1991; Wisniewski & Toomey, 1987; Young, 1988). These attitudes have ranged from viewing gay men and lesbians as pitiful and emotionally unstable to seeing them as immoral and disgusting.

Even more alarming than the existence of these negative attitudes among helping professionals is the fact that these attitudes can manifest themselves in professional service delivery with gay men and lesbians. For example, gay men and lesbians of all ages have reported having negative experiences with medical professionals (Dardick &



Grady, 1980; Smith, Johnson, & Guenther, 1985; Stevens & Hall, 1988). In extreme cases, negative attitudes of physicians have been correlated with refusal to care for gay men with HIV/AIDS (Kelly et al., 1987; Scherer et al., 1991). Often, partners of gay men and lesbians have also been excluded by professionals in health care decision-making and planning (Schwartz, 1996). Negative attitudes and experiences can also result in a lack of trust and a patient's withholding of important information (about significant others or lifestyle). Additionally, patients may internalize a sense of homophobia (the acceptance of negative attitudes about homosexuality by gay men and lesbians) as a result of negative experiences with professionals (Schwartz).

#### Attitudes of Social Workers

Negative attitudes towards gay men and lesbians have been found among social workers. Although the social work profession purports to respect diversity and support members of minority and oppressed groups, surprising attitudes can be found with regard to homosexuality. Wisniewski and Toomey (1987) found that one-third of their sample of 77 social workers held attitudes that could be classified as homophobic (having an extreme aversion to gay men and lesbians). Berkman and Zinberg (1997) found in their sample of 187 social workers that although a small minority was homophobic, the majority showed heterosexist (tied to a belief that heterosexuality is superior and more natural) attitudes. Unfortunately, the heterosexism scale used in the study does not seem to adequately differentiate between heterosexism and homophobia.

Mallon (1998b) goes on to contend that social workers may not be homophobic but are, instead, “homoignorant.” This means that social workers are not adequately informed about the special issues of this client population, which includes gay men and lesbians of all ages. Similarly, Mellor (1996) states that there is a lack of knowledge in the field of gerontology regarding “special populations” of older adults, including gay men and lesbians. These two assertions are seemingly supported by the observation that coverage of the topic of older gay men and lesbians is scarcely found in gerontology texts as well as in geriatric social work practice texts.

### Summary

The traditional caregiving and bereavement, gay and lesbian caregiving and bereavement, gay and lesbian aging, and professional attitude literature, combined, can provide a starting point for understanding the experiences of midlife and older gay men and lesbians providing care for partners or following the cessation of care. Unfortunately, these perspectives cannot fit together to form a complete picture of the experiences of midlife and older gay men and lesbians. As mentioned in Chapter One, the various limitations of these segments of the literature hinders the ability to account for the experiences of gay men and lesbians over the age of 50. For these reasons the present qualitative study was designed to uncover the potential uniqueness of this experience for older gay men and lesbians. Chapter Three describes the methods that were used to uncover the experiences of this special population of caregivers.