

Caregiving and Post-Caregiving Experiences of Midlife and Older Gay Men and Lesbians

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ABSTRACT. *Purpose:* This study examines the experiences of midlife and older gay men and lesbians caring for chronically ill, same-sex partners. This study also accounts for their experiences in “post-caregiving,” or the period following the cessation of care. *Design and Methods:* Using a qualitative methodology, in-depth interviews were conducted with nineteen gay men and lesbians over 50. *Results:* Respondents reported similar experiences in caregiving as those in previous studies looking at caregiving for older adult spouses and relatives (including physical and emotional strains). Similarly, respondents experienced loneliness and depression following the loss of the caregiving role. Unique aspects of the experience for gay and lesbian caregivers caring for same-sex partners, however, involved their interactions with formal and informal support persons and services and their long-term planning and decision-making processes. *Implications:* In light of their experiences, respondents offered their opinions about formal support services and professionals as well as their suggestions for changes that should be made to these as well as larger systems. Their suggestions and experiences guided the implications offered for health and human services. doi:10.1300/J083v47n03_08 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

Research on the subject of family caregiving for older adults has been accumulating since the late 1970s. In this attention, studies have shown caregiving to be a very challenging role, as numerous studies have pointed to the often aversive effects caregiving can have on a caregiver, including physical, psychological, financial and relationship strains (Brody, 1981; Cantor, 1983; Poulshock & Deimling, 1984; Robinson, 1983; Zarit, Todd, & Zarit, 1986). Despite these effects, research has also shown that persons provide care out of a commitment to their loved ones and to avoid institutionalization and many caregivers for older relatives take pride in their care and ability to keep loved ones in the home environment (Farran, Keane-Hagerty, Sallowat, Kupferer, & Wilken, 1991).

Studies on caregiving for older family members have contributed greatly to the understanding of the caregiving experience and its often-aversive effects. Unfortunately, the majority of subjects in these studies have been white, middle class, and (presumably) heterosexual, while also studying caregivers who are either (heterosexual) spouses, daughters, and daughters-in-law. Caregiving models, then, may reflect the biases of these populations and largely exclude the experiences of those providing care in the gay and lesbian community.

Apart from research focusing on caregiving for persons with HIV/AIDS, very few studies have tackled the topic of caregiving in the gay and lesbian community. Based upon a survey of 1,466 gay men and lesbians, Frederikson (1999) describes the prevalence and characteristics of gay men and lesbians providing child care and care to adults with disabilities and illnesses. Of the 27% of the sample who were 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).

A smaller study by Frederikson (as cited in Frederikson, 1999) suggests differences between the caregiving experiences of gay men and lesbians who provide care to partners as compared to 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 (health and social services) and informal (partners, friends and family of origin) 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.

Although adding greatly to what is known about caregiving in the gay and lesbian community, these studies do not adequately represent the experiences of those over the age of 50. For example, under 10% of the respondents in Frederikson's (1999) study were over the age of 50 and only 8% were caring for someone over the age of 65. In addition, over 90% of those Tully (1989) surveyed had described their health as "excellent" or "good" and were not currently candidates for hands-on care.

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, South, & Spade, 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 percent 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).

Steven Zarit, a forerunner in caregiving research, asked the question in a 1989 editorial, “Do we need another stress and caregiving study?” (Zarit, 1989). This author believes the answer is “yes.” In addition to the wealth of information regarding caregivers for older adults, future studies need to continue to shed light on caregiving in social minority populations. In particular, the caregiving literature needs to be expanded to include the experiences of midlife and older gay and lesbian caregivers that provide care for same-sex partners. An exploratory study examining the unique experiences of this caregiving population is long overdue and certainly warranted.

In response to this need for exploration and expansion, a qualitative study was designed to understand the unique experiences of midlife and older gay men and lesbians who provide care for chronically ill, same-sex partners. The study also sought to understand the experiences of these caregivers after care had ended. Given this understanding, it is then possible to develop and share implications for supportive policies

and effective health care and human service practice with this special population of caregivers.

DESIGN AND METHODS

Purpose and Research Questions

The purpose of this exploratory study was to elicit the experiences of midlife and older gay men and lesbians in providing care for older, chronically ill partners as well as their experiences following the death or relocation of the partner for whom they had provided care. This period following the cessation of care will be called “post-caregiving.” Toward this aim, the following served as the general research questions for the study:

1. What are the strains and positive aspects involved in providing care and following the cessation of care?
2. Given these experiences, what are the long-term plans and decisions that are made and how are they made?
3. What are the implications of the caregivers’ experiences for health and social service professionals and for supportive policies and programming?

METHODS

Sampling

This study sought to recruit midlife and older adult respondents who are (current caregivers) or were caregivers (post-caregivers) for chronically ill, older adult, same-sex partners. Both caregivers and post-caregivers needed to be at least 50 years of age at the time of the interview. Purposive sampling methods as well as the recommendations of prior research with older gay men and lesbians and the suggestions of the study participants themselves guided sampling for the study.

Advertisements were placed in the following locations/mediums: the gay media (including independent newspapers) and in the bulletins of gay social, political, and spiritual organizations. Flyers were also sent to gay and lesbian organizations, bookstores, social groups, groups for gay

and lesbian cultural minorities, and support groups, as well as hospice agencies and support groups for persons with HIV/AIDS. Flyers were also sent to university women's centers and to personal contacts. Approximately 1,000 flyers and advertisements were sent to 175 individuals and organizations in 15 states and the District of Columbia. This was primarily accomplished in the Eastern and Southern United States. Additionally, several ads were posted on several older gay and lesbian and general caregiving message boards on the Internet. A total of nineteen participants were acquired using this sampling strategy.

Data Collection and Analysis

Data were collected by the researcher through in-depth, semi-structured interviews using an interview guide including topic areas to be explored with each study participant. The interview guide focused on the strains and positive aspects of the caregiving and post-caregiving experiences, formal and informal supports, and future plans and decision-making. As topics and themes emerged, the interview guide was revised for subsequent interviews. Interviews included face-to-face ($n = 5$) as well as phone interviews ($n = 14$) and were audiotape recorded. Phone interviews used the same interview guide as face-to-face interviews and were necessary as sampling was done throughout the country and it was thought that some members of this population may have been more comfortable with phone rather than face-to-face interviews. In fact, one respondent mentioned that he preferred a phone interview rather than conducting the interview in person. Fieldnotes were taken during interviews and were later expanded through use of the audiotapes.

Data analysis was accomplished through the use of a constant comparative method by the researcher. The goal of the constant comparative method is to identify themes and develop, refine, and show relationships between concepts. This goal was accomplished through the simultaneous processes of coding and analyzing data (Taylor & Bogdan, 1998).

Rigor and Limitations of the Study

Rigor involves the standards or criteria by which a qualitative study will be judged. One set of criteria by which qualitative inquiry is often judged is "trustworthiness," which assesses the quality and the extent to which study findings are believable to a reader (Schwandt, 1997). To ensure trustworthiness, member checking, peer debriefing, the maintenance of a field log and field journal were employed.

Member checking involves seeking feedback from study participants about the data and study conclusions (Guba & Lincoln, 1989). Member checking was conducted with five respondents following data analysis and feedback was solicited on a draft of the study findings. Peer debriefing involves the use of a colleague familiar with the research methods who checks on the inquiry process (Lincoln & Guba, 1985). This individual periodically meets with the researcher to share ideas about methods (including sampling and data analysis) and makes suggestions of ways the study should proceed (Schwandt, 1997). There were three peer-debriefing sessions for this study. During these sessions, issues such as sampling strategies, self-disclosure, record keeping, and style for the write-up of findings were discussed. The peer debriefer also reviewed and provided feedback on the study methodology, fieldnotes, and coding.

The field log consists of dates, times, and strategies that were used to attain respondents. A database was specifically designed and maintained for this purpose. Each set of fieldnotes also contained specific information regarding the negotiation of the interview. The field journal includes observations of emerging themes, issues of validity, and questions for future interviews. A journal entry was completed after each interview as well as during other critical points in the study.

Although this study applied methods to assure trustworthiness, several limitations are apparent. The study did not achieve a very culturally, chronologically (age), or economically diverse sample. The majority of respondents were Caucasian, middle to upper class, had some form of higher education, and resided in or near major metropolitan areas. There were also few participants that were 70 years of age or older. Additionally, more "post-caregivers," as opposed to current caregivers, were recruited, which introduces the limitation of respondents' memory of past caregiving events. The majority of male respondents had also cared for partners who had HIV/AIDS. This condition may involve more stigma than other health conditions. In addition, fourteen participants were interviewed over the telephone (restricting observation of non-verbal cues and cues in the environment) (see Hash & Cramer, 2003, for a discussion of the methodological challenges involved in the study).

RESULTS

Respondents

The study consisted of nine female and ten male participants. The majority (17) were Caucasian, and one was Hispanic and one African

American. Interestingly, three of the care-receiving partners were members of ethnic minority groups. The ages of respondents ranged from 50-77, with an average age of 60. Fourteen of the respondents completed at least a bachelor's degree. Ten were employed at the time of the study, while seven were retired, one not employed, and one disabled. Duration of care ranged from four months to twenty-two years, with an average of five years of care provision to partners. Duration of partner relationships ranged from two to thirty-four years with an average of fourteen years together. The primary health condition of care receivers included HIV/AIDS (6), cancer (6), diabetes (4), heart condition (3), brain tumor (1), Parkinson's Disease (1), Lou Gehrig's Disease-ALS (1). During the conduction of the study, the majority of respondents (8) resided in the Southern, while others lived in the Northeast (5), Western (3), and Midwest (3) United States. All but one respondent was a "post-caregiver," either due to the death or relocation of their partner. Post-caregivers reported on both their previous caregiving and current post-caregiving experiences.

MAJOR FINDINGS

In this study, the main categories of aspects of the caregiving experience, aspects of the post-caregiving experience, interactions with informal and formal support persons and services, long-term planning and decision making, and suggestions for changes to health and human services emerged from the data (see Table 1.1 for a listing of main categories and subcategories). Respondents experienced similar strains and positive aspects as those in previous studies of those who provided care to and experienced the loss of older spouses and relatives. In addition, they were faced with unique issues and challenges during and following the cessation of care, including interactions with formal and informal support persons and long-term planning (see Table 1.2 for common and unique aspects). These issues and challenges are thought to be unique to gay men and lesbians who provided care to and often suffered the loss of a same-sex partner. In addition, respondents provided suggestions for changes to health and human services to better support older same-sex couples.

The Caregiving Experience

Respondents had similar experiences in caregiving as those in previous caregiving studies, including managing the bulk of the caregiving

TABLE 1.1. Main Categories and Subcategories

Categories	Subcategories
Caregiving experience	Strains of caregiving Positive aspects of caregiving Commitment to caregiving
Post-caregiving experience	Strains of post-caregiving Positive aspects of post-caregiving Reconstructing lives Outcomes of the experience
Informal and formal supports	Informal supports Formal supports and services Disclosure of the relationship
Long-term planning and decision-making	Decisions regarding the couple Long-term plans of the caregiver
Suggestions for changes to health and human services	Treatment of consumers Education and training Changes to larger systems Responsibility of consumers

responsibilities and experiencing physical and emotional strains and difficulties managing both caregiving and employment responsibilities. An added strain was managing doctor's appointments, medications, and treatments and the increased dependence by and required care for a partner. Caregiving also presented challenges and changes to the partner relationship, including changes to the physical aspect of the relationship and the division of household tasks. One respondent describes the relationship change as, "They become less your partner and more your roommate." Additionally, another respondent recalls, "I assumed responsibility for everything . . . laundry, cooking, cleaning, shopping . . . because she couldn't get out of bed." The progression of the illness brought about a great deal of emotional strain for the caregiving partner. In the face of dealing with the progression of their partner's illness, one overwhelming theme was that many respondents noted the need to be strong for their partner and not let their partner see the emotional toll the situation was taking on them.

Reflecting on the overall difficulty of providing care, one respondent confesses,

No matter who it is, whether they are homosexual or heterosexual, what people really don't understand is that when you agree to do

TABLE 1.2. Common and Unique Aspects of Caregiving and Post-Caregiving for Midlife and Older Gay and Lesbian Primary Caregivers

	Common Aspects	Unique Aspects
Caregiving	Shoulders most of the caregiving responsibilities	Deals with family, coworkers, or professionals as well as policies and practices that are not sensitive to or supportive of their relationship
	Experiences emotional, physical, and financial strains as well as conflicts with employment responsibilities	Faces disclosure issues related to the nature of their relationship
	Values the opportunity to show love and commitment through providing care	Makes unique plans and decisions and reasons for them may relate to being accepted or to protect the relationship
Post-caregiving	Experiences emotional distress following the cessation of care	Has the challenge of reentering the gay community
	Feels a sense of loss over the caregiver role	May have outcomes of the experience that are related to being gay or lesbian
	Experiences positive effects from no longer providing care	Deals with family, coworkers, or professionals as well as policies and practices that are not sensitive to or supportive of their relationship
	Faces the challenge of moving on after the cessation of care	Experiences grief that may not be recognized Makes unique plans and decisions and reasons for them may relate to being accepted or to protect the relationship

something like that, be a caregiver for someone, when the door closes and clicks it's a whole different game than what you think it will be. You have no idea of what you will be called to do for this person.

In spite of the many strains involved in caregiving positive aspects of the experience were also noted by the respondents. For the respondents, caregiving was an opportunity—to expand the relationship, to grow as an individual and convey love and commitment. Seeing this opportunity in the midst of a stressful life event is described by one respondent as she relates, “Clearly, the most positive aspect was discovering what love is . . . discovering the depths of love . . . in the face of this horrendous tragedy.”

The Post-Caregiving Experience

As stressful as the caregiving experience had proven to be, post-caregiving introduced a new set of strains, described by respondents as a “tremendous transition” and an “on-going process” where the changes are continuous. During this time, most of the respondents were dealing with the death of their partner. Respondents who had not experienced the death of their partner were still faced with the loss of the caregiver role and the life changes that occur as a result. In post-caregiving, respondents experienced the strains of emotional distress and difficulties adjusting to the loss of the caregiver role.

Most of the respondents experienced emotional distress following the cessation of care. Respondents expressed feelings of loss, loneliness, and depression during this time. The loss of a partner was deeply felt and described as one that a person never really “gets over.” This terrific sense of loss was often accompanied by an incredible feeling of loneliness.

Respondents also mentioned having difficulty adjusting after the loss of the caregiver role. These respondents provided care for their partners for months and sometimes years and endured great emotional and physical hardship in order to keep up with the daily demands of caregiving. As their partners became increasingly more ill, caregivers continued to meet the escalating care needs. It is not surprising, then, that several respondents mentioned a “crash” following the cessation of care. One respondent shared his feelings about the loss of the caregiver role,

I miss the good feeling I had about myself when I was taking care of James. I had devoted myself so completely, using all my mental, physical, and emotional resources, doing something I cared about, believed in, and felt was important. Then when he died and the caregiving was suddenly over there was a huge void, the loss of feeling good about myself to which I had become accustomed. . . . Now (after 7 months) I realize that I still miss that joy of caregiving.

Although post-caregiving provided many challenges for the respondents, the cessation of care also involved many positive aspects. Respondents enjoyed improved physical health, increased social interaction, and more time to attend to their own needs. It was mostly those who had ended care by leaving the situation and/or terminating the relationship that mentioned positive aspects of post-caregiving.

In looking at the hardships as well as the joys of caregiving and post-caregiving, it is not surprising that these experiences would have a major impact on the lives of the respondents. For many, increased involvement in the gay and lesbian community and becoming more open and "out" in communication regarding oneself became outcomes of this experience. For example, two respondents each started a support/social group for older lesbians. In becoming more open, when asked if he is "married," one respondent will now say, "I am not married, I'm in a domestic partnership" and he admits, "Now I set the boundaries where I want them and not where others want them."

Informal and Formal Supports

Informal and formal support persons had the capability to greatly affect the caregiving and post-caregiving experiences. Respondents were often faced with informal support persons (family, friends, coworkers) who were not accepting of their relationship. As a result, some family and coworkers did not acknowledge the relationship or provide the level of support needed during caregiving or bereavement. Ex-spouses and adult children, in some cases, were particularly hostile toward the couple and the caregiver. Some had the advantage of a "family of choice" (Weston, 1991), which included friends and chosen family members who provided support to the couple during caregiving and to the caregiver during post-caregiving.

Formal support persons (health care and other professionals) and services also affected the caregiving and post-caregiving experiences. Even though homophobic attitudes were not often overtly expressed by professionals, they were apparent to the respondents through "slighting remarks" or "rude" or "hostile" behavior. Some policies and practices of organizations and professionals were also insensitive to same-sex partners, often rejecting a partner as the "next of kin." Although some poor treatment was attributed to homophobia, much was seen as the result of a health care system that has become far too impersonal. Others experienced further discrimination based on race, age, mental health status, and HIV status. Unsupportive policies and practices were also apparent outside of health and human services in community businesses. For example, the term "partner" was in some cases omitted from newspaper obituaries and in one case two male partners were not permitted to share a mausoleum drawer.

During caregiving, respondents encountered health and human service professionals in hospitals and skilled nursing facilities. All but one

of the respondents also received one or more formal support service, including home health and hospice. Unfortunately, respondents expected to be faced with insensitive professionals and policies in hospitals and other organizations. Respondents were especially apprehensive about in-home services and attending “straight” support groups. A respondent shares this anticipation and fear of discrimination by professionals,

Even though I was not treated badly, I always had that fear that I could be treated badly . . . there is always a threat that you carry around in your heart that they can be bad to you.

To increase the likelihood of supportive treatment, respondents suggested: making connections with gay and lesbian specific or HIV/AIDS related services; networking with other gay men and lesbians to find supportive professionals and services; being upfront with professionals about the nature of the partner relationship; and drafting advanced directives. Respondents described supportive professionals as those who were supportive and respectful of the partner relationship and those who referred the respondents to other supportive professionals and services. At times, these professionals also bent the rules and treated partners as immediate family as far as policies and decision-making were concerned.

In caregiving and post-caregiving, respondents also faced disclosing the nature of their same-sex relationship to family, professionals, and co-workers. Some practiced a “don’t ask, don’t tell” style of disclosure, while others maintained clear communication about the nature of the partner relationship. For some, this stressful life event was the first time they “came out” to informal and formal support persons. Disclosure was a sensitive issue in the workplace as many respondents were the sole breadwinners in their households and could not risk being fired. Even if they were out to employers, leave policies did not always extend to unrelated or unmarried persons.

Long-Term Planning and Decision-Making

In many ways the long-term plans and decisions made by the couple and the caregiver appear to be very different from those of their heterosexual counterparts. Although many couples set up advanced directives, the reasons the respondents and their partners drafted these documents were seemingly very different. Many set up advanced directives to ensure that their wishes would be protected within health care

and other settings. For some, this was based on fear that their family members would try to interfere with their plans. Additionally, some used advanced directives to clarify the nature of their relationship and their wishes to health care professionals. There was also great variety in the arrangements of finances and property ownership among the respondents and their partners. As far as their own long-term plans, several respondents voiced concern over who would be available should they need care in the future. Very few felt that they could rely upon a circle of friends for assistance and many feared the type of treatment they would encounter (as a gay man or lesbian) should they need skilled nursing care.

Suggestions for Changes to Health and Human Services

Because of their caregiving and post-caregiving experiences, respondents were eager to offer suggestions for changes that should be made to health and human services as well as larger systems. Health and human service organizations should provide an accepting environment that is receptive to diversity in lifestyles. Toward this end, organizations can evaluate their policies and procedures to ensure that they are sensitive to a variety of human relationships. Within these organizations, same-sex couples should be granted the same privileges as legal spouses and relatives, and sensitivity training should be provided to staff. Professionals should not judge consumers and should spend more time getting to the special needs and circumstances of their clients.

Several respondents felt that before changes could take place in organizations, changes would need to take place at the societal level. The institution of equal rights, including granting marital privileges and making discrimination on the basis of housing and employment illegal would also go a long way in protecting the rights of same-sex couples of all ages. In addition, federal benefits (including Social Security) should also be extended to same-sex partners. Changes in these and other policies have the potential to change the attitudes of individuals and create a society that is more accepting of same-sex relationships. One respondent expanded upon the image of what equal rights will mean for same-sex partners,

Equal rights in the hospital . . . in insurances . . . health benefits . . . and I want to be able to hold her hand in public like husbands and wives do and people who love each other do. I think we have to continue to work towards that.

According to the respondents, members of the gay and lesbian community also have a responsibility to influence change. To begin, older gay men and lesbians can be more open about their relationships and give professionals and others the opportunity to be accepting and supportive. They can also be more informed, inquisitive and assertive with professionals. Gay and lesbian staff members working in health and human service organizations can become more visible to consumers (e.g., wear a pink triangle pin) and can advocate for sensitive policies and procedures. In addition, older and younger members of the gay community can provide more support to caregiving couples and work to develop specialized services and supports.

DISCUSSION

Professionals in health and human service organizations (such as physicians, nurses, and social workers) need to acknowledge that midlife and older gay and lesbians have many of the same needs and challenges in caregiving and post-caregiving as those in the general population (see Table 1.2). They can also benefit from the same types of services to reduce the strain of caregiving and reconstruct their lives following the cessation of care. It cannot be stressed enough that all caregivers, regardless of their sexual orientation, need to be treated as individuals. This becomes more difficult to achieve as health care organizations are under increasing pressure to cut costs and increase productivity. Although this involves more time, professionals need to make an effort to get to know consumers and their special needs and circumstances.

It is also important for professionals to recognize that this population of caregivers has unique challenges as well as unique resources in caregiving and post-caregiving (see Table 1.2). One of the most sensitive and delicate areas of practice with midlife and older gay men and lesbians is the area of sexual identity. As evident in this study, individuals have different styles of disclosure. Because older members of this population may not necessarily be comfortable with being out, professionals must tread lightly in this regard. Cook-Daniels (1997) suggests that practitioners “gently probe” about the nature of a suspected gay or lesbian relationship so as not to put an individual in an uncomfortable position (by trying to identify them as gay or lesbian). With regard to disclosure, it is also important to listen to the client’s definition of his/her identity and his/her relationships. For example, many women

may not self-identify as "lesbian" or may refer to their partner as their "friend" (Humphreys & Quam, 1998; Kehoe, 1988).

Respondents have mentioned the need to be among persons who can understand, accept, and support them in caregiving and post-caregiving. This includes peers as well as professionals. To help meet this need, professionals need to be informed of resources in the community and ways clients can meet other gay men and lesbians who are going through the same experience. Similarly, they need to be informed of gay and lesbian support services in the community.

Some larger communities have the luxury of specialized service organizations for gay men and lesbians in later life. Unfortunately, most professionals are not able to access such services for their clients and must rely instead upon referrals to respectful agencies and supportive groups within the gay community. Lists of gay and lesbian as well as "gay friendly" agencies and professionals should be made available and visible in all health and human service organizations. In addition, the Internet can be suggested (for those with computer access) as a way to connect with other midlife and older gay men and lesbians. Gay and lesbian clients can also be excellent resources for connections to "gay friendly" organizations and professionals.

Professionals must not only be aware of the formal supports that are available to midlife and older gay men and lesbians, but they should also seek to understand the informal support persons involved in the client's life. In this sense, it is important for professionals to understand relationship patterns among midlife and older gay men and lesbians and to utilize their special support networks (Berger, 1982, 1984; Berger & Kelly, 1986). Additionally, professionals must deal with the "dual family" concept, which includes working with families of origin as well as families of choice (Gunter, 1992). In this manner, professionals can expect to work with not only the older gay man, but also with his partner, his former partner (now friend), mother, and possibly, his adult son from a previous marriage. On the other hand, professionals should not expect that a gay man or lesbian has a "family of choice" or that his/her friends are able to assist with care. Similarly, a professional must not assume that the families of origin are not available for support.

Regardless of the involvement of informal support persons, midlife and older gay and lesbian couples have special issues related to their long-term plans and decisions. Because they are not afforded many of the protections that come with legal marriage, gay and lesbian couples cannot be confident that their plans and wishes will be respected. In defense of partner relationships, professionals should be prepared to assist

gay and lesbian consumers with advanced directives, including powers of attorney, living wills, and personal wills.

In a society of ever-increasing diversity, future services must meet the needs of diverse caregivers and care-receivers. To meet these needs it is essential to be open to diversity among human relationships and seek to understand and support gay and lesbian as well as other populations of caregivers. For example, many of the difficulties experienced by the study respondents could also be encountered by other caregivers that are not legally related to the care-receivers. These persons may include friends or unmarried partners. As one respondent pointed out, "If I have a common law husband, what do I say when I take him in (to the hospital)?"

Along with increasing diversity, the future may also see a dramatic increase in the number of persons with chronic physical illnesses and the necessity to provide care to these individuals. Unfortunately, the resources (human and monetary) required to meet this need may be in short supply. Supporting and sustaining persons who agree to provide care, then, will become even more crucial. Understanding the needs of diverse caregivers and implementing changes on societal, organizational, and individual levels will be essential in providing needed supports to these caregivers. With adequate supports, individuals can remain in the community, surrounded by the persons who love them and who are enhanced through their ability to provide care.

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