
Caregiving and Post-caregiving Experiences of Midlife and Older Gay Men and Lesbians (2001) Executive Summary

Background and Purpose

Since the 1970s, numerous studies have focused on the phenomenon of family caregiving for older adults. Although contributing greatly to the understanding of the caregiving experience, the bulk of these studies have primarily included respondents who are white, middle class, and (presumably) heterosexual, while also studying caregivers who are either (heterosexual) spouses, daughters, and daughters-in-law (e.g. Baum & Page, 1991; Brody, 1981; Cantor, 1983; Zarit, Todd, & Zarit, 1986). To increase the diversity of caregiving studies and to expand the family caregiving model, a qualitative study was conducted to explore the unique experiences of midlife and older gay men and lesbians caring for chronically ill same-sex partners. In addition, their experiences in “post-caregiving,” or the period following the cessation of caregiving, were also explored.

To illuminate their experiences, in-depth interviews were conducted with 10 gay men and 9 lesbians over 50. The respondents ranged in age from 50-77 (average 60) and the majority resided in the Southern and Northeast United States. Most were also Caucasian, although one respondent was Hispanic and one was African American. The duration of care ranged from 4 months to 22 years (average 5 years) and the health conditions of the care-receiving partners included cancer, HIV/AIDS, diabetes, heart disease, ALS, and Parkinson’s Disease.

Major Findings

Respondents had similar experiences in caregiving as those in previous caregiving studies, including managing the bulk of the caregiving responsibilities and experiencing physical and emotional strains and conflicts with employment responsibilities. Similarly, respondents experienced loneliness and depression following the loss of the caregiving role and faced the challenge of moving on with their lives after this loss. As with other caregivers, respondents also valued the opportunity to show love and commitment through providing care.

Important in this study were the unique aspects of caregiving and post-caregiving for the respondents. Their unique experiences involved their interactions with informal (family, friends, coworkers) and formal (health care and other professionals) support persons and services and their long-term planning and decision-making processes. Persons outside of the partner relationship had the potential to greatly affect the caregiving and post-caregiving experiences. Respondents were often faced with informal support persons 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. Despite family and coworkers who were unsupportive, some had the advantage of a strong network of friends and family members who were supportive of the partner relationship.

Although homophobic attitudes were not often overtly expressed by professionals, they were many times apparent through slighting remarks or rude or hostile behavior on the part of professionals. Some policies and practices were also insensitive to same-sex partners, often insisting that the “next of kin” was not a partner. 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, support in hospitals and other settings was generally not anticipated and respondents expected to be faced with insensitive professionals and individuals. Respondents were especially apprehensive about in-home services and attending “straight” support groups. 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.

Respondents also had unique challenges in disclosing the nature of their same-sex relationship to family, professionals, and coworkers and in reconstructing their lives following the cessation of care. Some maintained a “don’t ask, don’t tell” practice of disclosure, while others advocated direct communication of the nature of the partner relationship. 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 persons.

In post-caregiving, many also faced the challenge of re-engaging in the gay community and establishing new romantic relationships. The caregiving and post-caregiving experiences also affected their lives in extraordinary ways. As a result, some became involved in activism in the gay community and/or became more open about who they were, while others changed vocations in order to help other caregivers.

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 are 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.

Recommendations for Change

In light of their experiences, respondents offered their suggestions for changes that should be made to health and human services as well as larger systems. These suggestions are combined with the suggestions of the researcher in the recommendations below.

Larger Systems and Society. The institution of marital or domestic partner rights 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.

Organizations and Professionals in Health and Human Services. 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.

Gay and Lesbian Community. 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.

Future Challenges in Caregiving and Post-caregiving

In the future, we must support those who accept the challenge of providing care to their chronically ill loved ones. This primary caregiver is often the last line of defense in preventing nursing home placement and we must eliminate barriers that make their job even more difficult. Similarly, those who provide care to loved ones should be appropriately supported following the cessation of care. We are a society of ever-increasing diversity. Future services must meet the needs of diverse caregivers and care-receivers. To meet these needs we must be open to diversity among human relationships and seek to understand and support other populations of caregivers.

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.

References

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