

ABSTRACT

CAREGIVING AND POST-CAREGIVING EXPERIENCES OF MIDLIFE AND OLDER GAY MEN AND LESBIANS

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This qualitative study expands the existing family caregiving model to include the unique 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. To illuminate their unique experiences, in-depth interviews were conducted with nineteen gay men and lesbians over 50.

Respondents had similar experiences in caregiving as those in previous caregiving studies (including physical and emotional strains). Similarly, respondents experienced loneliness and depression following the loss of the caregiving role. Unique aspects of their experience, however, involved their interactions with formal and informal 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. Unfortunately, support was generally not anticipated from others and respondents expected to be faced with insensitive individuals.

In fact, some drafted advanced directives to assure that professionals and family members would respect their wishes.

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. 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 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. Respondents also provided suggestions for sampling and researching this hard to reach population of caregivers. Their suggestions and experiences guided the implications offered for health and human services as well as for future research in this area.