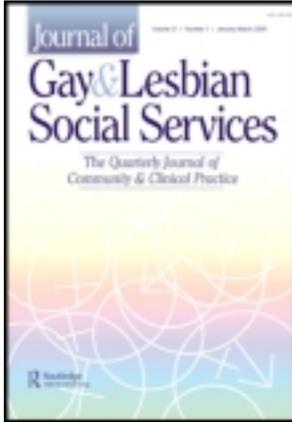


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Caregiving with Pride: An Introduction

Karen I. Fredriksen-Goldsen
Charles P. Hoy-Ellis

Oh, boy. I would say there would be times that I was absolutely terrified and she would still be there, and that could be as simple as trying to take a bath. And, she always managed to pull it off.

I mean there's things that have been particularly important—he had a problem a few years ago where he was passing out and I ended up taking him to the hospital and he actually had to get a pacemaker. So that was actually a very stressful time, but it was something we got through.

Well, she fell out of bed, broke both of her feet, we called 911 and they came. They weren't paying attention to what I was saying. And it was sort of a nightmare that time. It gets very bad when in a period of a week she's got so many conditions that there will be a crisis with this condition, a crisis with that condition, like three different urgent things and I'm trying to be with her in some way with all of them, and it's just absolutely exhausting.

And I had kind of hit the wall in terms of my pain level and energy level. So after that point I was like—he must really love [me].

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INTRODUCTION

Family members and friends are the primary caregivers in this country, providing the majority of assistance to ill and disabled persons when needed. It is more common now than ever before for partners, family members and friends to provide informal care because of the aging of the population and the trend toward noninstitutional care. Yet, caregiving in LGBT (lesbian, gay, bisexual and transgender) communities has received insufficient attention, even though informal caregiving across diverse communities is the backbone of our long-term care system.

Caregiving is defined here as unpaid assistance, provided primarily by family members, friends and neighbors, to help individuals remain in the community. The significant increase in the older population and the trend toward noninstitutional care are significantly altering caregiving in this country. Most long-term care for adults age 65 and over is provided not in nursing homes but informally and privately, at little or no public cost, within private homes or other community-based settings (National Academy on an Aging Society, 2000; Stone, 2000; Tennstedt, 1999). If informal supports such as these were not available, the long-term care costs of older adults would more than double (Arno, Levine, & Memmott, 1999). The cost of elder care is projected to grow from 38% of total health care costs to nearly 75% when the population of adults over age 65 doubles, between 2000 and 2030 (Evashwick, 2001; Feinberg, 2001).

These dramatic expenditures result in part from the following factors: the increase in the number of people age 85 and older, who have the highest risk of multiple health problems, physical frailty and cognitive impairment; the extended longevity of people experiencing significant disabilities earlier in life; and the 49% increase in the age 65+ cohort by 2010 (U.S. Administration on Aging, 2000; U.S. Census Bureau, 1999). Although informal care to elders is not a new phenomenon, it now is typically more intensive and technologically demanding, of longer duration, and is provided for multiple family members (Bengston, 2001). Current state and federal pressure to reduce health care costs—including hospital downsizing and cuts to managed care and Medicaid—place even greater demands on informal supports. Given these national trends, the identification of vulnerable caregivers and factors that support or hinder their ability to provide high-quality care are critical practice, research, and policy issues.

As a result of their history of disadvantage, marginalization, and invisibility, LGBT caregivers and care receivers may encounter distinct

obstacles in securing support, including discrimination in health care and long-term care settings, limited access to services, and the lack of legal protection for their partners and other loved ones. Such obstacles may be encountered if the caregiver and/or care receiver are members of the LGBT community. These unique and challenging circumstances suggest that caregivers and care receivers in LGBT communities may be at especially high risk for deleterious health and caregiving outcomes.

In this introduction we will examine what is currently known about caregiving in LGBT communities, including the prevalence of caregiving responsibilities and the unique structural issues that have been identified as differentiating LGBT caregiving from other types of informal care. Lastly, we will outline the topics that are included in this special edition to advance our understanding of caregiving within historically disadvantaged communities and to create a blueprint for future development in services, research and policies to better meet the growing needs of caregivers and those receiving care.

PREVALENCE AND CAREGIVING PROVIDED

Although an accurate assessment is difficult given the ambiguities of defining sexual orientation as well as the reluctance to self-identify, estimates of the proportion of the population who are lesbian, gay or bisexual range from as low as 2% to as high as 18-20% (Sell, Wells, & Wypij, 1995; Tanfer, 1993; Cahill et al., 2000). Michael, Gagnon, Lauman and Kolata (1994) found, in one of the largest representative data sets available, that 5% of males and 4% of females had engaged in same-sex sexual behavior since the age of 18. Based on a reinterpretation of the Kinsey findings and related research, it is generally estimated that 2.4%-10% of the population is lesbian, gay or bisexual (Cahill et al., 2000).

An analysis of the 2000 U.S. Census data found that 594,391 households self-identified as same-sex unmarried partners, representing nearly 1.2 million gay men and lesbian adults (Bradford, Barrett, & Honnold, 2002). The older lesbian and gay male population is projected to grow from approximately two to over six million by the year 2030 because of the significant overall increase in the older population (Berger, 1996; Cahill, South & Spade, 2000). There are currently no population estimates for transgender individuals, although in 1996 it was reported that more than 25,000 persons had obtained sex reassignment surgery and more than 60,000 planned to do so (Goldberg, 1996).

LGBT individuals are tremendously diverse with respect to sexual orientation, gender identity, age, ethnicity and race, culture, geographic location, education, income, family relationships, health and physical abilities; and these important differences must be recognized in any discussion of caregiving. For many LGBT persons, their families encompass both family of origin and family of choice, including partners, children, grandchildren, parents, grandparents, and other biological relatives, as well as intimate friends and other extended family members. Caregiving in LGBT communities may occur through a variety of relationships: they may be caring for or receiving care from partners, friends, parents, children, and grandparents, as well as neighbors and others.

LGBT individuals, like other caregivers, tend to assist their loved ones with a wide spectrum of illnesses and disabilities and to provide a range of caregiving assistance, including instrumental activities inside and outside the home (e.g., transportation, meal preparation, and housework), personal care (e.g., bathing, feeding, and dressing), emotional support, financial assistance, and mediating with formal services. Contrary to the myth that LGBT persons do not have families, the first national study on lesbian and gay caregiving across the lifespan found that they have extensive caregiving responsibilities; for example, 32% of the gay men and lesbians were providing some type of informal care, ranging from the care of children to the care of adults with serious illness or disability (Fredriksen, 1999). Among the 27% providing adult care, 23% were assisting someone age 18-64 and 8% were assisting someone 65 or older. Among the caregivers providing care for ill and disabled adults, the majority of those they cared for were friends (61%), followed by parents (16%), partners (13%), and other biological family members (10%).

In another early study at a large worksite setting, 13% of the sample that were taking care of a disabled or sick partner or spouse were in a same-sex relationship (Fredriksen, 1996). More recently among lesbians and gay men 50 and older in New York, 8% reported a current need for assistance while 19% had needed care in the past (Cantor, Brennan & Shippy, 2004). Among lesbian, gay male and bisexual adults 50 and older, 45% were currently providing care to a partner, friend or biological family member, usually a parent (Cahill, Ellen, & Tobias, 2002). In a recent study of 32 pairs of LGBT care recipients age 50 and older and their caregivers one-half were partners, 44% were friends, 3% were members of their biological family (most often siblings) and 3% were neighbors and others (Fredriksen-Goldsen & Muraco, 2006).

RISK FACTORS

Historical Context

Some studies suggest that aging experiences are qualitatively different as a result of the double stigma experienced from the intersection of age and sexual orientation (Connidis, 2001; Gabbay & Wahler, 2002; Wojciechowski, 1998). The current cohort of older LGBT individuals has lived through historical periods marked by active hostility toward them. The severe stigmatization as well as the historical context and negative attitudes toward LGBT caregivers and care receivers likely influence caregiving experiences and outcomes, affecting not only the attitudes of family members, friends, and helping professionals, but also self-disclosure and help-seeking behaviors among LGBT adults.

Self-Disclosure

De Monteflores and Schultz (1978) define coming out as “the developmental process through which gay people recognize their sexual preferences and choose to integrate this knowledge into their lives” (p. 59). Coming out is a normative life-long developmental process that requires LGBT persons to remake a stigmatized identity into a positive one. Research to date suggests a positive correlation between one’s psychological health and being honest and open about one’s sexual orientation (Rand, Graham, & Rawlings, 1982; Weinberg & Williams, 1974), except in those cases involving highly vulnerable populations, such as very frail and ailing individuals, for whom “coming out” is perceived as especially threatening (Cole, Kemeny, & Taylor, 1997).

Unlike some other minority groups, LGBT persons are not readily identifiable; thus, as caregivers and care receivers, they may monitor and manage the issue of disclosure of their sexual orientation or gender identity and the nature of their primary relationships. Insufficient disclosure can result in the restriction of one’s support system, while readily disclosing can expose an individual to hostility from the outside world (Gonsiorek, 1995). Yet, the extent of self-disclosure determines the nature and depth of one’s support system, and a high degree of social support available to a caregiver has repeatedly been found to be associated with more positive caregiving outcomes (Magana, 1999). Furthermore, caregiving itself often results in the restriction of personal and social opportunities (Callery, 2000; Clipp, Adinolfi, Forrest, & Bennett, 1995; Turner, Catania, & Gagnon, 1994), which compounds any restriction

resulting from lack of disclosure of one's identity or personal relationships to family, friends or service providers.

Kinship Relations

In the general caregiving literature, kinship ties have been found to be related to the extent and pattern of care received. Among those in the general population, more than 50% of older adults outside institutional settings and needing assistance rely primarily on family to help with daily activities—typically their adult children (42%), followed by their spouses (25%) (National Academy on an Aging Society, 2000). In general, biological family members tend to be a primary source of support for caregivers. However, LGBT caregivers may receive less support than they need from their own or the care recipient's family of origin. On the one hand, they may be expected to provide unrealistic levels of caregiving assistance within their families of origin, due to an assumption that their partners and close friends are of less importance and do not constitute family.

Contrary to existing stereotypes, most gay men and lesbians caring for a disabled adult do receive some support from their biological families: only 7% reported no support whatsoever from biological family members, while 68% received at least *some* support and 25% reported that their entire family was supportive of them (Fredriksen, 1999). Although perhaps supportive, a few studies suggest that biological family members may not be as actively involved in helping them meet their caregiving responsibilities when they are providing assistance to disabled partners, friends, or others in their extended support network (Aronson, 1998; Hash, 2001; Hash & Cramer, 2003). Among lesbians and gay men 50 and older, the vast majority report that they would go to their partners first for assistance; among those without partners, most would seek assistance from their friends (Cahill et al., 2002).

Support Services

In the general caregiving literature, it has been found that caregivers experiencing diminished access to formal support systems face significantly more physical, psychological, emotional, social, and financial risks (George & Gwyther, 1986). LGBT caregivers and care recipients have been found to be less likely to benefit from formal services, both because of providers' insensitivity and prejudice as well as their own reluctance to utilize formal services. Unfortunately, many LGBT caregivers

and care receivers are reluctant to openly acknowledge their sexual orientation or gender identity and their primary relationships in formal care settings because of fear of prejudice among service providers.

Prejudice expressed by professionals or embedded in services can be subtle or blatant (Coon, 2003). Service providers may fail to acknowledge or may openly disregard significant relationships within LGBT families. Others may discredit the role of these caregivers by, for example, more readily providing biological family members with information. Furthermore, biases may be so deeply embedded into the delivery of services that they limit or deny access such as not allowing visitation rights in hospital settings.

For reasons such as these, LGBT caregivers and care recipients tend to not seek out supplementary support or formal services, even when it is understood that there is a need for specialized care (Tully, 1989). Those that conceal their sexual orientation or gender identity may be the most isolated and in need of assistance, yet the least likely to use formal support services. It is generally assumed that patients receive higher quality and more thorough care when they are able to be honest and open with their health care and social service providers (Lambda Legal, 2003; Nystrom, 1997; Robertson, 2003). It is important to note that support services developed within LGBT communities may lack sensitivity to aging issues and tend to be most utilized by individuals who openly self-identify.

Discrimination and Lack of Legal Protection

Discrimination and prejudice intensify risk factors for LGBT caregivers and recipients. For example, as many as 94% of lesbians and gay men report experiencing some type of harassment or discrimination due to their sexual orientation (National Gay and Lesbian Task Force, 1990). The majority of gay men and lesbians providing care to an ill or disabled adult also report experiencing harassment related to their sexual orientation, including verbal (93%), emotional (46%), physical (14%), and sexual (8%) (Fredriksen, 1999).

Lack of support and discrimination at the workplace may place LGBT individuals at higher risk for negative caregiving outcomes. Unsupportive workplaces will likely fail to recognize the legitimacy of their relationships and caregiving responsibilities, which may increase caregiving stress by denying them the day-to-day emotional support and access to workplace benefits that are accorded to other families in similar situations.

Many federal and state laws and policies that provide family-based benefits are inherently biased against LGBT caregivers and care recipients. The range of institutional inequities includes: denying same-sex partners health care benefits and family leave; not providing for equivalent Medicaid spend-downs, social security benefits or bereavement leave; and exclusionary requirements in some managed care and insurance policies. If extensive legal planning is not completed in advance, LGBT caregivers' and care recipients' wishes and decisions may not be honored, especially if they conflict with the desires of biological family members. Yet, in one recent study it was found that the majority of LGBT care recipients and their caregivers do not have sufficient legal protections; for example, among LGBT care recipients 60% do not have a will despite the fact that many are living with serious disabling health conditions (Fredriksen-Goldsen & Muraco, 2006). Fifty-three percent of their caregivers also had not executed a will. In terms of a durable power of attorney for health care, 50% of the LGBT care recipients and 50% of their caregivers did not have one.

Caregiving Outcomes

The majority of general caregiving studies suggest that informal care for a relative with disabilities results in negative consequences for caregivers and their families (Owens, 2001; Polen & Green, 2001). In the general caregiving research, caregiving strain is repeatedly associated with decreased physical and psychological health among caregivers, including increased levels of caregiver burden (Braithwaite, 2000), role strain, fatigue (Polen & Green, 2001), anxiety (Cochrane, Goering, & Rogers, 1997; Polen & Green, 2001), depression (Berg-Weger, Rubio, & Tebb, 2000; Han & Haley, 1999) and poor health outcomes over time (Beach, Schulz, Yee, & Jackson, 2000). In terms of mortality, spousal caregivers who report caregiving strain are 63 percent more likely to die within four years when compared to matched controls (Schultz & Beach, 1999).

Little is known about the physical and psychological health of LGBT caregivers and care receivers. Hash (2001) reported increased risk for physical and psychological strain, poor nutrition, and financial problems among gay male and lesbian caregivers. In addition, a few community-based surveys have documented relatively high levels of physical, financial, and emotional strain among LGBT caregivers (Fredriksen, 1999; Hoctel, 2002; Shippy, Cantor, & Brennan, 2001). Employed caregivers assisting ill and disabled same-sex partners, as compared to

opposite-sex partners, provide significantly more hours of care and higher levels of assistance as well as higher levels of role strain and increased likelihood of job termination as a result of their care responsibilities (Fredriksen, 1996). In a recent LGBT caregiving study, care recipients, as compared to their caregivers, were found to have significantly higher levels of depression and strain combined with poor health (Fredriksen-Goldsen & Muraco, 2006); although care recipients are most often left out of caregiving studies, 68% of the care recipients had clinical levels of depression as did 43% of their caregivers.

At the same time, research demonstrates a high level of resilience among LGBT elders, likely due to the capacities they have developed through surmounting obstacles as members of a disadvantaged and disenfranchised group (Berger, 1996; Clunis, Fredriksen-Goldsen, Freeman, & Nystrom, 2005). Their skills at both adaptation and role flexibility need to be further explored as they may help them in meeting caregiving demands.

MOVING FORWARD

Caregiving is changing dramatically as a result of the growing elder population, the increasing diversity of families, and on-going shifts in health and long-term care services. The research described in this collection illustrates the significance of caregiving and care receiving within LGBT communities and highlights the importance to further understand the diversity of caregiving experiences, the impact of these responsibilities and the resulting needs of caregivers and their loved ones within marginalized communities.

In this volume, Grossman, D'Augelli, and Dragowski explore the prevalence of caregiving and care receiving among lesbian, gay, and bisexual (LGB) older adults, and their willingness to offer care in the future. Next, Shippy examines not only the burdens of caregiving, but also the impact of stigma and discrimination and social support on both family of origin and family of choice caregivers. Based on a framework of caregiving resilience, Fredriksen-Goldsen considers the extent of variations in HIV/AIDS caregiving outcomes and what risk and protective factors impact caregiver distress and well-being.

Illustrating the significance of the cultural context, Evans-Campbell and her colleagues explore contemporary experiences as well as the historical roles of caregiving among Native American Indian two-spirit people and the implications of these roles within Native communities.

Research on the lives and concerns of transgender elders is presented by Williams and Freeman; their analysis illuminates important issues that must be considered if effective and respectful interventions are to be developed to support transgender elders and their caregivers across the life course.

Providing an overview of intervention issues and strategies designed to assist caregivers, Coon describes a community-based intervention specifically developed to assist LGBT caregivers. Lastly, Fredriksen-Goldsen and Hooyma explore ways to increase both theoretical and methodological rigor in future research, and outline a blueprint for service and policy development to sustain caregivers, care receivers and their loved ones in marginalized communities.

As we move forward in caregiving research, services and policies, this volume provides a unique opportunity to explore the realities and possibilities for caregiving across diverse communities.

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