LGBT Caregivers

Informal, unpaid caregiving of chronically ill adults is far more common among LGBT individuals than cisgender or heterosexual adults, and stronger support systems for LGBT caregivers are needed, particularly for those who are giving care to a friend, and not to a partner or biological family member.

Data from a 2014 caregiving study shows that one out of every six adults in the general U.S. population are unpaid caregivers to a sick adult, while one out of every three LGBT adults are serving in an unpaid caregiving role. Put another way, 9% of caregivers to adults identify as LGBT, whereas only 4.1% of U.S. adults identify as LGBT (Boehmer, 2018). This same study also found that LGBT individuals were more often the primary caregiver for sicker individuals. Interestingly, LGBT caregivers are far more likely to be friends and “chosen family” to the person they care for, rather than partners or biological family members. Among older LGBT adults, 21% are caring for a sick friend, whereas only 6% of heterosexual/cisgender older adults serve that role for a friend (MetLife Mature Market Institute & American Society on Aging [MetLife], 2010), as cited in (Shiu, 2016). Some studies point to the HIV/AIDS crisis of the 1980s and ‘90s as the origin of a culture of mutual caregiving within the LGBT community (Muraco, 2011). At that time, blatant discrimination against LGBT individuals, and fears and stigma about HIV/AIDS among the general population and healthcare workers thrust caregiving upon LGBT friends of the ill as a cultural imperative that continues today.

As in the general population, LGBT adults face increased concerns about caregiving as they age and face multiple potential chronic illnesses, including cancer. A number of studies have identified a higher caregiving burden within the LGBT community, and have begun to examine the physical, emotional and financial burden it places on LGBT caregivers. A literature review (Washington, 2015) points out that heterosexist and gender normative systems of care intensify this burden. LGBT caregivers have experienced microaggressions such as rendering a partner’s role in care decisions as “illegitimate”, or hostile remarks and behaviors by medical staff, along with macro-level discrimination such as prohibitions against including same-sex partners on health insurance, designating visiting spaces as “family only,” or fining same-sex partners for parking in areas where family members can park for free. At the same time, LGBT caregivers point out that a “one size fits all” approach is inappropriate, since the caregiving and social support needs of individual lesbians, gay men, bisexuals, and transgender people often differ. In one example, a medical team arranged a respite day for a gay male caregiver so that he could attend Pride Week activities, when he had not intended to take part in that event.
Support needs of LGBT individuals may differ as a result of differing diagnoses, urban or rural environments, racial and ethnic groups, age, and socioeconomic class.

After many experiences with mainstream support services that are designed for heterosexual partners and biological family members such as adult children, LGBT caregivers often anticipate discrimination from and avoid other offered sources of support, including caregiver support groups (Washington, 2015) that are not specifically intended for the LGBT community. LGBT caregivers, especially those who are friends and not partners of the care recipient, are rarely recognized for the primary caregiving role they serve. They may experience legal barriers to having next-of-kin resources that spousal or family member caregivers have, such as Power of Attorney or health care proxy documents. This disparity can make the LGBT friend-caregiver invisible and unable to be an effective liaison to medical care providers at critical points in the care-recipient’s treatment, leading to further stress.

One study that looked at the demographics of LGBT caregivers (Anderson, 2018) found that LGBT caregivers are more likely to be of lower socioeconomic status, younger, more racially and ethnically diverse, and less likely to be married than their cisgender and heterosexual counterparts. Another study (Muraco, 2011) found that LGBT caregivers are likely to suffer from several chronic illnesses themselves, making them more vulnerable to the stress of caregiving. A quantitative study of two national data sets (Shiu, 2016) found that LGBT friends who are caregivers to adults with chronic illnesses other than HIV/AIDS report lower levels of caregiving demands or difficulty than other caregivers, but also receive lower levels of social support than others. This study found that caregiving difficulty is determined by four variables: the extent of care given; the number of hours of care given per week; the total duration of care; and the money spent on care by the caregiver. The authors also describe four different types of caregiving: instrumental care (e.g. transportation, laundry, grocery shopping); financial assistance; health care management or coordination with providers; and personal care (i.e. bathing, grooming, toileting). When all these factors were considered, the study concluded that LGBT caregivers had a lower level of caregiving demands than other caregivers, and that led to a lower level of stress. But LGBT caregivers used fewer sources of social support, and that was related to greater stress and depression. In other words, LGBT caregivers were less likely to use available resources to manage their stress and were more likely to report poor physical and mental health than their heterosexual counterparts. In another study (Anderson 2018), LGBT caregivers reported that they more frequently helped their care recipients with medical nursing tasks than their heterosexual counterparts and experienced higher levels of financial strain. LGBT individuals who were the adult children of their older adult care-recipient were more likely to report higher levels of emotional strain than other relationship types.
A study of the support needs of sexual minority women (SMW) with breast cancer who had undergone mastectomy (Paul, 2014) found that single women faced the greatest challenges and that former partners were often key sources of caregiving support. Another study of 167 SMW breast cancer survivor and caregiver dyads (Boehmer, 2016) found that the caregivers’ fear of cancer recurrence and their sexual orientation had a significant effect on survivors’ fear of recurrence (FOR), in that SMW reported less fear or recurrence than heterosexual women, concluding that caregiver interventions will likely benefit survivors’ fear of recurrence.

There are several ways that healthcare providers can improve services to LGBT caregivers: 1) increasing cultural competence training in the needs of LGB patients and caregivers (see https://cancer-network.org/programs/cultural-competency-training/); 2) consistently recognizing LGBT caregivers and their rights to make decisions as primary caregivers; and 3) creating more open and accepting environments where LGBTQ patients and caregivers can feel comfortable discussing issues with health care staff. (Czaga, 2016) (Valenti, 2014)

We strongly recommend that social workers target specific outreach to LGBT caregivers by: promoting awareness of LGBT caregiving in both the LGBT and service providing communities; offering psychoeducation in caregiving and stress management for LGBT caregivers; fostering greater inclusion of LGBT friend-care into policies; and providing training in LGBT cultural competency for health and aging service providers. We also need more research on large numbers of LGBT caregivers.

A good place to learn more is the book “Caregiving with Pride” (Frediksen-Goldsen, 2014). It provides an overview of the issues facing LGBT caregivers, featuring original research and summaries of existing literature, and recommending areas for future research, interventions and policies to better serve the caregiving and caregiver needs of the LGBT community. Online resources for LGBT patients and caregivers and healthcare professionals can be found at the Family Caregiver Alliance website, using the search term LGBT. Resources at the site include Day 12: Caregiving in the LGBT Community; Special Concerns of LGBT Caregivers; LGBT Caregivers – What Does the Future Hold; LGBT Caregiving – Frequently Asked Questions; and Legal Issues of LGBT Caregivers.

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