North American attitudes toward the end of life cluster around denial and avoidant behaviors (Kearl, 1995); thus, preparations for end of life often are wanting. If, as research shows (The Conversation Project, 2016), the uncomfortable issues surrounding life’s ending are rarely discussed by families, it should be no surprise that such topics fall outside the fuzzier boundaries of friendship discourse, with its more sociable focus (Barker, 2002; Johnson, 1983). Such dynamics pose particular challenges for those who stand outside of traditional family structures, including LGBT older adults.

Anxieties Exist Over Late-Life and End-of-Life Planning
As reported elsewhere and also in this journal, LGBT older persons, especially gay men, disproportionately reach the very later years without partners, without children, without traditional families—i.e., without those people typically called upon to provide care or to participate in end-of-life preparations (de Vries, 2013). Concomitantly, LGBT older adults report poorer overall health (MetLife Mature Market Institute, 2010), higher rates of disability (Fredriksen-Goldsen et al., 2011), and greater psychological distress (Wallace et al., 2011) than do heterosexual persons of similar ages. As a result, LGBT older adults may have higher needs for care and fewer traditional resources for care provision in the very later years than do heterosexual and gender-conforming older persons. The importance of preparing for later life and end of life arguably is greater among LGBT persons—as is their anxiety about these preparations.

Research supports this assertion. In a large, national survey study, LGBT baby boomers, relative to those of comparable age in the general population, were found more likely to fear dying alone and dying in pain, particularly in settings wherein LGBT rights are poorly defended (de Vries et al., 2009)—which is how long-term-care settings are viewed within this community (SAGE, 2011). De Vries and colleagues (2009) linked these fears—a type of unfortunate spur

**Abstract** LGBT persons disproportionately reach later life without partners or children—the people most likely to provide support to older adults, and to engage them in conversations about advance care planning and end-of-life issues. Friends often rise to the challenges of caregiving, but with limits imposed by family-centered social customs and family-first policies and practices. Friends often feel unqualified to discuss advance care planning, or are not invited into such conversations. This dynamic, these limits, and their consequences are the focus of this article, which summarizes the literature, with examples drawn from the authors’ qualitative study. | **Key words:** LGBT caregiving, families of choice, advance-care planning, end-of-life discussions
into positive action—to higher rates for completing end-of-life documents. LGBT older adults were more likely to have completed living wills and durable powers of attorney. Still, such documents (including wills and trusts) were completed by fewer than 50 percent of all older persons in this national survey.

LGBT older persons were found more likely to identify friends as potential caregivers (MetLife Mature Market Institute, 2010; Fredriksen-Goldsen et al., 2011). Notwithstanding the positive implications of this finding, friends as actual or anticipated caregivers tend to be individuals of similar age and health (among other shared attributes), a factor that challenges their availability and ability to provide the high level of care potentially needed in life’s very later years (de Vries and Croghan, 2014).

Moreover, friend relations fall outside of typical policy and program parameters, which focus on traditional family ties and obligations for care provision (Barker, 2002). And even as the rise of the LGBT community often is invoked with reference to LGBT persons’ community-building and caregiving efforts during the early years of the HIV/AIDS crisis (de Vries and Croghan, 2014), much has changed socially and politically since the first wave of HIV/AIDS; age has not served as an effective rallying point for action. Older LGBT adults too often remain vulnerable and hidden (as LGBT persons in heteronormative service systems, and as older persons in LGBT organizations, though there have been several admirable efforts to redress this).

Questions of Care and Support Remain

Within-group differences also have been noted. We found that higher percentages of gay men and transgender persons (almost a third in both cases), reported that they did not know who their caregiver might be when the need arose (de Vries, in press). And, absent the support for initiating conversations about end-of-life care and support, such discussions with friends are rare. In pilot research conducted in California (de Vries, in press), we found that more than half the sample of older gay men and lesbians interviewed had not had any discussions about end-of-life care—with anyone. Interestingly, included among interviewees who reported at least some discussions were people who raised these issues in jest, as a way of sneaking it into the conversation. The only explicit end-of-life conversations noted were held by lesbians, with their biological children.

LGBT older adults report poorer overall health, higher rates of disability, and greater psychological distress.

We have recently completed focus groups exploring preparations for end of life, and barriers to the same, with older gay men, lesbians, transgender persons, and service providers in five regions of Canada; these data will be more fully reported in subsequent publications. Overall, there was a realization among participants that their preparations so far have focused more on disposition of assets and possessions than on care in the final months or weeks of life. When the focus group discussion was directed to this time period, LGBT groups uniformly voiced concerns about “nobody being there” at the end of life, and the obstacles to engaging friends in such care (“friends have their own lives”). Concern also was expressed about the heteronormativity of healthcare and social services and the related absence of a “safe space” to receive care, with frequent mention of having “to go back into the closet” to receive needed care.

There also were themes more particular to the specific groups under the LGBT umbrella. Gay and bisexual men spoke of their history and experience with HIV, with allusions to “going through all of this again” (including the loss of friends); lesbians and bisexual women spoke of
the need for political action and organizing; transgender women and men noted the uniqueness of their needs and the general discomfort people have about transgender issues, within and beyond the LGBT community.

The groups also expressed how, in many ways, aging and dying are not specific to sexual orientation or gender identity: aging is unrestricted and ageism is prevalent, independent of community. In many ways, death is a great leveler. Hence, better understanding of the experiences and preparations for end of life among LGBT elders offers benefits to all older persons, many of whose lives do not conform to arbitrary and often idealized templates. 

Brian de Vries, Ph.D., is a professor of gerontology at San Francisco State University. He is former co-Chair of ASA’s LGBT Aging Issues Network constituency group and served on the Institute of Medicine Board on the Health of Select Populations Committee, authoring The Health of Lesbian, Gay, Bisexual and Transgender People: Building a Foundation for Better Understanding (Washington, D.C.: National Academies Press, 2011). Gloria Gutman, Ph.D., developed and directed Simon Fraser University Gerontology Research Centre and the Gerontology Department from 1982 to 2005. In 2010, she was elected president of the International Network for Prevention of Elder Abuse (INPEA), and is now a member of INPEA’s Board of Directors.

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