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Ethnicity and the Dementias

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CHAPTER 21

Working with Gay, Lesbian, Bisexual, and Transgender Families

DAVID W. COON AND MARY H. BURLESON

The majority of accounts to date exploring lesbian, gay, bisexual, and transgender (LGBT) caregiving appear in the HIV/AIDS literature and describe outcomes associated with the LGBT community's response to the AIDS epidemic (e.g., Fredriksen, 1999; Wight, 2002). However, results from several surveys in larger U.S. cities (i.e., New York, San Francisco, San Jose, California) are emerging that provide data on LGBT caregivers to older adults (Cantor, Brennan, & Shippy, 2004; Hoctel, 2002; Outword Online, 2000; Reiter, 2003). The data suggest that LGBT caregivers provide similar kinds of care as heterosexual caregivers, but that both LGBT caregivers and recipients experience sexual-orientation-based discrimination that is a barrier to service utilization. These barriers are probably even worse in areas without established LGBT communities (Coon & Zeiss, 2003a).

In this chapter, we take the position that until LGBT caregivers no longer experience the discrimination and social isolation that create barriers to receiving competent care, professional ethics demand that providers increase both their understanding of issues LGBT caregivers face and their competence in providing LGBT caregiver referrals and services. In this chapter, we provide an overview of key issues related to LGBT caregiving that appear in the literature and provide program developers and practitioners with a framework to help bridge the gap between research and

practice and to assist in translating information about LGBT caregivers. Readers desiring more detail and a thorough review of these issues should see Cahill, South, and Spade (2000), Cantor et al. (2004), Coon (2003), Coon and Zeiss (2003b).

Defining LGBT: Issues for Service Provision and Research

Today's LGBT caregivers encompass a diverse group in terms of ethnicity, race, language, national origin, and physical challenges, crossing both cohort and cultural boundaries. Many of them, especially older LGBT caregivers, do not self-identify to service providers (Cahill et al., 2000), which can negatively impact the quality of care they receive. The number of LGBT caregivers is unknown, and efforts to estimate their numbers based on prevalence of LGBT individuals in the general population are complicated by the complexities in LGBT definitions and issues around self-identification (e.g., Fox, 1996). Knowing the number of LGBT caregivers could improve planning and delivery of services but is not required to maximize competence in the development and implementation of effective services for LGBT caregivers. Simply ignoring issues of sexual orientation and LGBT discrimination permits heterosexism to guide service provision, limiting professionals' ability to serve all types of caregivers (Coon, 2003; Coon & Zeiss, 2003b). Therefore, professionals need ongoing training and consultation that helps increase their awareness of the sociocultural contexts that impact LGBT caregivers and enhance their professional competence for service provision.

Sociocultural Contexts Surrounding LGBT Caregiving

Sociocultural context substantially influences LGBT caregivers' beliefs and expectations about dementia, illness, and family caregiving, as well as their perceptions of caregiver burden and stress, the appropriateness of help-seeking behavior, and the palatability of existing services (e.g., Coon, Ory, & Schulz, 2003; Gallagher-Thompson et al., 2003b). Several components of the larger sociocultural context emerge in unique ways for LGBT caregivers and warrant additional consideration. These include issues related to *Cultural*, *Historical*, *Employment* (and related contexts), *Social Support*, and *Spiritual* (CHESS) contexts. The CHESS framework (Coon, 2001) provides guidelines for researchers, administrators, program developers, and practitioners to approach culturally competent assessment of LGBT caregiving situations. Table 21.1 briefly illustrates some of these issues and their impacts, as viewed through the CHESS framework. For

Table 21.1 The Chess Framework: Issues and Impacts in LGBT Caregiving

Acronym	Examples of issues and impacts
C Cultural context	Cultural contexts vary in openness about sexuality, acceptable forms of sexuality, and ramifications of violating prohibitions. Cultural attitudes may influence whether LGBT caregivers withhold or alter information, avoid personal contact, or opt for more anonymous services to protect themselves or preclude family interference. Cultural context is related to use of nontraditional health care; service providers must be open and informed about these methods in order to enhance goal alignment with clients.
H Historical context	Relevant historical events and processes include changes in societal attitudes about sexuality and the HIV/AIDS epidemic. Historical changes differentially affect older and younger cohorts of LGBT caregivers in ways that impact their knowledge about and willingness to utilize services.
E Employment, financial, and legal contexts	Impacts of caregiving on employment are compounded by discrimination against LGBT employees. Lack of legal protection for LGBT partners prevents access to health benefits and allows for interference by blood relatives or facility personnel in visiting rights and decision making.
S Social support context	Service providers should avoid the inaccurate stereotypical view that older LGBT persons are childless or alone; LGBT support networks include both family of origin and family of choice. Future cohorts of caregiving gay or bisexual men may have smaller support networks due to losses from HIV/AIDS; thus, they may need more assistance.
S Spiritual context	Because LGBT caregivers and recipients must often uphold, adapt, or discard religious doctrine and spiritual beliefs discordant with their sexual orientation, religious coping may be turned to less frequently or perceived as being less effective. In areas with large LGBT populations, churches and temples may exist to serve the LGBT community; in other areas, institutionalized religion may not provide effective support or may actively discriminate against them.

relevant reviews and discussion of the material in Table 21.1, see Cahill and colleagues (2000), Coon (2003), Coon and Zeiss (2003b).

Exploring and Overcoming Potential Barriers to Service Utilization

Identifying barriers to LGBT caregiver service utilization is another essential tool to increase service providers' awareness and competence. While family caregivers from all backgrounds can face many barriers to service utilization across their caregiving careers, LGBT caregivers typically encounter additional obstacles. These obstacles can be found across multiple levels of service provision and intervention, from those targeting individuals and families all the way to the policy levels on Capitol Hill, and the theme of discrimination and intolerance is woven throughout (DiPlacido, 1998; Herek, Gillis, & Cogan, 1999). The DISCuSS model (Coon, 2001) is a framework to help providers identify barriers and develop or implement strategies to overcome them at each level: *Discrimination* (hatred and intolerance), *Individual/Interpersonal* level, *System/Organizational* level, *Community* level, and *System and Social policy* levels. Table 21.2 illustrates examples of barriers and strategies at each level. Readers interested in more information should see Cahill and colleagues (2000), Coon (2003), and Coon and Zeiss (2003b), for relevant reviews and discussion.

Table 21.2 DISC(u)SS Framework: Exploring and Overcoming Service Utilization Barriers

Acronym	Examples of Barriers	Examples of Current or Potential Strategies to Overcome Barriers
D Discrimination, Insensitivity, Harassment (throughout levels)	Fears of discrimination, including hate crimes, loss of employment, and social stigma, stop many LGBT caregivers and care recipients from seeking services.Health-care providers, nursing homes, and senior centers sometimes discriminate against LBGT clients, who then retreat from seeking care.Heterosexism, ageism, and HIV/AIDS-related discrimination combine to affect many LGBT caregivers.	Provide a safe place where LGBT caregivers can talk openly. Honor LGBT staff members' rights to privacy, and assign staff to work with caregivers based on competence, rather than LGBT identity.Remain mindful of the pervasive impact of discrimination; adopt a zero tolerance policy for discrimination, and apply it uniformly; adopt inclusive language and challenge discriminatory language in both verbal and written communications.

(continued)

Table 21.2 (continued)

Acronym	Examples of Barriers	Examples of Current or Potential Strategies to Overcome Barriers
I Individual/ Interpersonal level	Caregiver–care-recipient dyads may be differentially "out" across different contexts. Sociocultural contexts may influence caregivers' self-identification.The additional stress of coming out may be too much for a caregiver to handle. Internalized homophobia may impede caregivers and care recipients seeking help from LGBT-specific resources.LGBT caregivers may be suspicious of agencies and professionals.	Learn to work effectively across a continuum of "outness." Respect individuals' levels of outness and self-identification in light of their sociocultural contexts. Openly discuss limits to confidentiality and strategies to protect privacy. Provide referrals to LGBT-sensitive informal and formal care resources.Recognize that LGBT suspicion of health-care and social services professionals may be realistic, based on past experiences.
S System/ Organizational level	Health-care systems, insurance companies, and service agencies often have discriminatory policies.Few organizations provide domestic partner benefits.Care-related decision-making power is often automatically given to biological relatives.LGBT partners may be denied visitation rights.LGBT applicants for long-term care may be discriminated against.	Educate staff about LGBT resources for caregiving, and request feedback from clients about these referrals.Create a "safe place" symbol to indicate that agencies are sympathetic to and have received training in working with the LGBT community.Foster staff participation at continuing education presentation, consultation, and formal staff trainings on LGBT topics.
C(u) Community level	Many geographic regions and municipalities have minimal protection for LGBT persons. Some communities (e.g., religious-based) actively reject LGBT members.Some segments of LGBT communities hold racist or ageist attitudes that deter some LGBT caregivers from accessing available LGBT-specific services.Ageism in LGBT communities may limit availability of formal support for LGBT elders and caregivers.	Encourage communities to take advantage of the inclusive definition of the National Family Caregiver Support Program (NFCSP) for needs assessment and service development.Promote stronger ties between LGBT community agencies and agencies working under NFCSP to ensure LGBT needs are included in outreach. Rally LGBT communities to develop broadly inclusive LGBT-sensitive caregiving-related services. Promote use of "safe place" symbol.

(continued)

Table 21.2 (continued)

Acronym	Examples of Barriers	Examples of Current or Potential Strategies to Overcome Barriers
S S System/Social Policy level	Even decades-long LGBT partnerships are often not recognized by government entities.Lack of recognition may lead to inability for partners to access Social Security spousal benefits, disability benefits, and retirement benefits.LGBT couples do not receive tax benefits (e.g., marital deductions, spousal exemptions for gift and estate taxes); hence, they have fewer financial resources in late life.LGBT couples do not receive equal treatment in Medicaid spend-down.	Encourage and support LGBT representation and full involvement in White House Conference on Aging to help LGBT older adults.Train home-care assistants in LGBT awareness and competence to ease LGBT access to mainstream home health services.Build partnerships with LGBT organizations to create local systems of caregiver support.

Extending Recent Interventions to Future Work with LGBT Caregivers

Recent research reviews have been unable to identify the one best intervention to ease family caregiver distress and enhance well-being (e.g., Bourgeois, Schulz, & Burgio, 1996; Coon et al., 2003; Dunkin & Anderson-Hanley, 1998; Kennet, Burgio, & Schulz, 2000; Pusey & Richards, 2001). This may be due in part to the diverse sociocultural contexts and backgrounds of caregivers for those with dementia and the varying courses dementia may take with care recipients. Nevertheless, several promising programs have proven effective in reducing caregiver emotional distress or burden and are seen as useful by caregivers. The promising intervention approaches identified to date tend to develop caregivers' skills to effectively manage care recipients' problem behaviors or their own stress levels (e.g., Burgio et al., 2003; Gallagher-Thompson et al., 2003a; Teri, Logsdon, Uomoto, & McCurry, 1997); modify physical and social environments of the caregiving dyad to help support its activities (Gitlin et al., 2003); capitalize on technological approaches, such as telephone-based or online support, combined with skill-focused education (e.g., Eisdorfer et al., 2003; Steffen, Mahoney, & Kelly, 2003); and integrate multiple program components, such as individually tailored caregiver counseling, support, and education (e.g., Mittelman, Roth, Coon, & Haley, 2004). However, no research to date has examined the effectiveness of these interventions with LGBT caregivers.

Although few formal services exist that target LGBT older adults, caregivers, or care recipients, practices that focus on LGBT sensitive information and referral, published material, and face-to-face and online support groups (Coon, 2003; Reiter, 2003) are increasing around the United States. LGBT older adults in the recent New York survey most frequently cited social and emotional support as the type of support they needed; and in response to being questioned about why the LGBT community should help its senior members, most participants indicated the community is best at caring for its own. This may be a reflection of the persistent discrimination and insensitivity experienced by LGBT individuals (Cantor et al., 2004). LGBT face-to-face support groups for caregivers of older adults, particularly those with memory impairment, have become available in a number of areas in the country, with several sponsored by local Alzheimer's Association chapters (Ceridwyn, 2002; Gollance, 2003; Levine & Altman, 2002). In general, LGBT caregiver support groups provide a haven in which to share concerns and get support without the added burden of masking one's sexual orientation, identity, and relationships.

The final framework presented in this chapter is intended to assist LGBT support group leaders, but it can be easily adapted for other populations. The SURE 2 Framework (*Sharing* and *Support*, *Unhelpful thinking* and *Understanding*, *Reframes* and *Referrals*, and *Education* and *Exploration*) has been used successfully in an LGBT caregiver support group in San Francisco and also can be extended to LGBT individual, couple, and group counseling arenas (see Coon & Zeiss, 2003b, for additional information). This approach is built from an empowerment perspective and integrated with basic cognitive and behavioral therapy (CBT) methods (Beck, Rush, Shaw, & Emery, 1979; Lewinsohn, Muñoz, Youngren, & Zeiss, 1986).

In a typical SURE 2 support group meeting, members first *share* their concerns with other members, and an "agenda" is developed by the group for topics to be covered during the rest of the meeting, when informational and emotional *support* will be the focus. Members help each other identify thinking or behaviors that are *unhelpful* while acknowledging and *understanding* that it is easy to be caught up in negative patterns of thought and action. SURE 2 caregivers are encouraged to *reframe* their thinking and change behavior through basic problem solving, positive reframing, and other CBT techniques, and to elicit ideas for doing so from the group. These ideas include identification of unique obstacles facing LGBT caregivers, such as the challenges of managing "outness" effectively and the difficulty in finding LGBT-sensitive services, along with the sharing of *referrals* when competent professionals and organizations are identified. Each meeting includes an *education* component, with topics ranging

from caregiving- and dementia-related research findings to information about upcoming seminars or presentations by local organizations. Group members *explore* each others' recent experiences with alternative coping strategies or referrals, and finally, they explore and decide on strategies or referrals to try before their next meeting.

The SURE 2 framework was developed in response to several concerns that appear specific to LGBT caregivers (Coon & Zeiss, 2003b; Levine & Altman, 2002), beyond the concerns they share with their heterosexual counterparts (e.g., acceptance of the disease process, information on services, grief and loss):

- When biological family members need care, LGBT caregivers can experience insensitivity and ignorance on the part of other family members who automatically assume that because they are "single," they can handle a larger share of caregiving responsibilities. This perspective ignores LGBT primary partnerships or nontraditional family relationships. In the New York survey, one third of almost 350 LGBT older adults reported that family members expected more caregiving responsibilities of them, because they were LGBT and assumed they had fewer explicit family responsibilities—an assumption that was typically false (Cantor et al., 2004).
- Such expectations can ultimately force LGBT caregivers either "out of the closet" or further "in the closet," exacerbating caregiver stress, negatively impacting their family-of-choice relationships, and diminishing positive aspects of caregiving.
- Prior experience with HIV/AIDS caregiving, particularly among gay-identified men, creates both knowledge and skill with regard to the caregiving career but can also lead to burnout and tap into a deep well of grief for community members who have lost so many from their support networks.
- Some LGBT caregivers may be asked to care for an individual who once disowned them. These caregivers may be asked to endure ongoing overt or subtler forms of homophobia from the care recipient and other family members during the course of caregiving.
- Conflicts at work can arise when employers minimize the importance of caregiving responsibilities to LGBT partners or lifelong friends.
- LGBT caregivers frequently face homophobia in home health and long-term care settings, with some institutions impeding LGBT caregivers' access to their partners or refusing to allow LGBT partners to openly express affection for fear that heterosexual staff, patients, or family members will become uncomfortable.

- LGBT partners may have to endure ongoing conflicts with biological relatives over substitute decision making, given the limitations of various local, state, and federal laws, and particularly when relevant legal documents are not in place. By contrast, they also can experience complete withdrawal of biological family members, now that the gay or lesbian partnership can no longer be avoided or denied.

Moreover, the lack of a single best intervention for dementia caregivers may also be due to the multiple levels of obstacles family caregivers face in today's world. These obstacles, in turn, can be directly tied to the corresponding need for multiple levels of intervention (i.e., interventions at the individual/interpersonal, systems/organizational, community, and systems/social policy levels). These interventions, programs, and services should build on strategies aimed at the obstacles to LGBT caregiver service utilization mentioned earlier and create purposeful linkages between successful interventions identified within each level (Emmons, 2001). Table 21.3, drawn from earlier work (Coon, 2003; Coon & Zeiss, 2003b), provides examples of existing and suggested types of intervention programs and services categorized by intervention level. Clearly, this list needs ongoing review and expansion in order to foster the development and integration of effective services for LGBT caregivers.

Table 21.3 DISC(u)SS Framework: Program and Service Examples by Level of Intervention

Acronym	Examples of Current or Potential Programs and Services
D Discrimination, Insensitivity, Harassment	Adopt a zero tolerance policy for discrimination across all levels of service provision and apply to all employees and volunteers. Challenge discriminatory language, thinking, behavior, and policies; adopt inclusive language in conversations and printed materials.Increase opportunities for students in social and health-care programs to receive education, training, and supervision experiences related to LGBT clients and issues.
I Individual/ Interpersonal level	Distribute LGBT-sensitive information and referral for caregivers. Develop, market, and help facilitate face-to-face and online support groups for LGBT caregivers.Develop and support LGBT caregiver respite weekends.Implement LGBT caregiver skill training workshops to provide information and teach caregivers to effectively navigate legal, financial, and service delivery barriers.Create caregiver and care recipient education and support groups for LGBT friends and partners.

(continued)

Table 21.3 (continued)

Acronym	Examples of Current or Potential Programs and Services
S System/ Organizational level	Conduct in-service training for national and local staff of senior and LGBT advocacy agencies on unique needs of LGBT seniors, care recipients, and caregivers.Pool resources and develop partnerships between LGBT community-based organizations, senior service organizations, health-care organizations, and Area Agencies on Aging (AAA) to create more effective pathways of care for LGBT caregivers and their care recipients.Incorporate LGBT information into program intake and survey information (particularly important is the identification of opportunities to share such information anonymously).
C(u) Community level	Adopt LGBT media and community/service campaigns to increase LGBT caregiver awareness of available resources. Persuade professional organizations to support media and community service campaigns to increase provider knowledge of the distinct needs of LGBT older adults and caregivers.Encourage newly forming LGBT retirement communities to incorporate community education, training, and support interventions to help inform the entire retirement community about caregiving.
S S System/Social Policy level	Recognize LGBT families through adoption of spousal benefits, disability benefits, retirement benefits for same-sex partners, and elimination of unequal treatment in "Medicaid spend-down."Train home-care assistants in LGBT awareness and competence to ease LGBT access to mainstream home health services.Revise the Family and Medical Leave Act to include same-sex partners.Champion the National Family Caregiver Support Program's broad definition of "family" that can help support services for LGBT caregivers and friends and partners providing care to LGBT seniors.Enlarge government and private foundation support for needs assessments, caregiver intervention research, and demonstration projects targeting the LGBT community. Require LGBT sensitivity training as part of state- and federal-supported programs for seniors and their caregivers. Include sexual orientation in all antidiscrimination policies protecting employment, public housing, and access and delivery of services.Back the Joint Commission on the Accreditation of Healthcare Organizations' (JCAHO) addition of respect for "residents' habits and patterns of living (including lifestyle choices related to sexual orientation)" to the requirements in its accreditation manual for assisted living facilities.

Concluding Comments

Professionals and organizations working with LGBT caregivers need to expand their mission beyond merely increasing their awareness of some LGBT-related issues and barriers to developing competence in the design and administration of effective interventions across multiple levels, from daily individual practice to national policies that impede LGBT individuals' ability to meet their caregiving demands. By raising awareness of the array of unique issues and contexts LGBT caregivers face and building professional competence through ongoing education, training, and consultation, they can become the change agents and change agencies needed to effectively serve LGBT care recipients and their caregivers.

Finally, this chapter has purposely focused on many of the challenges encountered by LGBT caregivers. However, professionals must also celebrate the diversity of LGBT community members and recognize that LGBT caregivers and care recipients alike often experience great joys that counterbalance the hardships and obstacles described herein. Caregivers in the recent New York survey mentioned throughout the chapter reported that caring for either a family of origin or family of choice member also nurtured them spiritually or emotionally, gave them a sense of purpose, or made them a better person (Cantor et al., 2004). As one LGBT caregiver shared not too long ago with his LGBT support group, "We often talk about that book [Kath Weston's *Families We Choose: Lesbians, Gays, Kinship*]. My family is really both: it's my nuclear, my blood family, and it's the gay and lesbian family Todd and I chose together here in the city and from back home, years ago. Many of them are still with us. They are our champions" (Coon & Zeiss, 2003b, p. 289).

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Appendix: Additional Resources

Administration on Aging
(Web site: www.aoa.dhhs.gov/prof/aoaprog/caregiver/careprof/progguidance/resources/nfcsp_resources_guide.asp)

Access the Web site to read the National Family Caregiver Support Program (NFCSP) Resource Guide for the Aging Network; especially, see chapter 8, "Designing the NFCSP in the Context of Diverse Caregiver Populations."

American Society on Aging
Phone: 415-974-9600
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e-mail: info@caregiver.org
Web site: www.caregiver.org

The report "LGBT Caregiving: Frequently Asked Questions" is available free online at www.caregiver.org/factsheets/lgbt_FAQ.html. The report "Legal Issues for LGBT Caregivers" is available free online at www.caregiver.org/factsheets/lgbt_legal.html.

Gay and Lesbian Medical Association
459 Fulton Street, Suite 107, San Francisco, CA 94102
Phone: 415-255-4547
e-mail: info@glma.org
Web site: www.glma.org

Gay Men's Health Crisis
The Tisch Building, 119 West 24 Street, New York, NY 10011
Phone: 212-367-1000
Web site: www.gmhc.org

Gay Yellow Pages
Web site: www.gayellowpages.com)

Go to "Organizations/Resources: Age-Group and Senior Focus." This provides a national directory of programs and groups for LGBT older adults.

Lambda Legal Defense Fund
120 Wall Street, Suite 1500, New York, NY 10005-3904
Phone: 212-809-8585; fax: 212-809-0055
Web site: www.lambdalegal.org

LGBT Caring Community Program and Online Support Group
www.caregiver.org/lgbt-sptgroup.html)

National Association on HIV over Fifty
Web site at www.hivoverfifty.org
Also see "Bibliography on Caregiving."

National Center for Lesbian Rights (NCLR)
870 Market St., Suite 570, San Francisco, CA 94102
Phone: 415-392-6257
Web site: www.nclrights.org

National Gay and Lesbian Task Force
1325 Massachusetts Ave., NW, Suite 600, Washington, DC 20005-4171
Phone: 202-393-5177
Web site: www.ngltf.org

New Leaf Outreach to Elders (Formerly GLOE/Gay & Lesbian Outreach to Elders)

The New Leaf Outreach to Elders is located in San Francisco, California. Additional information can be obtained by phone (415-255-2937) or by visiting the Web site (www.newleafservices.org).

Old Lesbians Organizing for Change
P.O. Box 980422, Houston, TX 77098
Web site: www.oloc.org

Pride Senior Network
22 W. 23rd St., 5th Floor, New York, NY 10010
Phone: 212-675-1936
Web site: www.pridesenior.org

Senior Action in a Gay Environment
305 Seventh Avenue, 16th Fl., New York, NY 10001;
Phone: 212-741-2247
Web site: www.sageusa.org

Senior Pages
Web site: www.seniorpages.com

Click on "Gay Seniors" for a listing of national organizations that support LGBT older adults.

Transgender Aging Network
Web site: www.forge-forward.org/TAN

UCSF AIDS Health Project Monograph Series
See P. Zeifert, M. Leary, A. A. Boccellari. (1995). *AIDS and the impact of cognitive impairment: A treatment guide for mental health providers* (No. 1). San Francisco: University of California San Francisco.