

Informal Caregiving and LGBT Communities



This In Focus, the third in our **Informal Caregiving** series, looks at the challenges of providing informal care for **Lesbian, Gay, Bisexual and Transsexual/ transgendered** populations. It uses the abbreviation “LGBT” to refer to diverse groups who share experiences of discrimination based on sexual orientation and gender identity including also intersexed, two-spirited and queer identified communities. For definitions of terms, see the glossary at the end of this *In Focus*.

Here we use the terms “informal” and “unpaid” “carer” and “caregiver” interchangeably, while recognizing the debates and lack of consensus around terminology. Caregivers provide ongoing assistance, without pay, for family members and friends needing support due to physical, cognitive, or mental conditions (Canadian Caregiver Coalition, 2001).

Why focus on informal caregivers and the LGBT community?

Informal caregivers within LGBT communities may be friends, neighbours, family members or members of a person’s “family of choice” (See glossary). They may include:

- LGBT caregivers caring for older LGBT friends or relatives (e.g., spouse of friend of an older person);
- LGBT caregivers caring for heterosexual older people (e.g., LGBT adult children caring for parents);
- Heterosexual caregivers caring for LGBT relatives or friends.

Each group will have differences in approaches to care but will need support from the LGBT community.

As noted in our previous **Informal Caregiving In Focus**, informal carers are important in maintaining the social, mental and physical well-being of individuals. In so doing, they also contribute substantially to the sustainability of the broader health system.

Aside from the challenges which all carers face, informal carers within LGBT communities encounter additional issues at the individual, organizational, community, health and social care system and public policy levels (Coon, 2003).

- Older LGBT people may have fewer caregiver options than people outside this community. They are less likely to have children or grandchildren (Barker, Herdt & Vries, 2006) or they may be isolated from their families of origin.

“...I’ve actually got a younger generation [a late partner’s family] that might be of help to me as an older person, because most of us have got nobody younger that they would consider to be close” (Almack et al., 2010, p. 916).

- Some older LGBT people may conceal their sexual orientation from family members if they do accept their care -- a decision that can negatively affect their well being and quality of care (Hash & Cramer, 2003).
- Care receivers may keep their gender identity hidden and therefore not benefit from recent changes in attitude, policy and law.

"I know many lesbians and gay men who ... are not really out, and you just wonder how they're going to cope; isolation is a big thing as we get older" "... some people ... because they're not out, they can't express themselves, only within their own circle. It's going to make life so much more difficult for them" (Almack et al., 2010, p. 917).

- Health issues affecting members of this community have been linked to lifelong feelings of stigma and shame coupled with years of being exposed to overt discrimination (Brotman & Ryan, 2008).
- The LGBT community has a youth-focused culture which can be an unwelcoming environment for older LGBT people and their caregivers. Services and community supports tend to focus on younger members of the LGBT community, contributing to the invisibility of older members (Harmer, 2000).
- Despite an increasing desire within LGBT communities to develop systems of support dedicated to older LGBT people, there remains a financial inability to do so (Ryan, 2010).

Without strong caregiving networks, LGBT older people may face unnecessary health crises or premature institutionalization (Barker, Herdt & Vries, 2006).

Positive spaces and informal caregiving in LGBT communities

A positive space for LGBT recipients and their carers is one that positively affirms LGBT identities and allows older LGBT people to feel safe when accessing health and social care services rather than forcing them back into the closet (Brotman et al., 2003; The Centre, 2006).

"I had a very large support group ... our friends (mostly lesbians) were in and out ... I mean all the time ... the house was never locked and the lights were never off. I never had to call anybody; they were just there" (Hash & Netting, 2009, p. 327).

A complicating factor is that a person may be "out" to some people but not to others.

As well, it is important to recognize that caregivers may not be LGBT themselves but recognize, support and validate the gender identities of their care recipients.

Challenge homophobia and heterosexism among health and social care systems and providers

Informal caregiving is rarely provided in isolation, but rather as part of a greater network of care that includes professional healthcare providers, staff in hospitals and long term care facilities, home care personnel and personal support workers. Homophobia is one of the greatest barriers that informal caregivers within the LGBT community encounter as they and their care recipients attempt to access services (Brotman & Ryan, 2008). With few exceptions, hetero-centred principles frame most policies and practices within mainstream health and social service agencies. For example, hetero images and terms such as husband/wife convey a lack of understanding and acceptance of alternate sexual orientations and identities.

As a consequence, older LGBT people and their carers may hesitate to seek needed professional care, supportive services or even respite due to long-standing experiences of discomfort, homophobia and discrimination. In the end, avoiding additional supportive services or specialized care negatively affects a person's quality of life (Brotman, et al., 2007).

"... people don't come in with an open mind, they come in with assumptions" "I've got a friend who has to think twice if [a cleaner or carer is] coming in, [she] puts away the photographs with her and her partner in a lovely embrace or something like that" (Almack et al., 2010, p. 918).

Broaden the definition of “family”

The traditional concept of “family” is based on biological kinship. This definition needs to expand to encompass members of a person’s family of choice. LGBT caregivers who are long-term partners of the care recipients want the same access, recognition and respect as their heterosexual counterparts.

Similarly, LGBT carers from a person’s family of choice would like access, recognition and respect comparable to traditional family members.

“I’ve no other family, [my ex partner and her current partner] are my family... They both look after me if I have to go into the hospital, they do everything for me...” (Almack et al., 2010, p. 913).

Assess the needs of both the care receiver and the informal caregiver as a unit

As the Ontario Balance of Care Projects (Williams et al., 2009) suggest, there is a need to address the individual and their caregiver(s) as a unit of care when planning home and community care packages. In this case, care managers must recognize members of caring relationships as a unit when assessing for necessary programs and services.

Build information “hubs”

While there are increasing numbers of national and international on-line, web-based and face-to-face informal care networks which provide information exchange and resource materials, there are far fewer networks dedicated to caregiving in LGBT communities. Building a national, LGBT specific network with international linkages to enable easy-to-access and easy-to-navigate information and resource sharing would be highly beneficial.

Enhance research opportunities

Research and study within this community tends to focus on HIV/AIDS specific informal caregiving. Very little is known about the contributions of other aspects of informal caregivers in the LGBT community. Even less is known about older LGBT people and their carers living in rural communities. Without further study, the needs of

older LGBT people and their carers will remain invisible.

What has been done to support informal caring and LGBT communities?

Here we showcase some useful policy and practice initiatives which support LGBT individuals, their carers and the formal health system.

Toronto LGBT Homecare works with caregivers to provide specialized support for older LGBT people, offering “respect, dignity, compassion, and understanding” for both general and palliative caring needs.

<http://www.torontolgbthomecare.com/>

Kipling Acres, is one of three long-term care homes operated by Toronto Long-Term Care Homes and Services offers a LGBT positive environment. Specializing in dementia care, this facility also supports older people who wish to remain at home but require some assistance. Families and members of the community are welcome to become involved through volunteer opportunities and participation in meetings, advocacy, and resident/family surveys measuring service satisfaction. Additionally, informal caregivers are offered a short-term (1-60 day annually) respite care service if they need stress relief, are going on vacation, or are otherwise unable to provide care.

<http://www.toronto.ca/ltc/kiplingacres.htm>

The Re kai Centres (Re kai Centre & Wellesley Central Place) seek to transform traditional models of long-term care by ensuring integration within a stimulating downtown Toronto community. All care and service provided is inclusive and respectful of LGBT older people.

<http://www.rekaiCentre.com/>

Internationally, the UK’s *Alzheimer’s Society* offers an LGBT inclusive helpline designed to provide support and advice for carers (of older people with dementia) experiencing isolation,

discrimination, and other challenges intensified by sexual orientation.

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200369>

Many of these LGBT friendly community supports exist in central urban locations. Older LGBT people and their caregivers who live in rural locations require similar models of integrated carer support.

How can I learn more?

Senior Pride Network is a Toronto-based association comprised of individuals, organizations and community groups interested in expanding LGBT specific programs and services. They also operate as an advocacy group for older people and members of their extended care networks.

<http://www.seniorpridenetwork.com/about.html>

The 519 Church Street Community Centre is a supportive downtown Toronto meeting place for LGBT people. It has an **Older LGBT Program** that facilitates special events, guest speakers and promotes related community resources. The program offers weekly drop-ins (open to everyone, regardless of gender identity or sexual orientation), and programming for older people such as monthly book club meetings.

<http://www.the519.org/>

Sherbourne Health Centre offers a wide range of innovative LGBT specific supports in a dignified, non-judgmental way, as they seek to fill known gaps in care. These include primary health care, counselling, outreach, health promotion, and education.

<http://www.sherbourne.on.ca/programs/programs.html>

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Rainbow Health Ontario promotes LGBT health and works to improve access to services, increase knowledge, highlight innovative practice, and foster networking and collaboration within the community.

<http://www.rainbowhealthontario.ca/home.cfm>

The *411 Seniors Society* is a Vancouver based resource and drop-in centre with programs and services (mindful of individual diversities) that help low income older people maintain healthy community lives.

http://www.411seniors.bc.ca/Contentpages/about_us.htm

Canadian Rainbow Health Coalition provides LGBT related resources and relevant research to educate and support older caregivers and care receivers.

<http://www.rainbowhealth.ca/english/seniors.html>

Trans-Health.com is an online magazine that links readers to a number of resources that focus on an aging transgender community.

<http://www.trans-health.com/displaysection.php?sid=1>

Qmunity Generations: BC's Queer Resource Centre provides older LGBT people with access to age specific service and delivery, education, support and discussion groups, and other community activities. *Prideline BC* is linked to this webpage. This volunteer-run organization offers a wide range of support and referral services for LGBT networks of care.

<http://www.qmunity.ca/older-adults/>

Definitions

A person's sexual orientation may be either a transitional step in the process of self-discovery or a stable, long-term identity. This glossary contains additional terms that may be helpful for understanding the complexities of sexual orientation, gender identity, sex and gender outside the heterosexual population. Please note that we use LGBT to include those who self identify as transsexual, transgendered, two-spirited, intersex and queer.

The definitions below are adapted from Rainbow Health Ontario and *LGTB health matters: An education & training resource for health and social service sectors* published by The Centre in Vancouver, BC. For more information, please see: <http://www.rainbowhealthontario.ca/glossary.cfm> and <http://www.seniorpridenetwork.com/pics/downloads/LGTB%20Health%20Matters.pdf>.

Bisexual. Refers to a person who is attracted to, and may form sexual and romantic relationships with, both women and men.

Coming Out. Refers to the process by which LGBT people acknowledge and disclose their sexual orientation or gender identity to themselves and others. "Coming out" is often an ongoing process. People who are "in the closet" hide their sexual orientation or gender identity. They may "come out" in some situations (e.g., with others in the community), but not in other situations (e.g., at their place of employment).

Family of Choice. Refers to a wide circle of friends, partners, companions and ex-partners who are a source of support, validation and sense of belonging.

Family of Origin. Refers to the biological family or the family that was significant in a person's childhood.

Heterosexism. The assumption expressed overtly and/or covertly that all people are, or should, be heterosexual. Heterosexism excludes the needs, concerns, and life experiences of LGBT people while giving advantages to heterosexual people. It can be a subtle form of oppression that reinforces a history of silence and invisibility for LGBT people.

Intersex. Intersex people may have external genitalia which do not closely resemble typical male or female genitalia, or the appearance of both male and female genitalia. Intersex people have generally rejected the term "hermaphrodite" as out-dated. An intersex person may or may not identify as part of the transgender community.

Gay. Refers to a person who forms sexual and affectionate relationships with those of the same gender; often used to refer to men.

Lesbian. Refers to a woman who forms sexual and romantic relationships with other women. Less commonly, some women may prefer the term "gay woman".

Queer Identified. The word "queer" has traditionally been a derogatory and offensive term for LGBT people. Many LGBT people have reclaimed this term and use it proudly to describe their identity.

Sexual Orientation. Is different from gender identity and sex. It is about who you are sexually/erotically attracted to and want to form an intimate relationship with. Such relationships may be with people of the same sex (i.e., lesbian, gay), the opposite sex (i.e., heterosexual), or either sex (i.e., bisexual).

Transgender/Trans. Trans is a broad term used to describe the continuum of people whose gender (i.e., masculine/ feminine), does not correspond with their biological sex (i.e., male/female).

Transsexual. A term for a person who has an intense long-term experience of being the sex opposite to his or her birth-assigned sex and who typically pursues a medical and legal transformation to become the other sex. There are transmen (female-to-male transsexuals) and transwomen (male-to-female transsexuals). Transsexual people may undergo a number of procedures to bring their body and public identity in line with their self-image, including sex hormone therapy, electrolysis treatments, sex reassignment surgeries and legal changes of name and sex status.

Two-spirit[ed]. Used by some North American Aboriginal societies to describe what western societies call gay, lesbian, bisexual and transgendered. Many Aboriginal communities had two-spirit people who were visionaries, were considered to be blessed, and were regarded as spiritual advisors. Often, two-spirit people were the mediators of the community/band because it was believed they understood both sides of disagreements between women and men.

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