CANADIAN
VirtualHospice

A Literature Review & Environmental Scan of
The 2SLGBTQ+ Population and Palliative and End of Life Care

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THE 2SLGBTQ+ POPULATION AND PALLIATIVE AND END OF LIFE CARE

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Executive summary

The aim of this literature review is to identify the information and support needs of caregivers within the Two-Spirit (2S), Lesbian (L), Gay (G), Bisexual (B), Transgender (T) and Queer (Q) communities. The acronym used for these communities is 2SLGBTQ+, the plus sign (+) signifies the inclusion of other sexual orientations and gender identities. The focus is on the needs of caregivers for those with advanced illness who require palliative and end of life care.

2SLGBTQ+ communities in Canada, the United States (US), the United Kingdom (UK) and Australia are included in this review. The sizes of the communities in the different countries can only be estimated as a result of challenges in identifying their members. In 2014, 1.7% of Canadians aged 18-59 years reported that they considered themselves to be gay or lesbian, and 1.3% of the same age group considered themselves to be bisexual. Estimates suggest that approximately 395,000 older adults in Canada currently identify as lesbian, gay or bisexual. 2SLGBTQ+ communities are under-researched and underserviced. Research on Canadian Two-Spirit and LGBTQ+-identified Indigenous communities is particularly limited.

The social history of 2SLGBTQ+ communities is marked by of stigma, marginalisation, discrimination and victimisation, including institutionalised discrimination in healthcare, employment and social services. Despite legislation to support 2SLGBTQ+ individuals in the countries included here, discrimination continues to affect these communities today.

Individuals who identify as 2SLGBTQ+ have an increased risk of certain life-limiting illnesses and are more likely to present with advanced disease. There are higher rates of mental illness and health risk behaviours, including drinking, smoking and drug use. This has been linked to the stress of being part of minority communities subject to discrimination. Despite these problems, the 2SLGBTQ+ communities are resilient and have a history of caregiving for other community members, which has been linked to the HIV/AIDS crisis in the 1980s.

Caregiving means providing physical, psychological and/or emotional assistance to another person. It also carries a burden because it is stressful caring for someone whilst continuing with one’s own life. Caregivers can experience increased rates of depression, anxiety, isolation, financial strain and compromised physical health, which lead to a greater mortality risk.

2SLGBTQ+ caregivers may be 2SLGBTQ+ individuals caring for other members of the community or they may care for a non-2SLGBTQ+ person such as an aging parent. Additionally, a non-2SLGBTQ+ individual may care for a member of the 2SLGBTQ+ community. All of these caregivers need access to 2SLGBTQ+ inclusive healthcare services. Further, given the caregiver burden, they need to know about the existence of, and gain access to, services supporting caregivers.

Advanced illness is when an individual has one or more conditions that result in a decline in general health and deterioration in function, which will continue until the end of life. At this stage there is a need for palliative and end of life care. There is a need for person-centred care, which ensures that preferences and priorities for decision-making are met. The use of advance care plans can ensure that this happens, although they are underused by both the 2SLGBTQ+ communities and the general population.

The core principles of palliative and end of life care are that the patient and the family comprise the unit of care, and that the patient has the right to determine who will be involved with their care. Research shows that caregivers for members of the 2SLGBTQ+ communities are more likely to be from the care recipient's family of choice than their family of origin. It should not be assumed, however, that all 2SLGBTQ+ people have negative or problematic relationships with their family of origin.

Families of choice may be made up of partners, friends, neighbours or other members of the community and are often formed when individuals are rejected by their family of origin as a result of their sexual orientation and/or gender identity. Within the 2SLGBTQ+ communities, these families of choice have the same significance as the heteronormative nuclear family. Whilst some members of the 2SLGBTQ+ communities have formalised their relationships with their partners through marriage or civil partnership, the majority have not. This means that they may not be recognised as partners by healthcare service providers. Caregivers for 2SLGBTQ+ individuals report being underserved by healthcare services that assume heteronormative family structures.

Members of the 2SLGBTQ+ communities are less likely to access medical or social services than the general population. This is particularly the case for older adults and is a result of past experience of stigma or harassment from providers. The anticipation of discrimination, however, can also prevent access to healthcare services. This means that 2SLGBTQ+ patients may access palliative and end of life care late, or not at all, exposing themselves and their caregivers to unnecessary suffering. Further, some 2SLGBTQ+ caregivers and/or the 2SLGBTQ+ individuals for whom they care, will choose to keep their identities secret unless they are sure that they will be welcomed. This negatively affects the quality of care received.

Palliative and end of life care starts at diagnosis of an advanced illness and ends with support for those affected by grief and bereavement. Consideration of religion and spirituality has been shown to be important to 2SLGBTQ+ individuals and their caregivers to give a sense of life's meaning and support its closure. Some religions and faith communities are intolerant of 2SLGBTQ+ community members, who need to have access to 2SLGBTQ+ affirming religious and spiritual organisations.

In bereavement it is important that those who were important to the deceased are recognised and supported. If there is a lack of social recognition and acceptance that the bereaved person has suffered a significant loss the subsequent lack of support can lead to disenfranchised grief. This can lead to significant depression; thus, there is a need for 2SLGBTQ+ inclusive bereavement counselling.

Healthcare providers can support 2SLGBTQ+ caregivers during palliative and end of life care by:

- Using 2SLGBTQ+ inclusive verbal and written communication.
- Displaying 2SLGBTQ+ inclusive symbols such as the rainbow.
- Clearly stating policies and procedures related to discrimination.

- Allowing the patient to define who they consider to be family and the role of this family in their care.
- Providing the opportunity and a safe physical and social environment for 2SLGBTQ+ patients to disclose their sexual orientation and/or gender identity. If caregivers are from the 2SLGBTQ+ communities, they may also wish to disclose.
- Ensuring continuity of care to avoid the necessity of repeated disclosures.
- Ensuring chosen family and close others receive bereavement and grief support services.
- Being aware of the existence of disenfranchised grief where grieving occurs in isolation because a relationship with a deceased member of the 2SLGBTQ+ community has not been acknowledged and providing counselling if disenfranchised grief is identified.

Engagement and/or partnerships with 2SLGBTQ+ community groups will help healthcare providers to improve palliative and end of life care for both 2SLGBTQ+ patients and their caregivers by making it both inclusive and affirmative.

In conclusion, there are universal needs for caregivers of those receiving palliative and end of life care in all communities. Caregivers in the 2SLGBTQ+ communities, however, face unique challenges and needs. 2SLGBTQ+ caregivers often come from families of choice and many give care in isolation, which increases the caregiver burden. They may be less likely to self-identify or be identified as caregivers due to these family structures. They are also less likely to access support services due to past experiences of, or anticipation of, discrimination. Healthcare and social services can support the caregiver, which will in turn improve the quality of life for the care recipient. Understanding the 2SLGBTQ+ communities will help health and social services provide affirming and inclusive services for caregivers in 2SLGBTQ+ communities.

Introduction

The objective of this literature review is to identify the information and support needs of caregivers within the Two-Spirit (2S), Lesbian (L), Gay (G), Bisexual (B), Transgender (T) and Queer (Q) communities. The acronym for these communities used in this review is 2SLGBTQ+ where the plus (+) is inclusive of other sexual orientations and gender identity groups such as asexual, intersex, pansexual and omnisexual. The focus is on the needs of those caring for individuals with advanced illness who require palliative and end of life care. The need for support to deal with bereavement, grief and disenfranchised grief is also considered.

2SLGBTQ+ is an acronym that is not widely used outside Canada. The acronym LGBTQ2 was used by the Canadian Prime Minister, Justin Trudeau, when he delivered a formal apology in the House of Commons to individuals harmed by federal legislation, policies and practices that led to the oppression of, and discrimination against, LGBTQ2 people in Canada (Trudeau, 2017). He described how members of the LGBTQ2 communities are still the victims of violence and discrimination that often results in mental health problems and homelessness. The abbreviation LGBTQ2 is not inclusive, some individuals do not fall under these labels or feel recognised or supported by the communities identified using this term e.g., those who are pansexual or intersex (Employment and Social Development Canada, 2018). This has led to the use of LGBTQ2+ which includes such identities. This term is not, however, preferred by older LGBT adults (Kortes-Miller, Wilson and Stinchcombe, 2019).

In this literature review 2SLGBTQ+ is used as an all-encompassing abbreviation to refer to different groups who have a common experience of discrimination due to sexual orientation and/or gender identity. Two-Spirit people are acknowledged first, as a step toward reconciliation, recognizing that Indigenous peoples were the first people here, in what is now called Canada. Other acronyms such as LGBT or LGB are used if they were the terms employed by the original source of the information.

Methods

There is no globally accepted standardised acronym for those who self-identify as non-cis-gender and/or non-heterosexual (Eliason, 2014; Lee, Ylioja and Lackey, 2016). A number of acronyms have been used including: LGB; LGBT; LGBTQ (the Q referring to queer or queer-identified); LGBTQQ (the second Q referring to questioning); LGBTQI (the I referring to intersex); LGBT+ or LGBTQ+ (the plus (+) sign is inclusive of other sexual orientation and gender identity minority groups such as asexual, intersex, pansexual, omnisexual); 2SLGBTQ+ (the 2S referring to Two-Spirit or Two-Spirited); LGBTQ2 (the 2 referring to Two-Spirit or Two-Spirited); LGBTQ2+; LGBTT (the second T referring to transvestite); LGBTQU (the U referring to undecided); GLBT and SGM (sexual and gender minority). **Appendix 1** describes the meanings of the nomenclature associated with the 2SLGBTQ+ communities.

In this literature review, the following search terms were used in addition to the aforementioned acronyms: caregiver; caregiving; lesbian; gay; homosexual; bisexual; transgender; gender identity; sexual orientation; sexual minority; sexual preference; health; health disparities; hospice; palliative care; end of life; social support; legal issues; elder; senior; older adult; aging; gerontology; advanced illness; palliative; end of life care; bereavement; grief and disenfranchised grief. The search engines used were PubMed and Google Scholar. Grey literature (i.e., unpublished in academic journals was also included). The scope of the review is international, with focus on data from Canada, the United States (US), the United Kingdom (UK), and Australia.

The composition of 2SLGBTQ+ communities

2SLGBTQ+ communities are heterogeneous not only in terms of sexual orientation and gender identity but also regarding age, race, ethnicity, culture, religion, socioeconomic factors and geographic location (urban versus rural). The 2SLGBTQ+ communities represent people whose sexual orientation is not heterosexual. This includes those who are lesbian (attracted to women), gay (attracted to men) and bisexual (attracted to both men and women).

The 2SLGBTQ+ communities also include people whose gender identity and expression of it differs from the one assigned at birth i.e., male or female. This is termed gender nonconformity. A portion of these communities identify as transgender or transsexual, often abbreviated as trans. Transgender and gender nonconforming persons can be referred to using the acronym TGNC. TGNC is an all-encompassing term used to describe people who vary from or reject socially constructed definitions of dichotomous gender, and those whose assigned sex at birth differs from their gender identity or expression of it (Institute of Medicine, 2011). While the term “transgender” is commonly accepted, not all TGNC people self-identify as transgender. It should be noted that terminology in this area is complex and there is a developing understanding of constructs and a shifting usage of terms (American Psychological Association, 2015; Hyde et al., 2019). Current definitions of some commonly used terms are provided in **Appendix 1**.

Transgender is generally defined as movement away from an initially defined gender position, usually the gender that one is assigned at birth. This movement can encompass movement into another binary sex category or movement to a non-binary gender. Movement into another binary sex category may be male to female (MtF) or female to male (FtM). In order to conform to and affirm their desired gender, trans individuals undergo gender transitioning. This includes changes of name and associated pronoun (which may be legalised) and making modifications to appearance including style of dress, hair and body shape. Some individuals undergo hormone treatment with oestrogens prescribed for MtF and testosterone for FtM transitions. Surgery to alter the physical anatomy to correspond to the desired gender may be undergone. Gender transitioning can be fluid and take several months to years or be a life-long process. Hormones need to be taken for life (Miller and Grollman, 2015). Not all trans people undergo medical transitioning (hormones and/or surgery). The sexual orientation of trans individuals may be toward men, women, other transgender people or any combination of these groups (Institute of Medicine, 2011).

There may be movement to a non-binary gender. These are genders that do not conform to socially accepted definitions of man and woman. Non-binary genders completely reject established gender categories and norms, can mix characteristics of any number of genders, or can express gender fluidity. Such individuals may identify themselves as: genderqueer and may think of themselves as both man and woman (bigender, pangender, androgyne); neither man nor woman (genderless, genderfree, gender neutral, neutrois, agender), moving between genders (genderfluid); or embodying a third gender. Genderqueer individuals typically reject the term "transgender" because it implies a change from one binary gender category to another (American Psychological Association, 2015).

Transgender historian Stryker (2008) summarises the concept by suggesting that “gender identity could perhaps best be described as how one feels about being referred to by a particular pronoun”, a notion that holds true for both binary and non-binary transgenders and which demonstrates the weight that pronouns and other language conventions have in constructing and experiencing transgender identity (Hord, 2016). The term folx is used as an inclusive gender-neutral term used to describe people of all genders (Folx (term), 2019).

The use of the term ‘queer’ remains controversial because from the mid-20th century it was used as a derogatory term to refer to those with same-sex desire, in particular gay men. Consequently, for many people especially the older generations ‘queer’ still carries negative connotations. Gay rights campaigners in the 1970s and 80s reclaimed the word as an umbrella term for gender and sexual minorities. Today ‘queer’ can be used to refer to individuals who are not heteronormative and/or not cisgender. It includes people beyond the LGBT spectrum or those whose identities fall outside these categories. Further it is used by some individuals who do not wish to be identified as LGBT as they reject being categorised and labelled. In addition, their sexual orientation, gender identity and/or gender expression may be fluid.

The term Two-Spirit is used by Indigenous[1] people across the North American continent. It was chosen in the early 1990s at a conference for gay and lesbian Indigenous people as an Indigenously defined pan-Native North American term. It refers to LGBTQ identities as well as culturally-specific non-binary gender identities (Morgensen, 2011). The term is often used to refer to the cultural role of a person who possesses both masculine and feminine spirits; however, it is also used as an umbrella term to describe Indigenous people who identify as LGBTQ. Two-Spirit distinguishes the wide variety of Indigenous concepts of gender and sexual diversity as separate from gender binarism and heterosexuality. It reflects a traditional Indigenous view of a fluid nature of gender identity and sexual orientation and its connection with spirituality (Hunt, 2016). This broad meaning of the term means that not every Indigenous person who identifies as LGBTQ will identify as Two-Spirit, and not everyone who identifies as Two-Spirit will identify as LGBTQ (Rainbow Resource Centre, 2014). Some people identify with nation-specific terms, which are difficult to translate into English, as they refer to both a person’s holistic role in a spiritual and cultural system as well as their gender identity and sexual orientation. The term Two-Spirit can also be used by Indigenous people in order to distance themselves from colonial society, who try to impose the European construct of gender binarism (Laing, 2016).

Although being a member of the “2SLGBTQ+ communities” is the result of gender identity (non-cisgender) and/or sexual orientation (non-heterosexual), the communities comprise unique individuals. Gender identity may be complicated by the degree of gender expression and gender

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[1] In common with a document produced by Rainbow Health Ontario (Laing, 2016) the present document uses the term Indigenous (an inclusive, international term predicated on self-identification) instead of Aboriginal (a term defined by the Government of Canada) in reference to individuals and communities who identify as being related to the pre-colonial inhabitants of the land now known as Canada. The Indigenous people referred to in this document are the First Nations, Inuit or Métis unless otherwise identified. Exceptions are made when referencing statistics which used other terms (e.g. Aboriginal)

role conformity. Importantly, as discussed above, the gender identity of some individuals does not fall into a specific category but exists along a spectrum. Further, not all persons who experience same-sex attraction self-identify as lesbian, gay or bisexual.

Whilst sexual orientation and gender identity are important aspects of an individual's identity, they interact with many other factors including race, ethnicity, culture, religion, age, physical ability, social circumstances (such as class and income), geographical location and individual life-experiences. The unique result of the intersection of these characteristics contributes to an individual's health and their access to and experience within the healthcare system.

The acronym 2SLGBTQ+ (as well as other acronyms in use throughout the world) represents diverse communities with differing healthcare requirements. Worthen (2013) underlined the importance of disaggregating LGBT communities for understanding their different needs. It is especially important in relation to health because while some issues LGBT individuals face are similar, others are very different depending on their gender identity and sexual orientation. Some may face needs due to their sexual orientation but not with regard to their gender identity, others may have gender-related needs but not sexual ones, whilst others will have needs related to both (Nowakowski et al., 2019). Much current research has treated the LGBT communities as a single body. Recent studies show that this approach has missed important variations within such communities as well as the significant needs of some sections.

Studying the 2SLGBTQ+ communities

Interpreting the results of research on the 2SLGBTQ+ communities is complicated by its heterogeneity, variation in nomenclature and the use of small study populations.
Three challenges with regard to conducting research in LGBT communities have been identified (Institute of Medicine, 2011):
"(1) operationally defining and measuring sexual orientation and gender identity; (2) overcoming the reluctance of some LGBT individuals to identify themselves to researchers; and (3) obtaining high-quality samples of relatively small populations." Research is skewed towards the lesbian and gay male communities. Separate information on bisexual, trans and queer individuals is limited. There is a lack of data about the Two-Spirit community.

In order to provide information about LGBT life and health that can be generalised to all LGBT communities it is necessary to use probability-based methods. Probability sampling identifies a well-defined target population and sampling frame and uses a probabilistic method of selection to obtain a sample that is representative of the target population. Due to the small size of LGBT communities, a lack of research funding and the sensitivity of questions about gender identity and sexual orientation, much LGBT health research has relied heavily on nonprobability sampling. Although these studies have produced useful information, for example regarding the health challenges faced by LGBT communities, they can produce biased results that cannot be generalised to all LGBT communities.

In an effort to overcome some of these problems, researchers have recently started to include details on gender identity and sexual orientation in healthcare settings, but this is still largely reliant on self-disclosure. Further, the use of longitudinal studies that track individuals over time allowing researchers to observe changes in health has been introduced. The current LGBT data landscape in Canada has recently been reviewed (Waite and Denier, 2019).

The aging 2SLGBTQ+ communities

Although the numbers of sexual and gender minority older adults are growing rapidly, they remain an under-researched segment of the older adult population. LGBT older adults were identified as especially understudied communities (Institute of Medicine 2011). LGBT aging research is complicated by the study population of a historically marginalised population of older adults who may not wish to self-identify or participate in research. The population proportion of LGBT older adults is relatively low compared to some other demographic groups, so probability sampling is difficult. Most large public health and aging surveys have not included sexual orientation or gender identity questions or have only asked them of younger age groups (Fredriksen-Goldsen and Kim, 2015). In an effort to combat this, longitudinal studies have been used (Fredriksen-Goldsen and Kim, 2017; Stinchcombe et al., 2018).

The size of the 2SLGBTQ+ communities

The challenge with 2SLGBTQ+ research methodology means that the size of the population and its constituent members can only be estimated. Further, assessing the size of the population is complicated by a lack of self-disclosure.

Canada

The Canadian Community Health Survey in 2014 was the first Statistics Canada survey to include a question on sexual orientation to a target of 120,000 respondents. 1.7% of Canadians aged 18-59 years reported that they considered themselves to be gay or lesbian. 1.3% of the same age group considered themselves to be bisexual. This survey used the concept of identity i.e., whether a person considers themselves to be lesbian, gay or bisexual. Data from other countries suggest that the number of people who consider that they identify as a minority with regard to sexual orientation is much smaller than those who report having had sexual relationships with someone of the same sex (Statistics Canada, 2017). Estimates suggest that approximately 395,000 older adults in Canada currently identify as lesbian, gay or bisexual (Kortes-Miller et al., 2018).

US

Data on the size of the US LGBT communities vary. This may be due to different methodologies for data collection (Kates et al., 2017). A Gallup Daily Tracking poll using telephone interviews has collected data from a random sample of over 1.6 million US adults (aged 18 or over) in the 5 years from 2012-2016. In 2016 4.1% of those interviewed answered “yes” when asked whether they personally identified as lesbian, gay, bisexual or transgender. This implies that there are around 10 million adults living in the US who self-identity as LGBT (Gates, 2017). In comparison in 2012, only 3.5% of those interviewed self-identified as LGBT, suggesting an increase of 1.75 million LGBT individuals from 2012-2016.

The National Health Interview Survey (NHIS) is a nationally representative survey and the principal source of information on the health of the US population. The NHIS began including a question on sexual orientation in its 2013 survey. The most recent 2016 data available from the

NHIS indicate that 2.8% of adults aged 18 and older identify as lesbian, gay or bisexual, equating to more than 5.5 million people (Dawson, Kates and Damico, 2018).

With regard to the aging population approximately 2.7 million US adults aged over 50 years currently self-identify as LGBT, this includes 1.1 million aged 65 and older. These figures are projected to double to over 5 million by the year 2060 (Fredriksen-Goldsen, 2016). Fredriksen-Goldsen and Kim (2017) further estimate that by 2060, nearly 20 million adults aged over 50 years will self-identify as LGBT and/or engage in same-sex behaviour or will have had romantic relationships with members of the same sex.

There is limited data on the size of the population that identifies as transgender, but a recent 2014 US study using the Behavioural Risk Factor Surveillance System (BRFSS) and questionnaire data from 19 states produced an estimate that 0.6% of the national population (in all 50 states) identifies as transgender. This equates to around 1.4 million people; the youngest age group of 18-24 year olds was more likely to identify as transgender than older age groups (Flores et al., 2016).

UK

In the UK in 2017 there were an estimated 1.1 million people aged 16 and over identifying as lesbian, gay or bisexual, out of a total population of 52.8 million in the same age group. Individuals aged 16 to 24 years old were more likely to identify as lesbian, gay or bisexual (4.2%) than older age groups. About 70% of the lesbian, gay or bisexual population was single and had never married or registered in a civil partnership. This reflects the fact that legal union of same-sex couples is relatively new (Office for National Statistics, 2019).

Australia

The Second Australian Study of Health Relationships (ASHR2) took place between October 2012 and November 2013. Computer-assisted telephone interviews were completed by a representative sample of 20,094 Australian residents aged 16–69 years from all states and territories. Approximately 3% reported a gay, lesbian or bisexual identity (Richters et al., 2014). In a different survey taken between 2006 and 2014, Roy Morgan Research asked almost 180,000 Australians (aged over 14) to agree or disagree to the statement, “I consider myself a homosexual” (Ray Morgan Research, 2015). In 2006-08, around 1 in 42 people (2.4%) agreed, and in 2009-11 about 1 in 32 (3.1%) agreed. During the latest triennium 2012-2014, the figure was about 1 in 29 (3.4%) (Ray Morgan Research, 2015).

The social history of the 2SLGBTQ+ communities

Canada has advanced legal rights for the 2SLGBTQ+ communities. Canada had nationwide legalisation of single sex marriage in 2005, which was not the case in all US states until 2015. In other countries e.g., Iran, Sudan, Saudi Arabia and Yemen, homosexuality is still punishable by death under Sharia law. In the Commonwealth, 53 countries outlaw homosexuality, and of these, 37 countries criminalise homosexuality. Detailed information on legislation affecting people on the basis of their sexual orientation is available in the ‘State-Sponsored Homophobia’ report published by the International Lesbian, Gay, Bisexual, Trans and Intersex Association (Mendos, 2019).

Although there is a more accepting society in Canada today, many 2SLGBTQ+ seniors will have lived through a period of stigma, marginalisation, discrimination and victimisation. 2SLGBTQ+ adults can be stratified according to their life experiences in a social and legal context. Fredriksen-Goldsen, 2018 defines three generations in the US, although these considerations will also be applicable to other countries such as Canada, the UK and Australia. The groupings are the ‘Invisible Generation’, the ‘Silent Generation’, and the ‘Pride Generation’.

The oldest generation are the ‘Invisible Generation’, born from the 1920s onwards (assuming a maximum age of 100 years old). The ‘Invisible Generation’ would have lived through a time when LGBT issues were rarely publicly discussed.

The ‘Silent Generation’ (now in their eighties), would have reached adulthood in the 1950s when an LGBT identity was best kept hidden. In the US, it could be associated with a sympathy for communism (as promoted by McCarthy) and considered a threat to national security. As a result, government employees who were gay men or lesbians were fired (the so-called Lavender Scare). At this time, same-sex acts were against the law, and the American Psychiatric Association treated homosexuality as a psychiatric disorder.

In the 1950s in Canada the so-called ‘fruit-machine’, a homosexuality detection system was commissioned by the government and largely developed by a psychologist at Carleton University in Ottawa. The system was a series of psychological tests and was used to in an attempt to keep all gay men out of civil service, the Royal Canadian Mounted Police, or the military. A number of people lost their jobs until funding for the machine was discontinued in 1967 (Pritchard, 2016).

In Canada in 1965, George Everett Klippert was labelled a dangerous sexual offender and imprisoned indefinitely for admitting he was gay and had sex with other men. Homosexuality in Canada was not decriminalised until 1969, and Klippert was released in 1971.

Finally, the ‘Pride Generation’, (now in their seventies), would have become adults against a background of the Stonewall riots (1969), which were a catalyst for gay and lesbian rights in the US and globally. In the US, consensual sex between same-sex couples began to be decriminalised, and in 1973, homosexuality was no longer classed as a psychiatric disorder. In Canada in 1977, Quebec became the first province to pass a gay civil rights law. ‘The Canadian Stonewall’ is considered to have happened in 1981 after nearly 300 men were arrested during police raids known as ‘Operation Soap’ at four bathhouses in Toronto. Subsequent to these raids, many people in the gay community ‘came out of the closet’ to protest, and the events are considered as a positive turning point in LGBTQ history in Canada. In the 1980s, the global HIV/AIDS pandemic began, with its own stigmatising and bereaving effect on LGBT life experiences, particularly those of gay men, and this is when 2SLGBTQ+ care communities originated.

As a result of these lifetime events, the older ‘Invisible’ and ‘Silent’ generations are individually less likely to have experienced discrimination and victimisation but are more likely to have hidden identities and to have more limited social networks. Such social isolation has been associated with both personal factors and environmental factors. Personal factors include living alone, not being in a conjugal relationship and not having children or having fewer children than heterosexual seniors. Environmental factors include a fear of discrimination which then becomes a barrier to seeking social contact. As a result, the social networks of some LGBTQ seniors are composed mainly of other LGBTQ people (Employment and Social Development Canada, 2018). Conversely, the younger 'Pride Generation' is more likely to have disclosed their sexual orientation and gender, but to have experienced discrimination and victimisation. In Canada, Prime Minister Justin Trudeau has made a formal apology to LGBTQ2 Canadians for state-sanctioned discrimination (Trudeau, 2017).

These experiences of LGBT older adults will differentiate their attitudes and access to healthcare. Their location is also important, with those in rural areas feeling less safe than those in urban areas with larger LGBT communities. LGBT older adults lack confidence that the healthcare system will address their needs and fear stigma and discrimination by healthcare service providers. A recent study of Canadian healthcare professionals and frontline staff has shown that healthcare providers want to provide safe and inclusive care for older members of LGBT communities but lack the knowledge to do so (Kortes-Miller, Wilson and Stinchcombe, 2019).

For more detail see **Appendix 2** Key points in Canadian 2SLGBTQ+ social history.

The social experience of the 2SLGBTQ+ communities today

Despite legislation homo-, bi- and transphobia still exist. Both actual and anticipated discrimination negatively affect the lives of 2SLGBTQ+ individuals. 2SLGBTQ+ seniors can experience social isolation; however, shared experience of stigma and discrimination has promoted resilience in some sections of the 2SLGBTQ+ community.

Canada

The LGBT+ Realities Survey, a research report prepared for the Jasmin Roy Foundation, surveyed LGBT (n=1897) people and heterosexual cisgender individuals (n=800) aged 15 years and over from across Canada. 75% of the LGBT communities had been victims of bullying compared with 45% of the cisgender heterosexual population, with the majority of bullying having taken place at school and/or in a public venue. In the survey, the LGBT communities expressed reservations about Canadian society's willingness to encourage the integration of LGBT individuals, with only 17% feeling that it is very much inclined to do so. Respondents felt that schools, the media and public institutions (particularly healthcare services) would have the most impact on making a difference toward a more LGBT tolerant society.

Despite these issues, the LGBT respondents on average displayed an overall happiness with life, which matched that of the heterosexual cisgender population, although the younger LGBT age group (15-24 years old) were a little less happy than their heterosexual cisgender counterparts (Jasmin Roy Foundation, 2017).

The LGBT+ Realities Survey also compared LGBT Caucasian respondents (n=1563) with those from non-Caucasian ethno-cultural groups, Aboriginals (n=109) and other non-Caucasians (n=257). All subjects were under 55 years old. Aboriginal respondents stood out as being more comfortable with living with their sexual orientation and gender identity as compared with the

LGBT communities average. They perceived a greater acceptance of their sexual orientation and gender identity from people around them. Overall, however, non-Caucasian LGBT people were a little less happy in life than their Caucasian counterparts (Jasmin Roy Foundation, 2017).

US

In the US, LGBT adults experience discrimination in housing, employment and basic civil rights, in addition to being the victims of harassment and violence. LGBT youth can experience bullying, familial rejection, lower educational attainment and higher levels of imprisonment. Transgender individuals experience a higher frequency of discrimination related to housing and employment than the cisgender LGBT communities. Factors associated with experiencing discrimination include gender identity, length of disclosure of sexual orientation and/or gender identity, age and race (Kattari et al., 2016).

A survey of LGBT adults aged 50 and over (n=2560) showed that over two-thirds have experienced victimisation and discrimination more than three times in their lives, including discrimination in health, aging, and disability services (Fredriksen-Goldsen et al., 2011). LGBT older adults participating in the 2010 Caring and Aging with Pride: The National Health, Aging and Sexuality Study (n=2463, aged 50 years and older) reported an average of 6.5 lifetime victimisation and discrimination events (Fredriksen-Goldsen et al., 2015).

Bisexual people have been shown to experience greater mental health concerns and discriminatory treatment than their gay, lesbian, and heterosexual counterparts (Fredriksen-Goldsen et al., 2017a).

Transgender individuals do not identify with the sex assigned to them at birth by the healthcare system. Transgender individuals who undergo gender transitioning often face discrimination from all components of society, including their place of employment and healthcare provider (Miller and Grollman, 2015). They frequently encounter the use of incorrect gender terminology, denial of bodily privacy, exoticisation, and assumptions of sexual pathology (Nadal et al., 2016).

Despite the challenges faced, or perhaps because of them, three quarters of LGBTQ older adults in the US reported engaging in antidiscrimination activism, with particularly high rates among bisexual women and transgender older adults. One third regularly attended religious or spiritual activities (Fredriksen-Goldsen et al., 2017b).

UK

In 2015, the Government Equalities Office (GEO) commissioned the National Institute of Economic and Social Research (NIESR) to conduct a wide-ranging, critical assessment of the evidence base regarding inequality experienced by LGBT communities in the UK. The NIESR review found that “the evidence base for an effective assessment of inequality and relative disadvantage by sexual orientation and gender identity is deficient and has major gaps” (Hudson-Sharp and Metcalf, 2016). Further, it found there was a lack of research involving robust sample sizes that could look at different sexual orientations and gender identities at a more granular level. It also noted that national and administrative datasets tend not to hold LGBT-related data, limiting the government’s ability to understand how LGBT communities access public services and what their experiences are. Yet, despite the above, NIESR noted that the research tended to point in one direction – continued inequality for LGBT communities in many areas of public life.

With regard to healthcare in the UK, the NIESR report found that the existing evidence base points to LGBT people being more dissatisfied with health services in comparison to those who are not LGBT. This can include lack of knowledge among medical staff about the health needs of LGBT people, specific concerns with mental and sexual health services and, among transgender people, concerns with the gender identity services provided by the National Health Service (NHS) (Hudson-Sharp and Metcalf, 2016).

To respond to these problems, in 2017, the UK government launched the National LGBT survey (UK government, 2018). The survey asked LGBT and intersex people for their views on public services and about their experiences more generally living as a LGBT person in the UK. Given the lack of data on the LGBT communities in national and administrative datasets, an online survey was used as it was considered the best way to access a large number of respondents, and it allowed the provision of anonymous and confidential responses. The survey was promoted widely by the UK Government Equalities Office (GEO), by stakeholders, at national LGBT pride events, via national media coverage and on social media. Ministers publicised it during multiple interviews and videos during the 2017 LGBT Pride celebrations.

The survey received over 108,000 valid responses, making it the largest national survey to date of LGBT people in the world. In this survey the acronym LGBT was used as an umbrella term; respondents could be from any minority sexual orientation (such as asexual or pansexual) or gender identity (such as non-binary or genderqueer). The survey was also open to intersex individuals. Respondents had to self-identify as LGBT; as such these people may have a different experience to those who are unwilling to identify in this way, even in an anonymous survey.

Whilst respondents were generally positive about the UK’s record on LGBT rights, a number of issues specific to the LGBT communities were identified:

- LGBT respondents are less satisfied with their life than the general UK population (average rating satisfaction 6.5 out of 10 compared with 7.7). Transgender respondents had particularly low scores (around 5.4 out of 10);
- More than two thirds of LGBT respondents said they had avoided holding hands with a same-sex partner for fear of a negative reaction from others;
- At least 2 in 5 respondents had experienced an incident because they were LGBT, such as verbal harassment or physical violence, in the 12 months preceding the survey. However, more than 9 in 10 of the most serious incidents went unreported, often because respondents thought ‘it happens all the time’;
- 2% of respondents had undergone conversion or reparative therapy in an attempt to ‘cure’ them of being LGBT, and a further 5% had been offered it;
- 24% of respondents had accessed mental health services in the 12 months preceding the survey.

Australia

A study of life satisfaction and sexual minorities analysed data from two large surveys in Australia (n=12,388 aged 15 years or over) of which 1.6% were gay or lesbian, 1.5% bisexual, 0.7% other and 2% did not disclose, and in the UK (n=32,964 aged 16 years or over) of which 1.4% were gay or lesbian, 1.1% were bisexual, 1.1% other and 2% did not disclose. Evidence of low levels of life satisfaction (other things held constant) was found among sexual minorities in both the UK and Australia. The most important difference between the two countries was the lack of any significant direct effect of being gay or lesbian in Australia. This finding suggested that stigma effects are now largely absent in Australia, which would be a major change from the past (Powdthavee and Wooden, 2015).

The health of the 2SLGBTQ+ communities

The 2SLGBTQ+ communities have specific health issues as compared to the cisgender heteronormative population. Some of these issues are linked to negative societal attitudes to the 2SLGBTQ+ communities, which has meant that they are less likely to access healthcare and education and may adopt unhealthy lifestyles as a coping mechanism. Other health issues such as HIV/AIDS and some cancers are linked to sexual orientation. The health needs of the 2SLGBTQ+ communities are under researched, and several countries have noted that the 2SLGBTQ+ population is underserviced with regard to healthcare needs.

Research shows that there are health disparities between the 2SLGBTQ+ communities and the heterosexual population. The US Healthy People 2020 (US Department of Health and Human Services, 2010), a set of 10-year national health improvement objectives, has highlighted LGBT people as a health-disparate population and outlined goals to improve their health, safety, and well-being. Healthy People 2020 organises the social determinants of health around five key domains: economic stability; neighbourhood and physical environment; education; community and social context and the healthcare system. Consideration of these determinants may explain health disparities in the LGBT population.

In the US, lesbian women, gay men and bisexuals aged 18-59 years were found to have a greater all-cause mortality than heterosexuals (Cochran, Björkenstam and Mays, 2016). Major health concerns included HIV/AIDS, mental illness, substance use, and sexual and physical violence.

Amongst LGBT adults in the US aged 18 years and over there are higher rates of cancer, arthritis, hepatitis, lung disease and disability (Ward et al., 2015). There are also higher levels of health-risk behaviours compared with heterosexual adults. Binge drinking and drinking and driving were significantly more common amongst lesbian and bisexual women than heterosexual women. Lesbian, gay and bisexual individuals were more likely to be current smokers than their heterosexual peers (Blosnich et al., 2014). LGBT adults also have lower self-ratings of their general physical and mental health than their heterosexual counterparts (Gonzales, Przedworski and Henning-Smith, 2016).

The American Cancer Society has noted that the most important factor in increasing cancer risk for the LGBT communities is tobacco smoking. Smoking is responsible for almost a third of cancer cases, is a risk factor in over 12 cancers, and accounts for 87% of lung cancer cases. Alcohol consumption is increased in the LGBT population, and this increases risks of cancers of the breast, colon and rectum, liver, oral cavity and pharynx, and pancreas. Amongst lesbian or bisexual women compared with heterosexual women, obesity rates are higher, which increases the risk of oesophageal, colorectal, kidney, liver, post-menopausal breast, pancreatic and gynaecological cancers (Quinn et al., 2015, Wender et al., 2016).

There are no precise data on cancer rates among LGBT communities because cancer registries do not document sexual orientation (Bowen and Boehmer, 2007, Boehmer et al., 2014). The available evidence, however, suggests that sexual minority status may contribute to excess risk for the development of certain types of cancers, including breast cancer (Cochran and Mays, 2012) and anal cancer (Machalek et al., 2012). Although it appears that lesbian and bisexual women have an increased prevalence of breast cancer risk factors, currently it is unclear whether they are indeed at an increased risk of breast cancer (Quinn et al., 2015), and further research is needed. LGBT individuals are less likely to attend routine screenings and so do not receive early detection and intervention; diagnosis of cancer at a more advanced stage results in a poorer outcome (Blosnich et al., 2014; Quinn et al., 2015).

Sexual behaviour is associated with certain diseases and disorders. The risk of anal cancer is increased by infection with the human papilloma virus (HPV). The likelihood of HPV infection is increased by having anal sex. The incidence of anal cancer is increased amongst men who have sex with men (Quinn et al., 2015).

There is limited data on gynaecological cancers in lesbian and bisexual women. A meta-analysis found that bisexual women may have higher rates of cervical cancer than heterosexual women (Robinson et al., 2017). Cervical cancer is associated with HPV infection. Cervical cancer can take 10 to 20 years to develop after initial HPV exposure; therefore, most cases of advanced cervical cancer occur in women without previous screening. Lesbian women may assume that they do not need regular Pap tests or cervical smear tests as they are not at risk for HPV because they do not have sex with men. HPV can, however, be transmitted by skin to skin contact. Further, many lesbians will have previously had a male sexual partner. The lesbian community needs better education as to the benefits of regular Pap testing (Waterman and Voss, 2015). Most female-to-male (FtM) transgender men retain their cervixes and need comprehensive sexual healthcare, including cervical cancer screening. FtM individuals obtain cervical cancer screening less frequently compared with cisgender women and so are an at-risk population (Gatos, 2018).

In England the 2009/2010 English General Practice Patient Survey compared the health status of gay, lesbian or bisexual individuals (n=27,497) with their heterosexual counterparts (n=2.14 million). The sexual minority population were more likely to report a longstanding psychological or emotional problem and to report either fair or poor health (Elliott et al., 2015).

The minority stress model was proposed by Meyer to explain the higher prevalence of mental disorders in lesbian, gay and bisexual people as compared to the heterosexual population (Meyer, 2003). The model proposed that the excess of social stressors related to stigma, prejudice and discrimination explained this higher prevalence. Such stressors include not only the experience of prejudice and discrimination but also the anticipation of it. Stress processes may include being vigilant in interactions with others due to the expectation of rejection and discrimination and hiding identity for fear of harm (concealment). Further, there can be an internalising of stigma resulting in an internalised homophobia where negative societal attitudes are directed toward the self, which causes a poor self-regard. The experience of such a hostile and stressful social environment may cause mental health problems (Meyer, 2003).

These social stressors are thought to explain the health-risk behaviours such as smoking and drinking alcohol amongst the LGBT communities. They may also explain the higher prevalence of some diseases in the population. There is evidence supporting the associations between chronic stress and inflammatory processes leading to chronic diseases, including cancer (McEwen, 2017).

Transgender people face high levels of discrimination in society, which may contribute to their increased risk for poor health compared with the cisgender population. Amongst trans people, gender nonconformity is a form of stigma visibility, where others are able to "read" that a trans individual's sex, gender identity and gender expression do not align. Gender nonconformity serves as a visible and known marker of status as a trans person, and, most importantly, it can shift a person's status as transgender from concealable to conspicuous (Levitt and Ippolito, 2013). Data from the largest survey of transgender adults in the US, the National Transgender Discrimination Survey (n = 4,115), suggest that gender nonconforming trans people face more discrimination and, in turn, are more likely to engage in health-harming behaviours (such as attempted suicide, drug/alcohol abuse, and smoking) than trans people who are gender conforming (Miller and Grollman, 2015).

A probability study of the health status of transgender people in the US and Guam (n=691) compared with cisgender people (n=150,675) showed that transgender people had poorer general, physical and mental health and a higher prevalence of myocardial infarction. However, transgender people did not differ from cisgender individuals with regard to the prevalence of chronic diseases, cancers, depressive disorders or health-risk behaviours such as smoking and binge drinking (Meyer et al., 2017).

The health of older LGBT adults

The Canadian Longitudinal Study on Aging (CLSA) (Stinchcombe et al., 2018) has identified a sample of 51,208 Canadians 45 years old and over, 2% (n = 1057) of respondents identified as lesbian, gay or bisexual. Health-risk behaviours were increased amongst both sexual minority females who reported excessive drinking and former smoking, and sexual minority males who were more likely to be current smokers. Such behaviours have been associated with the risk of chronic disease. Gay and bisexual males were more likely to have a cancer diagnosis. Both female and male sexual minorities were more likely to have reported an anxiety or mood disorder (including depression) compared to cisgender heterosexuals and so may be at risk of poor mental health. The findings are consistent with the minority stress model of Meyer (2003) with poor health outcomes being associated with being a member of a marginalised group and experiencing the associated social stressors.

The US Aging with Pride: National Health, Aging and Sexuality/Gender Study (NHAS) 2014 is a longitudinal study that aims to study the intersection of sexual orientation, gender identity and aging (Fredriksen-Goldsen and Kim, 2017). The final sample size was 2,450 LGBT adults, with birth year ranging from 1916 to 1964, including 1,092 participants aged 50–64 (born 1950–1964) and 1,358 participants aged 65 and older (born 1949 or earlier). An investigation of health disparities among lesbian, gay, and bisexual adults aged 50 and older found that sexual minority older adults, compared with heterosexual older adults, showed significantly higher likelihoods of chronic health conditions, including low back or neck pain, weakened immune systems, and disabilities (Fredriksen-Goldsen et al., 2017c). Lesbian and bisexual older women were significantly more likely to report strokes, heart attacks, asthma, arthritis, or multiple chronic conditions, and gay and bisexual older men were more likely to report angina pectoris and cancer compared to their heterosexual male counterparts. There were higher rates of disparities in cognitive impairments in lesbian, gay, and bisexual older adults. LGBT older adults of colour and those living in poverty also have elevated rates of health disparities (Fredriksen-Goldsen and Kim, 2017).

Transgender older adults have been shown to be at higher risk of poor health outcomes compared to non-transgender sexual minority older adults through community-based data analysis. They were more likely to experience poor general health, disability, and mental distress, which were associated with elevated rates of victimisation, discrimination, and lack of access to responsive care (Fredriksen-Goldsen et al., 2014).

Community-based data have also shown higher risks of poor health among bisexual older adults when compared with their lesbian and gay counterparts. Bisexual people may experience elevated stress and social isolation, perhaps due to marginalisation within lesbian and gay communities as well as within society in general (Fredriksen-Goldsen et al., 2017a).

HIV/AIDS has become a chronic condition that is largely manageable due to the use of anti-retroviral medication (ARVs). This has increased life expectancy for people living with HIV/AIDS. The leading cause of mortality amongst older people living with HIV/AIDS is now liver disease and cardiovascular disease. These are both associated with the long-term use of ARVs. Older people living with HIV are commonly socially isolated, and stigma related to HIV and homosexuality have been shown to interact with age-related stigma, increasing stress and affecting the quality of life and mental health of elderly HIV-positive individuals (reviewed in Cahill and Valadéz, 2013).

A danger with all older adults is polypharmacy. Because LGBT persons may be taking chronic medications such as hormone replacement therapy amongst transgender individuals or ARVs for HIV/AIDS, there is an opportunity for the LGBT senior to be on long-term drug therapies, which may potentially cause serious side effects (Greene et al., 2013).

Another consideration for older adults is cognitive impairment and dementia. Alzheimer’s is the most common form of dementia. The life course experience of LGBT older adults with regard to discrimination and marginalisation puts them at increased risk of cognitive impairment. HIV/AIDS can also damage the brain. Key competencies for healthcare providers, caregivers, families and communities working with older LGBT adults living with cognitive impairment and dementia have been described (Fredriksen-Goldsen et al., 2018).

LGBT identity affirmation has been associated with positive mental health (Fredriksen-Goldsen et al., 2017c). Such identity affirmation may be help LGBT older adults to access social resources, which promote good mental and physical health. Conversely, marginalisation during one's life course is negatively linked to use of social resources and to mental health. Hiding LGBT identity in environments an individual knows, or suspects, to be hostile toward sexual or gender minorities may be socially protective for LGBT older adults, but may be personally damaging, whereas being consistently open may be psychologically protective but be socially damaging.

It should be noted that despite the health inequalities found amongst older LGBT adults there is a resiliency amongst the LGBT population, as demonstrated by the strong sense of social support within the whole population and its constituent communities (Institute of Medicine, 2011). Further, they may be better able to adjust to aging having lived through an adverse socio-historical period (Friend, 1991).

The Two-Spirit population

Discussions with Two-Spirit people indicate that achieving a positive self-identity is associated with self-esteem, which in turn results in good health. This is especially important for those who do not live in Aboriginal communities or who left after coming out (Brotman et al., 2002). The study of Brotman et al. (2002) indicated that Two-Spirit people face potential marginalisation and exclusion from at least three sources: their Aboriginal communities because of their status as gay, lesbian, bisexual or transgender; LGBT communities because of their status as Aboriginal; and mainstream communities because of their multiple identities as both gay/transgender and Aboriginal.

Most of the published research on the health of Two-Spirit people was conducted in the US. Research in Canada is restricted to small samples based on surveys, so understanding of the health issues of Canadian Two-Spirit and LGBTQ-identified Indigenous communities is limited (Hunt, 2016; Laing, 2016). It is important to note that health inequalities exist amongst the Indigenous population as a whole, and these have been linked to colonial and racist oppression by society and government (Greenwood and de Leeuw, 2012). The Indigenous 2SLGBTQ+ communities face additional health problems due to their marginal status resulting from their gender identity and sexual orientation.

Many studies show that Two-Spirit and LGBTQ Indigenous people show high levels of depression and anxiety leading to poor mental health. Associated with this, health-risk behaviours such as substance use, smoking and high-risk sexual activity have been found (Albert, Monette and Waalen, 2001; Balsam et al., 2004). Homophobia, isolation and rejection increase the risk of suicide for Two-Spirit people above that of the Indigenous heterosexual population (National Aboriginal Health Organisation, 2012). The Trans PULSE project in Ontario identified Aboriginal transgender individuals (n=32, of whom 44% identified as Two-Spirit) and found 76% had seriously considered suicide (Scheim et al., 2013). The risk of suicide can be decreased if Two-Spirit individuals are connected to their culture and traditions and are able to recognise the impacts of colonisation on the Indigenous community as a whole (National Aboriginal Health Organisation, 2012).

The prevalence of HIV/AIDS infection amongst the Indigenous 2SLGBTQ+ population is unknown (Hunt, 2016), although studies do show double the prevalence rate of HIV/AIDS in the

Indigenous population as compared to the general population in 2016 (Public Health Agency of Canada, 2016).

Despite these health concerns a resilience can be identified amongst the Indigenous 2SLGBTQ+ population. This is associated with the fact that the Indigenous population has had to live through adverse social conditions. There has been a rebuilding of knowledge about traditional Two-Spirit roles and identities. There is evidence that in some communities, prior to colonisation, Two-Spirit people had important roles such as leaders, teachers, artists and spiritual guides (Brotman et al., 2002). An additional strength is the formation of Indigenous LGBTQ and Two-Spirit communities (Hunt, 2016).

Challenges to the access to healthcare by the 2SLGBTQ+ communities

In addition to the higher rates of illness and health challenges, 2SLGBTQ+ individuals are more likely to experience challenges obtaining healthcare. A recent international survey found implicit preferences for heterosexual people versus gay and lesbian people by heterosexual healthcare providers (Sabin, Riskind and Nosek, 2015). Associated with this the main barriers to healthcare access are experiences and/or expectation of discrimination within the healthcare system. These barriers can prevent patients from disclosing their sexual orientation and/or gender identity to their healthcare providers, despite the fact that this information can help their providers identify health risks. Recommendations for best practices with regard to culturally competent care for LGBT people have been made (Lim, Brown and Kim, 2014).

Canada

The review of Mulé and Smith (2014) showed that LGBTQ health concerns were marginalised in federal health policy indicating that LGBTQ healthcare needs were not being effectively addressed in Canada.

Interviews with older LGBT Canadians highlighted the lack of LGBT-affirmative social and health services (de Vries et al., 2019). Transgender participants noted particular insensitivity pointing to a need for trans-affirming healthcare services which respect the bodies of transgender individuals and address them with the pronouns and names of their preference (Pang, Gutman and de Vries, 2019). In Ontario an absence of formal education of healthcare providers in trans issues (Snelgrove et al., 2012) and high frequencies of harassment and discriminatory practices experienced by trans individuals in healthcare settings (Bauer et al., 2015) have been previously identified. The Ontario-wide Trans PULSE project found that 43.9% transgender Ontarians (n=433) reported a past-year unmet healthcare need as compared with 10.7% expected for cisgender Ontarians (Giblon and Bauer, 2017). The authors suggest that this excess of unmet need may be due to trans individuals having a higher need for medical services and/or being less likely to access healthcare.

An online survey of LGBTQ individuals (n=283, aged 16 years or over) resident in Nova Scotia found that the majority reported being uncertain about the level of LGBTQ-friendliness of their family doctor, their knowledge and cultural competence about LGBTQ issues, and the inclusiveness of the healthcare system in Nova Scotia (Gahagan and Subirana-Malaret, 2018). However, the majority of LGB (66.2%) and trans individuals (68.7%) were also satisfied with their primary healthcare provider or family doctor having had at least one good experience within the healthcare system. At least one bad experience was reported by more trans (55.5%) than LGB (36.4%) individuals. LGBTQ self-identified (n=53) and non-LGBTQ self-identified (n=56) individual healthcare staff were also surveyed. Many of these healthcare staff did not feel knowledgeable, comfortable or culturally competent enough with regard to LGBTQ populations and their primary healthcare needs regardless of their own sexual orientation. This may be related to the lack of formal training on these issues in their medical education (Gahagan and Subirana-Malaret, 2018).

Two-Spirit people face specific barriers when accessing healthcare. Research has found that within their own communities they feel constrained about coming out as ‘being different’ conflicts with community values. Further, there are problems with confidentiality in small rural places and reserves where everyone knows each other and there is limited access to LGBTQ-specific health resources or support (Brotman et al., 2002). As a consequence, Two-Spirit people migrate from rural areas or reserves to larger city centres to find a more accepting community where they can affirm their gender identity and sexual orientation (Ristock, Zoccole and Passante, 2010; Ristock, Zoccole and Potskin, 2011). A study in Winnipeg of Two-Spirit and LGBTQ-identified Aboriginal individuals (n=24) with experience of migration found that one third of respondents had been forced out of their communities because of their sexual or gender identity (Ristock, Zoccole and Passante, 2010) It is important to note, however, that Indigenous communities are not homogenous; while some 2SLGBTQ+ individuals may experience discrimination, others may find support and acceptance.

Migration from one’s own community brings its own problems in that there is then exposure to racial discrimination and cultural isolation. Further, LGBTQ-specific health services may have little knowledge of Two-Spirit identity or the unique concerns of Aboriginal communities (Brotman et al., 2002). Although LGBTQ and Two-Spirit experiences may overlap, the two are distinct identities. Historical negative experiences, such as those associated with the residential school system, can translate into a lack of trust of any non-Aboriginal person. Research indicates that access to healthcare services could be improved by the presence of Aboriginal front-line service providers who understand the intersection of an Indigenous heritage and 2SLGBTQ+ identity. Further, access to traditional health and wellness teachers alongside Western medicine would allow integration of culture into healthcare (2-Spirited People of the 1st Nations, 2008).

US

A study of US LGBT older adults (n=210, average age 60 years) investigated health and social services needs of the communities. They found that doctors were often ignorant of the lives and bodies of LGBT people; as a result, they missed important aspects of care necessary to understanding experiences common within LGBT communities. The lack of disclosure of sexual orientation and /or gender identity by LGBT individuals meant many doctors did not know patients were LGBT. This lack of disclosure is a result of the long-term underservice of LGBT people in medicine (Croghan, Moone and Olson, 2014) and service providers’ general lack of training on LGBT specific health and life issues (Porter and Krinsky, 2014).

UK

The UK national LGBT survey (n=108,000) (UK government, 2018) found that 80% of respondents had accessed public healthcare services in the 12 months prior to completing the survey. Access was higher among trans women (87%) and trans men (89%). Forty six per cent of cisgender respondents said they had never discussed their sexual orientation with healthcare staff in the 12 months preceding the survey, in most cases because they thought it was not relevant. The figure was much higher for bisexual respondents (67%) than gay/lesbian respondents (36%). When sexual orientation was disclosed by cisgender respondents, 75% said it had no effect, 18% said it had a positive effect and 8% said it had a negative effect. Twenty one percent of trans respondents said their specific needs were ignored or not taken into account when they accessed, or tried to access, healthcare services in the 12 months preceding the survey. Eighteen percent said they were subject to inappropriate curiosity and 18% said they avoided treatment for fear of discrimination or intolerant reactions.

With regard to sexual health services, the UK survey found that 27% of respondents had accessed sexual health services in the 12 months preceding the survey. A further 2% tried but were unsuccessful. Most respondents said they had been easy or very easy to access, with only 26% saying they had not been easy to access. Almost nine in ten (87%) of respondents who did access sexual health services reported a positive experience. However, a number of respondents to the optional free-text question used it to highlight negative experiences. Comments frequently focused on the NHS not having a full understanding of LGBT-specific issues such as access to post-exposure prophylaxes (PEP), a time-sensitive treatment aimed at preventing patients from becoming infected with HIV/AIDS.

In England, the 2009/2010 English General Practice Patient Survey found that sexual minorities were about one and one-half times more likely than heterosexual people to report unfavourable experiences with each of four aspects of primary care, namely confidence in the doctor, communication from the doctor, communication from the nurse and satisfaction with healthcare overall (Elliott et al., 2015).

Australia

In a national survey of LGBT Australians (n= 3,835 age range 16-89 years) 18.5% reported that their doctor did not know their sexual orientation whilst 12.8% reported that they did not know if their doctor knew (Leonard et al., 2012). Ignorance of sexual orientation can reduce the quality of the healthcare delivered. Further a study of Australian (n=14) medical schools found that there is limited content on LGBTQI health and that it is focused on sexual orientation rather than transgender, gender diverse and intersex people (Sanchez, 2017). Developing cultural competency among medical students might reduce barriers to healthcare access and improve health outcomes for LGBTQI patients

Caregiving in the 2SLGBTQ+ communities

Caregivers are defined as those who provide informal ongoing, unpaid assistance to family members and friends who need support as a result of physical, cognitive or mental conditions (Lum et al., 2011). Caregiving involves instrumental care (transportation, shopping, preparing meals, housework and personal care including bathing, feeding, dressing, toileting, administering medication), financial assistance, emotional support and interacting with health, social and legal services on behalf of the care recipient.

Caregiver burden has both objective and subjective aspects (Vitaliano, Young and Russo, 1991). The objective burden reflects the direct effect on caregivers' lives, and the subjective burden reflects the caregiver's attitudes to, or emotions about, the caregiving experience.

Jeane Anastas called caregiving within the LGBT communities 'caregiving with pride' because "the care that LGBT people provide within their families of origin, to their partners, within their friendship networks and within their communities as a whole should be indeed a source of pride" (Anastas, 2007).

Within the 2SLGBTQ+ communities, caregivers may be family members (either from a person's biological family or their family of choice), friends or neighbours (Lum, Hawkins and Ying, 2011). They may include:

- 2SLGBTQ+ caregivers caring for other members of the 2SLGBTQ+ communities (e.g., their partner)
- 2SLGBTQ+ caregivers caring for heterosexual people (e.g. 2SLGBTQ+ children caring for their parents)
- Heterosexual caregivers caring for 2SLGBTQ+ relatives or friends

2SLGBTQ+ caregivers are more likely to be from the care recipient's family of choice (sometimes called their fictive kin) than their biological family (or family of origin) (Muraco and Fredriksen-Goldsen, 2011; Hash and Mankowski, 2017). It is important to recognise that caregivers may not be 2SLGBTQ+ themselves (Lum, Hawkins and Ying, 2011).

Identity and numbers of caregivers within the 2SLGBTQ+ communities

Much of the data on the numbers of caregivers within the LGBT communities comes from the US. The data presented here for Canada is the author's estimate. Currently, there is no formal research from the UK that describes the number of LGBT caregivers.

Data from the 2012 General Social Survey (GSS) on Caregiving and Care Receiving showed that over one quarter (28%), or an estimated 8.1 million Canadians aged 15 years and older provided care to a chronically ill, disabled, or aging family member or friend in the 12 months preceding the survey. Such care included driving someone to an appointment, preparing meals, helping with bathing and dressing, or administering medical treatments (Sinha, 2012). Given that about 3% of Canadians are lesbian, gay or bisexual, there may be around a quarter of a million Canadian caregivers with a minority sexual orientation.

The numbers of caregivers in the US amongst LGBT communities has been extensively studied and compared with that in the cisgender heterosexual population. The Caregiving in the US 2015 national probability based online survey of 7660 adults aged over 18, conducted in 2014 by the National Alliance for Caregiving (NAC) in collaboration with the American Association of Retired Persons (AARP), found 16.6% were caregiving for an adult (National Alliance for Caregiving NAC and AARP Public Policy Institute, 2015) . This would equate to 39.8 million Americans. This 2014 study included a question about sexual orientation and gender identity for the first time in its history. Amongst the caregivers to adults in the survey, 9% self-identified as LGBT, which would equate to 3.6 million LGBT caregivers to adults in the US.

Various studies amongst the US population have found that caregiving for an adult was more common among those who identified as LGBT as compared with cisgender heterosexual, although estimates of the number of caregivers in each population vary. A 2006 MetLife Survey of 1000 LGBT individuals aged 40-61 years (the so called Baby Boom generation born between 1946 and 1964) found that 1 in 4 LGBT people are likely to be caregivers versus 1 in 5 cisgender heterosexuals (Metlife Mature Market Institute® & The Lesbian and Gay Aging Issues Network of the American Society on Aging, 2010). In a further 2009 MetLife Survey comparing LGBT individuals aged 45-64 (n=1206) with individuals of the same age from the general population (n=1200), 21% of LGBT respondents had cared for an adult friend or relative in the last six months compared with 17% of the general population (Metlife Mature Market Institute® & The American Society on Aging, 2010). A further analysis by Boehmer et al. (2018) suggests that more than one out of three LGBT adults is an informal caregiver to another adult compared with one in six adults being a caregiver to an adult in the general population.

The identity of the caregiver is most often the partner for both older heterosexuals and older LGBT adults. However, the older LGBT communities also rely on close friends to provide care because they have a smaller family network than their heterosexual counterparts e.g., older heterosexual adults may also have children to help them (Fredriksen-Goldsen et al., 2013). Thus, older LGBT individuals rely more heavily on their close peers to provide informal care. In one sample of older LGBT adults (n=2560 aged 50-95 years), over half (54%) were receiving care from their partner and nearly a quarter (24%) were receiving care from a friend (Fredriksen-Goldsen et al., 2011).

The 2009 MetLife comparative study of the LGBT and non-LGBT populations aged 45 to 64 years (Baby boomers born between 1946 and 1964) showed that more LGBT respondents had received care or help on a regular basis from a friend or family member in the last six months as a result of a health problem (14% versus 6%), suggesting a more sickly population. Both LGBT and general population caregivers most commonly cared for parents and partners (or spouses), with about a third of care going to each. The data suggested that more LGBT caregivers than non-LGBT caregivers cared for a sick friend (21% versus 6%) (Metlife Mature Market Institute® & The the American Society on Aging, 2010).

This same MetLife study demonstrated the importance of friends of LGBT individuals. As well as being more likely to have a friend as a caregiver, LGBT persons reported having more close friends and were more likely to live with and get emotional support from those friends than the comparative non-LGBT population. They were also twice as likely to have discussed their preferences with close friends. Nearly two-thirds said they consider their friends “chosen family.” A 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 (Lum, Hawkins and Ying, 2011).

It has been suggested that the HIV/AIDS pandemic that started in the 1980s initiated caregiving for families of choice within the LGBT communities (Muraco and Fredriksen-Goldsen, 2011). The lack of knowledge about HIV/AIDS and the accompanying fear amongst healthcare providers and the general population exacerbated the existing stigma and discrimination against

LGBT communities. This resulted in members of the LGBT communities caring for their own, a culture that continues today.

The caregiving burden of an 2SLGBTQ+ individual can be large if they care for members of both their family of choice and their biological family. A study of 155 gay, lesbian and bisexual persons aged over 50 from New York found that nearly half were caregivers to both their biological and choice families (Shippy, 2007). There can be an assumption amongst their heterosexual biological family members that gay, lesbian and bisexual adults are more available for caregiving as they do not have a traditional family lifestyle because they are less likely to be parents themselves and so have more available time. This can result in conflict (Hash, 2006). A further US survey of 350 LGBT older adults reported biological families expected more caregiving responsibilities of them because they were LGBT and single (Cantor, Brennan and Shippy, 2004). Both these studies demonstrate that gay, lesbian and bisexual older adults are not necessarily estranged from their biological families.

The characteristics of heterosexual cisgender caregivers and LGBT caregivers of adults over 50 years of age have been compared using data from the Caregiving in the US 2015 survey (Anderson and Flatt, 2018). The data sample comprised 90 LGBT caregivers (n=90) and non-LGBT caregivers (n=1057). Several differences were identified:

- LGBT individuals who were the adult children of their care-recipient were more likely to report higher levels of emotional strain than in other care relationship dyads. One contribution to this strain could be past parental disapproval of their child's LGBT status;
- With regard to the demographics, LGBT caregivers were significantly more likely to be single, of lower socioeconomic status, younger and more diverse in race and ethnicity;
- A significantly greater number of LGBT caregivers were a relative other than a spouse, or a friend of the older adult care recipient, compared with their heterosexual counterparts who were more frequently caring for their spouse. The lack of marriage equality across the US for the LGBT communities compared with the non-LGBT population at the time of the data collection would have meant that having a spouse to provide care would not have been an option. This reinforces the importance of families of choice as caregivers in the LGBT communities;
- To a significant extent, LGBT caregivers more frequently helped their care recipients with medical nursing tasks compared with their heterosexual counterparts (e.g., giving medications or injections, preparing food for special diets or tube feedings, wound care, monitoring blood pressure or blood sugar, helping with incontinence, or operating equipment like hospital beds, wheelchairs, oxygen tanks, or nebulizers);
- LGBT caregivers experienced significantly higher levels of financial strain and made more frequent modifications to the home of the care recipient.

Shiu, Muraco and Fredriksen-Goldsen (2016) used data from the National Health, Aging and Sexuality Study: Caring and Aging with Pride, which surveyed adults aged 50 years and above in 2010 to compare caregiving to a partner with that to a friend. They sampled LGBT (n=451) participants of whom 52% were providing care to a partner and 44% were providing care to a friend. The level of caregiving demand was 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 extent of care was determined by four different types of caregiving: instrumental care (e.g., transportation, laundry, grocery shopping); financial assistance; healthcare management (i.e., coordination with healthcare providers) and personal care (i.e., bathing, grooming, toileting).

The study found that those who provided care to friends had fewer caregiving demands, but also perceived less social support compared with those who provided care to partners, who had higher caregiving demands but more social support. The two groups of caregivers thus had similar levels of perceived stress and depressive symptomatology. These factors considered, the study concluded that LGBT caregivers to friends had a lower level of caregiving demands than other caregivers, and that led to a lower level of stress. But LGBT caregivers to friends used fewer sources of social support, and that was related to greater stress and depression. LGBT caregivers to friends were also less likely to use available resources to manage their stress and were more likely to report poor physical and mental health (Shiu, Muraco and Fredriksen-Goldsen, 2016).

Two-Spirit caregiving

There is limited information on caregiving experiences among the Two-Spirit population. Data from a large scale American study of Two-Spirit health (the HONOR Project) included the narratives of 22 American Indian, Alaskan, Native, First Nations or Métis who self-identified as LGBTQT_S caregivers (here T_S refers to Two-Spirit) (Evans-Campbell, 2007). The study identified that Two-Spirit people may be more likely be caregivers for non-biological family members than others in their community. Further, caregiving for children or community members may be expected from Two-Spirit people, and caregiving actually appeared to be part of their Two-Spirit identity. The Two-Spirit caregivers spoke of the need for community support and for health service providers that understood their culture. In particular, service providers need to be aware of the large tribal and cultural diversity amongst Two-Spirit populations.

Health of 2SLGBTQ+ caregivers

All caregiving is associated with a burden with physical, emotional and financial components. Caregivers might face declining health related to their own aging, the challenges of maintaining paid employment while providing care, and an increased need for social support (Cantor, Brennan and Shippy, 2004). Experiencing high caregiving demands and role conflicts can lead to stress and depression. However, informal caregivers often continue to provide care at the cost of their own mental and physical health (Smith et al., 2011).

A number of studies have indicated that there is a higher burden associated with caregiving in the LGBT communities as compared with the heterosexual community. LGBT caregivers were found to be less likely to use formal services and received less support from family members. This decreases LGBT caregivers’ resources and hence their abilities to manage the demands, burden, and stresses related to their caregiving responsibilities (Cantor, Brennan and Shippy, 2004; Croghan, Moone and Olson, 2014; Fredriksen-Goldsen, 2007). Emotional stress can be compounded by the cisgender heterosexist assumptions of society and healthcare providers.

LGBT caregivers are more likely to report poor physical and mental health compared with LGBT non-caregivers. In addition, LGBT caregivers are likely to suffer from several chronic illnesses themselves, making them more vulnerable to the stress of caregiving (Muraco and Fredriksen-Goldsen, 2011).

While a health-disparate population, some 2SLGBTQ+ older adults are doing well despite the risks. More lesbian, gay, and bisexual older adults, compared to heterosexual older adults, are engaging in preventive health measures, including obtaining blood pressure screenings and HIV tests (Fredriksen-Goldsen et al., 2017b).

Despite the burden associated with caregiving, positive psychological effects have been reported. Both the care-recipient and caregiver can benefit from the caring partnership. Research on LGBT caregiving dyads has shown that relationships can be strengthened, and the caregiver can gain self-esteem and self-efficacy (Kia, 2012; Muraco and Fredriksen-Goldsen, 2011). A US study of lesbian, gay and bisexual adults (n=199 age range 40-85 years) found that participants willing to give care viewed it as an opportunity for personal development. In addition, it was understood as a chance to give back to the community and to build a caregiving network that they could access themselves in the future (Grossman, D'Augelli and Dragowski, 2007).

Aspects of caregiving specific to the 2SLGBTQ+ communities

Most studies on 2SLGBTQ+ caregiving have used qualitative research methods to explore caregiving experiences among small sample sizes of LGBT caregivers. As a result, limited information is available about 2SLGBTQ+ caregiving, including the burden of caregiving and the support available to caregivers (Washington, 2015).

Hash (2006) compared aspects of caregiving for older adult partners of lesbian and gay individuals (US study n=19) with those identified from previous studies of the heterosexual population. Common caregiving aspects were shouldering most of the caregiving responsibilities, experiencing emotional, physical and financial strain as well as conflicts with their employment responsibilities. There was a valuing of the opportunity to show love and commitment through providing care. The lesbian and gay individuals, however, had the extra burdens of dealing with family, work colleagues or professionals, as well as policies and practices that were not supportive of their relationship. Further, they had to face disclosure issues relating to the nature of their relationship. Finally, after the caregiving role had ceased, they had to make plans and decisions whilst still considering whether their past relationship would be accepted, or the necessity of protecting that relationship.

A literature review of 19 studies of informal caregivers for adults with non-AIDS-related chronic illness amongst the sexual and gender minority communities (Washington et al., 2015) identified five dominant themes that characterise the caregiving experience, including sexual and gender prejudice, anticipating sexual and gender prejudice, valuing families of choice, becoming visible, and reflecting within-group diversity.

1) Sexual and gender prejudice

Microaggressions reflecting sexual and gender prejudice are regularly encountered by caregivers amongst the sexual and gender minority communities. These are commonplace social exchanges that send disparaging messages to certain individuals because of their minority status. Nadal, Rivera and Corpus (2010) have identified a taxonomy of LGBTQ-targeted microaggressions or subtle discriminatory practices. These are described in Kia, MacKinnon and Legge (2016): (1) use of heterosexist terminology that overtly discriminates against sexual and gender minorities; (2) endorsement of hetero- and gender-normative culture and beliefs; (3) reference to the experiences of LGBTQ people as being homogenous or unidimensional; (4) exoticisation of LGBTQ microaggressions (e.g., using LGBTQ people for comedic relief); (5) discomfort with visible expressions of non-heterosexuality, such as same-sex displays of affection; (6) denial of the reality that LGBTQ people experience discrimination on the basis of their sexual and/or gender identities; (7) pathologisation (assuming all gay men have AIDS) or oversexualisation of LGBTQ individuals; and (8) denial of individual experiences of discrimination among sexual and gender minorities.

Macroaggressions reflecting sexual and gender prejudice may result from discriminatory policies from healthcare providers. Previous negative experiences may inhibit 2SLGBTQ+ people from being open with their physicians and other providers, and as a result restrict information about potential health concerns, such as breast or prostate cancer, or HIV risks. Health and social care staff can make heteronormative assumptions about people’s sexuality or gender identity that have an impact on their healthcare experience (Neville and Henricksen, 2006). Further, the importance of sexual orientation and gender identity to patients can be underestimated by healthcare professionals as they understand sexuality as ‘who someone has sex with’ rather than an important part of someone’s identity that might affect their healthcare. This view was found amongst Marie Curie UK hospice staff and volunteers (n=153, Marie Curie Foundation, 2016). The UK Unhealthy Attitudes project for Stonewall (n=3001 health and social care staff) found 57% of health and social care professionals did not think that a person’s sexual orientation had anything to do with their healthcare needs (Somerville, 2015).

Caregivers need to feel safe in the healthcare environment in order to live openly, with their sexual and gender minority status recognised. To promote this there should be a clear and explicit communication of a commitment to non-discriminatory behaviour and policies by the service provider. However, just a commitment to non-discrimination is not enough (Washington et al., 2015). Sexual and gender minority caregivers have unique needs and are repeatedly frustrated with providers who aim to treat everyone “the same,” seemingly ignoring the population-specific legal, social/interpersonal, and emotional realities of sexual and gender minority caregivers’ lives.

2) Anticipating sexual and gender prejudice

Anticipating sexual and gender prejudice is informed by past personal experiences and by hearing stories of others’ negative experiences (Brotman et al., 2007). The UK Unhealthy Attitudes project for Stonewall, (n=3001 health and social care staff) found that 24% of patient-facing staff had heard their colleagues make negative remarks about lesbian, gay or bisexual individuals, and 20% made similar remarks about trans people in the last five years (Somerville, 2015).

The results of a survey entitled the ‘Last Outing’ of LGBT individuals (n=237, n=60 participated in a sub-survey interview) aged 60 years or over, or with a partner aged 60 years or over) have been reported by Almack et al. (2015). This found that 63% of respondents would like to access palliative care services organised by the LGBT communities, although they did not wish to be segregated. The participants suggested that promotional materials for palliative care services, including LGBT imagery such as the rainbow flag, would promote access by the communities. Language about and images of LGBT people were also suggested to allow LGBT individuals to feel acknowledged and visible. This could allow LGBT individuals to be open about themselves, and their support network, which is necessary for experiencing a so-called ‘good death’. This has been defined as ‘the best death that can be achieved in the context of the individual’s clinical diagnosis and symptoms, as well as the specific social, cultural and spiritual circumstances, taking into consideration patient and carer wishes and professional expertise’ (London End of Life Care Clinical Network, 2014).

These findings are echoed by a qualitative study of aging LGBTQ+ Canadians in Ontario (n= 23) (Kortes-Miller et al., 2018). A fear of entering long-term care homes was identified as participants anticipated social isolation, decreased independence and capacity for decision making, increased vulnerability to LGBTQ+-related stigma, as well as exposure to unsafe social and physical environments. Unsafe social environments referred to unaccepting staff and residents, whereas unsafe physical environments referred to a lack of LGBTQ+ inclusive symbols. One participant revealed that the presence of a crucifix made her feel uncomfortable. Similarly, thinking about their own future care in retirement, older gay and lesbian carers did not wish to reside in a long-term care facility fearing stigmatisation and harassment from both staff and residents (US study n=19), (Hash and Netting, 2007).

Experiences of caregivers amongst the sexual minority communities are influenced by the need for disclosure of their sexual orientation and the responses to these disclosures by healthcare providers. A qualitative study in England explored the experiences of gay men and lesbian women (n=21) who were caring for, or had cared for, a person with dementia (Price, 2010). The aim of the study was to explore how a person's gay or lesbian sexuality might impact upon their experience of providing care. The results demonstrated the ways in which caregivers mediated disclosures of their sexualities to health and social care service providers and, for some, their wider support network. The participants indicated that the point where they needed to use outside support was the first time they had to decide whether to come out about their relationship. The decision to come out was affected by respondents’ previous experiences of negative reactions to their sexuality, their perceived feelings of discrimination and, their anticipation of negative responses. The combination of these considerations affected their willingness to inform service providers about their sexuality.

The results showed that there was active disclosure, passive disclosure, or passive nondisclosure (i.e., patients neither revealed their sexuality nor claimed a heterosexual identity). Some caregivers felt it necessary to come out, others felt it unnecessary to do so as their sexuality was obvious, whilst others were ‘outed’ by the person they were caring for as a result of dementia. The choice, or necessity, of coming out was an additional stressor for the carers. Further, the decision about to whom to disclose one’s sexuality, the relative safety of those disclosures and the subsequent flow of such information through and between service providers proved to be an additional source of stress, which in turn affected the caring process and the caregivers themselves. If it was perceived to be unsafe to come out, feelings of isolation or marginalisation were increased. For many caregivers, responses to these disclosures proved to be a critical issue and one that shaped their experience of providing care. Management of transitions to different healthcare settings is important to avoid the need for repeated disclosures (Cloyes, Hull and Davis, 2018).

Further, a study of lesbian women with breast carcinoma (US study, n=39) showed that the majority of women (n=28) did disclose their sexual identity, even though they had not been asked, and this was because they felt safe to do so (Boehmer and Case, 2004). Nondisclosure occurred because 1) clinicians were unwilling to ask; 2) a fear of homophobia; 3) the woman did not have a partner; or 4) because she felt that sexual orientation was private.

An openness about sexuality or disclosure about a same-sex relationship amongst lesbian and bisexual women after a diagnosis of breast cancer was linked to more satisfaction with the healthcare provided (US study, n=55 lesbians, 6 bisexuals and 3 individuals who partner with women (Boehmer, Linde and Freund, 2005). Actually identifying as lesbian or bisexual, rather than just reporting a same-sex partnership, related to less cognitive avoidance coping (which is associated with better psychosocial outcomes), and lesbian identity related to lower distress. The study also provided evidence that women in relationships more frequently disclosed to providers. This may be because they wished to involve their partner in their care. Those who had disclosed perceived that they had greater social support, suggesting that the healthcare providers responded positively.

A study of the support needs of sexual minority women with breast cancer (US study, n=13) who had undergone mastectomy found that single women faced the greatest challenges and that former partners were often key sources of caregiving support (Paul et al., 2014). The study found that some sexual minority women may experience discomfort and isolation in predominantly heterosexual cancer support groups when they perceive a lack of lesbian/bisexual/queer awareness. A Canadian study (n=26) reported that lesbian women were reluctant to join predominantly heterosexual support groups because of expectations of homophobia (Sinding, Barnoff and Grassau, 2004). Similarly, a study of gay and bisexual men with prostate cancer (n=30) found that they would prefer support groups that were specific for gay and bisexual males (Capistrant et al., 2016).

3) Valuing families of choice

Brotman et al. (2007) defined families of choice as “friends and community members who are present to provide support and love in the absence of biological family”. Although the informal care provided by friends is comparable to the tasks performed by the biological family, the challenges of caregiving—especially when dealing with medical and other service systems—can be compounded when the friend-caregiver does not have the care recipient’s power of attorney or other next-of-kin privileges (Muraco and Fredriksen-Goldsen, 2011). In addition, current support services for informal caregivers have been largely designed for heterosexual partners or other biological family members, leaving older LGBT adults who provide care to friends or partners as a potentially underserved group (Brotman et al., 2007; Fredriksen-Goldsen, 2007).

One Canadian study reported data on a specific need relating to palliative care, noting that, for gay men and lesbian women (n=7) partners were important in the decision making and for support in the experience. The lack of support groups for gay and lesbian patients with cancer was highlighted (Katz, 2009).

The importance of the role of partners as caregivers in palliative care and at the end of life was highlighted in a US study of lesbian women with cancer (n=24 of whom 14 had breast cancer) (Matthews, 1998). Participants wanted their families of choice (partners and friends) involved in their care and included in decision making and treatment planning. They felt inhibited from doing so, however, by the heteronormative environment where the other women had heterosexual partners involved.

A US study comparing lesbian (n=29) and heterosexual (n=246) women with newly diagnosed breast cancer showed that lesbian women used families of choice as social support (Fobair et al., 2001). They had a poorer perception of the healthcare system than heterosexual women as they were less satisfied with the care they received and with the degree of inclusion of their partner in decision-making. Further, lesbian women were more likely to express their anger but less likely to share their emotions, use avoidance coping or show a fighting spirit than heterosexual women. This showed the presence of more emotional stress amongst the lesbian sample.

Above all, LGBT caregivers need to be recognised as primary caregivers and their rights to make decisions acknowledged. There should be more open and accepting environments where LGBT patients and caregivers can feel comfortable discussing issues with healthcare staff (Valenti and Katz, 2014; Czaja et al., 2016).

4) Becoming visible

There is a lack of research and so a need for increased attention to be given to the population-specific experiences, strengths, and needs of 2SLGBTQ+ caregivers is apparent. A study of sexual minority female breast cancer survivor and caregiver dyads (n=167) (Boehmer et al., 2016) found that the caregivers' fear of cancer recurrence and their sexual orientation had a significant effect on survivors' fear of recurrence. Sexual minority women reported less fear of recurrence than heterosexual women, indicating that caregiver interventions will likely benefit survivors' fear of recurrence. This strength of lesbian caregivers needs to be highlighted and the reasons for it translated to the heterosexual population.

5) Reflecting within-group diversity

In addition to highlighting the ways in which 2SLGBTQ+ caregivers' experiences differ from their heterosexual counterparts, many studies stress the importance of diversity within the communities. This was strongly emphasised by participants who identified as transgender. They stressed the need for awareness of the distinct differences between the experiences of transgender caregivers and cisgender caregivers even if they have the same-sexual orientation (Willis, Ward and Fish, 2011). To be culturally responsive, health and social care providers need to differentiate care within the sexual and gender minority communities. Importantly, all caregivers, whether 2SLGBTQ+ or not, will differ with regard to the care-recipient's diagnosis and for example, religious or spiritual, age-related, socioeconomic, racial, ethnic and geographic considerations.

Specific needs of 2SLGBTQ+ caregivers regarding palliative and end of life care

Although identifying as 2SLGBTQ+ is not biologically hazardous to health, enduring social stigma, prejudice and homophobia is (Kates et al., 2017). 2SLGBTQ+ people have a higher incidence of life-limiting and life-threatening disease than people who are cisgender and heterosexual. The World Health Organisation (WHO) states that palliative care should be considered from diagnosis onwards and integrated into care for people with any condition that means they may die in the foreseeable future (WHO Secretariat, 2014). Palliative care can improve the quality of life of patients and their families through "timely identification of deteriorating health, holistic assessment of needs, management of pain and other problems (physical, psychosocial, and spiritual), and person-centred planning of care" (Murray et al., 2017). Palliative care should be seen as the beginning of a continuum leading to end of life care and a 'good death'. For the caregiver, there is then a transition to a need for aftercare to deal with the bereavement, including feelings of grief and loss and support with coming to terms with the death (Cloyes, Hull and Davis, 2018).

Research by the Marie Curie Foundation UK shows that two of the most important indicators of good end of life care for LGBT people are whether or not they are receiving care centred around them as an individual, and whether or not their partner is accepted and involved (Marie Curie Foundation, 2016). LGBT people access palliative care services late or not at all, either because they anticipate stigma or discrimination, or they think the service is not for them. This can result in increased pressure on informal carers.

Further, as with the heterosexual population, many LGBT individuals would prefer to die in their own home. This requires external support services, and LGBT individuals and their carers may feel that they have to hide their true identity even in their own homes. A further issue for LGBT caregivers is that they may not want to 'come out' themselves, which has negative effects on the caregiver's wellbeing and the end of life experience for the care recipient (Marie Curie Foundation, 2016).

There is limited evidence about LGBT people's experiences of palliative and end of life care. A review by Harding, Epiphaniou and Chidgey-Clark (2012) identified papers that looked at LGBT needs, experiences or preferences in palliative care. Most of these papers have been discussed above and only one focused on a 'need' (Katz, 2009). All the papers reported on limited sample numbers that were mainly of white middle-class well-educated individuals. The authors concluded that "existing evidence is explicit and indeed repetitive in highlighting the educational needs of healthcare professionals to explore sexual preferences, avoid heterosexist assumptions, and recognise the importance of partners in decision making". All the studies highlighted the need for enabling patients to reveal their sexuality and discuss their needs related to it in a safe-environment; this would enable holistic patient-centred care. Further, a need for respecting the patient's wishes and their partner in decision making and treatment discussions was identified. Finally, the need for supportive groups where individuals felt safe to reveal their sexuality and voice their needs and concerns was noted. Most of these papers focused on the experience of gay and lesbian women with cancer and so did not relate to experiences of LGBT people living and dying from other diseases. Additionally, information on the issues faced by bisexual and transsexual individuals was missing.

The key issues facing caregivers, the needs identified and recommendations for action have also been highlighted in the report ‘Hiding who I am – the reality of end of life care for LGBT people’ (Marie Curie Foundation, 2016). In palliative and end of life care the patient and “family” are addressed together as the unit of care. As described previously, “families of choice” may include partners (and former partners) and friends, as well as biological family members. For the existence of these non-traditional families to be respected and recognised, disclosure of sexual orientation and gender identity is required.

In support of the above considerations, in 2018 the UK ACCESSCare study was published (Bristowe et al., 2018). It is the first national study to examine in depth the experiences of LGBT people facing advanced illness and potentially being in their last year of life. Participants (n=30) were either facing advanced illness themselves (n= 20) or were current (n = 6) or bereaved (n = 14) unpaid caregivers of an LGBT person with advanced illness. They self-identified as gay (n = 19), homosexual (n = 1), gay and intersex (n = 1), lesbian (n = 14), bisexual (n = 2), lesbian and trans (n = 2) and friend of a trans woman (n = 1). The illnesses were cancer (n = 21), non-cancer (n = 16) and both a cancer and a non-cancer condition (n = 3). Interviews were used to elicit views regarding sharing identity (sexual orientation/gender history), accessing services, experiences of discrimination or exclusion and best-practice examples. Five main themes emerged from the interviews:

(1) The provision of person-centred care (addressing individual needs and preferences) may require additional/different consideration for LGBT people (including different social support structures and additional legal concerns).
Individuals in same-sex relationships are unlikely to have wide family networks either due to estrangement or because they do not have their own children. Further, there may be lack of recognition of bereavement if they have not ‘come out’ or if society does not recognise the loss of a civil partner in the same way that loss of a husband or wife is recognised. There is a lack of language to describe the loss of a same-sex partner e.g., the uncertainty of a lesbian partner as to whether to describe herself as a widow and her access to the social resources and expectations that accompany that descriptor;

(2) The presence of service level or interactional (created in the consultation) barriers/stressors (including heteronormative assumptions and homophobic/transphobic behaviours).
These included experiences of overt homophobic behaviour such as refusing to recognise a same-sex partner and transphobia when a clinician refused to use the appropriate pronoun. Trans participants described insensitivity regarding disclosure of identity in an open ward setting and of worry over the provision of intimate care when their genitalia did not match their gender identity. Further, disregarding the nature, depth and duration of a relationship can be hurtful when discussing emotive issues such as prognosis. A lack of LGBT friendly support services or being unaware of what might be available was also described, with a particular worry being about what other people attending the service might think;

(3) The presence of invisible barriers/stressors (including the historical context of pathology/criminalisation, fears and experiences of discrimination).
These considerations not only affect whether individuals will disclose their identity but also whether they felt able to show intimacy or affection with their partner in care settings;

(4) The presence of service level or interactional facilitators (including acknowledging and including partners in critical discussions). Where identity was recognised, acknowledged and accepted, individuals felt well-supported by healthcare professionals. This included LGBT visibility, for example, healthcare institutions partnering with LGBT organisations to communicate a visible message of acceptance and support;

These four themes all shaped the fifth theme: (5) individuals' preferences for disclosing identity. Prior experiences of discrimination or violence, in response to disclosure, were carried into future care interactions and were exacerbated by the morbidity of advanced illness.

These findings are echoed in interviews with Canadian LGBT-identified individuals (n=23 aged 57-78 years) about concerns associated with end of life, which highlighted that identifying as LGBT matters (Wilson, Kortes-Miller and Stinchcombe, 2018). Participants were worried that their gender identity and/or sexual orientation might affect their end of life experience. Their worries were based on previous experiences with healthcare providers. There was a fear of social isolation if families of choice were not recognised by a healthcare provider, and an inability to advocate for their rights to the same provision of healthcare services as their cisgender heterosexual counterparts. Further concerns were around a lack of inclusivity from healthcare organisations for LGBT individuals, especially around institutions that had religious affiliations that were non-accepting of LGBT communities. Finally, concerns about heteronormative assumptions of healthcare providers led to fears that participants would be forced to hide their LGBT identities and ‘go back into the closet’. This would be needed in order to feel safe at a time in life when they anticipated being vulnerable and lacking advocacy.

As with heterosexual individuals, the 2SLGBTQ+ population needs comfort, safety and a freedom from pain at the end of life. There is a need for person-centred care that addresses individual needs and preferences (Bristowe et al., 2018). This does not mean that 2SLGBTQ+ people want ‘LGBT-bespoke services’; rather, there is a need for healthcare providers to use a holistic assessment of their care and provide accordingly. Trans participants needed clinicians to consider interactions between treatments provided by their gender clinics and those for their illness. Two trans women interviewed had been refused gender affirming surgery due to their lung conditions and the associated risk of receiving an anaesthetic. These interactions also impacted in the reverse instance, with hormone therapies affecting their lung health (Bristowe et al., 2018).

Caregivers of trans patients need to be aware of their unique requirements. The lack of specific guidelines and standards of care for transgender patients in palliative and hospice settings should be acknowledged (Rawlings, 2012). Patient wishes regarding wound care, burial rights, and when to discontinue hormones should be openly discussed and addressed. If the patient so desires, hormone medications should be continued in hospice settings (Maingi, Bagabag and O’Mahony, 2018).

Support for caregivers in the 2SLGBTQ+ communities

Research on the needs for caregivers in the 2SLGBTQ+ communities is mostly qualitative relying on interviews of sexual and gender minority caregivers (Washington et al., 2015). There is a need for more investigation into the experiences of such caregivers. This would promote culturally responsive, evidence informed support.

As an 2SLGBTQ+ individual approaches the end of life many of the specific problems related to being a member of a minority population resurface. 2SLGBTQ+ caregivers need healthcare providers to improve services in several ways. Healthcare professionals could get involved in supporting caregivers earlier to ease the pressure on them. They need to take a person-centred approach to care by understanding the relationship between the caregiver and recipient, and the best way to recognise that relationship.

The US National LGBT Cancer Network (National LGBT Cancer Network, no date) strongly recommend that social workers target specific outreach to the LGBT caregiver. Training in LGBT cultural competency should be provided for health and aging service providers. Healthcare professionals need to ensure that they use inclusive non-heteronormative language to allow patients to self-identify as 2SLGBTQ+. They need to identify whom the patient would like to be involved in their palliative and end of life care.

An awareness of 2SLGBTQ+ caregiving in both the 2SLGBTQ+ populations and service providing communities should be promoted. There should be an acknowledgement of 2SLGBTQ+ friend-care and this should be included in service provider policies. Access to 2SLGBTQ+ educated healthcare staff from the Indigenous population for Two-Spirit individuals is also required.

Specific recommendations for healthcare providers with regard to effectively meeting 2SLGBTQ+ caregivers' needs associated with palliative and end of life care have been made (Bristowe et al., 2018; Cloyes, Hull and Davis, 2018; Maingi, Bagabag and O'Mahony, 2018).

Healthcare services and institutions should:

- Make clear statement of policies and procedures related to discrimination;
- Include content regarding 2SLGBTQ+ communities in training on diversity and discrimination;
- Increase 2SLGBTQ+ visibility in materials (in written content and images);
- Provide specific markers of inclusion e.g., rainbow pin badges, lanyards;
- Initiate partnerships and/or engagement with 2SLGBTQ+ community groups.

Individual healthcare workers should:

- Avoid using heterosexually framed or assumption-laden language;
- Demonstrate sensitivity in exploration of sexual orientation or gender history;
- Respect individuals' preferences regarding disclosure of sexual identity or gender history;
- Carefully explore intimate relationships and significant others, including biological and chosen family (friends);
- Explicitly include partners and/or significant others in discussions.

In support of these recommendations a focus group study in Ontario (n=18 healthcare professionals and support staff) on the provision of person-centred care for older LGBT adults found: 1) a lack of formal training with regard to the health and social needs of LGBT older adults; 2) the need to create safer physical and social environments for LGBT individuals; and 3) the need to build relationships with LGBT-focused groups organisations (Kortes-Miller, Wilson and Stinchcombe, 2019).

Emotional and Psychological support

Caregiving for a loved one who is receiving palliative and end of life care carries a large emotional burden. This can be reduced by both professional and informal support.

An intervention framework comprising of strategies designed to help LGBT caregivers has been described (Coon, 2007). The SURE2 framework was designed to provide an individual and interpersonal intervention. It is based on trained facilitators working with groups of LGBT caregivers. This framework consists of: 2S's- Sharing and Support; 2 U's- Unhelpful thoughts/ behaviours and Understanding; 2 R's- Reframes and Referrals; and 2 E's- Education and Exploration. SURE2 is designed to create a safe place for LGBT caregivers to identify and overcome barriers such as managing disclosure, dealing with biological relatives and finding LGBT competent services.

- The Sharing and Support input refers to LGBT caregivers sharing concerns and then working as a group to solve issues raised;
- The Unhelpful thoughts/behaviours and Understanding component is designed to help caregivers identify negative impacts on their social and emotional health (e.g., worrying, drinking, smoking, eating or working too much in an effort to manage stress) and then to work on developing skills that reduce stress and promote coping;
- Reframes and Referrals is where group members are encouraged to think positively and recognise the problems that they as caregivers face – e.g., barriers due to their sexual orientation, problems finding LGBT culturally competent care, challenges of managing their 'outness' in different situations e.g., with biological family, friends, neighbours, employers, healthcare and social service providers and religious leaders and congregations. The facilitator and group members share referrals where competent professionals and organisations have been identified to overcome these problems;
- Education and Exploration is about including information about a care recipients' diseases and issues regarding co-morbidities. Caregiver related information, such as the course of caregiving and palliative and end of life care, should also be provided. Recent research findings and opportunities to join in research would also be included here.

In this framework the needs of the caregiver are emphasised in order to help them look after themselves. This contrasts with the usual focus of the caregiver on strategies to assist the care recipient. The SURE2 model could be adapted for use online and it is proposed that an approach combining education, support and skills-based training can alleviate caregiver distress and so enhance care recipient quality of life.

The importance of reducing stress amongst 2SLGBTQ+ caregivers has also been identified. A recent US study examined stress levels of survivors of non-metastatic breast cancer and their caregivers (n=167 dyads, of which 43 were heterosexual women and their caregivers and 124 sexual minority women and their caregivers, surveyed an average of 5 years post diagnosis) (Boehmer et al., 2018a). Survivors and caregivers reported stress levels consistent with population norms, irrespective of survivors' sexual orientation. The findings of similar stress levels of sexual minority women survivors and their caregivers compared to heterosexual women dyads may indicate that cancer represents one additional stressor above and beyond the chronic minority stress with which sexual minorities have learned to cope. However, differences by sexual orientation were noted such that caregivers' stress increased sexual minority survivors' stress, but not heterosexual survivors' stress. Whilst the authors could not make causal inferences from this finding, they suggest that interventions to reduce caregivers' stress in sexual minority populations are warranted.

Practical support

There is a practical burden associated with caregiving, and support may be needed to alleviate this. The number of caregiving tasks will depend on the location of care, with care at home being associated with the biggest burden.

Caregiving involves the management of medication, doctor's appointments and any associated therapy, such as physical therapy. Personal care, such as bathing, eating, dressing, toileting and grooming, may also be needed. In addition, household tasks such as cooking, cleaning, laundry and shopping will need to be completed. A further consideration is emotional care, which involves companionship, conversation and completing joint activities. Such caregiving can be physically demanding if the care recipient needs to be moved. Further, there may be challenging behaviour to deal with if the care recipient has dementia.
Caregivers report sleep deprivation, poor eating habits, a lack of exercise and a reduction of self-care when they are ill themselves, including a postponement of or failure to make medical appointments.

Outside help with such caregiving tasks may be needed. This may be professional or informal assistance. Caregivers and recipients from the 2SLGBTQ+ population will need to be sure that they can rely on such help to be non-discriminatory and trustworthy.

In the US National Alliance for Caregiving online survey that was conducted in 2014, LGBT caregivers (n=101) were significantly more likely to report financial strain, as well as showing trends toward elevated levels of poor health and emotional stress, than non-LGBT caregivers (n=1098) (Boehmer et al., 2018b). The caregiver may, therefore, need financial assistance to support the caregiving burden, particularly if extra resources are needed, such as equipment or private caregiving assistance. This is especially relevant if the caregiver has had to reduce employment hours, leave employment or has a low level of income, such as might exist in the aging caregiver population.

Caregivers need to understand the medical needs of 2SLGBTQ+ patients and advocate for them. They may need to be educated with regard to administration of medicine and the specific healthcare procedures associated with palliative and end of life care.

Education

Caregivers need information on where to find 2SLGBTQ+ friendly healthcare providers including hospitals, hospices and homecare provision for palliative and end of life care.

Access to information on health concerns associated with the 2SLGBTQ+ communities would also be beneficial. Caregivers could then consider their own health and disseminate information within the 2SLGBTQ+ communities e.g., dealing with alcohol, tobacco and drug addictions; screening for prostate, breast and cervical cancer; and education about anal cancer and HIV/AIDS. Such literature needs to be 2SLGBTQ+ affirmative, for example by displaying relevant symbols and pictures of 2SLGBTQ+ couples. As mentioned above, caregivers may need to be taught how to provide specific medical aspects of the necessary care.

Finally, caregivers need information on how to access 2SLGBTQ+-inclusive caregiver and care recipient support groups. These could be related to the specific disease being experienced, for general social support or for bereavement and grief support. Individuals accessing such groups need to feel safe to reveal their sexuality and voice their needs and concerns.

Advance care planning

Although same-sex marriage and civil partnerships are now legal in some countries, including Canada, many 2SLGBTQ+ individuals will not have formalised their partnership. As they approach the end of their lives, they can feel concerned that the most important person in their life will not be recognised as next-of-kin. Writing an advance care plan (also known as a healthcare directive or living will) is particularly important for 2SLGBTQ+ care receivers. This can ensure recognition for their partner or caregiver and reduce potential conflict between family of choice and biological family when making end of life care decisions. Such conflict can also be avoided by appointing a proxy to make healthcare decisions when the care receiver is unable to communicate their own wishes.

A recent UK survey of lesbian, gay or bisexual adults (n=522) identified that 34% had concerns about arranging end of life care and 24% expected to face barriers relating to their sexual identity when planning a funeral (Stonewall, 2014). ‘The Last Outing’ survey (Almack et al., 2015) showed that advance care planning is important for LGBT people. Whilst 82% of respondents agreed that it was particularly important for LGBT people to make and record plans for future care, only 18.5% had actually done so.

In a study on end of life care, sexual minority participants (86%) preferred palliative care to extending life (USA study, n=348 gay, n=180 lesbian, n=36 bisexual, n=6 other) (Stein and Bonuck, 2001). The majority were more likely to know about advance care planning (72%) and living wills (90%), but less likely to have acted on them (42% and 38%, respectively). Those under the age of 30 were more likely to prefer extending life over pain relief, and less likely to know about healthcare proxies or to have signed one. For the majority of participants, partners were the most commonly chosen person to take decisions, but only 21% reported that their partners had the legal right to do so.

In a study of older gay and lesbian carers (US study, n=19, age 50-77 years) (Hash and Netting, 2007), the majority of patients had made advanced directives mainly to protect themselves and their partner or caregiver from family members and professionals who might have disregarded their plans. Further, a study exploring the knowledge of prior directives showed that of patients with HIV/AIDS (US study, n=1031 men), those who were white, male, gay or bisexual, and well educated, were more likely to be knowledgeable and to have received counselling about prior directives (Teno, Mor and Fleishman,1990).

Trans people are concerned about being recognised as their birth gender or a gender with which they do not identify when they can no longer advocate for themselves, and in some cases, being treated after death as a gender that their family feel is appropriate but may not align with their wishes. Acquisition of a gender recognition certificate to legally recognise their gender was seen as desirable. Importantly, they wanted their gender to be correctly identified on their death certificate and in memoriam. For those facing advanced illness, there was concern that the certificate would not be acquired in time (Bristowe et al., 2018).

Overall, caregivers for 2SLGBTQ+ individuals need information on advance care planning, inheritance, wills and funeral arrangements, with specific regard to including families of the care recipient’s choice. They may need support for potential conflict resolution between the biological family and family of choice. Further, the formalisation of custody of dependent children could be required.

Spirituality, religiosity and end of life care in the 2SLGBTQ+ communities

As with the heterosexual population, the end of life is associated with seeking spiritual comfort and guidance. 2SLGBTQ+ people may have religious affiliations or other faith or belief structures that need to be recognised if the approach to end of life care is to be truly holistic. If they have conflict with biological family members, patients must decide whether resolution at the end of life is possible. Funeral services and practical matters, such as the handling of personal belongings, need to be decided. Palliative and end of life care services may not always ensure LGBT patients and their families have the same spiritual needs addressed at end of life as any other patient (Marie Curie Foundation, 2016).

2SLGBTQ+ individuals may feel conflict between their sexual orientation and religion, due to the predominance of many religious denominations that continue to condemn non-heterosexual relationships and homosexuality (reviewed in Pachankis and Goldfried, 2013, see, for example, a US study of n=66 lesbian, gay and bisexual respondents to a survey, Schuck and Liddle, 2001). Despite a growing number of lesbian and gay -friendly communities of faith, lesbian and gay couples tend to have lower rates of participating in church or religious communities than their heterosexual counterparts and, as such, seek out spiritual or social support through different forms (Schuck and Liddle, 2001). These include various forms of extrafamilial sources of support, such as families of choice or different types of 2SLGBTQ+ -friendly social organisations. Further, lesbian, gay and bisexual participants often experience conflict between their sexual orientation and religion. These sources of conflict include scriptural passages, denominational teachings, and congregational prejudice. Similarly, the LGBT community can view hospices affiliated with religions whose doctrines are anti-LGBT with suspicion.

Few studies have explored spiritual resources among 2SLGBTQ+ older adults. A study of LGBTQ people from the East coast of Canada (n=35, age range 20-68 years) with various faiths explored experiences with religion and spirituality (Beagan and Hattie, 2015). Although not all participants experienced conflicts, the psychological and emotional harms done to some participants through organised religion were extensive. The authors state that, “it is clear that religions have caused and continue to cause immense pain and suffering in LGBTQ lives” and participants spoke of “a void, an emptiness and a search for greater meaning” (McDonell, Abell and Miller, 1991).

A US study of lesbian women suffering from cancer (n=8) showed they valued spirituality, and although their definitions varied, they all described ‘peace’ and ‘hope’ as outcomes of spirituality (Varner, 2004). They commonly relied on spirituality to deal with their fears of cancer and its uncertainties. Not all participants believed that religion was helpful but felt that religion was a tool towards spirituality.

A US study of LGBT older adults (n=210, aged 50 years and older) found that although spirituality was a vital component of their lives, many faith communities were unsupportive of them and in some cases they needed to remain closeted within their faith community. One study of a younger age group (n=175, age range 18-25 years) found that religious faith enhances resilience among Black lesbian, gay, and bisexual adults, even in the presence of negative thoughts regarding one’s same-sex behaviour (Walker and Longmire-Avital, 2013).

Healthcare providers must consider the role of recognised and unrecognised religious affiliations in delivering a holistic approach to end of life care (Marie Curie Foundation, 2016). Such acknowledgement of a person’ spirituality and religious beliefs is associated with a ‘good’ death. It should be recognised that there is a negative view of 2SLGBTQ+ in some religions, while others are more liberal. Caregivers need access to 2SLGBTQ+ inclusive spiritual and religious provision. The particular needs of Indigenous caregivers to the Two-Spirit population also need to be researched and recognised.

Bereavement, grief and disenfranchised grief amongst 2SLGBTQ+ caregivers

Grief is a universal human response to the death of someone with whom a bond had been formed. Grief describes the emotional, cognitive, functional and behavioural responses to the death. The term ‘bereavement’ is used to refer to the fact of the loss (Zisook and Shear, 2009).

Attempts have been made to describe stages of grief such as an initial period of numbness leading to depression and finally to reorganisation and recovery. The experience of grief, however, varies among cultural groups, and from person to person, and theories have not explained how people cope with loss, why they experience grief differently and how or when they adjust to a life without a loved one. Grief is a process that proceeds from an acute form into an integrated or abiding grief. When the grief is integrated, the bereaved person is able to continue with a fulfilling life and find new and meaningful ways of continuing the relationship with the deceased. In contrast to acute grief, integrated grief does not persistently preoccupy the mind or disrupt other activities; however, acute grief may reoccur during significant events e.g., birthdays, holidays or during stressful times (Zisook and Shear, 2009).

Bereavement can lead to severe, persistent and disabling grief reactions, also known as 'complicated grief' or 'prolonged grief', among a minority of bereaved individuals (Shear, 2015). This is associated with substantial impairment in work, health, and social functioning which continues at least six months after bereavement. It results from the failure to transition from acute to integrated grief. Symptoms include separation distress (recurrent pangs of painful emotions, with intense yearning and longing for the deceased, and preoccupation with thoughts of the loved one) and traumatic distress (sense of disbelief regarding the death, anger and bitterness, distressing, intrusive thoughts related to the death, and pronounced avoidance of reminders of the painful loss). This type of grief may also reveal exaggerated reactions, such as clinical depression, anxiety disorder, substance abuse and post-traumatic stress disorder (Shear et al., 2011).

Disenfranchised grief (Doka, 1989) may be a contributing factor to the development of complicated grief (McNutt and Yakushko, 2013). Doka states: "I define disenfranchised grief as grief that results when a person experiences a significant loss and the resultant grief is not openly acknowledged, socially validated, or publicly mourned. In short, although the individual is experiencing a grief reaction, there is no social recognition that the person has a right to grieve or a claim for social sympathy or support." He has described loss experiences within the LGBT communities as disenfranchised when society does not recognise and validate the significance of the bereaved person's relationship with the deceased, for example between same-sex partners.

The caregiving experience will often lead to the loss of a care receiver. Predictive factors for bereavement outcomes for caregivers have been defined. These constitute the nature of the stressor (e.g., type of death- sudden, expected, unprepared, untimely; type of loss- spouse, child), intrapersonal factors regarding the caregiver (e.g., previous depression, socioeconomic factors), interpersonal factors regarding the caregiver (e.g., family dynamics, social support), and appraisal and coping strategies (cognitive processes and emotion regulation) (Stroebe et al., 2006). A high level of preparedness for the death has been associated with an improved outcome for the caregiver (Nielsen et al., 2016).

As with caregiving in general, the research in the area of bereavement among 2SLGBTQ+ individuals has identified unique features for this population. Unfortunately, this research is quite limited. After bereavement, both heterosexual and 2SLGBTQ+ individuals experience emotional distress following the cessation of care, feel a sense of loss over the caregiving role itself, experience positive effects from no longer providing care and face the challenge of moving on after ceasing the caregiving role. Those who performed a caregiving role are 20%–50% more at risk of mental health problems in bereavement than non-caregivers (Moriarty et al., 2015). Further, there is an increased risk of ill-health and even death amongst those who have lost their partner or primary relationship (Elwert and Christakis, 2008).

A 2016 review (Bristowe, Marshall and Harding, 2016) identified barriers and stressors for lesbian, gay, bisexual and/or trans people experiencing end of life care and bereavement, including homophobia, failure to acknowledge the relationship, additional legal and financial issues and the 'shadow' of HIV/AIDS. A novel model was developed to explain how the experience for lesbian, gay, bisexual and/or trans people is shaped by whether the relationship was disclosed and acknowledged in life and into bereavement and how this impacted upon needs and access to care. The proposed model suggests an important interaction between acceptance and disclosure – from a position of complete invisibility to overt acceptance. The position an individual occupies in the model shapes their access to support and also their access to the societal role of ‘widow’ and so to the usual sympathetic treatment society affords that role.

Consideration of this model could help shape bereavement counselling services for LGBT individuals. Such services will need to take account of the bereaved individual’s preferences regarding disclosure. Those whose relationship had been acknowledged and accepted by the community may need less support. However, negative experiences during bereavement can occur, so shifting an individual’s need towards more support. Those whose relationship had been accepted within society, but not openly disclosed, may need additional consideration in bereavement as healthcare professionals could fail to realise that they have lost their primary relationship. If a relationship had been acknowledged by society but not accepted by friends or family, there is an increased risk of adverse bereavement outcomes. Additional bereavement support from healthcare professionals may be needed and there may be an expectation of discrimination from such professionals even if it is not actualised. Those whose relationship had been invisible within society and their community will rely on recognition of it by healthcare professionals to access the support they need. If the relationship remains unrecognised, the result of experiencing grief in isolation, may be force individuals to ‘come out’ to access support. Bereavement services need to proactively assess needs and then act to provide the support required (Bristowe, Marshall and Harding, 2016).

Experiences around the time of death depend on whether the interaction with the healthcare provider is positive or not. A US study of gay men (n=6 surviving partners of men who had died of HIV/AIDS-related complications) who were recognised as a couple felt well supported, and caregivers who were specifically asked about their well-being felt especially well -supported (McGaffic and Longman, 1993). In contrast, anticipated or experienced homophobia was an additional stressor. Further, two studies have shown that if there was exclusion of a gay or lesbian partner at the time of death, or barring from being with the body after death due to lack of acknowledgement of a relationship, individuals felt ‘denied the opportunity to say goodbye’(Irish study, n=7 bereaved individuals, 3 male and 4 female whose partners had died of HIV/AIDS, (Glackin and Higgins, 2008)); (US study, n=6 bereaved lesbian women, (Bent and Magilvy, 2006)).

The additional challenge for lesbian and gay individuals of re-entering the gay community alone has been identified by two US studies (n=55 bereaved lesbian women (Jenkins et al., 2014); n=19 same-sex partners, 10 male and 9 female, (Hash, 2006)). A bereaved bisexual described additional challenges in bereavement, particularly the internal struggle of redefining oneself as bisexual, after the loss of long-term same-sex partner (Bristowe et al., 2018).

Even after ceasing the caregiving relationship, individuals who had cared for same-sex partners had to face disclosure issues relating to the nature of their past relationship. Further, having lost their partner, individuals worried about who would now care for them in the future (Hash, 2006).

Access to professional bereavement support after their partner’s death was a positive experience for gay and lesbian caregivers when they felt that their loss was recognised, however, for others, anticipated homophobia prevented them from accessing such support (Hash, 2006). A UK study (n=3 bereaved gay men and n=1 bereaved lesbian woman) has shown that some who did attend non-LGBT orientated support groups experienced open or subtle marginalisation (Fenge, 2014). Informal support was essentially provided by the LGBT communities and the family of choice.

Support for the bereaved 2SLGBTQ+ partner from their own biological family is often limited, especially if they were not ‘out’ with them (reviewed in Bristowe, Marshall and Harding, 2016). For example a US study comparing gay (n=6) and heterosexual (n=6) men who had lost a partner found that although all of the gay men believed that their relationships with their partners were recognised and accepted by family and friends, some of them found that this was not true once their partner had died. This lack of recognition and empathy exacerbated their feeling of loss as the support they had anticipated was not forthcoming (O’Brien, Forrest and Austin, 2002). Support from their partner’s biological family has been reported in a UK study, (n=15 LGB people, 10 male and 5 female, (Almack, Seymour and Bellamy, 2010)), but others have experienced a distancing of that family even if they had been close when their partner was alive (US study, n=55 lesbians, (Jenkins et al., 2014)).

In 2SLGBTQ+ individuals, if the relationship had not been recognised, then the grief would not be publicly recognised. This is an example of disenfranchised grief (Doka, 2002). It may not be accepted or identified as legitimate by family, friends, co-workers, or even policies. Doka, (1989) described three primary forms of disenfranchised grief, including (1) the lack of social recognition of the grieved relationship; (2) the lack of recognition of the bereavement experience itself; and (3) the lack of recognising the significance of the individual griever. Disenfranchised grief can lead to, or contribute to, complicated grief.

Such disenfranchised grief was also identified in the US study of bereaved lesbians (n=55) (Jenkins et al., 2014). Participants believed their experiences were very different from those of women whose partner died in a heterosexual relationship. They felt that the importance and depth of their loss was devalued by people they knew. Many described the way in which the death was often ignored completely by their friends and associates. In another US study of lesbians (n=24), participants reported that whilst they had a lot of support in their lives, there was no public recognition, socially, legally, or financially, now that they were widows (Whipple, 2006). The authors suggest that counselling using an appropriate grief model and understanding disenfranchised grief will be able to empower the widow. Additionally, educating family and friends of the widow about grief will help create a support system for her apart from professional services. The creation of lesbian-only support groups and written resources will help to end the sense of invisibility.

This experience of disenfranchised grief amongst lesbian and gay individuals has been extensively reviewed (McNutt and Yakushko, 2013). Many lesbian and gay bereaved partners are vulnerable to experiencing disenfranchised grief due to marginalisation and stigmatisation. Expectations of these may prevent individuals from accessing bereavement counselling or other mental health assistance.

HIV/AIDS carries unique stigma that can shape the caregiving experience. Among the general population, HIV/AIDS is stigmatised in that it is commonly associated with risky sexual behaviour and injection drug use and, thus, may be viewed as the result of irresponsible or immoral behaviour. The ‘shadow’ of HIV/AIDS means that there are additional stressors for men who lose their partner due to this disease. For many older LGBT individuals, the impact of early multiple HIV/AIDS-related deaths has resulted in psychological distress, including depressive symptoms and, often, traumatic stress related to cumulative losses (Mahmood, Manier and Hirst, 2004). The impact of bereavement on many of these individuals cannot be underestimated. Those currently living with HIV who may have cared for (or are currently caring for) partners and friends and may have witnessed difficult deaths that they may fear experiencing themselves are also negatively affected.

When a partner has died from HIV/AIDS, individuals have experienced disenfranchised grief as they were forced to conceal the nature of the loss and of the relationship, for fear of the impact on their support network and job (O’Brien, Forrest and Austin, 2002). Negative occurrences following a death (e.g., ongoing legal battles, being shut out of the hospital room or friends not recognising the relationship) lead to a longer period of bereavement and to less resolution of the grief and hence disenfranchised grief (Bent and Magilvy, 2006).

A US study (n=110 gay men) identified high levels of depression amongst such bereaved partners, (Folkman et al., 1996), especially amongst those who were HIV-positive themselves and where relationships had been lengthy. A further US study, (n=253 gay or bisexual men of whom 156 became bereaved during the course of the 2 year study) showed that the loss of a partner to HIV/AIDS was associated with high-risk sexual behaviour and suicide risk, particularly amongst those who had a high burden of caregiving, (Rosengard and Folkman, 1997). A positive state of mind was associated with a better likelihood of recovery from such depression in a US study of gay or bisexual men (n=86) (Moskowitz, Folkman and Acree, 2003).

A US study of gay and bisexual men (n=78) living with HIV/AIDS themselves who had lost a partner to HIV or AIDS, showed immune changes relevant to HIV progression less than one year after the bereavement, which were not explained by risk behaviours (alcohol, smoking and drug use) or antiretroviral medication. This suggests a physical, as well as psychological impact, of losing a partner to HIV or AIDS (Kemeny et al., 1995).

Caregiving partners of deceased HIV-positive individuals are often assumed to be (and could be) HIV-positive themselves, which also presents unique challenges and needs. A Canadian study of gay men (n=8) showed partners needed to explain such deaths in more detail than they would have chosen to avoid such assumptions (Hornjatkevyc and Alderson, 2011). Assumption of an HIV-positive status led to less support after bereavement. A bereavement coping group therapy intervention in the US was shown to reduce overall psychiatric distress among HIV-positive men and women (n=235, 150 men and 85 women), with reductions in HIV/AIDS-related grief and depression also exhibited among women (Sikkema et al., 2004).

Caregiving can be associated with positive outcomes for the caregiver despite bereavement. A Canadian study interviewed bereaved caregivers (n=176, 91 male, 81 female and 4 transgender) for deceased individuals with HIV/AIDS (Cadell, 2003). The respondents were gay, lesbian or bisexual (51%) or heterosexual (49%) and were either a friend (22%), a partner (22%), a member of a family of choice (10%), a member of a family of origin (15%) or other (such as a volunteer or colleague, 13%). The range of number of deaths experienced was 0-111, mean 13.8, standard deviation 22. Forty-four per cent of the carers were HIV-positive. Post-traumatic stress disorder was shown by 86.4% of caregivers, however despite the enormous stress involved in caring about someone who has died of HIV/AIDS, 81.8% showed evidence of post-traumatic growth.

Spirituality plays an important role in the creation of meaning in caregiving (Richards and Folkman, 1997). Canda (1989) has defined 'spirituality' as the general human experience of developing meaning, purpose, and moral relatedness among people, with the universe, and with the ground of our being. In contrast 'religion' is used to refer to formal institutional contexts of spiritual beliefs and practices. A Canadian study interviewed individuals (n=15, 8 male, 4 female and 3 transgender) who were self-identified as gay (n=10, 8 male and 2 transgender), lesbian (1female), bisexual (1 female) or heterosexual (2 female and 1 transgender) who had experienced at least one HIV/AIDS-related bereavement of someone they were caring for (Cadell, Jansen and Haubrich, 2006). Many of the participants (n=9) were also HIV-positive themselves. The study showed that engagement with spirituality was important in coping with their bereavement and through the grieving process most participants developed a spiritual connection to the deceased. Further they were able to move forward and make meaning of their own lives. HIV-positive individuals also gained strength to cope with their own disease through their spirituality. For most participants spirituality was viewed as distinct from religion.

This growth through spirituality can be associated with post-traumatic growth. All of the individuals interviewed had been positively changed by their experience of caring for someone who had died of HIV/AIDS. Even though they continued to experience distress regarding their circumstances, personal growth was still evident (Cadell, 2007). This research, and that of Cadell (2003), suggests that individuals can experience benefits from stressful life events. Support from bereavement counsellors to focus on spirituality and positive outcomes may help caregivers cope with their loss.

Since the inception of pre-exposure prophylaxis, antiretroviral therapy and the demotion of HIV/AIDS from life-threating to a chronic, nonfatal disease, the number of newly acquired infections has dramatically decreased in the United States by 18% between the years of 2008 and 2014 (Centers for Disease Control and Prevention, 2017). In Canada in 2016 the diagnostic rate was lower than in all years prior to 2012. There was a slight increase compared with the years between 2013 and 2015; this might be accounted for by increased testing (Bourgeois et al., 2017). Recent research has even suggested that mortality risks among LGBT and heterosexual individuals might be more similar than previously thought, with the greatest number of deaths resulting from heart disease, cancer, and suicide (Cochran and Mays, 2015).

There is a large body of literature on bereavement as a result of HIV/AIDS and a comparative lack of research on LGBT individuals who have lost partners for other reasons (Bristowe, Marshall and Harding, 2016). Bereaved caregivers of partners who had died as a result of non-HIV-related causes felt that insufficient resources existed to support their bereavement, in contrast to what they viewed as more adequate support for gay men whose partners had died as a result of an HIV-related cause (Hornjatkevyc and Alderson, 2011).

The review of Patlamazoglou, Simmonds and Snell (2018) suggests that the experiences of those who have lost partners to non-HIV-related deaths are different from experiences of HIV-related deaths due to the latter being complicated by the impact of previous multiple losses, survivor guilt, fear of developing HIV/AIDS themselves, resentment toward the deceased, stigmatisation and consequent hesitation to seek support. The authors advise that further research is required to identify the impact of disenfranchised grief on those bereaved by non-HIV-related causes and how to better support these mourners. The experiences of subpopulations within the 2SLGBTQ+ communities, including those residing in rural or remote areas and those identifying as ethnically diverse, remain significantly under researched as do the experiences of those bereaved partners who choose to remain closeted. The review identified that social support and community were vital components of coping among the bereaved, particularly to those older in age.

A study of interviews from an international sample of self-identified LGBT* adults (n=29, 15male, 12 female and 2 transgender, of whom 17 identified as gay, 10 lesbian and 2 bisexual) recruited through an online social media platform, who had experienced the death of a partners through non-HIV-related causes has been reported (Nolan, Kirkland and Davis, 2019). Good social support was associated with bereavement experiences marked by positive coping behaviours. In contrast, poor social support was marked by negative coping behaviours, self-isolation and a sense of abandonment. Strong resilience, however, was also identified, despite the lack of social support. The authors highlight the lack of LGBT* centred bereavement support services available within social networks, communities, and online.

There is limited research on the bereaved partners of transgender and gender non-conforming persons (TGNC). Despite recent efforts to protect the rights of TGNC persons, the death of a TGNC partner is often complicated. Posthumous de-transitioning of transgender women has been described (Weaver, 2018). This occurs when family members hide the fact that the deceased had chosen to live a gender identity different from that assigned at birth. They act as if this had not happened. Family members who choose to de-transition loved ones seek to mourn an identity previously lost. Loved ones who contest the gender expression presented at viewings and funerals and in memorials and remembrances can experience disenfranchised grief. In such cases of de-transitioning, the deceased's family of origin, members of the funeral home industry and religious organisations dictate the parameters of grief and mourning through explicit denial of transgender people. The dead themselves are excluded from the funeral ritual, and the role of the caregiver, friend or other close relationship may simply be ignored or unrecognised.

Nolan (2019) analysed how the 36-year-old self-identified 'heterosexual male' bereaved partner of a TGNC person who committed suicide described his experience of bereavement. The findings highlighted the importance of early detection and screening for complicated grief, particularly among bereaved persons with preceding substance use and mental health issues. The authors note that support programmes must be anti-stigmatic in origin, address substance use issues, and sufficiently target social isolation to reduce the burden of complicated grief experienced by bereaved partners of TGNC persons.

Bereaved LGBT partners also face legal and financial issues. Although, more recently, there is more equality with heterosexual couples, there can still be more difficulty around financial entitlements of same-sex couples compared to their heterosexual peers. If relationships with biological family are difficult, there could be contesting of wills and assets around the time of death (Hornjatkevyc and Alderson, 2011). Conflict between family of choice and biological family over wills and assets is an additional stressor at bereavement. Social workers might be advocates with the deceased partner's biological family in an effort to reduce the tensions that can exist (Bent and Magilvy, 2006). A referral to legal services may be appropriate when there is an issue with settling the estate or in accessing other benefits that might be available.

Bereavement counsellors need to understand the implications of disenfranchised grief for 2SLGBTQ+ caregivers. Research shows that there is ignorance of the scale of their loss by others, a denial of their need to grieve, a lack of access to shared resources, a loss of social and emotional support, and a feeling of isolation. Healthcare providers must be culturally competent and understand the special needs of bereaved 2SLGBTQ+ individuals. Mortell (2015) suggests that interventions including support groups where members develop relationships and explore the effect of loss on their lives can help with validation of the loss through the connection with others. A sharing of coping mechanisms is beneficial and the helping of others can boost self-esteem.

In bereavement there is a need for healthcare professionals to avoid assumptions of heterosexuality and explore identity sensitively in line with preferences for disclosure. Additional sources of support should be signposted to ensure 2SLGBTQ+ caregivers receive the individualised holistic care they need in bereavement. Healthcare providers and those working with patients and their family of choice should encourage discussions about who is important to patients. Healthcare staff should be supported to explore any existing relationship dynamics which may affect a patient's last wishes and preferences and help identify who needs support during bereavement by having honest and open discussions with the patient (Marie Curie Foundation, 2016).

Conclusion

Caregivers for those with advanced illness within the 2SLGBTQ+ community wish to ensure effective and high-quality palliative and end of life care, which leads to a 'good death'. Research shows that two of the most important indicators of achieving such good care for people within the 2SLGBTQ+ communities are that:

- the care is person-centred i.e., addresses individual needs and preferences
- the care recognises the people who are important to the care recipient i.e., families of choice and, in particular, their partners.

The 2SLGBTQ+ acronym includes heterogeneous communities with regard to gender identity and sexual orientation. Individuals within each community will also differ and can belong to more than one community. Trans individuals, for example, will not all have the same sexual orientation, and some may have an anatomy inconsistent with their chosen gender if they have not undergone medical treatment. Person-centred healthcare needs to take account of these differences.

Caregivers for 2SLGBTQ+ individuals may be their partners, friends or community members who form a family of choice, or members of their biological family. Caregivers may or may not be members of the 2SLGBTQ+ community themselves. In palliative and end of life care both the patient and their family are considered as the unit of care. Healthcare providers need to recognise who the patient considers to be family and to treat them as such. 2SLGBTQ+ individuals often have partners who are not formally recognised in civil partnerships or marriage and/or families of choice to whom they are not biologically related. The use of an advance care plan can ensure that these significant others are recognised during the patient's care and in bereavement. Where the 2SLGBTQ+ individual is also supported by their biological family conflict can arise and advance care planning can protect against this.

If either or both the caregiver and care recipient are from the 2SLGBTQ+ communities disclosing their sexual orientation and/or gender identity will improve the quality of palliative and end of life care. In order to disclose individuals must feel that it is safe to do so. Barriers to disclosure include past experience of discrimination, or the anticipation of discrimination by healthcare professionals. This is particularly relevant for older 2SLGBTQ+ individuals in same-sex relationships who have lived through a time during which such relationships were stigmatised or illegal. These barriers to disclosure may even lead members of the 2SLGBTQ+ communities to access palliative care services late, or not at all, which can result in an increased pressure on caregivers, as well as pain and discomfort for the care recipient.

Caregivers for 2SLGBTQ+ individuals who need palliative and end of life care, therefore, need 2SLGBTQ+ supportive healthcare providers. Providers need to create and maintain a non-discriminatory and inclusive practice setting. This might include increasing 2SLGBTQ+ visibility in information materials and providing specific signs of inclusion, such as the rainbow symbol. Research has suggested that some healthcare providers desire more training in order to create safe physical and social environments for 2SLGBTQ+ individuals. This might be enhanced by direct engagement with groups from 2SLGBTQ+ communities.

Individual healthcare workers need to learn and practise 2SLGBTQ+-inclusive communication skills and avoid heteronormative assumptions. They need to be able to sensitively explore sexual orientation and gender identity to promote disclosure and respect individual's preferences regarding such disclosures. Ensuring continuity of care to avoid the necessity of repeated disclosures is also important. Further, they need to carefully identify who is important to the patient and who has a role in caregiving. Identified partners and significant others who are caregivers need to be explicitly included in discussions about palliative and end of life care.

Caregivers need emotional and psychological support to cope with the emotional burden of caregiving for an individual receiving palliative and end of life care. This is especially important when a care recipient is suffering from dementia, which can be challenging and stressful and may result in unintended disclosure of sexual orientation or gender identity of either or both the caregiver and care recipient.

All caregivers may need practical support be it with household tasks, administration of medication, sourcing medical or legal information and accessing support groups. Caregivers for those within the 2SLGBTQ+ communities need to make sure that support is 2SLGBTQ+ affirmative. Medical information specific to the 2SLGBTQ+ communities may be needed, such as in regard to continuing retroviral treatment for HIV-positive care recipients or hormone treatment for trans individuals whilst in the receipt of palliative and end of life care.

Consideration of the religious and spiritual needs of caregivers is important. Many 2SLGBTQ+ individuals feel conflict between their sexual orientation and the views of any religion that they may be affiliated to. When caring for someone at the end of life turning to religion and spirituality can be helpful in a search for meaning, but religious and spiritual providers need to endeavour to be 2SLGBTQ+ -inclusive.

Finally, provision of palliative and end of life care includes support for grief and bereavement. The loss of a partner or loved one is associated with universal experiences of grief and continuing life alone, regardless of sexual orientation or gender identity. 2SLGBTQ+ caregivers can experience extra stressors in bereavement, including homophobia, the failure to acknowledge that they have lost a relationship, legal and financial issues and stigma related to HIV/AIDS, even if the death was from another cause.

Expectations of discrimination can lead to 2SLGBTQ+ caregivers failing to access bereavement counselling; this can result in depression and mental health problems. If a relationship has not been openly acknowledged in society disenfranchised grief can occur, as the griever cannot publicly mourn and so lacks social support and becomes isolated. Healthcare providers need to recognise this disenfranchised grief and provide support so that the loss and grief can be justly validated.

In conclusion, caregivers have specific needs when caring for someone within the 2SLGBTQ+ communities. Meeting these needs requires culturally-competent, affirming and inclusive healthcare provision. The available evidence indicates that whilst the 2SLGBTQ+ communities remain under-researched and underserviced, they have strengths and resilience. There is a need for improved healthcare provider education and training to improve care experiences and outcomes for 2SLGBTQ+ patients and caregivers.

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Appendix 1: Definitions

(adapted from Fredriksen-Goldsen and Kim, 2017; Institute of Medicine, 2011; LGBTQIA resource centre glossary, 2019).

Asexual - a term that describes one who generally does not feel sexual attraction to any person.

Bisexual - romantic or sexual attraction to both males and females.

Cisgender - persons whose gender identity corresponds to their assigned sex at birth; persons who are not transgender.

Coming out - the process of recognising and acknowledging one's sexual orientation and/or gender identity to oneself and/or sharing it with others.

Gay - primarily refers to a homosexual person or the trait of being homosexual. Often used to describe homosexual males but lesbians may also be referred to as gay.

Gender - the range of characteristics pertaining to and differentiating between masculinity and femininity.

Gender binary (binarism) - the classification of sex or gender into two distinct, opposite and disconnected forms of masculine and feminine.

Gender dysphoria - a mismatch between a person's emotional and psychological identity as male or female and their biological sex.

Gender expansive - an umbrella term used for individuals who broaden their own culture's commonly held definitions of gender, including expectations for its expression, identities, roles, and/or other perceived gender norms. Gender expansive individuals include those who identify as transgender, as well as anyone else whose gender in some way is seen to be stretching the surrounding society's notion of gender.

Gender expression - the expression of gender through behaviour, appearance, mannerisms, and other such factors.

Gender fluid - a person whose gender identification and presentation shifts, whether within or outside of societal, gender-based expectations. Being fluid in motion between two or more genders.

Genderfree - not having or attaching relevance to gender.

Gender identity - the personal sense of one's own gender, which can correlate with sex assigned at birth or may differ from it. Gender Identity refers to an individual's internal sense of being male, female, or something else. Since gender identity is internal, one's gender identity is not necessarily visible to others.

Gender (sexual) orientation - a pattern of romantic or sexual attraction to persons of a particular gender. This may be to the opposite gender, the same gender or more than one gender.

Genderqueer - a person whose gender identity and/or gender expression falls outside of the dominant societal norm for their assigned sex, is beyond genders, or is some combination of them.

Gender role conformity - refers to the extent to which an individual's gender expression adheres to the cultural norms prescribed for people of his or her sex.

Heteronormative - leading a lifestyle as if one is heterosexual.

Heterosexual - sexually attracted to people of the opposite sex

Homosexual - sexually attracted to people of one’s own sex, gay is a synonym for homosexual, female homosexuals are often referred to as lesbians.

Intersex - intersex are persons born with genitals, organs, gonads, or chromosomes that are not clearly male or female, or both male and female.

LGBTQ2S+ - an abbreviation for the lesbian, gay, bisexual, transgender, queer, Two-Spirit community, the plus signifying inclusion of other sexual and gender minorities.

Lesbian - a female homosexual, a female who experiences romantic love or sexual attraction to other females.

Non-binary (genderqueer) - gender identities which are not exclusively masculine or feminine, they may express a combination of masculinity and femininity or neither. Individuals may prefer gender neutral pronouns such as they. Non-binary identity may be fixed or fluid.

Pansexual - pansexual people are sexually, affectively and/or emotionally attracted to people irrespective of and with no preference toward a person’s gender or sex, regardless of whether the person identifies as female, male, trans, genderless or other

Queer - an umbrella term to describe people whose sexual orientation, gender identity and/or gender expression are not heterosexual or cisgender and/or do not fit into commonly used labels or categories. It may refer to people whose sexual orientation and/ or gender identity is fluid. Queer was originally used pejoratively against those with same-sex sexual desires but from the 1970s scholars and activists began to reclaim the word.

Questioning - the questioning of one’s gender, sexual identity or orientation, or all three. Used by people who are unsure, still exploring or concerned about applying a social label to themselves.

Sex - based on biological, anatomical, and genetic characteristics and indicators; typically assigned at birth, includes male, female, intersex.

Sexual identity - identification of one’s sexuality.

Sexual orientation - encompasses sexual identity, sexual behaviour, attraction, and/or romantic relationships. For example, a person can identify one’s sexual orientation as lesbian, gay, bisexual, heterosexual/straight, or other, reflecting their romantic or sexual attractions. Someone may be attracted to members of one’s own sex or gender (gay or lesbian), or other sex or gender (heterosexual or straight) or both sexes or genders (bisexual). There may be incongruence between sexual identity, behaviour, attraction, and/or romantic relationships. For example, one may identify as heterosexual but have sex with someone of the same-sex or gender.

Transgender - transgender refers to individuals whose sex at birth is different from their identity as male, female, or elsewhere along the gender spectrum. FtM denotes female-to-male; MtF denotes male-to-female. People who identify as transgender may live their lives as the opposite gender and may seek prescription pharmacologic treatment and/or surgical transformation. Transgender people may identify as heterosexual, lesbian, gay or bisexual, or somewhere else along the spectrum of sexual orientation.

Transition - an individualised process by which transsexual and transgender people “switch” from one gender presentation to another. There are three general aspects to transitioning: social (i.e., name, pronouns, interactions), medical (i.e., hormones, surgery), and legal (i.e., gender marker and name change). A trans individual may transition in any combination, or none, of these aspects.

Two-Spirit - a term used by the Indigenous population of the continent of North America to signify a continuum and fluidity of sexualities and genders. Two-Spirit can be used to refer to LGBTQ members of the Indigenous people of Canada but not all Indigenous people who identify as LGBTQ will identify as Two-Spirit and not all Two-Spirit people identify as LGBTQ.

Appendix 2: Social history of the Canadian 2SLGBTQ+ population

A timeline showing milestones in the development of 2SLGBTQ+ rights in Canada and internationally adapted from the timeline in the document ‘ Social isolation of Seniors – A focus on the LGBTQ Seniors in Canada’ (Employment and Social Development Canada, 2018) and information from Indigenous Services Canada.

As part of Canadian and international social history, 2SLGBTQ+ seniors have experienced a number of decisive events (in the legal, political and medical realms, for example) in the evolution and recognition of rights. Some of these changes have facilitated the gradual social recognition of 2SLGBTQ+ people. This Appendix briefly presents the significant changes.

1960’s: The Royal Canadian Mounted Police developed a list of 9,000 presumed homosexuals, in the National Capital Region alone. The government had a ‘Fruit Machine’ to discover and weed out homosexuals.

1965: George Everett Klippert is sent to prison for having consensual sex with other men.

1969: Homosexual acts carried out in private between consenting adults are decriminalised (Omnibus bill, Canada). Same-sex sexual activities between consenting adults were considered crimes punishable by imprisonment before 1969.

The Stonewall riots took place in the US. Members of the LGBT community demonstrated against the police. This is considered to be the start of the gay liberation movement.

1971: George Everett Klippert is released.

1973: Homosexuality is no longer classified as a mental illness in the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association.

1977: Quebec becomes the first jurisdiction in Canada to amend its provincial Charter of Human Rights to include sexual orientation as a prohibited ground for discrimination.

1978: Homosexual immigrants were not entitled to receive Canadian citizenship until 1978.

1981: Marches take place to protest against raids on bathhouses in Toronto. Now regarded as the Canadian equivalent of the Stonewall riots and the start of Canadian gay liberation.

1992: The World Health Organisation (WHO) removes homosexuality from its list of mental disorders. In Canada homosexuals were actively persecuted by the federal public service up until the 1990’s, and discharged from the armed forces if discovered up until 1992.

1995: Same-sex partners were not allowed to adopt children; Ontario becomes the first province to allow this is in 1995.

1996: Federal organisations are prohibited from discriminating against a person because of sexual orientation. Discrimination or harassment based on sexual orientation is made illegal under the Canadian Human Rights Act.

1998: The right to equality for homosexual people is upheld by the Supreme Court of Canada. Discrimination based on sexual orientation is deemed to violate the Constitution. There was a call for an inquiry into the purge of homosexuals by the use of the ‘Fruit Machine’ from the government.

1999: The Supreme Court of Canada recognises the right of same-sex partners to seek spousal support when their relationships end. This decision pushes the provinces and territories to amend their legislation to recognise the entitlement of same-sex couples to support payments, custody and visitation rights, adoption, employment benefits and more.

2000: Parliament passed Bill C-23 which gives same-sex couples the same social and tax benefits as heterosexuals in common-law relationships.

2005: Canadian legislation on marriage is enacted to include same-sex adults (legalisation of homosexual marriage), the Civil Marriage Act.

2017: Bill C-16 is enacted at the federal level to prohibit discrimination based on gender identity and expression. Before that, several provinces amended their human rights legislation to include gender identity and/or expression. Bill C-16 protects transgender people against hate propaganda by adding gender identity and expression as a prohibited ground of discrimination under the Canadian Human Rights Act. It also introduces an amendment to the Criminal Code to clarify that judges are to consider discrimination against a person on the basis of gender identity or expression as an aggravating factor at the time of sentencing.

November 28 2017: Prime Minister Justin Trudeau offers an apology to the LGBTQ2 community in the House of Commons saying sorry for decades of “state-sponsored, systematic oppression and rejection”.