

Centering sexual and gender diversity within Compassionate Communities: insights from a community network of LGBTQ2S+ older adults

Pamela Grassau , Arne Stinchcombe , Roanne Thomas and David Kenneth Wright

Palliative Care & Social Practice

2021, Vol. 15: 1–15

DOI: 10.1177/
26323524211042630

© The Author(s), 2021.
Article reuse guidelines:
sagepub.com/journals-
permissions

Abstract

Background and Rationale: The Compassionate Communities movement emphasizes the importance of illness, disability, dying, caregiving, and grief across the lifespan and highlights the communal responsibility of caring for one another. There is a need to recognize and incorporate the needs of diverse communities within this movement and research on dying, caregiving and grief. An important axis of this diversity is related to individuals' sexual orientation and gender identity.

Methods: As part of the early phases of Healthy End of Life Project Ottawa, a Compassionate Communities, community-based, participatory action research project, we held focus groups with older members of lesbian, gay, bisexual, transgender, queer, and two-spirit communities. Nine older lesbian, gay, bisexual, transgender, queer, and two-spirit people participated in the focus groups (mean age = 72 years). Data were analysed using an inductive, reflexive thematic approach.

Results: Through an iterative analysis process, we identified themes related to lifecourse experiences of trauma, the need for safety within care contexts, the importance of relationships and connection, as well as participants' ability to ask for and receive help. A core tenet of Compassionate Communities involves responding to the needs of diverse communities with respect to aging, end-of-life, and grief. Our findings emphasize the importance of incorporating the voices of diverse sexual and gender identities and promoting health equity within Compassionate Community initiatives.

Keywords: aging, community-based participatory research, Compassionate Communities, end of life, grief and loss, LGBTQ2S+ populations

Received: 22 February 2021; revised manuscript accepted: 11 August 2021.

The Compassionate Community movement is gaining momentum in Canada and around the globe and is grounded in the World Health Organization's *Ottawa Charter for Health Promotion*¹ and *The Compassionate City: A Charter of Actions*.² Compassionate Communities are 'communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities' (p. 80).² They recognize the importance of illness, disability,

dying, caregiving and grief across the lifespan and emphasize the communal responsibility of caring for one another.²⁻⁴ Integral to the Compassionate Community approach is the notion that end-of-life care is everyone's responsibility and requires strong collaboration, communication and a shared vision among: policy makers, municipal leaders, formalized care providers, local organizations, and informal care networks. Compassionate Communities recognize schools, workplaces, spiritual and faith sites, libraries, art galleries and

Correspondence to:

Pamela Grassau
School of Social Work,
Carleton University,
Ottawa, ON K1S 5B6,
Canada

pamela.grassau@carleton.ca

Arne Stinchcombe
School of Psychology,
University of Ottawa,
Ottawa, ON, Canada

Roanne Thomas
Faculty of Health Sciences,
University of Ottawa,
Ottawa, ON, Canada

David Kenneth Wright
School of Nursing,
University of Ottawa,
Ottawa, ON, Canada

local streets and neighbourhoods as critical sites to build and promote compassion, care and connection for all, with a specific focus on people who are living with frailty, chronic and advanced illness, at the end-of-life, and those who are caregiving and/or grieving.

Compassionate Communities around the world share central tenets in working to address social change across core institutions and activities. How each community comes together, the community partners and organizations involved, and the ways in which each community develops, implements and evaluates their initiatives and approaches vary considerably.^{2,5-8} One initiative that is gaining international attention is the Healthy End of Life Project (HELP).^{6,9,10} Developed in Australia, HELP 'provides a comprehensive guide for building the community capacities and capabilities needed to form, maintain and sustain Compassionate Communities' (p. S75).^{9,11} HELP was initiated in a community located in the Dandenong Ranges of Victoria, Australia, and was centrally guided by community development principles, practices and action areas.⁹ Strongly reflected in the early phases of data collection in the HELP project

was the reluctance of carers to accept help when it was offered by family, friends and neighbors. This was the case almost without exception, even when the carer had regular access to family members and had a healthy network of friends. Declining offers of support was an instinctive response, made without considering the merit or value of the proposed offer of assistance, and irrespective of whether support was needed ..., equally problematic was that asking for help was not seen as an option. (pp. S75-S76)⁹

Emphasizing social norms around accepting help, the outcome of the HELP project was a 'health promotion and community development framework to guide community driven initiatives' (p. 95).⁶ HELP Ottawa, launched in 2019 with support from community and academic partners, is a community-based participatory action research project designed to develop a Canadian-focused HELP framework. Working with four community sites in Ottawa (Ontario, Canada), two community health centres and two faith communities, HELP Ottawa is determining what capacity building strategies work effectively for within each community site, and under what circumstances and contexts. Critically, we are examining the

effectiveness, sustainability and the collective impact(s) that unfold when community health centres and faith communities, draw on public health palliative care approaches as they build their own Compassionate Communities.

Like many countries, Canada is experiencing population aging.¹² At the same time that Canada's population is aging, the need to recognize diversity within this aging population is connected to the impetus of Compassionate Communities and research addressing dying, caregiving and grief.¹³⁻¹⁵ An important axis of this diversity is related to individuals' sexual orientation and gender identity. Members of lesbian, gay, bisexual, transgender, queer, and two-spirit (LGBTQ2S+) communities have unique life-course experiences relative to their majority peers, often involving minority stress experiences which impact health and health help seeking behaviour. In Canada, the aging experiences of older LGBTQ2S+ people have been impacted by distinct histories and contexts. Specifically, prior to 1969, homosexual acts were against the law, the *gay purge* systematically targeted members of LGBTQ2S+ communities in the federal public service, and the AIDS epidemic brought about loss, fear and increased stigma for members of these communities.¹³ These lifecourse experiences are critical to understanding the health and end-of-life needs of LGBTQ2S+ older Canadians and implementing Compassionate Community initiatives that are inclusive, meeting the needs of diverse populations.

Existing evidence shows that LGBTQ2S+ older adults have lower household incomes, are more likely to be single, and are more likely to rely on rich social networks, often recognized as 'families of choice', for support and care needs.¹⁶⁻¹⁸ In addition, LGBTQ2S+ older adults are more likely to experience minority stressors, such as stigma and discrimination, within and outside of healthcare settings, reducing their participation in society and compromising well-being.¹⁹ Concurrently, evidence also points to the availability of resources among LGBTQ2S+ people through social supports, connection to community, self-acceptance, crisis-competence, and resilience.^{20,21}

There is a small body of literature examining end-of-life concerns among older LGBTQ2S+ people in Canada. For example, de Vries and colleagues²² held focus groups with LGBTQ2S+ people 55-89 years old in Vancouver, Edmonton, Toronto,

Montreal, and Halifax; focus group questions were centred around care plans for later life and the role of community in supporting end-of-life care. Their findings highlighted that end-of-life preparations are informed by social isolation and relationships with friends and chosen family as well as ambivalent relationships with families of origin. Future directions emphasized the importance of developing and highlighting novel approaches which actively address LGBTQ2S+ individuals' fears, and experiences of stigma and discrimination that arise in end-of-life care discussions. In a subsequent study examining the completion of advance care plans (ACPs) among LGBTQ2S+ older Canadians, researchers found that individuals who were single and living alone (the majority of the sample) were less likely than those in a relationship to have completed ACP documents.²³ These findings highlight gaps for LGBTQ2S+ people in end-of-life planning. Other research has emphasized the unique fear related to staying out of the closet and maintaining identity throughout aging and end-of-life.²⁴ While these research projects direct attention to key issues that LGBTQ2S+ older adults have with respect to end-of-life care, related to their minority sexual and/or gender identities, gaps remain in understanding how Compassionate Communities can meet the needs of diverse communities and ensure equitable end-of-life care.

Compassionate Community initiatives must consider and meet the diverse needs of LGBTQ2S+ people. The purpose of this article is to explore what a group of older LGBTQ2S+ persons, nestled in an LGBTQ2S+ community-based network, believe others need to know about their lives and experiences. We focused on central questions for Compassionate Community initiatives that would help address the needs of LGBTQ2S+ older adults.

Method

HELP Ottawa

The first phase of the HELP Ottawa project involved conducting interviews and focus groups with carers (formal care providers, and family, friends) and learning about individual and community networks that supported end-of-life care. As part of an initial community consultation, and in an effort to centre the voices of LGBTQ2S+ people from the outset of this larger project, our team held two focus groups with nine members of an

Ottawa-based community group of LGBTQ2S+ older adults.

Sample

Ottawa Senior Pride Network (OSPN), is a volunteer community-based network of LGBTQ2S+ and allied older adults in Ottawa (Ontario, Canada). OSPN's mandate is to increase opportunities for LGBTQ2S+ senior engagement and connection, while promoting LGBTQ2S+ affirming and safe health care and social services. OSPN has over 800 members and engages on a number of issues through volunteer-led subcommittees. OSPN volunteers have delivered over 70 training sessions to a broad range of long-term care (LTC), home care, community support services and seniors centres. OSPN's End-of-Life Care Committee has, since 2010, organized workshops, film nights and panel discussions which have focused on advocacy and education around important issues in end-of-life care: palliative care, assisted death (legalized as 'Medical Assistance in Dying' in Canada in 2016), and the legal, ethical, financial and practical issues in protecting LGBTQ2S+ older adults and their families of choice. Building on a previously existing collaboration between OSPN and one of our HELP Ottawa sites, in addition to past connections between the research team and OSPN, the principal investigator approached OSPN. Within subsequent discussions, OSPN shared information about the scope and breadth of their work, and conversations unfolded about how needs related to frailty, chronic and advanced illness, and end of life were being addressed within their programming. Seeing shared interests and concerns, HELP Ottawa objectives and project details were discussed. OSPN's Coordinating Committee reviewed all of the research materials (consent forms, demographics and focus group interview guides), and OSPN was asked how recruitment could unfold. OSPN agreed to distribute a recruitment flyer over email to members of OSPN's Coordinating Committee ($n = 6$) and End-of-Life Committee ($n = 6$).

In order to accommodate varying schedules, two focus groups were organized, and participants self-selected which focus group they attended. One focus group had seven participants, and the second focus group had two participants. Eight out of the nine participants completed a brief demographic questionnaire. Among participants who completed the questionnaire, ages ranged

from 67 to 78 (mean age = 72) years. All participants had attended university and half of participants had a graduate degree (e.g. Master's or PhD). One participant reported their race as black while the other participants were white. Five participants reported their gender as women and their sexual orientation as lesbian; three participants reported their gender as men and their sexual orientation as gay. Four participants noted that they lived with a partner, while three participants lived alone, and one participant lived with others. Because one participant did not return a demographic form, we do not know how they identify their sexual orientation.

Data collection

Each of the semistructured focus groups lasted approximately 1.5 h. The study took place during the COVID-19 pandemic, precluding in-person contact; thus, the focus groups took place using a video-conferencing platform (i.e. Zoom). Prior to the focus group, participants completed an informed consent document and a brief demographic questionnaire. Research ethics boards (REB) at Carleton University (#110268) and University of Ottawa (#H-02-19-3437) approved this study. Focus groups were facilitated by the principal investigator, a white, cis-gender, queer woman, who has extensive experience in qualitative research. At the beginning of each focus group, participants shared their varying connections with OSPN and our HELP Ottawa site. These introductions were important as they offered each participant an opportunity to position themselves across a number of different social locations. Participants were invited to share their perspectives, needs and experiences in supporting older LGBTQ2S+ people, who are facing frailty, chronic or advanced illness, end-of-life, caregiving, or grief and loss. We asked them: 'What kinds of things are important for someone from the outside to know?' Field notes were taken by a HELP Ottawa Community Site Facilitator. The focus groups were digitally recorded, later transcribed, and manually reviewed for accuracy.

Data analysis

Data were analysed using an inductive thematic approach involving in-depth engagement with the data.^{25,26} While thematic approaches and analysis are utilized in many different ways, our reflexive thematic analysis^{25,26} focused on the meaning that our participants ascribed to their experiences,

how these meanings and understandings were situated within and across varying contexts, and our own subjectivity as researchers involved in this project. In team meetings, we openly discussed how our own identities were informing our reading of the data and our impressions of its significance. Drawing on a modified three-phase reflexive thematic analysis approach, the first phase of analysis focused on familiarization with the data and generating and crafting codes, as the transcripts were independently reviewed by different members of the team. In further constructing the codes, and in revising and defining the codes, the entire research team met to discuss similarities in their analysis and to decide on codes for further analysis. Unlike other forms of thematic analysis that draw on codebooks and interrater reliability, reflexive thematic analysis emphasizes deep engagement, reflexivity and close attention on how researchers code and engage with raw data.^{27,28} Drawing on codes as 'the building blocks for themes (larger) patterns of meaning' (p. 298)²⁹ themes were developed which reflected central and core elements unfolding across the data. In reflexive thematic analysis, 'themes are conceptualized as meaning-based patterns, evidence in explicit (semantic) or conceptual (latent) ways' (p. 848),²⁵ encouraging the researchers to actively engage with the multiple meanings and contexts arising in the data. In reviewing, developing and refining our themes, reflexive themes were identified that offered a nuanced understanding of participants' reflections on the needs and experiences of older LGBTQ2S+ peoples in relation to frailty, chronic and advanced illness, end of life, caregiving and grief and loss. Finally, we provided, 'a coherent and compelling interpretation of the data, grounded in the data' (p. 848).²⁵ To promote trustworthiness, all members of the research team reviewed the coding and the themes; discrepancies were resolved through a process of consensus. Furthermore, the consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist for interviews and focus groups, was used to guide the study (See Supplemental Appendix A). Through this process, the themes outlined below were identified.

Findings

As individuals and also as members of a shared culture, LGBTQ2S+ people's lives are shaped in important ways by historical events, which in turn shape both individual and community responses

to aging, death and grief. The group articulated links that need to be understood between the past and the present. In the following sections, we explore specific themes of past–present interaction, which emerged from these discussions.

Many of us are survivors of trauma

For LGBTQ2S+ people, discrimination and oppression are not limited to a series of isolated moments. Rather, there is a constancy to these experiences, often beginning in childhood and then continuing through later life. As one participant explained:

Many of us are survivors of trauma. And I would say that life as a teenager, a queer teenager, is often an ongoing trauma. (Gay man)

Elaborating on this idea, another participant explained the implications of such ongoing trauma for when queer people face (physical) health challenges. For this participant, the intersection between past trauma and present illness has a *double impact* on well-being.

When we start talking about the physical illnesses that can affect our community ... It is the double impact of our past history. And because of the past psychological traumas that so many of us in our generation have ... that will always be there ... It's been there for years. And unless that is really looked at and identified, that can have a tremendous impact on your overall being, and on your physical being. (Gay man)

Participants spoke about various sources of trauma that have long-term effects on health. Some of this trauma, such as having lived through all phases of the HIV pandemic, religious oppression, as well as disconnection or rejection from families of origin, is broadly relevant to LGBTQ2S+ people everywhere as expressed by the following two passages:

I do know the impact of things that happen earlier in your life ... that trajectory affects you your whole life. And I think the HIV AIDS crisis is one thing. I think religion is another, you know, recovering from being Catholic. (Lesbian woman)

Last year, [two] members of our community died. Neither of them had family of origin involved in their care. And we know that a large percentage of our community are single, often living alone. And so

I think there are real strong implications as a result of that for care. As we're aging. (Lesbian woman)

Other sources of trauma, however, were more specific to participants' geopolitical context. As the national capital of Canada, Ottawa acts as the focal point for government activities, with a full 20% of the region's labour force employed by the federal government. From the 1950s until the early 1990s, the Royal Canadian Mounted Police had a special unit devoted to removing members of LGBTQ2S+ communities from their employment with the Canadian government. This removal was organized in response to a purported threat that sexual minorities could be blackmailed by the Soviet Union and coerced into divulging government secrets. Police used surveillance, threats, and intimidation to obtain the names of sexual minority people in government.^{30,31} The participants described the long-lasting impact that such systemic homophobia, known as 'the purge', continues to have on Ottawa's LGBTQ2S+ community. The impact is exemplified in the following two passages:

I also think that the purge and impact of the fear and shame and grief that people lived with for such a long time in Ottawa, has an impact on everybody now. Even though we may not have been directly affected, we know people that were. Or we worked with people that were too afraid to, for example, get same sex benefits even when it was offered [years later] in the federal government ... So I think that's another layer of what everybody's living with in this community. (Lesbian woman)

One of the very, very unique things about Ottawa is the purge. Thousands of people were affected by it. That informs how we think today, and how we feel and how we approach a number of things. Including death and dying and interaction with others. Even though things have changed dramatically from those times, if you were in that environment where you felt you couldn't trust the guy who worked next to you because he might turn you in and you would lose your job. You don't get over that. That stays with you. (Gay man)

An additional source of trauma, described as occurring in the past and having an impact on end-of-life issues in the present, was abuse. It was noteworthy to us that abuse was only mentioned in our second focus group, which was a much

smaller gathering that was attended only by women. The following two passages show a conversation between two participants on this topic.

I would say I have a number of close friends who have fairly long-term issues ... [stemming from] a background of sexual abuse from childhood. (Lesbian woman)

I think that it's a really important point, because in general they, well men are abused as well, [but] the abuse experience is often very different ... So the lasting legacy can be profoundly different ... women in general, when they have a history of sexual abuse, I think all of us when we come to the end of our lives, start looking back over our lives and reflecting. And that's often going to bring trauma back even if the woman has done a lot of work on her abuse issues. But I think that as we come to the end of our life, we try to make meaning of what our life has been like and that can raise different questions about your abuse experience in your past growing up. (Woman, sexual orientation not specified)

'Where can I go that is safe?': creating our own safety

LGBTQ2S+ people are often othered through a dominant narrative that normalizes heterosexual and cis-gender identities.³² When health challenges occur, they confront a healthcare system that was not designed for them, and consequently is often unable to meet their needs. The participants explained how this othering results in community-oriented approaches of support – out of sheer necessity. In other words, LGBTQ2S+ people look to one another to create safe spaces within illness, because everyone else looks away.

Because of past history within our community, people of our age who might become ill ... I think the first thing that goes through our mind is the community itself. Because it's always been the community who rallied. Especially during HIV/AIDS, and especially with men, it was very often and probably the majority of times that their LGBTQ family was the ones they looked to, received all the support, resources, etcetera. So even now if you have, say, another pandemic that strikes, the first thing I think that most people would think of is you know ... where do I go? Where can I go that is safe? What organizations are there? What is out there? So that is part of the history of looking towards our own community just out of necessity.

And that's still ingrained in a lot of people's minds. (Gay man)

Another participant echoed this sentiment, recalling the early years of the HIV pandemic and drawing links to the present day, in light of COVID-19.

We developed a training program based on palliative care models ... in those first horrible years, say the first five years, literally we were doing frontline primary care [another participant nods]. I can remember hauling people off bedpans because they were left there by the nurses who would not enter the door ... This pandemic currently [COVID-19] is bringing back a lot of really tough memories [voice cracks with emotion, participants nod].

And I can remember picking up a guy's lunch from outside the room because people wouldn't take – open the door and take it to him ... we had to also take on the medical community and teach them ... about gays, about gay families ... I think I was probably involved in 60 to 100 deaths. (Gay man)

These quotes illustrate how LGBTQ2S+ communities, both past and present, have taken on the work of providing care to fill gaps in health care systems and have built community-based organizations to provide complementary services. By doing so, they have created practices and systems of mutual care and support that provide safe(r) spaces to address LGBTQ2S+ community needs.

'Connection is very important': disrupting ageism and stigma. As members of a community network that promotes the well-being of LGBTQ2S+ older adults, much of the participants' reflections focused on the importance of connection.

A lot of our emphasis has been on social connection and creating community, like building community where people can feel safe as out LGBTQ+ seniors. (Lesbian woman)

Connection was described as important in providing a safe space to work through past trauma. For example, in speaking about a discussion group for women seniors, one participant highlighted the value of such spaces existing over time, giving people an opportunity to become comfortable and trusting of each other, to share their life

experiences and the implications that these have on their health.

Most of us are in our late 60s, 70s, and 80s. And as we have been meeting for a number of years ... you know, there's a comfort level that has arisen because it's been a constant, persistent available resource. And discussing all kinds of different topics. But what I really noted is at a point in time women become comfortable enough to talk about when they were isolated, and marched out of their office and you know, questioned about being lesbian and stuff like that. So the stories ... they only start coming out after a period of time, of comfort, of people having been together and trusting each other [another participant nods] ... so that people can get to a level where they feel like they can share some of that stuff. Because it is an internal kind of burden that they carry. And they're just amazing stories ... [To] have a space for people to talk about things, I think, [is] very, very helpful. Connection is very important, I think. And there are too many women that are isolated. And everybody that we know, knows many people that are isolated. So, it's a matter of getting to those folks. (Lesbian woman)

In the passage above, reference is made to the social isolation that many LGBTQ2S+ older adults experience. Isolation was seen as resulting, in part, from the fact that for some LGBTQ2S+ people, aging is something that is ignored. People therefore fail to establish connections that would otherwise better support health and well-being as they age.

Older gay men ... they will not admit that they are getting old. If you don't first of all admit that you're getting older, then you don't admit that you're slowing down [that] your health is deteriorating. And they ignore those signs of ill health advancing on them to the point where they get so incapacitated almost, that you know, then what do they do? And they often have not formed those connections, really good friendship type connections where those friends would come in and help them, just the simplest of things like mowing their lawn or whatever. But they get to the point where they've neglected their health and wellbeing. (Gay man)

Thus, while past trauma was largely described as being caused by forces outside (and inflicted upon) LGBTQ2S+ people, ageism was explained

as a force that operates *within* queer culture. Participants spoke about a 'fear of aging' that is endemic among gay men, and the impact this fear has on well-being. In the passage below, a participant suggests that self-loathing related to sexuality *combines* with internalized ageism, contributing to isolation and undermining opportunities to experience connection.

Something very important [about] safety within the community. Safety within the community, because of ageism in our community, is a big factor. Older people not feeling safe, to talk about the issues associated with age because our community is so – especially the men – is so age oriented. And there's a lot of ageism within our – the gay men's community. So that is a tremendous factor. I can remember when [our network] started, a lot of gay men who were certainly of age, and past age to join, simply did not join because of the word senior in the organization [participants nodding]. It scared them. I mean they would joke about it, but when they were joking about it, you knew they were frightened to use the word senior. And some of them would come right out and say, well why do you have to call it senior pride? So you saw right away that self-loathing of their age within them, which was associated with what they had been brought up, or self-loathing of their sexuality. It was all combined. It was like a snowball. (Gay man)

Participants considered whether having spaces to share and process each other's stories, such as the one described above for women, would be equally beneficial for men. Some participants suggested that men are less likely to engage with each other in such ways; that they internalize their angst, are uncomfortable with such explicit sharing of emotion, opting instead for connections that are more social in nature. One participant, however, disagreed with this assessment.

I don't know if I agree. I think there's a yearning for this ... to honour our – to talk about and honour our life journeys because this is seldom – this is – there's no place where this is done. You know, when you're straight you have your grandchildren, you have your great grandchildren, at my age. You have a list of accomplishments that are ... in many ways unavailable to gay men. And unless we affirm each other, we're not going to get a lot of affirmation. (Lesbian woman)

Part of the work of fostering connection, then, in response to internalized ageism and also the need for affirmation, is contributing to a

counter-narrative within LGBTQ2S+ cultures. This counter-narrative recognizes the unique life histories of LGBTQ2S+ older people and validates aging as healthy and cause for celebration:

[The] history of our age group is so much different from the younger queer folks coming up. (Woman, sexual orientation not specified)

[There is a] tremendous fear of aging in the younger gay community ... gay men in their 30s don't think they'll ever grow old. And I think it's important that there be visibility of people who are growing old. And fight that ageism. (Gay man)

Being visible seniors ... it's demonstrated at Pride tremendously when we're in that parade ... we're visible, we're there, we're queer, we're old, we're fantastic. I think the visibility part is ... very important. (Lesbian woman)

The participants also reflected on the impact the current COVID-19 pandemic is having on such efforts to promote the visibility of LGBTQ2S+ seniors, further undermining opportunities for connection and aggravating isolation. As one participant suggested, using the metaphor of the closet, the isolation that a queer person experiences under pandemic quarantine has implications for broader experiences of isolation that result from being a sexual minority in a heteronormative world.

I wouldn't be surprised to see within our community that people have started isolating again, almost subconsciously using the pandemic as an excuse, subconsciously, to isolate again ... we've worked so hard with getting people out. We've all encountered people ... coming out to a dance for the first time in 30 years. Or coming out to Pride [for the first time] and they're 80-some years old. I can see this [COVID lockdown] just having such a negative impact on people, and then just like [sending them] right back into that closet, even subconsciously. (Gay man)

Asking for – and receiving – help. The previous three themes, around trauma, safety and connection, illuminate some of the ways that life history and social positioning can be expected to influence queer experiences of aging, end of life and grief. In this section, we explore some of these experiences by focusing on stories participants told to us about asking for, and receiving, help. Wanting to acknowledge how each of these stories

were shared within specific contexts and relationships and recognizing that asking for and receiving help is a relational activity that unfolds between people, we utilize a narrative approach^{33,34} in presenting these findings.

One of the participants, Doris* (* all names are pseudonyms), spoke of participating in a small circle of care for an older lesbian woman with metastatic cancer at the end of her life. This was a woman who was determined to have control over the end of her life and her care, and who was thus very specific about what would, and what would not, occur. What Doris took away from this experience was an appreciation for this woman's self-determination and assertion of agency, something Doris herself would not have seen herself capable of doing before this experience.

And what I took from that is everybody has a right to do that. And before that, before I was part of that team, I didn't know that. I didn't think I was worthy of saying to somebody, no, actually I don't want you to be in my room as I'm sick and throwing up. I want this person. But she was able to do that very, very clearly. And I learned really a lot from that whole session. (Lesbian woman)

Noteworthy in the above passage are Doris's reflections around self-worth, particularly in light of the broader group discussion around feelings of self-loathing and isolation that appear to characterize some queer peoples' experiences of health and illness.

Another participant, Sheila, told us a story about how showing up for a fellow community member in grief, without being asked to do so, can have a meaningful impact. Sheila told us about a woman and her partner who had been attending the same discussion group for older women seniors mentioned earlier. Although they attended, they did not participate much, and so the connections with other group members did not appear particularly strong. When this woman's partner died however, a handful of group members attended the funeral. Sheila describes learning of the impact that this action had, when this woman later returned to the discussion group.

She came back to the group. And she just talked and cried and said, 'I looked out and I was so surprised to see you there ... I can't tell you how much that meant to me. (Lesbian woman)

A third participant, Ruth told a story about caring for her partner with amyotrophic lateral sclerosis (ALS). Her partner was a very private person, not wanting anyone else involved in her care except for Ruth. Ruth was the sole caregiver for her partner for almost 3 years without any outside assistance, until eventually she and her partner allowed a very small group of close (mostly straight) friends to provide some help. Throughout this time, what stands out for Ruth was how disconnected she became from her queer community.

I lost that community. The sicker she got. For me it was you know, a handful of close (mostly straight) friends who were not afraid to say we'll do whatever. And then in the last six months of her life she did allow a few people, literally three, to come into the apartment ... And so I felt like I lost my queer community. And that was a huge – a huge piece for me. (Lesbian woman)

A fourth participant, Grace, told us about several different experiences in which she and several other people formed a 'circle of support' around someone needing help. She characterized these experiences as 'extraordinary and powerful'. Belonging to such networks were incredibly meaningful, because of the 'bonding' that occurs among those within the circle, but also incredibly draining. The sheer exhaustion that results from caregiving, for Grace, necessitates the involvement of professional support. In her words, a layer of professional support would, 'back up and to really hold that circle, so that it can be protected'. In further explaining one of these caregiving circles that Grace had participated in, she told a story of negotiating a balance with her friend – the care recipient – between intimacy and respite. As Grace described,

I'm just thinking of my other friend that I was living with her. We weren't partners, but we were friends and yeah. We had a group of us around her too. And one thing I remember that she said, she had a great palliative care doctor who came to see her and she said, I remember the doctor was talking about well bringing other people in and she said oh no. She said I have this great group friends and I said well actually I think you want to save your friends, I think you also need a lot of help. (Lesbian woman)

Each of these stories reveals something different about asking for and receiving help in situations of vulnerability. Doris's story raises questions

around the intersections of queer identity and self-determination in terminal illness; while Sheila's and Ruth's stories both suggest – in very different ways – the impact that gaining or losing support from other LGBTQ2S+ people can have for peoples' experiences of end-of-life care and grief. Grace's story, meanwhile, reminds us that while informal caregiving within the LGBTQ2S+ community is 'extraordinary and powerful', it does not obviate the need for professional support. As these stories were raised by two lesbian women in each focus group, there are important questions to consider about how asking for and receiving care may be gendered.

In describing the ways that the LGBTQ2S+ community has and continues to support itself in relation to trauma, safety, and connection, our participants highlight its strength and resilience, and also its vulnerability. In other words, while stories of queer people being available and willing to support one another around health and well-being are rightfully inspiring, our participants were careful to point out what such stories also reveal about the lack of adequate support available to queer people within the mainstream healthcare system. For example, in reflecting about the ways that queer people helped one another at the heights of the AIDS crisis:

Back then you didn't have the time to stop and think ... if you were going to offer help, or ... ask for help ... It was hitting the ground running. [For the] gay men's community, our biggest allies were our lesbian sisters. They were the ones who came on board. We didn't trust nor did we have any reason to trust the medical system, the political system, the social support system, the religious system or our families. So people just dove in ... when they saw somebody who was ill or somebody's partner who was ill, it just happened ... Anybody who came through those early years, you literally did it without even thinking. It was like going through a war. (Gay man)

Although the participants described changes that have occurred in the intervening years, with respect to sensitivity of the healthcare system and to the dynamics of asking for and providing help among LGBTQ2S+ people themselves, this critical reflection on the ethics of expecting LGBTQ2S+ people to look after one another remains relevant today. As one of our participants plainly and poignantly stated:

We have a right to health and to care and appropriate care. We [shouldn't] have to continually make volunteer organizations as the stopgap. And I think we have to start demanding – demanding treatment for people who are suffering mental health issues because of whatever their situation is, but linked to being queer. (Gay man)

Discussion

In the World Health Organization's Ottawa Charter for Health Promotion, 'fundamental conditions and resources are outlined as prerequisite for health: peace, shelter, education, food, income, a stable eco-system, sustainable resources, *social justice and equity*' (p. 1)¹ (emphasis added). Further articulated in *The Compassionate City: A Charter of Actions* is a specific reference to *diversity* as a core area to be advanced and strengthened:

All our compassionate policies and services, and the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered and sexual identity through the social experiences of poverty, inequality, and disenfranchisement. (p. 81)²

Strongly positioned within the statements above are central social justice and equity principles, urging an understanding of *how* diversity shapes end-of-life experiences through our social locations, identities and positionality, and importantly, *how* these elements are interwoven with social experiences of marginalization, structural vulnerabilities, inequity, and oppression. Further emphasized is the explicit focus on actively acknowledging, respecting and doing something about these inequities. This explicit focus on social justice and equity emphasizes the critical importance of Compassionate Communities actively engaging with social justice and equity within their initiatives.

Compassionate Community initiatives are often physically situated in the community, drawing on principles and approaches of community development that emphasize local knowledge and experience. Strong examples exist of initiatives which are designed *with* and *for* community members, which can begin to alter how and in what way ageing, illness, dying and grieving are (re) connected within our social contexts. As these

initiatives continue, critical learning, approaches and outcomes will further inform the breadth of this work in ensuring our communities

publicly encourage, facilitate, support and celebrate care for another during life's most testing moments and experiences especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trails and burdens of long term care. (p. 80)²

As Compassionate Communities move forward, we are also beholden to think critically about how each initiative centrally addresses diversity and social justice. This requires an explicit recognition of the many communities who have been and continue to be marginalized and oppressed across multiple individual, relational, social and health care contexts. There is mounting evidence emphasizing how minority stress (i.e. homophobia, transphobia, discrimination and marginalization) is linked to health outcomes across the lifecourse,^{35,36} including greater mental health needs,^{37,38} substance use,^{39,40} intimate partner violence^{41,42} and loss and bereavement.^{43,44} In addition, there are greater risks of life-limiting and life-threatening illness among members of older LGBTQ2S+ communities.^{45,46}

The OSPN participants that shared their experiences offered critical insights about how experiences of trauma are woven into their historical, present and future contexts and understandings of frailty, ageing, chronic and advanced illness, end of life, caregiving and grief and loss. There is growing evidence in the hospice palliative care literature about the specific concerns that can arise for members of LGBTQ2S+ communities in relation to aging, living with HIV/AIDS, end-of-life, and bereavement.⁴⁴ Compassionate Communities are asked to think critically about how experiences of trauma from past, present and future contexts are considered and supported within conversations about death and dying, advanced care planning, goals, wishes and belief activities and experiences of grief and loss.^{47,48}

Explicit attention to how intersections between the past and the present might influence the health experiences of LGBTQ2S+ people is helpful in informing trauma-informed approaches to LGBTQ2S+ palliative care.^{49,50} Such approaches account for the ways that trauma has affected peoples' lives and take deliberate care to

avoid re-traumatization. Rather than seeing trauma-informed practices as uniquely relevant for LGBTQ2S+ communities however, we encourage hospice and palliative care providers and services to embrace anti-oppressive, equity-based, and trauma-informed practices and policies as critically important for all patients, families, and community networks.^{49,51,52} Furthermore, we believe that these practices and policies are also critical for the wellness, safety and resilience of health care providers, allied health providers, administrators, volunteers and students who work within hospice, palliative care.^{53,54}

Consideration of how the past relates to the present is also valuable for considering the implications for LGBTQ2S+ health experience of societal changes that occur with time. In analysing narratives of HIV caregiving among gay men, Kia⁵⁵ theorizes that as HIV was transformed from a condition requiring short-term end-of-life care to longer-term support, experiences of marginalization in relation to systemic homophobia and HIV stigma transformed as well. Specifically, these now may ‘occur routinely and diffusely across formal systems of care involved indefinitely in the provision of chronic care’ (p. 497).⁵⁵ Thus, while expressions of homophobia and stigma may change with time, their existence as a force that affects LGBTQ2S+ health experience continues into the present. For example, in their interviews with an older lesbian woman (Esther) after the death of her wife (Cathy), Candrian and Cloyes⁵⁶ describe the insidious ways that LGBTQ2S+ people are harmed when seeking health-related help:

Cathy and Esther started noticing subtle changes with the way the nurse was interacting with them. The nurse came less frequently to their room and when he did, he spent noticeably less time in the room. The couple noticed that the nurse asked fewer questions than before, and the questions focused on medical needs rather than emotional ones. When the nurse did ask a question, very little eye contact was made with Esther and Cathy. As Cathy got sicker, she noticed the nurse’s demeanor becoming more overt and negative when Esther disclosed their relationship status, and therefore their sexual orientation. Cathy got anxious about how far this behavior would go and how it might influence the treatment and care she and Esther would receive. At the next appointment, Cathy told Esther, ‘Don’t say anything about being married anymore’. (p. 2)⁵⁶

In this case, the couple decided to stop referring to themselves as married in all of their interactions with the healthcare system, which had important consequences. For example, after Cathy died, Esther was seen as a friend, not a wife of 33 years, contributing to disenfranchised grief. This example helps to underscore the contemporary relevance of a question that participants in our focus groups asked themselves in relation to seeking care – *where can I go that is safe?* It also highlights the importance, as discussed in our findings, of connection in supporting experiences of grief and loss among LGBTQ2S+ people.

As the Compassionate Communities movement gains momentum, it shifts attention from formal systems of care onto more informal community networks. Although this shift is important and helpful in many ways, we cannot allow it to pull focus from the radical transformations that are needed within formal care systems, to make them safe for LGBTQ2S+ people. Furthermore, attention to informal systems of support begs the question about whether LGBTQ2S+ people are themselves safe within their own geographic communities. The Compassionate Communities approach, for example, is premised on the somewhat optimistic view that ordinary citizens can be trusted to look out for their neighbours.⁴ The ethics of this model, in relation to principles of equity and inclusivity, are viable only to the extent that these ordinary citizens can transcend hetero- and cis-normativity, and develop knowledge and understanding about how LGBTQ2S+ realities operate as important social determinants of health. As Candrian and Cloyes have recently observed, ‘If a person’s center – who they truly are, who they truly love – is rendered invisible, ignored, devalued, or otherwise negated, equitable end-of-life care is compromised’ (p. 4).⁵⁶ Ordinary citizens have both an individual and communal responsibility in ensuring this does not happen.

Limitations

This study adds to the growing body of evidence supporting the Compassionate Communities movement and, more specifically, the HELP approach. In addition, it highlights the importance of considering the end-of-life needs of diverse communities. However, this study is not without its limitations, the first of which relates to gender, race, and socioeconomic status. Gott and colleagues⁵⁷ provide a comprehensive review

of the ways in which gender is systemically ignored within palliative care research, including within emerging literature on Compassionate Communities. They call for increased interrogation by palliative care scholars of the gendered dimensions of caregiving, of symptom experience and treatment, and of providing and receiving palliative care support, while also accounting for how gender intersects with other axes of oppression and privilege. In our focus groups, participants did challenge each other on their own interpretations regarding gender differences in help seeking behaviours by, for example, disagreeing with one another around the discourse that men engage less than women in emotion-focused support. We also noticed that in holding one focus group that was attended only by women, different topics were raised (e.g. abuse). Importantly however, while OSPN represents a large group of older LGBTQ2S+ people with diverse identities, participants in our focus groups were gay men and lesbian women. Existing evidence highlights the distinct needs of transgender people, and the ways in which their needs, concerns, and ultimately identities are *erased* within prevailing systems of knowledge production and service delivery.⁵⁸ It is important for Compassionate Communities, including projects such as ours, to centre their voices and consider their needs. Moreover, most of our participants were white, and had attended university, and while they reported varying levels of reported incomes, inequities related to socioeconomic status did not feature strongly in their discussions. Intersections between structural vulnerability and palliative care, for example, the unique experiences of LGBTQ2S+ people living in poverty, who are racialized, and/or who use drugs, are increasingly being recognized by palliative care scholars as a core area of focus for our field⁵⁹ and will be an important area of follow-up over the course of our project.

Geography is another limitation. Our focus groups took place in Ottawa, Ontario, which is a focal point for the federal public service where LGBTQ2S+ have unique lived experiences. As mentioned in the focus groups, ‘the purge’ is a specific historical event which took place largely in this region. Although the specifics of our participants’ experiences related to ‘the purge’ will have limited transferability to other contexts, they call attention to how lifecourse experiences that are specific to local contexts do inform end-of-life needs.

Concluding remarks

In reflecting on the narratives of older LGBTQ2S+ people about receiving and providing help, and the sharing of such narratives through research projects such as ours, it is important to consider the implications that such narratives and their retellings have for broader cultural understandings of LGBTQ2S+ people. Explicating the influence of trauma and discrimination is important in understanding how many LGBTQ2S+ experience aging, end of life, and grief. At the same time, however, this focus risks perpetuating an overly narrow interpretation of the lives of sexual and gender minority people. In a recent analysis of how older LGBTQ2S+ people are represented in Canadian news media, for example, Hurd and colleagues⁶⁰ found older LGBTQ2S+ people are depicted in news stories in one of two forms: victims of discrimination and marginalization, or extraordinary and resilient role models. In theorizing the implications of these portrayals, they write that ‘the type casting of older LGBTQ persons into one of two cultural options [victims and success stories], obfuscated, if not denied, the positioning of queer old people as ordinary folk’.⁶⁰ Importantly, in our focus groups, participants did speak about their lives in ways that transcended these two discursive framings, centering the more ‘ordinary’ dimensions of end-of-life experience. Grace told us a story about caring for a friend who was not a romantic partner, and described her negotiating with this friend around whom to include in the caregiving circle. Stories such as Grace’s reveal how LGBTQ2S+ narratives of end-of-life caregiving are unique and ordinary all-at-once.

At the same time, this story hints at the ways that informal caregiving, when accomplished by friends as opposed to romantic partners or legal family members, can result in precarious conditions. In their study of LGB caregiving provided by friends, Muraco and Fredriksen-Goldsen⁶¹ highlight the tenuousness of relying on friends for essential care, within a heteronormative social order:

the existing structures of care presume that a caregiver is a romantic partner or legal family member. Cultural and social expectations fuel the distinction between partners versus friends in providing care such that caregiving is implicit in the definition of a partnership, but not a friendship. (p. 1089)⁶¹

Such presumptions have important consequences for the full recognition of caregivers' roles within formalized end-of-life care processes (e.g. advanced care planning and family visiting restrictions during COVID-19); undoing such presumptions should be an important target of the Compassionate Communities movement.

Acknowledgements

The authors would like to acknowledge Ottawa Senior Pride Network (OSPN), for partnering with HELP Ottawa in this work, and specifically we thank the participants who shared their critical insights and experiences within these focus groups. The authors would also like to acknowledge Hayley Miloff, HELP Ottawa Project Coordinator and Christine Klerian-Rodriguez, HELP Ottawa Community Facilitator, who were centrally involved in this work. The authors also acknowledge the critical role of Compassionate Ottawa as the core sponsor of HELP Ottawa, and the Mach-Gaensslen Foundation of Canada for their generous funding and support of this project.

Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This work was funded and supported by the Mach-Gaensslen Foundation of Canada and Compassionate Ottawa.

ORCID iDs

Pamela Grassau  <https://orcid.org/0000-0003-1526-1134>

Arne Stinchcombe  <https://orcid.org/0000-0002-2101-3535>

Supplemental material

Supplemental material for this article is available online.

References

1. WHO. Ottawa Charter for health promotion. In: *First international conference on health promotion*, Ottawa, ON, Canada, 21 November 1986, pp. 17–21, [https://www.who.int/teams/health-](https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference)
2. Kellehear A. The Compassionate City Charter: inviting the cultural and social sectors into end of life care. In: Wegleitner K, Heimerl K and Kellehear A (eds) *Compassionate Communities: Case studies from Britain and Europe*. Abingdon: Routledge, 2016, pp. 80–82.
3. Kellehear A. *Compassionate cities: Public health and end of life care*. London: Routledge, 2005.
4. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* 2013; 106: 1071–1075.
5. Abel J, Kingston H, Scally A, *et al.* Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities. *Br J Gen Pract* 2018; 68: e803–e810.
6. Grindrod A. Choice depends on options: a public health framework incorporating the social determinants of dying to create options at end of life. *Prog Palliat Care* 2020; 28: 94–100.
7. Horsfall D, Psychogios H, Rankin-Smith H, *et al.* Researching Compassionate Communities in Australia: a short-term longitudinal study, 2020, <https://palliativecarewa.asn.au/wp-content/uploads/ResearchingCompassionateCommunitiesinAustraliaDebbieHorsfalletal.2020.pdf>
8. Kumar S. Public health approaches to palliative care: the neighbourhood network in Kerala. In: Sallnow L, Kumar S and Kellehear A (eds) *International perspectives on public health and palliative care*. Abingdon: Routledge, 2012, pp. 98–109.
9. Grindrod A and Rumbold B. Healthy end of life project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. *Ann Palliat Med* 2018; 7: S73–S83.
10. Worldwide Hospice Palliative Care Alliance. Australia: healthy end of life project (HELP): creating collaborative cultures at the end of life. In: Connor SR (ed.) *Global atlas of palliative care*. 2nd ed. London: Worldwide Hospice Palliative Care Alliance, 2020, pp. 71–72.
11. Grindrod A. *The healthy end of life project (HELP): Supporting communities to generate local solutions to their end-of-life concerns* [Information guide]. Melbourne, VIC, Australia: Public Health Palliative Care Unit, La Trobe University, <https://www.latrobe.edu.au/public-health/research/centres/palliative-care-unit/research/help>
12. Statistics Canada. Population projections for Canada, provinces and territories: highlights,

- <https://www150.statcan.gc.ca/n1/pub/91-520-x/2010001/aftertoc-aprestdm1-eng.htm> (2015, accessed 11 February 2021).
13. Laher N. *Diversity, aging, and intersectionality in Ontario home care*. The Wellesley Institute, 2017, <http://www.wellesleyinstitute.com/wp-content/uploads/2017/05/Diversity-and-Aging.pdf>
 14. Pfaff KA, Dolovich L, Howard M, *et al*. Unpacking ‘the cloud’: a framework for implementing public health approaches to palliative care. *Health Promot Int* 2020; 35: 160–170.
 15. Tompkins B. Compassionate Communities in Canada: it is everyone’s responsibility. *Ann Palliat Med* 2018; 7: S118–S129.
 16. Stinchcombe A and Wilson K. Aging in Lesbian, Gay, Bisexual, Transgender, Queer and Two-Spirit (LGBTQ2+) communities. In Rootman I, Edwards P, Levassuer M, *et al*. (eds) *Promoting the health of older adults: The Canadian experience*. Toronto, ON, Canada: Canadian Scholars, 2021, pp. 252–265.
 17. Brennan-Ing M, Seidel L, Larson B, *et al*. Social care networks and older LGBT adults: challenges for the future. *J Homosex* 2014; 61: 21–52.
 18. Kim H-J and Fredriksen-Goldsen KI. Living arrangement and loneliness among lesbian, gay, and bisexual older adults. *Gerontologist* 2016; 56: 548–558.
 19. de Vries B. Stigma and LGBT aging: negative and positive marginality. In: Orel NA and Fruhauf CA (eds) *The lives of LGBT older adults: Understanding challenges and resilience*. Washington, DC: American Psychological Association, 2015, pp. 55–72.
 20. Fredriksen-Goldsen KI, Kim H-J, Bryan AEB, *et al*. The cascading effects of marginalization and pathways of resilience in attaining good health among LGBT older adults. *Gerontologist* 2017; 57: S72–S83.
 21. Stinchcombe A, Hammond NG and Wilson K. Differential effects of social support by sexual orientation: a study of depression symptoms among older Canadians in the CLSA. *Res Aging* 2020; 42: 251–261.
 22. de Vries B, Gutman G, Humble Á, *et al*. End-of-life preparations among LGBT older Canadian adults: the missing conversations. *Int J Aging Hum Dev* 2019; 88: 358–379.
 23. de Vries B, Gutman G, Soheilipour S, *et al*. Advance care planning among older LGBT Canadians: heteronormative influences. *Sexualities*. Epub ahead of print 17 March 2020. DOI: 10.1177/1363460719896968.
 24. Wilson K, Kortess-Miller K and Stinchcombe A. Staying out of the closet: LGBT older adults’ hopes and fears in considering end-of-life. *Can J Aging* 2018; 37: 22–31.
 25. Braun V, Clarke V, Hayfield N, *et al*. Thematic analysis. In: Liamputtong P (ed.) *Handbook of research methods in health social sciences*. Singapore: Springer, 2018, pp. 843–860.
 26. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
 27. Braun V and Clarke V. *Successful qualitative research: A practical guide for beginners*. Thousand Oaks, CA: SAGE, 2013.
 28. Braun V and Clarke V. Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Couns Psychol Res* 2021; 21: 37–47.
 29. Clarke V and Braun V. Thematic analysis. *J Posit Psychol* 2017; 12: 297–298.
 30. Austen I. Commemorating the victims of Canada’s ‘Gay Purge’. *The New York Times*, 25 January 2020, <https://www.nytimes.com/2020/01/24/world/canada/canada-gay-purge-monument.html> (accessed 11 February 2021).
 31. Kinsman G and Gentile P. *The Canadian war on queers: National Security as sexual regulation*. Vancouver, BC, Canada: UBC Press, 2010.
 32. de Vries B and Croghan C. LGBT aging: the contributions of community-based research. *J Homosex* 2014; 61: 1–20, <https://www.tandfonline.com/doi/full/10.1080/00918369.2013.834794> (accessed 11 February 2021).
 33. Clandinin DJ and Connelly FM. *Narrative inquiry: Experience and story in qualitative research*. 1st ed. San Francisco, CA: Jossey-Bass Publishers, 2000.
 34. Riessman CK. *Narrative methods for the human sciences*. Thousand Oaks, CA: SAGE, 2008.
 35. Fredriksen-Goldsen KI, Bryan AEB, Jen S, *et al*. The unfolding of LGBT Lives: key events associated with health and well-being in later life. *Gerontologist* 2017; 57: S15–S29.
 36. Rice CE, Fish JN, Russell ST, *et al*. Sexual minority-related discrimination across the life course: findings from a national sample of adults in the United States. *J Homosex* 2021; 68: 252–268.
 37. Bränström R, Hatzenbuehler ML, Pachankis JE, *et al*. Sexual orientation disparities in preventable disease: a fundamental cause perspective. *Am J Public Health* 2016; 106: 1109–1115.

38. Ramirez JL and Galupo MP. Multiple minority stress: the role of proximal and distal stress on mental health outcomes among lesbian, gay, and bisexual people of color. *J Gay Lesbian Ment Health* 2019; 23: 145–167.
39. Agosto S, Reitz K, Ducheny K, *et al.* Substance use and recovery in the transgender and gender nonconforming (TGNC) older adult community. In: Hardacker C, Ducheny K and Houlberg M (eds) *Transgender and gender nonconforming health and aging*. Cham: Springer International Publishing, pp. 97–112.
40. McCabe SE, Bostwick WB, Hughes TL, *et al.* The relationship between discrimination and substance use disorders among lesbian, gay, and bisexual adults in the United States. *Am J Public Health* 2010; 100: 1946–1952.
41. Longobardi C and Badenes-Ribera L. Intimate partner violence in same-sex relationships and the role of sexual minority stressors: a systematic review of the past 10 years. *J Child Fam Stud* 2017; 26: 2039–2049.
42. Stephenson R and Finneran C. Minority stress and intimate partner violence among gay and bisexual men in Atlanta. *Am J Mens Health* 2017; 11: 952–961.
43. Acquaviva KD. *LGBTQ-inclusive hospice and palliative care: A practical guide to transforming professional practice*. New York: Columbia University Press, 2017.
44. Bristowe K, Marshall S and Harding R. The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: a systematic review, thematic synthesis and modelling of the literature. *Palliat Med* 2016; 30: 730–744.
45. Corroero AN 2nd and Nielson KA. A review of minority stress as a risk factor for cognitive decline in lesbian, gay, bisexual, and transgender (LGBT) elders. *J Gay Lesbian Ment Health* 2020; 24: 2–19.
46. Quinn GP, Sanchez JA, Sutton SK, *et al.* Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA Cancer J Clin* 2015; 65: 384–400.
47. Wicks MN, Alejandro J, Bertrand D, *et al.* Achieving advance care planning in diverse, underserved populations. *Nurs Outlook* 2018; 66: 311–315.
48. Richards N, Koksvik GH, Gerson SM, *et al.* The global spread of death café: a cultural intervention relevant to policy? *Soc Policy Soc* 2020; 19: 553–572.
49. Ricks-Aherne ES, Wallace CL and Kusmaul N. Practice considerations for trauma-informed care at end of life. *J Soc Work End Life Palliat Care* 2020; 16: 313–329.
50. Rosa WE, Shook A and Acquaviva KD. LGBTQ+ inclusive palliative care in the context of COVID-19: pragmatic recommendations for clinicians. *J Pain Symptom Manage* 2020; 60: e44–e47.
51. Candrian C, Furuno JP, Kavalieratos D, *et al.* Collaboration makes us better: time to increase equity in the science of hospice and palliative care. *J Palliat Med* 2019; 22: 1492–1492.
52. Quest TE, Periyakoil VS, Quill TE, *et al.* Racial equity in palliative care. *J Pain Symptom Manage* 2021; 61: 435–437.
53. Jovanovic M. Cultural competency and diversity among hospice palliative care volunteers. *Am J Hosp Palliat Care* 2012; 29: 165–170.
54. Brown C, Peck S, Humphreys J, *et al.* COVID-19 lessons: the alignment of palliative medicine and trauma-informed care. *J Pain Symptom Manage* 2020; 60: e26–e30.
55. Kia H. From acute palliation to chronic care: using the narratives of two gay caregivers to explore experiences of providing HIV support across sociohistorical contexts. *J Gay Lesbian Soc Serv* 2015; 27: 482–501.
56. Candrian C and Cloyes KG. ‘She’s Dying and I Can’t Say We’re Married?’: end-of-life care for LGBT older adults. *Gerontologist*. Epub ahead of print 11 December 2020. DOI: 10.1093/geront/gnaa186.
57. Gott M, Morgan T and Williams L. Gender and palliative care: a call to arms. *Palliat Care Soc Pract* 2020; 14: 1–15.
58. Bauer GR, Hammond R, Travers R, *et al.* ‘I don’t think this is theoretical; this is our lives’: how erasure impacts health care for transgender people. *J Assoc Nurses AIDS Care* 2009; 20: 348–361.
59. Stajduhar KI. Provocations on privilege in palliative care: are we meeting our core mandate? *Prog Palliat Care* 2020; 28: 89–93.
60. Hurd L, Mahal R, Ng S, *et al.* From invisible to extraordinary: representations of older LGBTQ persons in Canadian print and online news media. *J Aging Stud* 2020; 55: 100877.
61. Muraco A and Fredriksen-Goldsen K. ‘That’s what friends do’: informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults. *J Soc Pers Relat* 2011; 28: 1073–1092.