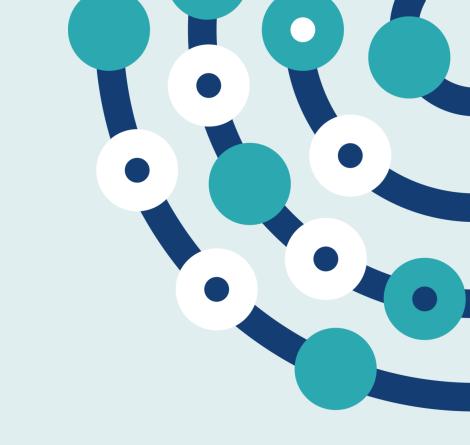


Palliative Care in the LGBTQ+ Community

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Introduction

Lesbian, gay, bisexual, transgender and queer (LGBTQ+) people experience unique healthcare experiences throughout life, which creates distinctive palliative care needs. Despite this, the experiences of LGBTQ+ individuals in palliative care has received little attention until relatively recently. Where research has directly addressed queer patients receiving palliative care, this is often limited to oncology patients [1, 2]. Research frequently focuses on individual cases, lacks exploration of the differences of palliative care between LGBTQ+ and non-LGBTQ+ populations [3] and fails to engage in the methods to dismantle obstacles in accessing LGBTQ+ affirming palliative care [4]. The aim of this review is to investigate the evidence specific to the issues around LGBTQ+ palliative care and how these factors shape the care queer palliative patients receive.

Methods

A review of the literature was conducted to appraise the relevant studies concerning LGBTQ+ issues in palliative care. Grey literature and electronic databases were searched using keywords.

Chosen Families

• Queer palliative patients often create a "chosen family," of friends, partners, biological and adopted children. Chosen families can facilitate the same or greater levels of support as heteronormative, biological families [2]. Chosen families may face barriers to accessing and engagement in bereavement support [5]

Providers of Palliative Services

- There is a lack of education of LGBTQ+ issues throughout undergraduate and post graduate medical training [6,7]
- Ignorance of LGBTQ+ issues may result in a failure to engage palliative patients about their end-of-life requirements
- Education is weighted towards historical stigma to the LGBTQ+ community, but is lacking in wider psychosocial issues [8]
- Alienation and distrust of healthcare systems due to the legacy of the HIV/AIDs crisis may delay access to palliative services

Heteronormative bias in Palliative Care

- Palliative teams often fail to enquire about a patient's sexuality or gender identity due to apprehension about offending patients or lack of awareness [9]
- Patients may feel like they have to 'go back into the closet' to receive care [10]

Engagement with advanced care planning

- LGBTQ+ individuals demonstrate increased levels of advanced care planning than heterosexual counterparts [11]
- LGBT individuals are more likely to engage with advance planning if they are not in a relationship, but the opposite is true if they have children [11]
- A key motivation for marriage within same-sex relationships is to allow for security regarding future medical management for their partners [12]

Discrimination

- LGBTQ+ palliative patients are subject to **disrespectful**, **inadequate and abusive** care [13]
- Transgender patients receive more discrimination than LGB patients', including intentional misgendering, offensive comments and incomplete or refusal of care [14]

Queer Isolation in Palliative Settings

- Childless LGBTQ+ palliative patients have the danger of becoming 'elder orphans' as they are less likely to have children [15]
- Fear of persecution in countries where homosexuality is illegal, can create a preference to die alone in hospital rather than return to home settings [16]
- Patients in supported accommodation may fail to connect or be rejected by others because of their queerness [17]

Chosen Families

They were having a meeting for newly bereaved people... I was opposite a man whose wife had died ... And, in the end, he just said to me, "You've only lost a friend", he said, "And I've lost my wife" ... I never felt as lost and isolated as I did that night' [5]

Providers of Services

"People of my sort of age who have particularly in earlier years experienced prejudicial discrimination ... you can't predict and rely on a totally integrated service necessarily giving a feeling of safety" [18]

Heteronormative Bias

'So I mean in a way you're kind of thinking well, "I'll have to go back into the closet"... I'[II be] straight, you know...in order to be in a home, to be looked after' [10]

Engagement with Advanced Care Planning

'I don"t have a lot of faith that I'll actually find a partner, so then what-my friends are stuck taking care of me? And then I feel like a burden. Even if it meant going off by myself and dying alone, I would rather do that than be a burden to my friends' [15]

Discrimination

'A doctor who refused to treat transgender patient saying "I gotta know what's under the hospital gown, I can't take you as a patient."' [14]

Queer isolation

'So isolation comes in, discrimination and you find many people dying quietly without any family support ... They will say you were doing your gay things on your own that's why, now it's payback time for your sins' [16]

Figure 1. Lived experiences of LGBTQ+ patients in palliative care

Recommendations

- Development of LGBTQ+ befriending telephone services
- LGBTQ+ specific educational programmes regarding advance care planning
- Greater emphasis on LGBTQ+ issues throughout undergraduate medical education.
- Incorporate a Health Equity Promotion Model when assessing queer patients
- Post-graduate teaching workshops tailored to specific LGBTQ+ palliative care needs
- Create more inclusive and less restrictive data collection systems
- Increase audit work in the UK and Europe to assess levels of discrimination

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