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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'[ll 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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