



Background

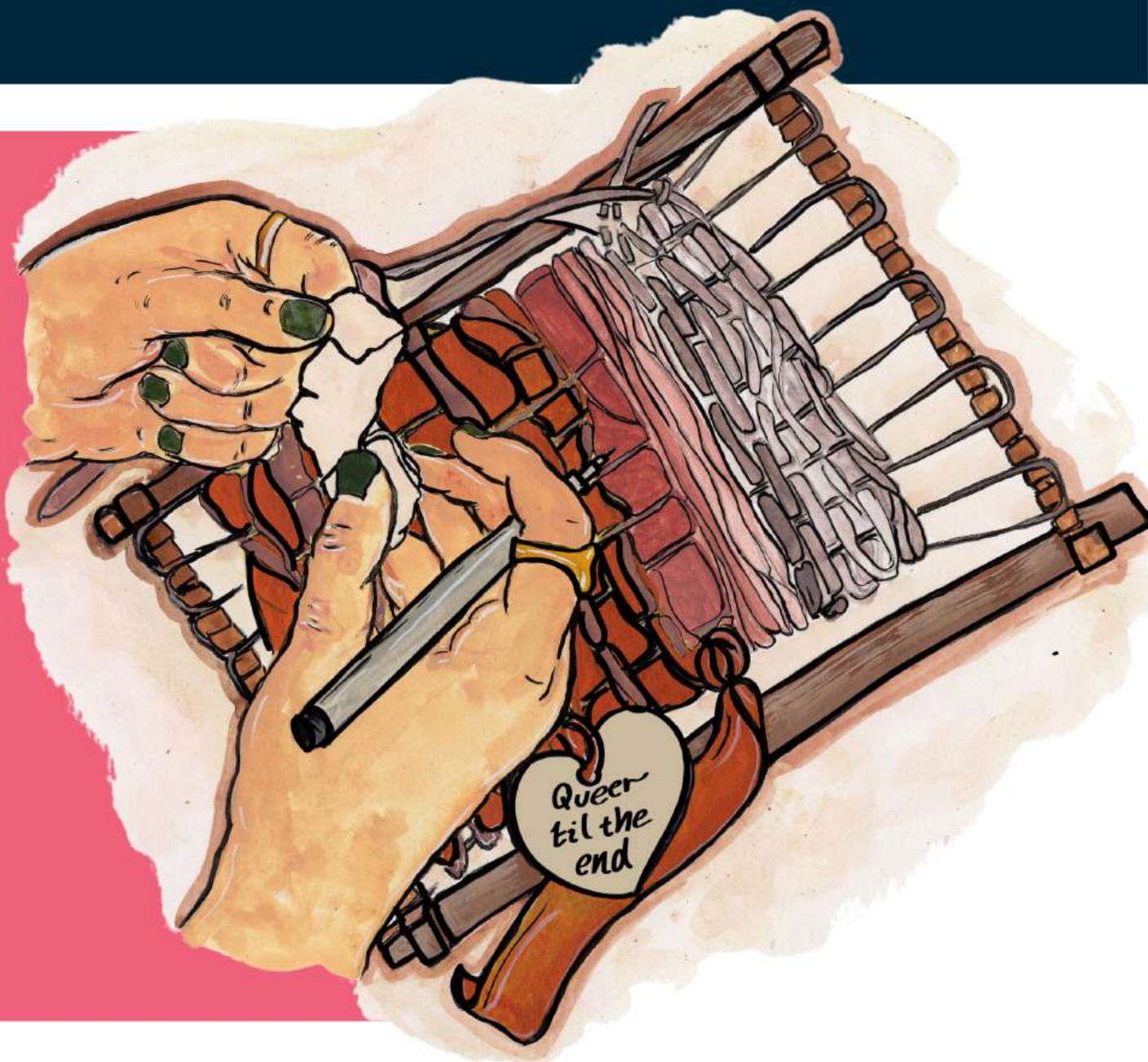
Lesbian, gay, bisexual, transgender, queer and other gender diverse (LGBTQ+) people experience healthcare inequity due to discrimination, assumptions made by healthcare workers and anticipating discriminatory behaviour. It often may not feel safe to access screening programmes and ignored symptoms may result in late diagnoses, advanced illness, and delayed referral to palliative care. Previous negative experiences frequently create societal exclusion and a fear of rejection related to gender, identity, or sexual orientation. In recent years rainbows and pride flags displayed in healthcare environments have suggested a movement toward inclusive care. However, it goes beyond well-meaning gestures to better understand the principles of equitable palliative care for LGBTQ+ people.

Aim

- To provide a safer environment for LGBTQ+ people to express themselves and to share their experiences, including when they have faced experiences and attitudes of bias, prejudice and discrimination when accessing and working in healthcare or facing ill health
- To explore the experiences and concerns of LGBTQ+ people accessing palliative and end-of-life care
- Co-develop a resource to increase healthcare workers awareness and curiosity of LGBTQ+ inclusive palliative and end-of-life care

Methods

- 9-month qualitative, equity-oriented study
- Directed by the values of co-production with 10 LGBTQ+ people and allies recruited to a co-production team
- The use of arts-based methods for community workshops delivered by LGBTQ+ facilitators
- Reflexive thematic analysis



Results

- LGBTQ+ people continue to feel excluded from palliative and wider healthcare services, with previous experiences adversely impacting how people feel about accessing care, often hiding their identity or holding negative perceptions of their own end-of-life care. People accessing palliative care and hospices have concerns if the care provided, including psychological support and spiritual care, is safe and inclusive.
- Service providers often homogenize LGBTQ+ people, placing people into a singular collective identity and this comes at the expense of individual needs and identities. LGBTQ+ identities become foregrounded and other intersecting identities often get lost.
- There is a greater need to support LGBTQ+ people to plan ahead for growing older and the end-of-life. Decision making and thinking about future care should be prioritised through early conversations and using methods such as No Barriers Here which provides the time and space to discuss a person's fears and concerns. This is particularly important when considering the underlying issues of trust, safety, discrimination and previous negative experiences LGBTQ+ people may have.

“ So many of us have faced prejudice in healthcare...it's no wonder people don't come forward to talk about this [end-of-life care] but as people in non-traditional family units, we need to get our wishes down and tell those important to us. ”

“ I just felt judged. The counsellor was well-meaning, but unsure of her language about simple things like asking if I had a partner or a husband, and I felt like the spectacle, the different one, the unusual one – as a gay man this shouldn't be the case in this day and age. ”



Conclusion

The study findings highlight that the barriers experienced by LGBTQ+ people are significantly likely to influence, challenge and disrupt the decisions made when planning for end-of-life care and access to palliative care. LGBTQ+ inclusive care is not available consistently and there is a long way to go beyond tokenistic gestures such as displaying rainbows in reception areas. Research grounded in co-production and viewed through the lens of people with lived experience is fundamental to addressing inequity in palliative care. Findings from this study have produced key recommendations for use at individual, organisational and leadership level to improve inclusivity in palliative care. Everyone should receive equitable and inclusive palliative and end-of-life care regardless of their sexuality, gender identity or other aspects of identity and getting things right for minoritised groups and individuals always leads to better care for everyone.

Acknowledgements

No Barriers Here works with and listens to the voices of people with lived experience to positively impact palliative and end-of-life care, education, policy and practice. The co-production team's contributions and their personal experiences in relation to healthcare, aging and palliative care have added richness and the impact of this study and associated publication lies with the voices of all those involved.

Illustrated by Cass Humphreys-Massey. Funded by Marie Curie (RF22-502) and Black Country Integrated Care Board.

Authors

Dr Jed Jerwood (he/him)
Honorary Clinical Associate Professor, University of Birmingham.
Co-founder of No Barriers Here, The Mary Stevens Hospice.
j.jerwood@bham.ac.uk @JedJerwood

Gemma Allen (she/her)
Palliative Care Inclusion and Community Partnerships Lead.
Co-founder of No Barriers Here, The Mary Stevens Hospice.
gemma.allen@marystevenshospice.co.uk @gemma_allen1

New LGBTQ+ resource available
www.nobarriershere.org
[@NoBarriersHere](https://www.instagram.com/nobarriershere)



References

• Jerwood, J., Allen, G., Juffs, H., Humphries-Massey, C., Wakefield, D., Hudson, S., Baron, L., Burgess, S., Kane, E., Simpson, K., Maxwell, P. and Brown, C. (2024) 'It's more than rainbows in receptions' - Working with LGBTQ+ People in Palliative and End-of-life Care. Stourbridge: The Mary Stevens Hospice. DOI: 10.13140/RG.2.2.20525.91363

• Hospice UK. (2023). 'I just want to be me' Trans and Gender Diverse Communities' Access to and Experience of Palliative and End-of-Life Care. chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://hospiceuk-files-prod.s3.eu-west-2.amazonaws.com/s3fs-public/2023-02/I%20Just%20Want%20To%20Be%20Me.pdf

• The Mary Stevens Hospice. (2021) No Barriers Here. <https://www.nobarriershere.org>

• Wakefield, D., Kane, C. E., Chidiac, C., Braybrook, D., & Harding, R. (2021). Why does palliative care need to consider access and care for LGBTQ people? Palliative Medicine, 35(10), 1730-1732. <https://doi.org/doi:10.1177/02692163211055011>

• Wilson, K., & Kortes-Millere, K. Stinchcombe, A. (2018). Staying out of the closet: LGBT adults' hopes and fears in considering end-of-life. Journal on Aging/ La Revue Canadienne Du Vieillessement, 32, 22-31.