

# Palliative care over the rainbow: perspectives of middle-age and older LGBT+ adults regarding their end-of-life

Cuidados paliativos além do arco-íris: perspectivas de pessoas idosas LGBT+ relacionadas com o final de suas vidas

Milton Roberto Furst Crenitte<sup>a,b</sup>  , Leonardo Rabelo de Melo<sup>a</sup> , Wilson Jacob Filho<sup>a,c</sup> ,  
Thiago Junqueira Avelino Silva<sup>a,c,d</sup> 

<sup>a</sup>Divisão de Geriatria, Hospital das Clínicas, Faculdade de Medicina, Universidade de São Paulo – São Paulo (SP), Brazil.

<sup>b</sup>Faculdade de Medicina, Universidade Municipal de São Caetano do Sul – São Caetano do Sul (SP), Brazil.

<sup>c</sup>Laboratório de Investigação Médica do Envelhecimento, Divisão de Geriatria, Hospital das Clínicas, Faculdade de Medicina, Universidade de São Paulo Medical – São Paulo (SP), Brazil.

<sup>d</sup>Faculdade Israelita de Ciências da Saúde Albert Einstein – São Paulo (SP), Brazil.

## Correspondence data

Milton Roberto Furst Crenitte – Av. Dr. Eneas de Carvalho Aguiar 155, 8º andar – Cerqueira César – CEP: 05403-000 – São Paulo (SP), Brazil. E-mail: milton.crenitte@gmail.com

Received on: 16/05/2022.

Accepted on: 26/07/2022.

Associate Editor in Charge: Einstein Francisco de Camargos

**How to cite this article:** Crenitte MRF, Melo LR, Jacob Filho W, Silva TJA. Palliative care over the rainbow: perspectives of middle-age and older LGBT+ adults regarding their end-of-life. *Geriatr Gerontol Aging*. 2022;16:e0220026. <https://doi.org/10.53886/gga.e0220026>

## Abstract

**Objective:** Reports show that LGBT+ people may face several struggles during their end-of-life (EOF) preparations, reporting higher rates, for example, of harassment and fear of feeling pain during these moments. We thus aimed to investigate variables related to EOF preparations among LGBT+ people and compare them with heterosexual cisgender individuals.

**Methods:** This is a cross-sectional study in which Brazilians aged 50 or older were invited to answer an anonymous online survey between August 2019 and January 2020. The survey was widely distributed in neighbourhood associations, nongovernmental organizations, and social media. Those who identified as homosexual, bisexual, pansexual, non-heterosexual, transgender, *travesti*, or non-binary were grouped as LGBT+; cisgender and heterosexual participants were grouped as non-LGBT+.

**Results:** The questionnaire was answered by 6693 participants with a median age of 60 years. Out of all respondents, 1332 were LGBT+ (19.90%) and 5361 were non-LGBT+ (80.10%). Compared to their non-LGBT+ peers, LGBT+ people reported higher rates of loneliness (25.30% vs 16.32%,  $p < 0.001$ ), fear of dying alone (15.69% vs 9.79%,  $p < 0.001$ ) or in pain (35.21% vs 25.74%,  $p < 0.001$ ), and less social support (19.44% vs 13.48%,  $p < 0.001$ ).

**Conclusions:** Being LGBT+ was associated with challenges and inequalities regarding EOF preparations and discussions. Sexuality and diversity should be addressed in palliative training programs to address the needs of the LGBT+ population and to provide them with a dignified death.

**Keywords:** palliative care; terminal care; sexual and gender minorities; aged; long-term care.

## Resumo

**Objetivos:** Estudos observacionais mostram que pessoas LGBT+ enfrentam diversas barreiras e desafios em suas preparações de fim de vida, como, por exemplo, taxas maiores de discriminação e medo de sentir dor nesses momentos. Dessa forma, nosso objetivo foi investigar variáveis relacionadas às preparações de fim de vida entre pessoas LGBT+ e compará-las com as de indivíduos não LGBT+.

**Metodologia:** Este foi um estudo de corte transversal, no qual brasileiros com 50 anos ou mais foram convidados a responder a um questionário *online* anônimo entre agosto de 2019 e janeiro de 2020. O *link* para respostas foi distribuído amplamente em associações, organizações não governamentais e mídias sociais. Aqueles que se identificassem como homossexuais, bissexuais, pansexuais, não heterossexuais, transgênero, travestis ou com gênero não binário foram agrupados no grupo LGBT+; pessoas cisgênero e heterossexuais constituíram o grupo não LGBT+.

**Resultados:** O questionário foi respondido por 6693 participantes, com mediana de idade de 60 anos. Entre eles, 1332 eram LGBT+ (19,90%) e 5361 não LGBT+ (80,10%). Comparadas com seus contemporâneos não LGBT+, as pessoas LGBT+ referiram maiores taxas de solidão (25,30% *vs.* 16,32%,  $p < 0,001$ ), medo de morrer sozinhas (15,69% *vs.* 9,79%,  $p < 0,001$ ) ou com dor (35,21% *vs.* 25,74%,  $p < 0,001$ ) e menor suporte social (19,44% *vs.* 13,48%,  $p < 0,001$ ).

**Conclusões:** Ser LGBT+ esteve associado com iniquidades e desafios relacionados às preparações e discussões de fim de vida. Sexualidade e diversidade devem ser abordadas em programas de formação em cuidados paliativos para se acessarem as necessidades e particularidades da população LGBT+ e, dessa forma, ser proporcionada uma morte com dignidade a todos.

**Palavras-chave:** cuidados paliativos; assistência terminal; minorias sexuais e de gênero; idoso; assistência de longa duração.



This article is published in Open Access under the Creative Commons Attribution license, which allows use, distribution, and reproduction in any medium, without restrictions, as long as the original work is correctly cited.

## INTRODUCTION

Sexuality ought to be understood as a nuclear component of all human beings and therefore must be included in palliative care plans. It does not simply encompass the sexual act, but also intimate contact, physical proximity, and emotional connection, which can become more important in the latter stages of life.<sup>1</sup>

Many lesbians, gays, bisexuals, and transgender people (LGBT+) report fear of suffering discrimination and a lack of confidence in health care centres, even in contexts of palliative care; this can consequently be associated with failure to provide a dignified death.<sup>2</sup> Fear of dying alone, in pain, or suffering discrimination at the time of death are frequently described concerns.<sup>3</sup> They also show inequalities in access to health care and assistance, less social support, and greater chances of living alone, being childless, and not having anyone to call in case of emergency, which are issues that play a pivotal role in this phase of life.<sup>4-6</sup>

Other observational studies report greater difficulty, when compared to non-LGBT+ persons, in discussing issues regarding end-of-life (EOF) with health care providers.<sup>3,7</sup> The lack of welcoming long-term institutions also compels these individuals to remain at home even when care and assistance are inadequate.<sup>8</sup>

Few studies have been published on this subject, especially in the Brazilian medical literature.<sup>2,9</sup> Therefore, we aimed to investigate the ageing and EOF perceptions of older LGBT+ adults and to compare them with a corresponding heterosexual, cisgender sample.

## METHODS

### Study design and population

This study is part of a bigger questionnaire that aimed to investigate inequalities in access to health care. A cross-sectional study involving Brazilians aged 50 years or older was conducted. Participants were invited to answer an anonymous online survey developed and managed using REDCap resources<sup>10</sup> between August 2019 and January 2020. They were encouraged to answer the questionnaire following a snowball sampling recruitment strategy.<sup>11</sup> The study was also advertised in medical associations, patient organizations, neighbourhood associations, nongovernmental associations, and social media. The study received unofficial support by important Brazilian LGBT+ associations such as GGB (Grupo Gay da Bahia), ESOU (Associação EternamenteSOU), and ANTRA (Associação Nacional de Travestis e Transexuais), which increased its propagation among LGBT+ communities.

To reduce the risk of recruitment bias, the study was disclosed under the most generic scope of the research: the investigation of sociodemographic aspects associated with health care access, whose questions could be answered both by LGBT+ and non-LGBT+ people. Questions related to sexual orientation and gender identity were placed at the end of the questionnaire.

### Data collection

Participants filled out a thorough questionnaire detailing sociodemographic and clinical characteristics, use of health care services, and previous discriminatory and victimization experiences.

Our main independent variables were gender (cisgender male, cisgender female, transgender male, transgender female, *travesti*,<sup>12</sup> non-binary, other) and sexual orientation (heterosexual, homosexual, bisexual, pansexual, asexual, other). For analysis purposes, we created an additional variable grouping non-LGBT+ (cisgender male, cisgender female, heterosexual) vs LGBT+ participants (transgender male, transgender female, *travesti*, non-binary, homosexual, bisexual, pansexual, other).

### Statistical analysis

We described our data using central tendency and dispersion measures, counts, and proportions. We compared LGBT+ and non-LGBT+ participants using contingency tables, chi-squared tests, Fisher's exact tests, Student's t-tests, or Wilcoxon's rank-sum tests as appropriate. Statistical analyses were performed using Stata SE 15 (Stata Corp, College Station, TX). All statistical tests were two-tailed, and an alpha error of up to 5% was accepted.

As this article is based on a secondary and exploratory analysis of a larger study that aimed to investigate inequalities in access to health care, no other associations were performed.

### Ethical aspects

The Institutional Review Board of Universidade de São Paulo Medical School (FMUSP) approved the study – (approval number: 3 492 814 on 08/08/2019). The online survey required eligible patients to read, understand, and accept a consent form to participate. The questionnaires were anonymous and de-identified.

## RESULTS

After excluding incomplete data (1.82%) and those who did not consent to participate (4.84%), our final sample included 6693 participants: 1332 of them were in the LGBT+ group

(19.90%) and 5361 were in the non-LGBT+ group (80.10%). Regarding sexual orientations in the LGBT+ group, 70.49% were homosexual, 16.29% were bisexual, and 3.75% were pansexual. Most of them identified as cisgender (81.30%).

Overall, the median age was 60 years; 68.39% of the participants were female and 78.76% were White. Participants had high literacy levels, with 78.76% having completed university or graduate courses. LGBT+ participants were more frequently single (37.53% vs 10.27%,  $p < 0.001$ ) and used the public health system more often. They were also more likely to live in a rental (18.24% vs 10.25%,  $p < 0.001$ ) and earn less than the minimum wage (9.53% vs 6.24%,  $p < 0.001$ ).

LGBT+ participants were more likely to report that they did not have anyone to assist them if they became bedridden (19.44% vs 13.48%,  $p < 0.001$ ) and that they feared dying alone (15.69% vs 9.79%,  $p < 0.001$ ), in pain (35.21% vs 25.74%,  $p < 0.001$ ), or while depending on others (41.59% vs 37.41%,  $p = 0.005$ ). They would also more frequently prefer to die than live in a long-term facility when compared to their non-LGBT+ peers (7.58% vs 5.46%,  $p = 0.006$ ).

We also completed a sensitivity analysis modifying our primary independent variable to transgender people, non-binary genders, and other genders as non-cisgenders. The tendency of data was maintained after excluding these groups.

## DISCUSSION

The data found in this study are consistent with findings of other observational investigations on the topic.<sup>3,13,14</sup> In our sample, we found a greater proportion of LGBT+ people who expressed fear of dying in pain, alone, and dependent on others. Such findings reinforce the importance of discussions about inequalities in health care access, social support, and the knowledge of health care professionals on issues related to sexual and gender minorities.

Loneliness and social isolation can have a negative impact on the management of people in life-threatening situations. North American data show that 80% of older LGBT+ people are single, 90% are childless, and 75% live alone. In the general population, these numbers reach 40%, 20%, and 33%, respectively.<sup>15</sup>

Another specificity of this population refers to the importance of the concept of “family of choice” at their end of life. As such, it is up to the professionals to respect these relationships and/or provide guidance for the making of legal documents that guarantee their voice and preferences.

The numbers related to perceptions on living in long-term facilities are also relevant, since it is not uncommon for older people to live in these places at moments of greatest

vulnerability or at the end of their lives. The higher preference for dying rather than living in such an institution observed among LGBT+ people may be justified by the fear of suffering discrimination or needing to “go back into the closet” and by the hetero-cis-normative way these places are organized.

In this context, a survey performed in the United States with institutionalised older LGBT+ adults showed that 23% had suffered verbal or physical harassment from other residents and 14%, by health care providers.<sup>16</sup> Another study showed that the employees of these institutions were better prepared to respect cis-heterosexual relationships than those between two men or two women.<sup>17</sup>

This set of findings reinforces that issues related to sexual and gender diversity should not only be part of macro-politics within the debate on public policies aimed to reduce inequality, but also of micro-politics, reflecting upon the creation of welcoming institutions and the inclusion of this theme in palliative care training programs.

Our study has limitations. First, our sample was subject to possible biases intrinsic to snowball sampling and the use of social networks to encourage participation. These include literacy and socioeconomic levels that were above the mean Brazilian indicators. Second, the fact that we used an online questionnaire may also have affected the engagement of older contributor age groups.

On the other hand, our work also presents important strengths. We included a considerable number of participants, both non-LGBT+ and LGBT+, and examined numerous aspects of our respondents’ health. Another essential element of our survey was the participants’ anonymity, which enhanced the likelihood of receiving accurate answers concerning subjects that are usually considered taboo. Furthermore, we had a high percentage of complete responses and minimal exclusion of missing data, which asserts the quality of our data.

## CONCLUSION

LGBT+ Brazilians aged 50 years or older presented a higher prevalence of experiencing fear of dying alone, in pain, and dependent on others. The fear of having to live in a long-term care facility also had a negative impact on their lives, considering the higher prevalence of those who would rather die than live in such an institution.

Public policies and training programs in palliative care aimed at alleviating vulnerabilities are essential to include these people in health care facilities so as to enable the provision of a dignified death.

## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

## FUNDING

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## AUTHORS' CONTRIBUTIONS

MRFC: conceptualization, data curation, formal analysis, writing – original draft, writing – review & editing. LRM: conceptualization, data curation, formal analysis, writing – original draft, writing – review & editing. WJF: conceptualization, writing – original draft, writing – review & editing. TJAS: conceptualization, data curation, formal analysis, writing – original draft, writing – review & editing

## REFERENCES

- Griehling TL. Sexuality and aging: a focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care. *Curr Opin Support Palliat Care*. 2016;10(1):95-101. <https://doi.org/10.1097/SPC.0000000000000196>
- Crenitte MRF, Miguel DF, Jacob Filho W. Abordagem das particularidades da velhice de lésbicas, gays, bissexuais e transgêneros. *Geriatr Gerontol Aging*. 2019;13(1):50-6.
- Kcomt L, Gorey KM. End-of-life preparations among lesbian, gay, bisexual, and transgender people: integrative review of prevalent behaviors. *J Soc Work End Life Palliat Care*. 2017;13(4):284-301. <https://doi.org/10.1080/15524256.2017.1387214>
- Kim HJ, Fredriksen-Goldsen KI. Living arrangement and loneliness among lesbian, gay, and bisexual older adults. *Gerontologist*. 2016;56(3):548-58. <https://doi.org/10.1093/geront/gnu083>
- Fredriksen-Goldsen KI, Kim HJ, Barkan SE, Muraco A, Hoy-Ellis CP. Health disparities among lesbian, gay, and bisexual older adults: results from a population-based study. *Am J Public Health*. 2013;103(10):1802-9. <https://doi.org/10.2105/AJPH.2012.301110>
- Corrêa-Ribeiro R, Abdo CHN, Camargos EF. Lésbicas, gays e bissexuais idosos no contexto do envelhecimento. *Geriatr Gerontol Aging*. 2016;10(3):158-63. <https://doi.org/10.5327/Z2447-211520161600023>
- Wilson K, Kortjes-Miller K, Stinchcombe A. Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life. *Can J Aging*. 2018;37(1):22-31. <https://doi.org/10.1017/S0714980817000514>
- Gillis L, Aronson J, St. Pierre M, Brotman S, MacDonnell JA, Daley A. Providing health and social services to older LGBT adults. *Annual Review of Gerontology and Geriatrics*. 2016;37(1):143-60. <https://doi.org/10.1891/0198-8794.37.143>
- Henning CE. Gerontologia LGBT: velhice, gênero, sexualidade e a constituição dos "idosos LGBT." *Horiz Antropol*. 2017;23(47):283-323. <https://doi.org/10.1590/S0104-71832017000100010>
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-81. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Biernacki P, Waldorf D. Snowball sampling: problems and techniques of chain referral sampling. *Sociol Methods Res*. 1981;10(2):141-63. <https://doi.org/10.1177/004912418101000205>
- Garcia MRV. Identity as a 'patchwork': aspects of identity among low-income Brazilian travestis. *Culture, Health & Sexuality*. 2009;11(6):611-23. <https://doi.org/10.1080/13691050902825282>
- Westwood S, Willis P, Fish J, Hafford-Letchfield T, Semlyen J, King A, et al. Older LGBT+ health inequalities in the UK: setting a research agenda. *J Epidemiol Community Health*. 2020;74(5):408-11. <https://doi.org/10.1136/jech-2019-213068>
- Cloyes KG, Hull W, Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Semin Oncol Nurs*. 2018;34(1):60-71. <https://doi.org/10.1016/j.soncn.2017.12.003>
- SAGE. Social isolation [Internet]. [cited 2020 Jan 8]. Available from: [www.sageusa.org/issues/isolation.cfm](http://www.sageusa.org/issues/isolation.cfm)
- SAGE. LGBT older adults in long-term care facilities: stories from the field [Internet]. 2011 [cited 2020 Jan 8]. Available from: <https://www.lgbtagingcenter.org/resources/resource.cfm?r=54>
- Hinrichs KLM, Vacha-Haase T. Staff perceptions of same-gender sexual contacts in long-term care facilities. *J Homosex*. 2010;57(6):776-89. <https://doi.org/10.1080/00918369.2010.485877>