Revista Bioética
Print version ISSN 1983-8042 | On-line version ISSN 1983-8034

Palliative care and the trans population: a study analysis and integrative review

Luciano Máximo Scandiuzzi [1], *Marcia Regina Chizini Chemin* [2]

1. Hospital Santo Antônio, Blumenau/SC, Brasil. **2.** Pontifícia Universidade Católica do Paraná, Curitiba/PR, Brasil.

Abstract

Palliative care is the excellence in comprehensive care when there is no expectation of cure. This study investigated whether trans people have received palliative care in specialized services for their reality, if public policies contemplate the provision of these services and if there is any studies on the subject. An integrative literature review was conducted to find out how the situation is evidenced; if there were reports from patients and/or family members and what they reveal; the public policies in this regard were analyzed. The theme in the publications was incipient; there is no mention of specialized palliative care for trans people in public policies, and reports confirm the discrimination suffered by patients and family members. This invisibility can contribute to trans people not receiving the attention they deserve given the inequality they face due to discrimination. There is the need to conduct research to support public health policies.

Keywords: Transgender Persons. Sexual and gender minorities. Palliative care.

Resumo

Cuidados paliativos e população trans: análise de estudo e revisão integrativa

Cuidados paliativos é a excelência no cuidado integral para quando não há expectativa de cura. Investigou-se se pessoas trans têm recebido cuidados paliativos em serviços especializados para sua realidade, se as políticas públicas contemplam a oferta desses serviços e se há pesquisas na temática. Fez-se revisão integrativa de literatura para saber como está evidenciada a situação; se havia relatos de pacientes e/ou de familiares e o que revelam; analisaram-se as políticas públicas a respeito. Resultou como incipiente a temática nas publicações; não há menção a cuidados paliativos especializados para atenção a pessoas trans nas políticas públicas, e relatos confirmam a discriminação que sofrem paciente e familiares. Essa invisibilização pode contribuir para que pessoas trans, em desigualdade por discriminação, não recebam a atenção devida. Considera-se necessário realizar pesquisas para embasar políticas públicas de saúde.

Palavras-chave: Pessoas transgênero. Minorias sexuais e de gênero. Cuidados paliativos.

Resumen

Cuidados paliativos y población trans: análisis de estudios y revisión integradora

Los cuidados paliativos son la esencia en la atención integral cuando no hay expectativa de curación. Este artículo pretendió identificar si las personas trans han recibido cuidados paliativos en servicios especializados para su realidad, si las políticas públicas incluyen la prestación de estos servicios y si hay investigaciones sobre el tema. Se realizó una revisión bibliográfica integradora para conocer cómo se evidencia la situación; si existen relatos de pacientes y/o familiares y qué revelan; y se analizaron las políticas públicas sobre el tema. El tema fue incipiente en las publicaciones; no cita los cuidados paliativos especializados para personas trans en las políticas públicas; y los informes confirman la discriminación que sufren los pacientes y familiares. Esta invisibilidad puede contribuir a que las personas trans en condición de desigualdad por la discriminación no reciban los debidos cuidados. Se requieren estudios futuros para apoyar las políticas de salud pública.

Palabras-clave: Personas transgénero. Minorías sexuales y de género. Cuidados paliativos.

The authors declare no conflict of interest.

http://dx.doi.org/10.1590/1983-803420253762EN

"When I met her, her eyes expressed anguish, fear, an indescribable difficulty in expressing herself, not only because she faced a life-threatening disease in the process of finitude, but it seemed that her fear went beyond it. The fear of not being recognized, of not being perceived as she is, of not being respected and supported with compassion was evident. I called her by her social name, I affirmed the beauty of her name, how much her name was a representative construction of a beautiful story, that from that moment on I would like to be part of this journey and alleviate pain and suffering as much as possible. Her eyes closed, she relaxed and for a moment allowed herself to smile hopefully" (authors' report).

Discrimination among people can be due to ethnic-racial, cultural, socioeconomic, and gender and/or sexual aspects. Living in Brazil and being a transgender individual, a trans person, is intensely difficult, since it is the country in which the most trans people are murdered in the world, a statistic that has led consecutively for the last 14 years. Between October 2022 and September 2023, *320 murders of trans people and people with gender diversity were reported; 94% of the victims were trans women or trans feminine people.* (...) *almost a third (31%) of the total occurred in Brazil*[1]. This reality is challenging for trans people, either because of the non-recognition of their gender identity, the disrespect for their trajectory and way of life, the lack of support of public health policies, or because of the rare research regarding their health and illness.

There is a lack of knowledge of how to take care and support trans people when they reach aging and have their own demands because they are more susceptible to chronic-degenerative diseases, for example. The life expectancy of a trans person in Brazil is 35 years on average, but this fact does not prevent them from aging and being affected by cognitive disorders associated with aging, chronic diseases in general, cervical cancer, heart diseases and lung diseases, among others. Such a context should generate the construction of comprehensive health care centered on the sick person. If the sick trans person is eligible for palliative care (PC), these should be provided by the multidisciplinary team in a distinctive way, respecting gender identity, and its singularities, e.g., admitting non-blood family ties and the legitimacy of partners as valid, as occurs with cisgender people.

Ethically, there is no reason to deny understanding of the peculiarities of human relationships; when doing so during health care, even more so in PC, vulneration is produced: the increased vulnerability due to illness is exacerbated by the care uncommitted to the biography, affective ties, and/or values of the person who is suffering. This ethical aspect applies indiscriminately to cis or trans people, so it is worth thinking about how health care is being organized and offered.

This article is interested in investigating whether trans people have access to PC, that is, if they are respected for who they are, whether their partners are cared for as a family, and, therefore, welcomed as a care unit, as recommended by PC. The research aims to answer some questions: what has been published about PC and the trans population? If there are publications, what aspects were addressed? Are they addressed as public health policy? If there were studies with trans people, how did they, or their family members, report the care received at the end of life? Did they receive PC?

To this end, an integrative literature review was conducted. The discussion of the results takes place according to the aspect of protection bioethics, which *applies pertinently to any moral patient who cannot defend themselves or act autonomously for some reason independent of their will and capacities*[2], such as people in end-of-life care, i.e., in the most active phase of PC. Texts referring to public policies were investigated to find out if and how they address the need for specialized PC services for trans people.

Palliative care and trans people

Palliative care, as a therapeutic approach, corresponds to excellence in comprehensive care. This is made explicit when the prevention and control of pain (management of suffering), in the absence of expectation of cure, is the best to be provided as expanded care and, even so, centered on the patient[3]. Support to the family during illness and after death, during the period of mourning, and the scope of PC is seen as a principle[4,5].

The inaugural historical moment of the inclusion of sexual orientation and gender identity in the set of elements necessary for the analysis of the social determination of health was the 13th National Health Conference, in 2008[6]. Although numerous gaps remain, the recommendations of the conference have illuminated the negotiations.

In 2011, Ordinance No. 2,836 of the Ministry of Health instituted the National Comprehensive Health Policy for Lesbians, Gays, Bisexuals, *Travestis* and Transsexuals to be implemented within the scope of the Unified Health System (SUS)[7]. Days later, the Comissão de Intergestores Tripartite (CIT) announced the resolution resulting from the ordinance, which establishes strategies and actions that guide the Operational Plan of this National LGBT Comprehensive Health Policy[8]. In the following year, the Ministry of Health showed the National LGBT Health Policy as *a watershed for public health policies in Brazil and a historic milestone in the recognition of this population's demands in a condition of vulnerability. This is also a guiding and legitimizing document for their needs and specificities*[9], although it is in accordance with the precepts of the Constitution of the Federative Republic of Brazil[10], comply with the Universal Declaration of Human Rights[11], and the Letter of Users of the Unified Health System[12].

Among the reasons, in the Introductory Recitals of the Ordinance, it is stated *the need to expand health actions and services specifically aimed at meeting the peculiarities of the LGBT population*[9]. One of the objectives this ordinance[9], art. 2, II, is to *expand the LGBT population's access to SUS health services, ensuring people the respect and provision of quality health services and the resolution of their demands and needs*, that is, the necessary personalization during the service is recognized and there is a lack of preparation, since it is objective, according to art. 2, III, *qualify the SUS service network for the attention and comprehensive health care of the LGBT population.*

Palliative care is not mentioned in the entire content of the policy; although there is a need for cancer care, no palliative approach was listed, not even for end-of-life care. The aim in art. 2, XXIV: *conduct studies and research related to the development of services and technologies aimed at the health needs of the LGBT population*[9].

Palliative care did not receive proper attention and implementation guidance within the scope of the Unified Health System before 2018, even though entities, organizations, and global authorities had advised that PC should progressively reach all people in a consistent way with comprehensive care and continued health care. In 2018, the palliative care approach was included in the scope of the SUS[13], in line with the recommendations of the World Health Organization (WHO), which since 2014 has stated that PCs, which previously were aimed at cancer patients[14], should be indicated for all people who benefit from such conduct[15,16]. However, normative legislation has not yet been established so that PC is actually offered in a broad and equitable way.

The first edition of the *Global Atlas of Palliative Care*, in 2014, in line with the expansion of the PC scope by the WHO, advised that, for all people to have guaranteed access to PC, *special attention should be paid to populations such as children, older adults, and marginalized groups*[17]; those who were part of this group were not distinguished. In the most recent *Global Atlas of Palliative Care*, the recommendations for national governments are that anyone in need of PC should be served. Ensure respectful care, which recognizes their dignity, *is a crucial responsibility of national health systems*; it is highlighted that *this responsibility should include those who are systematically left behind, such as children, older adults, prisoners, sex workers, drug addicts, refugees, homeless people, and LGBT+ communities*[18].

One of the most consulted literatures in Brazil, the *Palliative Care Handbook* of the National Academy of Palliative Care (ANCP), in its three editions[19-21], which are a reference for palliative care professionals, makes no mention of LGBTQIA+ people, or the LGBT+ community, neither to

Research

observe singularities nor to draw attention to the lack of public policies actually implemented focusing on this population. In *Atlas of palliative care in Brazil 2019*[22], there is also no mention of the LGBT population, nor of trans people.

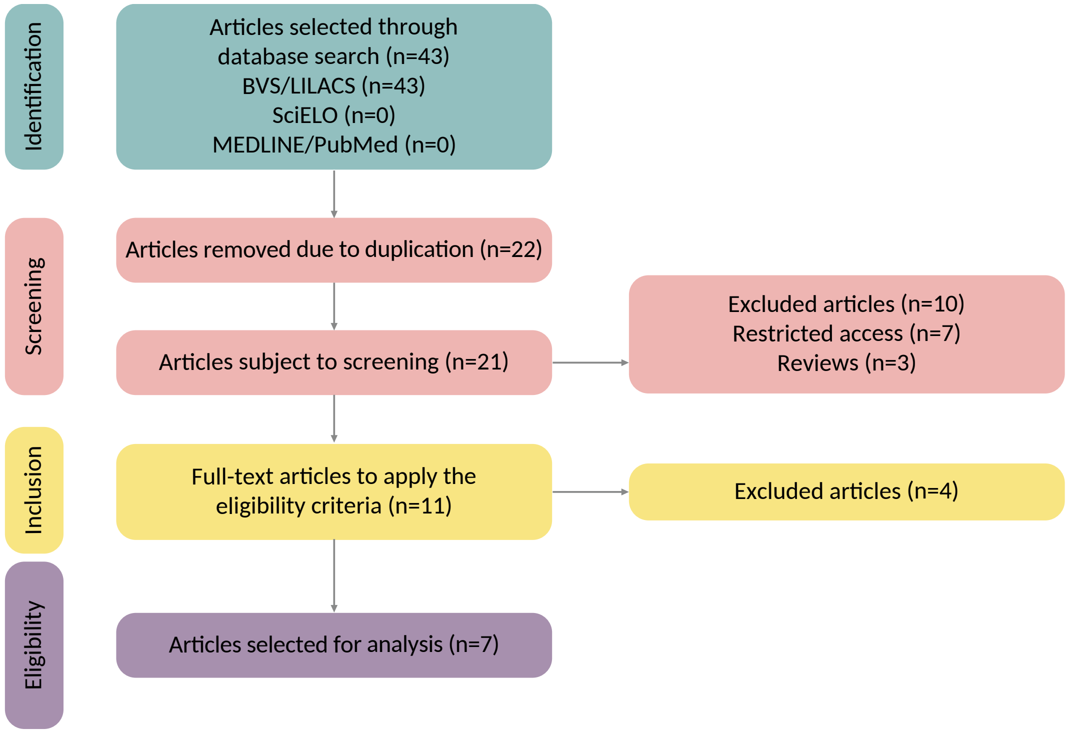
Still, there are no projects among the ANCP's actions that are entirely focused and dedicated to the trans population/community. There is no committee/working group in the ANCP that, as other[23], is dedicated, research, discuss the needs of trans people, have study projects for public discussions, and fight for better conditions of care and support for their finitude.

Method

Integrative literature reviews are broad analyses of the literature, which intend to contribute to the discussion on the results of other research[24]. This is a basic, exploratory, and bibliographic study[25]. The following electronic bibliographic databases were explored: Medical Literature Analysis and Retrieval System Online (Medline), Latin American and Caribbean Center on Health Sciencies Information (LILACS), Scientific Electronic Library Online (SciELO), and Scopus (Elsevier). Articles in Portuguese, Spanish, and English that were available in full and freely in the databases were searched. The exclusion criteria were as follows: duplicate articles and review articles. The descriptors used, in Portuguese, and correlated in English and Spanish, were: "palliative care," "transgender," "terminality," and "end-of-life care." To broaden the capture of articles, various combinations were used with the descriptors, and the publication period was not delimited. The publications should correspond to the focus of this research: to collect published knowledge about PC and its offer to the trans population.

The survey resulted in 43 articles, all of them in LILACS. Twenty-two duplicate articles were discarded, and the abstracts of the remaining 21 were read. Subsequently, ten articles were excluded according to the inclusion and exclusion criteria. Ten of the selected articles were read in full, to which the eligibility criteria were applied, resulting in the analysis and discussion of seven articles (Figure 1).

Figure 1. Flowchart based on PRISMA, with details of study selection



Source: adapted from Moher and collaborators[26].

Results

The detailed reading of the articles enabled us to observe the size of the samples, the number of participants, where they were conducted, in which contexts, the training of the researchers and the scope of the journals in which they were published.

The studies have a qualitative and quantitative approach and are descriptive, and cross-sectional (one with health service providers, and the other with LGBTQ+ older adults). Such studies bring evidence based on case reports. These are surveys conducted in the United States of America: four publications, in 2019, 2020, 2021, and 2023; in Canada: two publications, in 2015 and 2018; and in Brazil: one publication, from 2022. As the theme involves multidisciplinarity/interdisciplinarity, the authors are professionals from social work, nutrition, medicine, nursing, and psychology. The journals have the scope and interest of publishing interdisciplinary research, focusing on social issues related to aging (2), geriatrics and gerontology (2), nursing/palliative nursing (2), and, specifically, PC (1).

The participants were as follows: older or non-LGBTQ+ people[27-29]; people in general, assembled after the results according to self-identification, in LGBT+ and non-LGBT+[30]; transgender people at the end of their lives[31]; and PC professionals[32,33].

The study by Kortes-Miller and collaborators[27], which were conducted in Canada, had the participation of 23 older adults, who were aged 57 to 78 years, identified themselves as LGBTQ+, and answered the questionnaire with open questions. All participants reported they would feel at risk if they had to live their final phase of life in long-term care institutions after informing their sexual orientation and/or gender identity: *older LGBTQ+ adults* (...) *fear being forced to silence parts of identities to protect themselves and appease others*[34]. Although the focus of the research was not specifically on PC, the authors conclude that, concomitantly with the integration of PC in these institutions, there is the need to *address unique health needs* of LGBTQ+ older adults, and understand that the results should be used educationally for PC professionals, and to *establish professional competencies to promote equitable and differentiated care for LGBTQ+ older adults*[35].

A case study by Campbell and Catlett[31] aimed to learn about the spiritual care of a self-identified trans woman hospitalized in a hospice in the last months of life in PC. The volunteer spiritual caregiver was interviewed by the researchers via telephone; they based themselves on the book written by the person in PC and this volunteer, and on the chaplain's notes. The authors point out that *affirmation of gender identity is a spiritual necessity*[36] and they emphasize the importance of recognizing that the family is also the chosen one, expanded, because such recognition impacts the advance planning of care.

With the intention to verify if the care in PC is inadequate, disrespectful, and abusive due to sexual orientation or gender, to patients and family members, Stein and collaborators[32] recruited 865 participants, including physicians, social workers, nurses, and chaplains who provided services in PC and in hospice. More than half believe that lesbian, gay, and bisexual patients suffer discrimination. More than 64% reported trans patients are more likely to be discriminated against non-trans ones. More than 21% observed discrimination against transgender patients. As for spouses/partners of LGBT patients, 15% of participants noted their treatment decisions were disregarded or minimized, and more than 14% noted they disrespected. More than 80% reported having no trans patients or were unsure of having seen trans patients. They conclude that people from the LGBT community should be part of the staff; patients, family members, and staff should be able to report discriminatory treatment; and PC teams should be trained for non-discriminatory care.

The investigation, which is an excerpt from another with a broader scope (inequalities in access to medical care), by Crenitte and collaborators[30], aimed to compare the perceptions of end-of-life care of 6,693 older adults, 5,361 non-LGBT+, and 1,332 LGBT+. The result was that, in the comparison, LGBT+ participants use the public health system more, have lower salaries, are mostly single, and are more afraid of dying alone, however, they do not want to live in a long-term care institution, due to fear of discrimination. In a modified analysis for transgender people, the trend remained the same.

Based on a sample of 31 interviews with LGBT older adults, Candrian and Cloyes[29] show a study focused on a participant's story to illustrate how end-of-life care can be compromised if there is no open discussion with sick people about what and who is most important to each at the end of life. The authors state that LGBT older adults are particularly vulnerable at the end of life, as they may not receive adequate health care, and their families of choice are less likely to participate in decision-making. But it is precisely in this final phase of life that there can be reconciliation with people who have moved away/rejected. And yet, LGBT older adults who lose a spouse and/or partner are at risk of not receiving support during the mourning period. They conclude that the identity and meaningful relationships of the sick person must be recognized, without judgment, to provide person-centered care, regardless of whether they identify as LGBT.

In Hughes and Cartwright's[28] research regarding end-of-life care planning, with the participation of 305 LGBT people, more than half of the participants, mainly people self-identified as women and transgenders, answered they prefer to rely on a partner to make decisions, even when they can no longer manifest themselves. This research shows there are failures in the acceptance of professionals and understanding regarding planning care by sick people, making decisions or appointing a representative for this in advance: 52% had already talked to a partner about it, but less than 30% registered the desire formally; the authors believe that this reality can be changed with due attention to PC for this population.

Lippe and collaborators[33] aimed to describe elements of inclusive PC for trans and gender-nonconforming people (TGNC) and to show affirmative clinical practice recommendations for inclusion, specifically for nursing professionals who work in PC. The recommendations focus on critically ill TGNC people and their families, for whom family is choice, due to the rejection of the biological one. The authors cite that PC can be *complicated by several legal and policy issues that can prevent health care providers from contacting anyone who is not legally identified as next of kin* (…) *grief care can become especially difficult when the family of origin* (…) *does not support and affirm gender*[37]. The same authors also recommend active and attentive listening, starting by asking each person what name and pronoun they want to be used and with whom they want this instruction to be shared; observe hormonal and/or non-hormonal therapies in relation to PC medication and its continuity according to individual needs; note that there may be additional distressing conditions for mental health; promote dignity and the integration of spiritual care.

Discussion

Trans people are unique, and two aspects can be highlighted. First, each trans person *is a unique person, who, however, has common characteristics to all humanity*, which both approximate and differentiate, as well as *the region where we were born and raised*, *our race*, *social class*, *whether we have a religion*, *age*, *our physical abilities*, *among others that mark human diversity*[38].

Second, the issue that approximates and differentiates regarding gender, *transsexuality is a matter of identity. This is not a mental illness, it is not a sexual perversion, nor is it a debilitating or contagious disease*[39]. Stuart Hall[40] states that identity is something formed over time, via unconscious processes, and is always an incomplete process, like a lack of wholeness that is filled over time, which refers to the identification of the social, political, historical-cultural, spiritual, psychological, religious, economic, and biological individual.

These people, such as everyone else, are vulnerable to disease and are finite. At some point, they may be diagnosed with severe and fatal disease, be eligible for PC, and benefit from this approach to care. They face difficulties to be adequately cared for in health services because they are trans, since the stigma precedes and the lack of knowledge about their reality does not contribute. In other words, it is reasonable, and an ethical duty, to provide them with personalized attention. But are there specialized services to serve this population? None declared.

The reality faced by trans people in specialized access to health in Brazil is still deficient. When seeking information on health services with attention to the trans population, there is no mention of palliative care; in this regard, the most recent *Atlas* of the ANCP [23] did not identify any service.

Although the Ministry of Health showed the Health Care Program for the Trans Population (Paes Pop Trans) [41] in December 2024, which provides for a series of implementations, the provision of palliative care services is not foreseen nor included. Although a broad and comprehensive service is announced, it is not specified how the National Policy on Palliative Care will be complied with, or how Paes Pop Trans will be implemented.

The Brazilian panorama of health services aimed at the trans population is self-explanatory. There are three hospital care centers dedicated to trans people throughout the territory corresponding to the North (17.4 million inhabitants), Northeast (54.6 million inhabitants), and Midwest (16.3 million inhabitants) regions; another guideline: there are 21 health establishments in the country (203 million inhabitants) that are qualified to provide specialized care in the transsexualization process, of which only seven provide both outpatient and hospital care [42,43].

If since 2006 [12] a person can present themselves to the Unified Health System with their social name, if since 2008 [44] there is a public health policy so that trans women can receive hormone therapy/sex reassignment surgeries, if since 2013 [45] trans men were included in the same public policy, it is due to the consideration that there are trans people and who have specific needs. Because they exist, trans people can be affected by diseases, and diseases can be fatal, so it is indisputable that they can benefit from a better quality of life if they are under PC. While facing a fatal disease, quality of life implies providing quality of death, taking care of those who are under care and their families, offering PC services from the perspective of equity and treating unequally unequal.

Trans people seek to be in safe and inclusive environments when they need health care [27]. It is not surprising that this is not the case in Brazil, because, even in the most recent census, according to a process promoted by the Federal Public Prosecution's Office (FPPO), *the surveys do not have a national coverage collection and reduced capacity for disaggregation by sociodemographic group, which has prevented a reliable X-ray of the social, geographical, economic, and cultural profile of LGBTQIA+* [46]. The MPF also adds that *there are international precedents regarding the inclusion of the LGBTQIA+ population in demographic censuses* and *argues that both the Federal Supreme Court and the Inter-American Court of Human Rights have established jurisprudence to guarantee rights to the LGBTQIA+ population* [46].

In the decision of the action proposed by the MPF [46], it is reported that *the omission that the Brazilian State, historically, has used to the detriment of the LGBTQIA+ population is relevant and needs to be corrected*. The judge emphasizes that, in addition to the various discriminations *practiced by action, there is also the violation of rights by state omission. Ignoring them, Brazil does not turn to LGBTQIA+ people with the state apparatus that guarantees, at a minimum, dignity*. It also states that *problems such as violence and the failure to provide public health to the population in question* (…) *can be fought with the implementation of public policies by the Brazilian State*, and then questions himself and society: *but how to plan a policy for a population that does not even know how many are there, where are they, and what are their greatest needs in each Brazilian region?* [54] Despite the preliminary decision, the Brazilian Institute of Geography and Statistics (IBGE) alleged the financial impossibility of conducting a census with questions on sexual orientation and gender identity.

In this sense, the Human Rights Commission of the Federal Senate [47] approved a project that *obliges the IBGE to collect data related to the LGBTQIA+ population (lesbians, gays, bisexuals,* *transsexuals, queer, intersex, asexuals, and others) in censuses and other periodic surveys*; refers to Bill 1,082/2023[48]. This reality is in line with the study by Crenitte and collaborators that pointed out that *related issues and gender diversity should not only be part of macropolitics in the debate on public policies aimed at reducing inequality, but also of micropolitics*; this concerns the *creation of welcoming institutions and the inclusion of this type of theme in palliative care training programs*[49].

The affirmation of gender identity is also a spiritual necessity, in addition to being biopsychosocial. Thus, assist the trans person in their entirety means not depriving them of themselves; of being who they are, how they recognize and identify themselves; to be called by her social name; to be supported in their most urgent affections; and to have the presence of a partner at all times of their care and hospital treatment, as occurs with heterosexual and cis people[31,33]. Furthermore, Campbell and Catlett point out that *PC team members can support spiritual expression* (...) *and breaki down the barriers of stigma, lack of understanding and, complex family dynamics*[50].

Paying attention to the needs that exist in each dimension of human life—biological, social, spiritual, family, religious, or biographical—will allow the trans community to exercise its autonomy, being able to develop advanced care planning together with the health team. In other words, they can become the protagonist of their care, of their life and, so to speak, of their finitude, by deciding how they want to be cared for in the final moments of their life[28].

Final considerations

The critical analysis of the studies shows that it is still insufficient to include this topic on the agenda in the context of health care, especially when it comes to people diagnosed with a severe and/or fatal disease, eligible for PC, and already in end-of-life care.

The collaboration of bioethics in this context of end-of-life experiences involving trans people is to promote reflection, dialogue, and, when possible, provide bases for the promotion of public health policies. Some ethical-bioethical references illuminate the issue and are translated into actions; for example, the autonomy of the trans person translates into having the right to identify themselves as such when entering a health institution for treatment and having their social name and gender identity welcomed and respected—which must be included in their medical records. As well as having knowledge and contact information of their chosen family or their partner, who should be urged to participate in the decision-making process.

Barriers to access to health services are revealed as stigmatization and discrimination, in a perverse dynamic, often occurring quietly and occasionally gaining media spotlight, at the expense of more exposure and stigmatization; in this case, non-maleficence applies—if there is no way to promote good, at least do no harm. Caring for the sick person presupposes placing them at the center of attention in health practices and not focusing on the disease or in their gender identity.

From the point of view of social justice and equity, it is necessary to think of public health policies differently in the face of different situations and populations that are different from most of the population—in this case, heteronormativity. There are not a few gaps.

Thus, it is expected that the recently approved National Policy on Palliative Care[51], in which bioethical contributions are evidenced, recognizes the differences between people, valuing them. The hope is that other research will focus on the trans population and their needs to no longer be invisible and pay attention to them, after all, perceiving the intrinsic dignity and equally in each human being must be an always renewed calling.

References

1. Trans murder monitoring 2023 global update [Internet]. Berlin: TGEU; 2023 [acesso 28 jan 2025]. Tradução livre. Disponível: https://bit.ly/4kbVY4C

2. Schramm FR. Bioética da proteção: ferramenta válida para enfrentar problemas morais na era da globalização. Rev. bioét. (Impr.) [Internet]. 2008 [acesso 28 jan 2025];16(1):11-23. p. 18. Disponível: https://bit.ly/43umK0K
3. Saporetti LA, Andrade L, Sachs MFA, Guimarães TVV. Diagnóstico e abordagem do sofrimento humano. In: Carvalho RT, Parsons HA, editores. Manual de cuidados paliativos ANCP. 2ª ed. Porto Alegre: Sulina; 2012. p. 42-55.
4. World Health Organization. National cancer control programmes: policies and managerial guidelines [Internet]. 2ª ed. Geneva: WHO; 2002 [acesso 28 jan 2025]. Disponível: https://bit.ly/3ZvWNNb
5. Wenk R. Palliative care – 2018 IAHPC consensus based definition. Pallipedia [Internet]. 2019 [acesso 28 jan 2025]. Disponível: https://bit.ly/3YUeYvW
6. Brasil. Ministério da Saúde. Conselho Nacional de Saúde. Relatório Final da 13ª Conferência Nacional de Saúde: saúde e qualidade de vida: políticas de estado e desenvolvimento [Internet]. Brasília: Ministério da Saúde; 2008 [acesso 28 jan 2025]. Disponível: https://bit.ly/4mrD8I2
7. Brasil. Ministério da Saúde. Portaria n° 2.836, de 1° de dezembro de 2011. Institui, no âmbito do Sistema Único de Saúde (SUS), a Política Nacional de Saúde Integral de Lésbicas, Gays, Bissexuais, Travestis e Transexuais (Política Nacional de Saúde Integral LGBT). Diário Oficial da União [Internet]. Brasília, p. 35, 2 dez 2011. [acesso 29 jul 2025]. Disponível: http://bit.ly/4mhkkdB
8. Brasil. Ministério da Saúde. Comissão Intergestores Tripartite. Resolução n° 2, de 6 de dezembro de 2011. Estabelece estratégias e ações que orientam o Plano Operativo da Política Nacional de Saúde Integral de Lésbicas, Gays, Bissexuais, Travestis e Transexuais, no âmbito do Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, p. 45, 8 dez 2011 [acesso 28 jan 2025]. Seção 1. Disponível: https://bit.ly/4jmZcB5
9. Brasil. Ministério da Saúde. Secretaria de Gestão Estratégica e Participativa. Política Nacional de Saúde Integral de Lésbicas, Gays, Bissexuais, Travestis e Transexuais [Internet]. Brasília: Ministério da Saúde; 2013 [acesso 28 jan 2025]. p. 6. Disponível: https://bit.ly/3Fqw51H
10. Brasil. Constituição da República Federativa do Brasil. Diário Oficial da União [Internet]. Brasília, 5 out 1988 [acesso 28 jan 2025]. Disponível: https://bit.ly/3S9WB2F
11. Organização das Nações Unidas. Declaração Universal dos Direitos Humanos [Internet]. Paris: Unicef; 1948 [acesso 28 jan 2025]. Disponível: https://bit.ly/4muDPjO
12. Brasil. Ministério da Saúde. Carta dos Direitos dos Usuários da Saúde [Internet]. 3ª ed. Brasília: Ministério da Saúde; 2011 [acesso 23 nov 2023]. Disponível: https://bit.ly/3Z0LcFP
13. Brasil. Ministério da Saúde. Comissão Intergestores Tripartite. Resolução n° 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, n. 225, p. 276, 23 nov 2018 [acesso 28 jan 2025]. Seção 1. Disponível: https://bit.ly/3SiFP0Y
14. World Health Organization. Expert Committee on Cancer Pain Relief and Active Supportive Care. Cancer pain relief and palliative care: report of a WHO Expert Committee [Internet]. Geneva: WHO; 1990 [acesso 28 jan 2025]. (World Health Organization Technical Report Series; 804). Disponível: https://bit.ly/4dPy5xv
15. Organización Mundial de la Salud. 67ª Asamblea mundial de la salud. Ginebra. Resoluciones y decisiones. Anexos [Internet]. 2014 [acesso 28 jan 2025]. Disponível: https://iris.who.int/handle/10665/260341
16. World Health Organization. Palliative care. WHO [Internet]. Fact sheets; 5 ago 2020 [acesso 28 jan 2025]. Disponível: https://bit.ly/45lvxVl
17. Connor SR, Bermedo MCS, editores. Global atlas of palliative care at the end of life [Internet]. London: WPCA; 2014 [acesso 28 jan 2025]. p. 71. Tradução livre. Disponível: https://bit.ly/4kwZqX4
18. Morris C, Davies H. What is the way forward?. In: Worldwide Hospice Palliative Care Alliance. Global atlas of palliative care [Internet]. London: WHPCA; 2020 [acesso 28 jan 2025]. p. 93. Tradução livre. Disponível: https://bit.ly/4msO8F1
19. Carvalho RT, Parsons HA, editores. Manual de cuidados paliativos ANCP. 2ª ed. Porto Alegre: Sulina; 2012.
20. Castilho RK, Silva VCS, Pinto CS. Manual de cuidados paliativos ANCP. 3ª ed. Rio de Janeiro: Atheneu; 2021.

21. Academia Nacional de Cuidados Paliativos. Manual de cuidados paliativos [Internet]. Rio de Janeiro: Diagraphic; 2009 [acesso 28 jan 2025]. Disponível: https://bit.ly/3SQnOXW

22. Santos AFS, Ferreira EAL, Guirro UBP. Atlas dos cuidados paliativos no Brasil 2019 [Internet]. São Paulo: ANCP; 2020 [acesso 28 jan 2025]. Disponível: http://bit.ly/3H82rPC

23. Academia Nacional de Cuidados Paliativos. Comitês [Internet]. 2023 [acesso 10 nov 2023]. Disponível: https://bit.ly/3ZvaL1K

24. Fonseca JJS. Metodologia da pesquisa científica. Fortaleza: UEC; 2002.

25. Gil AC. Como elaborar projetos de pesquisa. 5ª ed. São Paulo: Atlas; 2010.

26. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med [Internet]. 2009 [acesso 28 jan 2025];6(7). DOI: 10.1371/journal.pmed.1000097

27. Kortes-Miller K, Boulé J, Wilson K, Stinchcombe A. Dying in long-term care: perspectives from sexual and gender minority older adults about their fears and hopes for end of life. J Soc Work End Life Palliat Care [Inernet]. 2018 [acesso 28 jan 2025];14(2-3):209-224. p. 214. Tradução livre. DOI: 10.1080/15524256.2018.1487364

28. Hughes M, Cartwright C. Lesbian, gay, bisexual and transgender people's attitudes to end-of-life decision-making and advance care planning. Australas J Ageing [Internet]. 2015 [acesso 28 jan 2025];34(2):39-43. DOI: 10.1111/ajag.12268

29. Candrian C, Cloyes KG. "She's dying and I can't say we're married?": end-of-life care for LGBT older adults. Gerontologist [Internet]. 2021 [acesso 28 jan 2025];61(8):1197-201. DOI: 10.1093/geront/gnaa186

30. Crenitte MRF, Melo LR, Wilson J, Silva TJA. Palliative care over the rainbow: perspectives of middleage and older LGBT+ adults regarding their end-of-life. Geriatr Gerontol Aging [Internet]. 2022 [acesso 28 jan 2025];16:1-4. DOI: 10.53886/gga.e0220026

31. Campbell CL, Catlett L. Silent illumination: a case study exploring the spiritual needs of a transgender-identified elder receiving hospice care. J Hosp Palliat Nurs [Internet]. 2019 [acesso 10 nov 2023];21(6):467-74. DOI: 10.1097/NJH.0000000000000596

32. Stein GL, Berkman C, O'Mahony S, Godfrey D, Javier NM, Maingi S. Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: perspectives of the palliative care team. J Palliat Med [Inernet]. 2020 [acesso 28 jan 2025];23(6):817-24. DOI: 10.1089/jpm.2019.0542

33. Lippe MP, Eyer JC, Roberts KE, Ritter ER, DiMauro PK, McKinney RE *et al*. Affirmative palliative care for transgender and gender nonconforming individuals. Am J Nurs [Internet]. 2023 [acesso 28 jan 2025];123(4):48-53. DOI: 10.1097/01.NAJ.0000925508.62666.99

34. Kortes-Miller K, Boulé J, Wilson K, Stinchcombe A. Op. cit. 2018. p. 214. Tradução livre.

35. Kortes-Miller K, Boulé J, Wilson K, Stinchcombe A. Op. cit. 2018. p. 222. Tradução livre.

36. Campbell CL, Catlett L. Op. cit. 2019. p. 469. Tradução livre.

37. Lippe MP, Eyer JC, Roberts KE, Ritter ER, DiMauro PK, McKinney RE *et al*. Op. cit. 2023. p. 51. Tradução livre.

38. De Jesus JG. Orientações sobre identidade de gênero: conceitos e termos. Guia técnico sobre pessoas transexuais, travestis e demais transgêneros, para formadores de opinião. Brasília: EDA/FBN; 2012. p. 7.

39. De Jesus JG. Op. cit. 2012. p. 14.

40. Hall S. A identidade cultural na pós-modernidade. 11ª ed. Rio de Janeiro: DP&A; 2006. p. 7-22.

41. Ministério da Saúde. Ministério da Saúde apresenta o Programa de Atenção à Saúde da População Trans. Agência Gov [Internet]. Notícias; 10 dez 2024 [acesso 8 fev 2025]. Disponível: https://bit.ly/4jeDLSv

42. Félix M. Serviços de saúde voltados à população trans no Brasil. Portal Drauzio [Internet]. 2025 [acesso 8 fev 2025]. Disponível: https://bit.ly/4kDFke1

43. Benevides B. Como acessar o SUS para questões de transição? ANTRA [Internet]. 27 jul 2020 [acesso 28 jan 2025]. Disponível: https://bit.ly/4kxKMPh

44. Brasil. Ministério da Saúde. Portaria nº 457, de 19 de agosto de 2008. Aprova, na forma dos Anexos desta Portaria, a Regulamentação do Processo Transexualizador no âmbito do SUS. Diário Oficial da União [Internet]. Brasília, 20 ago 2008 [acesso 8 fev 2025]. Disponível: http://bit.ly/4lWAny2

45. Brasil. Ministério da Saúde. Portaria nº 2.803, de 19 de novembro de 2013. Redefine e amplia o processo transexualizador no Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. Brasília, n. 225, p. 276, 20 nov 2013 [acesso 8 fev 2025]. Seção 1. Disponível: https://bit.ly/4kT8lmb

46. Brasil. Justiça Federal. Seção Judiciária do Acre. 2ª Vara Federal Cível e Criminal da SJAC. Ação Civil Pública nº 1002268-94.2022.4.01.3000/Classe:65. Decisão. TRF [Internet]. 2022 [acesso 29 jul 2025]. Disponível: http://bit.ly/4kZCAr2

47. Agência Senado. IBGE deve coletar dados sobre identidade de gênero, aprova comissão. Senado Notícias [Internet]. Matérias; 5 jul 2023 [acesso 28 jan 2025]. Disponível: https://bit.ly/43dDSJt

48. Brasil. Senado Federal. Projeto de Lei nº 1082, de 2023. Altera a Lei nº 8.184, de 10 de maio de 1991, para estabelecer a obrigatoriedade da coleta de dados sobre a população LGBTQIA+ pelos censos e outros levantamentos periódicos da Fundação Instituto Brasileiro de Geografia e Estatística (IBGE). Diário Oficial da União [Internet]. Brasília, 2023 [acesso 28 jan 2025]. Disponível: https://bit.ly/44Oamex

49. Crenitte MRF, Melo LR, Wilson J, Silva TJA. Op. cit. 2022. p. 3. Tradução livre.

50. Campbell CL, Catlett L. Op. cit. 2019. p. 470. Tradução livre.

51. Conselho Nacional de Saúde. Resolução nº 729, de 7 de dezembro de 2023. Aprova a Política Nacional de Cuidados Paliativos no âmbito do SUS (PNCP). Diário Oficial da União [Internet]. Brasília, p. 46, 15 jan 2024 [acesso 28 jan 2025]. Seção 1. Disponível: https://bit.ly/439E4cG

Luciano Máximo Scandiuzzi – Master – lucianomaximo28@gmail.com

0000-0002-9231-6517

Marcia Regina Chizini Chemin – PhD – maychizini@yahoo.com.br

0000-0002-2673-5107

Correspondence

Luciano Máximo Scandiuzzi – Centro de Saúde Rosânea Machado Pereira. Rua Dois de Setembro, 1212, sala 18 (SAD), Itoupava Norte. CEP 89052-000, Blumenau/SC, Brasil.

Participation of the authors

Both authors contributed equally in this article.

Editor in charge: Dilza Teresinha Ambrós Ribeiro

Received: 2.20.2024

Revised: 1.29.2025

Approved: 3.3.2025