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Original Article

Exploring the Lived Experience of Elderly Transgender People: Qualitative Phenomenological Study

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ABSTRACT

Objectives: This study explores the lived experiences of elderly transgender individuals residing in trans communities in Pondicherry, with a focus on their challenges in accessing end-of-life care and the broader societal, economic, and intergenerational issues affecting their well-being.

Materials and Methods: A phenomenological approach with descriptive analysis was employed over eight months. Six transgender individuals aged 50 and above were selected through purposive sampling. Baseline data were collected using a structured questionnaire, followed by in-depth, semistructured interviews conducted via Zoom. Each interview, lasting approximately one hour, was recorded, transcribed verbatim, and analysed using Hermeneutic Phenomenology to identify key themes.

Results: Eight constitutive themes emerged from the analysis: Challenges in Self-expression, reflecting struggles in living authentically; Dependency, indicating reliance on others for support; Generation Gap with Community Members, revealing disparities in values and perspectives; Handling Daily Struggles, highlighting daily adversities; Unheard Complaints, emphasizing societal neglect; Feeling Useless and a Burden, indicating diminished self-worth; Shrinking to Self, showing social withdrawal; and Segregation or Solitary Living, illustrating experiences of exclusion and isolation. These themes are encapsulated in the overarching theme, "Navigating Isolation and Dependency in the Lived Experience of Elderly Transgender Individuals."

Conclusion: The study reveals the profound impact of societal discrimination, economic hardship, and intergenerational gaps on elderly transgender individuals. It underscores the urgent need for advocacy, inclusive policies, and community-based support systems to address their unique challenges and enhance their quality of life, particularly in end-of-life care contexts.

Keywords: Elderly transgender, Lived experience, Palliatve care, Transgender

INTRODUCTION

In the global context, 'transgender' encompasses individuals whose gender identity or expression differs from their assigned sex at birth.^[1] Sexual and gender minorities, including transgender individuals, face significant marginalisation and vulnerability, affecting their access to high-quality medical care, including palliative and end-of-life (EOL) care.^[2] The 2011 census in India estimated that 4.8 million people identify as transgender, though social stigma likely causes underreporting.^[3]

Transgender individuals in India, particularly those experiencing economic and social vulnerabilities, face

unique care needs and significant barriers to accessing care due to economic constraints, oppressive policies and societal discrimination. These barriers lead to ongoing healthcare disparities for sexual and gender minorities. The EOL needs of transgender people are often overlooked, and most research focuses on elderly care for normative populations, neglecting those with diverse social positions.^[4] The transgender community in India deals with compounded stigma and violence due to multiple marginalised identities, including sex work and gender nonconformity, intersecting with issues such as economic insecurity, housing instability, employment discrimination and poverty. This increases their vulnerability,

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with high human immunodeficiency virus (HIV) prevalence and lack of social support, often resulting in them dying alone in inadequate settings. Research predominantly focuses on younger- or middle-aged transgender individuals, leaving the intersections of transgender identity and age largely unexplored.

The community is subject to compounded stigma and violence due to multiple marginalised identities, such as transgender status, sex work and gender nonconformity, which intersect with social inequities such as economic insecurity, housing instability, employment discrimination and poverty. These challenges contribute to high HIV prevalence and lack of social support, often resulting in transgender individuals dying alone in inadequate settings, such as acute care or on the streets.^[5] It is notable that transgender studies predominantly focus on younger- or middle-aged individuals, leaving the intersections of (trans) gender and age relatively unexplored.^[6]

The growing population of transgender older adults highlights the urgent need for inclusive and respectful EOL care tailored to their specific needs, as they often face discrimination, limited access to care and poor service quality, exacerbated by the COVID-19 pandemic.^[7,8] These individuals share ageing-related challenges, such as frailty and cognitive deficits, and frequently encounter restrictive policies hindering access to gender-affirming care.^[9,10] A study in South India by Madhavan et al. found high rates of non-communicable disease risk factors among 200 transgender individuals, emphasising their vulnerability compared to the general population.^[11] There is a significant gap in understanding the unique EOL experiences of elderly transgender individuals in India, particularly within trans communities, which underscores the urgent need for tailored support systems to address their specific challenges and vulnerabilities. This research aims to explore the lived experiences of elderly transgender people living in trans communities in Pondicherry, providing insights to inform more inclusive and supportive care practices.

MATERIALS AND METHODS

After obtaining ethical clearance from Institutional Human Ethics Committee (IHEC) (Ref No: IRC/43/2022), a phenomenological study with hermeneutic analysis was conducted to explore the unique perspectives and challenges faced by transgender individuals aged 50 and above in Pondicherry. Over 8 months, the study investigated the lived experiences of elderly transgender individuals in collaboration with the Sahodaran Community Oriented Health Development Society, an organisation dedicated to uplifting transgender people in Pondicherry. The recruitment strategy aimed to ensure a diverse and representative sample of elderly transgender individuals in Pondicherry using purposive sampling. Eligible participants were those aged 50 and above, willing to participate, accessible through Zoom, able to give informed consent and fluent in Tamil or English. Individuals with serious health issues or communication barriers were excluded. Recruitment was facilitated through local trans community organisations and referrals from community leaders. Interested individuals were screened for eligibility, and those who met the criteria and consented to participate were shortlisted. Zoom interviews were preferred due to their flexibility in scheduling, reduced need for travel and ability to include participants from various locations within Pondicherry. The virtual format also facilitated a comfortable and safe environment for participants, allowing them to engage in the interview from the privacy of their own homes, which was particularly advantageous during the COVID-19 pandemic.

The two-step data collection process began with a structured questionnaire to gather baseline information on demographics, medical history and socioeconomic status. Subsequently, in-depth semi-structured interviews were conducted to explore participants' lived experiences.

An open-ended semi-structured interview schedule was used to explore the lived experiences of elderly transgender individuals. The interview began with a self-introduction and background information, followed by a main question: 'Describe your experience with your ageing'. Five additional guide questions will address physical, psychological, spiritual, financial and social aspects, with probing prompts developed in collaboration with a transgender technical assistant. These prompts include questions such as, 'Could you share your problems due to ageing?' and 'How has ageing affected your life? Please provide examples or further explanations. The main leading question focused on describing the participants' experiences with ageing, while five additional questions covering physical, psychological, spiritual, financial and social aspects served as guide questions to explore detailed information. Probing questions, developed in collaboration with a transgender technical assistant, aimed to elicit comprehensive responses, addressing challenges related to ageing, its impact on various aspects of life and the participants' feelings and reflections. All interviews were recorded, transcribed verbatim and translated for manual analysis using Hermeneutic phenomenology,^[12] an interpretive approach within phenomenological research that focuses on understanding and interpreting the lived experiences of individuals while acknowledging the influence of the researcher's perspective. This method aims to uncover the essence of participants' experiences through deep engagement with their narratives.^[13] Participants shared their significant experiences, family histories, relationships, employment, spirituality, health challenges, mental health issues, substance use histories, interactions with healthcare providers and their evolving sense of self. A total of 18 interviews were conducted with six participants, each starting

with a self-introduction and collection of background information.

The interviews, lasting approximately 1 h each, were recorded, saved and transcribed. The questions catalysed participants to delve into various facets of their lives, providing rich insights into their unique journeys. The primary investigator prepared the transcripts, subsequently distributing them among the authors for in-depth examination. The authors conducted multiple readings to identify the data's emerging themes and constitutive patterns. Coding involved identifying significant statements and grouping them into overarching themes. This process was iterative and included multiple readings of the transcripts to ensure comprehensive analysis. Essential discussions ensued among the authors, focusing on the recognised themes and patterns. Any divergences in data analysis were openly acknowledged, prompting a revisit to the transcripts and fostering continuous analysis and discussion. To ensure rigour and reflexivity in the analysis, the research team engaged in iterative discussions and multiple readings of the transcripts. Divergences in interpretation were addressed through consensus-building discussions, ensuring that the themes accurately reflected the participants' experiences. The integration of direct quotes provided a robust and nuanced understanding of the challenges faced by elderly transgender individuals. This iterative process persisted until a unanimous consensus was achieved among the research team, thereby bolstering the rigour and reflexivity of the qualitative analysis.

Several challenges were encountered during the study, including technical issues with Zoom interviews due to poor internet connectivity, which disrupted conversations. Participants also showed hesitation in speaking openly in the virtual setting. To address these issues, interviews could be rescheduled, and rapport-building techniques were used to improve comfort. In addition, maintaining the accuracy of participants' expressions during transcription and translation was challenging, and this was managed through careful review and cross-checking by the research team.

The results underscore the complex interplay between individual experiences and broader societal factors, emphasising the need for targeted support and advocacy to address the unique challenges faced by this vulnerable population.

RESULTS

Among the six elderly transgender individuals, three were diagnosed with both hypertension and diabetes. Participants are renamed to A, B, C, D, E and F to ascertain anonymity. These individuals resided with and relied on support from community members for their daily living activities. The comprehension of the lived experience of elderly transgender individuals is derived from a hermeneutic analysis of the participants' narratives. Eight constitutive themes surfaced from the transcripts, providing a nuanced understanding of their experiences:

- I. Challenges in self-expression: Transgender individuals encounter difficulties in freely expressing their gender identity, often due to societal norms, discrimination, or a lack of understanding. Respondent B said, 'I always have to hide who I am. Society expects us to conform, and if I express my true gender identity, I fear discrimination.' This theme highlights the ongoing societal barriers that restrict authentic self-expression for older transgender people, emphasising the need for greater societal acceptance and inclusivity.
- II. Dependency: Some transgender individuals became dependent on community members or others for daily living activities, potentially influenced by health conditions, limited resources or societal support. Respondent D shared, 'As I got older, my health declined, and I had to rely on others for basic tasks. Some days, I feel like a burden, and it's tough to find the support I need.' This dependency underscored the importance of establishing comprehensive support systems within the transgender community.
- III. Generation gap with community members: The generation gap experienced by transgender individuals within their community suggested evolving perspectives and acceptance levels. When asked about social support, Respondent D said, 'There's this gap between the younger and younger generations. They have different experiences and acceptance levels. It's challenging to connect and feel understood.' This highlighted the need for intergenerational understanding and support to bridge these gaps and foster a more cohesive community.
- IV. Handling daily struggles: Daily challenges faced by transgender individuals, including economic hardships and social stigma, were magnified in the context of transgender ageing. For the question on managing daily living, Respondent A disclosed, 'Life is already tough, and ageing as a transgender person adds another layer. Economic hardships and societal stigma make daily challenges even harder to bear.' Addressing these struggles required targeted support and resources tailored to the unique needs of ageing transgender individuals.
- V. Unheard complaints: The feeling of being unheard or overlooked among transgender elders pointed to a broader issue of neglect or a lack of attention to their specific concerns. When asked about the support system, respondent B shared, 'I often feel like my concerns are ignored. It's like we're invisible.' Advocacy for better recognition and understanding of the challenges faced by ageing transgender individuals was crucial.
- VI. Feeling useless and a burden: The sense of feeling useless or burdensome resulting from societal attitudes, discrimination or internalised stigma associated with

ageing within the transgender community. When asked about their role in the community, respondent E said, 'It's disheartening to feel invisible, as if my experiences and contributions don't matter anymore. The discrimination adds weight to the struggle of ageing as a transgender person.' Promoting a positive and affirming environment was essential to counteract these negative perceptions.

- VII. Shrinking to self: The tendency to withdraw or shrink into oneself was seen as a coping mechanism in response to external pressures, discrimination or the cumulative challenges faced by transgender individuals. For the question on Quality of Life, respondent B shared, 'When faced with multiple physical issues, I withdraw to protect myself. It's a coping mechanism, but it shouldn't be this way. We need more understanding and acceptance.' Creating spaces for open dialogue and support could encourage a more resilient community.
- VIII.Segregation or solitary living: Respondent D said, 'Living in isolation is tough. Isolation takes a toll on our mental health. Social isolation is a real challenge for us.' Experiences of living in isolation or being segregated underscored the need for inclusive community spaces where elderly transgender individuals felt a sense of belonging. Combating social isolation is crucial for fostering a supportive and connected transgender community.

These nuanced constitutive patterns collectively provide a comprehensive picture of the complex and multifaceted experiences of elderly transgender individuals, shedding light on the various factors that shape their lives and well-being. An overarching theme that emerges from these constitutive patterns is 'Navigating Isolation and Dependency in the Lived Experience of Elderly Transgender Individuals.' This encapsulates the challenges associated with feelings of solitude, segregation and dependence on others, reflecting the intricate interplay between individual experiences and broader societal dynamics in the lives of elderly transgender individuals.

DISCUSSION

Older transgender individuals may occupy different social positions compared to their younger counterparts. Over the past two decades, the landscape of being transgender in contemporary culture has evolved significantly. New laws have been implemented, and the de-pathologisation of transsexuality is evident as it is no longer categorised as a mental disorder in the Diagnostic and Statistical Manual of Mental Disorders.^[2] This transformation, documented by scholars such as Stryker and Whittle (2006) and Witten and Eyler (2012), signifies substantial changes in socio-cultural perspectives on trans embodiment, particularly for older individuals who have witnessed this shift over their

lifetime. The altering social meanings of ageing further contribute to the nuanced intersections between ageing and transgenderism, an aspect that has not yet been thoroughly investigated in existing research.^[14,15]

The experiences of ageing transgender individuals reveal several poignant themes. The first theme identified revolves around the impediments to self-expression faced by transgender individuals. Freely expressing their gender identity proves challenging, given societal norms, discrimination and a lack of understanding. This underscores the crucial necessity for heightened awareness and inclusivity.^[16] Moreover, a significant barrier to healthcare access for transgender individuals lies in the inadequacy of knowledgeable providers. Financial constraints. discrimination, deficiencies in cultural competence among healthcare professionals, systemic barriers and socioeconomic challenges compound this.^[17]

A generation gap within their community reflects evolving perspectives and acceptance levels, underscoring the necessity for intergenerational understanding and support. Daily struggles, exacerbated by economic hardships and social stigma, emphasise the demand for tailored support and resources. The pervasive feeling of being unheard or overlooked among transgender elders highlights the broader issue of neglect, urging advocacy for better recognition of their unique challenges. The sense of feeling useless or burdensome, rooted in societal attitudes and discrimination, underscores the crucial need for promoting a positive and affirming environment. In addition, the coping mechanism of withdrawing or shrinking into oneself indicates the importance of creating spaces for open dialogue and support to foster resilience within the transgender community.

The theme, 'Segregation or Solitary Living', underscores the vital need for inclusive community spaces for elderly transgender individuals arising from their encounters with isolation and segregation. This aligns with findings from a study on residential addiction treatment settings, emphasising the significant influence of gender identity acceptance on the experiences of transgender individuals.^[18] Similar findings have also been reported in an interpretive content analysis of biographical interviews with 88 Transgender or Gender Nonconforming adults aged 50 and older, revealing the impact of stigma on their mental health at individual and interpersonal levels.^[19]

This study's findings emphasise the importance of gaining a comprehensive understanding of the experiences of transgender individuals to inform the development of supportive health and social care services, fostering improved health and well-being.^[20] It underscores the need to explore healthy coping mechanisms among transgender older adults and advocates for early integration of such strategies to enhance the quality of life for the younger generation. The intersection of gender-affirming care with gerontological nursing care needs to be further emphasised, particularly in palliative and EOL care settings. Factors such as limited healthcare access, unsafe environments, dependence and poor awareness contribute to their heightened physical and psychosocial risks. While the study acknowledges limitations, including a small sample size, it underscores the importance of amplifying the voices of this marginalised population.

CONCLUSION

The findings underscore the importance of creating supportive and inclusive environments to enhance the well-being of transgender individuals, both in residential settings and broader community spaces. Addressing these multifaceted challenges requires comprehensive efforts to enhance healthcare access, provider knowledge and cultural competency for the well-being of transgender individuals. Collaboration among physicians, human rights activists, the media and government administration is essential to address these issues comprehensively and ensure inclusive and respectful care for elderly transgender individuals. The conclusion calls for comprehensive care models, drawing attention to the unmet needs of gender minorities, especially in the context of India's ageing population. Recommendations include revising existing laws, adopting inclusive policies and promoting collaboration across healthcare, advocacy and governmental sectors to address the unique challenges faced by elderly transgender individuals.

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REFERENCES

- Defining Transgender Terms. Available from: https://www.apa.org/ monitor/2018/09/ce-corner-glossary [Last accessed 2024 Feb 02].
- Diagnostic and Statistical Manual of Mental Disorders: DSM-5TM. 5th ed. Arlington, VA, US: American Psychiatric Publishing, Inc.; 2013. p. 947.
- 3. Transgender/Others Census 2011 India. Available from: https://www.

census2011.co.in/transgender.php [Last accessed 2024 Feb 02].

- Javier NM. Palliative Care Needs, Concerns, and Affirmative Strategies for the LGBTQ Population. Palliat Care Soc Pract 2021;15:1-17.
- Ganju D, Saggurti N. Stigma, Violence and HIV Vulnerability among Transgender Persons in Sex Work in Maharashtra, India. Cult Health Sex 2017;19:903-17.
- Bremer S. Kroppslinjer Kön, Transsexualism Och Kropp i Berättelser Om Könskorrigering; 2011. Available from: https://gupea.ub.gu.se/ handle/2077/26653 [Last accessed 2024 Feb 03].
- Catlett L, Acquaviva KD, Campbell L, Ducar D, Page EH, Patton J, *et al.* End-of-Life Care for Transgender Older Adults. Glob Qual Nurs Res 2023;10:23333936231161128.
- Jarrett BA, Peitzmeier SM, Restar A, Adamson T, Howell S, Baral S, *et al.* Gender-affirming care, mental health, and economic stability in the time of COVID-19: A multi-national, cross-sectional study of transgender and nonbinary people. PloS One. 2021;16(7):e0254215..
- Does India's LGBTQ+ Movement Have an Age Problem?; 2020. Available from: https://www.thequint.com/fit/does-indias-lgbtq-movement-have-anage-problem [Last accessed 2024 Feb 05].
- Bakko M, Kattari SK. Differential Access to Transgender Inclusive Insurance and Healthcare in the United States: Challenges to Health across the Life Course. J Aging Soc Policy 2021;33:67-81.
- Madhavan M, Reddy MM, Chinnakali P, Kar SS, Lakshminarayanan S. High Levels of Non-communicable Diseases Risk Factors among Transgenders in Puducherry, South India. J Fam Med Prim Care 2020;9:1538-43.
- Miles M, Francis K, Chapman Y, Taylor B. Hermeneutic Phenomenology: A Methodology of Choice for Midwives. Int J Nurs Pract 2013;19:409-14.
- Suddick KM, Cross V, Vuoskoski P, Galvin KT, Stew G. The Work of Hermeneutic Phenomenology. Int J Qual Methods 2020;20:1-14.
- Stryker S, Whittle S. The Transgender Studies Reader. United Kingdom: Routledge and CRC Press. Available from: https://www.routledge.com/thetransgender-studies-reader/stryker-whittle/p/book/9780415947091 [Last accessed 2024 Feb 03].
- Witten TM, Eyler AE. Gay, Lesbian, Bisexual, and Transgender Aging. United States: Johns Hopkins University Press; 2012. Available from: https://www.press.jhu.edu/books/title/9086/gay-lesbian-bisexual-andtransgender-aging [Last accessed 2024 Feb 03].
- Safer JD, Coleman E, Feldman J, Garofalo R, Hembree W, Radix A, *et al.* Barriers to Health Care for Transgender Individuals. Curr Opin Endocrinol Diabetes Obes 2016;23:168-71.
- Sanchez NF, Sanchez JP, Danoff A. Health Care Utilization, Barriers to Care, and Hormone Usage Among Male-to-Female Transgender Persons in New York City. Am J Public Health 2009;99:713-9.
- Lyons T, Shannon K, Pierre L, Small W, Krüsi A, Kerr T. A Qualitative Study of Transgender Individuals' Experiences in Residential Addiction Treatment Settings: Stigma and Inclusivity. Subst Abuse Treat Prev Policy 2015;10:17.
- Fabbre VD, Gaveras E. The Manifestation of Multi-Level Stigma in the Lived Experiences of Transgender and Gender Nonconforming Older Adults. Am J Orthopsychiatry 2020;90:350-60.
- Banerjee D, Rao TS. "The Graying Minority": Lived Experiences and Psychosocial Challenges of Older Transgender Adults during the COVID-19 Pandemic in India, A Qualitative Exploration. Front Psychiatry 2021;11:604472.

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