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Original Research Article

Assessment of palliative care needs among elderly population in a slum of Kolkata: a qualitative study

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ABSTRACT

Background: Palliative care improves the quality of life for patients and families facing life-threatening illnesses. With the growing burden of non-communicable diseases and an aging population, the global demand for palliative care is rising. This study was conducted to identify individuals needing palliative care and explore their needs and unmet needs among the urban elderly in Kolkata.
Methods: A qualitative study was conducted from May 2019 to April 2020 among elderly residents (60 years and above) in selected slums of '*Khalpar-basti*', Rajdanga, Kasba, South Kolkata, West Bengal. Four Focus Group Discussions (FGDs) were held on different dates: two with elderly patients (one with males and one with females) and two with informal caregivers of elderly patients (one with males and one with females) using an FGD guide until data saturation was reached. Data was transcribed, coded, and analysed using a thematic map.
Results: The current study identified themes from FGDs with elderly females, including unmet physical, psychological, communication, spiritual, and existential needs, along with gaps in care and support. Similarly, FGDs with elderly males highlighted unmet physical, informational, psychological, spiritual, social, emotional, and practical needs, as well as care gaps. FGDs among caregivers revealed unmet communication, psychosocial, and practical needs among the elderly.
Conclusions: This holistic approach encompassing physical, psychological, social, emotional, practical, and informational domains of palliative care is essential for improving the quality of life in the geriatric population.

Keywords: Comfort care, Unmet needs, Eastern India, Urban slum elderly, Focus group discussion, Caregiver perspective

INTRODUCTION

Palliative care improves the quality of life for patients and families facing physical, psychosocial, or spiritual challenges of life-threatening illnesses. Globally, 56.8 million people, including 25.7 million in their final year of life, require palliative care annually, yet only 14% have access.[1] Most in need are adults over 50 years of age (67.1%), with 76% living in low- and middle-income countries (LMICs), where non-communicable diseases account for 69% of the demand.[2] In 2018, 79% of the global population, mainly in LMICs, consumed just 13% of morphine for pain relief, highlighting ongoing disparities in access to palliative care resources.[1]

The global demand for palliative care is rising due to the increasing burden of non-communicable diseases and aging population.[3] In India, this need is amplified by a growing elderly population and higher prevalence of such diseases. To address this, the Government of India

launched the National Program in Palliative Care (NPPC) in 2012, with the 2017 National Health Policy also emphasizing palliative care.[4]

Palliative care extends beyond cancer patients to include individuals with HIV, severe kidney disease, heart failure, end-stage lung disease, progressive neurological conditions, and other life-limiting illnesses.[5] Neglecting their symptoms can lead to heightened emotional distress and a diminished quality of life.[6]

Palliative care is now recognized as a human right.[1] The 67th World Health Assembly (WHA resolution 67.19) in May 2014 called for integrating palliative care into the continuum of care, urging member states to prioritize primary, community, and home-based care alongside policies, education, and accessible medicines.[7]

Palliative care in India began in Gujarat under the Department of Anesthesiology at the Gujarat Cancer and Research Institute (GCRI). A significant milestone was the establishment of the Indian Association of Palliative Care (IAPC) in Ahmedabad on 16 March 1994, with support from WHO and the Government of India. The IAPC, a registered public trust, serves as a national platform advocating for palliative care, setting standards, organizing training, and collaborating with the government to expand services. Over the years, it has become a key umbrella organization for palliative care in India.[8]

Palliative care coverage in India remains sparse and inadequate. As of November 2022, the country had 847 palliative care centers, with only 526 (62.1%) actively functioning, averaging 4 centers per 10 million population.[9] The IAPC has played a key role in the establishment of institution-based palliative care across the country and has facilitated the availability of palliative care services, to some extent, in every State and Union Territory, with the exceptions of Andaman and Nicobar Islands, Daman and Diu, and Dadra and Nagar Haveli.[10]

By 2050, 20.8% of India's population will be aged 60 and above.[11] Using data from the longitudinal ageing study of India (LASI), 12.2% of older adults in India are estimated to require palliative care, with West Bengal reporting the highest prevalence at 17% highlighting the need for geriatric palliative care.[12]

Previous studies have largely relied on hospital data of chronic end-stage patients or population-based secondary data analysis, with routine mortality data being commonly used to estimate the need for palliative care.[13-24] Community-based studies assessing the palliative care needs of elderly individuals are rare, both globally and in India. While numerous studies have explored the unmet needs of palliative care patients from the perspective of bereaved caregivers, there has been limited research focusing on the unmet needs from the perspective of current patients and their caregivers. Against this backdrop, the present study was conducted to identify the individuals in need of palliative care and explore their needs and unmet needs within the urban elderly community of Kolkata.

METHODS

A qualitative study was conducted among elderly population (aged 60 years and above) residing in the '*Khalpar-basti*', a slum area in Rajdanga of Kasba locality in the South Kolkata, West Bengal, from May 2019 to April 2020. The total elderly population was 457, as per the line lists derived from electoral data obtained from the Borough-XII (KMC) office in Rajdanga. Necessary administrative permissions, ethical clearance from the Institutional Ethics Committee at All India Institute of Hygiene and Public Health (AIIHPH), Kolkata, and informed written consent from participants were obtained prior to the study.

Qualitative data on unmet palliative care needs were collected through Focus Group Discussions (FGDs) with elderly males and females requiring palliative care, as well as adult caregivers (both male and female). On a pre-scheduled date, participants were invited to gather at a convenient location within their locality, where they were provided with a clear explanation of the interview's nature and purpose in their own language. They were informed that the FGD process would take approximately 45 minutes to 1 hour to complete. A separate researcher was assigned the task of audio recording the discussions.

A total of four FGDs were conducted on different dates: two with elderly patients – one with elderly males and another with elderly females, and two with informal caregivers of elderly patients – one with male caregivers and another with female caregivers. The interviews were audio-recorded, and field notes were taken during the sessions. Participants for the FGDs were purposively selected based on homogenous criteria (male and female). The FGDs continued until data saturation was reached, which was determined when no new perspectives emerged from additional data. The data was transcribed, coded, and a thematic map was created.

RESULTS

A total of four focus group discussions were held, each comprising six participants. The socio-demographic and clinical profiles of the participants are presented in Table 1.

Analysis of the transcriptions and notes resulted in the identification of key domains associated with unmet needs, as summarized in Table 2.

Focus group discussion – elderly females

The FGD with female elderly participants revealed themes such as unmet physical, psychological, communication, spiritual and existential needs, as well as gaps in care and support.

Table 1: Distribution of participants according to their demographic and clinical characteristics (n=24).

S. no.	Age (years)	Mean±SD (age)	Sex	Patient's clinical characteristics
FGD – 1 (elderly male patients)				
1	69	70.67±2.13	M	Severe COPD
2	68		M	Cerebro vascular disease (CVD)
3	74		M	Age related weakness/frailty
4	72		M	Cancer
5	69		M	End stage renal disease (ESRD)
6	72		M	Advanced neurological disorder
FGD – 2 (elderly female patients)				
7	84	71.17±6.33	F	Age related weakness/frailty
8	68		F	Cerebro vascular disease (CVD)
9	69		F	Cancer
10	66		F	Advanced neurological disorder
11	74		F	Advanced neurological disorder
12	66		F	Cancer
FGD – 3 (male caregivers)				
13	32	33.83±4.59	M	Age related weakness/frailty
14	28		M	End stage renal disease (ESRD)
15	39		M	Cancer
16	35		M	Cerebro vascular disease (CVD)
17	40		M	Severe COPD
18	29		M	Cancer
FGD – 4 (female caregivers)				
19	34	37.5±6.55	F	Severe COPD
20	48		F	Cancer
21	29		F	Age related weakness/frailty
22	39		F	Advanced neurological disorder
23	43		F	Cancer
24	32		F	Cerebro vascular disease (CVD)

Table 2: List of identified unmet needs through focus group discussions.

S. no.	Domains of unmet need	Definition
1	Physical	Essential bodily requirements focusing on relieving symptoms, managing distress, and providing comfort
2	Psychological	Requirements crucial for maintaining identity, dignity, comfort, and a sense of control
3	Communication/ informational	Requirements of clear, honest, and compassionate exchange of facts between patients, families, and healthcare providers
4	Spiritual and existential	Requirements for exploring meaning, purpose, and peace beyond the materialistic world
5	Gaps in care and support	Requirements for services, resources or interventions necessary to ensure an individual's well-being
6	Social	Requirements for maintaining relationships, meaningful interactions with friends, community
7	Emotional	Requirements for coping with feelings, managing reactions, and reassurance
8	Practical	Requirements for enabling individuals to perform daily activities and self-care
9	Psychosocial	Requirements for combined psychological and social support to improve overall well-being, and to enhance the quality of life.

Physical needs

Most elderly patients reported experiencing fatigue and sleep problems, with some suffering from severe depression and anxiety about death, as well as difficulty in breathing. One cancer patient complained of intense pain that limited their ability to perform daily activities. Terminal cancer patients faced challenges in obtaining morphine, leading to reduced pain relief. Those with

breathing difficulties cited the high cost of oxygen cylinders or concentrators as a barrier. Many also complained about medication side effects and the distress of taking multiple medications at once.

In this regard, an 84 years old female said, *"I feel tired all day long. No strength to do any work. I feel so bad to lie down the whole day"*. Another 68 years old female patient said, "*Doctor, I don't like to take so much of medicine, besides that If you take too much medicine, you feel dizzy and vomit"*.

Psychological needs

Majority of the patients were concerned about dealing with their family's fears and concerns while also coping with their own anxiety about physical deterioration. Almost all expressed fear about losing independence, facing social isolation, and becoming a burden. They also feared for their future and the well-being of their family after their death.

In this regard an 84 years old female said, *"I am so frightened every morning – I have palpitations – will I die?"*. A 69 years female said, *"I do not want to, die – please do something so that I can live – my grandson is still very young – I have to bring him up"*. Another 66 years old female patient said, *"I don't like to inform anything to my son or daughter –in-law, Doctor, I have become a burden to them"*.

Communication needs

Nearly all of them expressed a desire to learn more about the prognosis of the diseases they were suffering from. In this regard a 66 years old lady said, *"What happened to me…. No one says whether it will be cured or not…If I ask the Doctor, he says call the man of the house…. Son also doesn't tell anything."*

Some patients mentioned that healthcare professionals used complex jargon that was difficult to understand. Many also expressed a desire to spend time with a healthcare provider who could listen to and understand their concerns.

A 69 years old lady said, *"No one listens well in the hospitals I have so much pain…. If they don't listen properly, how could it be alleviated?"*

Spiritual and existential needs

Most patients expressed feelings of hopelessness and spiritual despair, while nearly all participants reported experiencing loneliness. A 74 years old lady said, *"I have never done anything wrong in my life…why did God give me this disease?"*.

Another lady of same age said, *"Kill me…. I don't like it anymore…. Pain all over the body…. irritates…. I can't sleep…can't go anywhere…. I don't want to sit down and talk to anyone…. I don't want to live anymore."*

Gaps in care and support

Some patients were reluctant to be hospitalized, citing poor behaviour from hospital staff and dissatisfaction with the food provided.

A 69 years old patient said, *"After calling many times, sisters come…if you call again and again, they are dissatisfied."*

Most patients mentioned that the high cost of allopathic medicines forced them to seek alternatives such as homeopathy or Ayurvedic treatments. They suggested that the government should work to control the prices of these medicines.

A 66 years old patient said, "*Medicine is so expensive. Where we poor people get so much of money? So, I generally consult homeopathy doctor."*

Focus group discussion – elderly males

The FGD with male elderly participants similarly highlighted unmet physical, informational, psychological, spiritual, social, emotional, and practical needs, along with gaps in care and support.

Physical needs

As a patient becomes progressively ill, symptoms and treatment side effects become more frequent and severe. While specific symptoms vary depending on the type and stage of the disease, the most common ones reported include pain, loss of appetite, fatigue, weakness, weight loss, constipation, difficulty breathing, confusion, nausea, vomiting, cough, and dry or sore mouth. The most common experience for the patient is to have a cluster or constellation of symptoms with one influencing the others.

In this regard a 69 years old male patient said, "*What's most troublesome? Well, I'd say it's not one thing. It's all of the symptoms – the pain, the tiredness, the nausea, not sleeping – it's all of them."*

Informational needs

Individuals who were becoming progressively ill wanted to understand their condition and be involved in decisions about how to spend their remaining days. Many described their illness as entering an unfamiliar world with complex, unfamiliar language.

They reported difficulty accessing relevant information about their disease and finding a healthcare professional who could help them apply that information to their own situation.

In this regard a 68 years old patient said, "*What happened to me? No one says. If I ask the doctor, he says you will be all right, but nothing is improving."*

Psychological needs

Individuals felt their bodies were no longer functioning as they once did, limiting their ability to do things they wanted. Along with changes in their body image, their sense of self and self-esteem were also affected. This led to psychological distress, often manifesting as anxiety or depression.

In this regard a 69 years old male said, "*I cannot move around any longer. I have now become a burden to my family, nobody listens to me now."*

Spiritual needs

A life-threatening diagnosis often used to evoke questions – Why me? Why now? Why this way? A 69 years old patient said, "*I have never done anything wrong in my life…why did God give me this disease."*

Social needs

The inability to engage in normal social activities resulted in a reduced sense of support. As patients became sicker, challenges arose, relationships changed, and family and friends experienced grief over the impending loss. The thought of a world without their loved one triggered feeling of overwhelming despair and helplessness.

A 74 years old patient said, *"When you are ill, you really find out who your friends are, and who will help. I have been both surprised and disappointed by what has happened; surprised at who has helped and who cannot even talk about that."*

Emotional needs

As a person begins to imagine the end of their life, a range of worries emerges. Frustration arises when they are unable to do things they would normally do. Regrets about past actions and things left undone lead to feelings of guilt and remorse. There are also concerns about dying in pain or discomfort, or dying alone.

A 72 years old male said, *"I cannot go outside as much. I am left alone very much. I really feel trapped and have no life at all now... I cannot do a lot of things I want to do."*

Practical needs

Patients were often dissatisfied with prolonged hospital stays, the lack of empathy from hospital staff, rigid schedules, mounting financial costs, standardized hospital meals, and a lack of privacy. Most patients expressed a preference to die peacefully at home, surrounded by their loved ones, rather than in the hospital.

A 72 years old male said, *"No one treats us well in the hospital, I don't like being admitted to the hospital for this."*

Gaps in care and support

Almost all terminal cancer patients reported that procurement of morphine was a significant challenge, which they believed should be addressed by the government.

A 74 years old cancer patient said: *"The painkiller doctor prescribes is nowhere to be found nearby… It has to be brought from far away…… again, doesn't give more every time…. When the medicine is in stock in market, then only I can buy it, otherwise I don't get it…. This makes the things very difficult."*

Focus group discussion – caregivers

The FGDs among caregivers revealed unmet communication, psycho-social and practical needs among study subjects.

Unmet communication needs

The majority of caregivers expressed a lack of regular communication with doctors and nurses, leading to uncertainty about whom to contact in times of need. Long waiting times and overcrowding at government facilities prevented prolonged interactions with physicians and healthcare workers. They also reported that doctors often did not have enough time to listen to their concerns.

A 34 years old lady informal caregiver said, *"Even if I ask something to the doctor, there is so much crowd outside that he doesn't listen well…he says everything will be fine…meanwhile, we face problems at home."*

Unmet psycho social needs

A common issue that emerged was the fear of death and concerns about future events among elderly patients. Their inability to participate in religious and social activities contributed to feelings of loneliness and depression. Some caregivers expressed a desire for palliative services to provide support in helping patients leave the house and engage in activities.

A 48 years old female caregiver said, *"Very scared to die…. only says 'I will die, please help me out. Otherwise kill me'."* Another 29 years old female caregiver said, *"Very upset that she can't go anywhere outside…. previously used to go for kirtan…now a days not able to go…. says there is nothing left in my life."*

One 39 years old female caregiver said, *"If any psychological counsellor would come and talk to her, I think she would feel a little better…. We can't give so much*

time due to our work…she is mentally dead…and also there is some psychiatric problem."

Practical needs

Although most patients wanted to die at home, their families and caregivers preferred them to stay in the hospital during their final days, due to the challenges of managing the patients at home without the support of healthcare professionals.

A 39 years old male caregiver said, *"It is better to stay in the hospital at last time...because what we will do then."*

DISCUSSION

The study highlighted various themes during FGDs. Among female elderly participants, unmet physical, psychological, communication, spiritual, and existential needs, as well as gaps in care and support, were identified. Similarly, FGDs with male elderly participants revealed unmet physical, informational, psychological, spiritual, social, emotional, and practical needs, along with gaps in care and support. FGDs with caregivers highlighted unmet communication, psycho-social, and practical needs among the study subjects.

A review by Okediji et al identified unmet needs in the areas of health system and information, psychological well-being, and physical and daily living, aligning with the findings of the current study.[25] Similarly, systematic reviews by Wang et al and Hart et al, focusing on advanced cancer patients and their caregivers, reported that the most prevalent unmet needs among patients were psychological, physical, healthcare services, and information. For caregivers, the primary unmet needs were in the domains of information, psychological support, and overall support.[26,27] Comparable results were observed in reviews by Moghaddam et al on advanced cancer patients and Valery et al on patients with chronic liver disease.[28,29]

Gupta et al, through a participatory action research (PAR) study among cancer patients in a rural region of North India, utilized a parallel convergent mixed-methods approach to gain a comprehensive understanding of palliative care. The most consistent themes identified were unmet physical, psychological, and financial needs among cancer patients.[30] Similarly, an exploratory study by Daya et al involving 21 palliative caregivers in an urban area of Pondicherry revealed that caregivers encountered physical, psychological, financial, social, and spiritual challenges related to caregiving.[31] These thematic findings align closely with those of the current study.

Unmet needs were identified across physical, psychological, informational, social, and even spiritual domains, highlighting the necessity of a holistic approach to improve quality of life of patients. Addressing these needs alongside pharmacological treatment is crucial, especially for chronic and severe illnesses. Palliative care should therefore integrate solutions for all common unmet needs. This qualitative study explored experiences of the patients, identifying major domains of unmet needs through focus group discussions from both patient and caregiver perspectives. Caregivers play a vital role in enhancing patients' quality of life, making it essential for palliative care to address their unmet needs as well.

The study is a qualitative one exploring unmet needs of palliative care through focus group discussions. The actual needs might not be accurately expressed through FGDs since the method itself has its own limitation. Dominant speakers might have expressed a lot, limiting the chances of others. In depth interviews could have been done in future which was not done in the current study due to resource constraint.

CONCLUSION

The current study depicted that alongside pharmacological interventions, palliative care and support must be prioritized to improve the overall well-being of patients suffering from chronic and severe illnesses. The ongoing demographic transition is contributing to a rising burden of palliative care needs, particularly among the aging population. It is crucial to approach geriatric care with respect and attention, prioritizing the challenges posed by aging-related and epidemiological shifts in disease patterns. A holistic approach encompassing various domains of palliative care like physical, psychological, social, emotional, practical, informational etc. can significantly enhance the quality of life for the elderly population in slum areas of Kolkata.

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