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Article (Published Version)

Akter, Sayema, Sarker, Malabika, Hossain, Puspita, Ahmad, Nezamuddin and Zaman, Shahaduz (2022) Solidarity and suffering: enrolled terminal patients' and their caregiver's experiences of the community-based palliative care programme in an urban slum of Bangladesh. *Palliative Care and Social Practice*, 16. pp. 1-12. ISSN 2632-3524

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Solidarity and suffering: enrolled terminal patients' and their caregiver's experiences of the community-based palliative care programme in an urban slum of Bangladesh

Sayema Akter^{*} , Malabika Sarker^{*}, Puspita Hossain, Nezamuddin Ahmad and Shahaduz Zaman

Abstract

Background: Palliative care has been recognised as a global health challenge. Although accessibility has increased, there is little recognition of the importance of palliative care in low- and middle-income countries. In Bangladesh, institutional palliative care is not accessible due to a lack of awareness, financial constraints, and fewer facilities. Hence, there needs to be a better understanding of providing and improving existing community-based palliative care. For this, it is essential to understand the experiences of patients and their caregivers who require palliative care. With this aim, this study explores the experiences of palliative patients and their primary caregivers enrolled in a palliative care project, 'Momotamoy Korail' run by Bangabandhu Sheikh Mujib Medical University in an urban slum, Dhaka.

Methods: This research is a part of a larger qualitative study that relied on a focused ethnographic approach. For this study, we used 19 in-depth interviews following a semi-structured guideline with the palliative care patients and their primary caregivers enrolled in the community-based palliative care project.

Results: Mostly women (wives and daughters-in-law) are the primary caregivers in a family. Therefore, male patients are more likely to receive family care than female patients. Both male and female patients expressed the desire for a death free of suffering. All patients felt lonely and socially abandoned with a perception of being a burden to their families. Despite the diversity in physical, social, psychological, and financial suffering, patients and caregivers were optimistic towards a healthy life free of illness. All respondents were satisfied with the care they received from the palliative care assistants, which provide them hope and dignity for life.

Conclusion: Experiences of the respondents can improve the quality of the existing community-based palliative care services and add great value to the discipline of palliative care in public health. The findings provided an understanding of what would be required to extend community-based palliative care to other healthcare settings. More awareness through community mobilisation about the need for and benefit of palliative care is needed to make it sustainable.

Keywords: Bangladesh, caregivers, experience, palliative care, terminal illness

Received: 24 October 2021; revised manuscript accepted: 25 March 2022.

Palliative Care & Social Practice

2022, Vol. 16: 1–12

DOI: 10.1177/

26323524221095104

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Background

Focus on death and end-of-life care conditions in the global context is growing.¹⁻³ The World Health Organization (WHO, 2002)¹ defines palliative care as an ‘approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness’. The importance of palliative care in the Sustainable Development Goals agenda was recently outlined in a commentary written by 12 recognised palliative care experts in the February edition of *The Lancet Oncology*.² An estimated 40 million people worldwide need palliative care annually, 78% of whom live in low- and middle-income countries (LMICs), but only 14% of them have access to palliative care at the end of life.⁴ There are two main approaches for delivering palliative care services: the institutional care model – mainly hospice care, which is preferred in Western countries and the community-based model – relatively less medicalised where the majority of the care is provided at home.⁵ The World Health Assembly has recommended that countries integrate evidence-based, cost-effective, and equitable palliative care services in the continuum of care, across all levels, with emphasising primary, community and home-based care.⁵ In this context, public health palliative care has gained interest, with the idea that care for terminally ill people should be returned to communities. The focus should be upon supplementing a *service delivery* model with an alternative *community development* model. However, socio-cultural variation in terms of understanding about death, dying and end-of-life care is increasingly seen as one of the key inhibitors of effective palliative care delivery.^{6,7}

According to the global mapping on the level of palliative care, low- and middle-income countries have a wide range of variations against the high-income countries on the readiness of their health systems for palliative care.⁸ Because of the numerous advantages of home-based care such as lower costs, comprehensive service, control of chronic disease, low costs, minimal need for hospitalisation, and increased patient satisfaction, home care is preferred in LMIC. In the vast majority of LMICs, there is no institutional palliative care. There is limited or no recognition of palliative care in health policy and a scarcity of specially trained human resources.⁹⁻¹¹ The *Lancet* Commission estimated that over 25 million people who died in 2015 experienced severe health-related suffering, 80% of whom were in LMICs.¹¹ Globally, approximately 15 million cancer patients

experience Serious Health related Sufferings (SHS) every year. According to 2015 Global data platform, Bangladesh has 673 people of serious health related sufferings (SHS) in total thousands.¹²

Alleviation from various suffering is a vital concern of palliative care services. Therefore, it is necessary to identify the patient’s plight in order to provide quality palliative care based on their needs.¹³ Patient experience is widely recognised as a quality pillar in healthcare service due to its intrinsic value.¹⁴ Another essential aspect of palliative care is the support of primary caregivers, usually close family members who provide care with no financial interest which often hampers their social lives.¹⁵ The demographics of the population change and patients’ preference to die in their own homes¹⁶ leads to a shift in caregiving responsibilities from more traditional medical personnel to spouses, families, and friends.

Bangladesh is in category 3a on the world palliative care developmental map, which means some isolated palliative care services and training provisions exist here.³ A recent situation analysis revealed that although Bangladesh has approximately 60,000 incurable patients at any point in time, at present it has only six, capital city Dhaka-based, comprehensive palliative care programmes, which served fewer than 1500 patients.¹⁷ Around a million people die in Bangladesh every year, 60% of whom are estimated to need palliative care.⁸ In Bangladeshi culture, people define ‘good death’ as that which takes place in the presence of loved ones.¹⁸ Good quality home care services can help reverse the present trend of materially and emotionally expensive institutionalised dying.⁹

Globally, there are very few examples of community-oriented end-of-life care in resource-poor settings. But very little is known about how the end of life is dealt with in low-income countries. A review showed that 90% of the studies on end-of-life care focus on just a few specific European countries.⁷ Although death happens to individuals, it is nevertheless a population experience, and therefore, palliative care should be considered a public health matter.^{5,6} As with other health problems, death, dying, and palliative care in low-income countries are characterised by enormous inequity.

In the urban slums of Bangladesh, poverty makes the impact of life-limiting conditions devastating to family and community members. Communities

that are already impoverished and marginalised care for each other without support. Their ability to earn is being taken away, and without any necessities being provided. Among the 160 million inhabitants of Bangladesh, it is estimated that more than two million people are currently living in slums in the city of Dhaka.¹⁹ Inspired by the *community development* model of palliative care, the Centre for Palliative Care (CPC) of Bangabandhu Sheikh Mujib Medical University (BSMMU, <http://www.bsmmu.edu.bd/>) – the only medical university of Bangladesh – established a home care outreach palliative care service in urban slums of Dhaka through trained community palliative care assistants (PCAs) in 2015. The CPC, in collaboration with the Worldwide Hospice Palliative Care Alliance (WHPCA), piloted a project on home care outreach palliative care service in Korail slum setting in Dhaka, Bangladesh. Korail is one of the largest slums in Dhaka, Bangladesh, which is situated on approximately 100 acres and more than 50,000 residents call this slum their home²⁰ (BRAC, 2017). To increase the quality of care in community-based palliative care which can be co-produced in collaboration with the community members, ultimately empowering them to take full control of an aspect of palliative care and develop their responses.

Very few studies have reported on the ultimate experience, sufferings, and issues of caregivers who care for people in need of palliative care in Bangladesh. Zaman²¹ has well explored the role of family members in a hospital setting, but until now, no study has been done in Bangladesh's household settings. The main objective of the broader study is to develop an innovative boundary-crossing interdisciplinary partnership to support to the sustainability of the urban slum palliative care project in Bangladesh, by developing a contextually appropriate strategy for enhancing public engagement through 'Community Theatre'. At the first phase of the study, a focused ethnographic exploration of local social and cultural understandings of death, dying and end-of-life care practices was conducted in the urban slum of Bangladesh. Through this study, one could understand what would be required to extend the community-based palliative care in other similar healthcare settings.

Methods

Study design and setting

This research is a part of a larger qualitative study that relied on a focused ethnographic approach.

The wider study aimed to develop an innovative boundary-crossing interdisciplinary partnership to support to the sustainability of the urban slum palliative care project in Bangladesh. The aim was to create a contextually appropriate strategy for enhancing public engagement through 'Community Theatre'.

The focused ethnography was conducted to explore local contexts, indigenous knowledge, capabilities, cultural practices, values, beliefs and the languages of death and dying and the end-of-life care practices in the urban slum of Bangladesh. Different data collection approaches were applied under the umbrella of focused ethnography, including participant observation, in-depth interviews with palliative patients, their primary caregivers, service providers and PCAs. Focus Group Discussions (FGDs) were also done with the volunteer of the programme from the community.

Here, in this paper we only draw on 19¹⁶ in-depth, 60–120 min individual interviews with palliative care patients and their primary caregivers enrolled in the community-based palliative care project named 'Momotamoy Korail' run by BSMMU.

Participants and data collection

Participants were purposively selected from the palliative care project run by BSMMU named 'Momotamoy Korail'. We received a list of patients with a diagnosis from the project staff. First, we found five types of illnesses and ailments [cancer, stroke, multiple bone pain, respiratory tract infection (RTI), chronic kidney disease (CKD)] were most common among the patients. Later we selected both male and female respondents (considering their age, disease condition, who gives suitable time for the interview) for interview. A total of 10 patients were interviewed; hence, we interviewed the caregivers of these 10 selected patients. However, we could not reach one of the caregivers due to their unavailability during the data collection period. Therefore, nine caregiver interviews were conducted. Two research assistants (RAs) with anthropology backgrounds were recruited and trained to conduct the interview. Two other experienced qualitative researchers directly supervised this focused ethnography; one was a certified medical doctor and public health professional, and another was an anthropologist by training. The overall duration of the focused ethnography was 2 months. Interviews were conducted using a semi-structured interview guideline

in Bengali and conducted in a private setting within the slum where the participant felt comfortable. The interview guideline focused on the history of patients' illnesses, their experiences with the diseases, daily life struggles, and the care they receive from the PCAs. The caregiver's experience centred on their support given to the ill patients in the light of familial contexts and cultural practices. Participants signed the consent forms after a verbal explanation. The illiterate respondents gave thumbprints (we provided a stamp pad) instead of their signature. Interviews were audio-recorded after their approval and took approximately 45 min to 2 h. Interview notes were written in notebooks and thus recorded, audio recordings were transcribed in Bangla, and memos and observation notes were written down simultaneously. Debriefing sessions were conducted by the two researchers who oversaw the data collection after each interview was completed to or any challenges they experienced during the fieldwork.

Data analysis

The recorded interviews were transcribed in Bengali and thematic analysis was done. The transcripts were coded in ATLAS.ti version 8. The initial focus was conducting an inductive analysis of the data and identifying the subthemes while analysing the transcripts. Through the inductive coding and categorisations, subthemes emerged, and quotations were retrieved from the findings. Two authors (SA and PH) independently coded and analysed the text to do a reliability check and ensure that the coding was intersubjectively understood. Finally, thematic analysis was done by the researcher through the guidance of the principal investigator.

Findings

The palliative care patients' and caregivers' background

The palliative patients and their respective caregivers migrated to the Korail slum 20–45 years back from their village to earn a living. All of them were Muslims and between the age of 40 and 85 years (Table 1). Except few, most of them were engaged in shopkeeping, rickshaw pulling, boat riding, and begging. The rest were unemployed. Only one patient was employed and lived with his family. Most of the caregivers were female (e.g. wife, daughter, daughter-in-law, wife of nephew, sister), and only one was male

Patient's perspective

- Dependence generated frustration and uncertainty
- Most patients felt socially isolated as they often stayed at home

Caregivers' perspective

- Most of the caregivers were female
- Women were more affected by the need for care at the end of life

Both perspective

- Suffered emotionally due to the patients' health condition
- Despite all the hardships, both were still looking forward to a disease-free long life
- Both the group showed satisfaction towards PCAs of 'Momotamoy Korail'

(husband). The caregivers were between 25 and 70 years of age. Six of them were involved in some sort of work, either small business, like owning a street-side shop/tea stall or was working as a housemaid.

Patients' experience and perception of suffering

We recruited patients of five disease elements but did not find differences in their experiences except health conditions. The patients were suffering from illness for more than 2–8 years. They suffered from various physical symptoms such as fatigue, nausea, drowsiness, pain in the body, loss of appetite difficulties in breathing, and sleeping. The majority of them could not talk for an extended period. Those who were paralysed could stand but not walk. The multitude of different symptoms and suffering made it hard for the patient to live an active and productive life.

Emotional suffering of the palliative care patients'

Many patients were bedridden and dependent on their family members for their daily activities. Therefore, they carried enormous guilt for being a burden on their families. Although they received physical, emotional and financial support from the family members whenever needed, the dependence generated frustration and uncertainty. They needed not only regular medical treatment but also non-medical assistance. It was more difficult for the male patients, the breadwinners of the family. Instead of taking care of the family, they required constant care and support.

Table 1. Profile of the patient.

Disease type	Gender and age	Occupation	Lives with whom	Primary caregiver	Duration of illness & current physical condition
Stroke	Male (50–60)	Unemployed (dependent upon wife)	Wife	Wife	5 years One arm is paralysed, can stand but cannot walk.
Cancer	Female (75–85)	Unemployed (dependent upon son)	Son's and grandson's family	Daughter and grand-daughter-in-law	3 years. Right side is paralysed. She cannot stand or sit by herself. Cannot talk for long periods.
	Male (65–75)	Unemployed (dependent upon wife)	Wife	Mainly wife, sometimes daughter	2 years. Diagnosed with liver cancer. He is suffering from generalised body ache. Cannot talk for extended periods of time, Difficulty in sleeping.
	Female (30–40)	Sweeper	Husband and children	Elder sister	1.5 years. Diagnosed uterine cancer. Suffers from fatigue, pain, and dizziness. Cannot talk for extended periods of time. Suffers from loss of appetite. Receives chemotherapy and radiotherapy.
Respiratory tract infection	Male (70–80)	Unemployed	Wife and son's family	Wife and grand daughter	7 years. Difficulty in breathing. Generalised body ache, fatigue, weakness, nausea.
	Transgender (55–65) (identifies herself as a woman)	Unemployed	Alone	Nephew's wife	2 years. Diabetes, vision impairment, breathing problems and weakness.
Multiple bony pain	Male (65–75)	Part time rickshaw puller	Son's family	Daughter-in-law	8 years. Suffers from severe pain in his right arm. Loss of movement and sensation on right arm. Pain spread to neck, chest and spine.
	Female (55–65)	Caretaker of a house	Husband and two grandchildren	Daughter living nearby	4–5 years. Generalised body ache, more painful in the neck and waist.
Chronic kidney disease (CKD)	Male (60–70)	Unemployed (dependent upon wife)	Wife only	Wife	4 years. Diagnosed as CKD. Diabetic. Legs are swollen. Fatigued and nauseous.
	Female (60–70)	Unemployed	Husband	Daughter-in-law living beside home	2 years. Diagnosed as CKD. Vision impairment. Pain on the right side of body. Nauseous.

One of them tearfully expressed,

I feel very helpless aunty (addressing the interviewer). My wife is also sick, yet I have to depend on her. She is suffering from a kidney problem. She worked as a maid, did lots of heavy work all day long; I cannot do anything. I cannot earn. Why doesn't Allah take me to Him, so I do not suffer anymore? (Patient_Male_55–60 years old)

Social isolation and loneliness of the palliative care patients

Most patients felt socially isolated as they were often at home. Limited ability to socialise with friends and family made them feel secluded, and they suffered from loneliness. Patients shared their helplessness with participating in social events such as chatting with the neighbours, festivals, marriage ceremonies, religious rituals, and local events. The male patients felt alone when their wives went to work and there was no other member to spend time with them. One male patient who lost his wife a few years back and now lives with his son's family felt lonely because he did not receive any support or respect from his son and daughter-in-law. At an old age, he still had to make his living. He said,

There is no one to take care of me. My daughter-in-law is busy with household tasks; I can't blame her; she does whatever she can. I sit in a corner all day long. I have to do my task. I bring my medicine and clothes by myself. There is no one even to cool my head with water if needed. (Patient_Male_65–70 years old)

Patients' financial crisis

Several patients had discontinued institutional treatment due to a lack of money. The respondents mentioned that they felt exhausted worrying about their family members without income. Some of the patients did not want to work, but they were still involved in income-generating activities for maintaining their families' expenses. One female patient worked as a janitor to run her family. Her children suffered from severe diseases (cerebral palsy and visual impairment), and her husband was a disabled street beggar. She suffered from anxiety and lost interest in life.

Few patients (male and female) were also working to earn money and manage household chores. One of the female patients previously sold bread on the street. However, due to their sickness she

was forced to leave the business and not do the household chores.

I used to sell bread, during winter I sold "pitha" (a type of cake), and in other seasons I sold bread and fried vegetables. I did very well in the business. I earned a lot of money, but now my business is over, and the money is finished. (Patient_Female_60–65 years old)

Caregivers' experience and perception

The caregivers' experience varied to some extent, as they had their own unique struggle in providing care. They were mainly involved with the patients from the start of their diagnosis till their round-the-clock care.

Caregivers' emotional suffering

The caregivers were more committed to their patients in the early stage of the disease because they perceived that taking care during the early stage would prevent further complications, and the condition would not deteriorate further. The female caregivers were actively involved with the caregiving process. Some of them were employed so in addition to being the breadwinner of the family, they had to care for the patient, included feeding, bathing, and helping them in the toilet and washroom. Taking care of the patient was an added pressure in their life. Witnessing the pain of their close ones caused them great emotional stress. One female caregiver respondent felt no one could understand her pain and suffering. The Almighty did not give her any happiness. Witnessing the pain of their close ones caused them great emotional stress.

Caregivers were habituated with the debilitating condition of the patients as they had to take care of their patients for such a long time. Also, they became frustrated, irritated, or disturbed by running the household round the clock. They had their plates full; hence, giving full attention to the patient did not always come naturally. However, they also felt an inner conflict during these moments. They believed it was their prime duty to take care of their family. Not doing so caused distress, and they suffered from a guilty conscience.

How can I not care for her? How can I leave a person by herself in such an ailing condition? It makes me feel guilty (বিবেকে বাধা দেয় /bibeke badha dey). My husband also asked me to take care of her as she may not have long to live. ((CG)_Female_20–25 years old)

Only one male caregiver mentioned assisting his wife in bathing, going to the toilet, and feeding her after returning from his tea shop. After doing all these works, there was not much time left for the caregivers to care for themselves. At the same time, he felt exceedingly sad for his wife's ailment as he could not share a life with her. This showed how a patients' illness disrupted their personal life and relationships.

One caregiver said,

I had to go to my work outside, and after coming back home, I had to do all household chores and take care of my children and my ill mother-in-law. It was stressful for me, I did not get any time to breathe! (CG_Female_30 years old)

Caregivers' financial struggle

Almost all of the caregivers shared that they were in constant need of money. Nearly all of them were impoverished or living on a daily wage so, bearing the cost of the treatment was even more difficult. Some caregivers spent all of their savings for treatment purposes and were later forced to borrow money. Whereas other respondents had taken out loans that they needed to pay back in instalments. They could not ask for financial help from other extended family members because even they had a limited income. The caregivers felt helpless because of the uncertainty and suffering of their loved ones. One of the respondents narrated,

The pain of poverty is massive... If I had a property, I did not have to ask for money or help from people. If I had the money, I did not have to go out for work; I could take care of him at home. If I do that now, I will have no money to sustain us. I have to work outside; then when I come back home, I have to clean him, feed him... That's why I want that Allah should take me to Him than keep me in this suffering and pain. (CG_Female_45–50 years old)

The double burden on women caregivers

Women were more affected by the need for care at the end of life. While the male patients received care from their wives despite their ill health and busy working schedules, the female patients were often deprived of care from their spouses or family members. They had to look after the routine household tasks despite their illness. Terminally

ill women were also often alone as their husbands had died earlier. We found only one female patient who received assistance from her husband, like buying the medicine, but she had to manage the household and her own needs most of the time. She described,

Whether I am sick or not, I have to do all my household chores. Sometimes I cannot move but must work. I feel aches, but there is no option. I have to take care of my two grandchildren and my husband. But by the grace of God, 'till now I haven't collapsed; in that situation, someone will have to take care of me. So far, I can manage everything- I am doing all the chores by myself. (Patient_Female_55–60 years old)

The responsibility of taking care of the palliative care patients often fell on the females of the household. In only one of the cases, the patient's husband was the primary caregiver. Sometimes, the sister (two among nine caregivers) of the patient also played the role of caregiver. As six among nine caregivers were working women, it reflected the fact that they maintained the home and took care of the palliative care patients. They repeatedly mentioned that they had to work; otherwise, they would not be able to sustain the family, as the patient cannot work.

Coping with the suffering by patients and caregivers

Despite all the hardships, several patients were still looking forward to a miracle. They were hoping to be cured and live a long life. Palliative care respondents who lived with an extended family and had people to look after them were more optimistic than those who lived with their spouses only. Almost every patient expressed their desire to return to their everyday and disease-free life to earn and do their household chores. They missed their regular active life before they got bedridden.

When my husband was alive, I had my household (shongshar); that time was the best in my life. Till now, I think about those wonderful days. (Patient_Female_75–80 years old)

In our study, all the participants believed in God, and they found peace by practicing their religion. They believed they would be cured if God (Allah) wished them to be. This belief gave them comfort and alleviated their suffering. One patient said,

I wish Allah will help me to recover soon. I have no regrets. I pray to Allah for my soundness. I do pray every time and seek forgiveness from Allah... Sufferings come from Allah and only he can relieve them. So, I do pray all the time for my recovery. (Patient_Female_75–80 years old)

Along with praying, many palliative patient respondents mentioned that they felt happiness and peace while playing with their grandchildren. The patients also spent a significant amount of time with the community. Non-bedridden male patients regularly walked to the markets, shops, mosques or chatted with the neighbours. Almost half of the respondents said they had good relationships with their neighbours which contributed to a better life. Male patients would spend their leisure time with their neighbours and their friends.

In the case of the caregivers, whatever the condition of the patients, they were optimistic about their close ones, that one day they would get better and live a long life. The situation reminded them about their own fate and health, bringing them close to the realisation that this illness could have happened to them as well.

I feel like crying at times. I don't blame anyone for my misfortune; God has given me this. I console myself saying that this could have happened to me as well. When these thoughts come to my mind, when I talk with people like I am talking with you about these issues, this makes me emotional. (CG_Female_65–70 years old)

And in the end, even though they had to suffer from their patient's, they still loved them dearly, which motivated them to keep taking care of the patients.

Receiving services from Momotamoy Korail: a community-based palliative care project

In the context of extreme poverty, and a complete lack of health services, the enrolled patients received essential medicines, various forms of care and food assistance from the 'Momotamoy Korail' project. By enrolling the patients in the 'Momotamoy Korail' programme, they were more confident and content. They lived a miserable life so they felt relieved and overwhelmed to receive the services from the PCAs who were recruited from their community.

Services received

The interviewed patients and caregivers highlighted many positive effects of these services. They received free medicine, doctor visits, food delivery and emotional support from the PCAs through this community-based palliative care project. The food packs (rice, peas, sugar, and potato) ensured their food security. The PCAs visited the patients' houses to provide physical, social, mental and spiritual support to the respondents. They also made the respondents' family members, relatives, and neighbours realise the importance of caring for the terminally ill or older adult patients. For the physical care, they helped the patients do physical exercise or supported them take a walk, especially those who could not move easily, had severe pain in the body, or were physically paralysed. As part of the social care, they counselled the family members or relatives of the patient. Furthermore, they gave company to lonely and stay-at-home patients. They helped them in taking medicines, baths, or cutting their nails. Periodically, PCAs also cleaned the lonely patient's houses by making the bed, washing their dishes, shopping, and cooking for them.

Some of the patients were worried about their impoverished condition and needed mental support. They were stressed and disappointed, after witnessing their children's negligence towards them. In such situations, the PCAs tried to spend more time with the patients, provided emotional support and gave them confidence.

Girls wearing a blue dress (PCAs) visit our home and care for us. They loved us a lot. We share our problems and thoughts to them. They are like our family. We feel relief to see them. (CG_Female_60–65 years old)

All respondents were grateful towards the PCAs. Whenever the PCAs visited a patient's home, the patient's family did not let them leave. If they were late or missed visits for any reason, the patient would get emotional. PCAs became very much engaged with the patient's family by providing the care they needed.

Discussion

It is the first study that explicitly reveals the contrasting experience of patients with long-term illness receiving palliative care and their caregivers in an urban slum in Bangladesh. The patients and

caregivers who participated in this study shared their physical, emotional and financial sufferings due to their loved one's chronic illness. Both groups expressed their sympathy and empathy for each other with a colossal toll of anguishes and torments. At the same time, they also showed optimism about life, particularly for being part of a community-based palliative care project.

The role of a context-specific, culturally and locally appropriate palliative care service provision is indisputable. In this case, the 'Momotamoy Korail' project plays a pivotal role and the enrolled patients and their families benefitted from the project.²² Nevertheless, family caregivers are an integral part of community-based palliative care. They provide the essential personal care needed in the terminal phase of chronic illnesses. Due to an absence of integrated palliative care in the national health system and life-threatening poverty, the terminally ill slum dwellers find ways to cope with the existing support.

Most of the patients reported having limited capacity to join in different social events. This loss of socialising with friends and family made them feel alone and lonely. Occasionally, their physical limitations and unemployment status stimulated thoughts of being abandoned by their family. The perceived lack of care and concern from family and friends during their illness also contributed to their loneliness. Loneliness and isolation have been shared experiences for terminally ill patients.²³ Theorists have distinguished loneliness as the perception of social isolation and discontent with the quality of relationships.²⁴ For well-being, social connection is crucial as it frees from loneliness. The physical changes that the patient undergoes and the consequently limited contact with the other community members mean that the patient does not get the connection that which would act as protection against loneliness.²⁵

The 'self-perceived burden' (SPB) is also common among terminally ill patients. A systematic review on this aspect of palliative care has shown that SPB correlates with loss of dignity, suffering, and a 'bad death'.²⁶ This has been the same for this study as well. Here the patients think they have become a burden for the family because of their unemployment status and inability to take care of themselves. Both male and female patients desired a death free of suffering. Furthermore, they wished that they had died earlier. The loneliness, feeling of abandonment and burden

instigated an experience of social death before the death of their physical body.²⁷

Women have a central role as primary caregivers for palliative care patients. This has been found in the existing literature and confirmed by this study where, except for one male, every other patient had female primary caregivers. Around the world, compared with men, women spend 2–10 times more time on unpaid care work.²⁸ Based on gender norms, women are viewed as responsible for caregiving tasks. Also, socially it has been internalised that caring is a woman's work which is common in most countries, particularly in the global South.²⁹

Our findings echoed existing literature that female caregivers are more likely to carry out personal care and household tasks than male caregivers.³⁰ According to the study participants, the caregivers are the silent saviours,²¹ and caring for the sick family members is a duty. According to Mahoney, the Bangla terms for 'duty' are 'kartabya' and 'daitya', those which do not carry the meaning of an abstract obligation. Instead, the implication is usually about the immediate task at hand or the relational obligation.³¹

Studies show that caring for a terminally ill person at home may lead to physical and mental fatigue and eventually to burnout if continued without any external support.³² Despite the sense of duty, enormous sympathy and empathy, the caregivers of this study felt frustrated and hopeless. They suffered from common psychological issues, like, depression, hopelessness, anger, and sleeplessness. Mostly female caregivers stressed most, as caring for a terminally ill person at home requires continuous balancing between care burden and capacity to cope.³² Caregivers often needed to reorganise their own lives and lifestyles to suit the patient's needs. On top of it, there were severe financial constraints. Stress was a common complaint, and the caregiver perceived that the sudden diagnosis of the patient's terminal illness had led them to have a higher stress level.

However, despite the physical and psychological sufferings, both patients and their caregivers expressed hope about life. They found consolation from the care and support they received from the community-based PCAs. They took this support as a blessing from God. Religious beliefs gave enormous hope to their life.¹² Religion, medicine, and healthcare have been

related in one way or another in all population groups since the beginning of recorded history. The previous study showed religious practice and beliefs could sometimes play an important role in the lives of poor people to help them understand themselves, interpret the world around them, their social and economic position in their immediate society.²

Loss of sense of community, loneliness, and lack of collectiveness is broadly Western societies' characteristics.^{33,34} Historically, people died at home within the comfort of the surroundings of their community, where their own religious beliefs and traditions were conducted with ease. However, due to rapid urbanisation, Bangladesh, a non-Western country, also lost social cohesion.³⁵ This is particularly true for urban slum-like 'Korail', where most inhabitants migrated from different parts of the country to hope for better livelihoods. They are involved in income-generating work, including the women in the families.³⁶ It has implications for end-of-life care provisions. Palliative care required care and support for both health-related and non-health-related aspects of life. Support from the PCAs of 'Momotamoy Korail' showed the light of hope among the palliative patients during their care. In addition, the community-based palliative care project of BSMMU has introduced an innovative way to fill up the gap between individuals and the community. The PCAs from the same community played a role in fulfilling the loss of sense of community by sharing the physical, mental, psychological and spiritual care responsibilities and the family members. Previous studies showed caregivers always add their own experience of suffering and support systems, influencing their ability to provide care to the patients.³⁷ Our study findings also accumulated showing that family caregivers dealt with their palliative patients according to their coping mechanisms.

However, the support the patients and the caregivers need are far from being inadequate. Only a fraction of the population of Bangladesh received palliative care. Also, the palliative care provision was still underdeveloped with few isolated initiatives. It is essential to mainstream palliative care in the Bangladesh health system to address terminally ill patients' physical, psychological, social, emotional and spiritual sufferings, which were coined as 'total pain'.¹² In a resource-poor setting like an urban slum, there is a need for innovative approaches for an integrated palliative

care service within the mainstream health system.

Limitation

First, the respondents were difficult to track. The patients could be found in their homes, but as most caregivers were involved in some sort of work, it was challenging to get their schedule. Second, understanding the speech of the terminally ill old-aged people was also challenging to realise. The researchers also had to go back to the same respondents to get better insights into their thoughts. Third and most important is the infrastructural point, that is, 'Korail' slum is a maze, and finding the patients' houses has been a challenge. As the data were conducted from April to June, heavy downpour was common in Korail. Heavy rainfall meant the alleys went underwater, and it became even more difficult to manoeuvre around the alleyways.

Conclusion

The experience and perception of the patient and caregivers depend on socioeconomic status, social network, and coping skills depending on the illness status. The suffering, spiritual beliefs, emotional crisis, and self-perceived burden intermingle, making a complicated scenario even more complex. The services and care they received that make them satisfied given their miserable livelihood condition. Further study is needed to explore which approaches are most effective in reducing patients' worries and pain about being a burden on their families. Caregivers can provide significant psycho-social support to the patients. Still, it must be realised that caregivers are exposed to long-term stress starting from the diagnosis of the patient's illness and continuing even after the patient's death. The caregivers are exposed to higher stress levels than the patients, which needs to be addressed appropriately. The experience of the patients and caregivers demonstrates that further research and adequate support for them are much needed. This study has shed some light on the patient and caregiver experience in urban slums, Bangladesh. Experiences of the respondents could increase the quality of the existing community-based palliative care services and add significant value to the discipline of palliative care in public health. Through this research, we understood what would be required to extend this strategy to other areas of healthcare settings. More awareness through

community mobilisation about the need for and benefit of palliative care is needed to make it sustainable.

Ethics approval and consent to participate

Ethical approval (ref no: 2018008 IR) was obtained from the institutional review board from both BRAC University and the University of Sussex. During the interview, participants were provided with a copy of the consent form explaining the purpose of the study and had the opportunity to ask questions. Written informed consents were taken. If the respondent could not sign the consent, he or she was asked to give his or her thumbprint. The interviewers explained the background and the aim of the research and were ensured that anonymity and confidentiality would be maintained.

Author contribution(s)

Sayema Akter: Conceptualization; Data curation; Formal analysis; Methodology; Resources; Software; Writing – original draft; Writing – review & editing.

Malabika Sarker: Conceptualization; Formal analysis; Funding acquisition; Investigation; Project administration; Supervision; Writing – review & editing.

Puspita Hossain: Conceptualization; Formal analysis; Methodology; Resources; Writing – original draft; Writing – review & editing.

Nezamuddin Ahmad: Conceptualization; Project administration; Resources.

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Acknowledgements

This study was coordinated by the University of Sussex, UK, and funded by Arts and Humanities Research Council (AHRC), UK. We thank all the study interviewed patients and family members who are part of a community-based palliative care project facilitated by Bangabandhu Sheikh Mujib Medical University (BSMMU) with a grant by the Worldwide Hospice Palliative Care Alliance (WHPCA). We thank the dedicated staff of ‘Momotamoy Korail’ for giving us all the necessary

support in conducting the research during the period of the study. We also thank two of the research assistant (SJM Shourov and Mahabuba Alam Ripa) for their incredible support during data collection for this research.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study was funded by Arts and Humanities Research Council (AHRC), UK.

Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Availability of data and materials

Data are available from the corresponding author on request or please contact irb-jpgsph@bracu.ac.bd. There is an institutional data repository board and can be contacted if required.

References

1. World Health Organization. *National cancer control programmes: policies and managerial guidelines*. World Health Organization, 2002.
2. Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health* 2019; 7: e883–e892.
3. Clark D. End-of-life care around the world: achievements to date and challenges remaining. *Omega (Westport)* 2007; 56: 101–110.
4. Crippen DW (ed.). *End-of-life communication in the ICU: a global perspective*. New York: Springer, 2008.
5. World Health Assembly. *Strengthening of Palliative Care as a component of comprehensive care through the life course*. Sixty-Seventh World Assembly, Agenda item 15.5, 2014, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf
6. Gysels M, Evans N, Meñaca AEA, et al. Culture and end of life care: a scoping exercise in seven European countries. *The Ethical Challenges of Emerging Medical Technologies* 2020; 335–350.
7. Pastrana T, Vallath N, Mastrojohn J, et al. Disparities in the contribution of low- and middle-income countries to palliative care research. *J Pain Symptom Manage* 2010; 39: 54–68.

8. Lynch T, Connor S and Clark D. Mapping levels of palliative care development: a global update. *J Pain Symptom Manage* 2013; 45: 1094–1106.
9. Macro OR. National Institute of Population Research and Training (NIPORT), Dhaka, Bangladesh.
10. Bingley A and Clark D. A comparative review of palliative care development in six countries represented by the Middle East Cancer Consortium (MECC). *J Pain Symptom Manage* 2009; 37: 287–296.
11. McDermott E, Selman L, Wright M, *et al.* Hospice and palliative care development in India: a multimethod review of services and experiences. *J Pain Symptom Manage* 2008; 35: 583–593.
12. Mehta C. Understanding of the concept of ‘Total Pain’. *J Hosp Palliat Nurs* 2008; 10: 26–32.
13. Ventura AD, Burney S, Brooker J, *et al.* Home-based palliative care: a systematic literature review of the self-reported unmet needs of patients and carers. *Palliat Med* 2014; 28: 391–402.
14. Corrigan JM. Crossing the quality chasm. *Building a better delivery system*, 2005, <https://www.ncbi.nlm.nih.gov/books/NBK22857/>
15. Meneguín S and Ribeiro R. Difficulties of caregivers of patients in palliative care in the family health strategy. *Texto Contexto Enferm* 2016; 25: e3360014.
16. Higginson I, Daveson BA, Sean Morrison R, *et al.* Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC* 2017; 17: 271.
17. NIPORT. *National situation analysis of palliative care in Bangladesh*, 2013. Dhaka, Bangladesh: Ministry of Health and Family Welfare, 2013.
18. Connor SR and Bermedo MC. *Global atlas of palliative care at the end of life*. London: Worldwide Palliative Care Alliance, 2014.
19. Bangladesh Bureau of statistics (BBs). *Population and housing consensus* 2011. dhaka: BBs, 2011.
20. Funk L, Stajduhar K, Toye C, *et al.* Part 2: home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). *Palliat Med* 2010; 24: 594–607.
21. Zaman S. Silent saviours: family members in a Bangladeshi hospital. *Anthropol Med* 2013; 20: 278–287.
22. Zaman S, Ahmed N, Ur Rashid M, *et al.* Palliative care for slum population: a case from Bangladesh. *Eur J Palliat Care* 2017; 24: 156–160.
23. Bentley B, De Jong MJ, Moser DK, *et al.* Factors related to nonadherence to low sodium diet recommendations in heart failure patients. *Eur J Cardiovasc Nurs* 2005; 4: 331–336.
24. Cacioppo JT, Hughes ME, Waite LJ, *et al.* Loneliness as a specific risk factor for depressive symptoms: cross-sectional and longitudinal analyses. *Psychol Aging* 2006; 21: 140–151.
25. Sand L and Strang P. Existential loneliness in a palliative home care setting. *J Palliat Med* 2006; 9: 1376–1387.
26. McPherson CJ, Wilson KG and Murray MA. Feeling like a burden to others: a systematic review focusing on the end of life. *Palliat Med* 2007; 21: 115–128.
27. Gaston KJ, Blackburn TM, Greenwood JJ, *et al.* Abundance–occupancy relationships. *J Appl Ecol* 2000; 37: 39–59.
28. Ferrant G, Pesando LM and Nowacka K. *Unpaid care work: the missing link in the analysis of gender gaps in labour outcomes*. Boulogne-Billancourt: OECD Development Center, 2014.
29. Williams LA, Giddings LS, Bellamy G, *et al.* ‘Because it’s the wife who has to look after the man’: a descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life. *Palliat Med* 2017; 31: 223–230.
30. Miller B and Cafasso L. Gender differences in caregiving: fact or artifact? *Gerontologist* 1992: 498–507.
31. Mahoney TA and Deckop JR. Evolution of concept and practice in personnel administration/human resource management (PA/HRM). *J Manage* 1986; 12: 223–241.
32. Proot IM, Abu-Saad HH, Crebolder HF, *et al.* Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. *Scand J Caring Sci* 2003; 17: 113–121.
33. Putnam RD. *Bowling alone: the collapse and revival of American community*. New York: Simon & Schuster, 2000.
34. Hofstede G. Cultural dimensions in management and planning. *Asia Pac J Manag* 1984; 1: 81–99.
35. Nilsson J, Rana AK and Kabir ZN. Social capital and quality of life in old age: results from a cross-sectional study in rural Bangladesh. *J Aging Health* 2006; 18: 419–434.
36. Ishtiaque A and Ullah MS. The influence of factors of migration on the migration status of rural-urban migrants in Dhaka, Bangladesh. *Human Geographies* 2013; 7: 45.
37. Siminoff LA, Wilson-Genderson M and Baker S Jr. Depressive symptoms in lung cancer patients and their family caregivers and the influence of family environment. *Psychooncology* 2010; 19: 1285–1293.