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

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Title: Solidarity and Suffering: Patients and their caregiver’s experiences enrolled in the community-based palliative care program in an urban slum of Bangladesh

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Abstract

Background: Palliative care has been recognised as a global health challenge. Although access has increased, there is very low 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: A qualitative study employing a focused ethnography was conducted where participants observation of the patients and the caregiver’s situation, nineteen in-depth interviews were carried out using semi-structured guidelines with the palliative care patients and their primary caregivers.

Results: All patients shared their feelings of loneliness and social abandonment, accentuated by the guilt of being a burden to their families, created a feeling of social death. Despite the sense of duty, sympathy and empathy, presence of physical, social, psychological, and spiritual suffering, both patients and caregivers felt cared for and hopeful. In a family, primarily wives and daughters-in-law are the primary caregivers. Therefore, male patients are more likely to receive family care compared to female patients. Both male and female patients expressed the desire for death free of suffering.

Conclusion: There is a need for innovative approaches for an integrated palliative care service within the mainstream health system. Gaps in research, workforce shortages, and lack of public
and professional knowledge need to be addressed if care for people with a terminal illness and their silent saviour is to be further improved.

Keywords
Bangladesh, Care-givers, Experience, Palliative Care, Terminal illness

Background
Focus on the conditions of death, and interest in the development of end of life care in the global context is growing (1-3). It includes variation in different cultures and resource settings, the scope for health and social care services, the contribution of families and communities, and the role of civil society and organisations. The literature revealed how palliative care started as a social movement. It has become a medical speciality in the west, and over time expanded its scope, moving beyond the clinical domain (4). It has been recognised that although death happens to individuals, it is nevertheless a population experience, and as a result, palliative care should be considered a public health issue (5-7). In recent years, the availability of palliative care has also been acknowledged as a human right (1). However, as with other health and health care issues, the issues around death, dying, and palliative care in developing countries are characterised by enormous inequity. Very little is known about how the end of life is dealt with in low-income countries. A review showed that ninety per cent of the studies on the end of life care focus on just a few specific European countries (8). 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. (9). Given the total number of people requiring palliative care worldwide, only 10% of them receive the care they need as very few countries have integrated it into their healthcare systems (10).
The Lancet Commission on “Alleviating the access abyss in palliative care and pain relief” identified 20 most common health conditions that require palliative care. Among these, the top 10 conditions account for more than ninety per cent of deaths in low- and middle-income countries (LMICs). Palliative care would have been beneficial for almost 78% of the adults from LMICs.

The provision of support varies from home-based palliative care to isolated clinical care to integrated palliative care offered within mainstream health services. 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 (11-13). Even though dying is a universal human experience, authors argued that more arrays must address it (14).

In the current map of world palliative care, Bangladesh is in category 3a, which indicates the existence of isolated palliative care services and training provisions (9). Recent situation analysis in Bangladesh reported that, even though Bangladesh has approximately 600,000 incurable patients, only a handful of centres provide palliative care, and Bangabandhu Sheikh Mujib Medical University (BSMMU) is one of them(15). In urban slums, the impact of life-limiting conditions becomes devastating for family and community members due to poverty. Given the situation, the Centre for Palliative Care (CPC) of BSMMU undertook a pilot project called “Momotamoy Korail/(Compassionate Korail)” in 2015 in an urban slum of Dhaka to provide care to the palliative and geriatric population at homes. Twelve Palliative Care Assistants (PCAs) were recruited from the community and trained to provide care and treatment support to patients and caregivers. The services included clinical examination and treatment, physiotherapy, home visit, and emergency physical care. Palliative Care Assistants (PCA) offer home-based palliative care services comprised of physical, social, psychological and spiritual care. They monitor the patient, provide information, needful physical care and grief support to the families when needed.
Alleviation from various suffering is a vital concern of palliative care services. Therefore it is necessary to identify the patient’s plight for providing quality palliative care based on the patients’ needs (16). Patient experience is widely recognised as a pillar of quality in healthcare service due to its intrinsic value (17). Another essential aspect of palliative care is the support of primary caregivers, usually close family members. The primary caregivers provide care with no financial interest and often hamper their social lives (18). The demographics of the population change and patients’ preference to die in their own homes (19) is leading to a shift in caregiving responsibilities from more traditional medical personnel to spouses, family, and friends. Family caregivers are crucial for providing the most physical and emotional care for individuals with life-threatening and terminal illnesses, especially those who wish to die at home (20). Family caregiving comes with its unique challenges and problems (21). In 2006, family caregiving was identified as a top international research priority in end of life care. Hence the effects of taking care of the dying patient, needs to be considered for providing a holistic care. Globally, there are very few examples of community-oriented end of life care in resource-poor settings.

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. The Centre for Palliative Care (CPC), in collaboration with the Worldwide Hospice Palliative Care Alliance (WHPCA), piloted a project on homecare outreach palliative care service in a slum setting in Dhaka, Bangladesh. 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. Zaman (23) 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. Given this context, we explored the experiences of terminally ill patients enrolled in the
Methods

Study design

This qualitative study relied on a focused ethnographic approach. A focused ethnography focuses on a particular problem in a specific context and is conducted within a sub-cultural group rather than a cultural group (24).

Study site and sample selection

The study site was an urban slum named ‘Korail’, one of the largest slums in Dhaka, Bangladesh(25). Participants were conveniently and purposively selected from the palliative care project run by BSMMU named “Momotamoy Korail”. A list of patients with the diagnosis was collected from the project staff. Both male and female patients with the most common five (cancer, stroke, multiple bony pain, respiratory tract infection, chronic kidney disease) types of ailments were selected. A total of ten patients and nine of their caregivers were interviewed. The researcher could not reach one of the caregivers due to her unavailability during the data collection period.

Data collection

After receiving the approval from the Institutional Review Board from both BRAC University and the University of Sussex, two anthropologists were hired as local Research Assistants (RAs) and trained by the local Principal Investigator to conduct the focused ethnography. This focused ethnography was directly supervised and led by two other experienced qualitative researchers; one was a certified medical doctor, and another was an anthropologist by training. The duration of the
focused ethnography was two months, and it involved participants observations and informal discussions as well as in-depth interviews and focus group discussions.

Participant observation was used to deepen the insights of the surroundings, the experience of the patients, and the caregiving process. Nineteen (19) in-depth interviews (IDIs) with palliative care patients and their primary caregivers were conducted. Interviews were conducted in Bengali and in a private setting, where the respondents felt comfortable. The interview guideline focused on the history of patient’s illnesses, their experiences with the diseases, daily life struggles, and the care they receive from the palliative care assistant (PCAs). The caregiver’s experience centred around their support to the ill patients in the light of familial contexts and cultural practices. Participants signed the consent forms after a verbal explanation. Interviews were audio-recorded after their approval and took approximately 45 minutes to two hours. Interview notes were recorded on paper forms. Debriefing sessions were conducted after each interview to summarise the content and quality of the interviews.

Data Analysis

The interviews were transcribed in Bangla and were analysed thematically. The initial focus was on an inductive analysis of the data and identifying the sub-themes that arise while analysing the transcripts’ data. A codebook was prepared by discussing the preliminary findings with the research team and validating the coding frame. The transcripts were coded in ATLAS.ti version 8, and a coding frame was created. Through a constant comparison approach, subthemes were produced, and quotations were retrieved from the findings.

Results

The respondent’s
The respondents migrated to the Korail slum 20-45 years back from their home village. The main reason for migration was to earn a livelihood. All of them were Muslim by religion, and the age of the patients ranged from 40-85 years (Table 1, end of the document). Most of them were unemployed, few of them were engaged in shopkeeping, rickshaw pulling, boat riding, and begging. Almost all of them lived with the family caregivers, and most of the caregivers were female (wife, daughter, daughter in law, nephew, wife, sister), and only one was male (husband). The range of the caregivers’ age was 25-70 years. Six of them were involved in some sort of work, either small business like owning a street-side shop/tea stall or being a housemaid.

**Patient’s experience and perception of sufferings**

*Physical sufferings*

Most of the patients were suffering from their illness for more than 2-8 years. Most of them were agonised from various physical symptoms such as; weakness, fatigue, nausea, drowsiness, and pain in the body, breathing difficulties, difficulties in sleeping. The majority of them cannot talk for an extended time, suffers from loss of appetite. Those who were paralysed can stand but cannot walk. The multitude of different symptoms and suffering made it hard for the patient to live an active and productive life or even enjoy the family life. Also, they shared their various familial stresses related to their life, which was hugely affected by the diseases they suffer. These difficulties caused emotional suffering, which is discussed below.

*Emotional sufferings*

Most of the patients were bedridden and dependent on their family members for their daily living and treatment. They needed not only regular medical treatment but also non-medical assistance. Despite the gratefulness, the respondents were carrying enormous guilt because of their
dependency on the family for survival. They received physical, emotional, and financial support from the family members whenever needed, but the dependence generated frustration and uncertainty.

It was more painful for male patients, the breadwinner of the family. Instead of taking care of the family, they now require care and support. 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, do 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**

Most patients felt socially isolated as they were often at home and felt left out by the family members and friends who worked outside. Most of them shared their helplessness with participating in social events like festivals, marriage ceremonies, religious rituals, and local events. Limited ability to socialise with friends and family made them feel secluded, and they suffered from loneliness. The male patients felt alone if 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 lived with his son’s family felt very 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. 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)
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 any income source. 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 continuing working as a genitor 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 disease condition, they were forced to leave their business and could not do the household activities.

‘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)

The caregivers’ experience varied to some extent, as each respondent had their struggle in providing care. They were mainly involved with patients during the diagnosis of disease, process of treatment and care provision.

The female caregivers were more actively involved; notably, working female caregivers contributed to the treatment process for male and female patients. The financial burden, as well as witnessing the pain of their close ones, caused emotional stress. The caregiver-respondents were
more committed to their patients in the early stage of the disease because they perceived that taking care during the early stage of the disease would prevent further complications, and the condition would not deteriorate further. In addition to being the breadwinner of the family, they had to care for the patient that included feeding and bathing, helping them in the toilet and washroom. The only male caregiver mentioned that he assisted his wife in bathing or going to the toilet and or fed her after he came back from his tea shop. Not much time is left for oneself after completing all the activities and taking care of the patient.

**The financial struggle of the caregivers**

Almost all of the caregivers shared that they are in a destitute condition and constantly need money. Those caregivers working outside start taking care of their dependents after coming back instead of taking rest. Their daily activities included washing, cleaning, grocery shopping, cooking for the household, filling up the water containers, and ensuring that all the family members are adequately fed.

“I do the grocery shopping and cleaning. I also have to take care of my mother—bathing her, feeding her, grooming her (making hairstyles). Then, there are clothes of the children which need to wash. All in all, a lot of work. Sometimes I become exhausted."

(CG_Female_25-30 years old)

Almost all of them were impoverished or living on a daily wager, bearing the cost of treatment even more difficult. Few caregivers had to spend all their savings for treatment purposes and were later forced to borrow money. Few of the respondents had taken out loans that they needed to pay back in instalments, an added stress for them. They could not ask for financial help from other
extended family members because 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 feeling of overburden and emotional distress

Taking care of the patient was an added pressure in their real stressful life. One female respondent felt no one could understand her pain and suffering. Although she suffered and lost a lot, the Almighty who sent her did not ascribe any happiness.

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 and taking care of the patients. They had their responsibilities to fulfil- taking care of the chores, the children, working to earn money to run the household and pay for the treatment- hence, giving full attention to the patient did not always come naturally. But they also felt the inner conflict within themselves during these moments, as they believed it was their prime duty to take care of their family. Not doing so distressed them emotionally, 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 (bibeke badha deyi). My husband also asked me to take care of her as she may not have long to live." (CG_Female_20-25 years old)

The only male caregiver shared the same feelings and opened up about his emotional attachment with his wife. He felt exceedingly sad for his wife’s ailment as he could not share his life with her, which showed how the patient’s illness disrupted the caregiver’s life and household.

The double burden of women caregiver

Women were affected more by the need for care at the end of life. At the same time, the male patients received care from their wives despite their ill health and busy working schedules. We found the female patients are often deprived of adequate care from their spouses or family members. Moreover, 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 received some 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 have to 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. As six among nine caregivers were working women, it reflected the fact that they maintain the home and take care of the palliative care patients. They repeatedly mentioned that
they have to work; otherwise, they will not be able to sustain the family, as well as that it becomes a burden that the patient cannot work. Mostly the responsibility of taking care of the patient fell on the wife or daughter-in-law of the patient. Sometimes the sister (2 among nine caregivers) of the patient also played the role of caregiver. In only one of the cases, the patient’s husband took care of her.

*Coping with the sufferings by patients and caregivers*

Despite all of the hardships, several patients were still looking forward to a miracle. They were hoping to be cured and living a long life. Respondents who lived with an extended family and had people around 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 when they could earn and do their household chores. They repeatedly mentioned that they missed their earlier active life. Most respondents said regular working life, family life, and life before the illness were the best part of life.

‘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 were theists, and they found peace by practising their religion. They believed they would be cured if God (Allah) wishes 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 it. So, I do pray all the time for my recovery ....’ (Patient Female 75-80 years old)
Along with praying, many 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 chatting with neighbours. Almost half of the respondents said that they had good relationships with their neighbour’s that contributed to a better life. Several respondents explained that their neighbours were friends and male patients spent their leisure time with them.

In the case of the caregivers, whatever the condition of the patients, they were optimistic about their patients, that one day they would get better and would live a longer life. The situation reminded them about their 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 as well with their patient’s, they still loved them dearly, which motivated them to keep taking care of the patients.

How the community-based palliative care project ‘Momotamoy Korail’ supported the urban slum dwellers and their perception towards the Palliative Care Assistants (PCAs)

Enrolment in the ‘Momotamoy Korail’ programme made the patients and their caregivers more confident and contented. They repeatedly recognised the positive effect of the services provided
by the programme. The respondents were pleased to receive the medicine, advice from the doctor
visit, food package and emotional support from the PCAs. The food packs ensured their food
security. They all showed satisfaction with the contribution of the PCAs in their life. The PCAs
made the respondents’ family members, relatives, and neighbours realise the importance of caring
for the terminally ill or older adults. The PCAs visited the patients’ houses, spent time and talked
to them and their families. They were providing physical, social, mental and spiritual support to
the respondents. As part of physical care, they help the patients doing physical exercise or helping
them take a walk who cannot move easily or have severe pain in the body or are physically
paralysed. They often visit patients’ houses and gave company when they feel lonely or stay alone
at home. They help them take regular medicine doses, take baths, and sometimes cut their nails.
Periodically they clean the lonely patient’s house, make the bed, wash their dishes, do the shopping
and cook for them. However, social care is mainly about counselling the family members or
relatives of the patient.

Regarding mental support, some of the patients were worried about their impoverished condition.
They were stressed and disappointed, witnessing their children’s negligence towards them. In such
situations, the PCAs tried to spend more time with the patients, provide emotional support and
instil confidence in them with their positive views toward life.

“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 felt grateful to the PCAs. As the PCAs were recruited from the community live
in this community, the patient family knows them and has confidence in them. Whenever the
PCAS visit a patient’s home, they (the patient’s family) do not let them leave, and if they are late or miss to visit them for any reason, the patient gets emotional.

**Discussion**

This is the first study that explicitly reveals the contrasting experience of patients with long term illness receiving palliative care and their home caregivers in an urban slum in Bangladesh. The patients and caregivers who participated in this study described their physical, emotional, and financial sufferings due to their condition. Both express their sympathy and empathy for each other with a colossal toll of anguishes and torments. On the other hand, they also illustrated optimism about life, particularly for being part of a community-based palliative care project.

In the context of the 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. The role of a context-specific, culturally and locally appropriate provision of palliative care service is indisputable. In this case, the ‘Momotamoyee Korail’ project plays a pivotal role, and the enrolled patients and their families benefited from the project (26). Family caregivers are an integral part of community-based palliative care and impart the essential personal care needed in the terminal phase of illness.

Most of the patients reported partial capacity to join in different social events, not getting chances to socialise with friends and family, making them feel unaccompanied and lonely. Occasionally their physical limitations and unemployment stimulate the thoughts of feeling abandoned by their family. Perceiving a lack of care and concern from others during illness also contributed to loneliness. Loneliness and isolation have been identified as a shared experiences of terminally ill patients (27). For well-being, social connection to each other is crucial; the presence of social association helps people be free from loneliness. Theorists have distinguished loneliness as the
perception of social isolation and discontent with the quality of relationships (28). The physical
changes that the patient undergoes and forced limited contact with the other community members
means that the patient does not get the protection against loneliness that the community interaction
provides (29).

Findings also elaborated that the patients think they have become a burden for the family because
of their unemployment and inability to take care of themselves. The “self-perceived burden” (SPB)
is also a common phenomenon among terminally ill patients, which is supported by other studies.
A systematic review on this aspect of palliative care has shown that SPB correlates with loss of
dignity, suffering, and a “bad death” (30). Both male and female patients desire a death free of
suffering, and many of them also indicated that they wished they had died earlier. The loneliness,
feeling of abandonment, and burden instigate an experience of social death before their physical
demise (31)

In support of existing literature, the study results also confirmed the central role of women as
primary caregivers (except only one man) for palliative care patients. Around the world, women
spend two to ten times more time on unpaid care work than men(32). According to the gender
norms, women are viewed as responsible for caregiving tasks, and both women and men internalise
caring as women’s work. Our findings echoed existing literature that female caregivers are more
likely to carry out personal care and household tasks than male caregivers (33)

According to the study participants, the caregivers are the silent saviour (23), but caring for the
sick family members is a duty. According to Mahoney, the Bangla terms for ‘duty’ is “kartabya”
and “daitya”, those do not carry the meaning of an abstract obligation. Instead, the implication is
usually about the immediate task at hand or the relational obligation (34). Despite the sense of
duty and enormous sympathy and empathy, the caregivers of this study felt frustrated and hopeless.
They also greatly suffered from common psychological issues among caregivers, including depression, hopelessness, anger, and sleeplessness. Caring for a terminally ill person at home requires continuous balancing between care burden and capacity to cope (35), mainly in severe financial constraints. Stress was also a common complaint, and the caregiver’s perceived that the sudden diagnosis of the patient’s terminal illness has led them to higher stress. It was found in the study that emotional stress for female caregivers because they had to manage both the patient and other household activities. All the caregivers had this view that women are supposed to be the primary caregivers. 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 palliative care assistants.

Caregivers often need to reorganise their own lives and lifestyles to suit the patient’s needs which illustrates that the caregiver needs to balance taking care of the patient and their capacity to cope with the burden of caring (36). 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 (35). The gender dimension of females being a carer for chronic conditions is common in most countries, particularly in the global South. (37).

Loss of sense of community, loneliness, and lack of collectiveness is broadly Western societies’ characteristics (38, 39). However, due to rapid urbanisation, Bangladesh, a non-Western country, also developed a loss of social cohesion (40). This is particularly true for urban slum-like ‘Korail’, where most of the inhabitants have migrated from different parts of the country to hope for better livelihoods and are involved in some form of income-generating work, including the women in the families (41). It has implications for the end of life care provisions. 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 play 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 (42). Our study findings also accumulate with this where it showed, family caregiver dealt
with their palliative patient according to their own coping mechanism. Palliative care requires care
and support for both health-related and non-health-related aspects of life.

However, the support the patients and the caregivers need is far from being adequate. A fraction
of the population of Bangladesh receives palliative care, and palliative care provision is 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 was coined as “total pain” (43). 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.

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, consequently making a complicated
scenario even more complex. 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 has to 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. Although studies have been conducted in
different countries and contexts, the numbers are inadequate. To date, there is limited research
available in the context of Bangladesh to understand the experience of palliative care patients and
caregivers. The experience of the patients and caregivers demonstrate that further research and
adequate support for them is much needed. Despite limitations, this study has tried to shed some
light on in the urban slum of Bangladesh in terms of patient and caregiver experience.

Abbreviations

BRAC JPGSPH   BRAC James P Grant School of Public Health
BSMMU         Bangabandhu Sheikh Mujib Medical University
CG             Caregiver
CPC            Center for Palliative Care
CKD            Chronic Kidney Disease
IDI            In-depth Interview
IRB            Institutional Review Board
LMICs          Low and Middle-Income Countries
PCA            Palliative Care Assistant
WHO            World Health Organization
WHPCA          Worldwide Hospice Palliative Care Alliance

Declarations

Ethics approval and consent to participate
This study was approved by the Institutional Review Board of the BRAC James P Grant School of Public Health, BRAC University. Interview participants gave their written informed consent for participation and analysis of all collected data.

Consent for publication

Not Applicable

Availability of data and materials

The anonymised dataset used during the study are available from the corresponding author on reasonable request.

Competing Interest

The authors have declared that no competing interests exist

Source(s) of Funding

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Authors’ contributions

MS and SZ contributed to the conception and design of the study. SA, PH contributed to the development of the tool. SA organised and led the field activity. MS, SZ, NA assisted with content development, as well as interpreting results. SA, PH drafted the initial version of the manuscript. SZ, NZ, SA and MS reviewed parts of the analysis and reviewed draft articles. All authors edited the manuscript for important content, read and approved the final manuscript.
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Reference


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15. NIPORT. National Situation Analysis of Palliative Care in Bangladesh. 2013.


Table 1: Patient Profile
<table>
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<th>Gender</th>
<th>Age in range</th>
<th>Suffering duration from disease (in years)</th>
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