

# The Psychosocial and Spiritual Experiences of Patients with Advanced Incurable Illness in Bangladesh: A Cross-Sectional Observational Study

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## Abstract

**Context:** The psychosocial and spiritual needs of individuals with life-limiting conditions in low- or middle-income countries have not been well described. Understanding these needs is important to providing holistic palliative care. **Aim:** This study aims to better understand the psychosocial and spiritual needs and supports of patients with advanced, incurable illness in Bangladesh. **Subjects and Methods:** Individuals with advanced incurable illnesses (advanced cancer and HIV/AIDS) from a wide geographical distribution across Bangladesh were interviewed about their health status, emotional and spiritual experiences with their illness, coping and support systems, and greatest needs and fears. **Results:** We interviewed 221 individuals with incurable cancer (82%) or HIV/AIDS (18%). Self-reported health status was poor or very poor for 48%, and 44% reported feeling unhappy all of the time. The majority (61%) rated their current level of unhappiness as 10/10. Spouses (50%), children (15%), and parents (13%) were the most common caregivers. Money and medical care were equally the most common needs (46%). Participants' greatest fears were for the future of their children (38%), being in pain (29%), and dying (28%). **Conclusions:** There is a significant burden of psychosocial and spiritual concerns among patients with advanced incurable illness in Bangladesh, with sadness being very frequent and of high intensity. Family and friends provide significant emotional and practical support to patients who are seriously ill, but very few patients access any professional support for these concerns.

**Keywords:** Advanced cancer, communication, developing countries, HIV/AIDS, palliative care, psychosocial issues, spiritual issues

## INTRODUCTION

Palliative care is a holistic approach to care that aims to improve the quality of life of patients with life-limiting illness, by addressing the physical as well as psychological, emotional, and spiritual needs of patients and families. Spiritual and emotional concerns may become particularly important to patients with terminal conditions, and several studies have described how patients in this situation search for a deeper meaning in life or turn to spiritual reflection.<sup>[1,2]</sup> In addition, emotional symptoms such as depression, anxiety, and hopelessness may be frequent among patients with incurable illnesses.<sup>[3]</sup> Several studies in palliative care have found that addressing patients' emotional and spiritual needs can improve their psychological functioning and quality of life.<sup>[2,4]</sup>

Despite widespread global recognition of the importance of palliative care to reduce unnecessary suffering in resource-limited settings, palliative care is still largely inaccessible to many individuals living in low- or middle-income countries (LMIC), where an estimated 78% of adults in need of palliative care reside.<sup>[5,6]</sup> Moreover, the majority of research on palliative care is conducted in high-income countries.<sup>[7]</sup> A recent review of spirituality within health literature found that only 2.8% of articles originated in non-Western countries.<sup>[8]</sup>

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Given the individualized nature of psychosocial and spiritual care, assessment and treatment tools designed based on high-income populations may not be applicable to those in LMICs. Differences in the psychosocial and spiritual needs of patients with advanced illness in non-Western countries may be due to differences in medical decision-making, pressure for collusion, extreme poverty, and cultural expectations about emotional and spiritual responses to severe illness.<sup>[9-11]</sup> In some cultures, the patient's relatives may be expected to direct healthcare-related decisions.<sup>[9]</sup> In addition, differences in levels of education, occupation, values, and religious beliefs among low-income populations have been observed to influence patients' greatest fears and concerns at the end of life.<sup>[12]</sup> It is clear that an improved understanding of the cultural, social, and emotional experiences of terminally ill individuals in non-Western countries is critical for improving psychosocial and spiritual aspects of palliative care in these settings.

The primary aim of this study was to better understand the psychological, spiritual, and social needs and experiences of patients with advanced, incurable illness in Bangladesh. Secondary aims were to study support systems and coping strategies which patients employed to manage their emotional and spiritual needs.

We hope that these findings will raise awareness about the emotional and spiritual needs of patients who require palliative care in LMICs and support efforts to develop and implement services to address these needs. Expanding our understanding of the needs of terminally ill patients in a variety of cultures is an important step toward accomplishing the World Health Organization's vision of improved palliative care services in all the countries in need.<sup>[6]</sup>

## SUBJECTS AND METHODS

### Recruitment and sampling

We recruited individuals through convenience sampling from the oncology departments of the government referral hospital located in the main city of each of the 7 administrative divisions in Bangladesh and in one smaller city in a divisional subdistrict in each district. We also recruited participants from local HIV/AIDS support organizations in each division. Potential participants were invited to participate by trained interviewers if they had a confirmed diagnosis of advanced, incurable cancer or HIV/AIDS and if the patient was aware of his or her diagnosis. All interviews were conducted between May and June 2014.

### Design and content of the interviews

Interview schedules were developed by reviewing relevant literature including the protocol for rapid situational analysis of palliative care in Vietnam.<sup>[13]</sup> The interview schedule was then culturally adapted and translated into the Bengali language. A pilot interview schedule was developed which was reviewed by local palliative care practitioners and subsequently tested with ten patients. The modifications from this feedback were to improve the clarity of the questions and response items to

reflect cultural and linguistic specificities. This study describes a psychosocial and spiritual interview which was part of the larger national situational analysis of palliative care. Other portions of the national situational analysis have been described elsewhere.<sup>[14]</sup> All participants provided written informed consent before participating in the study.

The demographic information collected included age, gender, marital status, religion, and occupation. Findings related to medical treatments and physical symptoms have been previously reported.<sup>[14]</sup> Participants were asked about their emotions and their severity, their support systems and coping mechanisms, their greatest needs, their experience after learning of their diagnosis, and the supports they received from family and friends.

### Interview process

Interview was conducted by trained interviewers and was typically 20–45 min in duration. For patients who were <18 years of age, informed consent was obtained from a parent, and the patient provided verbal assent. Individuals informed that they were permitted to skip any questions that they did not want to answer.

### Ethical approval

The study was approved by the Directorate General of Health Services (DGHS) of Bangladesh and all the institutions and programs involved in the study. Ethical approval was granted by the Institutional Review Board of Bangabandhu Sheikh Mujib Medical University and the Research Review Board of the DGHS, Ministry of Health and Family Welfare.

### Statistical analysis

Data are expressed as either mean, range, standard deviation (SD), or percentage of the total number of patients who provided a response for each item. Data analysis was performed using Microsoft Excel (Microsoft).

## RESULTS

### Participant characteristics

There were 181 individuals with advanced incurable cancer (81.9%) and 40 with HIV/AIDS (18.1%). The average age of study participants was 45.5 years (SD = 16.4, range: 7–95 years). Self-reported health status was described as poor or very poor by 48.4% ( $n = 107$ ) of individuals. The majority (97.7%,  $n = 216$ ) of individuals were receiving treatment for their disease at the time of the study. Further sociodemographic characteristics of the participants are shown in Table 1.

### Emotional experiences of receiving diagnosis and living with illness

When participants were asked to rate their peak unhappiness following diagnosis on a scale of 0 (no unhappiness) to 10 (maximum unhappiness), the majority (61.2%,  $n = 112$ ) rated their unhappiness as maximum (10/10). Almost half of all participants reported feeling unhappy all of the time (43.9%,  $n = 97$ ). When asked to categorize

**Table 1: Sociodemographic, health, and treatment characteristics of patients (n=221)**

Demographic details	n (%)
Age (years)	
Mean	45.5
Range (SD)	7-95 (16.4)
Gender	
Male	119 (59.5)
Female	102 (51.0)
<b>Social characteristics</b>	<b>n (%)</b>
Marital status	
Married	178 (80.5)
Single	19 (8.6)
Widowed	19 (8.6)
Separated/divorced	5 (2.3)
Highest level of education attained	
Primary school	115 (52.0)
Secondary school	14 (6.3)
College, university, or higher	7 (3.2)
No formal education	85 (38.5)
Occupation	
Homemaker	66 (29.9)
Unemployed	48 (21.7)
Public or private sector worker	40 (18.1)
Farmer	30 (13.6)
Small business owner/self-employed	19 (8.6)
Student	9 (4.1)
Other	9 (4.1)
<b>Health status and current treatments</b>	<b>n (%)</b>
Self-reported health status	
Very poor	48 (21.7)
Poor	59 (26.7)
Neither poor nor good	79 (35.7)
Good	31 (14.0)
Very good	4 (1.8)
Currently receiving treatment for disease	
Yes	216 (97.7)
No	5 (2.3)

Summarizes the sociodemographic and diagnostic characteristics of individuals with advanced incurable illness using simple descriptive statistics. SD: Standard deviation

their overall satisfaction with life, just over half of participants (51.4%,  $n = 112$ ) reported feeling somewhat satisfied and 19.3% ( $n = 42$ ) were not satisfied with life. The vast majority of participants (80.5%,  $n = 178$ ) denied ever facing discrimination because of their illness. There were forty-three individuals who reported discrimination (19.5%), most commonly by family members (67.4%,  $n = 29$ ) and neighbors (41.9%,  $n = 18$ ). Further details of participants' emotional experiences of illness are displayed in Table 2.

### Support systems and coping activities

Spouses were the most common main caregivers (49.8%,  $n = 110$ ), followed by children (14.9%,  $n = 33$ ) and parents (12.7%,  $n = 28$ ). When asked about sources of

**Table 2: Emotional experiences of receiving diagnosis and living with illness**

	n (%)
Have you experienced discrimination due to your illness (n=221)	
Yes <sup>a</sup>	43 (19.5)
By family	29 (67.4)
By neighbors	18 (41.9)
By friends	3 (7.0)
By healthcare workers	2 (4.7)
Unspecified	1 (2.3)
No	178 (80.5)
How often do you feel unhappy (n=221)	
All of the time	97 (43.9)
Almost everyday	25 (11.3)
At least once a week	34 (15.4)
At least once a month	10 (4.5)
Not often	10 (4.5)
Never	33 (14.9)
Unsure	5 (2.3)
Missing data	7 (3.2)
Peak intensity of unhappiness on scale of 0-10 since learning diagnosis (n=183)	
No unhappiness (0/10)	14 (7.7)
Mild (1-3/10)	8 (4.4)
Moderate (4-6/10)	24 (13.1)
Severe (7-9/10)	25 (13.7)
Maximal unhappiness (10/10)	112 (61.2)
How satisfied do you feel with your life (n=218)	
Very satisfied	12 (5.5)
Satisfied	52 (23.9)
Somewhat satisfied	112 (51.4)
Not at all satisfied	42 (19.3)

Summarizes participants' emotional experiences of diagnosis and living with illness including experiencing discrimination, frequency and intensity of unhappiness, and life satisfaction. Data are described using simple descriptive statistics. Sample size varied across items as a result of participants electing not to answer particular items and is denoted in subheadings in the case of deviance from the overall sample size.

<sup>a</sup>Participants could provide multiple responses

psychological or spiritual support, 151 participants (70.6%) were able to identify someone as a source of psychological or spiritual support. Common supports were other family members ( $n = 40.4%$ ,  $n = 61$ ), spouses (24.5%,  $n = 37$ ), or siblings (21.2%,  $n = 32$ ). Talking to family (40.2%,  $n = 78$ ) was the most common activity which participants reported using to cope with unhappiness. Further details of the support systems described by participants are shown in Table 3.

### Greatest needs and fears

When asked to describe their greatest needs, money and medical care were the most common responses, which were reported with equal frequency (46.0%,  $n = 99$ ). A need for pain relief (21.4%,  $n = 46$ ) or food (11.2%,  $n = 24$ ) were also common responses. Participants' greatest fears were commonly about the future of their children (38.3%,  $n = 82$ ), followed

**Table 3: Participant support systems**

	<i>n</i> (%)
Who is your main caregiver? ( <i>n</i> =213)	
Spouse	110 (49.8)
Child	33 (14.9)
Parent	28 (12.7)
Cares for themselves, or does not have a caregiver	19 (8.6)
Sibling	11 (5.0)
Other family member	10 (4.5)
Friend	2 (0.9)
Other (unspecified)	8 (3.6)
Source of psychological and/or spiritual support ( <i>n</i> =214)	
Do you have someone to provide support if needed <sup>a</sup>	151 (70.6)
Other family member	61 (40.4)
Spouse	37 (24.5)
Sibling	32 (21.2)
Parent	27 (17.9)
Close friend	23 (15.2)
Healthcare worker	15 (9.9)
Another person with the same disease	15 (9.9)
Neighbor	11 (7.3)
Nongovernmental organization worker	3 (2.0)
Spiritual leader (imam, priest, etc.)	2 (1.3)
Counselor	1 (0.7)
Does not have a person to provide support, if needed	63 (29.4)
Have you received support from ( <i>n</i> =131) <sup>a</sup>	
Family	93 (71.0)
Neighbors	30 (22.9)
People's committee	21 (16.0)
Friends	19 (14.5)
Hospital outpatient department	19 (14.5)
Social welfare officer	3 (2.3)
Local religious group	2 (1.5)
Nongovernmental organization worker	2 (1.5)
Home-based care team	2 (1.5)
Other (unspecified)	6 (4.6)
Activities used to cope with unhappiness ( <i>n</i> =194) <sup>a</sup>	
Talk to family	78 (40.2)
Go to a religious place	57 (29.4)
Talk to friends	45 (23.2)
Wander about with no aim in mind	27 (13.9)
Take medications	26 (13.4)
Listen to music, watch TV, or read	12 (6.2)
Meditate or sit silently	11 (5.7)
Sleep or rest	9 (4.6)
Exercise or walk	6 (3.1)

Summarizes the support systems and coping mechanisms used by individuals with advanced incurable illnesses using simple descriptive statistics. Sample size varied across items as a result of participants electing not to answer particular items and is denoted in subheadings in the case of deviance from the overall sample size. <sup>a</sup>Participants could provide multiple responses

by being in pain (29.0%, *n* = 62) and dying (28.0%, *n* = 60). Participants most commonly desired information about how to care for themselves (42.2%, *n* = 89) and their disease and its treatment (26.5%, *n* = 56). Further details about participants' needs are shown in Table 4.

## DISCUSSION

We describe the psychosocial and emotional experiences of individuals living with advanced incurable illnesses across a wide geographical distribution in Bangladesh. We found that family and friends were a frequent source of support for ill individuals, providing both emotional and practical caregiving support; however, a significant proportion of individuals reported having no one to provide them with psychological or spiritual support, and feelings of sadness were very common among patients. Patients frequently reported fears about the future of their children, dying, or being in pain. Money and medical care were the most common needs of patients.

### Emotional needs and support

We found that the majority of patients reported that they depended on family or friends for psychological or spiritual support. In Bangladesh and many other LMICs, access to psychosocial health professionals is often very limited, with a recent World Health Organization study estimating that at least 239,000 mental health workers are needed to address the current shortage of health professionals in the 58 LMICs which were sampled.<sup>[15]</sup> We found only a small number of patients were receiving support from a healthcare professional with only one patient specifically mentioning a counselor, which suggests that there is limited availability of psychosocial professionals to address the emotional and spiritual suffering of patients in Bangladesh. In the absence of professional mental health services, patients may seek the support of family and friends. Although many patients do derive support from family and friends, we also found that a significant number of individuals (29%) did not have anyone to provide them with these supports, further demonstrating the extent of this need.

We found that patients had very significant feelings of sadness, with 122 patients (58.4%) reporting that they felt sad almost every day or all of the time. These findings are similar to those from India where patients reported emotions such as fear and feeling useless or a burden, which caused unhappiness.<sup>[12]</sup> Our findings suggest a need for improved psychosocial and spiritual care for patients with serious illnesses and support the findings of a recent global mapping exercise of the significant gap in the availability of palliative care in Bangladesh.<sup>[16]</sup> Further studies are needed to better understand the psychosocial support services which will support patients and how to deliver these supports in a resource-limited setting.

### Practical caregiving support

We found that family members were the main caregivers for patients, with only one patient reporting a healthcare worker as their main caregiver. In many non-Western societies, family members are expected to provide care during times of illness, and there may be few options for nonfamily caregiving.<sup>[17]</sup> In Bangladesh, a shortage of nurses may limit patients' access to formal caregiving from the healthcare system.<sup>[18]</sup> In addition, the financial burden of paying for caregiving services, most of which are not publicly funded, means that most patients would struggle to afford these services in a resource-limited setting.



**Table 4: Patient needs and fears**

	<i>n</i> (%)
Greatest needs ( <i>n</i> =215) <sup>a</sup>	
Money	99 (46.0)
Medical care	99 (46.0)
Pain relief	46 (21.4)
Food	24 (11.2)
ART	20 (9.3)
Someone to take care of me at home	20 (9.3)
A job or source of income	19 (8.8)
Respect	16 (7.4)
Knowledge about taking care of myself	13 (6.0)
Treatment for disease	11 (5.1)
Love	9 (4.2)
Unspecified	8 (3.7)
Nothing	7 (3.3)
Greatest fears ( <i>n</i> =214) <sup>a</sup>	
Children's future	82 (38.3)
Being in pain	62 (29.0)
Dying	60 (28.0)
Disease or treatments	22 (10.3)
Not being loved	9 (4.2)
Not receiving a proper funeral	8 (3.7)
Feeling hopeless	7 (3.3)
Having symptoms other than pain	4 (1.9)
Future of other family members	3 (1.4)
Other	14 (6.5)
Nothing	17 (7.9)
Service needs ( <i>n</i> =208) <sup>a</sup>	
Pain relief	85 (40.9)
Relief from symptoms other than pain	63 (30.3)
Treatment for medical condition	50 (24.0)
Care for my children or grandchildren	33 (15.9)
Treatment for HIV	32 (15.4)
Help finding a source of income or financial support	25 (12.0)
Home-based care	22 (10.6)
Help sending children to school	20 (9.6)
Counseling or emotional support	15 (7.2)
Spiritual advice	5 (2.4)
Legal advice	3 (1.4)
HIV/AIDS support group	3 (1.4)
Other <sup>b</sup>	9 (4.3)
Informational needs ( <i>n</i> =211) <sup>a</sup>	
Information about how to take care of self	89 (42.2)
Information about disease or disease-specific treatments	56 (26.5)
Information about nutrition	45 (21.3)
Information about finding a job or source of income	34 (16.1)
Information about how to access treatment for the disease	15 (7.1)
Information related to helping family members	4 (1.9)
Information about how the government helps people with this disease	3 (1.4)
Information about symptom management	3 (1.4)
Spiritual or religious advice	2 (0.9)
Other <sup>c</sup>	13 (6.2)

Contd...

**Table 4: Contd...**

	<i>n</i> (%)
Nothing	10 (5.5)

Summarizes the current needs and fears of individuals living with advanced incurable illness using simple descriptive statistics. Sample size varied across items as a result of participants electing not to answer particular items and is denoted in subheadings in the case of deviance from the overall sample size. <sup>a</sup>Participants could provide multiple responses, <sup>b</sup>Includes: Do not know, and general or specific health information, <sup>c</sup>Includes: Unspecified, do not know, housing, and general health information. ART: Antiretroviral therapy

Our findings are similar to those of a study from Kerala, India, which reported that most terminally ill patients were cared for by their family.<sup>[12]</sup> This study from Kerala also found that the caregiving support provided by family members was a source of concern for patients since it make them feel or fear being a burden to their family.<sup>[12]</sup> Our study did not directly examine this aspect of family caregiving, and further studies are needed to better understand the caregiving experiences, patients in non-Western societies, and the impacts of family caregiving on both the patient and their family members.

### Greatest fears

We found that the most common fears identified by patients were related to the future of their children, dying, or being in pain. Concerns about the future welfare of family members have also been identified in previous studies exploring the fears of patients needing palliative care in other South Asian settings.<sup>[12,19]</sup> Previous studies from a wide range of cultures and resource levels have reported that fears about dying and having poorly controlled symptoms are common among palliative care patients.<sup>[12,19,20]</sup> A previous report about the physical symptom needs of patients in Bangladesh found that severe pain was frequent, with similar findings reported in other studies of palliative care patients in South Asia.<sup>[14,21]</sup> Although we did not examine healthcare providers' knowledge and skills in pain management, it may be that limited training in pain management among physicians and other healthcare professionals contributes to fears about pain among patients. Several previous studies of physicians' pain management knowledge and skill in Bangladesh found that most physicians were unaware of the role of opioids in cancer pain management, and the majority did not feel comfortable prescribing oral morphine for this indication.<sup>[22,23]</sup> Palliative care and pain management has yet to be incorporated into undergraduate-level training programs for healthcare professionals in Bangladesh.<sup>[14]</sup> Patients may also be aware that that will be unable to access pain medications in the advanced stages of their illness.<sup>[24]</sup> Our findings provide further evidence of the need for palliative care services and access to oral morphine across Bangladesh. Currently, there is no access strong opioids for those needing palliative care outside of the capital city of Dhaka.<sup>[14,16]</sup>

### Greatest needs

The most common need reported by patients in this study was money. In Bangladesh and many other LMICs, the cost of

serious or chronic disease is frequently borne by the patient and their family, with limited support from government sources. This expenditure can quickly lead a patient and family to exhaust their limited savings, and this may force the patient to discontinue treatment. In a study from India, patients often reported losing their job due to their illness which contributed to financial problems.<sup>[12]</sup> Although we did not specifically examine this specifically, it is possible that loss of employment by the patient or main wage-earner in the family contributed to the need for money among our patients. The need for money may also be linked to the very limited social security net which is available in Bangladesh, leading patients to be concerned about financially supporting their basic needs such as shelter, food, water and electricity. A recent study describing the provision of palliative care in an urban slum in Bangladesh incorporated food packets as part of the support provided to patients and their families.<sup>[25]</sup> Further studies are needed to explore the characteristics of the financial situation of patients with advanced illness in LMICs and demonstrate the best models of care for this particular need.

### Strengths

Our study provides a comprehensive assessment of the needs and experiences of individuals with advanced incurable illness from a wide geographical distribution across the whole country of Bangladesh. We describe a relatively simple methodology, which can easily be implemented to assess psychosocial and spiritual needs through interviews with patients.

### Limitations

The use of closed-ended interview questions and convenience sampling methodology may limit our findings' generalizability. Further exploration of patients' needs using qualitative methodologies may lead to greater understanding of patients' experiences.

### CONCLUSIONS

There is a significant burden of psychosocial and spiritual concerns among patients with advanced incurable illness in Bangladesh, with sadness being very frequent and of high intensity. Family and friends provide significant emotional and practical support to patients who are seriously ill, but few patients access professional support for these concerns. To reduce suffering, national plans and policies should be developed to address the emotional and spiritual concerns of individuals with advanced illness in all regions of Bangladesh.

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### Conflicts of interest

There are no conflicts of interest.

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