

Original Article

An Evaluation of Palliative Care Services at Different Settings — Patients' Perspective

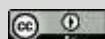
DOI: dx.doi.org

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Received: 21 November 2023
Accepted: 26 November 2023
Published: 28 November 2023

Published by:
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ABSTRACT

Introduction: Palliative care into the continuum of care of chronic life-threatening illnesses can improve the quality of life of patients and their family, upholding the dignity and meeting the care needs of people at the end of their lives. The present study aimed to evaluate the delivery of palliative care from patients' perspective. **Methods and materials:** This cross section quantitative study was carried out among 108 palliative patients selected conveniently to evaluate the palliative care services at different settings by face-to-face interview with pretested structured questionnaire. **Result:** A total of 108 palliative patients participated, with most receiving homecare (41.6%) and the rest split between outpatient (39.9%) and inpatient (18.5%) services. The majority was females (60.2%), married (70.4%), and had primary education (56.5%). Cancer (50%) and stroke (22.3%) were the leading

diagnoses. Using the CES-P scale, over 87% were satisfied with clinical and interpersonal aspects of care. However, organizational factors like environment and availability had mixed reviews, with up to a third dissatisfied. Regarding preferred treatment settings, home-based care was overwhelmingly favored across disease types, with no significant differences ($p=0.089$). A significant association was found between patients' level of dependency and preferred care location ($p<0.05$), with more independent patients favoring outpatient and home-based options. **Conclusion:** It may be concluded that PC services in Bangladesh is satisfactory from patients' perspective. This study may serve as a quality improvement initiative to identify the strengths and weaknesses of PC service delivery, which can be used to plan and conduct further studies.

Keywords: Palliative care, Evaluation, Palliative Care Settings

(The Insight 2023; 6(1): 214-221)

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INTRODUCTION

Palliative care is considered an emerging medical specialty focused on relieving suffering in patients with life-threatening illness and improving quality of life [1]. As defined by the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through prevention and relief of suffering via early identification and treatment of pain and other issues, whether physical, psychosocial or spiritual" [1]. This definition emphasizes palliative care's dual aims of enhancing patient well-being as well as supporting family members coping with the challenges of a serious illness. The need for palliative care services is growing substantially due to aging populations and rising rates of chronic diseases worldwide [1-2]. It is estimated that at least 40 million people could benefit from palliative care approaches if current knowledge was more accessible [1]. However, a World Health Organization study found that of 234 countries surveyed, only 20 had well-integrated palliative care programs [1]. Bangladesh is considered to be at Stage 3a in palliative care development, indicating some isolated services and training are available but the system remains limited [2]. Recently, the National Institute of Population Research and Training assessed the unmet need for palliative care in Bangladesh and reported over 600,000 people were in need of services [2]. Evaluation of health services aims to determine the value of interventions through examining processes, impacts and outcomes [3]. Patients' perceptions of care delivery are an important component of quality

assessment [3-4]. The purpose of evaluation is to inform policy and operational decisions by collecting and analyzing data on relevance, progress, effectiveness and other metrics of programs and treatments [3]. A central framework for evaluation proposed by Donabedian includes assessing structure, process and outcomes of care [4]. Structure refers to characteristics of resources, process focuses on diagnosis and management, and outcomes encompass measures like survival, symptom relief and quality of life [4]. Several settings for palliative care delivery have been utilized internationally, including hospitals, outpatient clinics, nursing facilities and in-home care [5]. Each model takes a different approach to determining who provides services and how care is optimally administered [5]. In Bangladesh, a Centre for Palliative Care (CPC) was established in 2011 at Bangabandhu Sheikh Mujib Medical University (BSMMU) - a significant development among the limited initiatives in the country at that time [6]. In 2015, the CPC began a pilot project extending its reach into two urban slums in collaboration with the Worldwide Hospice Palliative Care Alliance [6].

METHODS & MATERIALS

This cross-sectional study was conducted from July 2019 to April 2020 across settings of the Centre for Palliative Care (CPC) at Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka, Bangladesh. This included inpatient and outpatient services at CPC as well as a community-based palliative homecare project in Korail, the largest urban slum in Dhaka. The study population comprised palliative patients registered or admitted to

CPC at BSMMU. Purposive sampling was used to determine a sample size of 108 palliative cases based on population proportion formulas. The Care Evaluation Scale Patient Version (CES-P) was administered through face-to-face interviews to collect data on patient perspectives of palliative care structure, process and outcomes [7]. The CES-P comprises 23 items within 8 domains measured on a 5-point Likert scale. It was translated to Bengali and pretested. Data were analyzed using descriptive and inferential statistics in SPSS. Ethical approval was obtained from the Institutional Review Board of NIPSOM in accordance with the Helsinki Declaration. Written informed consent was provided by all participants.

RESULTS

Table I: Distribution of respondents by socio-demographic characteristics (n=108)

Characteristics	Category	f (%)
Age (in year)	≤ 50	34 (31.5%)
	51-65	44 (40.8 %)
	66+	30 (27.7%)
Mean ± SD 55.5 (± 10.5) years		
Sex	Male	43 (39.8%)
	Female	65 (60.2%)
Marital Status	Married	76 (70.4%)
	Widow/Widower	30 (27.7%)
	Unmarried	02 (1.8%)
Job Pattern	Homemaker	35 (32.4%)
	Service	32 (29.6%)
	Business	26 (24.1%)
	Unemployment	15 (13.9%)

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Educational Status	No education	25 (23.2%)
	Primary	61 (56.5%)
	Secondary & above	22 (20.3%)
Disease Profile	Cancer	54 (50%)
	Stroke	24 (22.3%)
	Respiratory	11 (10.2%)
	Renal	09 (8.3%)
	Musculoskeletal	03 (2.7%)
	Others	07 (6.4%)
Dependency	Completely capable	19 (17.6%)
	Capable after some limitation	45 (41.7%)
	Take care own self	17 (15.7%)
	Completely dependent	27 (25%)

A total of 108 palliative patients participated in the study. Most patients (41.6%) were receiving homecare services through the Korail palliative project, while 39.9% accessed outpatient care and 18.5% were inpatient cases at CPC, BSMMU. Regarding socio-demographic characteristics, over half of patients (56.5%) had primary education and the mean age was 55.5 years. Slightly more females (60.2%) took part than males. The majority (70.4%) were married. Most common job patterns were homemaker (32.4%) and service (29.6%). Cancer (50%) and stroke (22.3%) comprised the leading disease diagnoses. Nearly half (41.7%) reported some functional limitations, while 25% were fully dependent on caregivers.

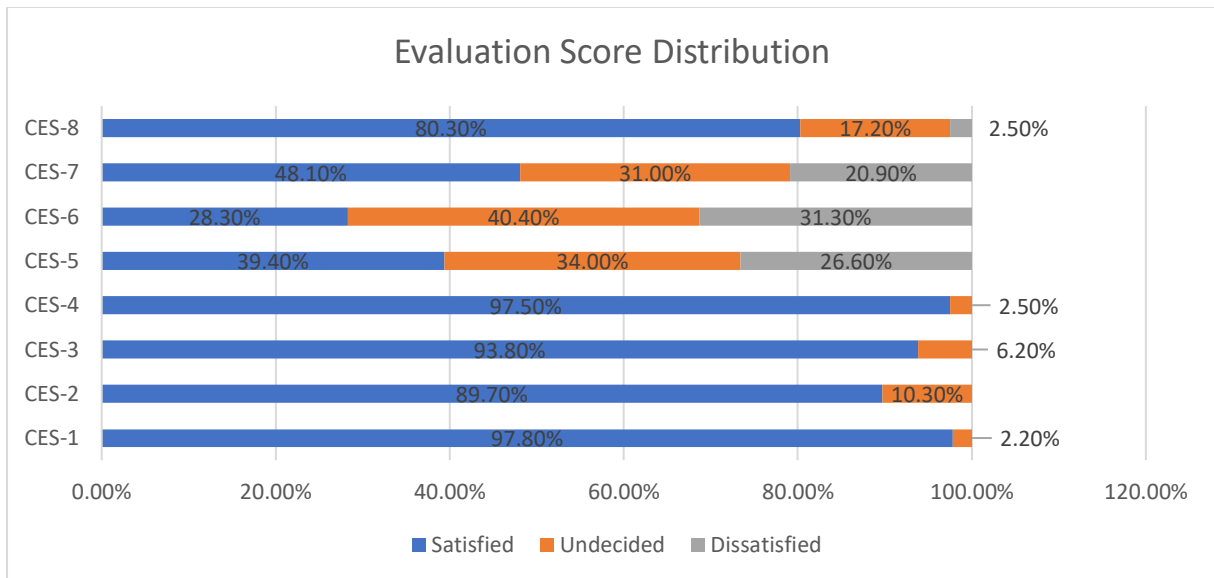


Figure 1: Distribution of patients by evaluation scores (n=108)

The CES-P was used to evaluate patient perspectives on eight domains of palliative care. CES-1 to CES-4 assessed physical care by doctors and nurses, psycho-existential care, and help with decision making. Over 87% of patients reported being satisfied with these clinical and interpersonal aspects of care. CES-5 evaluated perceptions of the care environment, which 34% of patients were undecided about and 26.6% reported being dissatisfied with. For CES-6, which assessed availability of care, and CES-7 regarding coordination of care, close to a third of patients reported being dissatisfied while around half were satisfied. CES-8 covered costs of care and had the highest satisfaction rate at 80.3%, though 17.2% remained undecided about costs. In summary, patients generally expressed satisfaction with the medical care and communication captured in the first four CES domains. However, a sizeable proportion of patients were less satisfied or undecided regarding organizational factors evaluated in CES-5 through CES-8 such as

environment, availability, coordination, consistency and costs of palliative care services. This highlights potential areas for quality improvement according to patient priorities and experiences.

Table II: Distribution of patients according to their disease and preferred place to be treated (n=108)

Variables	Indoor (%)	Home (%)	Outpatient (%)	p-value
Cancer	16.9	80.8	2.3	0.089
Stroke	13	82.6	4.3	
Respiratory	2	77.2	20.8	
Renal	11.1	86.9	2	
Neurological	4	93	3	
Musculoskeletal	21	60	19	
Others	17	70	13	

The table evaluated 108 palliative patients' preferred place of treatment according to their disease. For cancer patients, the majority (80.8%) preferred home-based care, while 16.9% chose indoor hospitalization and only 2.3% opted for outpatient treatment. Among stroke patients, 82.6% preferred care at home and 13% chose indoor care, with 4.3% selecting outpatient services. For respiratory diseases, 77.2% of patients wanted home treatment and 20.8% chose outpatient care, with only 2% selecting indoor hospitalization. Regarding renal diseases, the preferred places of care were

home for 86.9% and indoor for 11.1% of patients, with 2% selecting outpatient care. Neurological patients overwhelmingly (93%) preferred home treatment, followed by indoor (4%) and outpatient (3%) care. Musculoskeletal disease patients were more evenly split between home (60%), indoor (21%) and outpatient (19%) care. The category of other diseases mostly preferred home care (70%), followed by outpatient (13%) and indoor (17%) treatment settings. No statistically significant differences were found between disease types and preferred care locations ($p=0.089$).

Table III: Associations of patients by their dependency and preferred place to be treated (n=108)

Variables	Completely capable (%)	Capable with some limitation (%)	Take care own self (%)	Completely dependent (%)	p-value
Indoor	10.3	47.2	22.5	20	<0.05
Home	18.4	18.8	2.5	60.3	
Outpatient	38.2	15.2	34.5	12.1	

The table examined associations between 108 patients' level of dependency and their preferred place of treatment. Among those who were completely capable, 38.2% preferred outpatient care, 18.4% chose home treatment, and 10.3% opted for indoor hospitalization. For patients capable with some limitations, the majority (47.2%) preferred indoor care, followed by home (18.8%) and outpatient (15.2%) settings. Those able to take care of themselves most favored outpatient care (34.5%) and home treatment (22.5%), with indoor hospitalization chosen by 22.5%. The completely dependent group

overwhelmingly (60.3%) preferred home care, followed by indoor (20%) and outpatient (12.1%) treatment. A statistically significant association was found between dependency level and preferred care location ($p<0.05$), with more independent patients favoring outpatient and home-based options, and dependent patients mostly selecting home care.

DISCUSSION

Patients' opinions about the care they receive hold significant value. In a study conducted at various settings of CPC,

BSMMU, 108 palliative patients were consented and interviewed to assess the quality of palliative care services. Existing research has indicated that the assessment of care can be influenced by factors related to a patient's demographic and clinical characteristics [8]. Among the patients, 44 (40.8%) fell within the age group of 51-65 years, with a mean age of 55.5 (± 10.5) years [1]. Of these patients, 65 (60.2%) were female, and the majority (61, 56.5%) had primary education. The largest group in terms of employment status was homemakers (35, 32.4%). Cancer (54, 50%) and Stroke (24, 22.3%) were the two most prevalent conditions among the study group. Concerning the dependency of palliative patients, most of them (45, 41.7%) were classified as 'capable with some limitation'. These findings align with previous research, confirming typical palliative care patterns [8-10]. Previous studies have indicated that patients' evaluations of care can vary based on both person-related and organization-related factors [4,5,6]. In our study, the overall evaluation score of patients was 11.31 out of 15, with the highest score in Domain-1 (satisfaction with physical care by the doctor) at 13.85 out of 15, and the lowest score in Domain-6 (physical condition of the hospital). Donabedian's research also noted that patients felt a lack of privacy for conversations with loved ones and that inadequate staffing contributed to the low score in Domain-6 [11]. Patients in outpatient departments had the fewest negative comments, but those comments centered on the lack of physician support and inadequately educated or inattentive staff. In our study, the hospital environment received criticism for being noisy and busy, leading to patients feeling

undervalued and uncared for. Overall, the quality of care in various palliative care settings was generally perceived as 'moderate to high,' with an overall evaluation score of 11.31 out of 15. Domains 1 (physical care by the doctor), 2 (physical care by the nurse), 3 (psycho-existential care), 4 (help in decision-making process), and domain 8 (coordination and consistency) were 'satisfied' by most patients, with more than 80% indicating satisfaction. Research by Zimmermann et al. found that specialized palliative care improved patients' perception of care quality [12]. Most patients with the mentioned diseases preferred 'home' as their place of treatment, with the highest preference among neurological (93%), renal disease (86.9%), and cancer patients (80.8%). 45 (41.7%) of patients were capable of performing their daily activities with some limitations, while 27 (25.0%) were completely dependent. 60% of completely dependent patients preferred home as their place of treatment, while 47.5% of those capable with some limitations preferred indoor treatment. These findings are statistically significant. In-home palliative care interventions for terminally ill patients have been shown to improve patient satisfaction, reduce medical care costs, and increase the proportion of patients dying at home [13]. Hospital-based indoor/outdoor palliative care services seem to enhance patient outcomes by providing comprehensive care and better symptom management [14]. However, a few studies have indicated that 'PC at home' increased patients' perceptions of care quality, and outdoor services tend to reduce hospital stays if required in the future, facilitating a smooth transition to

community care [13,14]. In line with our study, patients expressed high satisfaction with care and evaluated the palliative care as 'good'. Defining the elements of quality care, developing appropriate quality indicators, and measuring patient satisfaction are essential steps to enhance palliative care provision. This study offers insights into patients' experiences of palliative care in different settings, emphasizing the preference for home settings. Patients were generally 'satisfied' with the care, but continuous development of palliative care services is crucial to meet current and future patient needs. Incorporating patient evaluations and preferences is vital in the pursuit of high-quality palliative care.

Limitations of the Study:

The study was conducted in a single hospital with a small sample size. So, the results may not represent the whole community.

CONCLUSION

Bangladesh faces huge unmet needs of palliative care where for patients with not only incurable but also life limiting diseases. Palliative care promotion has been strengthened by announcing that allocation of palliative care is a human right. In conclusion, this study showed the patients' perspective of the evaluation of PC including perceived reality of the care received. Perception for quality of palliative care received across different settings, as revealed in this study was mostly 'high' from patients' perspective. This study considers the integration of PC services in the existing health system at all level of care in all the settings. Further

studies are needed to investigate areas of strength and areas for improvement which eventually help to raise patient satisfaction and create a better overall PC experience which is our not only ethical but also moral obligation.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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