

Original Article

Palliative Care Services in Childhood Cancer in Bangladesh: Current Situation and Challenges

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Abstract

Background: Palliative care is a major priority in childhood cancer care strategy as it provides compassionate support both for the children and their families. **Objective:** The aim of the present study was to observe the current situation of palliative care services in childhood cancer in Bangladesh and its challenges. **Methods:** An anonymous survey was done between July and December of 2013 in some specialized pediatric oncology units of different public and private hospitals in Dhaka city of Bangladesh, based on a semi-structured questionnaire. A total of 300 respondents including physicians, nurses, caregivers, hospital managers who deal with childhood cancer, and parents of children suffering from cancer took part in this survey. Queries addressed are access to treatment, availability of drugs, palliative care, pain management, cost of treatment, quality of care and perceived challenges. **Results:** Difficulty in access to treatment (86%), out-of-pocket payment for oncology therapies (88%), palliative care (91%) were evident. 93% reported that availability of specialized palliative care services, pain management and psychological plus decision-making support were directly related to income level. Overall, 96% of respondents indicated that palliative care is important for their patients and 79% indicated that they were competent to provide this care; however, only 64% indicated that they had enough time to deliver quality palliative care. Challenges include lack of awareness, less availability of facility, high cost, limited and inefficient manpower, low quality of care, less communication between health professionals and parents/family members of the patient. **Conclusion:** In Bangladesh, pediatric oncology is usually practiced in resource-strained oncology units of pediatric divisions in different public hospitals along with few private hospitals. However, this survey confirmed that many of the children lack access to quality palliative care. Effective palliative care requires establishment of more facilities with cancer registry, availability of drugs for therapies and pain management, manpower development, communication with patients and families in decision-making.

Keywords: Palliative care, childhood cancer, pediatric oncology, Bangladesh.

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Introduction:

Palliative care is an approach that focuses on reducing severity of symptoms of diseases rather than delaying the progression of the disease or provide curative measures and improves the quality of life of patients (both adults and children) and their families who are facing problems associated with life-threatening illness such as cancer¹. It prevents and relieves suffering through the early identification, correct assessment and proper treatment of pain or any other physical/psychosocial problems^{1,2}. The World Health Organization (WHO) declares palliative care a human right and has proposed a comprehensive agenda for national policy, education, public

awareness, morphine availability, and palliation standards¹. Pediatric palliative care programs are increasingly common in resource-rich countries; however, there is little or no information about their availability and quality in middle- and low-income countries³. Bangladesh is a low-income country of South Asia, with a population over 160 million and more than one-third of its population are children⁴. In 2016, healthcare expenditures in Bangladesh remain low at 34US dollars per capita, with near about 72% of this spending being out-of-pocket⁴. Within this health economics, Bangladesh is estimated to have 6-9 thousand new cases of childhood cancer annually, although there is no available national population-based cancer

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registry^{5,6}. Moreover, statistics showed that a fewer than 25% of these children are actually diagnosed⁶. Barriers to optimal pediatric cancer care include lack of screening programme, delayed diagnosis, limited access to standard therapies, inadequate manpower and health care infrastructure, limited understanding of specific needs, unavailability of rural services, mismanagement of resources, limited clinical education, and misplaced priorities^{2,3,7,8}. For the limited number of children who begin treatment, cure rates are reported to be only 50-60%, even in specialized tertiary treatment facilities⁸. Due to financial difficulties and misperceptions about the incurability of cancer, 43% of children diagnosed with cancer do not start treatment or stop treatment prematurely⁷. Additionally, due to late diagnosis and advanced disease at presentation, more than 20% of children are incurable at the time of diagnosis and 10% die in early treatment phases^{7,8}.

Palliative care is a major priority in childhood cancer care strategy as it provides compassionate support both for the children and their families^{1,2,7,8}. There are an estimated 2 million children in Bangladesh in need of palliative care and 29 thousands children needing specialized end-of-life care annually in Bangladesh, including children with cancer and other life-threatening or life-limiting conditions; however, less than 1% of children requiring palliative care in Bangladesh have access to it⁷. There are very few palliative care services operating and most are focused on adult patients; however, only few pediatric palliative care services exist in government and private hospitals^{6,7}. Under the circumstances, I proposed this study to collect data on the current situation of palliative care services in childhood cancer in Bangladesh and find out the challenges identified by different stakeholders.

Methods:

An anonymous survey was done based on a self-administered, semi-structured questionnaire between July and December of 2013 in some specialized pediatric oncology units of different public and private hospitals in Dhaka city of Bangladesh. A total of 300 respondents including physicians, nurses, caregivers (both professionals who deal with childhood cancer and parents of the children suffering from cancer), and hospital/program managers who deal with childhood cancer patients took part in this survey. Queries addressed were access to treatment, availability of drugs, palliative care, pain management,

cost of treatment, quality of care and perceived challenges. All the participants were given detailed explanation of the study and informed written consent was taken from them. Data were collected and coded to ensure anonymity, then assembled, and compiled. All data were presented systematically in tables. Qualitative data were expressed as frequency and percentage.

Results:

Among 300 respondents, most of them are from 31-40 age group (49%), followed by 21-30 years group (24.67%), 41-50 years group (17%) and 51-60 years group (9.33%). 108 were males (36%), while 192 were females (64%). 28 physicians, 47 nurses, 8 hospital/program managers, 6 counsellors and 211 caregivers (both professionals and parents of the children) participated in the study (Table 1). Difficulty in access to treatment (86%), out-of-pocket payment for oncology therapies (88%), palliative care (91%) were evident (Table 2). 93% reported that availability of specialized palliative care services, pain management and psychological plus decision-making support were directly related to income level. Overall, 96% of respondents indicated that palliative care is important for their patients and 79% indicated that they were competent to provide this care; however, only 64% indicated that they had enough time to deliver quality palliative care (Table 3). Challenges include lack of awareness, less availability of facility, high cost, limited and inefficient manpower, low quality of care, less communication between health professionals and parents/family members of the patient (Table 4).

Table 1. Demographics of the participants (n=300)

Demographic Characteristics	Number	Percentage (%)
Age (in years)		
21-30	74	24.67
31-40	147	49
41-50	51	17
51-60	28	9.33
Sex		
Male	108	36
Female	192	64
Role in Oncology/Palliative Care		
Physician	28	9.33
Nurse	47	15.67
Hospital/Program manager	8	2.67
Counsellor	6	2
Caregiver	211	70.33

Table 2. Perceived difficulty in access to cancer care (n=300)

Barriers	Number	Percentage (%)
Access to diagnosis and treatment	259	86.33
Treatment cost	264	88
Access to palliative care	272	90.67

Table 3. Perceived scopes and provision of palliative care (n=300)

Barriers	Number	Percentage (%)
I think palliative care is important.	289	96.33
I think palliative care services, pain management and psychological plus decision-making support is available for money.	278	92.67
I think quality palliative care is available.	85	28.33
I think my facility is cost-effective.	93	31
I think in my role I have desired competence.	237	79
I think I have enough time to deliver my service.	191	63.67

Table 4. Perceived challenges in palliative care (n=300)

Challenges	Number	Percentage (%)
Lack of awareness.	105	35
Less availability of palliative care facility.	178	59.33
High treatment cost.	242	80.67
Low quality of care.	103	34.33
Limited manpower.	234	78
Lack of communication between health professionals and parents/family members.	209	69.67
Lack of national policy and regulations.	218	72.67

Discussion:

Palliative care is a multidisciplinary approach to patients' care to accomplish the possible highest quality of life (QOL) and promote dignity for patients who are suffering with incurable and life limiting disease such as cancer¹. The aspects of the palliative care in Bangladesh concern the matters of concentrating on the rights of the patients in getting release from sufferings of all kinds (physical, psychological, social and spiritual). There is increased awareness of the need for palliative care for chronic diseases especially for children, who remain more vulnerable to suffering. However,

there remains a huge unmet need for palliative care for chronic life-limiting health problems in most parts of the world¹. Palliative care is an essential part of cancer control, both for adults and children. World Health Assembly declared palliative care as part of human rights and called upon WHO and its member States to improve access to palliative care as a core component of health systems, with an emphasis on with an emphasis on primary health care and community/home-based care^{1-3,9,10}.

In Bangladesh, ASHIC Foundation started registering childhood cancer cases since 2001, as the first pediatric cancer focused institution. The pediatric oncology department of National Institute of Cancer Research & Hospital (NICRH) was introduced in 2008. Before that, childhood cancer patients were treated under medical oncology department at NICRH as well as other public and private hospitals. The ASHIC Foundation is a non-governmental organization whose purpose is to support childhood cancer patients and their families in Bangladesh. They provide housing during treatment, follow-ups in Dhaka city, palliative care service and psychological counselling support⁵. However, poverty is a major issue in Bangladesh; however, the national economy is showing positive growth in recent years⁴. Children present late with cancer as a result of poor public and local health worker awareness of the meaning of signs and symptoms of cancer. Consequently, only about 80% of children reaching secondary/tertiary hospitals can be offered potentially curative therapy, and of those many families cannot afford to pay for full treatment which is also true for access to palliative care⁷. The social welfare department of the government hospitals provide some support and help to patients/families. Nevertheless, at present the cost of cytotoxic chemotherapy falls to parents³. Children with incurable cancer require palliative care, particularly at the end of life,^{3,4} and all clinicians must recognize the moral and ethical obligations to address and attend the needs of the patients¹⁰. A maximum of 200 in-patient beds are available for palliative patients, which are government and private resources combined, such as Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka Shishu Hospital, NICRH, other government medical college/institutions, ASHIC Foundation Hospital, Ahsania Mission Cancer Hospital, Ahmed Medical Centre, Delta Medical Centre, Bangladesh Medical College Hospital, etc.^{6,11}. This survey confirmed that many of the

children in Bangladesh lack access to all or most of elements of palliative care. Islam & Eden⁶ also identified similar challenges as found in the present study; professional and public awareness, late diagnosis, perceptions of incurability, treatment refusal and abandonment, toxic deaths and drug costs/inconsistent availability. The perspectives and challenges are also supported by the evidence produced by Cruz-Oliver et al.³, Elsayem et al.¹², Caruso Brown et al.¹³, Sasaki et al.¹⁴ and Lorenz et al.¹⁵. Research has also identified the lack of knowledge about the philosophy of palliative care and misperceptions about palliative care as major barriers which could limit the access of patients to palliative care services and had the potential to restrict our abilities to develop the service¹³⁻¹⁵. This lack of awareness was a problem both for health administrators within the hospital and for healthcare practitioners¹²⁻¹⁵. However, efforts to engage the public and policy makers on the need for palliative care have met with limited success^{7,15}. Concerted efforts should be taken to raise public and professional awareness, develop more pediatric cancer hospitals in the country, reduce

diagnostic delays and subsidize drug and travel costs, through public-private partnership^{1,6,12-15}.

Conclusion:

In Bangladesh, pediatric oncology is usually practiced in resource-strained oncology units of pediatric divisions in different public hospitals along with few private hospitals. However, this survey confirmed that many of the children lack access to quality palliative care. Effective palliative care requires establishment of more facilities with cancer registry, availability of drugs for therapies and pain management, manpower development, communication with patients and families in decision-making.

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