



Providing Home-Based Support for Children with Chronic Conditions in an Urban Slum: Experiences from a Community-Based Palliative Care Program in Bangladesh

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Abstract

We describe the palliative care needs of children with chronic conditions and their caregivers in an urban slum in Bangladesh. In this cross-sectional study, we interviewed 25 caregivers whose children receive support from a community-based program lead by community health workers, that provides medication, medical supplies, food, caregiver training, and psychological support free of charge. The chronic conditions of children in the program included cerebral palsy (80%), congenital heart disease (8%), neurodegenerative conditions (4%), cancer (4%), and intellectual disabilities (4%). Common symptoms included cough or breathing problems (64%), fever (56%), and pain (56%). Most caregivers (96%) reported they were unable to do any paid work due to their child's needs and in all families, the child's condition had a significant impact on their financial situation. Community-based palliative care programs can be developed to support children with chronic conditions who may not access care from acute care facilities.

Keywords

palliative care, disabled children, caregivers, community health workers, global health

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What Do We Already Know about This Topic?

- Children with a range of chronic conditions should receive palliative care to address their physical, psychosocial, and spiritual suffering.
- In urban slums, the medical needs of children with chronic and life-limiting conditions are often overlooked and unmet.
- There is minimal evidence describing the palliative care needs of children with chronic or life-limiting conditions in low- and middle-income countries, particularly those in settings where resources are very limited, such as urban slums.

How Does Your Research Contribute to the Field?

- This is the first study to focus on the needs of children with chronic and life-limiting conditions

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in a community-based palliative care program, identifying that there are many children with chronic neurological conditions who need palliative care in this setting.

- Using a community-led approach with trained community health workers, supports the physical, emotional, and spiritual needs of children and their families.
- Children commonly have breathing programs, pain and fevers, while caregivers are unable to work due to their child's need for care.

What Are Your Research's Implications Toward Theory, Practice, or Policy?

- There is a significant unmet need for palliative care for children for children living in settings where resources are very limited, who are not identified through hospital-based palliative care programs.
- Community-based palliative care programs which use trained community health workers, suggest a model of palliative care which can be implemented in slum areas.
- Palliative care programs should seek to address the physical as well as the emotional, financial, and spiritual needs of children and their caregivers, to improve the quality of life for these children and their families.

Background

More than one third of the world's population lives in urban informal settlements or slums.¹ In these areas access to basic health services can be extremely challenging, due to extreme poverty, overcrowding. Additionally, poor water and sanitation services also negatively impact health outcomes. Health services are often very limited, and the medical needs of children with chronic conditions are often overlooked by the basic health programs available in informal settlements or slums.^{1,2}

In recent years, the focus of global child health efforts has been on reducing mortality, while little attention has been directed toward the needs of children with chronic or life-limiting conditions. Palliative care for children provides holistic support for children and their families, focusing on the prevention and relief of physical, psychosocial, and spiritual suffering. Globally, there are more than 21 million children who could benefit from palliative care, and more than 98% of these children live in low- or middle-income

countries (LMIC), where access to palliative care is extremely limited.^{3,4} Children with significant neonatal conditions, congenital anomalies, HIV/AIDS, cancer and other serious illnesses should receive from palliative care, which can be provided in combination with potentially curative treatments.⁵

Despite the recent decision of the World Health Organization (WHO) to include palliative care as a key component of universal health coverage, there is limited evidence about how to provide this type of support to children in resource limited settings, particularly those living in slums.⁶ Community-based palliative care programs suggest a relatively simple and low-cost model of palliative care which can be incorporated into universal health coverage.⁷

In community-based programs, health care providers provide care for patients in their own homes or in local health care facilities, reducing the need for patients to travel long distances for care.^{7,8} Such palliative care models may also reduce financial burden by reducing catastrophic health expenditure, by providing patients with a clearer understanding of their disease thus reducing spending on ineffective treatments.^{9,10}

In the state of Kerala in India, the community-based approach has been successfully implemented to support individuals with serious illnesses.⁸ In the Kerala model, trained volunteers identify community members in need of palliative care, run palliative care programs, raise funds, and mobilize community support. This simple model of care can be implemented in slum areas to provide community-based support for seriously ill individuals. In 2015, the Kerala model was adapted to provide palliative care for older adults living in 2 urban slums in Dhaka, Bangladesh.¹¹ In July 2016, this same approach was expanded to include a palliative care program specifically focused on children in the Korail Slum who had chronic or life-limiting conditions.

Several reviews have described the components of community-based palliative care programs in LMICs, however, there is no information describing the needs of children with chronic or life-limiting illnesses accessing palliative care service in these settings. There are currently no studies describing the experiences of children and their families receiving community-based palliative care, which would allow program managers and health care providers to better understand their needs to develop and evaluate effective interventions for them.

The primary objective of this study is to describe the illness experiences and palliative care needs of children with complex chronic or life-limiting conditions and their families in a slum within a resource-limited setting (Dhaka, Bangladesh). Our aim is to improve the understanding of the need for palliative care interventions to

support children and their families and explore how these may contribute to improving quality of life in this setting. This evidence will provide insights and guidance for clinicians, community members and policy-makers interested in developing community-based services for children with chronic and life-limiting illnesses globally.

Methods

Recruitment and Sampling

Primary caregivers for children who were receiving services from the Compassionate Korail Children's Palliative Care Project were invited to participate in this study. The primary caregiver was defined as the family member with the primary decision-making responsibility about the child's care. The sample size was determined by the maximum number of eligible individuals. Families were included if they had been enrolled in the project for at least 6 months prior to the data collection period.

Design and Content of Interviews

An interview guide was developed through a literature review that identified key themes from previously described assessments of palliative care in LMICs, with a particular focus on community-based programs. Three authors (MKC, KS, MD) provided feedback on the validity and comprehensibility of the draft interview questions, which were used to develop a pilot interview guide. This pilot guide was tested with 2 caregivers, which led to modifications to improve the clarity of questions and response options related to the lived experiences of those in the program.

Demographic information about age, sex, household size, education, and occupation was collected. Participants were asked about the child's health problems including characteristics of physical symptoms and needs for medications and medical supplies. Participants were asked about recent healthcare experiences, barriers to care, financial concerns, caregiving activities, and challenges, and their basic needs. Participants also completed the Pediatric Quality of Life (PedsQL) Family Impact Module (FIM) questionnaire to assess the presence of concerns or difficulties related to the child's illness. Individuals were told that they could skip any question which they did not wish to answer.

Interviewers and Linguistic Adaptation

One author (KS), who was the Compassionate Korail Project coordinator, conducted all of the interviews in

the Bengali language. The PedsQL FIM was previously translated and linguistically validated in Bengali. The interviews were conducted in March 2020, and typically took 20 to 30 minutes.

Setting

Occupying 100 acres, Korail is the largest urban informal settlement in Dhaka, Bangladesh, with an estimated 50 000 residents.¹² The majority of Korail's residents live below the poverty line, and have very low-income jobs.¹² The area has few health care facilities, and most people seek medical advice from the local medicine shops, run by unqualified personnel. Although there are several local general physicians who offer basic consultations for about 100 to 300 Tk (\$1-4 USD), but this is unaffordable for most of Korail's residents. There are a number of government health facilities in Dhaka, which provide medical consultation for minimal cost. However, at these facilities the cost of medicines and investigations is out-of-pocket, which most residents of Korail cannot afford.

In 2015, the Centre for Palliative Care at Bangabandhu Sheikh Mujib Medical University (BSMMU), a government-funded tertiary referral hospital, and World Hospice Palliative Care Alliance (WHPCA) developed a community model of palliative care for older people in Korail slum, known as Compassionate Korail.¹¹ In July 2016, Compassionate Korail was expanded to include a program for children with serious or life-limiting conditions, which was initially supported by World Child Cancer in 2016 and 2017. Since 2018, the children's program has been supported by a local organization, the Palliative Care Society of Bangladesh.

The Compassionate Korail Children's Project first identified children with serious illnesses during a community survey of all households in the slum. Children identified by the community survey were then assessed by a pediatric physician to determine their eligibility for the project. In determining which children to include, we used WHO guidelines, which suggest that palliative care is appropriate for children with serious health problems, including neonatal conditions, genetic and metabolic diseases, congenital conditions, and neurological conditions (including cerebral palsy and intellectual disabilities).⁵

Children in the project receive home visits weekly from the project's Palliative Care Assistants (PCA). The PCAs are secondary school graduates from Korail slum, who were recruited and trained in a palliative care training program at the Centre for Palliative Care (BSMMU). The training program includes 6 weeks of classroom training and 18 weeks of supervised clinical training. The PCAs' core responsibilities are shown in Table 1.

Table 1. Roles and Responsibilities of the Palliative Care Assistants in the Compassionate Korail Children's Palliative Care Project.

1. Measuring and documenting vital signs
2. Providing care for bed-bound patients (personal care and positioning)
3. Management of pressure sores and other wounds
4. Emotional support to patients and caregivers
5. Stretching and range of motion exercises
6. Developmental and play activities to promote child development
7. Dispensing medicines as per the physician's orders
8. Telephone support

The PCAs are supervised by a trained palliative care nurse and pediatric physician who develop care plans and review each child regularly. Compassionate Korail also has a small health center in the slum, with a play and therapy center where the children often receive developmental and rehabilitation services. A physiotherapist and speech pathologist provide assessments, treat patients several times per month, and train the PCAs to follow their therapy recommendations. Medications and medical services are provided free of cost for all program participants. All families in the program also receive a monthly food pack of rice, lentils, cooking oil, and salt. A full description of the program will be published elsewhere.

Ethical Approval

The study was approved by the Institutional Review Board of BSMMU (approval number BSMMU/2018/480). Written informed consent was obtained from all participants. All analyses were non-prespecified.

Data Analysis

Descriptive statistics were obtained using Microsoft Excel.

Results

Twenty-five families were eligible to participate, and all were invited and consented to participate in the study. Three families were not eligible as their child had recently joined the program. Since the program started, 46 children have been enrolled in the Compassionate Korail project. Seven (14.9%) children have moved away from Korail slum and 2 (4.3%) children have been discharged from the program after their medical condition improved substantially. Nine (19.1%) children have died from complications of their underlying conditions,

and all of these children received end of life care from the project team with the support of the Centre for Palliative Care at BSMMU. There was 1 (2.1%) child who was invited to join the project, but the child's caregiver was not interested in participating.

Conditions and Medical Care Needs

Of the children who participated, 8% (n=20) had cerebral palsy, 2 (8.0%) had Trisomy 21 with congenital heart disease and there was 1 (4.0%) child with a neurodegenerative condition, 1 (4.0%) with cancer, and 1 (4.0%) with intellectual disabilities. The majority (n=21, 84.0%) have had their medical conditions since birth. Eighty percent (n=20) of caregivers reported that the child's medical needs were somewhat better met since being part of the project. Twenty-four percent (n=6) of caregivers reported seeking medical care for their child in the past month, most commonly for medical appointments (n=3, 50.0%) or due to their child's worsening symptoms (n=2, 33.3%).

The average duration of support from Compassionate Korail was 2.3 years. The average age for the children was 7.7 years (range 1-17 years, SD 4.0). Most children were receiving medications (n=25, 100.0%), physiotherapy (n=24, 96.0%) and speech therapy (n=19, 76.0%) from Compassionate Korail. Further details of the children and their medical needs is shown in Table 2.

Physical Symptoms

More than half (n=14, 56.0%) of the children had pain in the past month, which prompted their caregivers to seek support from the Compassionate Korail team (n=12, 48.0%) or to provide massage or stretching (n=12, 48.0%). Other frequently reported symptoms included cough or breathing problems (n=16, 64.0%), fever (n=16, 64.0%), and loss of appetite (n=13, 52.0%). Table 3 shows further details of the physical symptoms which caregivers reported.

Financial Challenges

Caregivers categorized the child's illness as a medium (n=9, 36.0%) or large (n=16, 64.0%) financial problem for their family. In many cases, the family (n=5, 20.0%) sold assets or used up all or most of their savings to care for their ill child (n=17, 68.0%). Twenty-eight percent (n=7) of families reported having no savings. The most frequent costs were special foods (n=25, 100.0%) and house rent (n=22, 88.0%), with only 6 participants (24.0%) reporting medicines as a significant cost. Table 4 shows further details of financial challenges faced by families.

Table 2. Participant Characteristics, Health Care Needs, and Health Services.

Children invited to participate in Compassionate Korail since 2016 (n=47)	n (%)
Currently enrolled in the project	28 (59.6)
Died	9 (19.1)
Moved away from Korail slum	7 (14.9)
Physical and socioeconomic status improved	2 (4.3)
Declined to participate in the project	1 (2.1)
Child's primary serious health problem (n=25)	
Cerebral palsy	20 (80.0)
Trisomy 21 with congenital heart disease	2 (8.0)
Neurodegenerative condition	1 (4.0)
Cancer (brain tumor)	1 (4.0)
Severe intellectual disability	1 (4.0)
Since being part of Compassionate Korail, to what extent have your child's medical needs (for medicines and treatments) been met? (n=25)	
A lot better met	3 (12.0)
Somewhat better met	20 (80.0)
No change from before the project	2 (8.0)
What are the services the child is receiving from Compassionate Korail?* (n=25)	
Medications	25 (100.0)
Monthly food pack	25 (100.0)
Other practical/social supports (eg, clothing, money)	25 (100.0)
Physiotherapy	24 (96.0)
Art, music, play and/or developmental stimulation	21 (84.0)
Speech therapy	19 (76.0)
Medical supplies (eg, suction machine, nebulizer)	12 (48.0)
In the past month, has the child visited any other health centers for treatment (not including the Compassionate Korail center) (n=25)	
Yes	6 (24.0)
No	19 (76.0)
What was the main reason for the visit? (n=6)	
Follow-up doctor's appointment	3 (50.0)
Worsening symptoms	2 (33.3)
Missing data	1 (16.7)

*Participants could provide more than 1 response.

Socio-Demographic Profile: Caregivers

Most caregivers were mothers (n=18, 72.0%) or fathers (n=3, 12.0%). Their average age was 34.1 years (range 20-70 years). Most reported having limited or no formal schooling (60.0%), with only 1 (4.0%) person having studied beyond the primary level. The average household size was 4 (median 4). The majority of caregivers (84.0%) were not working outside of the home. Table 5 shows caregivers' socio-demographic profiles.

Caregiving Activities

Almost all caregivers (n=24, 96.0%) stated that caring for the ill child prevented them from doing any paid work outside of the home, and many (n=11, 44.0%) noted that it was also difficult to complete their regular

household work for the same reason. Caregivers commonly helped the child with bathing (n=25, 100.0%), administered medications (n=25, 100.0%), feeding (n=24, 96.0%), toileting (n=24, 96.0%) and played with the child (n=24, 96.0%).

Caregiver Challenges

The most common problems encountered by caregivers included worry about the ill child's future (n=24, 96.0%), worry about the future in general (n=21, 84.0%) and a lack of help in their caregiving role (n=21, 84.0%). Caregivers mentioned money (n=22, 88.0%), medications for the ill child (n=19, 76.0%), food (n=18, 72.0%), and respite care (n=17, 68.0%) as their greatest needs. Table 6 shows further details of the caregivers' activities, needs, and challenges.

Table 3. Physical Symptoms of Children participating in Compassionate Korail.

Has your child had pain in the past month? (n = 25)	
Yes	14 (56.0)
No	7 (28.0)
Missing data	4 (16.0)
If your child had pain in the last 1 month, how bad was the pain? (n = 14)	
Mild pain	3 (21.4)
Moderate pain	11 (78.6)
Severe pain	0 (0.0)
If your child had pain in the last 1 month, what did you do to help relieve the pain? * (n = 14)	
Brought the child to the Compassionate Korail center or the team visited the child at home	12 (85.7)
Provided the child with massage, physiotherapy, and/or stretching	12 (85.7)
Gave the child medicine from a pharmacy	2 (14.2)
Gave the child traditional medicine from a faith healer	2 (14.2)
Brought the child to another clinic or hospital	1 (7.1)
Gave the child medicines prescribed by the Compassionate Korail team	1 (7.1)
What additional symptoms did the child have in the past 1 month that were troublesome? (other than pain)* (n = 25)	
Cough and breathing problems	16 (64.0)
Fever	16 (64.0)
Loss of appetite	13 (52.0)
Seizures	10 (40.0)
Irritability or excessive crying	10 (40.0)
Spasticity or dystonia	9 (36.0)
Excessive oral secretions or drooling	9 (36.0)
Constipation	8 (32.0)
Sleeping problems	7 (28.0)
Nausea or vomiting	5 (20.0)
Weakness	5 (20.0)
Diarrhea	4 (16.0)
Mouth problems (thrush, etc)	4 (16.0)
Skin problems (bedsore, itching etc)	2 (8.0)
Symptoms of upper respiratory tract infection	2 (8.0)
Other (falling and frequent urination)	2 (8.0)
What is the most problematic symptom the child has had in the past 1 month?*(n = 25)	
Loss of appetite	8 (32.0)
Seizures	4 (16.0)
Irritability	4 (16.0)
Diarrhea or constipation	2 (8.0)
Symptoms of upper respiratory tract infection	2 (8.0)
Excessive oral secretions	2 (8.0)
Weakness	2 (8.0)
Sleeping problems	2 (8.0)
Skin problems	1 (4.0)
Breathlessness	1 (4.0)
Sudden falls	1 (4.0)
Cough	1 (4.0)

*Participants could provide more than 1 response.

Caregiver Support and Training

Almost all caregivers (n=24, 96.0%) reported having been trained in how to provide care for the child, most commonly by the Compassionate Korail project (n=22, 91.7%), with all (100.0%) reporting that the training

provided with them with some or all of the skills they needed.

Sixty percent (n = 15) of caregivers reported their role caused them to feel sad or worried. Most commonly when they felt sad, caregivers reported crying (n = 15, 60.0%) or going to a religious place or praying (n = 7,

Table 4. Financial Impacts of the Child's Illness (n = 25).

How much of a financial problem is the cost of your child's illness for your family?	n (%)
Large problem	16 (64.0)
Medium problem	9 (36.0)
Has your child illness meant having to use all or most of your family's savings?	
We have used all our savings	10 (40.0)
We have used most of our savings	7 (28.0)
We have used only a small portion of our savings	1 (4.0)
We had no savings to spend	7 (28.0)
What is costing your family so much?*	
Special foods	25 (100.0)
House rent	22 (88.0)
Medicines	6 (24.0)
Medical costs (eg, medical tests or consultation fees)	3 (12.0)
Traditional faith healer's treatment cost	1 (4.0)
Monthly loan payment	1 (4.0)
Has the child's illness prompted you or other family members to sell assets?	
Yes	5 (20.0)
No	20 (80.0)
How has the Compassionate Korail impacted on your household's finances?	
It is a bit better	21 (84.0)
It is the same as before	4 (16.0)

*Participants could provide more than 1 response.

28.0%) to feel better. All caregivers had received psychological or spiritual support from the project team. Table 7 shows further details of the psychological and spiritual supports.

Pediatric Quality of Life and Family Impact

PedsQL questionnaires found an average Family Functioning Summary Score of 51.0 (Median 50, SD 16.7) and Parent Health-Related Quality of Life Summary Score of 39.8 (Median 38.8, SD 8.7).

Discussion

We have described the illness experiences and palliative care needs of children with serious health conditions and their caregivers, living in an urban informal settlement (Korail Slum) in Dhaka, Bangladesh. We found that the majority of children in this setting have pain and other symptoms. Caregivers provide a significant amount of care which limits their ability to maintain their own emotional and physical wellbeing and provide financial support to their family. The children and families received important supports from the project, which improve the child's physical health as well as the families' financial situation.

Children with Serious Health Conditions

We are aware of only 2 other studies describing the characteristics and symptoms of children receiving palliative care in resource limited settings.^{13,14} These studies, in Bangladesh and Malawi, describe hospital-based palliative care programs which primarily include children with cancer and/or HIV/AIDS.^{13,14} Our study is one of the first focussing on children in a community-based program.

Our program included many children with neurological conditions, and this may be related to the fact that children with disabilities often struggle to access health care services, and are not likely to access traditional hospital-based palliative care programs.¹⁵ Providing community-based palliative care for children living in urban slums, may address some of the barriers to accessing acute care facilities such as mobility problems caused by the child's medical condition, medical treatment and transportation costs, and time and loss of wages for family members taking the child to the hospital.^{1,11} We modeled our program on those in Kerala, India, recognizing that those with chronic illnesses require life-long supportive care, which is typically overlooked by medical establishments which often primarily focus on acute illnesses.⁷

Table 5. Socio-Demographic Data for Caregivers (n=25).

Caregiver characteristic	n (%)
Sex	
Female	22 (88.0)
Male	3 (12.0)
Relationship to ill child	
Mother	18 (72.0)
Father	3 (12.0)
Grandmother	3 (12.0)
Aunt	1 (4.0)
What is your marital status?	
Married	22 (88.0)
Widowed	2 (8.0)
Separated/divorced	1 (4.0)
Highest level of education completed	
None	3 (12.0)
Can write name only	9 (36.0)
Some primary schooling	3 (12.0)
Completed primary schooling	9 (36.0)
Completed secondary schooling	1 (4.0)
Number of individuals living in household	
Mean	4.1
Range (SD)	2-8 (1.5)
Occupation	
Homemaker	21 (84.0)
Part-time rickshaw driver	2 (8.0)
Private sector worker (garment factory worker)	2 (8.0)
Number of children	
Mean	3.6
Range (SD)	1-7 (1.6)

Community Health Workers

Community volunteers are a key feature of the Kerala model, where volunteers are empowered to develop supports based on their knowledge of the needs of their local community.⁷ Similarly, our program's local community health workers are core palliative team members. In previous study of the palliative care project for older people in Korail Slum, the individuals in the project described the community health workers as being like family members to them.¹¹ Our findings support this, as caregivers frequently reported seeking support from PCAs when their child was in pain, as well as receiving personal psychological and spiritual support from PCAs. Further studies should evaluate this role and the benefits of this approach in more detail.

Financial Situation

Almost one quarter of the population of Bangladesh lives below the poverty line, and two-thirds of health

care spending is out-of-pocket, which leads to significant inequity for poor patients.^{16,17} We found that the financial impacts of having a seriously ill child were significant for all families were interviewed, with 40% having used all their savings due to the child's illness. Despite providing free medications, food and practical supports, most caregivers reported that their household finances were only a bit better as a result of the project. Since most caregivers were not able to work due to the child's illness, this may have limited the financial benefits of our program. A previous pilot study from India, which evaluated poverty reduction through palliative care, reported that palliative care reduced household spending on ineffective treatment and increased awareness of government support programs.¹⁰ Further studies should explore the sources of financial burden and how palliative care programs can effectively address this need.

Caregiver Training

Caregivers require training about how best to care for their child and our caregiver training program was informed by previous findings that identified this as a particular need of caregivers in resource limited settings.¹⁸ Studies from high-income countries have shown that caregiver training can reduce burnout and provide caregivers with skills to cope with emotional stress, and these effects should be evaluated in settings where resources are limited.^{19,20}

Strengths and Limitations

Our study, as far as we are aware, is the first to describe the experiences of children and caregivers in an LMIC, in a community-based palliative care program, which includes predominantly children with severe neurological impairment. Despite our efforts to adapt the interview items to the local situation, there may be issues related to cultural and linguistic equivalence of certain items. We use primarily closed ended question which limited the complexity of responses.

Conclusions

Around the world, there are very few examples of community-based palliative care programs for children, and our finding suggests that there is a significant unmet need for children's palliative care which may not be identified through hospital-based programs, particularly for children with chronic neurological conditions. Community-based palliative care programs, which incorporate trained community health workers,

Table 6. The Activities, Needs and Challenges of Caregivers (n = 25).

Item	n (%)
Activities performed by caregivers*	
Bathing the child	25 (100.0)
Give them medicines	25 (100.0)
Assisting the child to eat	24 (96.0)
Providing help with toileting	24 (96.0)
Playing with the child	24 (96.0)
Do physiotherapy exercises or stretching for the child	21 (84.0)
Taking the child out of the house	22 (88.0)
Providing emotional support to the child	13 (52.0)
Telling stories or talking to the child	2 (8.0)
Major challenges encountered by caregivers*	
Worry about the ill child's future	24 (96.0)
Worry about the future in general	21 (84.0)
Lack of help with caregiving	21 (84.0)
Lack of money for treatment for the ill child	17 (68.0)
Discrimination by neighbors or family	16 (64.0)
Caregiving is very hard work	16 (64.0)
Caregiving makes me sad or worried	15 (60.0)
Concern about deterioration in the ill child's condition	7 (28.0)
Unsure how to provide proper care to the ill child	4 (16.0)
Lack of time to provide care to the ill child	4 (16.0)
Caregivers' greatest needs*	
Money	22 (88.0)
Medications for the ill child	19 (76.0)
Food	18 (72.0)
Respite care so that the caregiver can have a break	17 (68.0)
Emotional support for the caregiver	12 (48.0)
Schooling for their other children	5 (20.0)
A job or way to make money	3 (12.0)
Daycare for their other children	1 (4.0)
Emergency medical care for the ill child	1 (4.0)
Care for their personal physical health	1 (4.0)
Caregivers' single greatest worry	
Who will care for my child if I am unable to provide care?	8 (32.0)
Will my child ever be able to care for him or herself?	7 (28.0)
Will my child be able to sit or walk?	4 (16.0)
Will my child be cured from their illness?	3 (12.0)
Will my child die from their illness?	3 (12.0)

*Participants could provide more than 1 response.

Table 7. Psychological and Financial Impacts on Caregivers (n = 25).

What do you do to make yourself feel better when you feel sad or unhappy?*	n (%)
Cry	15 (60.0)
Go to a religious place or pray	7 (28.0)
Spend time with my child	5 (20.0)
Talk to my friends or family	5 (20.0)
Talk with the palliative care assistant	4 (16.0)
Wander about with no aim in mind	4 (16.0)
Sleep	3 (12.0)
Watch television	2 (8.0)
Get angry with myself	1 (4.0)
Has anyone provided you with psychological or spiritual support?	
Yes	25 (100.0)
No	0 (0.0)
Who provided you with psychological or spiritual support?*	
Compassionate Korail Pediatric Palliative Care Team	25 (100.0)
Immediate family members (either spouse, mother, or father)	10 (40.0)
Friends or neighbors	7 (28.0)
Other relatives	2 (8.0)

*Participants could provide more than 1 response.

should be developed to support the medical needs of children, as well as the emotional, financial, and spiritual concerns of their caregivers and family members.

Author Contributions

Conceptualized and designed the intervention: MKC, MD, KS, NB, NA, MJ, NF
 Collection and assembly of data: MD, KS, MKC, NB, MB
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