Improving the quality of life of elderly people in the urban slums of Bangladesh (A BSMMU CPC Bangladesh Pilot Project)

Evaluation Report

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Section 1

Executive Summary

Palliative care was non-existent in the health and social services of Bangladesh until a decade ago, when a few isolated initiatives started taking place. In 2007, Bangabandhu Sheikh Mujib Medical University (BSMMU) – the only medical university of the country – recognized palliative care as one of its key services, and started the Centre for Palliative Care (CPC). This was the most remarkable breakthrough amongst the few palliative care initiatives in Bangladesh. In 2015, the Centre for Palliative Care (CPC) initiated a pilot project to extend the reach of palliative care services for older people and their families in two urban slums in Dhaka, in collaboration with the Worldwide Hospice Palliative Care Alliance (WHPCA). The project's goal was to improve the quality of life of elderly people in the urban slums of Bangladesh, as well as to introduce palliative care to the community. Following are the key observations from a mixed method evaluation of the project.

- A total of 106 patients' and their families were benefited through this project since its inception in 2015. Majority of the patients (62.3%) were female and the average age calculated for female patient was 66.8 years and male patient is 71.9 years. Eighty percent of the beneficiaries were illiterate with an average income of 180 US$ per month. The patients received essential medicines, various social, psychological, spiritual care as well as a food assistance worth 6 US$ per month.

- The beneficiaries were selected through a rapid situation analysis by consulting with Community Based Organizations (CBOs) in the slum and involving local adolescents. Selecting appropriate beneficiaries was challenging in the beginning. As time progressed, the project personnel endeavored to correct their own mistakes, and thus removed some primarily selected beneficiaries and included comparatively more appropriated patients as beneficiaries.

- In the beginning, the people within the community were uncooperative. In addition, due to the absence of previous experience working with this population group, the project had to proceed through a "learning by doing" approach.

- This project trained eight young women as 'vanguards', called Palliative Care Assistants (PCAs). These female volunteers in the community were trained to provide home-based palliative care including physical, social, psychological and spiritual care to their patients. Over time they developed a significant bond with beneficiaries and became part of their lives.

- Initially, PCAs experienced some resistance in the community for their work, but are now largely accepted within and play a pivotal role in the project. The beneficiaries hold the services PCAs provide to them in high regard.

- The PCAs expressed their plans to continue serving people even if the project shuts down. They have alluded to getting married someday, but their knowledge and willingness to serve people will continue to extend their services beyond the project.

- The beneficiaries were found to be highly satisfied with the food support provided to them. The packs ensured their food security and also increased their familial and social status and acceptance. The project was able to ensure the quality and quantity of the food packs with transparency and accountability.

- The beneficiaries were also found to be highly satisfied with the medical care they had received from the project. Aside from regular medical treatment and food, the beneficiaries were also pleased with other assistance provided to them from the project.

- The self-confidence and self-esteem of the beneficiaries were found to be highly increased after joining this project.

- Many of the project's staff also expressed their desire to take action for the homeless and those without anyone to look after them.

- It was evident that the leadership of Dr. Nezamuddin played a vital role in keeping the steady momentum of the project.

- A Memorandum of Understanding has been signed between the Centre for Palliative Care and Help Age officials in Bangladesh. The project also organized joint events with BRAC, Bangladesh Legal Aid and Services Trust (BLAST).Community involvement in this project is still limited.

- The project is still dependent on external resources, which is a challenge for its sustainability. However, since it has only run for a year, it would be premature to make judgments yet regarding its sustainability.

- Given the fact that almost all the available palliative care services in Bangladesh have taken institution-based approaches following western models, this community-based initiative is a highly innovative and challenging one. It appears from this rapid qualitative evaluation that the project has had remarkable success within one year and significantly

improved the quality of life of elderly people in the project area. Thus, this project has the potential to become a model for a public health approach to palliative care in a resource-poor setting.

Recommendations

a) Findings suggest that the project did not follow strict inclusion criteria for selecting beneficiaries. Thus, a well-defined inclusion and exclusion criteria needs to be developed. It could be helpful to determine and stick to an operational definition of this project in order to create an appropriate beneficiary selection process. However, it appears in the context of extreme poverty and complete lack of health services, it became very difficult for the project to demarcate the boundary of palliative care. This demands a discussion in the broader palliative care community.

b) In order to increase community involvement in the project, volunteers from colleges and universities could be trained on palliative care. Their contribution would be very effective for the success of the project.

c) All the information from beneficiaries could be preserved in a digital database, or using digital applications for better record keeping.

d) It would be helpful if the project had a rehabilitation component. It would be favorable for beneficiaries if the physically capable of the group or their family members could be engaged in some small-scale income generating activities.

e) Steps should be taken to increase the community ownership of the project in order to ensure its sustainability.

Project Brief

Introduction

The WHA 67.19 resolution adopted in the 67th World Health Assembly has recommended countries to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary, community and home-based care[1]. Bangladesh is in the stage 3a position on the world palliative care developmental mapping, which means some isolated palliative care services and training provisions exist here. A recent situation analysis revealed that although Bangladesh has Approximately 600000 incurable patients at any point of time, at present it has only six Dhaka-based comprehensive palliative care programs, which altogether served <1500 patients in 2013.[2] Same study found that 75% of cancer patients had pain and >90% of health professionals did not have any training in pain management or palliative care. Incurability remains a major unmet public health need in Bangladesh and the scenario is similar to global developing countries. With the rapid ageing of the population occurring, the highest number of patients needing PC will in future come from the elderly and terminally ill citizens. Most of the elderly and those with advanced chronic diseases will get relief from suffering if PC is available.

In Bangladesh, Only 5-6 organizations are providing palliative care services. ASHIC palliative care unit privately established the first palliative care unit (PCU) for childhood cancer patients in the country on 20th May 2006. It is also the first pediatric PCU in Asia Pacific region and only PCU in Bangladesh. After two years of ASHIC palliative care unit's establishment, the Centre for Palliative Care (CPC) Bangladesh, part of Bangabandhu Sheikh Mujib Medical University (BSMMU) included palliative care service in their service catalog. They improved their service for palliative patients in 2011 with indoor facilities of 15 beds. Later, CPC Bangladesh have initiated a pilot project to extend outreach palliative care services for older people and their families in two urban slums in Dhaka in collaboration with the Worldwide Hospice Palliative Care Alliance (WHPCA).

Project Goal

The project goal is to improve the quality of life of elderly people of urban slums of Bangladesh. Among 160 million population of Bangladesh, a significant number of people are living in urban slums. According to *Bangladesh bureau of statistics (BBS*), 2.23 million of people are currently living in nine thousand four hundred and forty three slums[3]. Among them, a huge number are

[1] WHA (2014) *Strengthening of Palliative Care as a component of comprehensive care through the life course*. Sixty-Seventh World Assembly, Agenda item 15.5. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

[2] NIPORT (2013), National Situation Analysis of Palliative Care in Bangladesh.

[3] *Bangladesh bureau of statistics (BBS*) Report (2011)

elderly people. As part of the pilot project last one year, BSMMU provided palliative care service to elderly slum patients under the 'Improving the quality of life of elder people in the urban slums in Bangladesh' pilot project of CPC Bangladesh.

Project Objectives

The one year pilot project mainly focused on the provision of palliative care in the slums through a community driven and led health approach. Another focus of the project is on the identification and development of volunteers from the communities, with support from health professionals. The overall objective of the pilot project was to improve the quality of life of elderly people within communities that will train and support healthcare workers and community members to help meet the palliative care needs of older people living within two slums in Dhaka, Bangladesh namely Agargaon and Korail.

Specific objectives of the pilot project are as follows:

- To undertake a situation and need analysis of the palliative care needs of older people and their care givers and the current care provision by family members, community members and organizations
- To identify and forge partnerships with community health workers, grassroots health and older people networks and other relevant organizations working in the two urban slums.
- To undertake a sensitization program to increase understanding and awareness of palliative care in the urban slums including developing an activist group of older people.
- To print 200 copies of the palliative care toolkit in Bengali.
- To train 6-8 assistants from the communities to provide and refer for care, using the palliative care toolkit.
- To establish a home care outreach palliative care service in two slum areas comprising nursing staff and the trained assistants.
- To provide treatment and support to 100 palliative care patients and their care givers/family members.
- To demonstrate an effective model of palliative care for older people within an urban slum through the production of a final evaluation report.

Project Activities

a) Project preparation

Considering the aforementioned objectives, at the very beginning of the pilot project, CPC Bangladesh conducted a rapid situation analysis (SA), a mixed method cross sectional study, in two urban slums in Dhaka city of Bangladesh to select program beneficiaries and program

operation strategy. For selecting program beneficiaries, the CPC Bangladesh's situation analysis team consulted with slum adolescents and slum Community Based Organizations' (CBOs) members. Based on their recommendations, the project selected program beneficiaries. Among the school level and CBO level recommendations, CPC Bangladesh finally selected the elderly people (male/female) as its pilot project's beneficiaries from two slums. Besides, based on the rapid situation analysis, CPC Bangladesh developed an implementation strategy for one year of the pilot phase of the program.

b) Project staff recruitment

The CPC recruited one fulltime project manager and one project coordinator followed by hiring part time accountant, visiting palliative care physician and nurse coordinator. Their activities started by holding two separate meetings with two groups of school teachers and school committee members of two schools in the two slums. The meetings discussed the objectives of the project, seek support in getting introduced to the slum dwellers, listen to their work experience in the slum, discuss the feasibility of the project activities and gather their opinion and suggestions about the project. Following the meetings, a 2-day-long sensitization program was organized with general people of the two slums targeting the parents of the students to introduce the issue of sufferings and need of care for elderly people in their community and see how they respond to it.

c) Palliative Care Assistants

Recruitment of the Palliative Care Assistants (PCAs) from both Agargaon and Korail slums was completed on the basis of a written exam and interview of the applicants. They underwent a thorough training program following a structured curriculum. Their first six weeks were class room teaching followed by six weeks in the hospital ward and the next 12 weeks mostly home visits as well as visiting enrolled patients in the slum under supervision. An assessment workshop was organized to determine the PCA's perceived level of confidence after twenty weeks of training.

d) Patients receiving support and care

Among the total number of enrolled patients during the total project period, some died and some others either went back to their village home or disappeared (might have moved to other cheaper places). So some patients were taken off the list to accommodate newer patients.

Following is a list of support and care provided to the patients:

Table 1: List of support and care provide to the patients from the project

Category	Services and Supports Provided	Timeline
Food Support	Rice (5 KG) Peas (2 KG) Sugar (1 KG) Salt (1 KG) Edible Oil (1 KG)	Once in every month
Livelihood and IGE support	Business materials (Weight machine, new and old cloth etc.)	Once in service timeline
Festival Support	New clothes, blankets and additional food support	During festival time
Health Support	Regular follow up Drug supply Emergency health service Routine checkup,	Regular basis
Care Support	Wound care, Helping in shower, nail cutting, hair cutting, home cleaning etc. Counseling to shocked/ bereaved family members	Based on necessary
Additional Supplement	Necessary materials (sun glass, exercise machines etc.)	Based on necessity

Food pack distributed: Food packs were distributed to all enrolled persons. Each patient and affected family received a food pack at least once a month during the project period.

Medicine provided: Medicine was provided to the patients as deemed necessary to reduce their suffering.

Other individual need based social and medical support: Need based support included engaging other disciplines, especially Eye department and Gynecology department of the medical university to access expert support:

- Eye refraction along with arrangement for glasses
- Cataract operations arranged.
- Gynecological medical support by the gynecologist of BSMMU.
- Physiotherapy consultation.
- Few elderly patients were provided with miscellaneous supports like Commode chair, rubber mattress, knee brace, rubber ball for hand physiotherapy, weighing machine and material to make paper packages as a means to earn day to day living.
- A few children of our enrolled patients were also supported to get readmission in the school as their parents had passed away.

Local sources also organized blanket distribution to all the enrolled patients and a few others and new clothes distribution before the Eid festival. These initiatives were taken by the volunteers with the help of PCAs and slum volunteers.

e) Community participation

Starting with two sensitization meetings organized with the cooperation of the two schools, 'Alok' in Agargaon and 'Educo' in Korail which gave access to those slums were followed by eight more meetings. After a number of separate meetings with two leaders leading two discreet fractions of groups of two slums, a discussion meeting on Palliative Care with the members of Korail Central Community Based Organization (CBO) committee was held. It was a real breakthrough in that project objectives were explained, views shared openly and opinions received regarding community participation. Later a base station of Palliative Care was inaugurated in Korail slum and the program was named 'Momotamoy Korail' meaning 'Compassionate Korail'.

f) Partnerships developed with other organization

A Memorandum of Understanding was signed between the Centre for Palliative Care and Help Age officials in Bangladesh following several meetings between the two organizations where both agreed on mutual cooperation. Help Age also conducted two workshops with the CPC staffs and PCAs focusing on geriatric care and Dementia. As the program continued, CPC participated in the 'Child Protection Fair' organized by BRAC and another fair organized by Bangladesh Legal Aid and Services Trust (BLAST) where 'Momotamoy Korail' explained its activities. Exchanging views with other NGOs give 'Momotamoy Korail' an opportunity to raise awareness and understanding of such care amongst other organizations involved in slum development activities.

Evaluation Objectives

The evaluation has three components and specific questions under each component as follows:

I. Management:

How was the programme implemented?

a. What are the socio-economic profile of the beneficiaries?
b. How the beneficiaries were selected?
c. How is the programme managed?

II. Effect:

What are the effects of the project?

a. On the beneficiaries life?
b. On the community?

III. Sustainability:

Is the project sustainable?

a. By the local beneficiaries and partners?

Methodology Overview

Study Approach

This evaluation study was carried out in Korail slum of Dhaka following a qualitative approach using various qualitative data collection techniques to collect primary data complemented by quantitative data from secondary source. Secondary information regarding demographic, medical and service related data was collected reviewing the project patient files.

Source of Data

The study utilized a set of qualitative research techniques including Focus Group Discussion (FGD), Key Informant Interview (KII) and Case Study. Primary data was collected from both male and female patients under palliative care, community volunteers or social leaders or leaders of Community Based Organization (CBO), Palliative Care Assistants (PCAs) and project officials. Following is a brief description of the qualitative research methods used for primary data collection of the study:

a) **Focus Group Discussion (FGD):** FGDs were conducted with Palliative Care Assistants (PCAs) to understand the efficiency and backdrops of project beneficiary selection process.

b) **Key Informant Interview (KII):** KIIs were conducted with an intention to understand perceptions and existing challenges of project implementation from project implementers' point of view. KIIs were conducted with community volunteers involved in project implementation, leaders of Community Based Organization (CBO) and Project officials.

c) **Case Study:** Case studies were conducted with male and female patients under palliative care or beneficiaries to explore various dimensions of their experience with the project. Cases were identified randomly from the project beneficiary list.

Table 2: Sample distribution of qualitative research

Research Techniques	Respondents	Sample
Case Study	Patients Under Palliative Care/ Beneficiaries	**10**
FGD	Palliative Care Assistant (PCA)	**02**
KII	CBO Leaders/ Social Leaders	**04**
	Project Officials	**04**

Selection of Cases

This study had a major focus on the case studies conducted with the beneficiaries or elderly people selected as palliative patients. A total of 10 beneficiaries were selected as cases considering different situation and characteristics. Following is a description of the reason and backdrop of selecting each respondent and using their pseudonym:

Name	Age	Disease Suffering From	Reason for Selection
Kohinur	60 years	Suffering from osteoporosis.	Kohinur was provided with the opportunity of income generating activities and is continuing to make paper-box (boxes made of paper) using old papers supplied from the project. So she was selected rationally as a respondent to understand the effect of this initiative.
Ameen	74 years	Suffering from Bronchitis	Ameen was selected as a respondent as a matter of interest to understand why he was not excluded from the project even after having his own house and being economically solvent.
Aalea	60 years	Suffering from cancer	Aalea, affected by colorectal cancer, is one of the few beneficiaries we considered to be a true Palliative patient.
Halim	70 years	Suffering arthritis and cataracts.	Halim and his wife live a miserable life in a small 'uninhabitable room'. Although their sons and daughters living in the slum are better off but they do not take care of their parents.
Razia Begum	60 years	Suffering from Parkinson's	Razia Begum is affected by a relatively rare disease in the context of Bangladesh called Parkinson's. She survives through some sort of external support and maintaining social network as she has no care giver. So she was selected as a respondent to allow understanding of the details of her condition.
Zahida	65 years	Suffering osteoporosis and cataracts.	Poor Zahida, dependent on beggary is helpless.
Obaidul	65 years	Suffering from arthritis.	In reply to the question why Obaidul was excluded from the project, one key informant explained- 'First of all the patient's condition is much better than before. Moreover he kept complaining that the medicines we provided (provided through the project) did not benefit him. Besides, his economic condition is also good as he has his own house in the slum and his son living abroad also sends him money regularly. He used to behave badly with us (project officials) if we could not provide him medicines on time.' Reasonably the research team

			found Obaidul as an interesting case.
Ojifa	60 years	Suffering from high level diabetes	Among the beneficiaries of the project only Ojifa is of third gender.
Swapon		suffering from permanent paralysis along with other senile diseases and the right side of his body is fully inactive	Swapon is selected as the respondent for being the household head suffering from his physical helplessness or vulnerability.
Laboni Khatun	60 years	Suffering from arthritis and cataracts.	Laboni Khatun was selected as she was excluded from the project a few days ago because her monthly income is good (BDT 13000).

Limitation

There were some difficulties particularly to interview the beneficiaries. As most of the respondents were financially insolvent and had fewer members in the family, and as they had to earn living by themselves, it was difficult for them to make time for the interviews. On the other hand due to their old age and illnesses it was not easy to continue discussion for a long time with them. We had to sit several times with each respondent to complete the interviews.

Ethical Consideration

During data collection, the researchers fully explained the objective and purpose of the study to the respondents. The respondents were informed that their identity would be anonymous in the report and the information would be used only for the assessment purposes. It was clearly described that they would receive no financial benefit for providing information, their participation would be voluntary and that they would not be penalized in any way if they choose not to participate. The all-important consent of the respondents was secured before starting the data collection. Moreover it was ensured that the data collection do not affect any human subjects adversely. Thus, protection and safety of respondents and the researchers was considered paramount. Last but not the least; the ethical clearance was also taken from ethical board of the Bangabandhu Sheikh Mujib Medical University (BSMMU).

Section 2

Evaluation Results

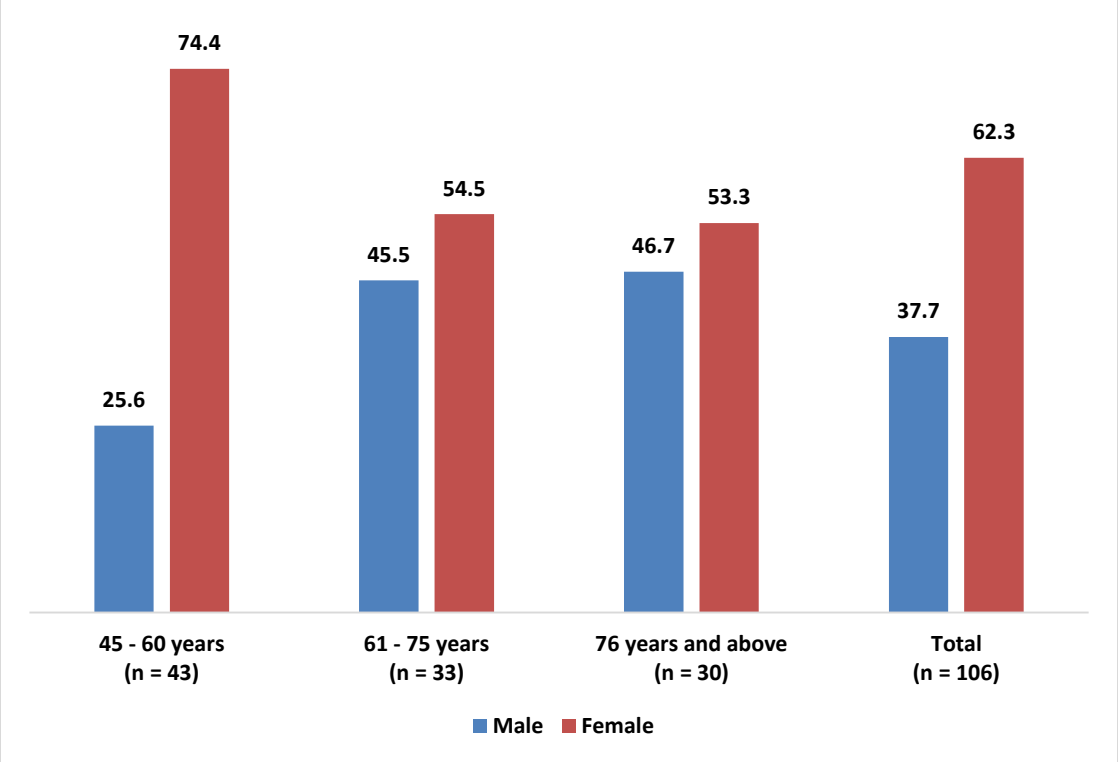
1 Management

1.1 How was the programme implemented ?

a. Socio-economic profile of the beneficiaries

With a vision to facilitate palliative care of elderly people living in slums this project worked in two different slums named Korail and Agargaon slum. The data collection for this evaluation study was conducted among the beneficiaries of Korail slum but the secondary quantitative information from the patients' profile was gathered from all the patients under the project's catchment areas. A total of 106 patients' profile was reviewed and information collected from all the patients was analyzed to understand their socio-economic status. The analysis shows that among 106 respondents majority of the patients (62.3%) are women. The average age calculated for female patient is 66.8 years and male patient is 71.9 years.

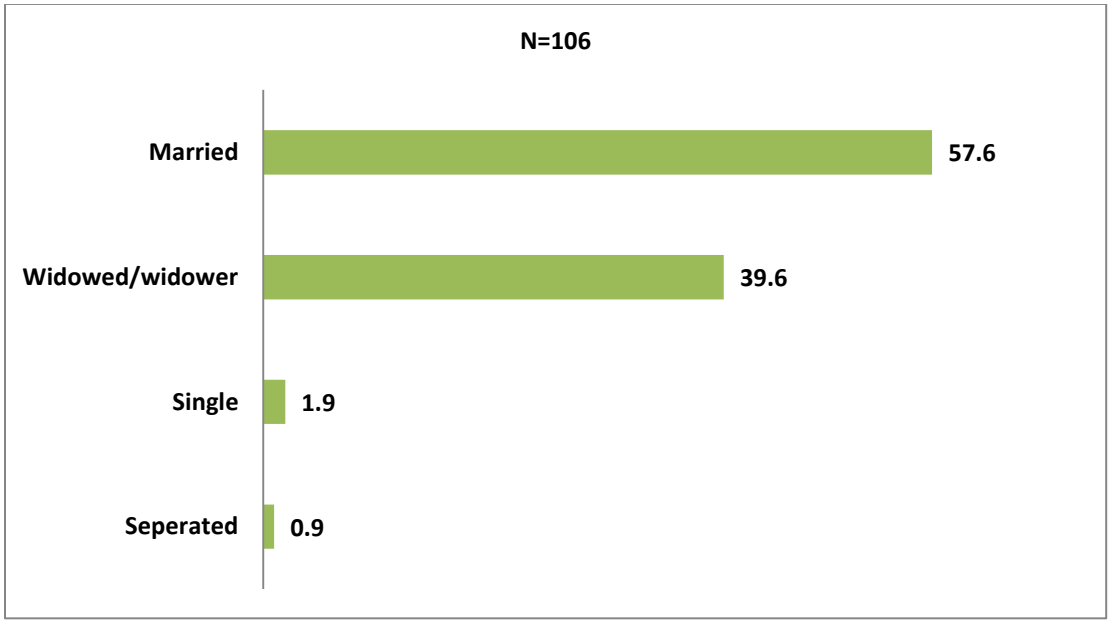
Figure 3: Percentage Distribution of the Beneficiaries According to Their Sex across Age Group



The above mentioned figure reveals that among the total beneficiaries most percentage of female (74.4%) are in the age cohort of 45 to 60 years and the most percentage of male (53.3%) are in the age cohort of 76 years and above.

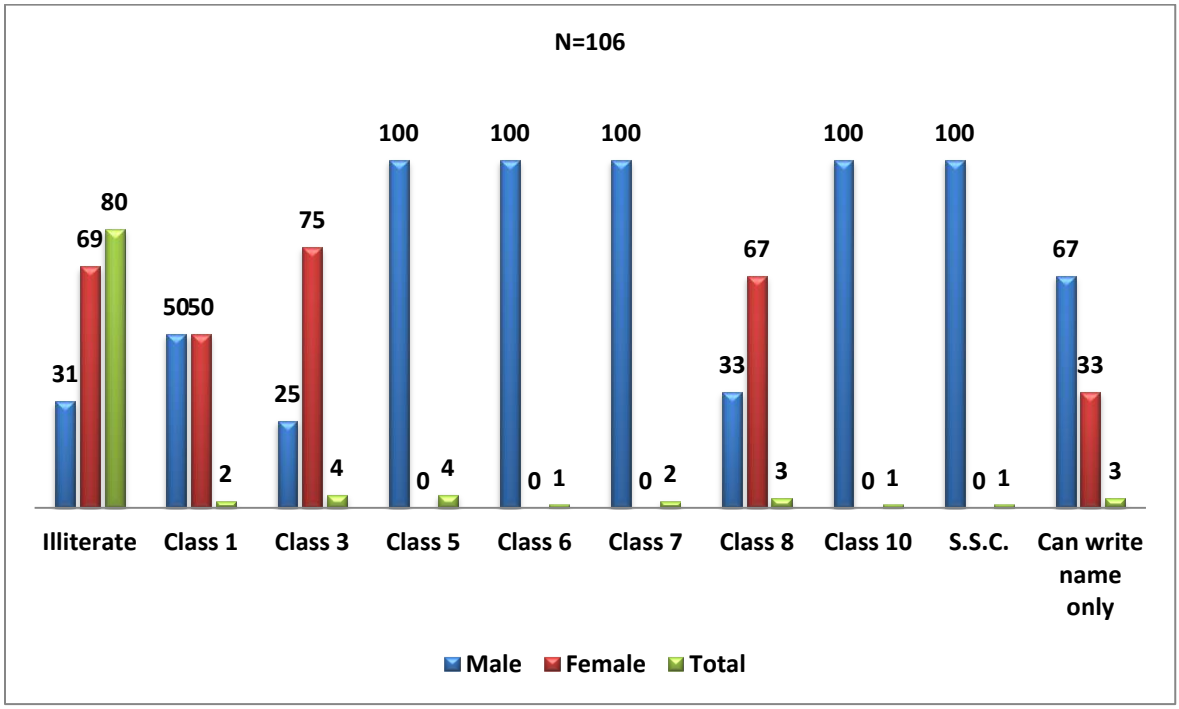
The following figure shows that most (57.6%) of the beneficiaries are married whereas a few (39.6%) of them are widowed or widower. Rest of the patients are single (1.9%) or separated (0.9%).

Figure 4: Percentage Distribution of the Beneficiaries According to Their Marital Status



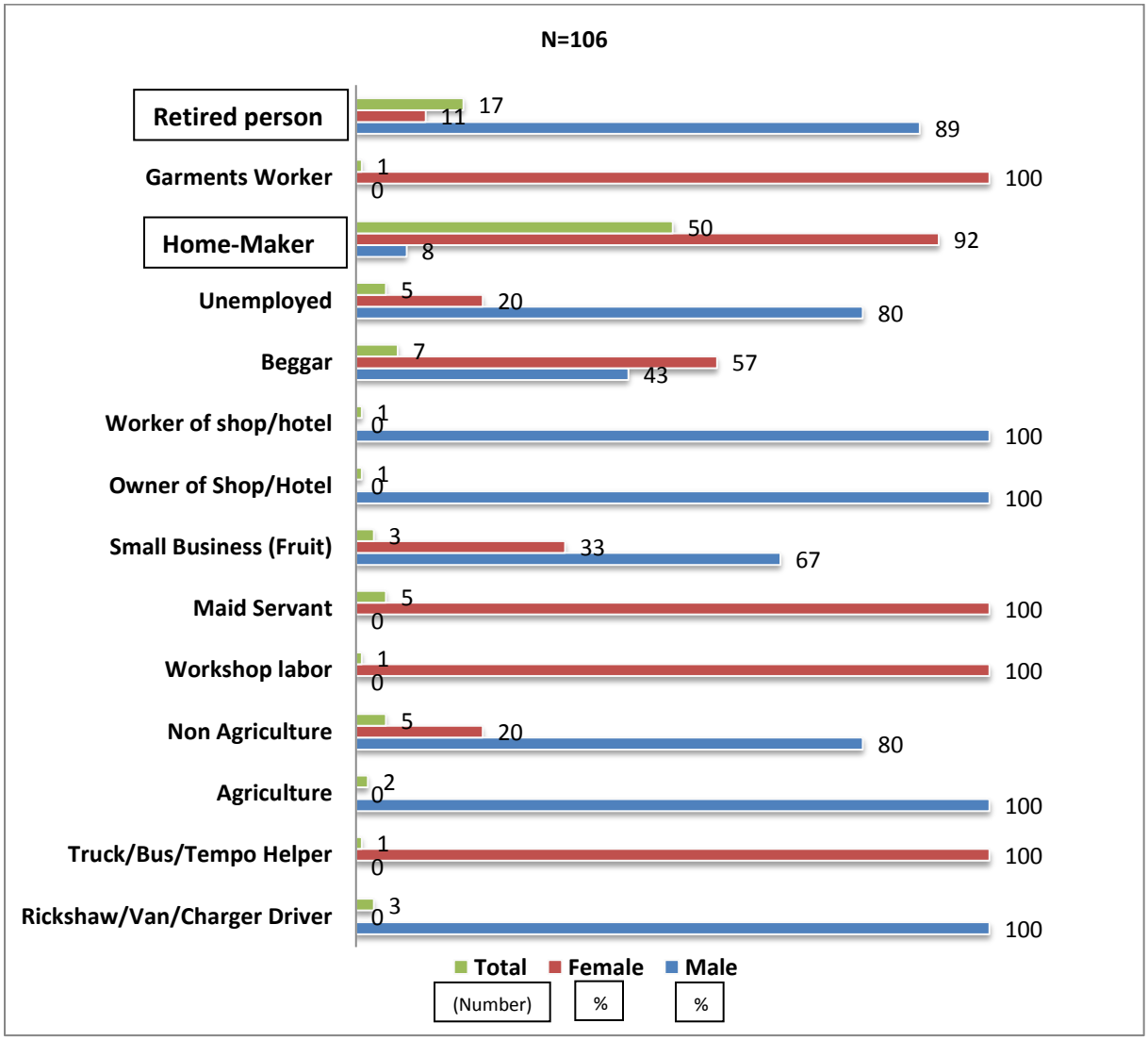
The figure below indicates that majority (80%) of the patients are illiterate. Only a few of them completed the primary level (class 5) education though all of them are male.

Figure 5: Percentage Distribution of the Beneficiaries According to Their Education



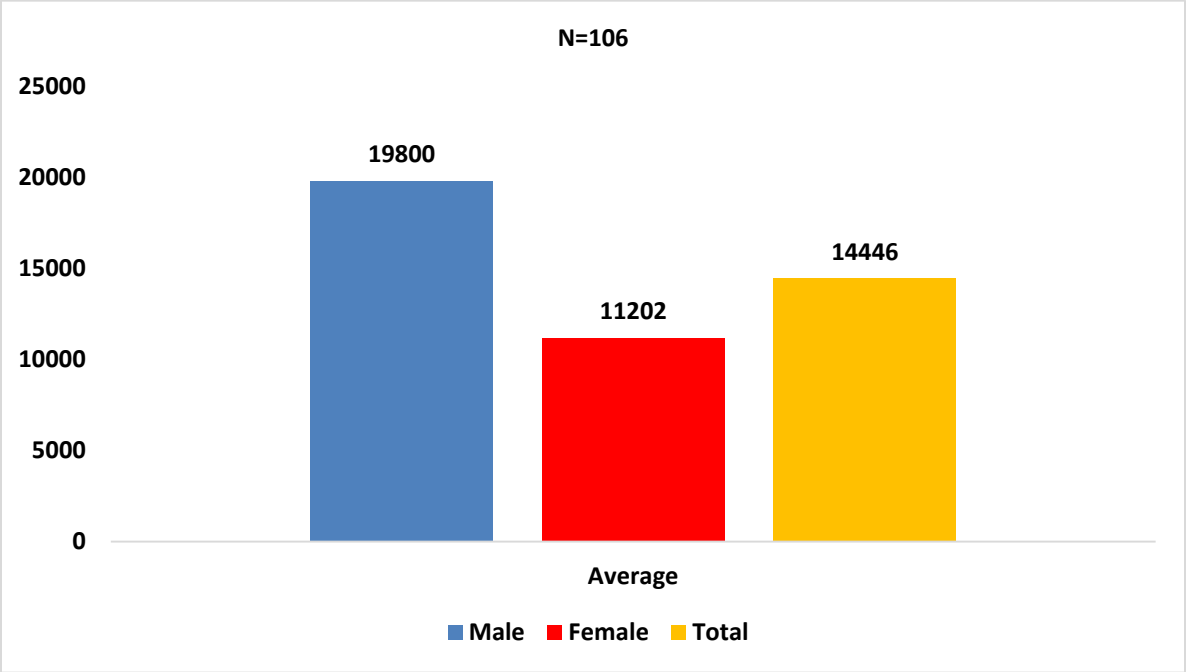
The following figure depicts that half (50%) of the total patients and majority (92%) of the total female patients are housewives. Among others some are engaged in beggary (7%), some are working as maid servant (5%) and in the non-agriculture (5%) sector. Very few patients were found to be engaged in small business (3%) and working as rickshaw/van driver (3%). On the other hand 17% patients were found as retired person and 5% were found to be unemployed.

Figure 6: Percentage Distribution of the Beneficiaries According to Their Occupation



In regard to the income of the beneficiaries the below mentioned figure indicates that the average household income of all the respondents is 14446 BDT per month. The monthly income of the male households was found to be higher (19800 BDT) than female households (11202 BDT).

Figure 7: Percentage Distribution of the Beneficiaries According to Their Income



b. Selection of the beneficiaries

We found that the beneficiaries were selected through a rapid situation analysis by consulting with Community Based Organizations (CBOs) in the slum and involving local adolescents. We explored the experience of the beneficiaries regarding the selection process. Findings indicate that although in most cases appropriate process/steps were maintained regarding selection of beneficiaries in keeping with the project's selection criteria, but in some cases the same selection process/steps were not followed. Even, to some extent an informal method based on mutual understanding were taken as basis for selection.

For example a male beneficiary has been selected through a formal selection process as he described:

> *"At first there was some sort of an assessment and then Mazeda (Palliative Care Assistant) came to take my name. Then a checkup was held by the doctor at the Educo school field, my photograph was taken and a month later they started to provide assistance."*

On the other hand a female beneficiary shared a different kind of selection process,

> *"I was sick before the Ramadan last year. Fatema, the palliative care assistant, who used to live beside my house, told me that a doctor from this organization would come to do a check up on me. Then she noted down my name and on the first day I was provided with*

100 taka from the office to eat fruits. The next week they took my name once again and started to provide me medicines."

It remains a question though whether this woman would have been selected as a beneficiary if she was not a resident beside Fatema, the Palliative Care Assistant.

While asked how and why a specific couple was selected for this project, the chief field coordinator on duty replied,

"Actually this couple was selected for humanitarian reasons. Both of them are above 70 years, affected with various senile diseases, having poor eyesight, feeling pain in body, suffering from headache and asphyxia and cannot move easily. Moreover they are extremely poor living in a shanty house having no one to look after them."

There may be debate as to the rationale and personal emotion about selecting this couple, but it is clearly understandable that efforts were directed towards selecting elderly people needing palliative care. A female beneficiary referred her own son as the main reason for being selected as a beneficiary,

"My son is a volunteer of this project and I came to know about this project through him. When he informed the project coordinator about my several physical problems, they selected me through different medical checkups."

In some cases the beneficiaries actively took initiative to be selected in the project. As one women said:

"On being informed about this job (project) I shared my problems with Fatema Khala. Then they recorded my name and took photograph after completing my checkup at the Ershad school field."

One beneficiary was selected coincidentally:

"I was sitting at the shop in front of my house. A lot of people were gossiping on their own while Mazeda appeared there from the office and asked if there was any old aged patient around. As I was present in the gathering and everyone present there named me, she wrote down my name."

Question could be raised if he was not sitting on that bench at that moment, would he be selected at all.

This response of a beneficiary summarizes the experience of most of the respondents:

'They were looking for patients through home visits. I knew nothing about this. One day when I was on my bed, all of a sudden they (project personnel) came into my house and asked me if there was any such patient. They were searching for patients with stroke as well as patients with other types of diseases though I do not remember any of those diseases now. They heard about my disease in details from my daughter and then they wrote down my name, address and

phone number. At that moment they also asked me how I felt. I shared my physical condition with them and shared exactly how I feel because telling lie has no benefit at all."

On the other hand comment from a field coordinator shows that they also followed informal process to select beneficiaries:

> *"When we first time visited her (beneficiary's) house we found her suffering from fever for three days. There was not much food in her house, she just had two days of old, stale and stinky little amount of rice and mashed tomato. The amount of food remaining was not sufficient for a single meal of one person whereas she had to take that food for three more meals. She was in such a worse financial condition that she asked for two food packs from us. We contacted the office asking for two food packs but could not provide her with the food packs. Momtaj's husband had gone to village leaving her alone. She had two girls and they were married off. She had two step sons but they live separately. So her husband, sons or daughters, none take care of her. She lives all alone and has no one to take care of her. As she lives alone, she always remains in anxiety. Considering all these she was selected as a beneficiary."*

The finding suggests that the selection of the beneficiaries followed a flexible process, sometimes using formal criteria, sometimes based on convenience and some circumstantial judgments.

As part of this evaluation effort was made to understand the types of diseases of the respondents and whether the beneficiaries fall in the conventional palliative care category or in other words whether they qualify to get included in this project. The analysis revealed that at the beginning of the project some patients were selected as beneficiaries for various reasons (reasons will be detailed out in the latter part of the report) who might not have qualified to be selected given the type, nature and severity of their disease. At later stage selection process was more judicious and initial mistakes were avoided in selection. One project personnel commented, *"We excluded many beneficiaries because they were cured."* Besides, it is also true that there were many patients in the selected list like Aalea, a colorectal cancer patient, whose selection as beneficiary was beyond any question. The discussion below will clarify this point further:

While asked about the disease of beneficiaries, the field coordinator explained:

> *"We usually consider certain things while selecting a beneficiary. First, we consider if he/she is old enough and then we consider if he/she is diagnosed with any incurable disease. As for the case of Momtaj, three of spine bones have decayed, causing her severe bodily pain and distress which has rendered her incapable of doing any heavy work. She is totally helpless as she has no means to make ends meet. So we chose her as a beneficiary."*

Her selection as a beneficiary brings forward an obvious question- given the type of ailment she is suffering for last two years; does she qualify to become a conventional palliative patient?

It raises question whether the vision of a project is to provide all types of services to someone falling sick who is helpless, poor, old aged and has no one to look after him?

However, a patient like Aalea suffering from colorectal cancer clearly qualifies for a palliative care. As she describes:

"When I went to the hospital I fell asleep with the dose of sleeping pills, a piece of meat was cut off from the anal path and I was said that the report would be provided after doing the tests. When the report was out the next day, I was diagnosed with cancer. When my children heard it, they started to cry instead of coming to me. They were running all over the hospital but did not tell me anything. When I asked them about the result of the tests, they said that I had no need to know the result. They took me to the hospital again. Then I asked a patient lying right beside my bed what this hospital was for. They replied it is a cancer hospital… all the cancer patients come here. I felt as though my heart was broken…what is this happened to me!" A few days later she started to go through chemotherapy but the complication remained, "I was feeling that my anal path was closing slowly. Then I was re-admitted in the cancer hospital. They did an operation, closed the anal path and created a new path piercing on the left side of my belly. Now I always have to keep a colorectal bag here and the stool is deposited in this bag. Later I clean up in the toilet. I wanted another hole in the same anal path made but the doctor said that I cannot bear the pain as I have grown older now. It is really painful not to defecate the way it should be. When I feel the pressure for defecation I keep sitting with pain instead of going to the toilet. A few moments later the bag gets full of stool and swelled. Then I go to the toilet slowly, open the bag and wash the stool out of it. I do not eat much because more meal will lead to more stool. Due to hanging the colorectal bag I cannot lie on the left side, I have to lie either straight or on the right side. I cannot sleep the whole night. I wake up at midnight, open the door, go out of the room, walk for a few minutes and then go to sleep again…"

An elderly couple was selected who have poor eye sight and the husband is suffering from asphyxia. The husband stated,

> *"When I suffer from asphyxia I cannot bear it at all. My wife rubs oil on the betel leaf and applies a massage on my chest and back and then burn that betel leaf into the fire. I feel better then. Both of us did the cataract operation but we do not see as good now as we did before."*

In some cases patients suffering from paralysis were also found to be selected as beneficiaries. A key informant was asked whether such diseases are incurable or not. In reply he said,

> *"There may be two different situations. Due to stroke the whole or some part of the body could be paralyzed. In some cases the hand or leg gets paralyzed due to blood coagulation in the nerve vein. Sometimes this paralysis may be cured if the coagulated blood is removed through exercise but it cannot be understood unless it is fully diagnosed previously. As we do not have the opportunity to do full diagnosis in our project, we cannot understand that. We select the patient examining their past treatment history, but*

people living in the slum hardly save their documents. So sometimes there may be some mistakes. We included few paralysis patients in the program and they are still with us. At the same time we have excluded few of them as they recovered later."

We also found that some people suffering from osteoporosis, arthistis and diabetes were also selected as beneficiaries. Some beneficiaries mentioned about asphyxia, decay of different organs of the body, pain in leg, knee and waist and even the gastric as their main problem.

Question remains about the suitability of all these above mentioned patients to be included in a palliative care project.

When asked about this issue one of the key officials related with the project said:

"It is true that we do not always have to implement the project following the western concept. It is not like that we have to see the palliative issue as it is seen in their society. I confess that our beneficiary selection process was imperfect. We did not entirely enter into the slum rather worked on the surface level. At the beginning we did not even know the total area of Korail slum. We knew it later while working that the slum is quite big. We did not even know initially that it has separate units. Due to time constraints there were few mistakes."

However, although questions could be raised on selection or types of diseases of such patients as the beneficiary but fact remains that every beneficiary is socially, financially and from their family perspective truly helpless and was benefitted in some ways after becoming involved in this project which will be elaborated in the later sections.

Table 8: Percentage Distribution of the Beneficiaries According to Their Disease

Indicators	Male			Female			Total
	45 - 60 years (n = 11)	61 - 75 years (n = 15)	76 years and above (n = 14)	45 - 60 years (n = 32)	61 - 75 years (n = 18)	76 years and above (n = 16)	
Respiratory Illness	45.5	40.0	28.6	28.1	27.8	18.8	30.2
Diabetes	-	13.3	-	9.4	-	6.3	5.7
Cancer	-	6.7	-	15.6	-	-	5.7
Bone disease	-	26.7	35.7	25.0	55.6	6.3	26.4
Hypertension (HTN)	-	40.0	14.3	21.9	22.2	25.0	21.7
Skin disease	9.1	-	-	-	16.7	-	3.8
Geriatric Problem	-	6.7	21.4	-	11.1	18.8	8.5

Gastro enteric disorder	9.1	13.3	14.3	3.1	-	-	5.7
Cerebrovascular disease	9.1	13.3	14.3	21.9	11.1	-	13.2
Kidney Prostate disease	9.1	6.7	7.1	6.3	-	-	4.7
Heart disease	9.1	6.7	7.1	3.1	-	6.3	4.7
Nervous system disease	18.2	-	-	9.4	5.6	18.8	8.5
Eye and ear problem	9.1	6.7	21.4	6.3	22.2	18.8	13.2
Gynaecological problem	-	-	-	3.1	5.6	6.3	2.8

The above table shows the analysis of the secondary information gathered from the patients' profile of BSMMU on their diseases. These 106 patients had 80 different types of diagnosis. Among them a large number were also diagnosed with multiple diseases. To simplify 80 diseases were grouped under 14 disease categories. Findings shows that 45.5% of the male patients aged 45 to 60 years were diagnosed with respiratory illness. The second major disease as diagnosed was that related to nervous system. Among other diseases suffered by males aged 45 to 60 years included skin disease, gastro enteric disorder, cerebrovascular disease, kidney prostate disease, heart disease and eye and ear problems. Male patients aged 61 to 75 years were mostly (40%) diagnosed with respiratory illness and hypertension. The male patients from this age group were diagnosed with bone related diseases (26.7%).Older male patients (aged over 76 years) were mostly diagnosed with bone diseases (35.7%). Second most common disease that these patients were diagnosed with was respiratory illness (28.6%). Patients from this age group were also diagnosed with geriatric problems and eye and ear problems (21.4%) respectively. Common disease that the male patients were diagnosed with, irrespective of age, was respiratory illness.

A majority (55.6%) of the female patients aged 45 to 60 years were diagnosed with bone related disease, while 27.8% were diagnosed with respiratory illnesses. About 22.2% female patients from this age group were also diagnosed with hypertension and eye and ear problem. Major proportion (25%) of female patients aged 61 to 75 years were diagnosed with hypertension. Other common diseases diagnosed were respiratory illness, geriatric problem, nervous system disease, and eye and ear problem. Older female patients were mostly diagnosed with respiratory illness (30.2%). About 26.4% of female patients aged above 76 years were diagnosed with bone disease, while 21.7% were diagnosed with hypertension. In general, female patients, irrespective of their age, were mainly diagnosed with respiratory illnesses and bone diseases. Findings and analysis of the study indicates that the beneficiaries suffered from various kinds of diseases not necessarily life limiting.

In the beginning, the project officials had to face some sort of pressure from the community in regard to including other similar patients (who are not beneficiaries) into this project. Thus everyone wanted to be included in the project. When asked, they shared how they dealt with this issue,

"We said you are not included because you have both the financial ability and people to take care of you. Sometimes they are not convinced and then we had to convince them in other ways."

There were cases when the project officials had to face even more negative reactions. Some slum dwellers said to them,

"The government has provided relief for all of us but the project's people grabbed those on their own and did not provide us."

It has been revealed from the discussion with the key informants that they had to face some difficulties in selecting the beneficiaries in the beginning of the project due to the aforementioned issues. The head of the project said,

"At first we assessed them just from their appearance and some basic information. Their financial condition was also considered but their real need was not assessed as we only worked on the surface level."

At initial stage the Korail slum area was hardly known to the project authorities as they didn't even know the actual size and area of this slum. One of the key informants said,

"It is necessary to initiate door to door survey to identify the actual needy people which we did not do at the beginning. It was also necessary to determine the operational definition of beneficiary. However, I also think that we should be flexible in terms of defining palliative care."

It was found that none of the non-medical project staff was aware of the term palliative care before joining this project. The community also never heard about this term before the project was introduced. The key informants acknowledged that unlike other community based projects on education, general health, they had to struggle even just to introduce the concept of palliative care.

It was observed that after selection, some of the beneficiaries were provided with all kinds of services but suddenly they were excluded from the project after a while. In an attempt to find out the reason behind this a discussion with a key informant revealed that, some difficulties were created due to time constrains in the process of patients' selection. For example, after the beneficiaries were selected some of the patients were found to have a better financial condition and have family members to look after them, so they were excluded. In other instances, it was found that after being selected as a beneficiary when they were provided with proper care and treatment for some months, some of them fully recovered from their illness. Some beneficiaries moved to other places. In some cases there was also such beneficiary who was found later to not have any diseases at all. Some beneficiaries refused to take services from the project. According to one key informant,

"We had a gynecological patient and we took her to the hospital for a surgery in uterus. But she preferred to take Homeopathy treatment instead of surgery."

These are the reasons that many beneficiaries were excluded from the project. The head of the project explained,

> *"There was a condition from donor end that there cannot be more than 100 beneficiaries. We considered comparative consequences in terms of eliminating the beneficiaries. Some patient may manage food for two times a day while others cannot manage a single meal for a day. So patients with comparatively good conditions were eliminated. Some beneficiaries expected that this is a medical camp as it is a project under PG hospital, so they can get all types of medicines here. As we cannot fulfill their demands, they were excluded."*

With the spirit of a pilot project all these were learnings for the implementers of the project.

We would also like to make note about the recording keeping of the project. As per our observation the paper based record keeping had various ambiguities. Patient profiles forms were not always filled up properly. This needs further attention.

c. Management of the project

Context of the project initiation:

We found that Korail Palliative Care project was inspired by a similar palliative care project at Kerala in India. We learned that Dr. Nezamuddin, the pioneer of "Compassionate Korail" was inspired by "Kerala Model" and wanted to take a similar initiative in his own country, Bangladesh. Dr. Nezam found that unlike the medical model he is familiar with the main goal of "Kerala Model" was to involve people into the palliative care service. He spent time in Kerala and had in depth discussion with Dr. Suresh Kumar, the pioneer of "Kerala Model". For Dr. Nezam the simple formula of Kerala model was to involve community people in the process of providing care to the patients in a socio-medical mode. In Kerala, the project is run by community volunteers who provide home care. The project runs mostly through community donations. Although palliative care specialists are involved, they play a limited role in the project. Dr. Nezam mentioned,

> *"For me the key element of the Kerala Model is the involvement of the mass people. In Kerala I found even the driver of our car was a volunteer of this program. He serves two days in a week and doesn't take any payment. Now Kerala government has extended their cooperation and 80% of the Kerala population is covered by the service. Kerala has a high education rate as well they are better in terms of economic indicators. There are various political and historical reasons behind the success of Kerala model. '*

When asked to compare it with Korail project Dr. Nezam said:

'It is not comparable at all. Korail is just a small project running for one year and initiated by PG hospital. We still run the project with paid workers. We do not have community donation and hardly any state support. We have long way to go. But we are trying to follow the main principal of Kerala and to involve people in the project. But it is very difficult. Our patients and even our doctors are not aware of palliative care.'

Dr. Nezam then went on to elaborate a personal experience from the hospital based palliative care unit. When her terminal condition was explained to a cancer patient admitted in the Center for Palliative Care (CPC) of BSMMU, she said *"I understand everything you said and that I'm going to die. But I want to see Dr. X (a famous doctor at that time) for once. May be he can help. "* Then the doctor on duty arranged a visit of Dr. X for that cancer patient. Dr. X visited her accordingly and prescribed some tests and diagnosis. The doctor on duty became very surprised with Dr. X's prescription. He was taken aback and asked the Dr. X, *"Do you really think these tests is going to help her in any ways?"* Dr. X relied, *"Why did you then ask me to visit her. I know there is nothing to do, her time has run out. But I can not say the patient that we can not do anything. At least we need to show her that we are trying to do something.'*

By telling this story Dr. Nezam emphasized that in Bangladesh on one hand the medical professionals do not recognize palliative care yet one the other hand patients are also not ready to receive palliative care. Both service providers and service receivers are still highly curative oriented. He pointed out to the challenges of delivering a community based palliative care in such context.

The evaluation found that before this project was introduced none of our respondents ever heard about palliative care. Most of the beneficiaries also did not have enough food for all the family members, could not afford sufficient edible oil for cooking food, did not have enough money for medical checkup and essential medicines. Some of them had nobody to take care of them. Mostly they had to depend on others' help or beggary or lend money from the neighborhood to run their family. Some of them had to starve a whole day as they were too old and weak to set out begging or seeking loan from the acquaintances.

In this backdrop, the project has delivered a systematic, people centered, communicative and participatory approach to provide the palliative services. This project was initiated with a patient based, family oriented and service focused approach rather than a typical medical care based concept. It was found that in the process the project was able to reach the extremely needy, helpless and elderly people of the slum who had no one to take care of. Alongside, individual patient-focused approach, community awareness building and community involvement was also an inherent part of the project. The community people witnessed for the first time, a new model of care and service meeting the patients' demands. The availability of such care in the neighborhood has raised awareness among the community regarding palliative care. Moreover, the project extended opportunity for the project officials, especially the PCAs to receive appropriate training and the scope for involvement in nursing service to others. The group

meetings, workshops and training of the young slum volunteers to understand the sufferings of poor elderly people and provide required services to them went extremely well.

The project also took the initiative to increase awareness of its activities among the general slum dwellers by distributing leaflets written in plain and simple Bangla language. The project also prepared a Tool Kit book and distributed among the literate CBO committee members. This Tool Kit served as the main resource book for the short volunteer sensitization programs.

Role of the Palliative Care Assistants (PCAs)

The PCAs played the most vital role in terms of implementing the project. It was a challenging task to train the PCAs, make them understand their responsibilities, allocate their activities and get their time into the whole process of service delivery as none of them were volunteers before. After the PCAs' training was over, a certain number of patients were allocated to some specific PCAs for care and nursing. It was unlikely that all the PCAs would be allocated equal number of patients to take care. The allocation of patients were based on their proximity to the house of a specific PCA. However, all the PCAs know all the patients in the slum and look after a patient if the assigned PCA is absent due to some other commitment. Practically it was a very sound strategy that helped the PCAs to stay close to the patients, provide necessary services to them as and when necessary, spend more time with them. As one of the PCAs shared,

> *"We choose patients closer to our home so that we can move to their house quickly at night or in times of any emergency to take care of them."*

The PCAs started to communicate with the patients and the community people as much as possible even before starting to provide the services officially. They visited all the patients' house, spent time with and talked to them and their family, and also started to take care of the patients initially. One PCA mentioned,

> *"We made the community people aware of the project and the services we were going to provide to the patients. Besides, the community people started to recognize us by our official dress (sky-blue apron over sky-blue Saloar-Kamij)."*

According to the PCAs, they are providing four types of services to the patients- physical, social, mental and spiritual. 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 paralyzed. They administer their medicine doses, help them to take bath, sometimes cut their nails too. They often buy glycerin or oil for the patients and rub on their body, especially in winter when skin gets dry. Sometimes they clean their house, make the bed, clean their dishes, do the shopping and cook for them. However, social care is mostly about counseling the family members or relatives of the patient. When the children or relatives do not take care of the patient, the PCAs counsel them about the necessity and importance of their care

for the patient. Regarding mental support, some of the patients were found always worried about their impoverished condition and some were tense and grief-stricken due to their children's negligence towards them. For this they are always anxious about their life. In such situations the PCAs tried to spend more time with the patients, relieve them of their grievances and instill confidence in them with their optimistic words which provided great mental support. One of the PCAs stated,

> *"The most important cure here is to touch the patient and make them feel that we are with him. We have seen that a hand on the patient's hand and appeasing words to change their perception of the causes of their illness cool them."*

Among all the patients a few always keep blaming their own fate and immoralities of their forefathers' activities for their sufferings. For these cases PCAs talk with them on spiritual issues and try to console them. One PCA mentioned

> *"If a patient becomes severely sick then s/he becomes mentally frustrated. S/he cries and continues telling, 'maybe I have committed some sin in life for which I'm suffering from this disease now, Allah has given me punishment.' Then we try to comfort them, listen to them with patience as to what they want to say. We try to make them understand that every human will die eventually, so there is no reason thinking about it, rather they should live the life as happy as possible."*

Although the PCAs used to visit the patients house almost every day at the beginning, but now they visit twice or thrice a week. Even for the older people, the PCAs or project officials come to their home to provide all the services, the patients do not have to go to the office. The PCAs inform the patients about the date and time of food pack delivery and doctor's visit at home. They often visit patients' house and give company when they feel lonely or stay alone at home. One of the patients stated,

> *"Both of us (husband and wife) are old enough now and there is no one to look after us. We take care of each other but when both of us get sick then there is no one left to take care of us in this shanty. Girls (PCAs) from the office visit our home regularly and look after us. They spend a good time with us, talk to us freely and we share our thoughts with each other. They are like family to us."*

Almost every beneficiary of the project talked highly positively about the PCAs. Following are some comments:

"That girl (PCA) comes every week and takes care of my hair, spends some time with me, talks to me, inquires about my requirements, helps me to take a bath and sometimes she cooks for me. I have my own daughter but she doesn't take care of me like the PCA. I find her as my daughter when she comes to me."

"Girls (PCA) take care of me as their mother. They check my blood pressure, massage my body, spend their time with us, have a chat and inquire about our health status."

"They (PCA) are well-acquainted with our regular needs, help us to do some exercise if we feel pain, help us to walk."

We found that some project beneficiaries sometimes feel shy to take services from (PCA) considering their workload. One of them said,

'They (PCA) want to cook for me but I don't allow them as they are busy; they take care of many people like me. We should understand their challenges.'

Other than above mentioned supports, the project tries to ensure some additional supports for its beneficiaries. For example- if any project beneficiary desires to eat something but can't afford financially, they can ask PCA concerned and then project tries to fulfill their wishes. Sometimes, community peoples are also takes part to do these sorts of services. One PCA said,

"We collect money from the community as subscription to ensure some more supports that is not covered by the project."

The importance of the PCAs could be felt from their involvement, activities and acceptance among the beneficiaries and the deep affection the beneficiaries and their families feel for them. According to the PCAs, as they all live in this community, so everyone knows them and have confidence in them. Whenever they visit a patient's home, they (patient's family) do not let them leave and if they are late or miss to visit a house by chance, they get emotional. If the PCAs refuse to take their served food, they get emotional too and say, *"Is it because we are poor that you do not want to take our food?"* When the beneficiaries bring vegetables, fruits from their village, they request the PCAs to take something and if they refuse, they express disappointment on the PCAs. One PCA cited,

"Once a beneficiary wished to eat beef and I thought that informing the office and completing all the formalities would take too long. So I cooked beef and rice at home and brought it to him. He is blind, so now he keeps praying, 'May Allah gives me my sight so that I can see Fatema (PCA)."

However, it was found that as all the PCAs are women, so they have to face challenges while serving the male beneficiaries. One of the PCAs shared her experience,

"All the male members we provide service to are mostly aged and bedridden. There is no problem to provide the daily services such as cutting nails or giving medicines. But when it comes to bathing, applying suppository or taking to the toilets, they do not want to co-operate and feel shy. It would be better to have some male PCAs from the project as they could serve the male members."

It has been found in the study that an effort was made to recruit some male PCAs, but all the candidates failed in the exam. Besides, men are not interested in such nursing jobs.

The PCAs mentioned that at the beginning of the project they had to confront various social constraints. Initially some local boys used to tease them and when they walked on the road wearing a sky blue dress, apron and hat like the nurse do, young boys from local tea-stall used to say,

> *"Doctor, doctor, check my pressure. I have heart problems, check my chest. We have headache, give us medicine…Look, there goes the doctor/sweeper."*

The PCAs were bold enough to face those boys and ready to tackle them face-to-face. When they were asked about their reply, they informed,

> *"We didn't care, they only whispered but did nothing serious to us because they knew that we belong to this area and would react badly if anything happened to us."*

The PCAs got good support from the family as well. One of them said,

> *"Our families co-operate with us. When we go to see any patient at night, someone from our family accompany us. As the film stars say that previously they used to be recognized by the name of their parents but now their parents are recognized by their name, the same happens with us now. Many call my parents as Anika's parents. It also feels good when people address us as doctor."*

Provision of food assistance:

Beneficiaries of this project were provided with various types of services and assistance under the project. One of the services included was four hundred and fifty taka (Six Dollar) food assistance in every month.



In most cases along with this money they were also provided with five kilograms of rice, one kilogram of lentil, one liter of oil and half kilogram of salt. The beneficiaries received this food assistance within the first ten days of the month. At the beginning of the project the food items were packed at CPC of BSMMU and carried through a car into the slum. But as this process was not suitable and there was no involvement of the community, a grocery shop was selected in the slum. The food pack was prepared in that

shop and delivered from there to all the beneficiaries. The project tried to give food pack directly to the patients. Either patients took it directly from the shop or PCAs supplied it directly to the patient's home. The study revealed that this food pack was given through utmost transparency and accountability. Although the beneficiaries could not tell us specifically about the exact date of the month they received the food pack and the monetary value of the food assistance, but they have confirmed us that they received the food assistance regularly. At the same time separate files created for different beneficiaries undersigned by "Food Assistance Received" ensured the delivery of food assistance.

In this regard, the following comments, observation and experiences of the beneficiaries will help us to understand the dimension of food assistance. One female beneficiary explained,

> *"We received food every month. We received rice, lentil, oil and salt. In last three or four months, we were provided with Minicate rice but in the past we used to receive ordinary rice. I can eat ordinary rice but my sons and daughters cannot. Five to seven months ago a renowned doctor came here and asked me, 'Can you eat this rice'? I replied him that that I couldn't eat this. It would be good for me to get improved quality rice. Following that they started to give us Minicate rice since last four months. At that time it was really difficult to digest that ordinary rice. I understand that the project people have nothing to do here because the grocery shop responsible for the supply gave this coarse rice."*

One male beneficiary expressed his own experience that,

> *"In every month we got 5 kilograms of rice, 1 kilogram of lentil, 1 kilogram of salt and one kilogram of oil. In the past I used to receive it on my own but few days later they started to send this food pack into my home. I always got the exact amount."*

Another beneficiary told us,

> *"They always gave me packed salt and never gave us open salt. They gave us crystal clear oil which is called bottle oil. We got everything into a poly bag. Sometimes the female (staff) came to my home to give me the packet. But most of the time the female informed me about the food distribution date and then I went to the school field and received these from the school field. The weight is always correct because I check it after reaching home."*

In this regard, some other information or comment is also worth mentioning. One beneficiary said,

> *"We survived with difficulties in the past but presently our condition is good just because of this food supply. It reduces our tension. Now the lentil supply we receive is free from worms. This lentil is totally fresh and clear. The office took our names and we continued to receive this every month."*

Another beneficiary told us, *"We can save some money because of this food. We save this money into the bank."*

From the above comments it is clear that except some insignificant difficulties, beneficiaries received this food regularly and properly. The quality of the food was also very satisfactory, according to the beneficiaries.

Efforts were made from the project to provide special support to beneficiaries during main religious festival 'Eid'. In this case, during Ramadan Eid (Eid-ul-Fitr), *semai*, sugar, *sharee* for women and *Lungi* for men were given along with food pack. However, only food pack was given during EId ul Adha. In this case too, the researchers observed that, like food pack other festival support was handed over to all the beneficiaries with transparency. Almost all beneficiaries mentioned clearly, *"A cloth was given during Eid along with semai and sugar"*. This time another male beneficiary told that, *"during Eid, I received lungi, along with semai-sugar, eggs and soap"*. One female beneficiary expressed her reaction in this way,

"It was a very good feeling when I received such things during Eid."

Sometimes additional food were given to some beneficiaries in special cases. One beneficiary said,

"Once I was extremely sick and office provided me with some fruits (Mango, berry, juice, Hog plum etc.)'. On another occasion, I was unable to go to work and had no food in my house; that time office gave me 1kg rice and four eggs. They wanted to know if I wanted to take milk but I said no because I feel they have done enough for me."

Income generating activities:

Some of the beneficiaries got opportunity to participate in various types of income earning activities beside the service they received. The project staffs explained it as a kind of accidental development of the project. One personnel explained,

"We collect information to assess the ground reality. We found here that, beneficiary Kohinur's previous job was to make paper packet and sell it into the market. Then project staff approached her and asked if she could make paper pack if supplied with paper. She agreed, 'they gave me two kilograms of paper. I made packets with that paper and sold it for 80 taka. But I spent all the money and now I have no capital. But I have a plan for the coming winter when many people will sell pitha (cake) in the roadside and demand for the packets will be increased. If I get paper again, I will make packet again'. We asked if she had asked for papers in the new projects. She told us, 'how can I claim this? I have no money of my own, rather I spent all of the money. But if they give me willingly, I will start it again. If I buy one kilogram of paper which costs 20 taka, I can sell it with 40 taka. This means profit is twenty taka."

In this regard the project related people told us that papers used for the project purposes and some unimportant papers were given to them to make packets. However, due to Kohinur's lack of experience her income generating activity could not be sustainable. Interestingly, inspired by such income generating activities, one third of the beneficiaries expressed their desire to start these types of business. One beneficiary commented:

"When the office discussed about my job, I expressed my desire to establish a tea stall because I am experienced in this job. At this time we came to know that to establish a small tea stall in the slum area we need 40-50 thousand taka. Moreover, it needs 6 thousand taka for monthly rent. When I informed this matter to the project people, they agreed to give this amount as a loan from one of the micro credit organizations. But I thought if I take this amount as a loan, then I have to earn 15000-20000 taka per month for repaying the loan installment as well as the tea stall rent. The office staff also told me that as I am a sick person, I can't think so many things critically. After thinking all those things I gave up my plans for setting up a tea stall."

The key informants felt that if they could engage the beneficiaries into income earning activities through proper and long term planning with the help of experienced and skilled manpower, then it could be very effective in terms of the beneficiaries' wellbeing.

Medical Services:

Beneficiaries are affected by various types of illness and thus necessary treatment services are provided to them. Generally two types of services are provided, one is through regular medical visit and another is emergency medical visit. We were informed by the project staff that, earlier doctors visited the slum twice in a week and during emergency or if anyone become seriously ill doctors could be called. Along with this, a team of nurses visited slum twice a week. Nurses are also sent to slum in case of emergency. Now the project is at its last stage and we found that doctors and nurses visit based on requirement. However, on every Saturday, both nurses and doctors come to the slum. Following are some of the comments by beneficiaries regarding the medical services:

A female beneficiary commented,

"Few more women had this illness like me in this slum, they died but I am still alive because of the treatment of the project. So many medicine were given from the office, I even don't know the names of all the medicines. Sometimes doctor come to examine me, measure my blood pressure, ask me how well I am now".

One male respondents said:

"Doctors and nurses come regularly for checkup. Earlier they came twice in a month but now they come once. They measure blood pressure, check the chest and check if the medicine is right or not."

However, in was found that in many cases beneficiaries could not differentiate the identity between doctors, nurses and project related other officials. All of them are doctor to them.

The cancer affected patient was particularly happy as she said:

"Every month 2 colorectal bags are provided from the project. Price of each bag is 850 taka, two bags 1700 taka. Other than that Seclo tablet and liquid antacid is provided".

In some cases, mixed reaction was noticed from beneficiaries about treatment:

"Earlier doctors came frequently but now not so much. They did a survey and after that they come once in a week. Though, if illness increase or if needed, doctor come on calls. I have throat problem, my throat is rustling and they give me medicine for that. But, they didn't give me medicine for shivering of my hands-legs. Though I don't know the reason but it would be better if they can give medicine for that."

However, most of the respondents seemed very happy while talking about the treatment provided by the project:

"Doctors and nurses come regularly for checkup. Earlier they came frequently but now they visit once in every 15 days. They measure diabetes and blood pressure and everything. My previous medicine was not working (before project), but your medicine (from project) is working."

Highlights of Management-

- The project was inspired by the community oriented approach of the 'Neighborhood Networks of Palliative Care' Kerala, India.
- The beneficiaries were selected through a rapid situation analysis by consulting with Community Based Organizations (CBOs) in the slum.
- Although in most cases appropriate process were maintained regarding selection of beneficiaries but in some cases the same selection process were not followed. The process of beneficiary selection became more formalized as the project developed.
- There is some confusion regarding the operational definition of palliative adopted by the project.
- In the beginning, the project officials faced some sort of pressure from the community to include other similar patients (who did not qualify to be beneficiary) into this project.
- The community people witnessed for the first time, a new model of care and service meeting the patients' demands and it raised awareness among the community people.
- The PCAs played the most vital role in terms of implementing the project. Although faced some challenges at the beginning, they are now highly admired by the community. One challenge for the female PCAs is to provide the service to male patients.
- The beneficiaries are highly satisfied with medical services and food assistance they receive. Some beneficiaries got the opportunity to get involved in income generating activities too.

- Given the challenging context of the slum the project has been managed well and with transparency.

2 Effects

2.2 What are the effects of the project?

a. Effect on the beneficiaries' life

The study revealed that almost all the beneficiaries acknowledge that their self-confidence and self-esteem has increased after joining this project. A beneficiary clearly mentioned during a discussion,

> *"I have confidence now… nothing will happen if my son/daughter does not look after me…. I have the confidence that these people from the office are beside me…. They will surely support me if anything happens".*

The project has some other positive impacts in lives of beneficiaries as well. They had a feeling that the medicine provided by the project works better. As one of the respondents said,

> *"I took same medicine before (being a beneficiary of this project) but that didn't work as good as now. But these government medicines come with good quality and works fast like the electricity. Moreover, now we are treated by the reputed doctor from PG hospital and when he touches his stethoscope on our chest we almost get well then and there."*

The project has helped to increase the value of the person in the family. A male respondent stated,

> *"I was sick before (the project) and I am not completely well now. But as I feel better than before, so now I can take care of some little household chore or look after the study of my son and just for this reason, I am now highly valued in my family."*

The beneficiaries thought the food assistance provided by the project indirectly helped them economically. One beneficiary mentioned,

> *"Due to the food pack we receive from this project, now we can save the money we used to spend in buying rice and other staple/necessary food. Now we can save that money, which can be used in any emergency in future."*

Increase of mental strength was evident in most of the statement of the beneficiaries. One respondent cited,

> *"Previously our pan remained dry, but now we can cook with some extra oil after receiving the oil from this project and the food feels tastier than before. Another important thing is that previously we had to run after the doctor or make a long queue to*

catch him but now the doctor directly comes to us. Our words cannot make you feel or understand what a great relief this is for us."

Some beneficiaries described the project as a "tension removal medicine" for their children. A beneficiary shared the feeling,

"Our children didn't look after us or didn't give us money. But I always knew that they would surely think about our well-being. I believe their tension has relieved now after my inclusion in this project. Now they believe that whatever happens at least my parents are not starving."

Another beneficiary said,

"I knew myself that I have problems with cold and asthma. So I need to be careful all the time but I couldn't resist myself from getting cold and asthma. But now those girls (PCAs) visit my home and remind me the facts like an alarm clock that I can't dry my sweat on my body and need to clean my sweat regularly, need to take bath everyday at the same time in the afternoon. It is a must to take bath with warm water etc."

The remark of a beneficiary with diabetes who is a third gender said,

"I used to feel weak previously and couldn't walk properly. But now I have recovered better and people say that they will marry me off."

Apart from this it was observed that some technical lessons taught to the beneficiaries through this project regarding diseases had a major positive impact on their lives. Due to the inclusion in this project, now the beneficiaries and their family members know how to take care of a paralyzed patient, how to change a colostomy bag, why they need to intake vitamin c tablet, which fruit or vegetables contain what types of vitamin etc.

Overall it is obvious from the responses of the beneficiaries participated in the research that the project has a clear positive impact on their lives socially, psychologically as well as economically.

The key informants also belief that their project has a strong positive impact on the beneficiary's lives. The key informants highlighted that before the project the patients would take medicines irrationally. Some of them took excess medicine from the home-side local pharmacy against a mild sickness whereas some others would take medicine only in case of serious sickness. Moreover, some of these patients did not take proper treatment mistaking their major illness as a mild sickness. Now through the project the beneficiaries are advised about the bad effect of taking excess medication, irregular medication and excess pain killers. The project officials have observed a better and rational use of drug now. The fact remains that it is only through the project that the treatment and intake of medicine of the beneficiaries were brought to a structured form or habit.



Despite the aforementioned positive impacts of the project the beneficiaries also mentioned some "minor problems" they have experienced so far. Some of the beneficiaries stated that in order to get benefit of the project they always needed to remain in the slum and cannot move to places wherever and whenever they wish to go. However, they said they are ready to sacrifice this in order to be benefitted by the project. A female beneficiary explained that her elder daughter is suffering from heart-disease but she cannot visit her. She said,

> *"It would be good if I could stay with her at this time, she is asking me repeatedly to visit her but I am unable to go because if I go I will lose every thing I get from the project."*

There was an exceptional case in which the wife of a beneficiary was tensed about the source of fund of this project and thereby concerned about her religious belief as she asked the researcher,

> *"Did this money come from the Christians? Do you (researcher) know anything? If that is the case then I might lose my religion!"*

What is a good death? Thoughts of beneficiaries

As part of the evaluation we also asked the beneficiaries about their thoughts on 'good death'. Some beneficiaries surrendered themselves to the religion,

> *"I wish Allah relieves me from this world with the faith (Eeman) I belong! I wish to have a sacred death and that will be a good death to me."*

Some beneficiaries were worried about the place they will be buried:

> *"I don't care how I will die. I shall even find peace in death only if my grave is beside my parents in my village."*

Another beneficiary explained that a good death is dying without sickness,

> *"I am suffering a lot from asthma. It would be better if the doctor could cure it. When someone is suffering from so much pain, it is impossible to die in peace."*

Some others think about death bit differently. They shared,

> *"I wish I could die in front of my son, his wife, my daughter, her husband and my beloved grand-children."*

Another respondent shared that would be a good death if she could die without creating an extra burden on others through her sickness. She said, *"I want to die suddenly just like my husband."* One beneficiary wants to see her son established before her death,

> *"I always pray to Allah that please establish by son. If I die before his establishment, my soul will not rest in peace."*

A beneficiary who lives in other's house said, to be able to die in his own house would be a good death to him. One beneficiary believes that a good death is worth dying quietly, *"I just pray to Allah to die quietly. May Allah grant me a quiet death!"* The beneficiary who is a third gender said:

> *"Is there any solution without thinking about death? There is no way to escape, everyone have to die. No one can ignore fate! I want to die near my own sister in my village. I am aged enough; if I can die and reach to Allah by leaving all the jealousy and with a pure soul that will be a peaceful death. Once I was young and beautiful but now my time (to die) has come."*

The wife of a couple beneficiaries stated,

> *"If he (her husband) dies first then it will be my suffering and if I die first then it will be his suffering. So, it will be a good death for us if we can die together."*

The beneficiaries mentioned although they are not sure whether they will have their expected good death but for now they at least feel good that they are not abandoned and there are people whom they can rely on at this stage of end of life.

b. Effect on the community

One of the main goals of the project was to involve community people in the program. As a part of that goal they held more than one meeting with CBO (community based organization) and celebrated World Palliative Care Day in the community. As part of involving the community they collected donation from community people. By doing this they included the community people in the project and made them aware of the term "Palliative Care". According to one of the key informant the experience was not always positive. As he said

> *"People were skeptical and commented negatively. Some of them said cancer patient will die sooner or later. What good it will be to collect money for them? We said, 'at least we can reduce their suffering. However, later many people donated, we collected donation even from a police officer."*

Once the project staff set up a stall in a fair held in the community, but they hardly collected any money. But the project stuff took it sportingly, as one of the staffs said:

'Money is not important; at least this initiative may let the people know about our activities'.

The project made some positive changed on the perspectives of community people regarding elderly people. The statement of a beneficiary, as he went to tears while expressing his experience, would help us to understand the impact of the project in the community. He said,

> *"Before being a beneficiary of this project, neighbors and shopkeepers used to hide in their house or in another lane seeing me from a distance thinking that I would ask for money or help. But now this is not the case. Now they talk to me when we meet on the way and they think that 'as he has some ability so he will not ask for help anymore."*

The project made the family members, relatives and neighbors of the beneficiaries' realize the importance of taking proper care of elderly people. The Bengali took kit published by the project also played a positive role in raising awareness of the community regarding palliative care. The key informant confirmed that it is not just about the medicine but the project also made an impact on the overall care culture of the community. One key informant gave an example of a patient suffering from Parkinson's disease,

> *"She stays alone at home all day. Her son used to go out giving her a bath and feeding her in the morning and then again took care of her after returning home in the evening. She had nobody to look after her at home. After the initiation of this project, we (project worker) have tried to give her bath, provide other services and look after her regularly. Her neighbors watched us and our activities closely and as a result of that if we are late to or do not visit her house, her neighbors bathe and look after her."*

At the beginning when the Palliative Care Assistants (PCAs) went to people's house they were suspicious, some even wanted to bit them, but, now as one PCA stated, 'when we go to their home, they don't want to let us leave".

A shopkeeper of the community said:

> *"The rice and peas for project beneficiaries are bought from my shop. I don't take profit from them, because they are doing a good job."*

These comments clearly indicate the positive impact of the project on the community.

Highlights of Effect-

- The self-confidence and self-esteem of the beneficiaries were found to be highly increased after joining this project.
- The beneficiaries felt that their quality of life has improved and the mental strength has increased as well after joining the project.
- The beneficiaries believe that their children will now be free of tension about how to take care of their parents.

- Some technical lessons taught to the beneficiaries through this project regarding diseases were found to have major positive impact on their health.
- The project officials observed a better and rational use of drug now among the beneficiaries.
- The community in general has become aware of the issues related to palliative care.
- Although at the beginning the community was reluctant to accept the project activities but now they are highly favorable.
- Although people did not contribute to the project in terms of money but there are sporadic examples of community participation in non-monitory means.

3 Sustainability

3.1 Is the project sustainable?

a. By the local beneficiaries and the partners:

Although in project's organogram PCAs are at the lowest level but we found that they are key mover of the project and the sustainability of the project depends greatly on them. When during the group discussion with the PCAs we asked, *"As all of you live in this slum, so what happens when you get married and have to leave this slum?"*

Everyone agreed with the reply made by one respondent:

> *"It is true that we will get married one day but the knowledge we have gained will not get married off. Wherever we go and live, we will use the knowledge we have gathered from this project and thus serve people. Even if the project is closed, we will continue our service; nobody can stop us from continuing our effort."*

Another PCA said,

> *"Even if we take job elsewhere, we will keep touch with them as much as we can. We learned to measure diabetes and blood pressure. We can at least help them by measuring these."*

Similar sentiment was expressed by other project staff as well. It was found from observation and the discussions with the project workers that most of them are emotionally motivated. They all consider themselves as "members of the same family". One office staff stated,

> *"Even if the project is closed, we will continue our work right from where they left us. We may not be able to give service like now but we will try our best to take care of the beneficiaries. Many patients told us that if the project is closed they don't need food pack or medicine. They just want us to visit them sometimes and give them company for some time. We won't be able to give them food or medicine but we will give them company and care."*

It was found that after joining the project the staff members have developed certain skills and knowledge which has now become part of their personal attribute. In other words they have developed a 'social capital'. We think this is a crucial element of sustainability of the spirit of the project. This social capital of the PCAs will be an asset of the community wherever they live. However, their social capital could be utilized in a far better and efficient way if that is channelized through an organized project.



This project is a pilot one with particular time limit. According to many of the respondents, the patients they are providing treatment/services with, are getting dependent on them. They fear that the beneficiaries will become helpless if the project gets closed someday. The community participation of the project is still quite limited. The project officials were concerned about their relationship with the community people as they faced problems to deal with them right from the beginning of this project. However, this relationship has improved a lot over time and the acceptance to the project has increased.

We think the leader of this pilot project, Dr. Nezamuddin (Head of CPC) played a crucial role and became the unsung strength of this project. His charismatic personality and ability to motivate others helped this project to reach this far. It was not an easy task to continue such activities in a new and unknown community (where the situation is entirely different than other places of Bangladesh, with migrants from different areas of the country and with most of them involved in informal occupation), with a group of people who had no prior experience about palliative care. He himself confessed in his interview:

> *"When I used to visit the slum initially, I tried to approach like a slum dweller but ultimately I would mix it up and it didn't work."*

Then he tried to learn and understand from that experience. Now the situation is different and he is more comfortable than before. Even the research team watched him attend some phone calls about complaints/problems from the slum dwellers while interviewing him. We found him open in terms of discussing the limitations of the project as well, as he *said "A pilot project is to learn more. If we don't make mistakes how can we learn?"* He says he dreams one day Dhaka would be a city as described by of Professor Allan Kellehear in his book "The compassionate City".

But he also pointed out another obstacle to the sustainability of the project. He stated,

'Both most of our project workers and the beneficiaries consider the project as a medical project only. But palliative care is more than a medical issue. Unless we are able to bring this project out of medical model this project will not sustain.'

Medicalization of palliative care seems to be a one of the major challenge of the project's sustainability.

However, while we debate about the sustainability of the Korail project, it is interesting to observe that the project has already started to inspire others. Recently being motivated and encouraged by the 'Compassionate Korail' model, people of *Sonargaon*, a small town near northern Dhaka has already taken the initiative to start a project called 'Compassionate Sonargaon' project. This is indeed an encouraging development and positive signal regarding the sustainability of the spirit of Korail project.

Highlights of sustainability:

- The PCAs and other project staff were found determined to continue to serve people through using the knowledge they have gathered from this project even if they move to other places.
- The project has provided a social capital to the beneficiaries as well as the staff members which are an asset of the community. This is an important element of sustainability which needs proper channel to be utilized.
- The leadership of Dr. Nezamuddin played a crucial role to motivate the staff members.
- The patients are still dependent on this project and the project is depended on external resources. It cannot be said that the project is community owned.
- Although there is potential to be sustainable, at this stage it cannot be guaranteed.
- The transfer of the Korial model to Sonargaon is an encouraging development.

Section 3

Conclusion and Recommendations

Conclusion

Running a community based palliative care in itself a challenge and it is further challenging to run the project in a community like slum which is characterized by highly mobile population, informal power structure, and uncertainty. Despite that it is apparent from the evaluation that the project has achieved considerable success within a year. The clients are highly satisfied with the services they have received. It is obvious that the clients have been benefitted physically, society, psychologically and spiritually which were the core component of the project. The community volunteers who were chased away by the community in the beginning of the project are now more than welcome in people's house. The activity of palliative care is now known and appreciated by the community. Credit also goes to the leadership of the project. However, question remains about the sustainability of the project as the community still does not own the project and the activities are still depended on external support. There are also questions to be answered regarding the selection criteria of the beneficiaries, which raises some broader question regarding the definition and boundary of 'palliative care' in a slum situation.

Globally there are few examples of community oriented end of life care particularly in the resource poor setting. It is widely argued that perhaps the most refined version of the model is The Neighborhood Networks in Palliative Care (NNPC) in Kerala, India. The NNPC is an attempt to facilitate a sustainable, community-led service capable of providing palliative care to all those in need, with limited resource. We have learned that Korial project of Dhaka is inspired by Kerala model. Given the fact that almost all the available palliative care services in Bangladesh have taken institution-based approach following western models, this community based initiative is a highly innovative and challenging one. It appears from this rapid qualitative evaluation that the project made remarkable success within one year and improved the quality of life of the project beneficiaries. This project has the potential to be a model for a public health

approach to palliative care in a resource poor setting. However, the sustainability of the project will depend on how the project overcomes the challenges in future.

Recommendations:

a) Despite a success so far, the project has few loopholes that might hinder the progress. As understood, the project was initiated in a hurry resulting in lack of resource, improper management and weak selection process of beneficiaries. As the findings suggest a proper planning regarding beneficiaries, resources based on rigorous situation analysis is crucial to implement such project particularly in a slum context.

b) There was dilemma in defining the boundary of palliative care in the slum situation. In a context of extreme poverty and complete lack of health services, it became very difficult for the project to demarcate the boundary of palliative care. This demands a discussion in the broader palliative care community.

c) This lack of clarity about the boundary of palliative care actually affected the beneficiary selection process. Findings suggest that the project did not follow strict inclusion criteria for selecting beneficiaries. It could be helpful to determine and stick to an operational definition of the project in order to create an appropriate beneficiary selection process.

d) Food distribution received a huge positive response among the beneficiaries. Most of the beneficiaries said that they have nothing more to ask to this project except some better food and that would make them real happy. However, procuring such food needs a source of continuous fund. This needs careful consideration. However, if money can be generated food assistance seems to be a good component of such project.

e) Paper based record keeping was found not to be an efficient one. All the information of the beneficiaries could be preserved in digital format or in digital database or using digital applications for better record keeping.

f) The project could think of including a rehabilitative component for the beneficiaries. Facilitating income generating activities for the beneficiaries has some potential. Collaboration with various NGOs working in the area may increase opportunities for such initiatives.

g) In order to increase community involvement, it would be effective to collect volunteers from the college level or from the university level students and train them on palliative care. It is expected that they will be able to work under the project and provide service throughout their student life.

h) The project is still dependent on external resources. This is a challenge for sustainability of the project. Steps should be taken to increase the community ownership of the project. However, it is understandable that one year is too short a time to ensure community ownership of a project.