# Compassionate Korail – External Evaluation

# Report

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# Table of Contents


- Executive Summary: 3

1. Background and Introduction: 8
2. Methodology: 10
3. Findings and Conclusions: 12
4. Recommendations: 29
5. Appendices: 33
    - Case Studies: 33
    - List of Essential Medicines 34
    - Tools used for data collection 36
    - Summary of data 48
    - List of People interviewed 52

# Executive Summary

## Background:

Centre for Palliative Care (CPC) at Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka initiated a Palliative Care project in Korail, the largest slum in Dhaka with an estimated 150,000 population. The population is extremely poor with practically no Primary Health Care facilities. The project named "Supporting Compassionate Palliative Care Communities for Older People" and referred to as 'Compassionate Korail', with external support from World Hospice Palliative Care Association (WHPCA) was started as a one-year pilot in 2015 and continued as regular project for two more years. The aim of the project was to evolve a system of palliative care for old people in need of palliative care in Korail and to develop this into a community based, community led sustainable program. The project, after completion of Year III was evaluated in May 2019 by an external consultant.

## Methodology:

Guidelines by World Health Organisation for evaluating community health projects have been followed in the evaluation process.

A mixed methodology (quantitative and qualitative approaches) was used. The quantitative methods included verifying records including case sheets to check percentages, numbers and rates of contact, consultations, and status of beneficiaries. Qualitative data collected from 219 stakeholders included information collected through 69 semi structured stakeholder interviews, information from the focus group meeting of community volunteers, a survey of social capital among 151 randomly selected residents and observing the activities of the home care teams and the Palliative Care Centre. The local socioeconomic, cultural and political context were taken into consideration during the process.

## Findings and Conclusions:

1. Compassionate Korail (CK) project has been trying to address the palliative care needs of an extremely marginalised group of people living without basic health

care or social support. The project addresses an important local need both from the angle of health and human rights perspectives. It is also local action on a national and global priority in view of ageing population, particularly in low- and middle-income countries.

2. Since no other primary health care / social support is available to the residents of the slum, Compassionate Korail had to facilitate a few more activities outside the Terms of Reference of the current project in Korail slum. These interventions addressing basic health and social needs of the community included regular support for the Differently Abled children in the slum, Eye Camps for the residents and Fortnightly Gynaecology Outpatient Services.
3. Services offered by the project have been found to be very cost effective.
4. The key objective of the project was to meet palliative care needs of old people with palliative care needs in Korail Slum. The project had a total of 580 beneficiaries over the period of three years including the pilot phase, 187 in group 1 (intensive support) and 363 in group 2 (basic support). 114 people in group 1 (of whom 34 are younger people with life threatening disease) and 359 people in group 2 are continued to be cared for by the project. In addition, a total of 32 children with disabilities have been looked after by a supplementary project for children.
5. In addition, a total of 1425 patients have attended the 14 eye camps at the Palliative Care Centre so far. A total of 42 patients have attended the recently started once a fortnight Gynaecology Outpatient services at the Palliative Care Centre.
6. Beneficiaries and other stake holders in the slum consider Compassionate Korail as a much-needed program and of good quality. A key request from the stakeholders is to use the project platform to bring in primary health care services to all the residents in the slum as no system of health care support is available to other residents.
7. 12 young people from the slum (11 girls and one boy) were recruited, trained and employed as Palliative Care Assistants (PCA) in Compassionate Korail Project. They were placed as grassroots level health care professionals in the project after a 6-month structured training program. PCAs function effectively as the key health care

workers delivering care. They are confident of delivering basic nursing and psychosocial support to the patients. Beneficiaries of the project expressed satisfaction about the services delivered by the Palliative Care Assistants.

8. Palliative Care Assistants recruited from the slum community have evolved to be a confident and competent local group improving the capacity of the community to address palliative care needs. But the 140 Community volunteers who received 2-3-hour sensitisation and training in palliative care are not involved in hand-on patient care as training was not oriented towards patient care.
9. The social capital survey and interviews of residents have shown that level of mutual support and compassionate approach to suffering in the slum community has generally been good.
10. The sensitization/ awareness generation work has contacted 2100 people one-to-one in addition to dissemination of information through events, leaflets, posters and T shirts. But this seems not to have made any major impact in the community as a whole. Non beneficiary/ non volunteer residents interviewed were not aware of the nature and role of the project.
11. The project has caused generation of interest and increased engagement of new partners from outside Korail to the slum. These include Civil Society Organisations from Dhaka and one agency from UK.
12. Only a very small fraction of the annual expenses could be raised from Korail Slum. The pattern of contributions to Compassionate Korail and to other participatory projects in the slum shows that it will be practically impossible to make the project financially self-sustainable on income from the locality.
13. But many Civil Society Organisations and institutions in Dhaka have expressed interest in supporting/ joining the project. Continuation of the project should be possible with this support.
14. The Palliative Care Program Committee formed with representatives from Korail Slum in it was mostly ‘ornamental’.

## Recommendations:

1. Compassionate Korail project brings to light some of the very important questions/ dilemmas related to Community Based Palliative Care projects. Lessons from this experiment in a poor, large and diverse community need to be discussed widely as

they have relevance to issues related to community participation, community ownership and sustainability for many ongoing and future palliative care projects in other regions of the world.

2. Compassionate Korail needs to stay as it addresses an important and urgent problem in the target community. The local community will not be able to raise adequate resources to sustain the project. But the Civil Society in Dhaka has shown interest in the Compassionate Korail project and willingness to support it.
3. There have been consistent differences between the community's priorities in health care and the project agenda. The local community was looking at ways to bring primary health care facilities to the slum and saw the palliative care project as addressing basic needs of old people within this primary health care frame they have in mind. Compassionate Korail had to bring 'non project components' like ophthalmology services, gynaecology services and services for differently abled children on the project platform due to local demand/ pressure. An important lesson for similar future projects will be to make a point to explore local priorities in health/ social care, look for overlapping areas in the palliative care project planned, place the project in the context of community agenda, work with the community on the palliative care project and also be a supporting agency in helping the community fulfil its agenda. This will help with bringing in better mutual trust and understanding and in making the palliative care project more stable.
4. The project committee with representatives from the community needs to be organised better. Terms of Reference of the committee with clearly defined roles and responsibilities need to be in place. The local community should have wider representation in the committee instead of representation by one/ few dominant groups with their own agenda.
5. Sensitization programs need to be purposeful, more regular and effective. Sensitization/ training programs need to be continued throughout the project and not just at the start of the project. Sensitisation / training will interest people only if the information introduced has something to do with their lives. Service delivery points like PCA visits and services at Palliative Care Centre need to serve also as sensitisation outlets. Training programs for carers may be an important point to start training. Structured courses for lay person can help.

6. Compassionate Korail project, through regular contact and regular follow up of enrolled patients, has generated important information on the state the marginalised elderly in the country. This information needs to be retrieved from case notes and organised into a document which will be very useful for advocacy and policy discussions in Bangladesh and many other low- and middle-income countries.
7. The Palliative Care Assistant program getting 'field tested' in Compassionate Korail, Compassionate Narayanganj and Centre for Palliative Care has great potential for expansion and replication in many low- and middle-income countries. The impact, competence and training module for PCAs needs to be evaluated as the first step for fine tuning the program and making it replicable in other places.
8. It will be useful to develop 'Home Care Protocols' and check lists to be used by Palliative Care Assistants. This is important because regular continuous monitoring of the PCAs by Staff Nurses / Doctors will not be practically possible in Korail or in any other region where the PCA system is introduced in future. Integrating protocols and check lists in the PCA system will be helpful from the point of view of quality control and documentation

# 1. Background and introduction

Korail is the largest slum in Dhaka. The 100 acres of land on which the slum is located is owned by the Bangladesh Telecommunications Company Limited (BTCL), where it plans to build an IT park. This IT park project has long been stalled as the government has been unable to relocate the current residents, many of whom have started living there from 1990. A report from Economic Empowerment of the Poorest (EEP), published in 2012, showed that the sprawling shanties housed more than 20,000 families. The number has gone up since then. Exact numbers are not available, but the community leaders estimate the current population as 22,000-25,000 families, corresponding to around 150,000 people. Korail has a highly mobile population with a huge percentage of the residents working in Dhaka city outside the slum and hence away during daytime.

The majority of Korail's residents are living below the poverty line and working in extremely low-income jobs. Monthly income for most of the families is less than Tk 20,000 (Less than US$ 250). There are very few health care facilities available to the residents. When home remedies do not work, most people approach the 35-40 local pharmacies (medical shops run unqualified persons). These shops are popular because they sell medicines without any prescription from a doctor, but there is no 'consultation fee' charged. The next level of help is from the 3-10 General Practitioners in the periphery who charge 100-300 Tk as consultation fee which is not affordable to most people in Korail. There is a maternity centre run by an NGO. This non-physician facility addresses perinatal care at a relatively cheap rate. There is also a twice a week community clinic operated by a Medical College, but the services are very irregular.

Administratively, Korail is probably the most well organised slum in the city. It has a system of self -established governance overseeing day to day activities in the complex background of an over-crowded diverse population, territorial issues, crime syndicates and inadequate basic amenities. A 32-member Slum Management Committee- the Central Community Based Organization (locally known as CBO) under the patronage of the local municipal councillor manages the slum and acts as 'local government'. Members of the committee, generally called 'community leaders' are not elected by the residents, but nominated by the Councillor and other members of the group.

It is likely that the slum will be non-existent in a few years' time. In 2014, Bangladesh Hi-tech Park Authority (BHTPA) the Public- Private Participatory Company for developing the IT park in the area submitted a few options for the resettlement of the slum dwellers before the High Court. Government is waiting for the High Court's final ruling on the matter before the final move but a few families living at the edge of the slum bordering the lake have already been served eviction notices.

Following a pilot project in 2015 April to 2016 August, an agreement was signed between World Hospice Palliative Care Association ( WHPCA) and Centre for Palliative Care, Bangladesh to build a self-sustaining compassionate community model for older people with life-limiting conditions in the Korail slum, building on the palliative care pilot model. The project named "Supporting Compassionate Palliative Care Communities for Older People" and referred to as 'Compassionate Korail' was funded by a donor who wishes to remain anonymous. The two-year project as per the Memorandum of Understanding started April 2017 and was concluded in March 2019.

The original plan was to do the project in two urban slums- Agargaon and Korail as the Pilot was done in these two slum areas. But most people from Agargaon slum got evicted by the Government by the time the regular project got launched. Hence the regular project got restricted to Korail. Support to patients from the Agargaon area registered during the pilot period and remaining in the neighbourhood was nevertheless continued till they died or dropped out. Some of the Palliative Care Assistants in the project still are young women originally recruited from Agargaon.

# 2. Methodology

The following 12 key criteria for evaluation of community projects recommended by WHO (2013) have been used to generate the plan for evaluating Compassionate Korail project.

1. Relevance
2. Efficiency
3. Effectiveness
4. Sustainability
5. Impact
6. Utility
7. Equity
8. Coherence
9. Synergy
10. Additionality
11. Deadweight
12. Displacement

A mixed methodology (quantitative and qualitative approaches) was used. The quantitative methods included verifying records including case sheets to check percentages, numbers and rates of contact, consultations, and status of beneficiaries. Key Performance Indices mentioned in the original MoU between partners were taken as project targets. Qualitative data collected included information collected through semi structured stakeholder interviews, information from the focus group meeting of community volunteers, a survey of social capital among 151 randomly selected residents and observations from shadowing Palliative Care Assistants during home visits and watching the activities at the Palliative Care centre established in Korail. A participatory approach was used throughout. Care was taken to make sure that the evaluation's focus does not lose sight of the local socioeconomic, cultural and political context.

The methodology followed was that of eliciting information from various stake holders, triangulating with other sources and going back to some of the initial respondents in case of inconsistencies in data.

In addition to going through the original project document, patients' case sheets and reports, a total of 219 stakeholders were contacted for information in different formats as below:

1. 69 respondents were interviewed by the evaluator using semi structured questionnaires. Interviews were done at locations convenient to the respondents. The shortest interview was of six minutes duration and the longest two hours. Average duration of an interview was 20 minutes. Services of interpreters were used in 51 cases when the respondents preferred to respond to questions in Bengali rather than English. Contemporaneous brief recordings were made by evaluator/ interpreter for later reference. The content of each interview was transcribed/documented in 24 hours.
2. 151 residents of the slum were contacted through a structured face to face social capital survey by the Palliative Care Assistants to check the background social dynamics of the slum.

Stakeholders interviewed included

1. Members of the Project Team -8
2. Members of Institutions/ Civil Society Organisations in Dhaka Associated with / Interested in the Project - 9
3. Beneficiaries of the Project: 13
4. Community Leaders in Korail slum: 3
5. Palliative Care Assistants in the project -9
6. Volunteers -15 (Focus Group meeting)
7. Local Fund-raising supporters -5
8. Staff in other Projects in Korail Slum -2
9. Non Beneficiary/ Un Connected Residents of Korail Slum (General Public) -5
10. Social Capital Survey by Palliative Care Assistants among residents of Korail slum - 151

# 3. Findings and Conclusions

## 3.1 General Observations:

The level of confidence, morale and sense of achievement of the project team is high. All the team members consider the project as a great learning experience.

The interface between the Project Team and the Monitoring/ Supervising agency (WHPCA) has been generally smooth and friction free. But there is a feeling that a dynamic community project like Compassionate Korail would have benefited from more frequent reviews and reorientation sessions involving stakeholders and experts

3.2 Findings Against WHO Evaluation Criteria

*3.2.1 Relevance*

*To what extent are the programme objectives justified in relation to needs? Can their raison d'être still be proved? Do they correspond to local, national and global priorities?*

Compassionate Korail (CK) project has been trying to address the health care and social needs of an extremely marginalised group of people (old people in extreme poverty) over the last three years. There are no other basic health care or social support available to the target group except a few among them receiving an old age pension of Tk 400 (Less than USD$5) per month. Beneficiaries of the program and members of the community aware of the project consider it as an extremely valuable intervention in a much-needed area. The project addresses an important local need both from the angle of health and human rights perspectives. It is also a national and global priority in view of ageing population, particularly in low- and middle-income countries. Since no other primary health care / social support available to the residents of the slum, Compassionate Korail had to facilitate a few more activities outside the Terms of Reference of the current project in Korail slum. These 'offshoots' of the CK projects namely regular support for the Differently Abled children in the slum, Eye Camps for the residents and fortnightly Gynaecology Outpatient Services for the residents are also well received as interventions addressing basic health and social needs.

Korail Slum is likely to get 'dismantled' in a few years' time. Korail community, as defined now, will not then exist as a single community. But services developed under the

project are immensely relevant till then and can serve as a model in similar situations elsewhere in future.

### *3.2.2 Efficiency*

*Have the objectives been achieved at the lowest cost? Could better effect be obtained at the same cost?*

The project has been found to be very cost effective. The total project spends for 2 years including all expenditure in Bangladesh and UK was US$228,739.80. This includes costs for discussions, travel, training, infrastructure building, development of services and monitoring. Now that the system is established, the main costs currently are the expenses for manpower and consumables for delivery of services. This can be calculated as the total salaries for health care personnel, cost of medicines and other consumables, electricity/ water charges at the palliative care centre. All the patients registered living in a small geographical area accessible by foot (and impossible to use vehicles in the narrow alleys) helps in cutting costs enormously by avoiding home care vehicle costs and improving the number of patients visited per day. With more than 110 patients in group 1 actively supported and services made accessible another 350 patients in group 2, the average cost of supporting a patient per month comes to less than 1000 Tk (less than US$12) The average cost per home visit by project team comes to about 400 Tk ( less than US$ 5). The process of sensitisation and training will incur additional costs. It will not be possible to cut costs further down from these basic costs.

Similar projects in other regions of the middle/ low income countries cost more. For example, the average cost per home visit in community based palliative care projects in Kerala (India), a region where awareness level is quite high, comes to about US$ 16

### *3.2.3 Effectiveness*

*To what extent has the outcome/impact been achieved? Have the interventions produced the expected effects? Could more results be obtained by using different instruments?*

### 3.2.3.1 Target Group of Beneficiaries:

The major aim of the project was to meet palliative care needs of old people in Korail Slum. Despite attempts to generate a google data sheet, there is no single register with registration and follow up data on all the patients enrolled in the project. But data could be retrieved from the case sheets and a google sheet maintained. All patients in Group I also get registered at Centre for Palliative Care at BSMMU. The project had a total of 580 beneficiaries over the period of three years including the pilot phase, 187 in group 1 (intensive support) and 363 in group 2 (basic support). 114 people in group 1 (of whom 34 are younger people with life threatening disease) and 359 people in group 2 are continued to be cared for by the project now. The number of patients actively in need of support (old people with life limiting diseases and the old bed ridden) registered has been more than the target set at the beginning of the project (100) while the number enrolled for basic support has been less than the target (620, although this was contingent on local resources being available) set. In addition, a total of 32 children with disabilities have been looked after by a supplementary project for children. The less than expected number of registrations in group II can be explained by factors like inadequate awareness in the community, old people moving back to their villages once they become economically non-productive and the feeling among Group II patients and carers that registered patients do not get much benefit unless they are seriously ill /bedridden.

Identification of patients has been by Community Leaders, Volunteers, other patients, neighbours in the community and by the doctor from patients attending the weekly outpatient clinic. Eye Camps and the fortnightly Gynaecology clinics which came up as ‘add on’ to the project also served as referral points to the project.

Age of the patient was verified by referring to their Identity Cards. Age was estimated by asking their ‘Age at the time of Liberation War (1971)/ Age at the time of the big flood (1980) in many situations in which it has not been possible to find the identity card.

A three-step procedure was used to register and categorise patients.

- Initial screening by the Palliative Care Assistant
- Assessment by the project coordinator
- Health screening by Medical Officer.

Diagnosis was made by checking the existing medical records (which were incomplete/ missing in many cases) and history taking and clinical examination by the doctor. Most of the patients had multiple conditions. The conditions documented included Cancer and non -cancer.

| **Non-Cancer Conditions** | | **Cancer** | |
|---|---|---|---|
| Diabetes Mellitus | 18 | Lung | 2 |
| Uncontrolled hypertension | 57 | Breast | 3 |
| Ischemic Heart Disease | 10 | Esophagus | 1 |
| Chronic Respiratory Diseases (COPD) | 38 | Colorectal | 2 |
| Peptic Ulcer | 5 | Prostate | 1 |
| Tuberculosis | 6 | Uterine Cervix | 5 |
| Bronchial Asthma | 10 | Oral cavity | 1 |
| Stroke | 27 | Non-Hodgkin's Lymphoma | 1 |
| Chronic Lung Disease | 1 | Unknown Primary | 2 |
| Chronic Kidney Disease | 8 | | |
| Multiple age related problems (Geriatric Problems) | 29 | | |
| Chronic neurological disorders including Dementia | 8 | | |
| Cardio Vascular Diseases | 19 | | |
| Arthritis | 41 | | |
| Frozen shoulder | 4 | | |
| Others | 59 | | |
| **Total** | **154** | **Total** | **18** |

Each Palliative Care Assistant has a caseload of 10-12 Group I patients allotted to her. Patients receive the following interventions depending on the group assigned.

Patients in group I:

- Follow-up and emotional support (The process includes regular home visits, listening to the patient and family, exploring physical and emotional problems,

checking whether medicines have been taken as prescribed, helping with cleaning and dressing of wounds, bathing and personal hygiene), ventilation/emotional support, social networking/mobilising other supports, linking with other resources etc, providing health related information, help with problem solving etc): Regular home visits by PCA (two visits per week on an average; four patients in the group without a named carer are visited more frequently).

- Medication support: Patients in Group I are provided their medicines free if the prescription is for drugs in the list of 21 essential drugs stocked. (List of medicines given as appendix)
- Food kit: Selected patients from group 1 get a basic monthly survival food kit (Rice 5 Kg, Pulses 850 grams, Oil 1 litre and Salt 0.5 Kg costing Tk 450 i.e. less than US$6 per month). Patients identified by PCA to be struggling to get three meals per day are included in the food-kit program. Inclusion in the list is a dynamic process and patients are taken out of the list if the family's financial condition improves. 3208 Food kits have been distributed over the three-year period of the project (90 food kits per month on an average). The food offered to the patient naturally gets shared within the family. Even otherwise, the amount of food offered is hardly adequate to sustain a person for a month. Nevertheless, this activity helps at least in addressing hunger partly and improving the status of the patient within the family as he/ she is now recognised as the responsible for bringing in food support.
- Access to medical/nursing interventions such as Nebulisation, inhaler, Catheter, Stoma Care, Dressing the wound, Lymphoedema care, Physiotherapy with support devices, assisted walking devices like walking sticks, portable commodes, electric air mattresses, plastic sheets when needed

Patients in Group II:

PCA home visits on demand. These patients who are mobile also have access to services offered at the Palliative Care Centre.

Centre for Palliative Care at Bangabandhu Sheikh Mujib Medical University acts as the referral unit for the patients registered at Compassionate Korail Project. This strong institutional back up has been helpful both from the practical and credibility aspects.

Patients in Group I, their carers and community members aware of the project all consider this as an extremely useful project for older people who otherwise do not get any

health care/ social support. The supplementary services of eye camps, gynaecology clinics and support for the differently abled children are also very much appreciated by the community.

Patients in Group II value their access to free medical consultation and occasional support with medicines and other interventions as there is no other free medical facility in the slum. But they also feel that it would have been better if they also got benefits that the Group I patients are offered such as free medicines. All the patients in Group II are people with a good functional status. This is pool of residents have the potential to help as volunteers in the project. But this has not happened.

A total of 1425 patients have attended the 14 eye camps at the Palliative Care Centre so far. A total of 42 patients have attended the recently started once a fortnight Gynaecology Outpatient services at the Palliative Care Centre.

3.2.3.2 Community Leaders

Community Leaders are happy about the project. They consider it as a much-needed program and of good quality. One suggestion from them is to use the project platform to bring in primary health care services to all the residents in the slum as no system of health care support is available to other residents. This is understandable in the background of non-availability of primary health care and social support in a community which cannot afford to pay for services.

### 3.2.3.3 Palliative Care Assistants:

12 young people from the slum (11 girls and one boy) were recruited, trained and employed as Palliative Care Assistants (PCA) in Compassionate Korail Project. The minimum qualification for applying for the position was Higher Secondary. They underwent a 6 month structured training program (6 weeks of classroom sessions at BSMMU and four and a half months of 'hands-on' training under supervision) with an assessment at the end. They had also undergone a few refresher training programs after the formal course.

PCA are the key professionals at the grassroots level in Compassionate Korail. Their responsibilities include

- Visiting patients at home
- Documenting vital signs
- Head to toe care for bed ridden patients
- Prevention and care of pressure sores
- Emotional Support to patients and carers
- Cleaning and dressing wounds
- Catheterisation/ Catheter care
- Stoma Care
- Training the family in Naso Gastric tube feeding
- Lymphoedema Care
- Passive Exercises
- Dispensing medicines as per Medical Officer's prescriptions

In addition, the PCA are also involved in sensitisation programs, coordinating volunteer meetings and documentation.

It is six- day week work for PCA, starting every day with a team meeting at the Palliative Care Centre at 9 am and continuing till 4pm. Time up to 2pm is spent on home visits and 2-4pm at the Palliative Care Centre, engaging in helping patients who visit the centre, completing case notes, helping the team in sensitisation programs and charity sales and engaging volunteers. Tuesdays are spent in Centre for Palliative Care with review meetings/ refresher sessions. Each PCA makes 5-6 home visits per day. There is very little supervision in the field by Medical Officer or Staff Nurses.

Palliative Care Assistants are confident about their job and competent in their tasks. They had a problem of lack of acceptance by some patients and carers in the beginning, but this was overcome over the time. Home visits and support offered by the PCAs are well appreciated by patients in group I and carers. Many patients in group II feel that they are not getting adequate support from the PCA. This is mainly in situations where a Group II patient / carer observes the care and support available to a Group I patient in the immediate neighbourhood. PCA address this by explaining the criteria for inclusion in Group I. A better option would have been to publicize the criteria for registration of

Patients in Group I and Group II (and inclusion in the Food-Kit list) so that the local community is clearly aware.

*3.2.3.4 To what extent has the project enabled people to meet their palliative care needs in Korail?*

Compassionate Korail tries to address the palliative care needs of old people in Korail. Palliative Care Assistants recruited from the slum community have evolved to be a confident and competent group of youngsters in addressing palliative care needs. Other than this, empowerment of the community at large to look after the needs has been a weak area of the project. Carers of patients have not received any formal training other than some basic instructions in care. One possible future option would be to offer a structured training program for all the carers. This will help in improving patient care and in preventing possible burn out. Existing manuals already available to the team can be used for this. 140 Community volunteers had undergone 3-hour sensitisation and training in palliative care, but this training also was not oriented towards patient care. Volunteers are not much involved significantly in patient care. Apparently, there was no clear plan to involve volunteers in 'Hands-on' patient care. A concrete plan to involve carers and neighbours in service delivery, supported by a structured training program for all carers (family carers and volunteer-carers) may make a difference.

*3.2.3.5 What evidence is there of increased knowledge, skills and awareness of compassionate approach and palliative care amongst community members?*

The level of mutual support and compassionate approach to suffering in the slum community has generally been good as evidenced by responses to questions in the background survey and interviews of residents done as part of the evaluation. 200 residents were approached randomly with a validated Social Capital assessment questionnaire. 151 responded. The responses showed a high level of mutual trust among neighbours and social support from neighbours and family in case of crisis like illness and death. This finding has been supported by information from more detailed interviews of residents randomly approached.

Social capital in any community is basically about members of the community having strong positive relationships embedded in existing or newly developed social structures with a lot of people from a variety of backgrounds. Any project encouraging people to

work together or establishing social structures for such activities is likely to enhance the social capital in the community. Compassionate Korail would also have contributed to social capital in Korail slum. But measuring/ quantifying this contribution by the project is difficult for two reasons.

1. The positive contribution to enhancement of social capital would be small since CK has been a project involving only a small fraction of the members of the community.
2. The existing social capital in Korail Slum is a result of multiple complex determinants like traditional customs, religion (e.g Islam strongly advocates mutual support among members), the practice of people migrating from the same original neighbourhood staying together one area in the slum and local culture. Most of these have evolved over a period of hundreds of years in the Bangladeshi community. To make a measurable impact in this area will mean working for a much longer time.

Anecdotal evidence is available, nevertheless. Enhancing social capital in a community is essentially is about generating goodwill. All the residents who are aware of the project consider it as a necessary intervention, several residents, though small, have shown willingness to volunteer on the CK platform to help others. Palliative Care Assistants have been narrating stories about many carers and neighbours showing more interest in patient care after the PCA visits.

Compassionate Korail platform has more potential in improving social capital in the community than what is experienced now. Possible activities in this direction include encouraging the stakeholders to talk more to each other, connecting patients and carers with each other and with other residents, encouraging people to give time for others, making sure that these contributions are valued, and demonstration of the impact of caring.

Non beneficiary/ non volunteer residents interviewed were not aware of the nature and role of the project though all of them have seen the Palliative Care Assistants moving around in their blue uniforms. Residents of the slum are aware that the PCAs are involved in some sort of health care activity but are not sure what exactly it is.

The project had sensitisation/ awareness work in parallel to service delivery. 2100 people have been contacted directly with information so far (Sensitization Program for CBO

committee Members, NGO Coordination Meeting, sensitisation programs on Palliative care day 2017 & 2018, Courtyard meetings, Sensitization program with schoolteachers, School based awareness programs). In addition, 11000 leaflets have been distributed in the area, 20 posters displayed in area, 100 T shirts with CK logo have been distributed to volunteers, Rikshaw Pullers and 500 pens with CK name and logo have been distributed to teachers / students. Two theatre performances were done in the slum with the help of a project supported by Sussex University.

Despite efforts at sensitisation and training, Compassionate Korail does not seem to have had much impact on the background knowledge/ skills/ attitude related to palliative care so far.

There are a few possible interconnected reasons for this.

There was very little 'personal touch' in sensitization programs. A look at the sensitisation/ awareness/ training material reveals that the rather impersonal key message the project has been trying to pass into the community was about the importance of the new concept of palliative care for older people. Why each member of the community should be involved and what their roles in it would be have not been emphasised. The training programs for volunteers / carers did not cover practical aspects of hands on care. Sensitisation/ Training programs in the community has been an 'add-on' and not a priority like service delivery.

3.2.3.6 *Has the project contributed to increased engagement and establishing different stakeholder partnerships*?

No activity can happen in Korail without the permission of the Community leaders who have organised themselves as the Central Community Based Organisation. Compassionate Korail also functions with the permission and support of this group. Members of the group also facilitate registration of patients and drop in occasionally to enquire about the progress/ problems.

There are 18 other projects by Non-Governmental Organisations operating in Korail area. The local culture is that of projects operating independently and most often in compartments. This is understandable as the philosophy (other than the willingness to help residents of the slum) and focus of each of these projects are different. Nevertheless, two of them, Educo, an educational initiative and CDD ( Centre for Disability in Development) have been collaborating with Compassionate Korail on the

ground. Educo had offered physical space for Compassionate Korail in their school building in the early days of the project. They have also been involving their teachers in sensitization programs. CDD has been supplementing the care provided by Compassionate Kerala to differently abled children in the slum. Both groups have expressed interest in continuing the informal collaboration.

140 residents have so far agreed to volunteer in the project and taken training. Most of them (95%) are women. About 10% are students. 35-40 of the trained people are active in the project. They help with organisation of awareness programs, running of the charity shop, and sometimes run errands in connection with patient care activities.

One of the stated objectives of the project was involvement of older people as volunteers. This has not happened. One of the reasons is non availability as many people go back to their original villages when they are old. The more important reason seems to be a 'strategy error' in registering the functionally active elderly as patients. Almost all of them have been registered as Group II patients, conveying to them a strong message that they are beneficiaries of the project. A better strategy would have been to register this group as 'Senior Volunteers'.

The project has generated interest and increased engagement of new partners from outside Korail to the slum. Both World Child Cancer (UK) and Children Palliative Care Initiative in Bangladesh became involved in the Differently Abled children component of the Compassionate Korail project which developed later. A theatre project by Sussex University has shown interest in collaborating. Compassionate Korail has been instrumental in bringing the Ophthalmology and Gynaecology Departments of BSMMU to Korail Slum on a wider platform of basic health care. These initiatives have been complementary to palliative care of old people in many ways.

#### 3.2.4 Sustainability

*Are the results and impacts, including institutional changes, durable over time? What will happen to the impacts in future if there is no external funding? To what extent is there local ownership of the project?*

A 7- member Palliative Care program committee with three members from Centre for Palliative Care and four from the Community Leaders has been formed to run the project. One of the Community Leader member died later and has not been replaced.

This committee does not have a formal Terms of Reference. Roles and responsibilities of individual members of the committee have not been defined. That the project coordinator who is the key person in the field is not a member of the committee has also been a handicap. The committee had met only for three times during the period of the project. The committee is not involved in making policy decisions or monitoring the project. Some of the Community Leader members of the committee have a complaint that the community leaders have not been taken into confidence.

Community volunteers are not involved in any decision making or monitoring.

There have not been any other visible attempts to facilitate community ownership. The current situation is that the local community see Compassionate Korail as a good project planned and managed by people outside the slum.

Local fund raising has been attempted through

- Local practice of Donation pots (74 boxes)
- Sales of used clothes collected from the main city (Charity Shop on Saturdays)
- Individual donations
- Fee for certain services like nebulisation at the Palliative Care Center.

Only a small amount of money could so far be raised through local fund raising. Details of money collected locally are displayed on the notice board outside the palliative care centre as part of the policy of ensuring transparency

Money raised locally during June 2017 to December 2018 (19 months) in Taka:

| Source | Amount raised Taka | Amount raised US$ |
|---|---|---|
| Donation pots ( 30 out of 74 opened): | Tk 3,222 | US$ 42.96 |
| Donation box at the Palliative Care centre | Tk 2,692 | US$ 35.89 |
| Charity sales | Tk 30,025 | US$ 400.33 |
| Collection from shops on Palliative Care Day | Tk 25,650 | US$ 342.00 |
| Fee collected for services | Tk 3,077 | US$ 41.03 |
| Donations received at the Palliative Care Center from local people | T 4,500 | US$ 60.00 |

| Donations received at the Palliative Care Center from visitors | Tk 93,675 | US$ 1,249.00 |
|---|---|---|
| TOTAL | Tk 162,841 | US$ 2, 171.21 |

So the total including donation from visitors to the Palliative Care Centre was just about US$2,200, of which, US$ 920 came from the Korail slum itself. This is just under US$ 50 per month.

There are two reasons for this low response to local resource mobilisation.

i. The level of awareness and information about the project is poor.
ii. The paying (contributing) capacity of slum population is much less than other communities. Previous attempts at collective fund raising for common causes in the slum points to this. For example, the most ambitious project in recent times was construction of a concrete road into the slum. Part of the work was completed (around 280 metres of road) at a cost of 2.1 million Taka. Despite all out efforts and 'forceful collection of money', only 8% of this money (200,000 Tk) could be raised over a period of a year from the local community. The partner organisation (BRAC) had to contribute the balance amount 1.9million Taka.

The implication is that Compassionate Korail will have to depend on external funding for sustenance.

There was no planned attempt to 'show case' the project locally or nationally. Even then, individuals, organisations and institutions have shown interest in collaborating in the project.

There was a gap of eight months between the end of the pilot project and starting of the actual project. None of the activities of the pilot project were discontinued during this period of discontinuation of external funding support. Project activities were continued with the support of local civil society organisations and philanthropists. Three key organisations involved in supporting the project during this period were

- Palliative Care Society of Bangladesh
- Rotary Club of Dhaka Metropolitan area and

- Afzalunnisa Foundation

These and a few other Civil Society Organisations like Ayat Education in Dhaka have expressed willingness to support the project in future. Funding from these domestic sources, supplemented by the unused amount from the existing project will be adequate to continue the project without compromising much on the activities. Centre for Palliative Care has already started taking steps to consolidate these offers.

3.2.5 Impact

*Are the results still evident after the intervention is completed?*

The project came to an end formally, but there is an underspend which was already discussed with the donor and agreed as part of the sustainability/exit plan to cover costs for a full year to March 2020. The intervention, hence, is not yet complete, but positive results, as mentioned above are evident.

3.2.6 Utility

*Are the expected or unexpected effects satisfactory from the point of view of direct or indirect beneficiaries?*

The expected effects of improved care of older people in the slum has been found to be quite satisfactory from the point of view of beneficiaries. All the beneficiaries of Group I were highly appreciative of the help. Many of them even say that surviving in Korail would have been impossible for them if it were not for the support from the project. An unexpected effect of the project was introduction of services for the differently abled children, ophthalmology services, gynaecology services and the availability of the Medical Officer in the Outpatient Clinic in the team weekly once for consultations to anyone in the slum. All these are greatly appreciated by the local community. Compassionate Korail project, in addition to delivering services, had also become instrumental in bringing in these essential services to the Korail community. It was possible to provide these services by liaising with other departments in BSMMU, at no additional cost to the project.

3.2.7 Equity

*Have the principles of gender equality, human rights and equity been applied throughout the intervention?*

Utmost care seems to have been taken in ensuring gender equality, human rights and equity. Recruitment of Project staff and enrolment of patients clearly show this. But the project also faces ethical dilemmas of any project focusing on a small group of people in a marginalised community. These are mainly in the domain of wider distributive justice. e.g; Is it justified in offering food kits to the project beneficiaries only when there are a lot of other deserving people in the community? Can an island of good care for the dying be developed in a place where practically nobody gets any heath care at all? But addressing these problems raised are beyond the capacity of a project with limited resources.

### 3.2.8 Coherence

*To what extent were the different interventions or components of an intervention complementary or contradictory?*

The interventions of sensitisation, training and deployment of Palliative Care Assistants, social support through food kits and introduction of services for the differently abled children, ophthalmology and Gynaecology services all are complementary to each other.

*Has the theory of change proven to be accurate? What are its main strengths? What elements could be added or deleted to make the model more robust? Are there any other inputs needed to lead to the outcome and impact?*

The proposed Theory of Change had identified the issue as 'Lack of essential compassionate health care & community support for people with serious illness, frailty and unmet care needs including older people in Korail'. Korail slum lacks basic health care, but good community support for people with serious illness and fragility has already been there, as evidenced by results of the Social capital survey and interviews with residents of the slum. Looking back, the issue was ''Lack of essential primary health and unmet care needs care for residents in Korail including the more vulnerable group of people with serious illness, frailty (including older people)"

Suggested inputs were

1. Development and delivery of community home based palliative care services in Korail

2. Training and ongoing support for community Palliative care Assistants & volunteers

3. Community mobilisation training and activities to scope and raise understanding of benefits and rights and possible action linked to palliative care focussed on older people

4. Research and dissemination activities to promote model of community palliative care delivery in urban setting

5. Stakeholder engagement focussed on CBO leadership, health providers, NGOs, government and possible funders

6. Build community and local fundraising for support of compassionate care in the community

The project had focussed mainly on inputs 1 & 2. This has generated the desired output of increased access to home based palliative care services in Korail.

It's not possible to say whether Inputs 3-5 would have produced desired results as consistent and focussed implementation of these ideas did not happen. The project did not have a clear purposeful plan (and hence dedicated budgetary and manpower provision) for these interventions. As the results of the interventions, an effective system of delivery of care for old people with palliative care has been developed. Community Participation/ Community ownership has been minimal. The assumption that the project will be financially sustainable through contributions from the local community seems to be misplaced.

On the other hand, the project has made visible the need for a stable primary health and social care system as basic condition for a community based palliative care program. It has also demonstrated the weakness of the proposed model of an 'island of self-sustained care' in a community. Compassionate Korail has shown the importance of wider networking and involving larger number of stakeholders inside and outside the target community for development and sustenance of a community based palliative care program.

Though there have not been consistent planned efforts to build community and local fundraising for support of compassionate care in the community (input 6), the project has generated adequate interest in Dhaka to secure promises of financial support to continue the activity.

Two additional inputs that could have made a difference are exploration of the community's priorities in health care to link them up with palliative care and bringing in other agencies interested primary health care/ social support and networking with them to deliver palliative care as part of a package of health services.

The outcome expected (A sustainable, community owned and led compassionate palliative care project in Korail ) seem to have been partly achieved as the sustainable compassionate palliative care project generated is not yet community owned or led.

The project can nevertheless legitimately claim that it has achieved the desired impact of increased access to compassionate health care and support in Korail for those with serious illness, frailty and unmet care needs through a compassionate community approach.

3.2.9 Synergy

*Is any additional impact observed that is the positive or negative result of several components acting together?*

The additional positive impact has been the awareness among stakeholders that Palliative Care for old people is a component of much needed Primary Health Care for all.

3.2.10. Additionality

*To what extent did the intervention add to the existing inputs, instead of replacing any of them, and result in a greater aggregate?*

All the interventions in the project were new

3.2.11 Deadweight

*Did the programme or intervention generate outputs, results and impacts that would in any case have occurred?*

No

3.2.12 Displacement

*Did the intervention cause reductions in palliative care development elsewhere?*

No

# 4. Recommendations

1. Compassionate Korail project raises some of the very important questions/ dilemmas related to Community Based Palliative Care projects. (For example, ‘How do you introduce community based palliative care in a region when the community’s priorities in health care are different? Are all communities capable of raising resources regularly to sustain palliative care / any other primary care projects? In ‘community owned’ projects, how can one make sure that project is ‘owned’ by the community and not one of the dominant power groups?) Lessons from this experiment in a poor, large and diverse community need to be discussed widely as they have relevance to issues related to community participation, community ownership and sustainability for many ongoing and future palliative care projects in other regions of the world.

2. Compassionate Korail needs to stay as it addresses an important and urgent problem in the target community. The local community will not be able to raise adequate resources to sustain the project. Even with expansion and intensification of local fund raising activities, it is unlikely to generate more than 7.5 -8% of funds for the project from Korail slum area because

    a. The community is extremely poor, and this is the biggest limitation in raising money.
    b. The local priorities are that of survival, food and primary health care in the background of poverty, lack of basic health care facilities and constant threat of eviction.

But the Civil Society in Dhaka has shown interest in the Compassionate Korail project and willingness to support. Dhaka Community had already proved that they can take the project forward by supporting it during the 8 months period. Compassionate Korail program can be sustained with financial support from Civil Society groups in Dhaka. The three agencies (Palliative Care Society of Bangladesh, Rotary Club of Dhaka Metropolitan area and Afzalunnisa Foundation Dhaka) which helped to sustain the program during the 8 months break in funding have all expressed willingness to support for continuing the program. A few other Civil Society Organisations also have showed

interest. The Rotary Club of Metropolitan Dhaka has already started discussing options for raising money for this.

Other stakeholders in project linked activities (Department of Obstetrics & Gynaecology, BSMMU, Department of Ophthalmology, BSMMU and BSMMU itself as an institution have expressed interest in continuing the role that they now play in the current Primary Health Care activities on the Compassionate Korail platform.

All these developments indicate that the recommendation to continue the project and move it forward in its present direction will be possible

3. There has been consistent difference in opinion/ subtle friction between the community's priorities in health care and the project agenda. The local community was looking at ways to bring primary health care facilities to the slum and saw the palliative care project as addressing basic needs of old people within this primary health care frame they have in mind. Compassionate Korail had to bring 'non project components' like ophthalmology services, gynaecology services and services for differently abled children on the project platform due to local demand/ pressure. An important lesson for similar future projects will be to make a point to explore local priorities in health/ social care, look for overlapping areas in the palliative care project planned, place the project in the context of community agenda, work with the community on the palliative care project and also be a supporting agency in helping the community fulfil its agenda. This will help with bringing in better mutual trust and understanding and in making the palliative care project more stable.
4. The project committee with representatives from the community need to be organised better. Terms of Reference of the committee with clearly defined roles and responsibilities need to be in place. The local community should have wider representation in the committee instead of representation by one/ few dominant groups with their own agenda. (This issue assumes importance in the context of Compassionate Korail as a background survey done as part of the evaluation has shown that more than 80% of the residents do not trust members of the group which represented the community in the project committee). The issue of wider representation without antagonising the existing power centres in the community will

not be easy, but this is important from the later question of ownership by the community.

5. Sensitization programs need to be result-oriented, more regular and effective. Sensitization/ Training programs are the key to community ownership and hence need to be a priority in projects considering Community Participation. This component will interest people only if the information introduced has something to do with their lives. Sensitization/ Training programs need to reorient to the question of what is there in it for the person targeted. Universality of death/ dying and suffering associated with it makes it easy for palliative care projects to get the message that it is 'everybody'd business' across. Purposeful interventions with targets/ review/ modifications are needed in this area. Interactive sensitization / training programs with one-to-one contact may give better results in a geographically small area like Korail slum. Sensitization/ training program need to be continued throughout the project and not just at the start of the project. Service delivery points like PCA visits and services at Palliative Care Centre can serve also as sensitisation outlets. Training programs for carers may be an important point to start training. Establishing formal training programs in areas like 'nursing care for the bedridden', 'talking to a person with serious illness' etc can help in the capacity building process locally.
6. Compassionate Korail project, through regular contact and regular follow up of enrolled patients, has generated important information on the state the marginalised elderly in the country. This information needs to be retrieved from case notes organised into a document which will be very useful for advocacy and policy discussions in Bangladesh and also many other low- and middle-income countries.
7. The Palliative Care Assistant program getting 'field tested' in Compassionate Korail, Compassionate Narayanganj and Centre for Palliative Care has great potential for expansion and replication in many low- and middle-income countries. The impact, competence and training module for PCA need to be evaluated as the first step for fine tuning the program and making it replicable in other places. Extended role of Palliative Care Assistants in sensitising and training the neighbourhood need to be explored. A designated Staff Nurse to supervise and monitor the clinical work of the PCA team will be helpful as the Field Officer without any clinical background cannot take this role. The 'grassroot level allrounder' role of PCA need to be reinforced and enhanced.

8. It will be useful to develop ‘Home Care Protocols’ and check lists to be used by Palliative Care Assistants. This is important because regular continuous monitoring of the PCAs by Staff Nurses / Doctors will not be practically possible in Korail or in any other region where PCA system is introduced in future. Integrating protocols and check lists in the PCA system will be helpful from the point of view of quality control and documentation. Samples of Home Care Protocols are available from Palliative Home Care Programs elsewhere, which can be modified for local use. An attempt in this direction is already on.

# Appendices

## Case studies or stories collected during the evaluation

### Case History I

Julfa khatun, an 85 year old widow lives in Korail with her son's family. She also has a daughter who got married off.  She was registered as patient in Compassionate Korail. Has Dementia and also multiple age-related illness. When the CK field team first went to her home they found her in a corner of the storeroom where she could just lay down. Her only carer was her daughter in law who could not find enough time for the patient. She was found in soiled clothes and lying in food, urine and faeces. The smell in the unventilated room was unbearable. Compassionate Korail team proceeded with cleaning and bathing the patient, cleaning the room and talking to the carer. A portable commode was made available and clean sheets on the bed. Daily visits by the Palliative Care assistant was arranged.  PCA also helped the carer in physical care of the patient. Frequently helping with feeding, cleaning, combing hair, cutting nails etc. Over the time the carer started looking after the patient better, keeping her clean and communicating with her better. She says knowing that someone is there to understand her and to share the care burden helps a lot

### Case History 2:

55-year-old Saiful Islam lives in Korail slum with his wife. Was surviving doing odd jobs when he had a stroke two years ago and got paralysed on one side of the body. Since he can not manage his daily living activities on his own, his wife has to remain with him. Neighbours He help occasionally. is being supported for the last couple of years by Compassionate Korail. He is visited regularly by a Palliative Care Assistant and once in two weeks by the Physio therapist. The project provides with his medicines. The Doctor in the project visits him as and when required. He also receives a food kit every month. "I survive just because of this project. I do not know how I will live if they stop supporting me", he says

### Case History 3:

Selina Akhter, President, Central Community Based Organisation, Korail Slum: " We were a bit skeptical when I first heard about the project. But when we started seeing how they support old people in this area, we realized how important the service is."

## Compassionate Korail: List of Essential Medicines stocked and dispensed

1 Morphine Sulphate

15mg/tab SR, 10mg/tab, 15mg/1ml Inj. , 5mg/5ml of 100ml syrup

2 Ibuprofen

300mg/cap SR, 200mg/tab, 400mg/tab, 100mg/5ml susp

3 Paracetamol/Acetaminophen

500, 665mg/tab, 500mg/dispersible tab, 120,150mg/5ml susp., 120,250mg/5ml syrup, 80mg/ml drop,60/, 125/, 250/, 500mg/supp, 1gm/100ml IV solution

4 Hyoscine butylbromide

10, 20mg/tab, Injection 20mg/1ml amp

5 Bisacodyl

5mg/tab

6 Aspirin

300mg/tab

7 Magnesium OH

Suspension 400mg/5ml

8 Diazepam

5mg/tab, 10mg/2ml Inj, 10mg/Suppository

9 Ranitidine

150mg & 300mg/tab, 75mg/5ml suspension, 50mg/2ml amp

10 Theophylline

200mg & 300mg/tab, 200mg, 300mg & 400mg/tab SR, 120mg/5ml/ 100ml suspension

11 Salbutamol salphate

2mg, 4mg/tab, 2mg/5ml solution, 100mcg/puff, 5mg/ml suspension

12 Amitryptiline

10mg, 25mg/tab

13 Metronidazole

200mg, 250mg, 400mg, 500mg/tab, 800mg/double strength tab, 200mg/5ml suspension, 5mg /ml suspension

14 Metformin

500mg, 750mg, 850mg, 1gm/tab

15 Amlodipine

5mg, 10mg/tab

16 Losartan Potassium

25mg, 50mg, 100mg/tab

17 Metoclopramide

10mg/tab, Inj 10mg/2ml amp, 5mg/5ml suspension, 1mg/1ml drop

18 Gabapentine

100mg, 300mg/tab

19 Chlorpheniramine meleate

4mg/tab, 2mg /5ml suspension

20 Gliclazide

80mg/tab, 30mg/tab MR, 60mg/tab MR

21 Oral Rehydration powder

# Tools used for data collection

## Semi structured Questionnaires:

### Project Team:

1. History of the project. Narrative report on events
2. Activities

a. Patient care
b. Volunteers
c. Local Fund raising
d. Sensitisation/ Training
e. Organisational activities
f. Additional activities

3. Key milestone
4. Barriers/ Difficulties
5. Targets achieved and not achieved
6. Good moments/ bad moments
7. Lessons learned
8. What are the things that you would have done differently if you get an opportunity to redo things? Why?

### Community Leaders:

1. History of Korail Slum
2. Functioning of the committee
3. Initial impressions about the project when the proposal came
4. Current impressions about the project

a. What is useful?
b. What is not so useful?
c. Suggestions for improvement

5. Present role of Community Leaders in running the project

6. Perceived role of Community Leaders in running the project in future

## Palliative Care Assistants:

1. Personal Background
2. What would they have become if the current option of PCA was not there
3. Details of training/ competencies
4. Schedule of daily activities
5. What are the services offered?
6. How do they link up with the mainstream palliative care system in BSMMU?
7. Barriers/ Difficulties
8. Good moments/ Bad moments

## Beneficiaries of the Project:

1. Background

a. Family

b. Financial

c. Clinical

2. What do they get from the project?
3. What is useful?/ What do they like about the project?
4. What is not so useful?/ Anything that they do not like about the project?
5. Suggestions for improvement
6. Who else helps?
7. Who helps when there is a crisis?
8. What would have happened if the project has not been there??

## Community Volunteers:

1. Background
2. What do they do in the project?
3. How did they know about the project?
4. Good moments
5. Bad moments
6. Suggestions for improvement
7. Suggestions for sustainability

## Local Fund-raising supporters:

1. Background
2. How did they know about the project?
3. What do they do to support the project?
4. Suggestions for improvement
5. Suggestions for continuation

## Non-Beneficiary/ Un Connected Residents of Korail Slum (General Public)

1. Background
2. How long have you been staying in Korail?
3. What do you do?
4. Challenges of living in Korail?
5. Eg: Problems of daily living/ frictions
6. Any good things about living in Korail
7. How do people in Korail manage when there is a crisis like major disease or death?
8. Do you know about the Compassionate Korail project?
9. *If yes,* What do they know? How do you know?
10. Do you think that it is a useful program?
11. *If the person does not know about Compassionate Korail*, Have you noticed the Compassionate Korail staff moving around in blue uniforms?
12. What do you think are they doing?

## Institutions/ Civil Society Organisations in Dhaka:

1. Background
2. How did they know about the project?
3. What do they do/ offer to do in the project?
4. Suggestions for improvement
5. Suggestions for continuation

## Staff in other projects in Korail slum:

1. Background/ What is your project in Korail Slum?
2. Do you know about the Compassionate Korail project?
3. How did you know about the project?

4. Have you associated with / supported Compassionate Korail in any way?
5. Suggestions for collaboration in future

## Tool used for Social Capital Survey – Original English Version

**Shortened and Adapted Social Capital Assessment Tool for use in Bangladesh (SASCAT-B)**

Age: Sex: For How long have you been living in Korail?

**Structural social capital**

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*Group membership*

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1a. In the last 12 months, have you been a member of the following types of groups in your area?

1. Vocational training group
2. Savings groups/community cooperative
3. Political group
4. Religious group
5. Microcredit program
6. Sports club
7. Youth/student club
8. Other: specify

1b. In the last 12 months, how would you describe your involvement in the groups in which you are a member?

1. Received a loan or other form of financial support
2. Attended meetings
3. Attended trainings
4. Participated in decision making

5. Served as a leader of the group
6. Other: specify

Social support

---

2a. Suppose you had something unfortunate happen to you, such as some one's sudden death in the family.Who would help you in this situation?

1. Immediate family
2. Relatives
3. Neighbors
4. Friends who are not neighbors
5. Community leaders
6. Religious leaders
7. Politicians
8. Government officials/civil service
9. Person from NGO
10. A group in which I am a member
11. A group in which I am not a member
12. Other: specify

2b. Suppose you suffered an economic loss, such as job loss. In that situation, who do you think would assist you financially?

2c. Suppose you are (FEMALE) / your wife is (MALE) preparing to give birth to your (FEMALE) / her (MALE) first child. Who do you think would provide you (FEMALE) / her (MALE) advice or assistance in this situationa?

Collective action

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3. In the last 12 months, have you joined together with others in your area to address important issues?

- Yes
- No

4. In the last 12 months, have you talked with a local leader, chairman, or governmental organization about the development of your area?

- Yes
- No

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**Cognitive social capital**

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Trust

---

5a. Can your neighbors be trusted?

- Yes
- Sometimes
- No

5b. Can leaders in this area be trusted?

- Yes
- Sometimes
- No

6. Do you think that the majority of people in this area would try to take advantage of you if they got the chance?

- Yes
- Sometimes
- No

Social cohesion

7. Do the majority of people in this area generally have good relationships with each other?

- Yes
- Sometimes
- No

8. Do you feel that this area is yours?

- Yes
- Sometimes
- No

Date:

Data Collected by:

## Tool used for Social Capital Survey – Bangla Translation

**Shortened and Adapted Social Capital Assessment Tool for use in Bangladesh (SASCAT-B)**

বয়স (Age ) :    লিঙ্গ (Sex ) :

আপনি কত দিন যাবত কড়াইলে বাস করেন? (For How long have you been living in Korail? )

**Structural social capital**

*গ্রুপ/দলের সদস্য (Group membership )*

1a. গত ১২ মাসে, আপনি কি আপনার এলাকার কোনো গ্রুপের সদস্য ছিলেন/হয়েছেন? (In the last 12 months, have you been a member of the following types of groups in your area? )

9. কারিগরি প্রশিক্ষণ গ্রুপ (Vocational training group )
10. কমিউনিটি কর্পোরেশন/সমবায় সমিতি গ্রুপ (Savings groups/community cooperative )
11. রাজনৈতিক গ্রুপ (Political group )
12. ধর্মীয় গ্রুপ (Religious group )
13. ক্ষুদ্র ঋণ কার্যক্রম/প্রোগ্রাম (Microcredit program )
14. ক্রীড়া সংগঠন (Sports club )
15. যুব/ছাত্র সংগঠন (Youth/student club )
16. অন্যান্য (Other: specify )

1b. গত ১২ মাসে, গ্রুপের সদস্য হিসেবে আপনার কাজকে আপনি কিভাবে বর্ণনা করবেন? (In the last 12 months, how would you describe your involvement in the groups in which you are a member? )

7. ঋণ পেয়েছি অথবা অন্য কোনো আর্থিক সহায়তা (Received a loan or other form of financial support )
8. মিটিং এ উপস্থিত ছিলাম (Attended meetings )
9. প্রশিক্ষণ কার্যক্রমে অংশগ্রহণ করেছি (Attended trainings )
10. সিদ্ধান্ত গ্রহণে অংশগ্রহণ করেছি (Participated in decision making )
11. গ্রুপের নেতা হিসেবে দায়িত্ব পালন করেছি (Served as a leader of the group )
12. অন্যান্য (Other: specify )

সামাজিক সহায়তা (Social support )

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2a. হঠাৎ করে যদি আপনার সাথে খারাপ কিছু ঘটে যায়, যেমনঃ পরিবারের কেউ মারা গেলে, এই অবস্থায় আপনাকে কে সাহায্য করবে বলে মনে করেন? (Suppose you had something unfortunate happen to you, such as some one's sudden death in the family.  Who would help you in this situation? )

13. বর্তমান পরিবার (Immediate family )
14. আত্মীয়-স্বজন (Relatives )
15. প্রতিবেশী (Neighbors )
16. বন্ধু বান্ধব-যারা প্রতিবেশী নয় (Friends who are not neighbours )
17. কমিউনিটির নেতারা (Community leaders )
18. ধর্মীয় নেতারা (Religious leaders )
19. রাজনৈতিক ব্যক্তি (Politicians )
20. সরকারী কর্মকর্তা/সিভিল সার্ভিস (Government officials/civil service )
21. এনজিও-র লোকজন (Person from NGO )
22. আমি যে গ্রুপের সদস্য (A group in which I am a member )
23. আমি যে গ্রুপের সদস্য নই (A group in which I am not a member )
24. অন্যান্য (Other: specify )

2b. ধরুন, আপনি কোনো আর্থিক ক্ষতির সম্মুখীন হলেন, যেমন- আপনার চাকুরী চলে গেল। এই ক্ষেত্রে আপনাকে আর্থিকভাবে কে সহযোগীতা করবে বলে মনে হয়? (Suppose you suffered an economic loss, such as job loss. In that situation, who do you think would assist you financially? )

2c. ধরুন, আপনি /আপনার স্ত্রী বাচ্চা জন্ম দেয়ার প্রস্তুতি নিচ্ছেন। এই অবস্থায় কে আপনাকে সাহায্য বা পরামর্শ দিতে পারবে বলে মনে হয়? (Suppose you are (FEMALE) / your wife is (MALE) preparing to give birth to your (FEMALE) / her (MALE) first child. Who do you think would provide you (FEMALE) / her (MALE) advice or assistance in this situationa? )

Collective action (সম্মিলিত কাজ)

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3. গত ১২ মাসে, কোনো গুরুত্বপূর্ন বিষয় আলোচনা করার জন্য আপনি এলাকার অন্য কারো সাথে যোগাযোগ করেছেন? (In the last 12 months, have you joined together with others in your area to address important issues? )

- হ্যাঁ (Yes )
- না (No )

4. গত ১২ মাসে, আপনি আপনার এলাকার উন্নয়ন নিয়ে স্থানীয় কোনো নেতা, চেয়ারম্যান বা সরকারী প্রতিষ্ঠানের সাথে কথা বলেছেন? (In the last 12 months, have you talked with a local leader, chairman, or governmental organization about the development of your area? )

- হ্যাঁ (Yes )
- না (No )

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**Cognitive social capital**

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বিশ্বাস (Trust )

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5a. আপনি কি আপনার প্রতিবেশীদের বিশ্বাস করেন? (Can your neighbors be trusted? )

- হ্যাঁ (Yes )
- কখনো কখনো (Sometimes )
- না (No )

5b. এই এলাকার নেতাদের কি বিশ্বাস করা যায়? (Can leaders in this area be trusted? )

- হ্যাঁ (Yes )
- কখনো কখনো (Sometimes )
- না (No )

6. আপনার কি মনে হয়, এই এলাকার বেশীরভাগ লোক সুযোগ পেলে আপনাকে ধোকা দিবে? (Do you think that the majority of people in this area would try to take advantage of you if they got the chance? )

- হ্যাঁ (Yes )
- কখনো কখনো (Sometimes )
- না (No )

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Social cohesion

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7. এই এলাকার বেশীরভাগ মানুষের কি একে অপরের সাথে ভালো সম্পর্ক আছে? (Do the majority of people in this area generally have good relationships with each other? )

- হ্যাঁ (Yes )
- কখনো কখনো (Sometimes )
- না (No )

8. আপনি এই এলাকাটিকে কি নিজের মনে করেন? (Do you feel that this area is yours? )

- হ্যাঁ (Yes )
- কখনো কখনো (Sometimes )
- না (No )

তারিখ (Date ) :

তথ্য গ্রহণকারী (Data Collected by):

# Summary of data collected

## Compassionate Korail - Summary of Data

| | Activity | Outcome |
|---|---|---|
| **1** | Direct Patient Care | **Group 1**<br>Currently Active: 114<br>Expired: 39<br>Discontinued: 64<br>Total in Group 1: **217**<br><br>**Group 2**<br>Currently Active: 359<br>Expired: 4<br>Total in Group 2: **363**<br><br>Total Patients during project period: **580** |
| **1a** | Gender wise Split up ( Group 1/ Group 2) | **Group 1**<br>Male: 83<br>Female 133<br>Third Gender 1<br>**Group 2**<br>Male 94<br>Female 265 |
| **1b** | Diagnosis | **Non-malignant- 154**<br>• Diabetes Mellitus- 18<br>• Uncontrolled hypertension- 57<br>• IHD- 10<br>• COPD- 38<br>• Peptic Ulcer Disease- 5<br>• TB- 6<br>• Bronchial Asthma- 10<br>• Stroke- 28<br>• CLD- 1<br>• CKD- 8<br>• Multiple age related problems (Geriatric Problems) - 29<br>• Chronic neurological disorder (Dementia/CP) – 8<br>• CVD- 19<br>• Multiple body pain- 41 |

| | | |
|---|---|---|
| | | • Frozen shoulder- 4<br>• Others- 59<br>**Malignant- 18**<br>• Lung- 2<br>• Breast- 3<br>• Esophagus- 1<br>• Colorectal- 2<br>• Prostate- 1<br>• Cervix- 5<br>• Oral cavity- 1<br>• Non-Hodgkin's Lymphoma- 1<br>• Carcinoma with Primary Unknown- 2 |
| **1c** | Medicines / interventions available for unpaid use by patients | There is a list of 20 essential medicines. Interventions: Nebulisation, inhaler, Catheter, Stoma Care, Dressing the wound, Lymphoedema care, Physiotherapy with support devices, Assisted walking like walking sticks, portable commodes, electric air mattresses, plastic sheets |
| **1d** | Number of food kits distributed | April 2015- August 2015 :<br>691<br>September 2015- February 2016:<br>356<br>March 2017-March 2019:<br>2161<br>**Total:**<br>**3208** |
| **1e** | List of items per food kit | Rice 5 Kg<br>Pulses 850 gram<br>Oil 1 L<br>Salt 0.5 Kg |
| **2** | Manpower sensitization & training | |
| **2a** | Palliative Care Assistants | 90 trained by Center for Palliative Care so far. 19 trained for Compassionate Korail ; 12 employed in Compassionate Korail Project |
| **2b** | Volunteers | 140 trained. (2-3 hour training)<br>Training in 4 batches<br>35-40 active now |

| 2c | Total number of people covered by sensitization programs so far | **Programs and number of people attended**<br>Sensitization Program for CBO Committee Members 35<br>NGO Coordination Meeting 63<br>Palliative care day 2017 31<br>Courtyard meetings 1156<br>Sensitization program with school teachers 26<br>School based awareness programs 280<br>Palliative care day 2018 400<br>Volunteer sensitization program 140<br>Total Number of people covered 2131<br>In addition,<br>11000 leaflets distributed in the area, 20 posters displayed in area, 100 T shirts with logo distributed to volunteers, Rikshaw Pullers, 500 pens with CK name and logo<br>Theatre performances. One drama ( 45 minutes) ,100 audience Two group songs ( 15 minutes) – 50 people in each place |
|---|---|---|
| 3 | Utilization of Other services | |
| 3a | Compassionate Korail Center/ Out Patient Clinic | CK Centre users ( Year 1) 962<br>(Year 2) 952<br>**Total: 19 14**<br>OPD Visits (Year 1) 420<br>(Year 2): 552<br>**Total: 972** |
| 3b | Eye Camps & Gynecology Services | Eye Camp (Year 1): 686<br>(Year 2): 739<br>**Total: 1425**<br>Gynecology Services: 42 |
| 3c | Services for Differently Abled Children | Male: 18<br>Female 14<br>**Total Beneficiaries: 32** |

| | | |
|---|---|---|
| **4** | Local Publications on the Project | Scientific Paper: 1 (Cancer pain management- still a challenge in a developing country like Bangladesh, May 2017, year-21, issue-02, Monthly Health Digest.)<br>2. TV programs : 5<br>3. Radio Programs: 5<br>4. News items in Print Media : 25 |
| **5** | Amount of money raised locally from Charity shop/ donation box/ other donations | • Donation pots ( 30 out of 74 opened): Tk 3222<br>• Donation box at the Palliative Care centre: Tk 2692<br>• Charity sales: Tk 30,025<br>• Collection from shops on Palliative Care Day: Tk 25,650<br>• Fee collected for services: Tk 3077<br>• Donations received at the Palliative Care Center: Tk 98,175 ( Out of which Tk 4500 was donation from local people. The rest was from visitors) |
| **6** | Events/ Celebrations | PC Day 2015 -2017, Id celebrated with gifts to patients, Iftar party 2018, Prayer session at the centre when a CBO member died, Art & poetry competition for kids, releasing the compilation as a book |

# List of people interviewed (with dates of interviews/Focus meeting)

Total Number of People interviewed during 26 April to 5 May as part of Evaluation of Compassionate Korail Project: 220

## Project Team

1. Prof. Nezamuddin Ahmed, Project Lead, Compassionate Korail (26, 27 April)
2. Dr Nadia Fraheen, Medical Consultant, Compassionate Korail ( 27 April)
3. Krishna Ray ( Project Coordinator, Compassionate Korail ( 27, 28 April)
4. Muhammed Julhash Uddin ( Project Manager, Compassionate Korail ( 27. 28 April)
5. Lailatul Ferdouse, Senior Staff Nurse, Center for Palliative Care, Volunteer in the Project Management Team ( 27 April)
6. Kahdija Shopna, Project Coordinator, Community Based Paediatric Palliative Care Program, Center for Palliative Care, Volunteer in the Project Management Team ( 27, 28 April)
7. Dr Mostofa Kamal Chowdhury, Assistant Professor, Department of Palliative Medicine, BSMMU, Volunteer in the Project Management Team ( 27 April)
8. Fazle Noor Biswas, Clinical Pharmacist, Centre for Palliative Care, Volunteer in the Project Management Team ( 28 April)

## Institutions/ Civil Society Organisations in Dhaka Associated with / Interested in the Project

9. Dr K M Iqbal, Chairman, Afzalunnisa Foundation ( 27 April)
10. Professor Khalilur Rehman, Executive Committee Member, Afzalunnisa Foundation ( 27 April)
11. K. P Roy, Director, Afzalunnisa Foundation (27 April)
12. Syed Mahbubur Rahman, Vice Chairman, Palliative Care Society of Bangladesh ( 27 April)
13. Khalid Hassan, Executive Committee Member, Past President Rotary Club of Metropolitan Dhaka ( 29 April)
14. Nusrat Feroze Aman, CEO, AYAT Education; 1 May

15. Prof. Kanak Kanti Barua, Vice Chancellor, BSMMU, 5 May
16. Prof. Shafiqul Islam, Department of Ophthalmology; BSMMU, 5 May
17. Prof. Sabera Khatun, Chairman, Department of Obstetrics & Gynaecology, BSMMU, 4 May

## Beneficiaries of the Project: (*Names to be masked if/ when the report is circulated outside the project team*

18. Saiful Islam, Group 1 Patient ( Stroke, chronic ulcer); 29 April
19. Lazatun Nessa, Group I patient ( 107 year old lady with multiple problems (29 April)
20. Salma, Daughter of a Group I patient ( Stroke); 29 April
21. Minana, Daughter in Law of a Group I patient ( Elderly, bed ridden); 29 April
22. Noorjahan, Group 2 patient ( Old age, arthritis, pain); 2 May
23. Nargis, Group 2 patient ( Diabetes, Diabetic Neuropathy): 2 May
24. Forida, Mother of differently abled child (29 April)
25. Anwar Hussein, Father of differently abled child ( 29 April
26. Shaheb Ali, Group 2 Patient ( Diabetes); 2 May
27. Nazma Begam, Group 1 Patient ( Stroke, Parkinson's Disease); 2 may
28. Baleal, Group 1 patient (Stroke, Chronic Kidney Disease); 2 May
29. Mumtaz Ali, Group 1 patient (Cardio Vascular Disease, Recovered Stroke); 2 May
30. Golesa, Group 1 patient ( COPD, Multiple illness); 2 May

## Community Leaders in Korail

31. Abdul Mannan ( Mannan Bhai), Secretary, Central Community Based Organisation (29 April)
32. Selina Akthar, President, Central Community Based Organisation; 29 April
33. Md Mahamadul Hassan ( Hassan Bhai), Member, Central Community Based Organisation; 29 April

## Palliative Care Assistants

34. Kulsum, Agaregaon; 29 April, 4 May
35. Sumi, Korail; 29 April, 4 May
36. Jahanara, Korail; 29 April, 4 May
37. Popy, Korail; 29 April, 4 May

38. Sumi, Korail; 29 April, 4 May
39. Shirina, Korail; 29 April, 4 May
40. Majeda, Korail; 29 April, 4 May
41. Shilpi, Agaregaon; 29 April, 4 May
42. Sajeda, Korail; 29 April, 4 May

## Volunteers ( Focus Group meeting on 30 April )

43. Halima Akter, Student
44. Rajiiea Sultana, Housewife
45. Joshna, Housewife
46. Rokeya, Assistant in an office
47. Fahmida, Housewife
48. Feroza, Housewife
49. Aysha, Housewife
50. Momotaza, Housewife
51. Mohammed Mahfuz, Student
52. Tethi Akter, Student
53. Shapna Akter, Student
54. Nasrin, Student
55. Khadiza, Housewife
56. Komala, Housewife
57. Laal Banu, Housewife

## Local Supporters Fundraising for the Project

58. Razu, Keeps a donation box in his shop (29 April)
59. Mahfuz Rahman, Keeps a donation box in his shop (29 April)
60. Abdul, Keeps a donation box in his shop (2 May)
61. Tofayed Ahmad ( Liton Bhai), Keeps a donation box in his shop (2May)
62. Alauddin, Keeps a donation box in his shop (2May)

## Staff in other Projects in Korail Slum

63. Shimul Akter, BRAC Maternity Centre; 2 May
64. Md Zakir Hossein, Educo; 2 May

## Non Beneficiary/ Un Connected Residents of Korail Slum (General Public)

65. Md Shah Alam Almas Vandari 52, Resident for 20 years ; 29 April
66. Names Nazma 27, Resident for 7 years ; 2 May
67. Abdul Karim 52, Resident for 15 years; 2 May
68. Azizul Haque 55, Resident for 15 years; 2 May
69. Jamal Mia; 2 May

## Social Capital Survey involving Palliative Care Assistants

69- 219. 151 Residents randomly surveyed using a structured questionnaire