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# Palliative care for slum populations: A case from Bangladesh

▶▶ As is the case in other developing countries, palliative care remains a major unmet need in Bangladesh. **Shahaduz Zaman, Nezamuddin Ahmed, Mamun-Ur Rashid** and **Ferdous Jahan** present a project undertaken to provide community-based palliative care to people living in two slum towns in Bangladesh.

▶▶ Inhabitants of Korail Slum living under an open sky in March 2017. The slum has experienced two major fires – in March this year and December 2016 – each of which destroyed several hundred shanties.

RAKIB HASAN/ALAMY

**T**he World Health Assembly has recommended that countries 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.<sup>1</sup> Bangladesh is in Stage 3a on the world palliative care developmental map, which means that some isolated palliative care services and training provision exist here.<sup>2</sup> However, a recent situation analysis revealed that although Bangladesh has approximately 600,000 incurable patients at any point in time, at present it has only six capital city Dhaka-based comprehensive palliative care programmes, which altogether served fewer than 1,500 patients in 2013.<sup>3</sup> The same study found that 75% of cancer patients experienced pain, and more than 90% of health professionals did not have any training in pain management or palliative care.

In 2007, Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka, which is the only medical university in the country, recognised palliative care as one of its key objectives and began to provide some rudimentary services. A Centre for Palliative Care (CPC) was formally established in 2011. This was a most remarkable breakthrough among the few palliative care initiatives in Bangladesh. In 2011, 15 inpatient beds were created in the centre. In 2015, the CPC initiated a pilot project to extend its activities into two urban slums in Dhaka, the Agargaon and Korail slums, in collaboration with the Worldwide Hospice Palliative Care Alliance (WHPCA).

### Goals of the slum palliative care project

Of Bangladesh's population of 160 million, it is estimated that 2.23 million people – many of them elderly – are currently living in over 9,000 slums.<sup>4</sup> Slum life is characterised by cramped

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conditions, lack of access to clean water, poor drainage, flooding, infections, exploitation and extreme poverty. The pilot project initiated by BSMMU mainly focused on the provision of palliative care to elderly people in the Agargaon and Korail slums. It was jointly funded by BSMMU and the WHPCA, with additional contributions from the Rotary Club of Metropolitan Dhaka and the Afzalunnessa Foundation. It was taken forward through a community-driven, public health approach, with the following specific goals:

- To undertake a situation and needs analysis of older people, and their caregivers, who require palliative care and assess the current care provision by family, community members and relevant organisations.
- To identify and forge partnerships with community health workers, grassroot networks for health and older people, and other relevant organisations working in the two urban slums.
- To undertake a sensitisation programme to increase understanding and awareness of palliative care in the slums, including developing an activist group of older people.
- To print 200 copies of the Palliative Care Toolkit in Bengali – the toolkit was originally produced in English by Help the Hospices (now Hospice UK) in 2008.
- To train six to eight Palliative Care Assistants (PCAs) from the communities to provide care and refer for further medical care, using the Palliative Care Toolkit.
- To establish a homecare outreach palliative care service in the two slums, comprising nursing staff and trained assistants.
- To provide treatment and support to 100 palliative care patients and their caregivers/family members.
- To demonstrate an effective model of palliative care for older people in an urban slum, through the production of a final evaluation report.

At the beginning of the pilot project, CPC Bangladesh conducted a rapid situation analysis

**Table 1.** Support and care provided by the project

Category	Services and support provided	Frequency
Health support	• Regular follow-up • Medicine supply • Emergency health service • Routine check-up	Regular basis
Care support	• Wound care, helping in shower, nail cutting, hair cutting, home cleaning etc. • Counselling to shocked/bereaved family members	Based on necessity
Food support	• Rice (5 kg) • Peas (2 kg) • Sugar (1 kg) • Salt (1 kg) • Edible oil (1 kg)	Monthly
Festival support	New clothes, blankets, special food	During festival time
Additional support	Exercise machines, cataract operation and other medical services	Based on necessity



▶▶ One of the pilot project's eight Palliative Care Assistants attends to the palliative care needs of an elderly woman in Korail Slum, with her colleagues from the Centre for Palliative Care.

CENTRE FOR PALLIATIVE CARE/BANGABANDHU SHEIKH MUJIB MEDICAL UNIVERSITY

to select programme beneficiaries and develop an operation strategy. Activities began by meeting with teachers and committee members of two schools in the slums to discuss the objectives of the project. During the meetings, support was sought for introductions to the slum dwellers, and experiences of working in the slums were shared. The feasibility of the project activities was also discussed and feedback obtained. Following the meetings, a two-day sensitisation programme was organised with people in the two slums, targeting the parents of the students. The PCA recruits underwent a thorough training programme on palliative care, following a structured curriculum: six weeks of classroom teaching, followed by six weeks in the hospital ward and then 12 weeks spent mostly on home visits in the slum under supervision.

### Support and care provided by the project

Eight young women were trained as 'vanguards', and took on the role of 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. Table 1 (see page 157) shows the

support and care provided by the PCAs to the patients. Various medical services, including emergency health services, were provided by nurses and doctors.

### Evaluation of the project

An independent evaluation of the project was carried out one year after inception by a local research organisation called Development Research Initiative (dRi) under the supervision of Shahaduz Zaman, a research fellow at the University of Glasgow. The evaluation study was carried out using various qualitative techniques, including in-depth interviews with project beneficiaries, key informant interviews with project managers and community leaders, and focus group discussions with PCAs, complemented by demographic, medical and service-related quantitative data reviewing secondary sources. Qualitative data were analysed manually using framework approach. The evaluation had three dimensions: the management of the project; the effects of the project on the beneficiary's life; and sustainability.

A total of 106 patients and their families benefited from the project during the first six months. The majority (62.3%) were female; the



average age was 66.8 years (female patients) and 71.9 (male). Eighty per cent of the beneficiaries were illiterate, with an average income of US\$180 per month. The patients received essential medicines, various forms of care and food assistance. The beneficiaries were selected through a Rapid Situation Analysis by consulting with community-based organisations in the slum and involving local adolescents. Selecting appropriate beneficiaries was challenging in the beginning. The evaluation showed that, initially, the project did not follow strict criteria for selecting beneficiaries. As time progressed, the project personnel endeavoured to correct their own mistakes and became more effective in targeting their resources. However, in the context of extreme poverty, and a complete lack of health services, it became very difficult for the project to determine the inclusion criteria for the palliative care beneficiary – this is something that demands a discussion in the broader palliative care community.

In the beginning, the people within the community were uncooperative. In addition, due to the absence of previous relevant experience, the project personnel had to proceed through a 'learning by doing' approach. Initially, the PCAs

► Today, Korail Slum, Dhaka's largest, seen here across Banani Lake, is estimated to have in the region of 40,000 residents; most of them live in shanties constructed from bamboo frames with corrugated tin walls and roofs.

PALASH KHAN/ALAMY

experienced some resistance to their work in the community, but they are now largely accepted and play a pivotal role in the project. The beneficiaries hold the services PCAs provide to them in high regard. The beneficiaries were found to be highly satisfied with the medical, social and food support provided to them by the project. As one elderly male patient said of himself and his wife:

*'Both of us are old 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.'*

The study revealed that almost all the beneficiaries found that their self-confidence and self-esteem increased after joining this project. During one discussion, a female beneficiary observed:

*'I have confidence now ... nothing will happen if my son or daughter do 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 also has changed some community perceptions. For example, one shopkeeper remarked:

*'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.'*

Questions remain, however, about whether the project is sustainable. The PCAs are the key movers of the project and much depends on them. When asked what will happen if they marry and leave the slum, most echoed this person's view:

*'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 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.'*

## Key points

- ▶ Bangladesh has approximately 600,000 incurable patients at any point of time. At present, it has only six capital city Dhaka-based comprehensive palliative care programmes, which altogether served <1,500 patients in 2013.
- ▶ In 2007, Bangabandhu Sheikh Mujib Medical University – the country's only medical university – recognised palliative care as one of its key services and established the Centre for Palliative Care (CPC). In 2015, the 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.
- ▶ A mixed methods evaluation of the project after one year reveals that it created highly positive impacts on the lives of the beneficiaries and the wider community.
- ▶ Nevertheless, the sustainability of the project remains in doubt while it continues to depend on external resources.
- ▶ In a country in which almost all the available palliative care services have taken institution-based approaches, following Western models, this community-based initiative in Bangladesh has much to commend it and could serve as a public health model for palliative care in other resource-poor settings.

Nevertheless, the project continues to rely on external resources. Its overall budget for the first year was approximately £5,000. According to many project staff, the patients to whom they are providing treatment and services are becoming dependent upon them. They fear that the beneficiaries will be left helpless if the project is closed. Community participation in the project is also still quite limited, but just one year in, it would be premature to make judgements on its future viability.

## Conclusions

There are enormous challenges in running a slum-based community palliative care project of this type, characterised by a highly mobile population, informal power structures and high levels of uncertainty. Yet 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 and appear to have benefited physically, socially, psychologically and spiritually – reflecting the component parts of the project. The community volunteers who were chased away by slum dwellers at the beginning of the project are now made welcome in people's houses. The objectives of palliative care are now known and appreciated by the community.

Globally, there are very few examples of community oriented end-of-life care in resource-poor settings such as this. It is widely argued that perhaps the most refined version of the model is The Neighbourhood Networks in Palliative Care (NNPC) in Kerala, India.<sup>5,6</sup> The NNPC is an attempt to facilitate a sustainable, community-led service capable of providing palliative care to all those in need, with limited resources. 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 in the slum may have much to teach us ■

### Declaration of interest

The authors declare that there is no conflict of interest.

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