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DIGNIFYING LIFE  
THROUGH  
PALLIATIVE CARE  
DHAKA, 2018

## Roundtable Discussion on Dignifying Life - a call for public awareness and policy inclusion

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Azimur Rahman Conference Hall, The Daily Star Centre

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Ayat Skills Development Centre and The Daily Star organized a roundtable titled "Palliative Care: A Call for Public Awareness and Policy Inclusion" on January 6, 2018. Here we publish a summary of the discussions.

# Dignifying Life Through Palliative Care

Nusrat Aman, Chief Patron, Ayat Skills Development Centre



Ayat Skills Development Centre was initiated with the commitment to contribute to youth development in the country. Providing enhanced specialized training to nurses is a part of this effort. In this program, we have placed special emphasis on training nurses on palliative care.

This is related to our effort to create a 360 degree approach to the movement of palliative care in Bangladesh. We are also endeavoring to create mass awareness about palliative care.

There is huge need for palliative care in Bangladesh but we do not have adequate facilities and manpower to cater to this demand. The government alone can't fulfill the need. Therefore, private enterprises should come forward and work in tandem with the government to take forward palliative care in Bangladesh.

Dr. Bimalangshu Ranjan Dey, Associate Professor, Harvard Medical School



Our healthcare system is disease-centred, not patient-centred. We are competent at providing medical services as far as our medical knowledge advances. But there are conditions or diseases where our medical knowledge falls inadequate in helping us best serve

seriously or terminally ill patients. It is not just about offering them a pain-free existence but the opportunity to live their life in as much comfort as possible. The suffering can be both physical and emotional, and palliative care addresses both. We also need to note that end of life care is a part of palliative care, not the whole of it.

Death is a fact of life. We need to change our perception about preparing for death. If you ask a terminally ill person about death, you will learn that the scariest thing about death is not the afterlife but the suffering of the dying process.

Palliative care intends to attend these seriously ill patients by improving their quality of life as well as the quality of life of their family members. In medical schools we learn a lot about mortality or pain management, but we don't talk about it. We should start fruitful discussions on these issues. The doctor comes to a diagnosis and prescribes medicines. The patient has no ownership in the treatment process. This attitude is gradually changing: a constructive partnership between a physician and their patient is now an emerging approach to treatment. When a patient's condition is incurable, try to improve their quality of life. You need to have the ability to anticipate, prevent, diagnose and treat every kind of ailments suffered by the patient; physical, emotional, psychological, spiritual and intellectual distress and anguish.

A doctor needs to ask four questions to the patients before beginning their treatment. First, are they aware of the diagnosis? What are their fears? What are their priorities? Many might answer that they don't care about how long they live but they want to have a quality life span. The fourth question should be what outcomes will not be acceptable to them. Many will say that they don't want to be put in the ICU or be resuscitated and so on. These wishes should be respected.

With the help of the Ministry of Health, we have done a lot of collaborative projects at the Dhaka Medical College Hospital, including bone marrow transplant programme and nursing training programmes. The Government of Bangladesh, particularly the Ministry of Health and its minister Mohammed Nasim, should be given a lot of credit for taking forward the health care system in Bangladesh. I hope he will be positive about this mission and will take initiatives to include pain management and palliative care in the curriculum of medical and nursing education.

Dr. Bushra Alam, Senior Health Expert, World Bank



As we move into a middle income status the aspiration of people about medical care also increases. Earlier the country invested a lot in reducing maternal and infant mortality and controlling communicable diseases like Malaria,

TB and other. Now we are seeing some investment in palliative care, even from the private sector.

The walkathon organized by Ayat on January 5, 2018, was a great initiative for raising awareness about palliative care and involving community in the effort to popularize this issue.

We need to take a multi-pronged approach towards palliative care and need to look at it from the perspective of patients and their families. A family undergoes a lot of emotional and family stresses when a member of the family suffers from serious illness. It is also a huge economic burden for them. Involvement of the community, particularly young people, in palliative care is very important because in many cases patients need to be provided care at their home.

Dr. Rumana Dowla, Founder, Bangladesh Palliative and Supportive Care



It is globally recognized that palliative care is one of the crucial constituents of comprehensive health services. In 2014 WHO assembly resolution called upon its member states to develop access to palliative care as a core element of health system and emphasize on primary healthcare and community-based care for inclusion of palliative care.

In order to achieve SDGs, palliative care needs to be brought under universal health coverage. We need to bring changes in national and local legislation and policies with reference to the WHO policy guideline on improving access to rational use of pain management medicines. Greater progress is needed in terms of service delivery and access to oral morphine for pain relief in primary care. We need a national policy guideline for palliative care and make amendments to our narcotic law to make it easier to take care of patients with severe pain. We need to train health professionals in palliative medicine and include palliative care in medical curricula.

I will urge our Honorable Deputy Speaker of the Parliament to look into this issue and help us in getting a national guideline on palliative care.

Dr. Anne Marie Barron, MGH and Simmons College of Nursing, Boston, USA



Every nurse is a palliative care nurse. When nurses and physicians are fully attentive to experiences of their patients and hold them in place of regard and care, patients can tell us what's most important to them. That relationship creates the opportunity for patients

to reflect deeply. We do not have much understanding about the power of growth at the end of life, the power of growth in the context of serious illness. We can talk openly and create opportunities to have conversations about the illness before opting for treatment.

Dr. Moarraf Hossen, Director, National Institute for Cancer Research and Hospital



Seventy percent of the patients coming to our cancer hospital are at a very advanced stage. Many can't continue the treatment due to financial constraints, lack of continuous residence facilities in Dhaka and misconception that

cancer has no treatment. These people need palliative care. If we can form palliative care units in hospitals where people from different age and professional groups, such as students, Imams, social activists will volunteer with medical professionals, we can bring relief to the sufferings of seriously ill patients. These volunteers will be trained and monitored on a regular basis. We can start this process on a pilot basis in 20 district hospitals in the country. We need to remember that every person contributes to the development of a society and therefore everyone deserves a dignified death.

## RECOMMENDATIONS

- ❑ It is absolutely essential to embed palliative care in our national health policy and sectoral budget plan
- ❑ Curriculum development for pain management and palliative care is essential for both medical and nursing courses
- ❑ Our healthcare system should be 'patient-centred, instead of disease-centred'
- ❑ Media involvement and community engagement is crucial for greater understanding of the importance of palliative care among the general public.
- ❑ Youth population should be actively engaged in awareness building and supporting of programmes related to palliative care
- ❑ Both public and private sectors should come forward and engage themselves to promote impactful social initiatives such as the comprehensive palliative care programme run by Ayat Skill Development Center.

Prof Swapan Kumer, DMCH



Local hospitals with junior doctors can't address the need of NCD patients. These patients are generally referred to tertiary level hospitals. Unfortunately, the number of tertiary level hospitals in the country is very low. Therefore, on the one hand, we should

introduce more courses on NCDs in our medical curriculum and on the other, community engagement in treatment of these diseases needs to be ensured through palliative care programmes.

The use of drugs for relieving pain is also a crucial part of palliative care. The drug (morphine) should be made available at a cheaper rate. Our media can also play a big role in creating awareness about palliative care.

Dr. Sathyanarayanan Doraiswamy, Chief, Health Programmes, UNFPA Bangladesh



We need to put women and girls at the centre of palliative care. We need to take a multi-disciplinary team approach for providing palliative care. We need to talk about how to deliver home-based care and how to provide services through the most decentralized facility that

we have in a community clinic. We need to think how our community health care providers can be trained in terms of providing these services.

We have to also look at palliative care from a health system perspective. We need strong leadership and governance from the Health Ministry in this regard. There should be strong legislative support for providing palliative care. We should also think about how we can make these services available within various tiers of the health system and where the funding for these services will come from.

Dr. Arif Mahmud, Asst Director, Medical Services, Apollo Hospital



According to the Economist's 2015 Quality of Death Index, Bangladesh stands at 79 out of 80 countries. Therefore, it's high time to start palliative care in the country. The government alone can't provide palliative care to the huge number of

patients. The private sector should come forward in this regard. We should also develop home-based care which will reduce the burden on hospitals. Finally, there should be massive awareness campaigns to popularize the idea of palliative care in Bangladesh.

Prof. Mohiuddin Khan, Head of Hematology, DMCH



The demand of palliative care is increasing rapidly but we do not have enough facilities to cater to a large number of patients. We also don't get enough funds to expand our services. I would urge the government to increase allocation for palliative care facilities.

Involvement of community is also very impor-

tant in this regard. Lastly, we should include more courses on palliative care in our medical curriculum.

Dr. Akhil Ranjan Biswas, Associate Professor, BMT Unit DMCH



We need to provide palliative care to the patients who can't be cured and who can't afford the cost of treatment. Therefore we should have adequate palliative care facilities in place all over the country. It should be recognized in our national health care system.

Shuriya Begum, Registrar, Bangladesh Nursing and Midwifery Council



In Bangladesh, there are so many specialized hospitals and doctors but we do not have specialized nurses. We do not recognize field-specific expertise of nurses. We can reduce the burden on doctors by developing specialized nurses, particularly providing them

training on palliative care.

Dr. Judy Beal, Dean, Simmons College of Nursing, Boston, USA



Nurses are key to palliative care. We don't only need more nurses but we need better educated nurses whether through formative education at nursing school or by continuing education at the professional level. We, the American Association of Colleges of Nursing (AACN), are fully committed to offering palliative care as part of the nursing curriculum. In fact, AACN has just come out with a policy statement stating that palliative care should be one of the four pillars of baccalaureate education in the USA.

Jocelyn Hulbert, Massachusetts General Hospital, Boston and Simmon College of Nursing



We are going to train nurses on palliative care which includes pain management, symptom management, how to care for families and so on. It is important for nurses because without understanding these issues, they will not be able to communicate the needs of patients to doctors. You need formal education that trains you to say the right things and understand what you can offer as treatment.

Nisha Wali, Massachusetts General Hospital, Boston and Simmon College of Nursing



The power really is with the nurses at the bedside of patients. Nurses are able to interact the most with patients. It is important to empower them as advocates and leaders in conversations on palliative care.

Md. Fazle Rabbi Miah, Deputy Speaker, Bangladesh Parliament



I must thank you for the effort to popularise palliative care in Bangladesh. This is a gigantic task and everyone should join this initiative.

Palliative care is particularly needed for rural people who can't afford to visit Dhaka on a regular basis for check-up and treatment. I would request you to organize more such discussions at the local level, at least at the divisional level, and engage young people of those areas. I will do my best to help this effort.

Rokia Afzal Rahman, Former Advisor to the Caretaker Government



As a business person, I have also been involved in development works, particularly development of women entrepreneurs. Today I am here to commit myself to the slogan of today's roundtable: Dignified Life. I will be with you and I am sure many people in business also share the same feeling. I have learnt a lot today. I am very happy to see the honourable Deputy Speaker in this discussion. Just one proposal from him can move mountains.

Yusuf Ahmed, Volunteer for Bangladesh



This is a great initiative to engage young people in developing our health care system. At this roundtable, I have learnt of the importance of palliative care for critically ill patients.

Nurullah Hasan, Scholartroop Program



Scholartroop, which has the largest network of private university students in Bangladesh is happy to be actively engaged in the effort of Ayat to create mass awareness about palliative care. This is a great opportunity for young people like us to contribute to development of the country. We need to take this campaign to the national level.

Laila Karim, Senior Advisor to Ayat Skills Development Centre



Media in Bangladesh have played a great role in creating mass awareness about various social and health issues, such as child marriage, violence against women, immunization and so on. I would request them to take up the issue of palliative care and make people aware about its importance.

Tahsin Aman, Chairman, Ayat Skills Development Centre & Vice Chairman, Aman Group of Companies



Bangladesh is a land of vibrant entrepreneurs and successful business houses and groups. Just the way our business groups make it their mandate to do well in businesses, I urge the business groups to also make it their mandate to do good for the society. Private enterprises and business entrepreneurs should come forward and implement the smartest and effective way to engage their available resources for the most measurable social impact.

I want to thank the team of Ayat, Mass General Hospital and Simmons College for arranging such a comprehensive week long and impactful program on Palliative Care. I want to thank The Daily Star and honorable guests and participants for a very vibrant roundtable session today.

In addition to our awareness programs, our nursing certification program will create opportunities for nurses to work with top national and international experts of the field. After successfully completing the training, they will be certified by the American Association of Nursing Colleges in the Core ELNEC Train the Trainer Program.