DIGNIFYING LIFE

A Call for Comprehensive
Cancer & Palliative Care
in Bangladesh

AYAT EDUCATION

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DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE

A Call for Comprehensive Cancer & Palliative Care

Published by :
AYAT Education
Taher Tower (5th Floor),Plot # 10
Gulshan North Circle,Gulshan-2
Dhaka-1212, Bangladesh

Coordination : Laila Karim
Illustrator : Kanakodaya Barman
Compilation : AYAT Education Team

Photo courtesy :
AYAT Education Team
Dhaka Medical College Hospital (DMCH)
Bangabandhu Sheikh Mujib Medical University (BSMMU)
*Collected

January 2019

ISBN 978-984-34-5975-6

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Ministry of Finance
Government of the People's
Republic of Bangladesh

Abul Maal A Muhith
Minister

8 October 2018

Message

I am pleased to learn that Ayat Education is going to publish a commemorative issue on its journey towards a 'Dignifying Life-A call for Comprehensive Palliative Care in Bangladessh'. I wholeheartedly endorse the call that they are making in reaching out to the population of Bangladesh through a structured nationwide program covering all the divisions of Bangladesh.

I had the opportunity to attend the national program held in Dhaka in January from 5th to 12th, 2018 and also the recently held first divisional program in Sylhet from 6-12th September 2018 focusing on 'Dignifying Life- International Conference on Cancer and Palliative Care for Sylhet, Bangladessh'. Both the programs set examples in mobilizing youth and community people on this emerging but critical health care issue and also were successful in attracting the national and local health professionals. The technical sessions like formation of 'tumor boards in hospitals and performance of critical surgery for female cancer patients, resource mapping of local capacity' by the experts from Havard Medical College and Massachusetts General Hospital (MGH) and training for the nurses by Simmons College of Nursing, USA truly demonstrated how technical cooperation with volunteerism of the global and local experts works well.

I heartily welcome the joint effort by Harvard Medical College, Massachusetts General Hospital & Simmons College of Nursing of USA in designing and organizing this

program. The man behind this unusual initiative is a son of the soil Dr. Bimalangshu R. Dey, MD, PhD, Associate Professor of Medicine at Harvard School of Medicine, Ms Nusrat Aman of Ayat Education in Bangladesh joined hands in organizing the program in all the divisional headquarters of Bangladesh. She deserves our sincere congratulations.

The Program holds a week long workshop in each venue where trainees take palliative Care of Cancer patients in the hospitals. Cancer, we know, is a cruel killer and was believed to be untreatable. Now, of course, cancer is curable if diagnosed early. Probably those patients who are not curable may be given drugs for reducing sufferings. But a good number are beyond drug treatment and for them only relief can be provided by palliative care.

As I attended the two workshops, I realized that palliative care is unknown in our country and possibly in most developing countries. We have set up old age homes but there old people only comfort each other and possibly their relations occasionally brighten them up by paying them visits.

The Sustainable Development Goals set out for the health sector, Goal number 3 seek to emphasize healthy lives and promotion of well being for all at all ages, access to quality health service and training of health professionals at all levels. Surely these are essential for achieving the goal for the helath sector.

I hope, Palliative Care will get due attention at the policy level. It will surely get required financial allocation from the government in the next fiscal year. This is an issue that will be touching every life and family in the coming days. Bangladesh needs to be ready for it.

I wish every success of this great program of Ayat started with the slogan 'Dignifying Life-A call for Comprehensive Palliative Care in Bangladessh'.

Abul Maal A. Muhith, MP 8/10/18

National Professor of Bangladesh

It's a great pleasure for me to write a message for the commemorative publication on the just completed "International Conference: Cancer and Palliative Care for Sylhet, Bangladesh" held from 6th to 12th September 2018.

I am fortunate to attend the program which is one of the urgent need of today's' health professionals. Because of increased longevity, we are living up to 71 years plus. And as you go aged you go to an active stage of cancer years range. Besides, because of the modern and super specialty treatment of any form of cancer gives a long post-therapy survival period. We know cancer is a deadly disease - treatment management is time-consuming, costly and very expansive & demoralizing for patients, families & friends and very unpredictable recovery progress. But the good news is that our ever enthusiastic cancer specialists and researchers are behind it – finding out ways & means to tackle this deadly disease. We are glad & thankful to the persons or teams who have arranged & sponsored the seminar at my hometown Sylhet. The organization responsible is Ayat Education – Nusrat Aman & Tahsin Aman and the team for arranging this program.

With the sponsorship & initiative, this young dedicated couple beside other responsibilities has taken active participation for providing important comprehensive palliative care in our country. All categories of health service professionals are benefited and will be benefited throughout their professional career.

The Ayat Education is lucky to have with them Dr. Bimalangshu Dey, MD, Ph.D. ('Bimal' to me) is an Associate Professor of Medicine at Harvard Medical School and a Physician in Bone Marrow Transplantation Unit at the Massachusetts General Hospital, USA. For many years Dr. Bimal is working to strengthen cancer care in Bangladesh. He also with his Boston based dedicated team of doctors and nurses are giving treatment, performing cancer surgery and providing training to our nurses to be able to manage cancer patients needs and provide palliative care services. I am glad that this week-long program a highly trained expert team of nurses (who are ELNEC Boston trained) gave training to our nurses of different institutions.

This seminar is an awareness program as well as educational, experience gathering and sharing process. A large number of participants are from Dhaka and Sylhet, public and private institutions and also invited the guest of Sylhet community. And it was a grand gathering.

I hope with the support and collaboration of concern persons, philanthropic people and support of the government of Bangladesh this program will be a sustainable project. I also came to know that the organization is planning to do similar programs in other divisions of Bangladesh. I appeal to the government of Bangladesh, particularly the Ministry of Finance, Ministry of Health & Family Welfare, Ministry of Public Health and related Ministries Directorates and national and International NGOs to support and help this project. So that our cancer patient gets proper attention, management and they enjoy a dignifying life.

I wish a success of this program.

Prof. Dr. Shahla Khatun
MBBS, FRCOG, FCPS, FICS, ECFMG

From the desk of

Chairman

In January 2018, Ayat team hosted its first Palliative Care program in Dhaka. The title was "Dignifying Life Thru Palliative Care, Dhaka 2018". The comprehensive program included training programs for Doctors and Nurses, Community and Youth Engagement, TV talk shows, Roundtable Discussions involving health care professionals, youth and government officials. The program was such a success that, we are back again in September 2018 with our second Palliative Care program. This time in Sylhet.

In our Sylhet program, September 2018, we focused on Cancer and Palliative care. A group of Nurses and Physicians visited Sylhet to train medical professionals as well as to conduct patient reviews and surgeries. Ayat Education believes that effective collaboration is an essential key to make sustainable impact.

With much help from our international and national partners, experts and policy makers, we believe we will create a deep and significant impact in the society. Ayat Education envisions a society where every person has the right to a dignified life. Dignifying Life through education, empowerment, employment and healthcare.

I am grateful and would like to thank everyone concerned for supporting our initiative. Your participation in this conference is an encouragement for Ayat Education in its journey forward in creating a unique center of excellence for capacity building initiatives to enhance deeper impact in the society.

Tahsin Aman

From the desk of

Chief Patron

It is an honor to be able to present this commemorative publication on our initiative 'Dignifying Life through Cancer and Palliative Care' in Bangladesh. Ayat Education is committed to making a footprint in the Healthcare sector of Bangladesh through Capacity Building and knowledge enhancement of our health-care providers.

Since Last year, we have committed ourselves to bringing forward the pertaining issue of Palliative Care to the health professionals, patients, caregivers, policy makers and youths of our society. As a part of this commitment, we have launched the ELNEC certification course for nurses. ELNEC is recognized by the American Association of Colleges of Nursing as a comprehensive and effective certification program for Palliative Care. The 5-day course is taught by international experts and Master trainers in the field. Our aim is creating a pool of local master trainers who will be able to carry forward the training program and help implement the learning for the benefit of the patients. The first phase of this program was launched in Dhaka in January 2018, where we were able to successfully train and certify more than 100 nurses in the ELNEC curriculum.

Our efforts to address the need of expert and sensitized caregivers were reflected in the walkathon with more than 500 participants that indicates community engagement as an essential element of palliative care. The need for Policy intervention for palliative Care was established in the round table discussion with policy makers and national and international experts in the field.

As promised, the second phase of ELNEC training to the nurses held in Sylhet. Along with Palliative Care training, we are also going to conduct training on safe handling of chemotherapy. We firmly believe the people of Bangladesh will benefit greatly through these upskilling training programs for our nurses.

We wholeheartedly acknowledge the comprehensive support , guidance and encouragement of our national and international partners and friends.

We intend to continue this movement on Palliative Care to spread nationwide and hope to be able to contribute to including 'Palliative Care' into the health care system of Bangladesh.

Warm regards.

Nusrat Feroz Aman

PALLIATIVE CARE

Bangladesh Scenario

As one of the most-densely populated countries in the world, cancer awareness, prevention, early detection, diagnosis, treatment and palliation of patients inflicted with cancer are at a shockingly preliminary state for the people of Bangladesh.

On average, 70% of cancer patients in Bangladesh are diagnosed at a very late stage of illness, often in an incurable stage. The only possible intervention for these seriously ill patients with severe sufferings is palliative care.

Palliative Care Medicine has been designed to end the suffering and improve the quality of life of patients with serious, incurable diseases. Universal, institutionalized palliative care medicine is not widely available in Bangladesh, and currently non-existent in other divisions.

Source: http://www.palliativecare.my/vision/the-symbol

PALLIATIVE CARE

Facts & Figures

- Palliative care improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual.
- Each year, an estimated 40 million people are in need of palliative care, 78% of them people live in low- and middle-income countries.
- For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa.
- Worldwide, only about 14% of people who need palliative care currently receive it.
- Overly restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate pain relief and palliative care.
- Lack of training and awareness of palliative care among health professionals is a major barrier to improving access.
- The global need for palliative care will continue to grow as a result of the rising burden of noncommunicable diseases and ageing populations.
- Early palliative care reduces unnecessary hospital admissions and the use of health services.

Source: http://www.who.int/news-room/fact-sheets/detail/palliative-care

PALLIATIVE CARE

Poor access to palliative care

Worldwide, a number of significant barriers must be overcome to address the unmet need for palliative care:

- National Health Policies and systems do not often include palliative care at all
- Training on palliative care for health professionals is often limited or non-existent
- Population access to opioid pain relief is inadequate and fails to meet international conventions on access to essential medicines.
- A 2011 study (1) of 234 countries, territories and areas found that palliative care services were only well integrated in 20 countries, while 42% had no palliative care services at all and a further 32% had only isolated palliative care services.
- In 2010, the International Narcotics Control Board found that the levels of consumption of opioid pain relief in over 121 countries were "inadequate" or "very inadequate" to meet basic medical needs. In 2011, 83% of the world's population lived in countries with low to non-existent access to opioid pain relief (2).

Source: http://www.who.int/news-room/fact-sheets/detail/palliative-care

PALLIATIVE CARE

Other barriers

- Lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems

- Cultural and social barriers, such as beliefs about death and dying

- Misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life

- Misconceptions that improving access to opioid analgesia will lead to increased substance abuse.

Source: http://www.who.int/news-room/fact-sheets/detail/palliative-care

PALLIATIVE CARE

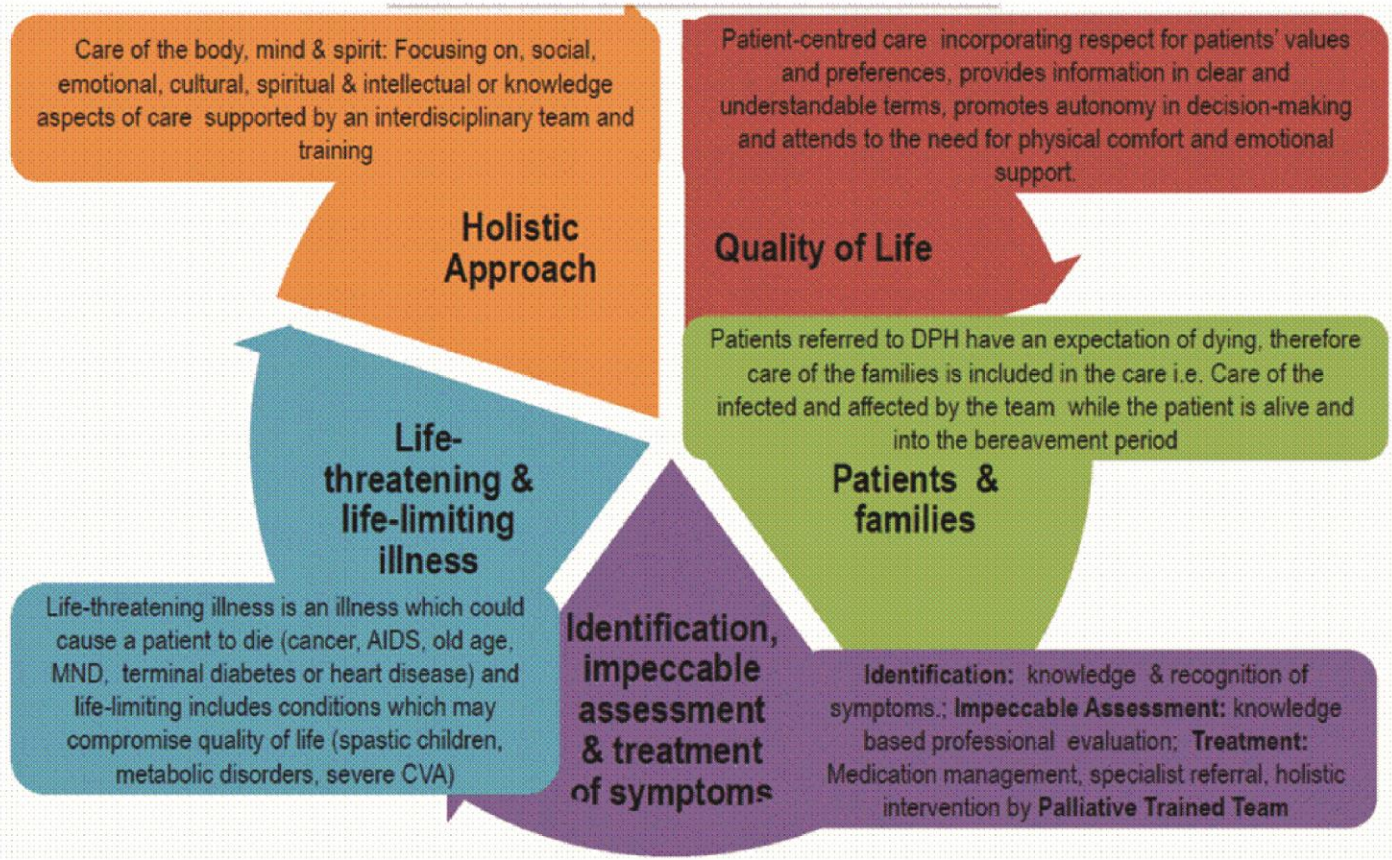
What can countries do?

National health systems are responsible for including palliative care in the continuum of care for people with chronic and life-threatening conditions, linking it to prevention, early detection and treatment programs. This includes, as a minimum, the following components:

- Health system policies that integrate palliative care services into the structure and financing of national health-care systems at all levels of care;
- Policies for strengthening and expanding human resources, including training of existing health professionals, embedding palliative care into the core curricula of all new health programs, as well as educating volunteers and the public;
- A drug policy which ensures the availability of essential medicines for managing symptoms, in particular opioid analgesics for the relief of pain and respiratory distress;
- Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services;
- Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups;
- Specialist palliative care is one component of palliative care service delivery. But a sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Providing palliative care should be considered an ethical duty for health professionals.

Source: http://www.who.int/news-room/fact-sheets/detail/palliative-care

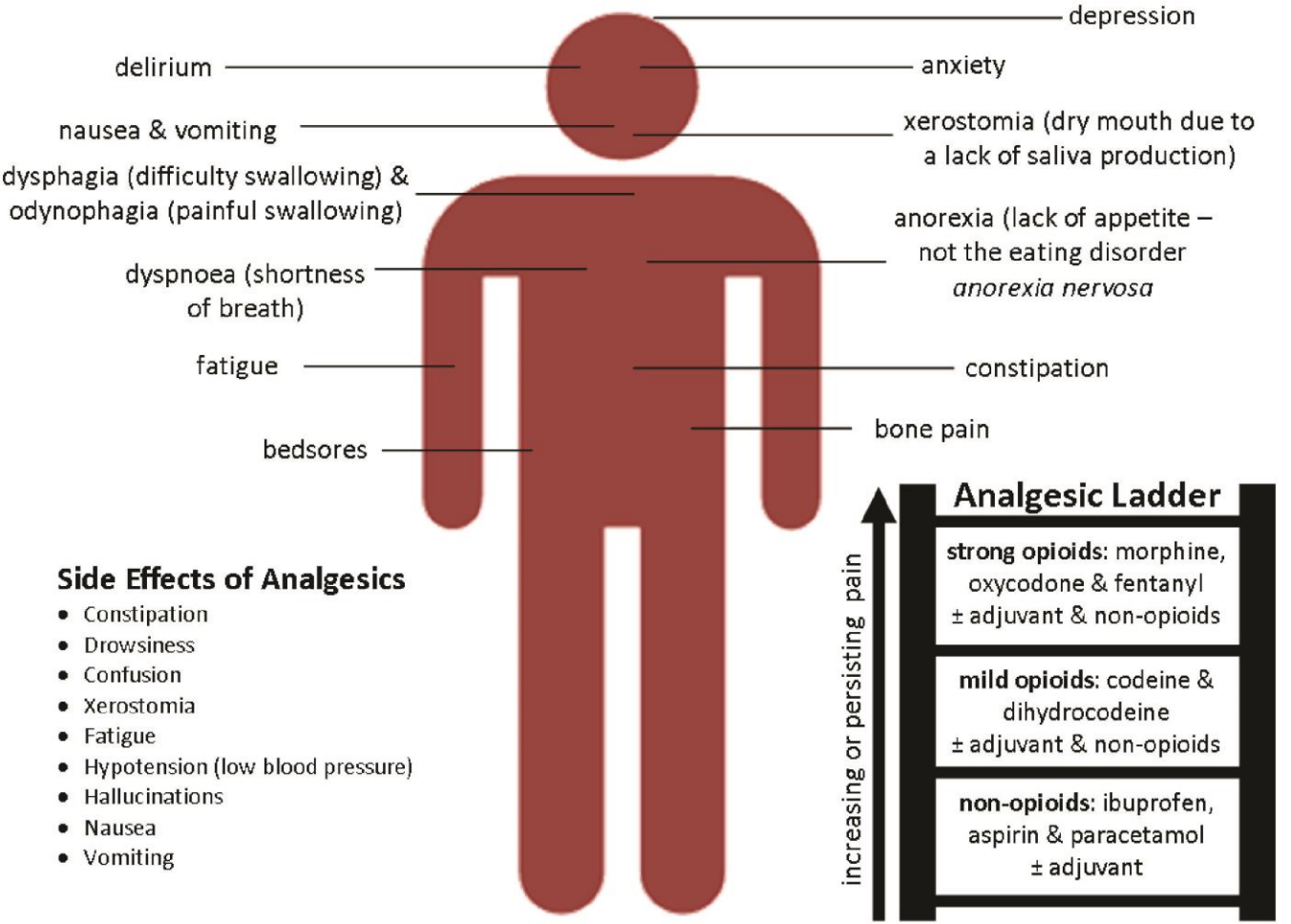
PALLIATIVE CARE



Source: www.thinglink.com

PALLIATIVE CARE

Key Symptoms



Side Effects of Analgesics

- Constipation
- Drowsiness
- Confusion
- Xerostomia
- Fatigue
- Hypotension (low blood pressure)
- Hallucinations
- Nausea
- Vomiting

Analgesic Ladder

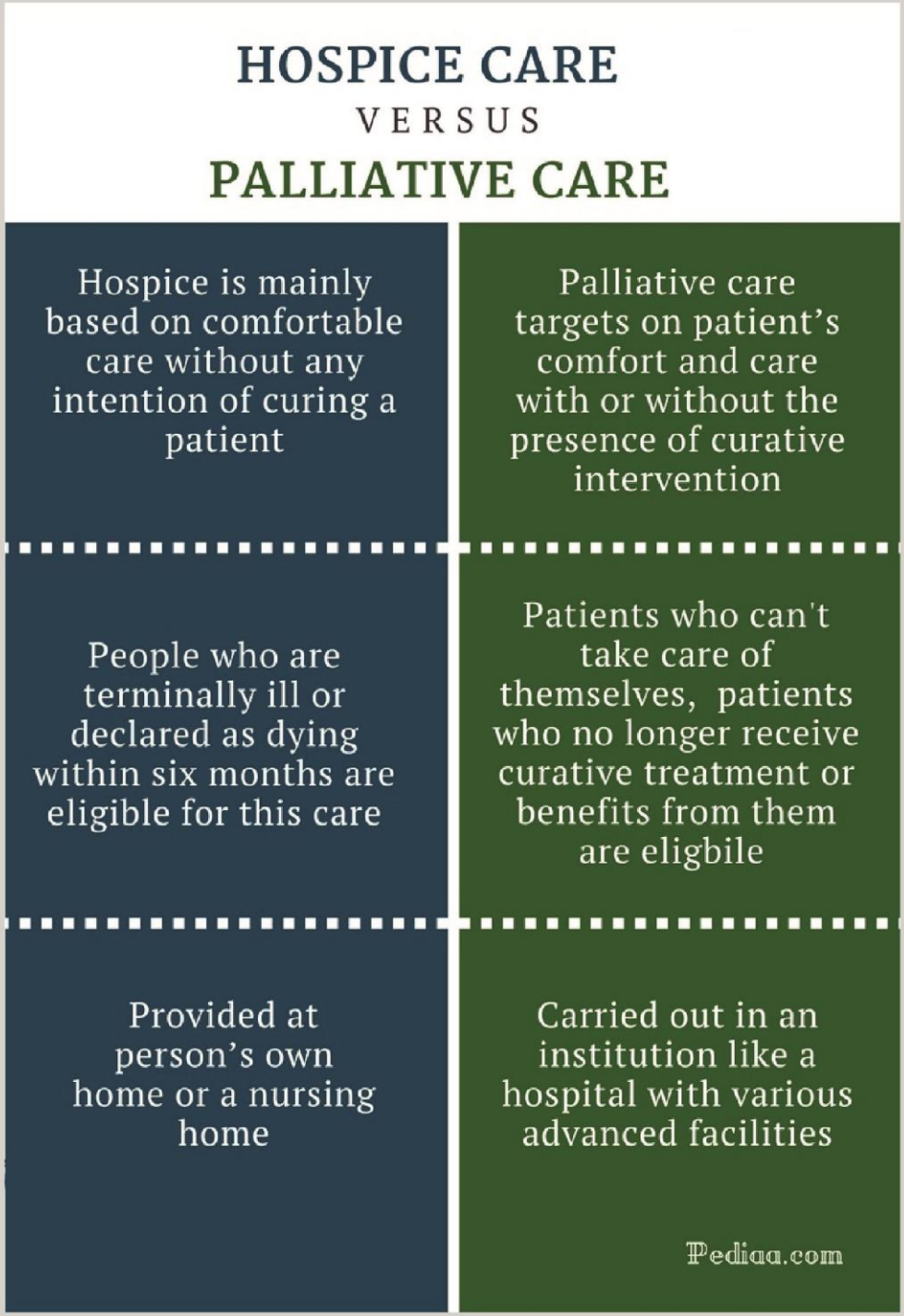
increasing or persisting pain

strong opioids: morphine, oxycodone & fentanyl ± adjuvant & non-opioids

mild opioids: codeine & dihydrocodeine ± adjuvant & non-opioids

non-opioids: ibuprofen, aspirin & paracetamol ± adjuvant

Source: www.pinterest.com


HOSPICE CARE
VERSUS
PALLIATIVE CARE
Hospice is mainly based on comfortable care without any intention of curing a patient
Palliative care targets on patient's comfort and care with or without the presence of curative intervention
People who are terminally ill or declared as dying within six months are eligible for this care
Patients who can't take care of themselves, patients who no longer receive curative treatment or benefits from them are eligbile
Provided at person's own home or a nursing home
Carried out in an institution like a hospital with various advanced facilities
Pediaa.com


WHY IS
PALLIATIVE CARE
IMPORTANT?
Financial catastrophe can be prevented
Suffering that can be avoided
Living longer
Providing hope
WWW.LIFEASKEDDEATH.COM/INFO

PRINCIPLES OF PALLIATIVE CARE MANAGEMENT

- **Scope of care:** Includes patients of all ages with life-threatening illness, conditions or injury requiring symptom relief from physical, psychosocial and spiritual suffering.
- **Timing of palliative care:** Palliative care should ideally begin at the time of diagnosis of a life threatening condition and should continue through treatment until death and into the family's bereavement.
- **Patient and family centred care:** The patient and family constitute the unit of care which should be managed as a whole.

Source: Parasuraman S., Senior Lecturer at AIMST University, Malaysia

Source: http://www.cancertherapyadvisor.com/palliative-care-physician-communication-and-patient-comprehension

Bangladesh health care sector :

Total Healthcare Expenditure is **merely 3.7%** of a GDP of **USD 221 bn. Allocation for healthcare sector in total ADP is only 6.2% for FY 2017-18**

Only 32 USD per Capita Healthcare Expenditure compared to India 75, China 420, USA 9,403 and UK 3,935 USD

Economic Intelligence Unit of The Economist has ranked 80 countries on the quality of healthcare facilities available. In that index, Bangladesh has ranked

- *79th on the Quality of Death Index*
- *80th on the Quality of Care Index*
- *80th on the Quality of Health Workforce Index*

Source: MoF, WHO, The Economist, The World Bank, 2017

Despite the rapid economic growth, people feel they are deprived of minimum healthcare facilities.
Bangladesh health care services are termed as inadequate.

64,434
Doctors

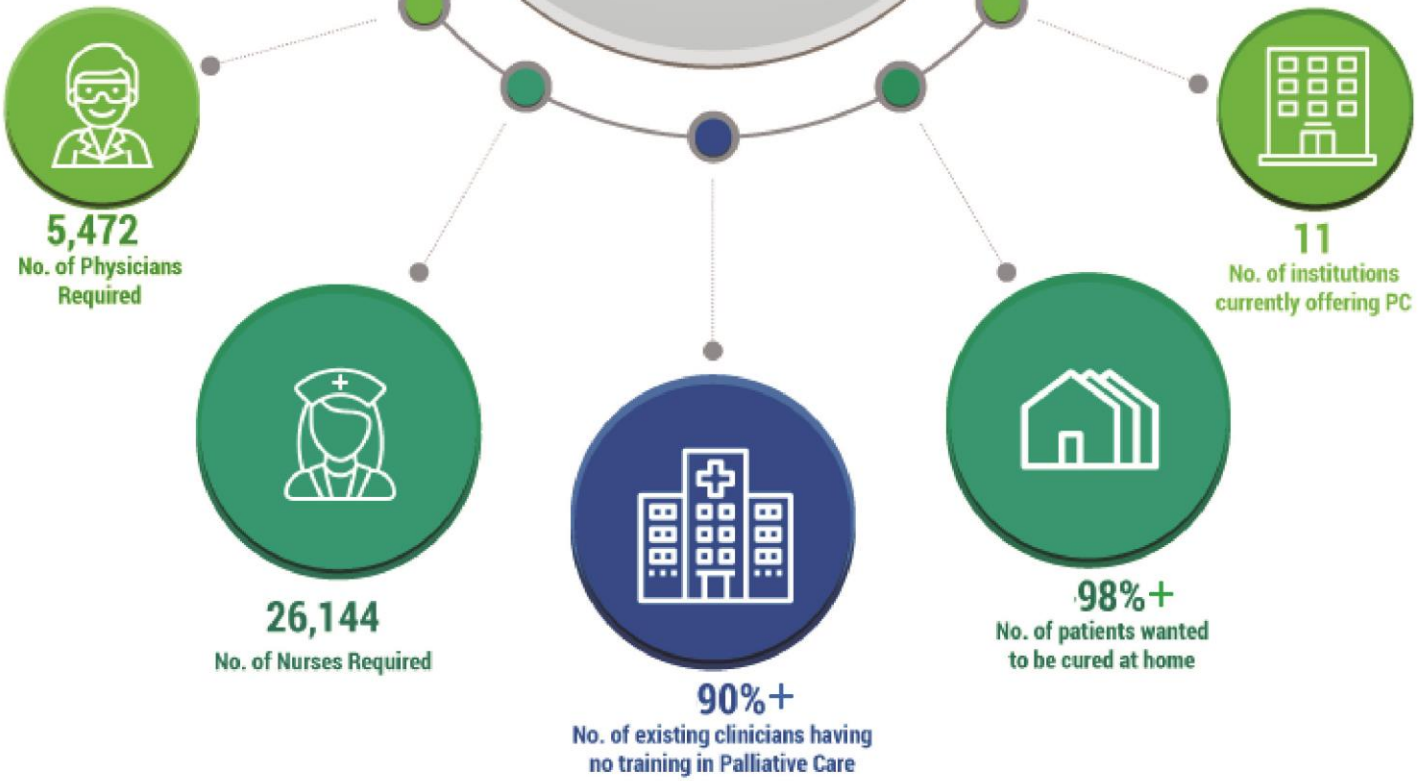
6,034
Dentists

30,516
Nurses

27,000
Midwives

In Bangladesh, health workforce ratio of Doctors to Nurses to Technologists is 1:0.4:0.2 while the WHO recommended ratio is 1:3:5
The National Health Policy 2011 identified Bangladesh as one of the 57 countries in the world suffering from a severe shortage in HWF (Health Work force). Qualified health personnel, like physicians, dentists, nurses and technologists, are insufficient in number, particularly in hard to reach rural areas. According to a WHO estimate, Bangladesh has a shortage of more than 60,000 doctors, 280,000 nurses and 483,000 technologists. Bangladesh also does not fare well compared to neighboring countries in terms of distribution of HWF across populations

Source: http://www.plancomm.gov.bd/wp-content/uploads/2015/11/7FYP_after-NEC_11_11_2015.pdf

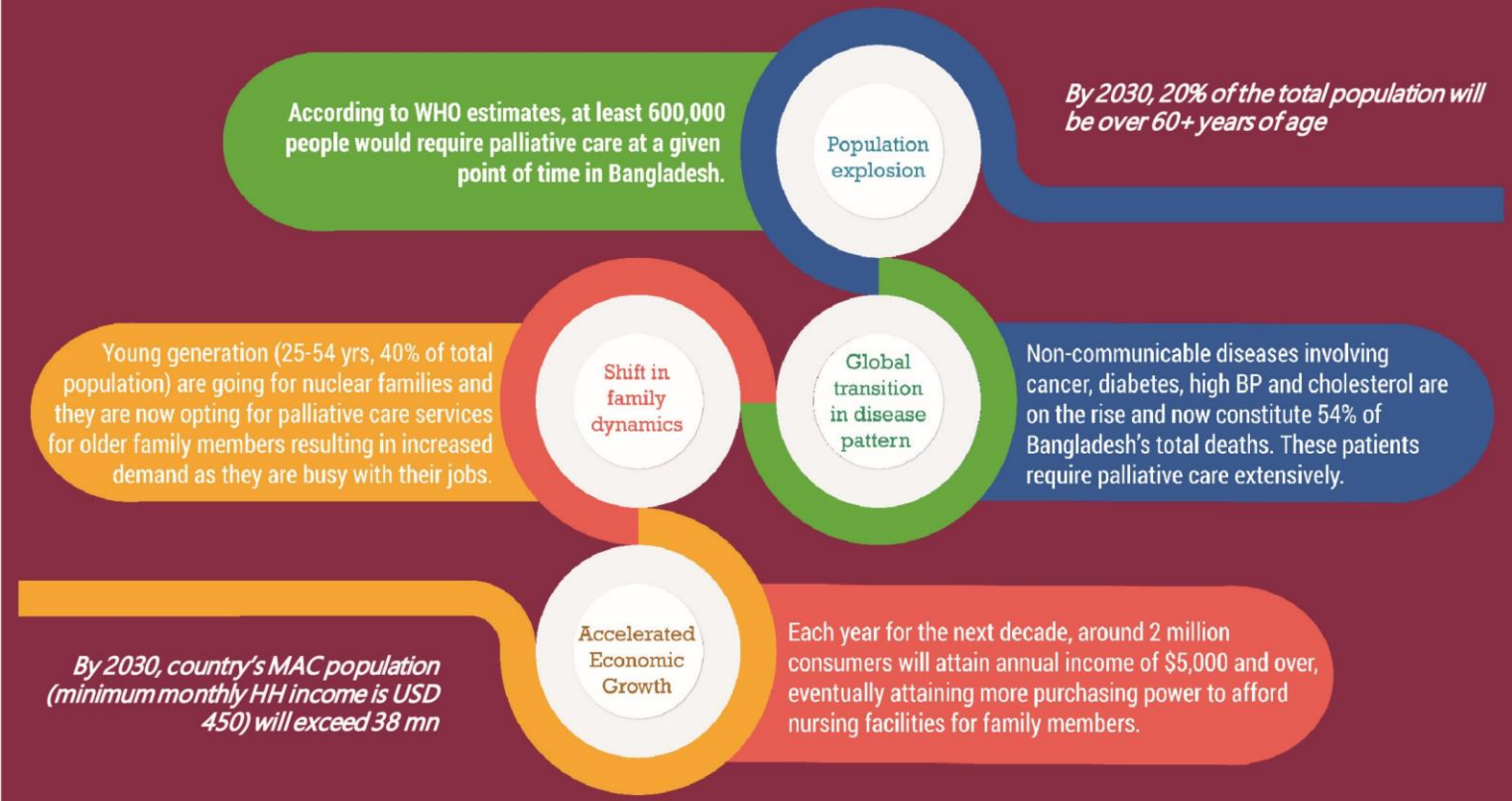


Palliative Care in Bangladesh at A Glance

Source: Bangladesh Medical Association, 2016-17

Lack of Infrastructure, Shortage of Health Workforce Dominating Palliative Care supply side dynamics

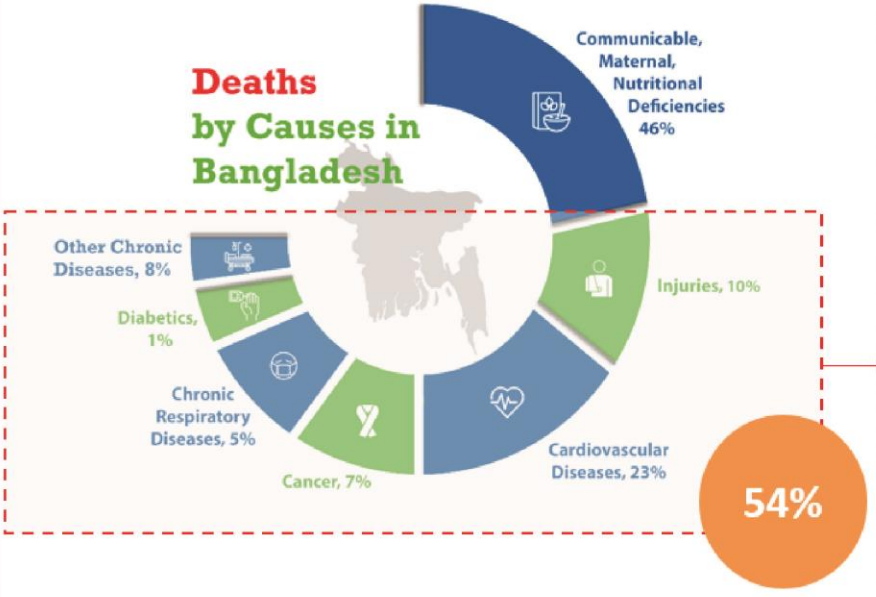
Source: LightCastle Primary Research Findings, 2016-17



Demand of Palliative Care is Ever-rising

Source: BCG, Bangladesh Medical Association, 2016-17

A Deep Dive into the Causes of Death stresses the Necessity of Palliative Care Facilities in Bangladesh



- There's a **sharp increase in death tolls due to non-communicable diseases**
- According to WHO, **~600,000 patients would require palliative care and support** annually in Bangladesh
- Besides, with at least 2 family members involved in each of these patients' care, a globally homogenous development of **palliative care could improve the quality of life of ~1,200,000 people nationwide, annually.**

Source: Bangladesh Medical Association, 2016-17

Increasing numbers of patients suffering from life -limiting major non -communicable diseases also strengthens this fact

~200,000 patients are newly diagnosed with cancer each year of which, 80-90% are in incurable state

~40,000 people die each year from chronic kidney diseases while **~30,000 more patients suffer from acute kidney failure** – all requiring palliative care along with the regular treatments

Every year, ~300,000 new patients are diagnosed with TB among whom, ~70,000 people die each year.

According to WHO, there are **~8,000 people living with HIV**

Among the ~12 million older people (aged over 60), **a few thousands may be suffering from some form of dementia**

Source: Bangladesh Medical Association, 2016 - 17

SDG 3 Emphasizing Healthy Lives and Promotion of Well-being for All at All Ages – Particularly in making Essential Meds Available for all and Health Workforce Capacity Development

SUSTAINABLE DEVELOPMENT GOALS

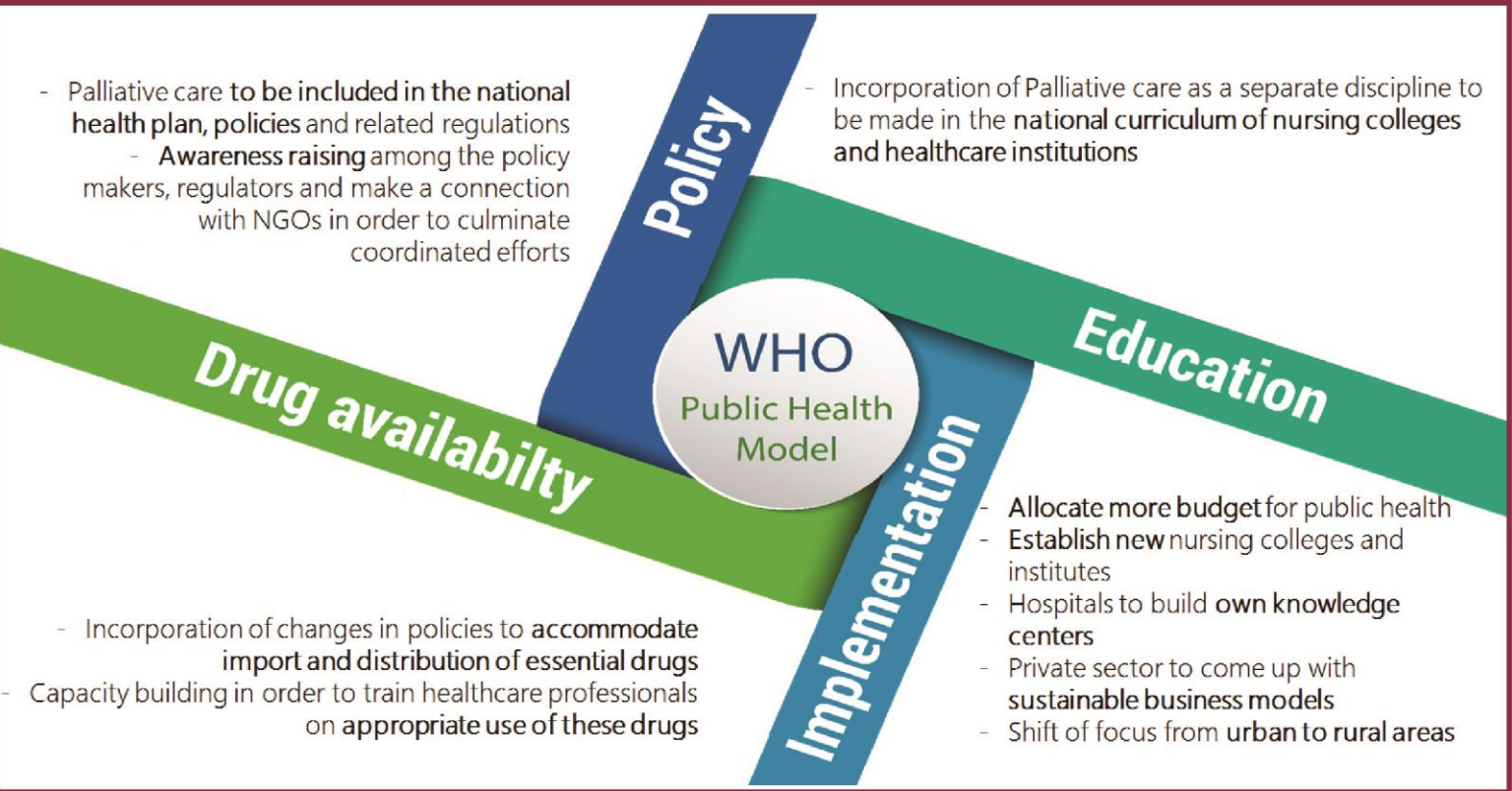
3 GOOD HEALTH AND WELL-BEING

3.8
Access to **quality essential healthcare** services and **access to safe, effective, quality and affordable essential medicines** and vaccines for all.

3.C
Substantially increase **recruitment, development, training and retention of the health workforce** in developing countries

Source: LightCastle Primary Research, 2016-17

Coordination and Collaboration among Govt., Donors, NGOs, Private Sector will be the Key solution



Source: LightCastle Primary Research, 2016-17

WHO Model

Policy Advocacy

Capacity Building

Essential Medicines

Coordination & Collaboration

National Policy Emphasizing Capacity Building, Drugs Availability, Curriculum Modernization

Clause 1 of major objectives and goals of healthcare policy

to ensure healthcare facilities for all as a human right

Clause 3 of specific purpose of national healthcare policy

to encourage the citizens to avail all required healthcare services

Clause 12 of principles of healthcare policy

Capacity building of health workforce i.e., doctors, nurses, technologists and other staffs

Clause 13 of major objectives and goals of healthcare policy

to modernize and improve the healthcare curriculum and education system in the field of nursing and medical technologies

Clause 15, 25 of strategic approaches of healthcare policy

to modernize and restructure existing capacity building institutions and establishment new ones

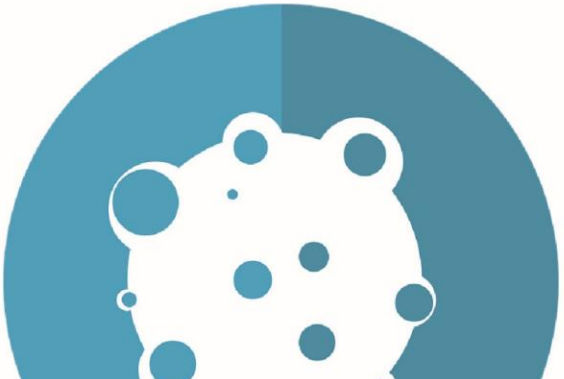
Clause 17 of major objectives and goals of healthcare policy

to ensure availability of essential medicines and control pricing

Cancer

Diseases once associated with affluence now place the heaviest burden on poor and disadvantaged populations. Non-communicable disease (NCDs) including cancer, heart disease, stroke, chronic respiratory disease, and diabetes represent a significant and rising share of the global burden of disease and account for more than half of all deaths in Bangladesh.

Per WHO statistics, cancer causes around 7.9 million deaths worldwide each year and nearly 70% of deaths occur in low- and middle-income countries (LMIC).



Source: WHO

Leading cancers and the prevalence in last 5 years

Male

Cancer type	Prevalence in last 5 years (%)
Lung cancer	13.1
Lip and oral cavity cancer	11.9
Other pharynx	8.2
Colo-rectal cancer	6.5
Stomach cancer	4.7
Esophageal cancer	4.1
Non-Hodgkin lymphoma	4.7
Hodgkin lymphoma	2.2
Bladder cancer	3.4
Prostate cancer	2.3
Liver cancer	1.5
Leukemia	0.6

Female

Cancer type	Prevalence in last 5 years (%)
Breast cancer	32.8
Cervical cancer	26.1
Lip and oral cavity cancer	6.5
Ovarian cancer	3.3
Colo-rectal cancer	2.7
Lung cancer	2.0
Esophageal cancer	1.9
Stomach cancer	1.8
Non-Hodgkin lymphoma	1.3
Hodgkin lymphoma	0.8
Liver cancer	0.6

Source: Comprehensive update on cancer scenario of Bangladesh

Cancer is a leading cause of death for children and adolescents worldwide. In high-income countries more than 80% of children with cancer are cured, but in many low and middle income countries (LMICs) only 20% are cured.

The reasons for lower survival rates in LMICs include an inability to obtain an accurate diagnosis, inaccessible therapy, abandonment of treatment, death from toxicity (side effects), and excess relapse, in part due to lack of access to essential medicines and technologies. Addressing each of these gaps improves survival and can be highly cost-effective.

Source: https://www.thedailystar.net/health/disease/childhood-cancer-causes-diagnosis-treatment-1646512)

Cancer

Bangladesh, at 142 million people, is the 9th most populous country in the world. There are 13 to 15 lakh cancer patients in Bangladesh, with about 2 lakh patients newly diagnosed with cancer each year. Bed capacity is around 500 beds all over the country which is insufficient for the current and future needs. Among these, 64 beds are for day care and remaining are in indoor facility. There are 150 qualified oncologists.
Lung cancer and mouth and oropharynx cancer rank as the top 2 prevalent cancers in males and in women, cervix uteri cancer and breast cancer are most prevalent.

Statistics

Total population (2016)	**162,000**
Life expectancy at birth m/f (years, 2016)	**71/74**
Probability of dying under five (per 1 000 live births, 0)	not available
Probability of dying between 15 and 60 years m/f (per 1 000 population, 2016)	**150/110**
Total expenditure on health per capita (Intl $, 2014)	**88**
Total expenditure on health as % of GDP (2014)	**2.8**

Latest data available from the Global Health Observatory

Palliative care is an essential part of cancer control, both for adults and children. In 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on with an emphasis on primary health care and community/home-based care.

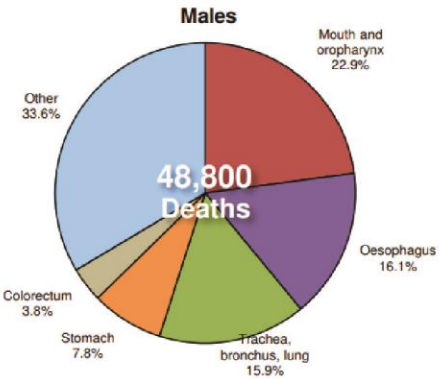
Source: WHO

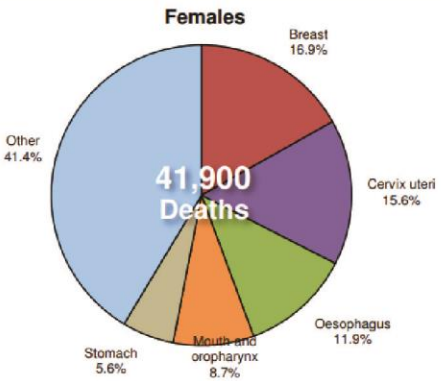
Cancer

Total population: 155,000,000 **Total deaths: 886,000**

Income group: Low **Life expectancy at birth: Total:70 Males:69 Females:71**

Cancer Mortality Profile*





9.6 million

people worldwide are estimated to die from cancer in 2018

US$1.16 trillion

is the estimated total annual economic cost of cancer in 2010.

30-50%

of cancers could be prevented.

Source: WHO

MYTHS & FACTS

Cancer

Myth: Excessive use of mobile (cellular) phones can cause a brain tumour and specific types of cancer, e.g. skin cancer and testicular cancer.

Fact: Mobile phones don't cause brain tumours or cancer. Mobile phones use radiofrequency (RF) waves, to send and receive signals from cellular towers. These RF waves are a form of non-ionizing radiation. There is no conclusive evidence to prove that these RF waves can cause a brain tumour or cancer.

Myth: Daily use of antiperspirants and deodorants can cause breast cancer.

Fact: Antiperspirants and deodorants are safe to use every day and they don't cause breast cancer. It is wrongly believed that aluminum and parabens in these personal care products are absorbed through the skin, or through cuts caused by underarm shaving, and cause breast cancer. A study on the use of underarm perspiration products and cancer, published in the Journal of the National Cancer Institute, found no link between breast cancer risk and antiperspirant use, deodorant use, or underarm shaving.

Myth: Wearing a bra can compress the lymphatic system of the breast and cause toxins to accumulate, leading to breast cancer.

Fact: It is completely safe to wear a bra. There is no scientific evidence to link wearing a bra, the type of bra worn (under-wired or non-wired) or the length of time it is worn, with breast cancer risk.

Myth: Using hair dye regularly to colour your hair increases your risk of breast cancer, bladder cancer, non-Hodgkin lymphoma and leukaemia.

Fact: Most studies on personal hair dye use and the link to bladder cancer and breast cancer have not found an increased risk. However, some studies do suggest that hairdressers and barbers, who have a high exposure to hair dye and other chemicals, may have an increased risk of bladder cancer.
The International Agency for Research on Cancer (IARC), part of the World Health Organization, considers hair dye use to be "not classifiable as to its carcinogenicity to humans".

Source: www.healthxchange.sg/cancer/mens-cancer-concerns/

"Palliative Care is in your pocket!"

-Dr. A. K. Goodman, MD, MPH
Massachusetts General Hospital, USA


DIGNIFYING LIFE
International Conference
ON CANCER AND PALLIATIVE CARE
6-11 SEPTEMBER 2018 | ROSE VIEW HOTEL , SYLHET 3100

Source: BSMMU

DIGNIFYING LIFE

An innovative project of AYAT Education that began in January, 2018 with a national call to address the rising need of quality palliative care services. Palliative Care is a prime interventional area of health care sector that requires much attention in Bangladesh.

54% **of deaths in Bangladesh incurred due to non communicable diseases or relevant causes**

600,000 **Requires Palliative Care in Bangladesh annually** (WHO)

AYAT Education aims to mobilize public, work with the state and non state parties together to enhance the national capacity of health professionals by linking them with the global knowledge and skills.


DIGNIFYING LIFE
THRU
CANCER
& PALLIATIVE CARE
DHAKA, 2019

DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE

DHAKA, 2019

Programs

1 - 5 FEB

Inauguration Ceremony

Nursing Workshop: Cancer and Palliative Care

End of Life Nursing Education Consortium (ELNEC) certification training

ELNEC Certificate Giving Ceremony

4 FEB

Surgery on Women with Gynecological Cancers: Transfer of knowledge and surgical oncology skills under leadership of Dr. AK Goodman **at NICRH**

5-8 FEB

Multi-disciplinary Tumor Boards at NICRH, DMCH, BSMMU & Apollo Hospital

- Patients with various cancers will be presented by the cancer clinician, radiologist and pathologist
- Distinctive discussant will briefly discuss the diagnosis and treatment decisions

6 FEB

Round-Table Discussion at Prothom Alo

Dignifying Life thru Youth Engagement & Leadership Role For Community Awareness on Palliative Care

8 FEB

Seminar on Cancer and Palliative Care

DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE SYLHET 2018

Programs

6 Sept

Experience Sharing & Resource Mapping
Lead by: Dr. Bimalangshu Dey, MD, PhD.

Inauguration Ceremony & Meet the Press
Cheif Guest: National Prof. Dr.Shahla Khatun, MBBS, FRCOG, FCPS, FICS, ECFMG

7-10 Sept

Nursing Workshop: Cancer and Palliative Care
End of Life Nursing Education Consortium (ELNEC) certification training

Surgery on Women with Gynecological Cancers: Transfer of knowledge and surgical oncology skills under leadership of Dr. AK Goodman

Multi-disciplinary Tumor Boards at NEMCH, PMCH and SOMCH

- Patients with various cancers presented by the cancer clinician, radiologist and pathologist,
- the diagnosis and treatment decisions.

11 Sept

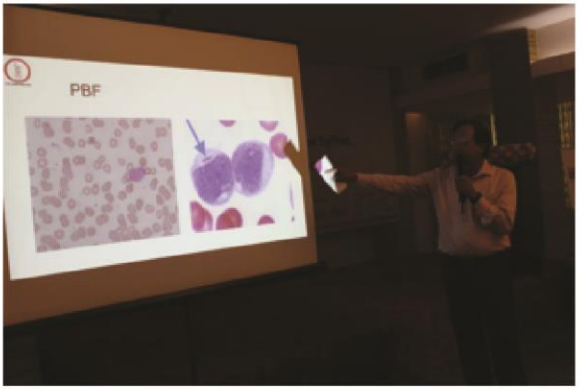
Seminar on Cancer and Palliative Care for Sylhet
Chief Guest: Honorable Minister, Mr. Abul Maal Abdul Muhit, Ministry of Finance, Government of People's Republic of Bangladesh

- **Infrastructure Development for Cancer-Palliative Care Medicine for Sylhet**
- **ELNEC Certificate Giving Ceremony**

INAUGURATION CEREMONY & MEET THE PRESS

6TH SEPT 2018

ELNEC WORKSHOP
CANCER & PALLIATIVE CARE
7TH–10TH SEPT 2018

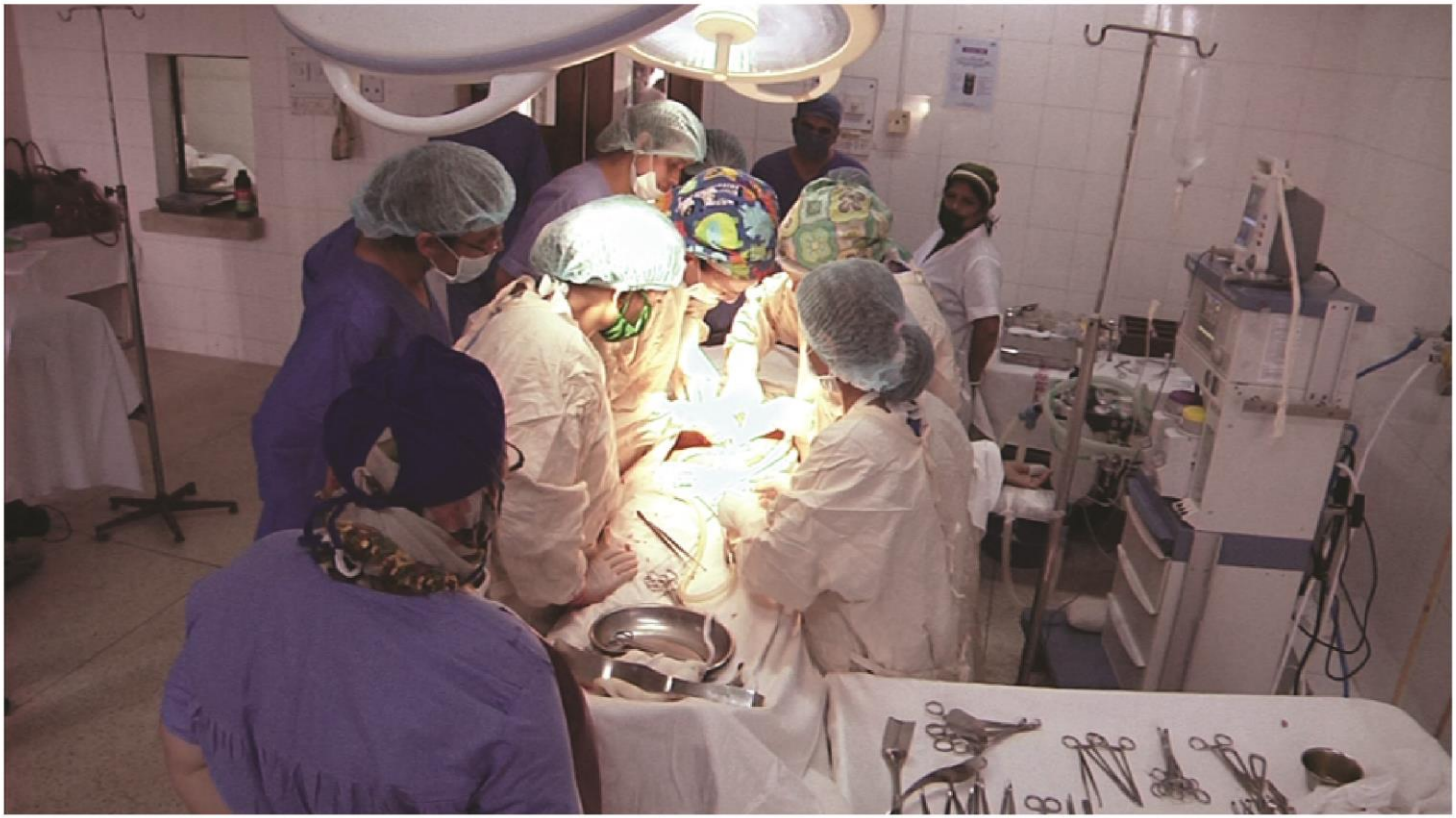


SEMINAR: CANCER & PALLIATIVE CARE FOR SYLHET

11TH SEPT 2018

MULTI-DISCIPLINARY TUMOR BOARDS

7TH–10TH SEPT 2018



SURGERY ON WOMEN & GYNECOLOGICAL CANCERS

7TH – 10TH SEPT 2018

ELNEC CERTIFICATE GIVING CEREMONY

11TH SEPT 2018

PUBLIC AWARENESS ON CANCER & PALLIATIVE CARE

11TH SEPT 2018

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

5 Jan
- Walkathon: For A Cause
- TV Talk-Show: Dignifying Life, Understanding Palliative Care
- Dignifying Life - Right to Information and Knowledge

6 Jan
- Round Table Discussions with The Daily Star: Dignifying Life, A Call For Public Awareness
- Inaugural Program with policy maker & stakeholders

7 Jan
Inauguration Of ELNEC And Physicians Training Program

8-12 Jan
ELNEC Training Program For The Nurses.

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

5 Jan 2018

Walkathon: For A Cause

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

5 Jan 2018

TV Talk-Show:
Dignifying Life - Understanding Palliative Care
Dignifying Life - Right to Information and Knowledge

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

6 Jan 2018

Round Table Discussions:
Dignifying Life - A Call For Public Awareness

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

6 Jan 2018

Inaugural Program with policy maker & stakeholders

DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA 2018

6 Jan 2018

Inaugural Program with policy maker & stakeholders

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

7 Jan 2018

Inauguration Of ELNEC And Physicians Training Program

DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA 2018

7 Jan 2018

Inauguration Of ELNEC And
Physicians Training Program

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

8 - 12 Jan 2018

Dignifying Life - Nurses Call to Care

ELNEC Training Program For The Nurses

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

8 - 12 Jan 2018

Dignifying Life - Nurses Call to Care

ELNEC Training Program For The Nurses

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

12 Jan 2018

ELNEC Certification Giving Ceremony

End-of-Life Nursing Education Consortium

This is to certify that

Mst. Mohochina Khatun

has completed the authorized Train-the-Trainer Core ELNEC Course

7 - 10 September, 2018
Sylhet, Bangladesh

SINCE 2000
ELNEC
END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve palliative care.
The ELNEC project is administered by the American Association of Colleges of Nursing (AACN) and City of Hope.

Tahsin Aman
Chairman
AYAT Education

AYAT Education

Dr. Anne Marie Barron
Associate Dean
Simmons College of Nursing, Boston

Dr. Bimalangshu R. Dey
Bangladesh Director
Global Health Initiative
Massachusetts General Hospital

MGH 1811

ELNEC Nursing Certificate

The End-of Life-Nursing Education Consortium (ELNEC)* Train the-Trainer Program
An International Collaboration to Offer Intensive Instruction in Caring for Patients with Serious Medical Conditions and Life Limiting Illnesses
Dhaka, Bangladesh
February 1st, 2nd, 3rd, 4th, 5th 2019

Nurses from Massachusetts General Hospital (MGH) and Simmons College in Boston will be traveling to Dhaka in early February to offer a five-day intensive palliative care training program for nurses in Bangladesh. Under the leadership of Dr. Bimalangshu Dey, the nurse faculty have been in Bangladesh previously, teaching the practicing nurses at Dhaka Medical College Hospital about the care of oncology and bone marrow transplant patients. Each of the nurse faculty has been trained in teaching the ELNEC curriculum and all are practicing in clinical areas at MGH where palliative nursing and end-of-life nursing care are offered with excellence and compassion to patients and their families. They are honored to be invited to present the ELNEC Train-the-Trainer Program to nurse in Bangladesh.

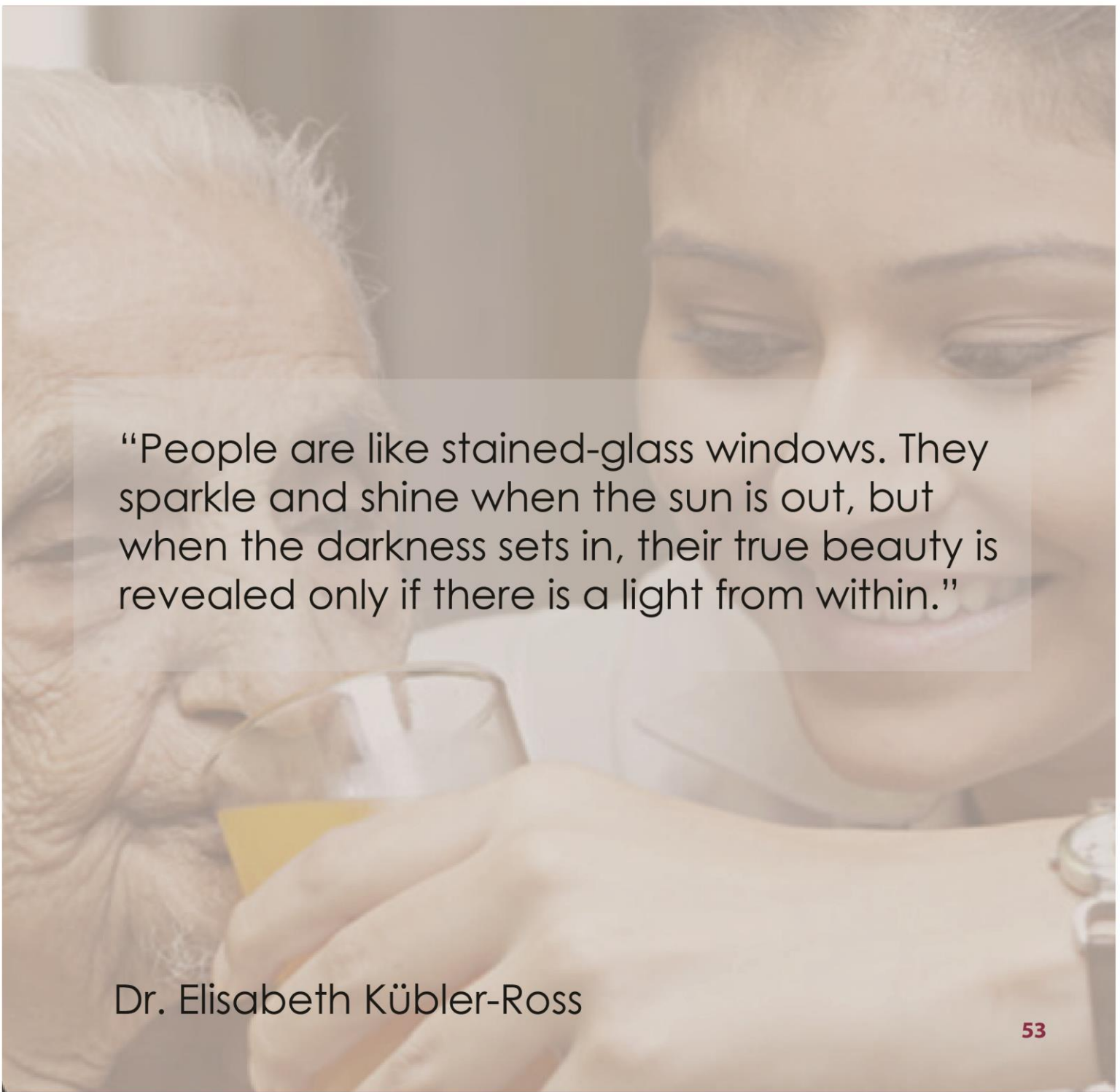
The End-of-Life Nursing Education Consortium (ELNEC) Project is a national end-of-life educational program administered by City of Hope (COH) and the American Association of Colleges of Nursing (AACN) designed to enhance palliative care in nursing. The ELNEC Project was originally funded by a grant from The Robert Wood Johnson Foundation with additional support from funding organizations (Aetna Foundation, Archstone Foundation, California HealthCare Foundation, Cambia Health Foundation, Milbank Foundation for Rehabilitation, National Cancer Institute, Oncology Nursing Foundation, Open Society Institute/Foundation, and the US Department of Veterans Affairs). Further information about the ELNEC Project can be found at www.aacn.nche.edu/ELNEC.

The five-day training will offer intensive, comprehensive, applied learning strategies to address the care of patients with serious medical conditions and the care of patients at end of life. Areas of focus will include:

- an overview of palliative nursing communication
- pain and symptom management
- loss, grief, and bereavement
- ethics
- cultural considerations
- care during the final hours
- self-care
- teaching strategies
- a review of ELNEC resources to achieve quality palliative care

This course will prepare nurse-participants to teach the ELNEC Curriculum in their own settings and become transformational leaders in the practice and teaching of palliative nursing concepts.

More than 23,000 nurses and other healthcare professionals in the United States and 92 countries across the world have participated in ELNEC Training Programs.



"People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within."

Dr. Elisabeth Kübler-Ross


DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA, 2018
Roundtable Discussion on
Dignifying Life - a call for public awareness and policy inclusion
6 January 2018
Azimur Rahman Conference Hall, The Daily Star Centre
Organized by
Supported by
DHAKA BANK
LIMITED
EXCELLENCE IN BANKING

REFLECTION

Dr Annekathryn Goodman, MD, MPH

Department of Obstetrics and Gynecology
MGH Global Disaster response
Massachusetts General Hospital
Boston, Ma

From Boston to Nepal: How to treat suffering without medical resources. "One never gets used to the idea that there is nothing one can do" (Connie Willis The Doomsday Book)

I was deployed to Nepal for three weeks after the April 2015 Earthquake as part of a first responder mobile medical team of the International Medical Corps. My 12-person team was helicoptered into remote, inaccessible mountain villages that had been devastated by the earthquake. We would set up a clinic, treat acute injuries, collect data on impending infectious disease epidemics, and triage severely injured earthquake victims for helicopter evacuation to Kathmandu. It was during this journey that I was confronted with the dilemmas of how to care for actively dying people when resources were not available.

The challenges after a natural disaster are complex and nuanced. There is a loss of civic infrastructure. Scarce resources include among others: medications, health facilities, and providers. There is also the terrible loss of family, food scarcity, and a lack of water and electricity.

The goals of first responders shift to acute care and includes saving lives, stabilizing injuries, and offering definitive therapy when possible. When a victim cannot survive, palliation of symptoms would be ideal if it is possible to do so. There is the tough business of triaging patients in this setting by whether or not they can be saved. The categories of triage range from immediate (immediate intervention will save the life), delayed (the injuries are not life threatening and can be treated later), minimal, and expectant. The expectant category is reserved for patients with devastating injuries where they will not survive or where the resources to help them are greater than what is available and even with the best care, their chance of pulling through is minimal.

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In contrast to a disaster-restricted setting, tremendous expense is routinely spent for ill cancer patients in the hopes of giving them an extra 3 to 6 months of life. In addition, early palliative care intervention in a non-disaster setting hopes to improve symptoms, relieve suffering, and help patients with advanced and incurable cancers to transition in a gentler and more gradual way towards the inevitable end of their lives. During a mass casualty event, palliative care services directly compete with definitive or life–saving care. This leads to an altered standard of palliative care where pain-control and sedation is the main goal.

Nepal, a country of 31.5 million people where the average age is 22 years is an agrarian society and among the poorest countries in the world. Pre-earthquake, narcotics prescribing were illegal and palliative care was not a widely known medical concept. On April 25, 2015, a 7.8 earthquake rocked the country. A second 6.8 earthquake followed on May 12. These earthquakes and the subsequent hundreds of severe aftershocks led to deaths, landslides, displacement, homelessness, and crop failure and food insecurity.
In this setting, my mobile medical unit treated over 2000 people during our three-week rotation. There were many cases of respiratory illness, dehydration, diarrheal diseases, pain, rashes, urinary symptoms, lacerations, fractures, pregnancy and gender based violence.

It was during one chaotic day that I met a 55-year-old gentleman whom I had to triage to the expectant category. I was in the middle of suturing a laceration when looking up I saw a group of people carrying a man down the mountainside in a large grain basket. Two years before, he had been treated in Kathmandu for bladder cancer and had undergone a pelvic exenteration, radiation, and chemotherapy. His family wanted him evacuated to Kathmandu. On examination there were multiple sites of tumor growing through the abdominal wall and he had developed a high output enterocutaneous fistula. His clothes were saturated by the fistulous output, and he was in obvious tremendous pain. His family had been walking for 2 days to get to us.

It was an awful moment. I gently tried to explain through an interpreter that he probably would not last more than a few days and we could not send him to Kathmandu. His son and I bathed him and wrapped him in some chux pads that we had on hand. The family was incredulous and angry.

There are guidelines for the ethical approach to allocation of scarce resources and triage. The concepts to consider include accountability, transparency, consistency, and proportionality. There is the issue of fairness – to be inherently just to all people. And there is the public health concept of the duty to obtain the best

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outcome for the greatest number of patients with available resources. These issues confronted me with this poor gentleman and his family. I could not even offer adequate palliation of his and his family's suffering.

I will always remember this patient and I bring back to our resource rich country some important concepts to consider in our care of cancer patients. The inability to give good care and alleviate suffering leads to moral distress among the providers. There is a balance of care and we must be thoughtful with treatment choices. On the one hand, we can cause harm with overly aggressive care that may be futile. In addition, beyond the individual patient, the inappropriate use of health care resources harms others who may not be able to receive care. However the inability to at least manage symptoms is unacceptable.

There is a movement to develop a crisis standard of care during disasters. These standards are also worthy of consideration in a non-disaster situation. Critical resources go to those who will benefit the most. We must prevent hoarding and overuse of limited resources. Limited resources must be conserved so more people can get the care they need. We must minimize discrimination against vulnerable groups who cannot advocate for themselves such as the poor, the minorities, the elderly, and immigrants.

Ultimately, regardless of the context we must maintain the basic human values of compassion, empathy, and respect for the dignity of others and to maintain professional codes of conduct.

Bimalangshu Dey, MD, PhD.

Massachusetts General Hospital
Associate Professor of Medicine
Harvard University
Boston, USA

I left Bangladesh when I was 18, to pursue my dreams, hoping I will be back soon. As a physician specializing in hematology, oncology and bone marrow transplantation at Massachusetts General Hospital of Harvard University, I knew I wanted to focus on cancer care for the people of Bangladesh. Working with exquisitely educated nurses, I also knew the importance of excellent nursing care in optimizing health and addressing the suffering of those struggling with cancer and other serious illnesses. In 2007, I started exploring ways to achieve this vision in earnest and I began to assemble a team in Boston to assist in creating strategic opportunities where our skills could make a difference in Bangladesh.

In the early years, we focused on learning about the needs in Bangladesh where our expertise could be effectively utilized in meaningful ways. We worked with the A.K. Khan Healthcare Trust in Bangladesh and identified initial goals in relation to offering cervical cancer screening in underprivileged women in slums of Dhaka and contributing to the education of nurses.

In 2012, the Ministry of Health, Government of Bangladesh, requested a collaboration with me and with MGH to develop the first bone marrow transplant program in Bangladesh at the Dhaka Medical College Hospital. Dozens of specialists from MGH traveled to Dhaka and many Bangladeshi physicians, nurses, and technologists traveled to MGH as the Program moved forward as planned. In 2014, the Bone Marrow Transplant Program was opened at DMCH. Thanks to the spectacular collaboration between the DMCH and MGH in Boston that, as of today, this new state-of-the-art facility of BMT at DMCH has been able to successfully perform stem cell transplantation in 39 ordinary citizens of Bangladesh. The zero percent transplant related mortality (thus far) at DMCH BMT Program, an outstanding outcome which is identical to that of MGH, is a testament to the commitment to the highest standard of the profession in cutting-edge discipline of medicine. Bangladesh has done it!

In January of 2018 in collaboration with the Ayat Skills Development Center, a five-day intensive Train-the-Trainer Program in Serious Illness and Palliative Care was offered to 87 nurses and four pharmacists in Dhaka. The Program was highly successful and is being presented for nurses in Syhlet along with a focus on general oncology care and chemotherapeutic interventions.

My dream now is to continue to broaden and deepen the vision of enhancing cancer care and elevating nursing practice through building on the collaborations so well established with the healthcare communities in Bangladesh, at MGH and at Simmons University in Boston, USA. This,

I hope, will slowly gather the momentum and take the shape of a nation-wide campaign to alleviate the suffering of people with serious illnesses, including cancers. The work in Bangladesh has been among the most rewarding joys of my career.

Anne-Marie Barron PhD, RN, PMHCNS-BD

Associate Professor and Associate Dean
School of Nursing and Health Sciences, Simmons College
Clinical Nurse Specialist and Faculty Nurse Scientist
Massachusetts General Hospital

A Nurse's Call to Care

I felt a call to be a nurse at a young age and that inner sense that nursing was the right career path for my life's work never wavered. I have been very fortunate with rich and excellent educational, clinical, and academic opportunities to realize that call. As I reflect on a now long and rewarding career, I am I filled with gratitude for all that a nursing career has offered to me.

There are few other professionals who have the opportunities we have, as nurses, to deeply touch the lives of others. As nurses, we are with patients and families during some of the most important moments of their lives. We are there at birth; we care for people throughout their lifetimes – promoting health and preventing illness, when possible, and providing care through illness, when necessary. We are there at death. We offer healing. Healing is an important word to us as nurses - healing comes from a root word that means "to make whole". We heal as we cure, at times. More often, we help our patients to become as whole as possible as they cope with chronic illness or adapt to the challenges and limitations imposed by injury or disease. We help our patients to become whole by seeing them as whole and worthy of our regard and respect, whatever their circumstance. We help our patients to become whole with our knowledge and skill, but also very importantly, with our compassion, caring, and presence.

In my clinical practice as a psychiatric clinical nurse specialist, I have focused on the intersection of serious medical illness and mental health, and the power of excellent nursing care to address suffering during critical moments in the lives of patients and families. For the past fifteen years I have practiced part-time as a psychiatric clinical nurse specialist on the Inpatient Oncology and Bone Marrow Transplant Unit at Massachusetts General Hospital (MGH).

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In my role at MGH I reflect with the nurses on their care care and consult with them on the patients who are experiencing high degrees of challenge and distress. I see patients and families with the nurses to offer additional nursing presence and frequently to offer a nursing intervention called Therapeutic Touch to promote comfort and relaxation for patients.

It is a privilege to work with the nurses at MGH. Each day I am on the unit, I am moved by the care I witness. Nurses care for the demanding physical and technical needs of their very ill patients with skill and expertise. What distinguishes their care as excellent and transformative is their capacity to be truly present with patients and to hold them with the highest regard and compassion as they offer technically expert care. They know their patients very well and commit to being with them throughout their journeys of serious, and potentially life-limiting, illness with caring and love. Those journeys are often arduous and difficult. Yet with their nurses' care, those journeys can be transformative. Serious illness invites deep reflection on meaning and life. The compassionate presence of the nurses offers patients and families healing possibility and an expansive recognition of what is truly important and meaningful in their lives, whatever the course and outcome of their illness. When the outcome is death, the nurses' care offers dignity, meaning, comfort, and peace.

In my academic practice at Simmons College, my goal is to assist students to recognize the transformative power of excellent nursing and support their skill and confidence as they learn to address the needs of their patients and create healing possibility. I teach a course each year focused on palliative and end of life care based on the End of Life Nursing Education Consortium (ELNEC) curriculum. The course is a joy to teach because it offers an opportunity to focus with students on the essence of nursing practice and enhances their understanding and comfort addressing the needs and suffering of patients and families. The offering of skillful and compassionate care is a gift for the patient and also for the nurse. There is no higher calling than to bring compassion to the world and nurses have that opportunity with every patient they encounter.

As Associate Dean and a leader within the School of Nursing and Health Sciences at Simmons, I view my role as helping to create a community of caring scholars. A community where every faculty member is supported in their teaching of the science and art of healing practice and every student is held in regard as they learn the skills and beauty of their chosen professional paths. Teaching and learning are exquisitely demanding. When faculty and students honor the vulnerability and risk inherent in true growth, the teaching and learning become transformative.

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For the past ten years I have had the privilege of traveling regularly to Bangladesh. Under the leadership of Dr. Bimalangshu Dey, I have explored nursing practice and education in Bangladesh with nursing leaders and participated with MGH colleagues in offering the Enhanced Specialized Nurse Training Program (ESNTP) at Dhaka Medical College Hospital. It has been one of the greatest honors of my career to be warmly received by nursing leaders and nurses in Bangladesh and participate in the sharing and exchange of nursing knowledge with colleagues across the world. Our recent teaching has focused on the nursing care of bone marrow transplant and oncology patients. A focus now on palliative and end of life care is a natural extension of our recent teaching. It is an honor to be offering the ELNEC curriculum to nursing colleagues in Bangladesh through the generous support of the Nusrat and Tahsin Aman and the Ayat Skill Development Center.

Dr. Nezamuddin Ahmad

FCPS, MD
Professor & Chairman
Department of Palliative Medicine
Bangabandhu Sheikh Mujib Medical University

Bangladesh had started practicing palliative care from 2005. As a continuing result Bangabandhu Sheikh Mujib Medical University has established the center for palliative care in 2011. According to the advice of Health Ministry of Bangladesh center for palliative care has done an audit in 2014 and got permission for the MD course in palliative care in 2015 for the necessity of knowledge of this care.

On 6th of October 2015 The Economist has published a research work named Quality of Death Index and Bangladesh has got the 79th place out of 80 palliative care practicing countries. The score was 14.1 out of 100, where United Kingdom placed the first position having 93.9 points. This indicates the need of development of this care in this region. Palliative care is not only for the patients of cancer patients rather it includes the AIDS, stroke, asthma, cardiovascular problems, diabetics and all the disease which make the people suffer for long time. So according to the situation of this country and the need of this care, it is very important to stabilize the practice of palliative care.

Dr. Arif Mahmud , MBBS (DMC), MPH
Head of Medical Services
Apollo Hospitals Dhaka

Palliative Care: Role of Healthcare Providers

Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment. Unlike hospice care, palliative care is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. Palliative medicine utilizes a multidisciplinary approach to patient care.

The aim is to increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. To improve the effectiveness and comfort level by communicating the necessity and benefits of palliative care with those patients with a serious illness. It also improves the assessment of the identified patient's palliative care needs, utilizing the domains of palliative care.

Evidence supporting the impact of palliative care on quality of life continues to grow as quickly as the field itself. Studies have showed early palliative care involvement not only improves quality of life and symptoms of anxiety and depression, but also improves survival in patients with cancer.

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We devote our lives as physicians to preserving the health and wellness of the living by first working with the dead (cadavers).
Caring for the dying fosters a vivid insight into the nature of true medicine and allows for the appreciation of the treatments, diagnostic measures, and management plans that can only go to an extent for terminal conditions. There are times when we must allow nature to take its course and witness the natural history of its progression all the while controlling the pain, the nausea, the agitation, and discomfiture as best we can. Those symptoms, although they may not seem to be on the surface, do matter to the patients and to their families.
We understand that when patients with terminal illness realize that nothing more can be done as far as treatment plan is concerned, all they want is to spend good quality time with their family members in a peaceful and comfortable manner. Palliative care flows from shared decision made by patient and their family where patient orchestrate their own care by focusing on what is important for them. Doctors continue to run investigations and provide the necessary treatment required to help them live a better life. It leads not only to better patient satisfaction but also to improved quality of life and which can eventually lead to a longer life.

On 6th of October 2015, The Economist has published a research work named 'Quality of Death Index' and Bangladesh has got the 79th place out of 80 palliative care practicing countries. The score was 14.1 out of 100, where United Kingdom placed the first position having 93.9 points. This indicates the need of development of this care in this region. Palliative care has always faced a lot practical as well as theoretical debate.The end of life is a difficult time for our patients and their families. Our actions and words should provide solace and redirect hope towards comfort and peace. This is where medicine becomes an art, and when the humanity of the clinician is most important.

Bangladesh faces huge unmet needs of patients with life limiting illnesses where it is about achieving the highest quality of life (QOL) and promoting comfort and self-respect for patients with not only incurable but also life limiting diseases. Palliative care promotion has been strengthened by announcing that allocation of palliative care is a human right. To overcome the barriers to successful implementation of palliative care we need continued efforts and it is our not only ethical but also moral obligation to do whatever we can.

We as health care provider couldn't deny our responsibilities without developing this specialized care for our patients. Though palliative is in very primitive stage in Bangladesh, but we have to come forward with our existing resources. Otherwise we have to face the consequences in future. The evolution and growth of palliative care services and hospices should come from the combined effort of both the public and private sectors. Without community involvement, establishment of this sector will not be possible. The fact that should not be overlooked is that if specialists and facilities dealing in palliative care become more prevalent in the future, a big proportion of the total number of patients with incurable, progressive diseases will benefit from this care.

I am pretty sure that we will succeed in this journey under the present leadership.

Our recent success in health care is unparalleled. Bangladesh has achieved the MDGs goals in recent past and we are proceeding for SDGs. With this aspiration I am looking forward for the success of Palliative care in Bangladesh.

Nisha Wali, RN

School of Nursing and Health Sciences, Simmons College
Massachusetts General Hospital

The great advances in science and medicine in Bangladesh have created the perfect opportunity to showcase the talented nurses and physicians working with the people of Dhaka. The role of the nurse as both an advocate and educational partner of the patient in the hospital can help to make the experience of chronic illness one that is less scary and ultimately beneficial for the patient. In protecting a person's dignity both in sickness and in health is one of the nurse's greatest roles. As the ability to prolong life without pain and suffering improves through the use of Palliative care medicine, we can care for the patient and their families as they navigate the challenges of chronic illness. Being a partner for the public as well as a knowledgeable healthcare worker we can better care for the sick all over Bangladesh. The area of Palliative care nursing has been a passion of mine since starting my career and consistently confirms why this education is so well placed in the hands of nurses. More often than not, the nurse is a very trusted member of the healthcare team who is aware of not only who the patient is but the challenges they are facing both medically as well as emotionally as they are hospitalized. This educational conference will begin to create a foundation to build upon the existing expertise of the nurses of Bangladesh and elevate the role of nurses as incredibly important members of the healthcare team.

Emily Erhardt, RN.

Massachusetts

Boston, USA

Nursing is a multi-dimensional and dynamic role. A nurse not only needs the knowledge to help treat a patient and their symptoms, but also the empathy to support them and their family throughout the emotional and psychological distress that chronic illness can have on an individual. To me, becoming a nurse has been the most humbling, gratifying, and rewarding decision I have ever made in my life. I consider it a true honor to be at a patient's bedside caring for them, assisting in making decisions with the physicians and family, and ensuring that above all, the patient's physical and mental wellbeing are regarded. This I believe, is the call of a nurse.

While working as a staff nurse at Massachusetts General Hospital, there have been many instances where I have been able to see the powerful effect of palliative care in patient's lives. While the concept has unfortunately been mislabeled in the past, palliative care is a systematic approach to medicine that encompasses all aspects of the patient care module. It is a way to integrate both physical health, psychologic health, and spiritual health to ensure all facets of a patient's life are considered. This is most evident in the field of oncology. While we can treat cancer with chemotherapy and radiation, we must also consider the psychological, financial and social burden the disease may have, as well as the side effects and symptoms that proceed most chemotherapies. In only treating the physical disease, we negate to recognize the other aspects of health, and thus do our patients a disservice. Palliative care is an opportunity for nurses, physicians, supportive personnel and family to come together, and ensure that the patient is best cared for. It is truly a calling of mine, and I could not be more grateful to be coming to Bangladesh and sharing the knowledge I have with my fellow nurses. I'm hoping that this conference will spark not only interest but excite both nurses and physicians to consider all features of health care.

Jocelyn Hulbert, RN

School of Nursing and Health Sciences, Simmons College
Massachusetts General Hospital

Nursing is a multi-dimensional and dynamic role. A nurse not only needs the knowledge to help treat a patient and their symptoms, but also the empathy to support them and their family throughout the emotional and psychological distress that chronic illness can have on an individual. To me, becoming a nurse has been the most humbling, gratifying, and rewarding decision I have ever made in my life. I consider it a true honor to be at a patient's bedside caring for them, assisting in making decisions with the physicians and family, and ensuring that above all, the patient's physical and mental wellbeing are regarded. This I believe, is the call of a nurse.

While working as a staff nurse at Massachusetts General Hospital, there have been many instances where I have been able to see the powerful effect of palliative care in patient's lives. While the concept has unfortunately been mislabeled in the past, palliative care is a systematic approach to medicine that encompasses all aspects of the patient care module. It is a way to integrate both physical health, psychologic health, and spiritual health to ensure all facets of a patient's life are considered. This is most evident in the field of oncology. While we can treat cancer with chemotherapy and radiation, we must also consider the psychological, financial and social burden the disease may have, as well as the side effects and symptoms that proceed most chemotherapies. In only treating the physical disease, we negate to recognize the other aspects of health, and thus do our patients a disservice. Palliative care is an opportunity for nurses, physicians, supportive personnel and family to come together, and ensure that the patient is best cared for. It is truly a calling of mine, and I could not be more grateful to be coming to Bangladesh and sharing the knowledge I have with my fellow nurses. I'm hoping that this conference will spark not only interest but excite both nurses and physicians to consider all features of health care.

Nazma Begum Feroz
Cancer Survivor

In her own words

Chemotherapy! The meaning of the word only be known who went through this trail!! It is simply not possible to realize by others, except the sufferers. When it came to my life – the first utterance of the word put me into a SHOCK, but I accepted the reality and prepared myself to face it. It was a turbulent period for the entire family – my younger daughter just got married and joined the in laws. The elder daughter – with a pregnancy complication was in the USA with her family for a safer delivery. But all of them joined together along with my extended family members. All united to hold me tight. I am thankful to God for granting me such a supportive family. I always got them besides me in fighting this battle against cancer.

But many of us, in our society are not so blessed. Family support gradually is fading out in these days considering the complexities and limitations of time and resources. Availability of qualified and experienced nurses care especially in our country context is also not so easily available, though this is very much needed. I feel our hospitals can do some - knowledge and skills upgradation training to build the capacity of our nurses. I think this is very much possible. I am finding hope when I heard that Nusrat Aman and Tahsin Aman of Ayat Skill Development Centre has started an initiative on the care issues, especially on Palliative Care with the help of a Bangladeshi expatriate physician Dr. Bimalangshu Ranjan Dey. I am feeling really happy to heard about it. My blessing are always with them as they are working for a good cause, for the betterment of people's health and wellbeing.
Those who are suffering in hospital beds – fighting for a life or longing for some comforts, it is unbearable if they are deprived of the touch of their near and dear ones. When it is not possible on special circumstances, it is the duty of the nurses to give that comfort, confidence - love and be at the side of the patients in those moments.

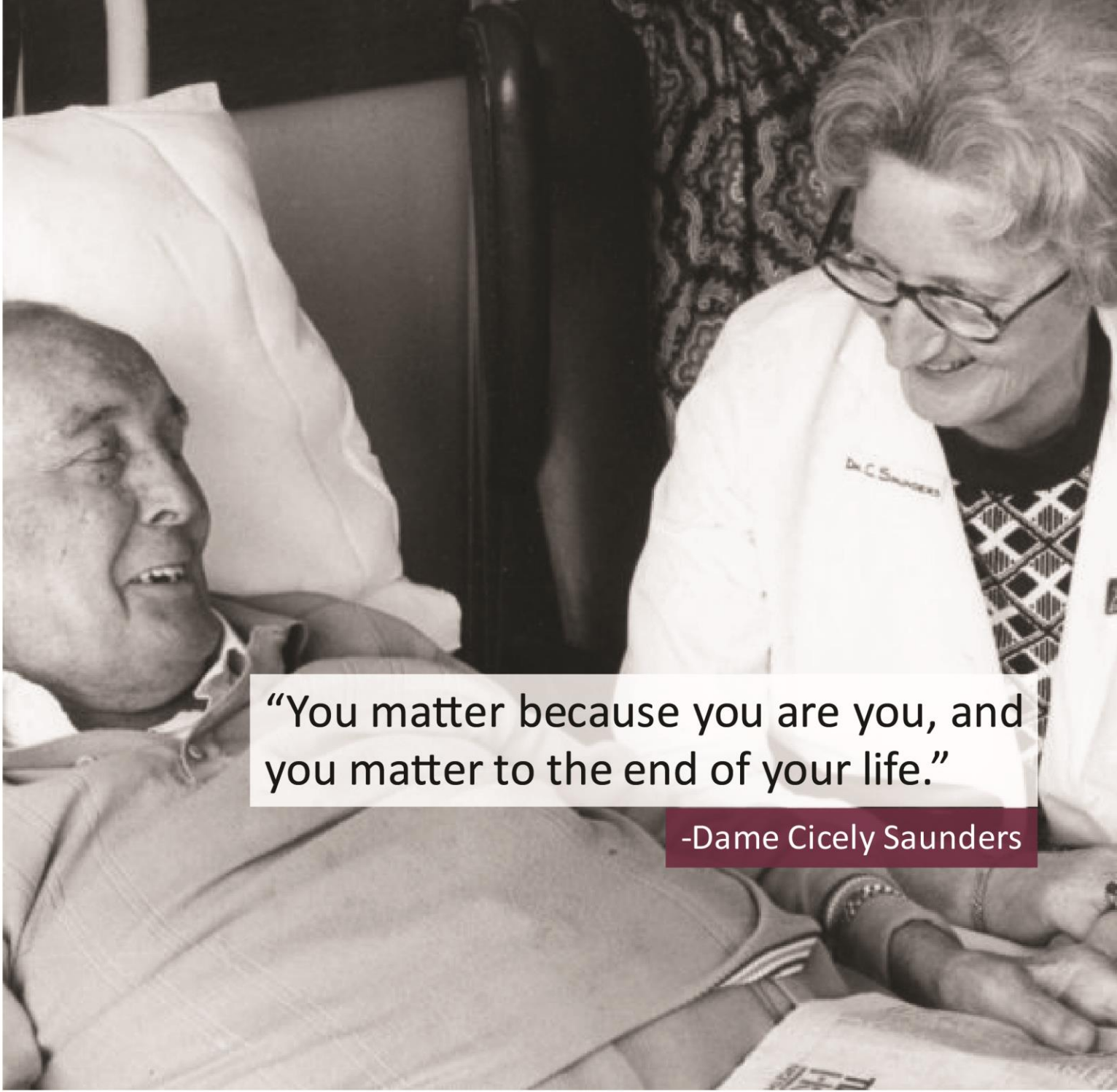
Shuchi Karim, PhD.

Assistant Professor
Women's Studies and Feminist Research Department
University of Western Ontario, Canada

Palliative Care to me and us

We have been coming to this hospital for the last ten- twelve years, or so - mostly for my parents' regular health checkups, or the occasional semi emergencies, or non life threatening type of surgery. All these years we have taken the elevators to different floors, standing closely to other visitors or patients in the cramped inside, eagerly waiting to get down to our destinations- sometimes the neurologist, or nephrologists, gynecologist, medicine, eye specialist and so on. But this time, our destination for almost a month was the fourth floor, Critical Care Unit or the CCU, as my father struggled to survive serious life threatening ailments, and I noticed, for the first time that the people who got down at the fourth floor looked different from the others in the elevator. We had a silent but intense sense of anxiety, an earnest prayer sealing our lips and an urgency that could only be felt and understood by someone who has known what it means to have a loved one treading the treacherous space between life and death. People on the fourth floor huddled together in visiting rooms and prayer rooms, somehow comforting each other, and hoping that no bad news comes out from the CCU when a patient's name is called out to draw the attention of his or her family. The power dynamics between doctors and patients families can be tricky, especially in our kind of culture where it is extremely difficult to figure out who actually is responsible for decision making when there is a need for one. One day I witnessed this family having a divisive argument about whether to 'order' the doctors to pull off life support machines from their elderly patient who was clearly losing the battle of life. Despite having the patient's wife, daughter and a younger son present , it was clearly the elders of the extended family who believed in a particular interpretation of religion regarding life and death, who put pressure on doctors to end the 'suffering ' of the patient. The doctors had a tough time explaining the protocol that they had to follow and their inability to oblige them. The highly tensed environment of emotion, rationally, and responsibilities can be a very difficult place for all parties involved.

Walking into the CCU, one can feel the eerie smells of medicine and hear the whispers, and one realizes the power of doctors and nurses who actually can either make or break your already dwindling existence of hope about life. How the doctors advise or responds to a patient and their needs, how family members are briefed and conveyed words of comfort even at the face of hopelessness, is crucial. The personal attachment that takes place between the patient and the care givers like nurses and personal care assistants can actually help a patient gather the willingness to fight for life a little more, a little better. My father returned to CCU again within a couple of weeks time as his health deteriorated, but this time he felt much more confident as he was greeted by his favorite and familiar faces amongst nurses and assistants. Despite witnessing patients passing away around him, which can distress anyone even in good health, it was the reassuring presence of the care givers that kept his morale high and optimistic.
My father, in his first three weeks stay there, hardly recognized us, his daughters and wife, as he gazed at us with almost no expressions, but would light up seeing his nurses and care givers. They would listen to his irrational demands to have an apple or a juice in the middle of the night, or comfort him when he felt embarrassed to ask for assistance to use the toilet or a change of clothes. They would call him father or grandfather with great love and affection, and smile all the time, even when he occasionally lost his temper. He appreciated that he got a shave done and they made sure that he was always clean and fresh (my father is obsessively clean in his personal life), and the pretend secrets of supplying him with mini biscuit packets when he got hungry or even bored. He would express his slight disappointment about my style of arranging his lunch plate later as the nurses apparently fed him with more care and expertise. Otherwise a highly critical man, and a difficult person to please, my father had tears in his eyes when he said goodbye to his favorite nurses and staff in the CCU. We walked out of the elevator, feeling blessed and lucky to have our father returning to home in better health, knowing that care for critically ill patients, especially the elderly ones, along with medical interventions, environment and the art of care giving play an equally important role.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-Dame Cicely Saunders

RESOURCE PERSONS

National Prof. Shahla Khatun

MBBS, MRCOG, FRCOG, (London) FCPS, (BD & Pak)

Prof. Shahla Khatun born in Sylhet in a highly educated family; the daughter of Late Advocate A.A.A. Hafiz, MA, LLB & Late Syed Sahar Banu Chowdhury. She graduated from Dhaka Medical College in the year 1961 and joined Government service in the same year. In December 1965, she went to UK for higher studies with Government Scholarship. After returning home from UK, she joined Institute of Post Graduate Medicine and Research (IPGMR; now Bangabandhu Sheikh Mujib Medical University-BSMMU) and worked there till retirement from Government Servicein 2011. In personal life is blessed with one daughter Lubna Kabir and one son Sayyied Bin Kabir who are well established in their career by their own potential.

Shahla Khatun is the founder member and 1st life member and past president of Obstetric and Gynaecological Social of Bangladesh (OGSB) which was established in 1972. Members of OGSB started a hospital at Mirpur, where middle and low income group of peoples mainly live. She is involved for more than 30 years in organizing, developing, improving and finding ways and means for sustainable health status of women & children in Bangladesh. From 1970, working hand in hand with MOHF, UNICEF, several national & international, NGOs, Bangladesh Diabetic Association, Bangladesh Menopause Society (BMS), OGSB,B-MA, Bangladesh Family Planning Association, and Lioness Club of Dhaka Green, Green Life Medical College Hospital(GLMC), Mother Care Hospital(MCH) and rendering free medical services, consultation and surgery in various parts of Bangladesh. She was a nonofficial, volunteer visitor of Dhaka Central Jail (the biggest Jail in Bangladesh) where worked to improve living conditions health status of prisoners, mainly young, underage girls and women. During her tenure of chairmanship of International Representative Committee of RCOG, she successfully introduce part – I and part – II MRCOG examination in Dhaka and every year 3-4 CME held in Dhaka under the banner of RCOG. She participated National and International scientific conferences home and aboard as a member, as a invited guest, as a faculty.

She was awarded National Professorship in June, 2011 by the Government of Bangladesh. She also received Mother Teresa award in 2004 and "Rotnogorva mother (Mother of Talents)" and many others medals and certificates recognizing her contribution to medical profession, improvement of women's and children health and social work. She attended all the program of "Dignifying Life through Cancer & Palliative Care" organized by AYAT Education in 2018. Prof. Shahla Khatun is also the founder Member & Life Member of Bangladesh Perinatal Society & Infertility Society. She is a Honorary Medical advisor of "Shimantik" from 1996 till today which is an education and health care service delivery organization based in Sylhet. She is also the Honorary Chairperson of the Technical Advisory Committee of Research, Training and Management (RTM) which is a nationally recognized NGO in Bangladesh.

Dr Annekathryn Goodman, MD, MPH

Dr. Annekathryn Goodman is a Professor of Obstetrics, Gynecology and Reproductive Biology at Harvard Medical School and a Fellow of both the American Congress of Obstetricians and Gynecologists and the American College of Surgeons. She has a fulltime practice in Gynecologic Oncology at Massachusetts General Hospital and is an affiliate of MGH Global Disaster Response and the Department of Global Health and Social Medicine at Harvard Medical School.

She completed medical school and residency training in obstetrics and gynecology at Tufts University School of Medicine in Boston and her fellowship training in gynecologic oncology at Massachusetts General Hospital (MGH). In addition to board certification in gynecologic oncology, she is certified in acupuncture, and has completed training in both pastoral and palliative care. She received a certificate in Clinical Ethics and Health Policy from the Center for Practical Bioethics, University of Kansas Medical School. She received a certificate in Global health and MPH in Health Policy and Management from New York Medical College. She has undergone advanced training in humanitarian disaster relief work through the Harvard Humanitarian Initiative, Missioncraft in disaster relief operations, the International Committee of the Red Cross and the Harvard Program in Refugee Trauma.

She was the Director of the Gynecologic Oncology Fellowship Program at Massachusetts General Hospital from 1998 through 2016. She is the past president of The Obstetrical Society of Boston and of the New England Society of Gynecologic Oncologists. She is also a member of the Ethics Committee at Massachusetts General Hospital.

She is a member of the national Trauma and Critical Care Team previously known as IMSuRT (International Medical Surgical Response team), a branch of the US department of Health and Human Services and has deployed to various international disasters including Bam, Iran 2004, Banda Aceh 2005, Haiti 2010, the Philippines 2014, and Nepal 2015. She received the 2012 ACOG International Service Award for service to pregnant women after the Haiti earthquake. Since 2008, she has been consulting in Bangladesh on cervical cancer prevention and the development of medical infrastructure to care for women with gynecologic cancers. She has also developed a two-month observership in gynecologic oncology at MGH for physicians from resource-limited countries.

Dr. Bimalangshu Dey, MD, PhD.

Dr. Bimalangshu Dey, MD, PhD. ("Bimal") is an Associate Professor of Medicine at Harvard Medical School, Harvard University, Boston, USA, and a Physician in Bone Marrow Transplantation Unit at the Massachusetts General Hospital, Boston, USA. He is an affiliated faculty at the Center for Global Health at Mass General Hospital. Since 2007, Dr. Dey has been actively engaged with the government of Bangladesh to strengthen public sector cancer care at the Dhaka Medical College Hospital and to enhance the status of public sector nursing through sub-specialty training. In response to the shortage of palliative care services and resources available in Bangladesh, Dr. Dey has recently worked with colleagues to implement the first national training for nurses with the international curricula developed by the End-of Life Nursing Education Consortium (ELNEC, Boston, USA).

In Bangladesh, hundreds of thousands of patients require palliative care each year but effective palliative care medicine, including end-of-life care and pain management resources and well-trained providers remain in critically short supply in Bangladesh. In an effort to improve the quality of life for patients living with serious illnesses and suffering from pain and equip healthcare providers with the appropriate tools and knowledge, a collaboration of the Dhaka Medical College Hospital, Simmons College, Ayat Network, and healthcare professionals from the Massachusetts General Hospital are introducing the first national training for nurses and physicians with the international curricula developed by the End-of Life Nursing Education Consortium. But, such a mission will reach the milestones only when the Government of Bangladesh joins this journey. The commitment of the Government and her partners to these initiatives, and the active participation by the Government in upcoming events, will be critical to efforts to expand access to essential palliative care services and enhance quality of life for millions of Bangladeshi citizens suffering from non-communicable diseases, including cancer, at any part of Bangladesh at any given time.

Judy A. Beal, DNSc, RN, FNAP, FAAN

Dean and Professor, School of Nursing and Health Science, Simmons College, BSN, Skidmore College, 1973, MSN, Yale University, Major Parent Child Nursing/ PNP, 1975, DNSc, Boston University, 1983

Dr. Judy Beal has had many leadership roles in her 40 years as a nurse. She currently serves as Professor and Dean of the School of Nursing and Health Sciences at Simmons College with responsibility for three nationally accredited academic programs. Prior to coming to Simmons in 1983, Dr. Beal taught at Boston University and Skidmore College. Dr. Beal has been a leader in nursing education since 1978.At Simmons she has been instrumental in building early innovative models of academic practice partnerships locally and then globally. In Boston, the unique model of "hospital as client" with the hospital financing the academic progression of employees in RN- BSN and RN-MSN programs grew from 1 partnership 5 years ago to 8 partnerships. With foundation funding, she partnered with the University of Cairo to replicate an accelerated second degree BSN program for unemployed university graduates. This effort significantly advanced workforce capacity and elevated the level of professional nursing practice in Egypt. With academic and practice partners in Saudi Arabia and with philanthropists in Bangladesh and Israel she is further replicating these programs.

As a RWJ Executive Nurse Fellow from 2008-2011, she created a national forum on academic-practice partnership by successfully engaging a national association to identify this issue as a strategic priority. She developed and co-led the AACN-AONE Task Force on Academic-Practice Partnerships. This group has significantly elevated the conversation on and strategy for developing academic-practice partnerships.

She has served as president, secretary, director and chair in many organizations including: Sigma Theta Tau International, the American Association of Colleges of Nursing (AACN), the Massachusetts Association of Colleges of Nursing (MACN), Massachusetts Association of Registered Nurses (MARN), and Yale University Alumni Association. Most recently, she has served as a two term elected board member and is the newly elected secretary of AACN, secretary and vice president of MACN, chair of the MARN Nominations Committee, and co-lead of the RWJF Massachusetts Action Coalition.

Dr Beal is widely published with more than 100 peer reviewed articles. Her well- funded program of research focuses on role development of neonatal nurse practitioners and for the past 16 years on the development of a model of clinical nurse scholars. She is sought after as a regional and national speaker. Dr. Beal is on the editorial boards of the American Journal of Maternal Child Nursing as well as a peer reviewer for the Journal of Pediatric Nursing, the Journal of Professional Nursing, Nursing Outlook, and Research in Nursing and Health.

Dr. Beal received her BSN from Skidmore College, her MSN from Yale University, and DNSc from Boston University. She is a Fellow in the American Academy of Nursing and the National Academies of Practice.

Anne-Marie Barron PhD, RN, PMHCNS-BC

Associate Dean, School of Nursing and Health Sciences, Simmons College Psychiatric Clinical Nurse Specialist (part-time) Inpatient Oncology and Bone Marrow Transplant Unit, Massachusetts General Hospital

Dr. Barron is Associate Dean for Student Affairs in the School of Nursing and Health Sciences at Simmons College. She received her B.S. in nursing from Boston College, her M.S. in Psychiatric and Mental Health Nursing from the University of Massachusetts at Amherst, and her PhD from Boston College. Anne-Marie has taught across the undergraduate curriculum in a number of courses, most notably, Psychiatric Nursing and Caring at the End of Life, a semester-long course based on the ELNEC Curriculum. Dr. Barron's teaching, practice, and research interests are focused on meaning and illness and the understanding and alleviation of suffering. Her central goals in nursing and health science education are to guide and support students as they develop perspectives and skills that enable them to offer healing presence in the lives of their patients. Anne-Marie currently practices part-time as a Psychiatric Clinical Nurse Specialist on the Inpatient Oncology and Bone Marrow Transplant Unit at Massachusetts General Hospital where she also holds an appointment as Faculty Nurse Scientist.

Anne-Marie has had the privilege of consulting on nursing education in Bangladesh since 2009 as part of an interprofessional team. The Nursing Program at Simmons College, Massachusetts General Hospital and MGH Center for Global Health, and the A.K. Khan Healthcare Trust in Dhaka, Bangladesh have collaborated on the education of practicing nurses at Dhaka Medical College Hospital. The collaboration is part of larger initiative between the Government of Bangladesh and Massachusetts General Hospital to establish the first Bone Marrow Transplant Program within Bangladesh.

Anne-Marie has been teaching the ELNEC curriculum since 2004 and is in close communication with leaders at the American Association of Colleges of Nursing in planning the offering of the ELNEC Train-the-Trainer Program in Bangladesh.

Emily Erhardt, BS, RN

Emily Erhardt is a registered nurse in Boston, Massachusetts. She received her undergraduate degree from Mount Saint Mary College in New York, and was accepted into a Nurse Residency Program that specialized in Critical Care at Massachusetts General Hospital. She worked for 5 years in a surgical/trauma Intensive Care Unit, and during that time became involved with the nursing education initiatives in Dhaka, Bangladesh. She traveled for the first time to Dhaka in 2015, where she lived for 2 months providing nursing education to the staff at Dhaka Medial College Hospital with the Enhanced Specialized Nurse Training Program. She then returned in January of 2017 to complete the third batch of nurses from the ESNTP, and provided support via Skype for the January 2018 ELNEC training program that took place in Dhaka. She is extremely excited to return to Bangladesh in September, and bring the cancer knowledge and ELNEC training to the people of Sylhet.

Nisha Wali, BS, RN

Nisha Wali currently works as an oncology specialized staff nurse at Massachusetts General Hospital. She first became involved in global health nursing during her undergraduate education taking on internships in South Africa and Sweden. Nisha started her career in Boston as a medical oncology nurse at MGH. She became affiliated with the Enhanced Specialized Nurse Training Program (ESNTP) in Dhaka, Bangladesh in 2014 as a Global Health Nurse Fellow. Taking on a long-term teaching assignment in Dhaka as a nurse educatorfor a group of nurses who would go on to work in Bone Marrow Transplant Unit and on medical oncology units. The camaraderie she experi enced in Bangladesh was characterized by fellowship and the shared goal of elevating the knowledge level of the nurses in Dhaka. Since becoming involved in ESNTP Nisha has expanded her oncology specialty to include infusion therapy with the use of traditional chemotherapy as well as cutting edge immunotherapies. This year Nisha returns to Bangladesh for the third time to deliver an international curriculum aimed at enhancing palliative nursing care to patients faced with critical illness. She hopes to grow her global health experience and continue a lasting dialogue with her fellow Bangladeshi nurses.

Jocelyn Hulbert, BS, RN

Jocelyn Hulburt is a registered nurse and has worked at Massachusetts General Hospital in Boston for ten years in three different units: Burn Intensive Care, Surgical Intensive Care, and Emergency Medicine. In these critical care environments, Jocelyn has developed a passion for improving patients' suffering and supporting end-of-life transi tions. She has truly valued and enjoyed sharing and learning the art of nursing through teaching new nurses and courses at Endicott College in Boston and traveling to provide medical aid in Kenya, Uganda, and Haiti. In 2017, she had the opportunity to travel to Bangladesh and fulfill this passion once again. Through the Bone Marrow Transplant Program partnership with Massachusetts General Hospital, Simmons College, and Dhaka Medical College Hospital she was able to share her knowledge of Bone Marrow Transplant and learn from the nurses in Bangladesh. She is honored to return again this year to share her passion for improving end of life care.

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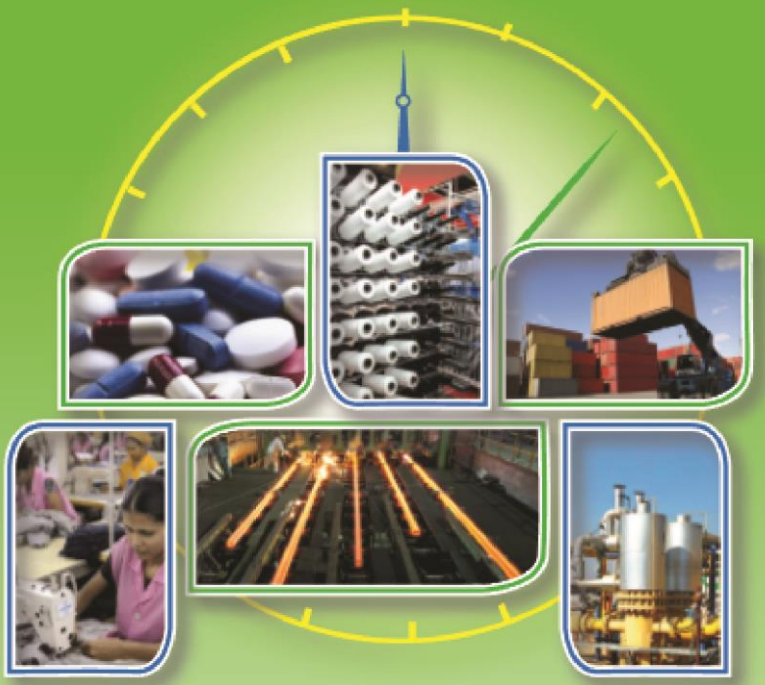

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Palliative Care

Palliative care is a multidisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing people with relief from the symptoms, pain, physical stress, and mental stress of the terminal diagnosis. The goal of such therapy is to improve quality of life for both the person and their family. World Health Organization describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'. The term "palliative care" is increasingly used with regard to diseases other than cancer such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure, HIV/AIDS and progressive neurological conditions. In addition, the rapidly growing field of pediatric palliative care has clearly shown the need for services geared specifically for children with serious illness.

Palliative care is provided by a team of physicians, nurses, physiotherapists, occupational therapists and other health professionals who work together with the primary care physician and referred specialists and other hospital or hospice staff to provide additional support. It is appropriate at any age and at any stage in a serious illness and can be provided as the main goal of care or along with curative treatment. Although it is an important part of end-of-life care, it is not limited to that stage. Palliative care can be provided across multiple settings including in hospitals, at home, as part of community palliative care programs, and in skilled nursing facilities (https://en.wikipedia.org/wiki/Palliative_care).

ISBN 978-984-34-5975-6