Dignifying Life

A Call for Comprehensive Palliative Care

in Bangladesh

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DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

A Call for Comprehensive Palliative Care

Coordination : Laila Karim
Illustrator : Kanakodaya Barman
Compilation : ASDC Team

31st December 2017

Photo courtesy : Sadia Ahmed Chowdhury
Dhaka Medical College Hospital (DMCH)
Bangabandhu Sheikh Mujib Medical University (BSMMU)
*Collected

Source: DMCH

Source: BSMMU

From the desk of

Chairman

Ayat Skill Development Centre envisions a society where every person has the right to a dignified life. Dignifying Life through education, empowerment, employment and healthcare. Our initiatives have included market driven skill development and employment generation of high school dropout youths, skill development and job placement of persons with disabilities, psychosocial counseling on safe migration and human trafficking and advocacy tours to rural high schools with SREDA (Sustainable and Renewable Energy Development Authority) on sustainable and renewable energy.

Ayat's awareness and capacity building initiative of healthcare professionals is a follow on of our commitment to the society of ensuring better healthcare for the general population as a basic human right. The United Nations Committee on Economic, Social and Cultural Rights states the need for Palliative Care as "Attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity". The World Health Organization has recognized the need for Palliative Care to be embedded in our health policy as imperative. According to WHO, access to essential medicines is a part of the minimum core content of the right to the highest attainable standard of care. Hence, it is time we took this seriously. Out of roughly 20 million adults and 1.2 million children who need palliative care assistance today, more than 80% adults and 98% children live in low to middle income countries.

We believe, through knowledge transfer, capacity building initiatives and community awareness such as the one happening this week, we can help pay our dues to the society. 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. This knowledge remittance conference, with much help and guidance from Dr. Anne-Marie Barron, Dr. Bimalangshu Dey and Dr. Judy Beal from Boston Massachusetts will help us create a strong national pool of resource persons to effectively scale up our initiative.
I am grateful and would like to thank you for supporting our initiative. Your participation in this conference is an encouragement for Ayat Skills in its journey forward in creating a unique center of excellence for capacity building initiatives to enhance deeper impact in the society.

Tahsin Aman

Foreword of

Chief Patron

It is an honor to be able to present this commemorative publication on our initiative 'Dignifying Life through Palliative Care' in Bangladesh. The publication contains basic information about the subject, presents some facts & figures revealed through a survey and secondary data derived from different sources in 2017. The third section is the reflections of healthcare professionals and also some personal views which are made from the individual points of the writers. The fourth section contains highlights of our key programs undertaken in the month of January 2018 with the assistance of our lead public health providers, namely Dhaka Medical College Hospitals (DMCH), Bangabandhu Sk. Mujib Medical University (BSMMU) and National Institute of Cancer Research and Hospital (NICRH) and especially the cooperation of the key officials of the Ministry of Health and Family Welfare of the People's Republic of Bangladesh.

We appreciate the whole hearted support and guidance of Dr. Bimalangshu Ranjan Dey of Harvard Medical School, faculty and nurses of Massachusetts General Hospital (MGH) and the Dean and Associate Dean of Simmons College of Nursing, USA, who, from their personal and professional commitments gave time, travelled to Bangladesh for providing technical assistance in up-skilling the capacity of the healthcare service providers of Bangladesh. We are thankful for their enormous support in designing the program and bring this initiative to a shape.

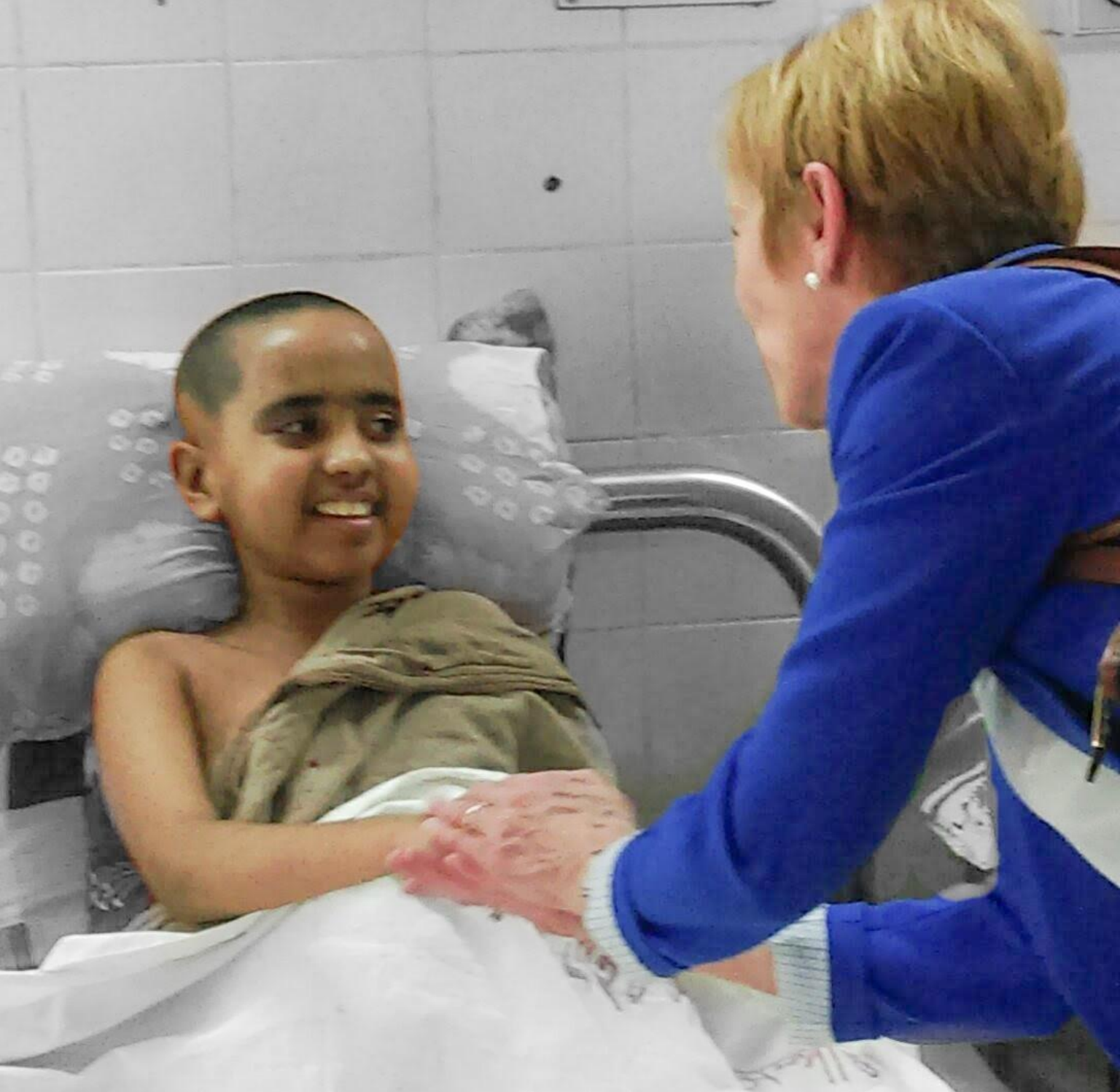
We would not be able to conduct the roundtable discussions without the guidance of the honorable Dy. Speaker of the Parliament of Bangladesh. The opinions and suggestions of the key stakeholders and experts on the subject matter of Palliative Care were invaluable in bringing the issue to public attention. Thanks to the senior members of the cabinet - especially to the honorable Minister of Finance and Honorable Minister of Commerce who gave us the courage to take the issue forward.

We gratefully acknowledge the sponsorship of the Dhaka Bank Limited, Apollo Hospital Dhaka, Aman Group of Companies and our other partners for their generous support in organizing the programs. Our special thanks to RTV, the Daily Star and Amader Shomoy for being with us in promoting the information and knowledge on Palliative Care issues in Bangladesh.

My personal thanks to our ASDC team for their untiring efforts in making the series of events and publication materialize. I must thank our Scholartroop team who came forward to help and mobilize the youth for a cause. Before I end, I owe enormous gratitude to the Chair of Ayat Skills Development Center (ASDC) who gave us continuous support, encouragement and guidance to transform our dream into a reality. I believe, together with you and the rest of our community, we shall move forward with our mission 'Dignifying Life with Palliative Care' and we shall be able to contribute to including 'Palliative Care' into the health care system of Bangladesh. Lastly, I would seek forgiveness for any inadvertent mistakes that occurred in the text or in any of part of our stated program/s mentioned in this publication.

Warm regards.

Nusrat Feroz Aman



Palliative care vs. hospice care

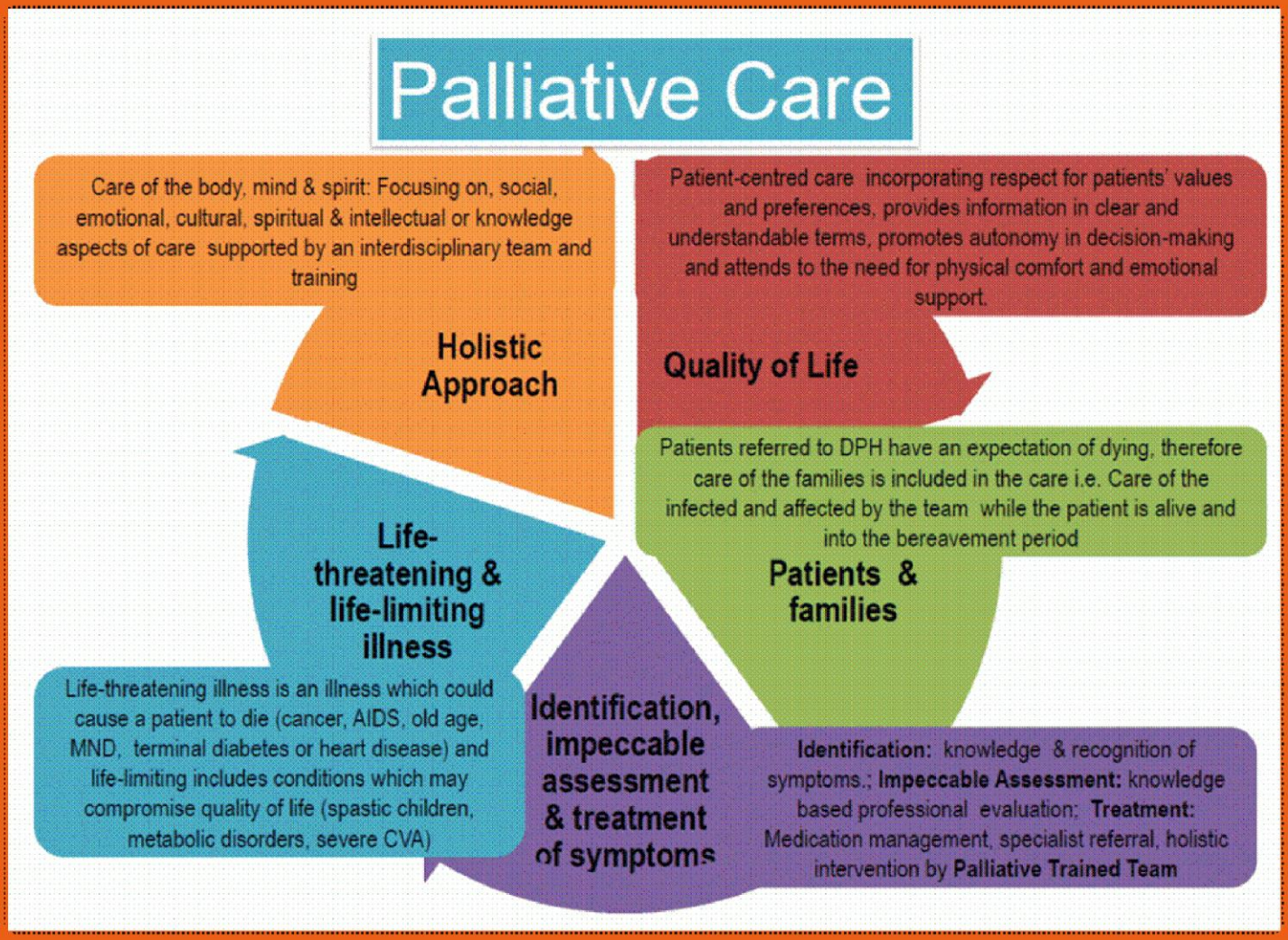
Palliative care is aimed at anyone who has been diagnosed with a life-threatening illness

Palliative care helps maintain quality of life and reduce illness symptoms – and recent findings suggest that cancer patients who receive palliative care alongside standard treatments can live longer

Hospice care is mostly aimed at patients who have been diagnosed with a terminal illness

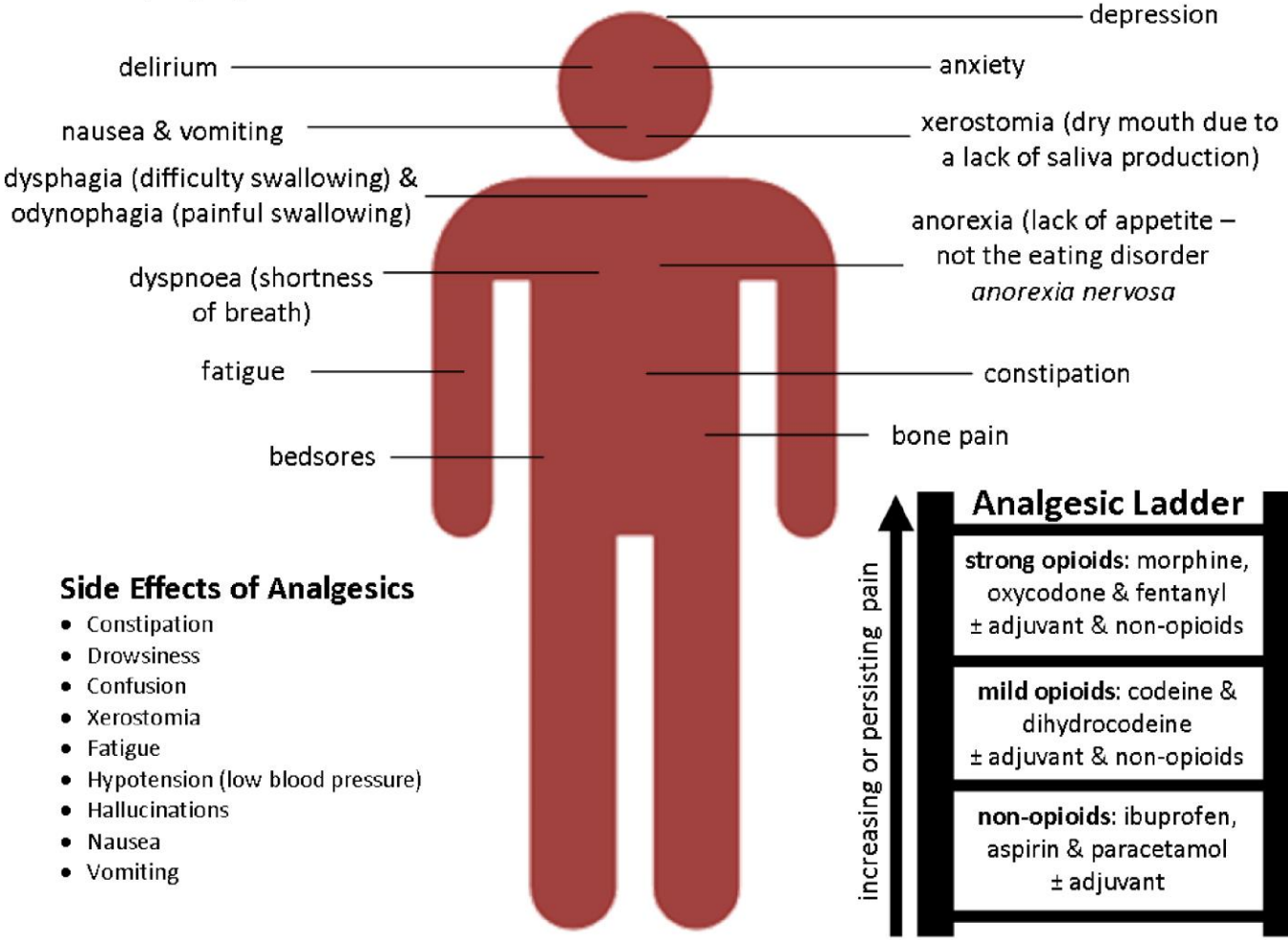
Hospice care is aimed at providing patients with a dignified, pain-free death – in the U.S., hospice care is mostly meant to be administered inside the patient's home, while in Russia, the concept of hospice care is just beginning to gain ground

Source: The Mayo Clinic (mayoclinic.com) and OncologyNurseAdvisor.com



Source: www.thinglink.com

Key Symptoms in Palliative Care



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

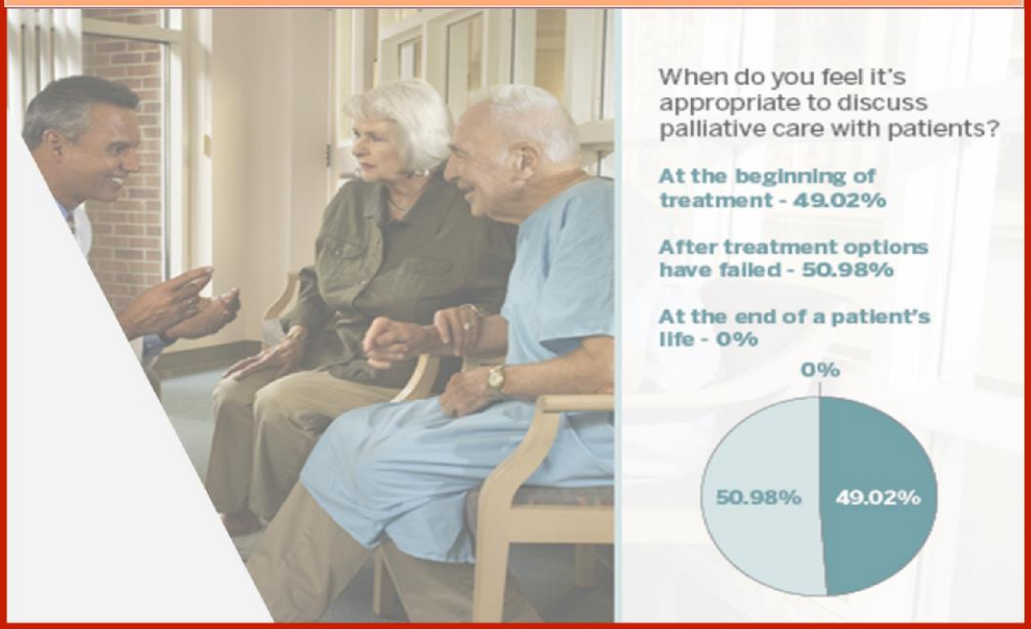
Source: www.pinterest.com


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

"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

Nurses Role in Addressing Ethical Issues

- Promoting family-centered care
- Respecting preferences
- Role models of clinical proficiency, integrity and compassion
- Balancing competing objectives

Lucy Oliva

Olive Oil

CARE comes in many forms but always from the heart

Heartiest congratulations for promoting PALLIATIVE CARE in Bangladesh

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA, 2018

* Photos Collected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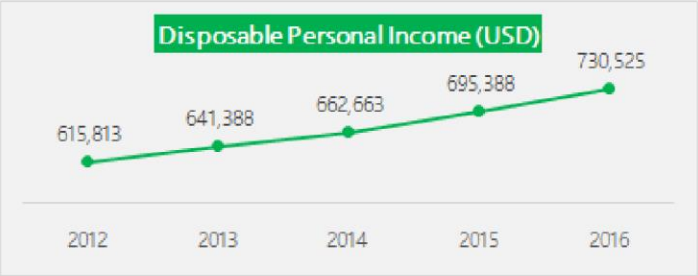
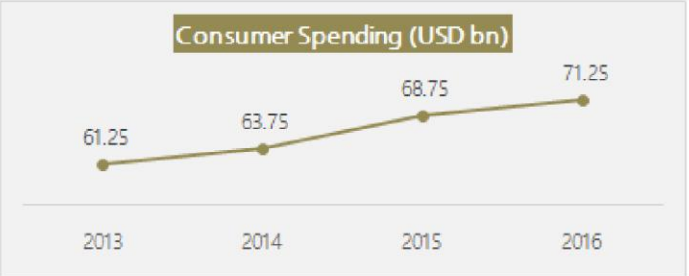
Dignifying Life with Palliative Care in Bangladesh

Bangladesh economy growing fast with GDP growth record 7.24pc, per capita income $1,602. *Growth 6.4pc to 6.8pc in 2017-18, predicts WB report*

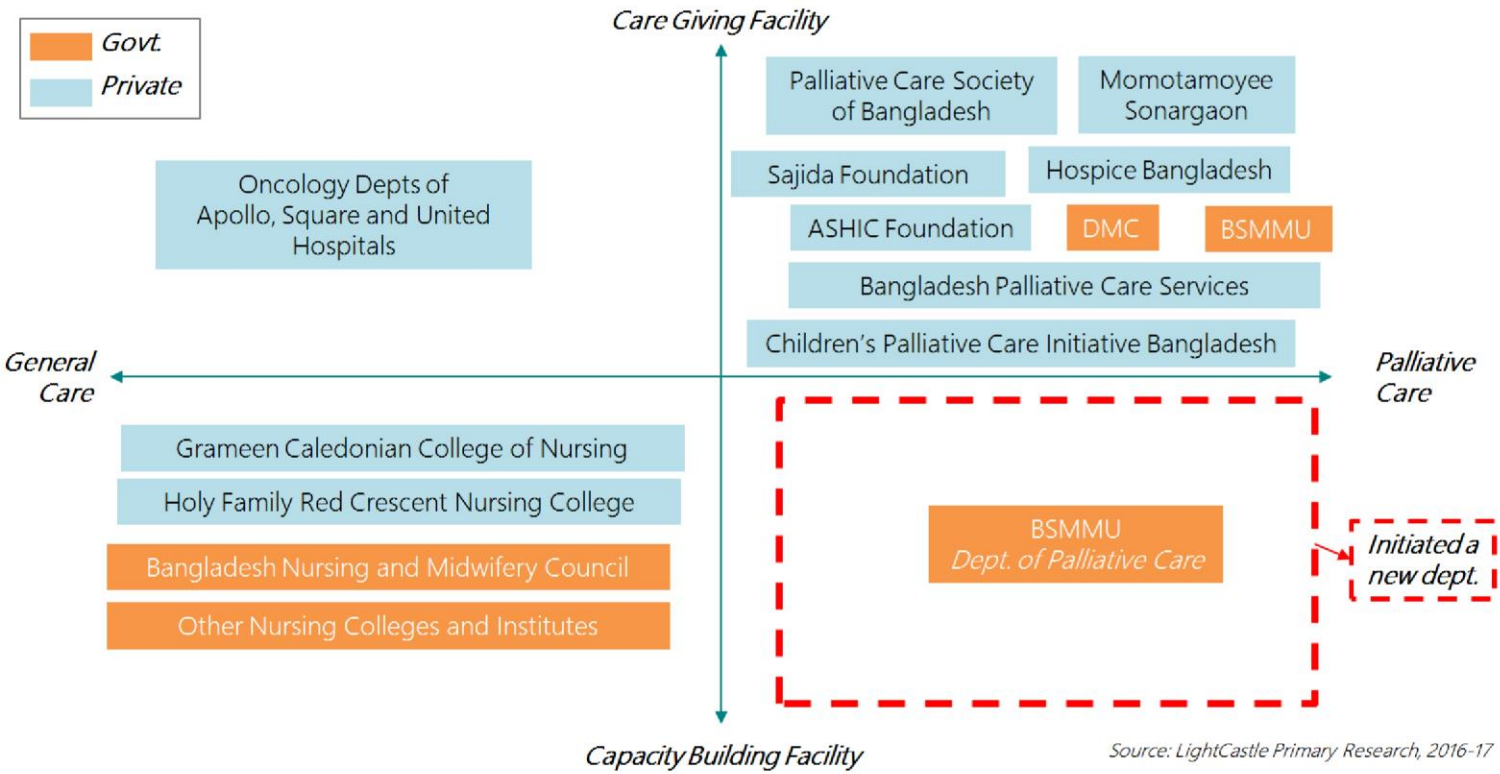




- All these indicators show that **Bangladesh economy has been in an upward trend in the last 5 years and this trend is expected to continue** over next few years as more investments are being made by both domestic and foreign investors in thrust sectors. http://www.thedailystar.net/business/bangladesh-gross-domestic-product-gdp-growth-record-724pc-capital-income-usd1602-1405051

Source: The World Bank, 2017

The competitive Landscape - Who is doing what in Palliative Care



Source: LightCastle Primary Research, 2016-17

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

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

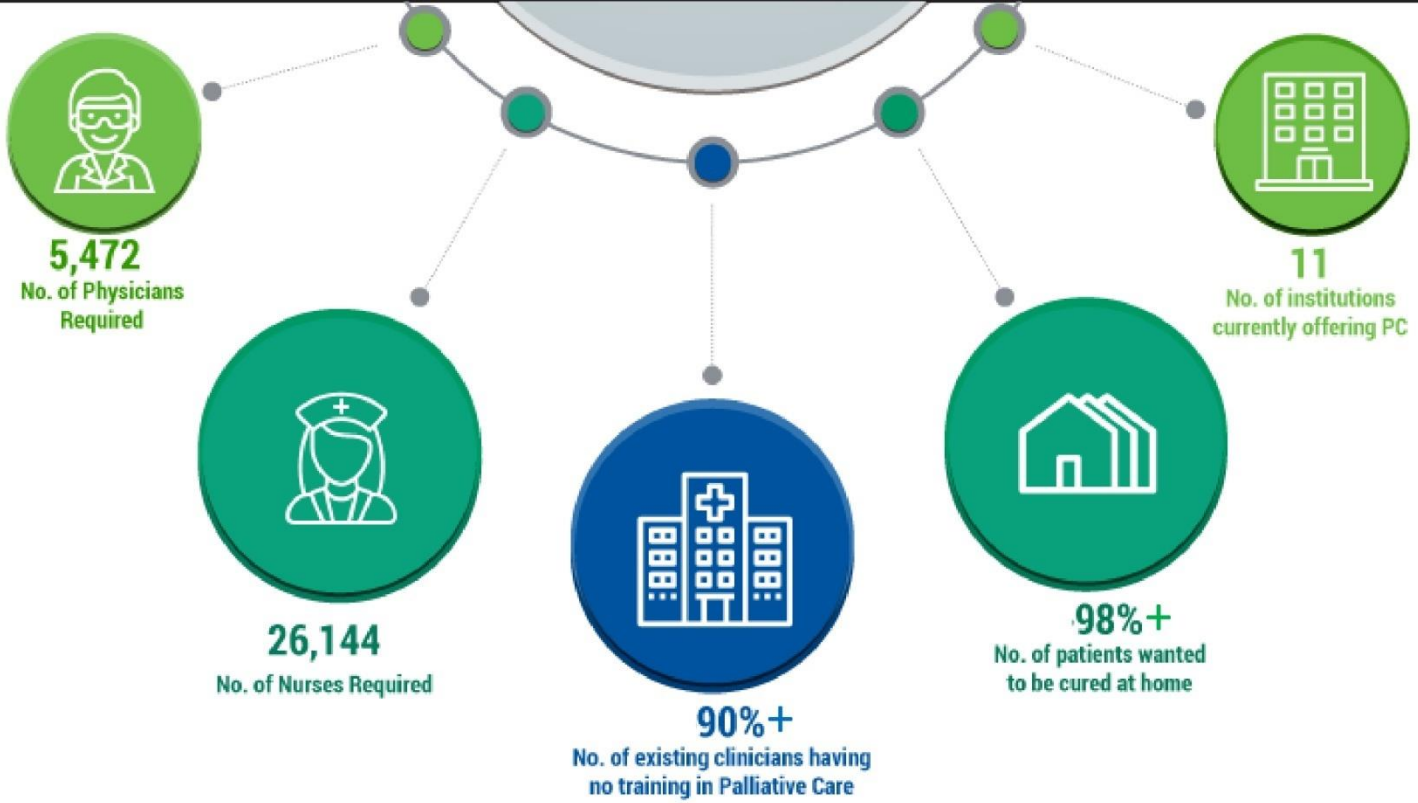
6,034
Dentists

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

Source: Bangladesh Medical Association (2016-17), Bangladesh Health System Review (2015)



Palliative Care in Bangladesh at A Glance

Source: Bangladesh Medical Association, 2016-17

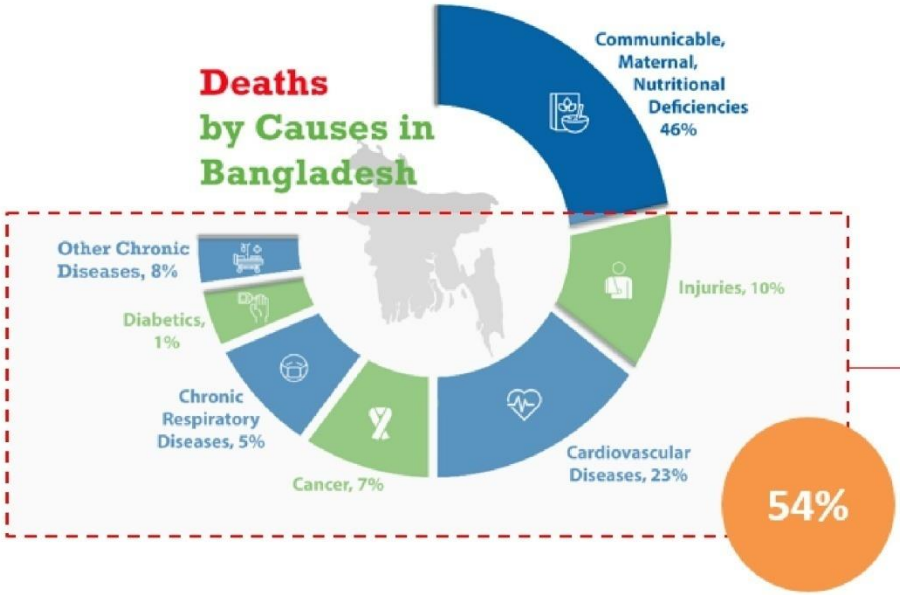
Lack of Infrastructure, Shortage of Health Workforce Dominating Palliative Care supply side dynamics

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**

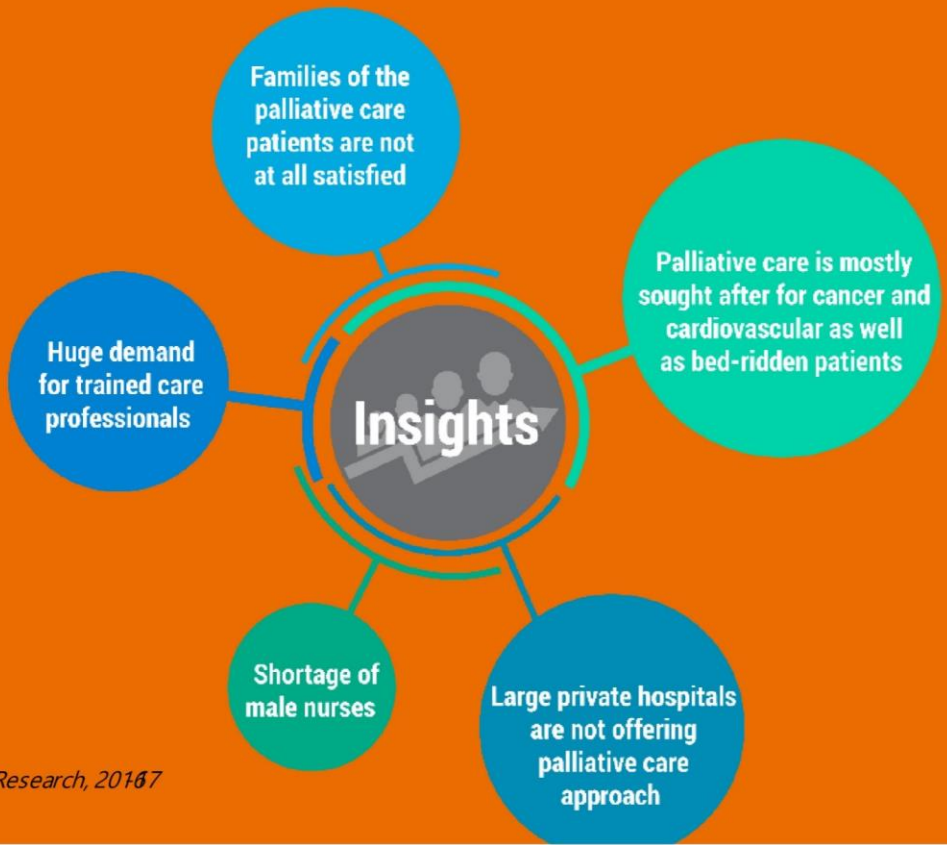
Source: Bangladesh Medical Association, 2016

Case Study 1:

Mrs. Alvira Begum, aged 78, lost her husband 20 years ago, lives with her only son and his second wife who are extremely busy with their own lives. She has faced a **chronic pneumonia attack** quite recently – but there was nobody to take care of her, except for the maid. She has been suffering from bed sores and some other critical injuries due to lack of movement and proper treatment. **She knows she's going to die but she wants to die with dignity and care.**

Case Study 2:

7 years old Nishat has been diagnosed with **Leukemia**. She has been in the care center for the last 2 months. She misses her home a lot but she has found new friends here as well. She plays with them whenever she can. **Nishat has made many wonderful friends and caring nurses here who often made her smile with funny stories and nice gifts.**



Source: LightCastle Primary Research, 2016

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

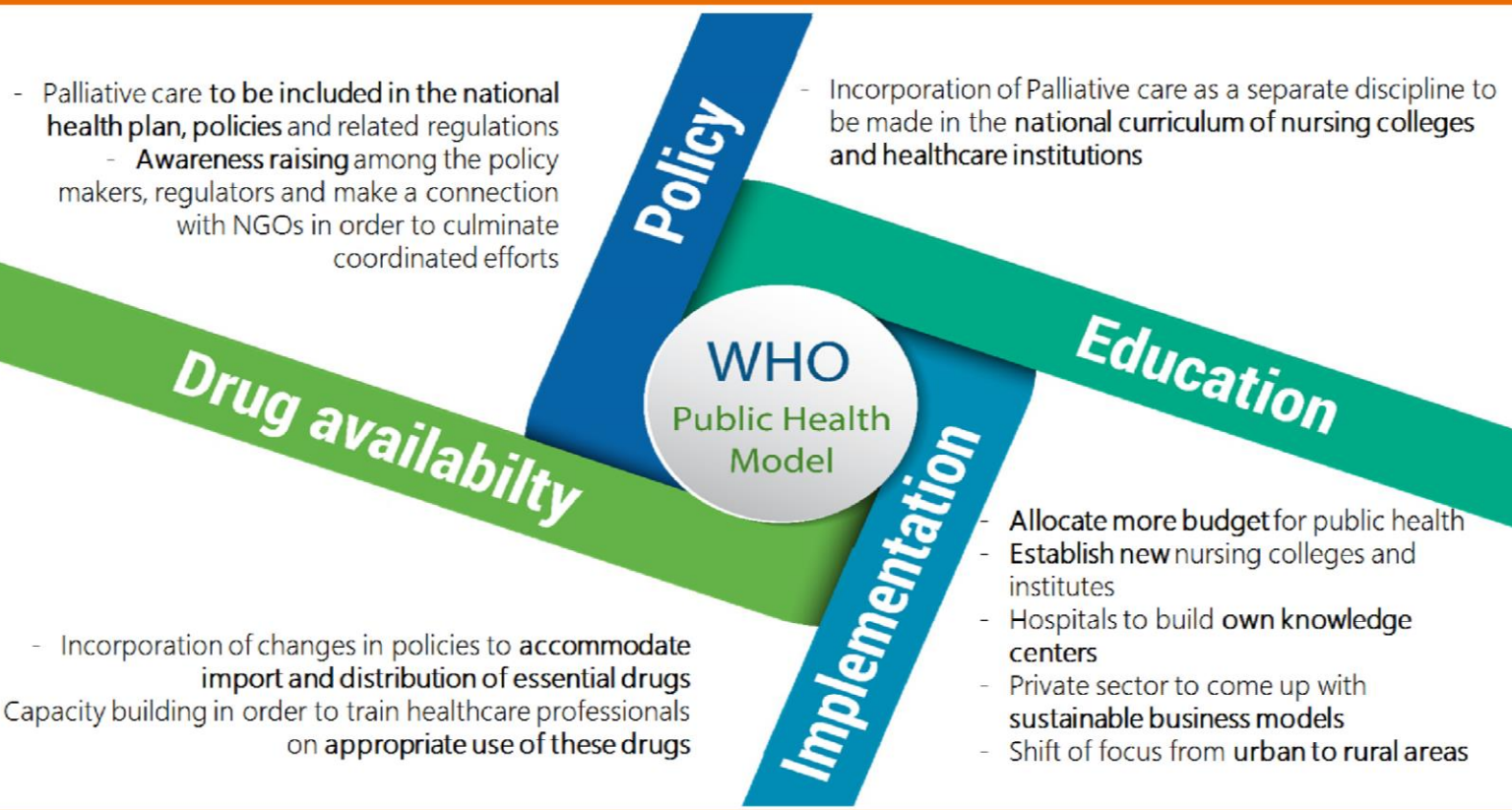
3 GOOD HEALTH AND WELL-BEING

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: Collected

WHO Model

Policy Advocacy

Capacity Building

Essential Medicines

Coordination & Collaboration

National Policy Emphasizing Capacity Building, Meds Availability, Curriculum Modernization

Clause 12 of principles of healthcare policy

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

Clause 3 of specific purpose of national healthcare policy

to encourage the citizens to avail all required healthcare services

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

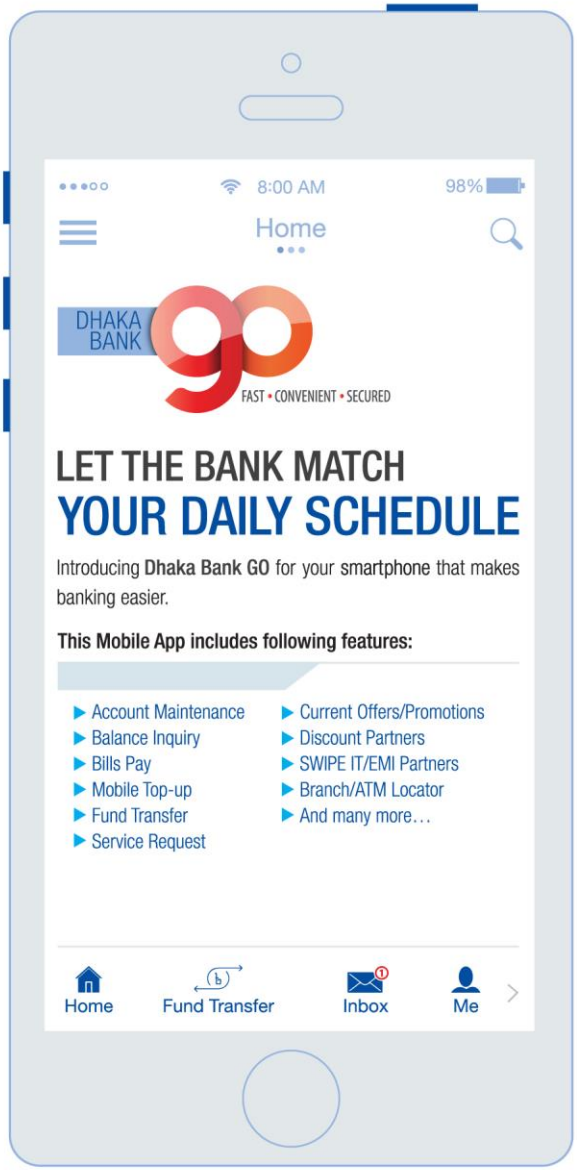
Clause 1 of major objectives and goals of healthcare policy

to ensure healthcare facilities for all as a human right

Clause 17 of major objectives and goals of healthcare policy

to ensure availability of essential medicines and control pricing

Source: LightCastle Primary Research, 2017



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Reflections

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). In my role at MGH I reflect with the nurses on their 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.

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 Centre.

Anne-Marie Barron

Nisha Wali, RN

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

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.

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.

Nazma Begum Feroz
Cancer Survivor

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.

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.

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

Palliative Care to me and us

Dr. Shuchi Karim

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.

An Evaluation of Palliative Care in Bangladesh: A Study

Dr. Rumana Dowla

Background of the study

Palliative care is an emerging discipline in medical health care system in today's world. The worldwide growing occurrence of non-communicable and chronic diseases such as cancer, cardiovascular diseases, chronic obstructive pulmonary diseases, kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological diseases, Alzheimer's disease, HIV/AIDS and drug-resistant tuberculosis has formed a growing public health and clinical need for palliative care.

Palliative care is one of the crucial constituent of comprehensive health services for NCDs. In 2014, World Health Assembly resolution WHA67.19, called upon WHO and Member States to develop access to palliative care as a core element of health systems, and the emphasis was on primary health care and community/home-based care [3]. In order to achieve Sustainable Development Goals (SDG), palliative care needs to include Universal Health Coverage. The palliative care is approaching to be regarded as a human right. Yet globally, palliative care development and services are generally unavailable [10].

The majority of palliative care services are located in developed countries although the higher incidences of Cancer, AIDS and other non-curative diseases occur in the developing countries. The need for palliative care in developing countries is a public health issue, which public health specialists and policy makers may not be prioritizing [12].

Objectives of the study

The present study will be identifying the present status of palliative and support care in Bangladesh. The primary objectives are:

1. To create awareness among people about palliative care
2. To investigate the problems while providing palliative and support care in Bangladesh.
3. To recommend possible solution.

Methodology

A systematic literature review was implemented to select articles that present data on patients receiving palliative and end of life care.

Literature Review

To identify relevant information and to outline existing knowledge, literature review is very significant for conducting research. A systematic literature review always bring out what is available in specific research areas and what is the gap that need to explore. Several numbers of relevant literature exists on palliative care from different disciplines.

Lynch, T., Connor, S., & Clark, D (2013) categorized the development of palliative care into a six-part typology. These are Group 1-no known hospice-palliative care activity, Group 2-capacity-building activity, Groups 3 and 4 have been subdivided to produce two additional levels of categorization: 3a- Isolated palliative care provision, 3b- Generalized palliative care provision, 4a- Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision, and 4b- Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. Bangladesh is in Group 3a.

Singh, Taranjit, and Richard Harding (2015) conducted a research on palliative care in South Asia. The major objectives of the research was to systematically review the evidence for palliative care models, interventions, and outcomes in South Asia. The study indicates that, in South Asia most of the research have been conducted in India whereas in Bangladesh, Bhutan, Afghanistan, Maldives and Sri-Lanka the result found no data.

Jocham (et al). (2006) investigated a study to get insight into the international standards of quality of life assessment in palliative care and to examine how nurse researchers define and assess this concept in the context of terminally ill cancer patients. The study found that, oncology and palliative care nurses have a great contribution to the development of the quality of life concept through instrument development and population description.

Webster, R., Lacey, J., & Quine, S. (2007) revealed that professional health education, availability of opioid, government commitment, and by ensuring public education about home care, palliative care services can easily be implemented.

Palliative Care

The word 'palliative' comes from the Latin 'pallium' which means 'cloak'. Palliative care focuses on relief, not cure, by concentrating on cloaking the severity of disease symptoms.

WHO defines palliative care as "an approach that improves the quality of life of patients (adults
and children) and their families who are facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain, and other problems, whether physical, psychosocial or spiritual [2]. Palliative care develops the quality of life of patients (those who are sufferings from chronic and life-limiting illness) and of their families by reducing unnecessary costs for treatment and use of health care services.

Palliative care is a care that helps the patients with Non-Communicable Diseases and their families to improve their life by providing supportive care to reduce the burden i.e. physical, mental, social and financial. Palliative care services focus mainly on non-communicable causes of death in addition to other chronic illnesses such as HIV/AIDS. Palliative care also reduces the unnecessary use of hospitals, diagnostic and treatment interventions, and non-beneficial intensive care.

Palliative care is an essential part of the health management sector for the patients and their families. The enabling factors for implementing this care level include caregiver burden, skills preparedness, overall Quality of Life (QOL), psychological distress, and self-care.

Palliative care is a term related to hospice care. Hospice care is end-of-life care in which a group of health care professionals and volunteers provides medical, psychological, and spiritual support. The ultimate purpose of the care is to help people who are dying have peace, comfort, and dignity. Hospice care also provide facilities to support a patient's family.

Present status of palliative care in the world

In 19th century, the term 'palliative care' began with the hospice movement in London which was run by religious order. The modern use of the term hospice established by Dr. Cicely Saunders in 1967 with the opening of St Christopher's Hospice, London [7].

The term 'palliative care' was first coined in 1975 by Canadian surgeon Balfour Mount. Mount developed a comprehensive hospital-based service including in-patient ward, consultation service, home care program, at the Royal Victoria Hospital, Montreal under the name Palliative Care service. His aim was to improve the quality of life [8].

By the year 1999, around 6540 palliative care services were established in 84 developed countries of the world.

A 2011 study 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 [4].

WHO estimates that, each year, 40 million people are in need of palliative care in which 20 million people need end of life palliative care. It is estimated that of the 20 million people needing palliative care at the end of their life, around 80% live in low and middle-income countries; in which about 67% are elderly (more than 60 years of age) and about 6% are children. Only 14% of people needing palliative care is being met at the end of life and less than 10% met overall care. In only 20 countries palliative care well integrated into the health care system.

According to WHO Global Health Estimates there were approximately 54.6 million deaths worldwide in 2011 in which about 66% are due to non-communicable diseases. In 2011, over 29 million (29,063,194) people died from diseases that requires palliative care. At the end of life over 20.4 million people need palliative care.

The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. Only 6% of all people in need of palliative care are children. Based on these estimates, globally each year, around 377 adults out of 100,000 population over 15 years old, and 63 children out of 100,000 population under 15 years old will require palliative care at the end of life.

Palliative care in Bangladesh

Bangladesh is one of the most densely populated countries in the world. Health and education levels are relatively low. Most Bangladeshis continue to live by subsistence farming in rural villages. Bangladesh faces a number of major challenges, including poverty, corruption, overpopulation and vulnerability to climate change but Bangladesh has gained remarkable improvements in life expectancy [9].

WHO indicates that, Bangladesh has gained notable progresses in population health status by achieving MDG 4 by reducing child death before the 2015 target, and rapidly improving on other key pointers including survival from some infectious diseases including malaria, tuberculosis, and diarrhea, immunization coverage, and maternal death. Bangladesh is currently enduring a demographic evolution and the proportion of the population 60 years and older is rapidly increasing. Bangladesh has made tremendous progress in health and development since independence. In some cases, the country has made more impressive gains than most of its neighbors. Bangladeshis now live longer. The average life expectancy at birth increased from 40 years in 1960 to 64 years by 2005. Bangladesh's elderly population is one of the largest in the world in terms of absolute numbers. Currently, older people amount for around 7% of the country's total population, amounting to roughly 10 million people. By 2050, the 60+ population will account for 20% of the total population- a four-fold increase from the present time. The increase in elderly population in Bangladesh during the period 1990-2025 is projected to be much faster (219%) than that of European countries such as Sweden (33%), UK (45%) or Germany (66%). While changing lifestyles, urbanization and the decline of traditional family support system have increased the plight of the elderly people, especially the poor and the women. With increasing life expectancy chronic and fatal diseases are also increasing. So, palliative care is crucial besides proper healthcare system.

Bangladesh is estimated to have more than 1 million patients with cancer at any point of time. Another million suffer from other incurable diseases like progressive neurological, cardiac and respiratory diseases and HIV/AIDS etc. About 0.6 million people needing palliative care per year. Approximately 75% of cancer patients attending for treatment are incurable and they can get treatment in palliative centers.

The health system of Bangladesh is diverse, which has four key actors that define its structure and function: Government, the private sector, NGOs and donor agencies. The Government or public sector is the first key actor.

By constitution, Government sector is responsible not only for setting policy and regulation but also for providing comprehensive health services, including financing and employing health staff [6].

Public sector care includes curative, preventive, promotive and rehabilitative services, while the private sector provides mostly for-profit curative services and not-for-profit curative services to a limited extent at the national and subnational level. NGOs, on the other hand, provide mainly preventive and basic care and not-for-profit services to the underserved population. This is the actual scenario of health care system in Bangladesh. In this context, starting palliative care movement requires a supportive contribution from all four key agencies.

In Bangladesh, first palliative care initiatives was started by a non-profit charity organization named ASHIC Palliative Care Unit in May 2006 with funding from UICC. It is the first and only facility in Bangladesh to offer palliative care to the terminally ill children. It is founded by Salma Choudhury named after her son Ashiq Hossain Choudhury. In 2005, ASHIC Foundation was the only parent-run organization out of 14 projects worldwide to receive funding for the country's first palliative care unit.

Dr. Rumana Dowla plays pioneering role in establishing Palliative Care in Bangladesh. Dr. Rumana Dowla is the first certified and trained Palliative Care physician in Bangladesh. After completing her MBBS from the prestigious Lady Hardinge Medical College, New Delhi, Dr Rumana was awarded the Commonwealth Scholarship in 2008 to pursue a Masters in Palliative medicine from Cardiff University, UK. Currently, Dr. Rumana provides palliation to patients and their families through Bangladesh Palliative and Supportive Care Foundation (of which she is the founder Chairperson), at United Hospital and honorary service at BSMMU Hospital and National Institute of Cancer Research And Hospital (NICRH).

The initiative of palliative care in BSMMU began as a service in 2007 and the Centre for Palliative Care (CPC) was established in 2011, it has taken over the pioneering role which not only includes development of a model replicable service, but also has been pursuing awareness creation amongst health professionals as well as community at large. He further mentioned that BSMMU has also been trying to convince the policy makers to incorporate palliative care program in the main stream health care program.

Hospice Care in Bangladesh is provided by Hospice Bangladesh, a home and palliative care center located in Mohammedpur, Dhaka. It provides Palliative Care to adults and children with life limiting illnesses through the inpatient, Home and Day Care services. It is founded by Dr. Shahinur Kabir.

Apart from these organizations, Sir William Beveridge foundation, Care Bangladesh, Dementia Bangladesh, Smileage Bangladesh Limited, Shanti Oncology and Palliative Care Unit also play a great role in establishing palliative care movement in Bangladesh.

Major challenges

Palliative care focused on improving quality of life for patients and their families. It also emphasis on improving planning and communication among the care team (patient, family, and medical staff), and ensuring emotional and spiritual needs. But unfortunately, there are various complications to fulfilling patients' and their families' hopes because of the geographical, social and medical backgrounds among different countries. As Bangladesh is a developing country, several obstacles resist in developing palliative care service. Followings are some major challenges in implementing sound palliative care services in Bangladesh.

- Lack of awareness among policy-makers, health professionals and the public about palliative care
- Lack of knowledge of palliative care among health care workers.
- There are so many misconceptions about palliative care such as, palliative care is for those only who are dying etc.
- Palliative care is not integrated into basic health care system.
- Adequate skilled staff are not available in Bangladesh.
- Basic infrastructure system of maximum healthcare institution for providing palliative service are not offered.
- Limited availability and accessibility of essential palliative care medications.
- Budget is a burning issue.

Recommendation

Various research and studies are needed to measure the efficiency of the strategies used for implementing effective palliative care centers in Bangladesh. Followings are some recommendations that can be applied.

- National policy on palliative care should be formulated and implemented as soon as possible.
- Palliative care must be integrated into national health care system.
- Palliative care needs to be affordable and cost effective.
- Government hospitals and other health care services need to introduce palliative care for terminally ill patients.
- Palliative and hospice care concept should be clearly stated among people.
- Public awareness about palliative care among people should be increased at a rapid pace.
- All medical and relevant professional institution should comprise basic training on palliative care.
- Professional education should include palliative care for existing health professionals.
- Every person should have access to quality, affordable health services, including palliative care
- Essential palliative care medicine should be affordable and available to the patients.
- If possible, palliative care treatment should be provided free at cost.
- Palliative care should be available and accessible at the community level.
- Research and evaluation processes are needed to ensure the quality of palliative care.
- Safe use of medications such as opioids should ensure.

Conclusion

The need for palliative care services will continue to develop, owing in part to the rising prevalence of non-communicable diseases and the ageing of populations everywhere. For non-communicable diseases, the pain could be reduced through their early detection and timely management to prevent complications. It can be said that a reconfiguration of national healthcare policy is required to integrate palliative care into existing health care services and to engage the wider community in supporting those in need of palliative care. Still, a lot needs to be done for creating awareness and training in Palliative Care.

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for the capacity building initiative of Palliative Care in Bangladesh

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Dignifying Life

A Call for Comprehensive Palliative Care

PROGRAMS

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
January 8th, 9th, 10th, 11th and 12th 2018

Nurses from Massachusetts General Hospital (MGH) and Simmons College in Boston will be traveling to Dhaka in early January to offer a five-day intensive palliative care training program for nurses in Dhaka. The training is being offered through the generous support of Nusrat and Tahsin Aman of the Ayat Skill Development Centre in Bangladesh. Dhaka Medical College Hospital will be convening the program in collaboration with BSMMU and NCIRH. 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.

DIGNIFYING LIFE THRU PALLIATIVE CARE

DHAKA 2018

5 Jan 2017

Walkathon
RTV Talk Show

6 Jan 2017

Round Table Discussion with The Daily Star
Opening Dinner

7 Jan 2017

Physician's Day
Dignifying Life – Roles of the Physicians in Relieving Suffering

8-12 Jan 2017

ELNEC Certificate Course for the nurses

End-of-Life Nursing Education Consortium

This is to certify that

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

has completed an authorized ELNEC-(designate Core, Peds, Critical Care, Gero, APRN) Training Course

8th - 12th January 2018

Dhaka, Bangladesh

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 Skill Development Center, Dhaka

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

Dr. Bimalangshu R. Dey
Associate Professor
Harvard Medical School

Certificate for the Nurses

Resource persons from USA

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.

Resource persons from USA

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.

Resource persons from USA

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.

Resource persons from USA

Emily Erhardt, BS, RN

While working as a staff nurse in and ICU at Massachusetts General Hospital, Emily was presented with the opportunity to become involved with the Enhanced Specialized Nurse Training Program (ESNTP) in Dhaka, Bangladesh. Focusing mainly on the care of oncology patient, and specifically bone marrow transplant patients, Emily was apprehensive that she would be able to educate nurses on a topic she was not all too familiar with herself. However, she knew it was an opportunity that she could not pass up, and in 2014 traveled for the first time to Bangladesh as a Global Health Nurse Fellow for the ESNTP. Soon after her arrival, Emily was relieved to find that nursing as a whole, is a universal language. Not only she did feel confident in guiding these intelligent women and men in the care of an immunocompromised patient, but she found that they too, had many things to teach her, as well. The compassion and empathy the nurses had for their patients, with limited resources, lit a fire within Emily, and made her realize oncology was her true calling in nursing. When she returned home, she made the transition from a critical care nurse to an oncology nurse, and has not looked back since. She has her Bengali friends to thank for that. This is her third trip to Bangladesh, and she is excited to be back, and to share her knowledge in palliative care with the End of Life Nursing Education Consortium.

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 experienced 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 transitions. 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.

Nurses expressing their commitments

Ayat Skill Development Center

Ayat Skill Development Center is to create skilled man power and to change the living standard of the people by proper technical training and providing employment opportunities. Training is the heart of all activities of ASDC that never cease to work. We add value to equip our trainees to compete and survive in the job market. We help unemployed and employed professionals to equip themselves with the marketable skills and help them with job placement facilities to be self-reliant and also to grow further. Our instructors are specialized in their specialized fields. Women empowerment and capacity building of the disadvantaged group and young adults with disabilities is our special focus. Recently ASDC is initiating to take part in the health care sector with "Dignifying life with Palliative Care"

The Centre emerged as an ultimate solution to the unemployment situation and as a Youth Skills Training Program ASDC focuses on the necessary attitudes, skills and knowledge into individuals for career success in this new era of work. The organization's services include specialized Technical Training (approved by Bangladesh Technical Education Board), Basic English Language training, Life Skills; Office Etiquette courses, Industry based practical training, Apprenticeship program, Job training and placement

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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).