DIGNIFYING LIFE THRU PALLIATIVE CARE

A Call for Comprehensive Cancer & Palliative Care in Bangladesh

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A Call for Comprehensive Cancer & Palliative Care in Bangladesh

Series 3

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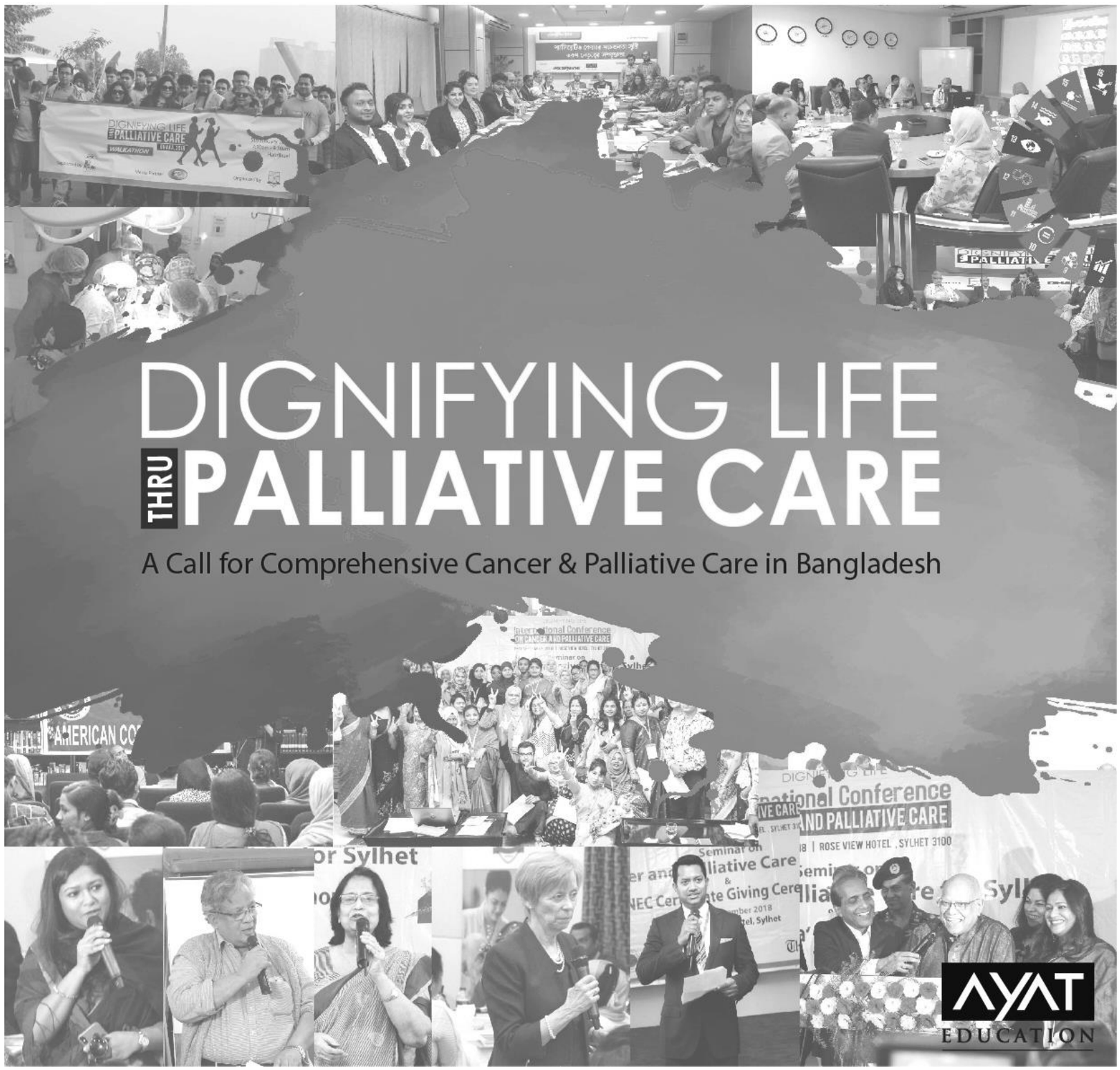

DIGNIFYING LIFE
THRU
PALLIATIVE CARE
A Call for Comprehensive Cancer & Palliative Care in Bangladesh
WALKATHON
International Conference
ON CANCER AND PALLIATIVE CARE
ROSE VIEW HOTEL , SYLHET 3100
AYAT
EDUCATION

CONTENT

Prime Minister's Office
Government of the People's
Republic of Bangladesh

Prof. Gowher Rizvi
International Affairs Adviser
to Hon'ble Prime Minister

It's my pleasure to write this message on an issue that is important and asks for attention of all strata. Palliative Care is still a new term in our health care vocabulary. We are aware that with the increasing number of non-communicable diseases patients, along with the extension of lifespan (with the associated ailments), Palliative Care became a necessity in our lives. We need to instill it in our care system.

Since the emergence of Bangladesh, the government has given utmost priority to ensure human rights and dignity of its population. The constitutional provisions are made to protect, promote and respect health care as a constituent of human rights in Bangladesh. In this regard, the government has taken up necessary steps to uphold the dignity of its citizens.

I am pleased to learn that AYAT Education has taken up a timely step with the slogan" Dignifying Life through Palliative Care". This is a call for valuing life up to the end of its journey. I shall urge upon to all of us, especially the Health & Family Welfare Ministry and its departments and civil society to join hands and let the program proceed in achieving its goals which is also in line with the Sustainable Development Goals (SDG 3) for 'Good Health and Well Being' by 2030.

I wish AYAT Education every success in this noble mission. Long Live Bangladesh.

Signature

Ministry of Health & Family Welfare
Government of the People's Republic of Bangladesh

Md. Ashadul Islam
Secretary
Health Service Division

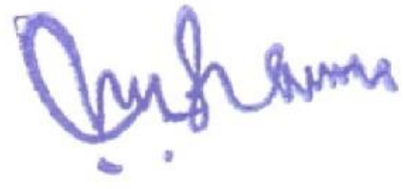
Palliative Care approach is for reliving the pain and suffering of patients living with serious life limiting illnesses. This approach improves the quality of life of those suffering from incurable diseases. Non-communicable disease (NCDs) including cancer, heart disease, stroke, chronic respiratory disease, and diabetes represent a significant and rising share of the national burden of disease and account for more than half of all deaths in Bangladesh.

In Bangladesh, about 800,000 (WHO) patients require palliative Care each year. It is also learnt that palliative care alone could improve the quality of life of 1,500,000 people per year, provided the services of skilled/trained health care service providers and resources are made available to the patients. In order to meet the requirement our health sector needs to be equipped with trained health personnel (i.e, physicians, nurses, technicians, care givers) and equally supported by the facilities (tools & updated knowledge). The awareness of general public, especially the involvement of the youth, is critically important. An effective collaborative approach between the government and private sector will assist to Health coverage of general people of Bangladesh and contribute to achieving the Sustainable Development Goals by the year 2030.

Comfort, dignity and love are the universal needs of a dying person, whether he dies in affluence or in poverty, and amongst latest medical equipments or in basic care. As a society our morals, values, patience and knowledge are tested when tending to patients or families with life limiting diseases and often the psychological and spiritual needs become as important, if not more, than our medical needs. Bangladesh is among the youngest countries in the world, with more than our medical needs. Bangladesh is among the youngest countries in the world, with more than half the population being below 30. As this is a great strength for us, there also is no denying that soon we will be catering to a huge segment of aging population. Keeping that in mind, the Government of Bangladesh is taking steps to capacitate our health care providers with knowledge and expertise on Palliative Care. We are working on a guideline as the first step to creating a holistic environment for making palliative care accessible to everyone in the community. Right now, Palliative Care delivery in Bangladesh follows and isolated, patchy approach. These are mostly small scale individual efforts which could benefit greatly through effective collaboration. Efficient and effective delivery of palliative care can be obtained through a synergy of these four components, policy implementation,

education and training, availability of pain management drugs and community engagement. The Ministry of Health's continuous effort to provide optimal solutions even in the most challenging environment is reflected in how well the community healthcare approach works in our country, this resulted in substantially reducing child mortality rate. Awareness and education in the community about Palliative Care can also create significant improvement for the quality of life during the last days of the patients, Continuous Education and training of our healthcare providers, in alignment with obtaining the sustainable Development Goals, will provide the initial steps to incorporate palliative Care in to the mainstream of our Healthcare practices.

I congratulate AYAT Education on their Efforts and wish them Best for the path ahead.



Signature

Message

Tahsin Aman
Chairperson
AYAT Education

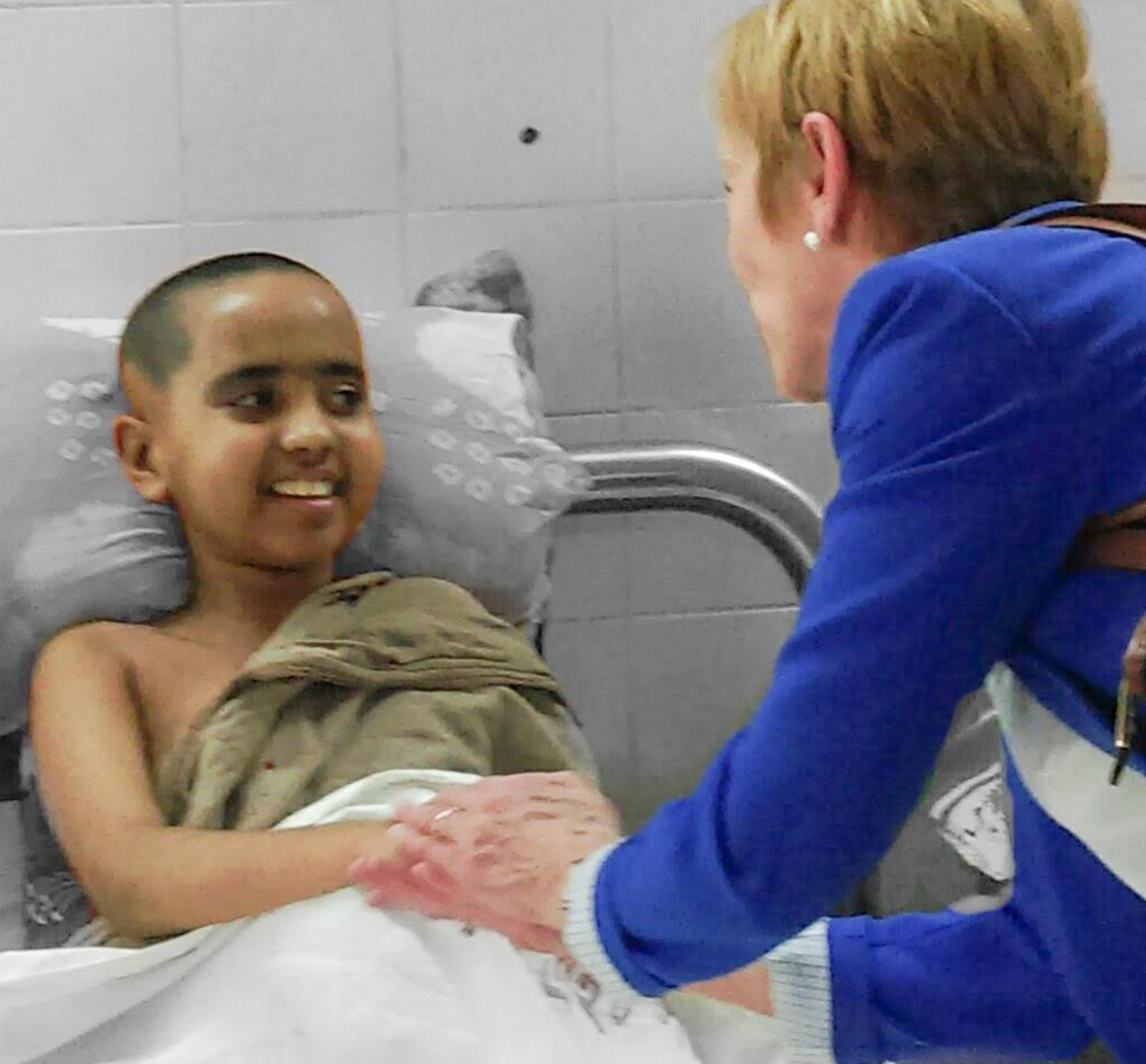
We, the Ayat Education team, have always stood in the forefront of advocating a dignified life. A life that is self- respecting and worthy. Hence, we are a big proponent of Palliative Care which gives patients an option for pain and symptom management and higher quality of life while still pursuing curative measures. A life of dignity as long as we live.

Our very first large scale program on Palliative Care started in January 2018. Since then we have had two more programs in Dhaka and Sylhet in September 2018 and January 2019, now we are back again in November 2019 for the fourth time. Our comprehensive program includes international standard training program for Doctors, Nurses, Community and Youth Engagement, TV talk shows and round table discussions involving health care professionals, youth and government officials. Our group of nurses and physicians also conduct patients reviews and surgeries.

It has been a truly humbling experience to see that as we progressed with our advocacy programs over time, we have received more and more, ever increasing support from the community and especially from the govt. sector and international agencies. Ayat Education firmly believes that effective collaboration is an essential key to make sustainable impact. The support that we receive from our international partners, highly capable local experts and policy makers, is the perfect example of collaboration that brings great minds together, fusing ideas for the betterment of our society.

I am very grateful and I want to thank everyone concerned for joining Ayat Education in this mission to Dignify Life. The support and appreciation makes me realize that we can do anything together. Let us all march forward and Dignify life through education, empowerment and healthcare. Let us focus on the value of every person as an individual.

Signature



Nusrat Feroz Aman
Chief Patron
AYAT Education

Message

I do mean it when I say that this was purely an honor and privilege that AYAT education had the opportunity to launch and support the Palliative Care Conference in January 2018 in Dhaka Bangladesh. Both inspired and invigorated by this clear success, we made an easy decision to continue and support the 6-day complex yet comprehensive Cancer and Palliative Care Conference in Sylhet. We bear no doubts that this intervention has also been very impactful. And hence the continuation of our commitment to build on the cancer and palliative care capacity in Bangladesh.

The third and fourth cohorts of this training program were held in February and November 2019. By now we have more than 350 clinicians and healthcare providers who have graduated with the ELNEC Train the Trainer Program, competent to teach and practice basic Palliative Care. We would have completed numerous multidisciplinary tumor boards, engaged in many rich conversations at policy, expert and public levels. We also continue to complete round table discussion with the leading newspaper on the role of youth leadership and community engagement to enhance palliative care and cancer awareness.

This would not have been possible without the tremendous and generous efforts of our national and international experts. Thanks to the Professionals, to each and every medical institution in Dhaka for their outpouring support which is making this conference such a seamless journey. Our Hope, this Journey will continue and we shall take this model forward to each and every corner of the country to help develop their own cancer and palliative care Program. You, the people of Dhaka, I Should Say, the People of Bangladesh, have our Promise AYAT Education will stand by it.

Thank you and with Deep Gratitude

Signature

GLOBAL

Cancer and

STANDARD

Palliative Care

PALLIATIVE CARE
KEY FACTS

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.

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.

Early palliative care reduces unnecessary hospital admissions and the use of health services.

The global need for palliative care will continue to grow as a result of the rising burden of noncommunicable diseases and ageing populations.

Source: https://www.who.int/news-room/fact-sheets/detail/palliative-care | 19 February 2018

BARRIERS

Population access to opioid pain relief is inadequate and fails to meet international conventions on access to essential medicines.

Poor access to palliative care

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

Training on palliative care for health professionals is often limited or non-existent

Common Misconceptions

-Improving access to opioid analgesia will lead to increased substance abuse.

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

Cultural and Social Barriers, such as beliefs about death and dying

What can Countries Do?

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 professionals, as well as educating volunteers and the public.

Medicines Policy which ensures the availability of essential medicines for managing symptoms, in particular opioid analgesics for the relief of pain and respiratory distress.

Integration of Palliative Care Services
(Based on a 2011 Study)

234 countries, territories and areas

26%	32%	42%
Integrated	Isolated	No Services

Source: https://www.who.int/news-room/fact-sheets/detail/palliative-care | 19 February 2018

Bangladesh Situation

Non-communicable disease (NCDs) such as cancer, heart disease, stroke, chronic respiratory disease, and diabetes, persons with long term illness, injuries represent a significant and rising share of the national burden of disease and account for more than half of all deaths in Bangladesh.

On average,

70%

of cancer patients in Bangladesh are diagnosed at an incurable stage of illness. The only possible intervention for these seriously ill patients with severe sufferings is ensuring Palliative Care.

Why Aren't More Women Working?

They're Caring for Parents

With the growth of the ageing population around the world, the need for care givers to help them with day to day routine and medication rises steadily. Currently, most of those providing care to this population in need are immediate family members. According to the US Labor Department, 15% of women and 13% of men in the age group of 25 to 54 sacrifice their time to take care of their elderly relatives in need of care. Hence, the growth of the aging population forcing this group of private care givers into part time work or abandoning work completely, losing a prime part of their earning years.

Among developed countries, the U.S. ranked only 30th in women participation in the overall workforce in 2017, compared to ranking 17th in 2000. From the late 1990s, women in general are increasingly facing the struggle of managing their elderly relatives as well as their children, while keeping full time jobs. Having to take leaves to care for children or elderly relatives, results American families to forgo at least $28.9 billion per year in wages (The Liberal Center for American Progress, 2016).

The burden of care is developing quickly into a political urgency in the US, with political leaders believing that an institution needs to play major role to take care of the aging group. If the US would subsidize the care of children and the elderly, like e.g. Canada or Germany, it would free 5.5 million women to work, leading to an increase in the GDP by 3.5%. Even though some states have policies to increase paid leaves or facilities for women to join a job after maternal leaves, these initiatives are still small in numbers. According to the National Academy of Social Insurance, care for the young, the old and the sick should be covered by social insurance.

Every year, care giving households are paying an average of $130,000 in medical coverages. This equals to more than 7% of those family's wages and salaries, leading to financial difficulties, with institutions and insurances for long time care are too expensive for low/middle income families.

But perhaps the hardest fact is the emotional toll woman pay for caring for of caring for children or old relatives. Not only they face losing their careers, a lot of times they also have to abandon their social life and free time activities, leading to frustration and anxiety.
It will take more awareness on this matter, as half of Americans who reach 65 will need long-term care, according to government projections.

Source:
https://www.nytimes.com/2019/08/29/business/economy/labor-family-care.html

Cancer Treatment at the End of Life

At the end of life, one of the biggest regrets lies in not having spent enough time to spend in peace and happiness.

Though nowadays, 2/3rd of cancer patients are cured due to early detection and treatment, 4th staged cancer treatment is highly difficult for patients and their families. Treatment is expensive and painful for patients; it may cost up to $100,000, maybe adding a few days in patient's life but, unfortunately often this is not the case.

In terminal patients, the question often remains how to spend their remaining days. Some of the patients would like to discontinue their treatment in the hope to get more quality time with their loved ones, especially with cancer or kidney diagnoses the pain of treatment is very high and often not promising.

These patients would like to rather spend their last days with family and friends, or they have specific wishes like attending their child's marriage or graduation or even a special concert.

On the other hand, some patients want to do everything to fight their illness and want to wait for new treatments to be discovered to prolong their lives.

Too often, people with incurable cancers pursue therapy beyond any hope of benefit.

Whatever the reasoning, the last remaining days of a patient should be a personal decision based on sound medical advice and free from other people's influence. Even though patients with terminal diseases should have the possibilities to engage in palliative therapy to enhance their last days, it is necessary that the therapy and its consequences are made clear to the patients and families before the start for them, so an informed decision is possible.

Source: https://www.nytimes.com/2019/08/05/well/live/cancer-treatment-at-the-end-of-life.html

REFLECTIONS

The Power to comfort

Annekathryn Goodman, MD MPH
Professor of Obstetrics, Gynecology, Reproductive Biology
Harvard Medical School
Massachusetts General Hospital
Division of Gynecologic Oncology

When I was beginning my career in oncology, I took care of a 52-year-old woman with an endometrial stromal sarcoma. She was beautiful and vibrant. She has two lovely teenage daughters and a big, warm husband. When I first met her, she was quite ill and in pain. Her cancer had metastasized to the para-aortic region and had obstructed her bowel. She underwent surgical excision of a big upper abdominal mass. This was followed by chemotherapy.

With this therapy, her cancer melted away and she resumed her happy life. I saw her frequently when she returned for her therapy. About one year after initial presentation, she developed pain again. She was admitted for evaluation and a CT scan showed widespread metastases to her lungs and liver.

I came into her room to discuss her results. Sitting on her bed and looking into her tired but beautiful face, my heart constricted. I found myself unable to talk. I was afraid I was going to cry and so I remained silent. She grasped my hand and in a soothing tone of voice said 'It's OK. I know." And she comforted me who was supposed to comfort her.

I left the room feeling disoriented and guilty that I had not helped her with this terrible news. I met another older oncologist at the nursing station and shared this encounter with him. He smiled at me and said "She does not have control over her disease, but she has the ability to give you comfort. That is her gift to you."

I have thought alot about that gift and I have treasured many other spiritual gifts from my patients since that moment. She taught me to open my heart and receive just as I give.

Loss

Tale of a granddaughter

Nusrat Feroz Aman
Chief Patron
AYAT Education

The heart monitor plateaued after a permanent dip……giving rise to a sudden hustle and bustle around me. I felt I was alone in a room full of familiar faces, chaotic in their own rhythm. I stood motionless, unsure what to feel, what to do. The floor beneath suddenly started spinning, signaling me to hold onto something to make myself steady, I reached out to something, unable to see as I was blinded by the tears, as if they had a mind of their own. But then again, they do.. our emotions can be very stubborn, not listening to reasons or rations.

I had just lost my grandmother to septisamya, an internal infection, triggered by a dialysis or was the renal failure triggered by the inborn infection? I didn't know and I didn't care. All I knew was that she was gone, gone forever, and we were wondering if we had been able to do all we could to see she lived a little longer. She was a 78 years old, loving, kind grandmother, but more importantly she was the last of my grandparents who hung out to see how we had done growing up. The others, 3 of them, I had lost one after another to cancer in my early teens. So she was important to me, very important, perhaps almost as important as she was to her ten living children. This was probably the reason that the 34 days she had spent in a ICU bed of an upscale private hospital, her children, their spouses and their children had spent in a prayer room below in the same building.I had just lost my grandmother to septisamya, an internal infection, triggered by a dialysis or was the renal failure triggered by the inborn infection? I didn't know and I didn't care. All I knew was that she was gone, gone forever, and we were wondering if we had been able to do all we could to see she lived a little longer. She was a 78 years old, loving, kind grandmother, but more importantly she was the last of my grandparents who hung out to see how we had done growing up. The others, 3 of them, I had lost one after another to cancer in my early teens. So she was important to me, very important, perhaps almost as important as she was to her ten living children. This was probably the reason that the 34 days she had spent in a ICU bed of an upscale private hospital, her children, their spouses and their children had spent in a prayer room below in the same building.

We were there, twenty four hours a day, praying, waiting, crying for her to wake up. Everyone put their lives on hold for indefinite amount of time to be near her during this time. However, in the best interest of my Nanu's health and wellbeing, we kept a distance from her. So much so that she didn't even know that most of the time all her children and their children were within a 100m radius of her. But because the experts advised us not to go near her, not to hold her hand, not to sit beside her bed, not to surround her, in the fear that the infection may become more vigorous, we lost the very valuable moments we could have spent holding her, reassuring her that she was not alone.

There were good days and there were bad days, there were days when she needed intense dosage of antibiotics, which would sometimes be hard for her body to tolerate. There were times when her veins had to perforated numerous times because the cannula could not be inserted as her veins had collapsed. The doctors were excellent, the nurses were phenomenal, they were meticulous and they were all trying their best to combat the regression, to fight the battle each time, to keep her breathing.. just as we had wanted. Because we wanted her to live, but live at what cost? Did we realize that when we were asking the clinicians to do their best to keep the infection in check, that we possibly could have been causing her unnecessary pain?

Maybe she would not have wanted this, maybe all she would have wanted was to be surrounded by her children and their extensions, laughing with her, singing to her, making her comfortable and minimizing her pain.
Giving her comfort during this time because sometimes the fate is inevitable and it is the right of a person to have comfort rather than a prolonged life. I wish someone had spoken to us, spoken to her about this and I wish we knew what her preferences would have been.

Sometimes communication and conversation around difficult topics helps us come out with understanding our own preferences. We live in a death denying society and often get carried away or loose focus on the must do's knowing that life is only finite. The more we talk about it, the more we think about it, we can decide and communicate what kind of care I would like to receive when I am near the end. When we decide that and communicate that to our loved ones. It is then that they may not have to carry the burden of wondering if they made the right decision for me.
Life is beautiful in all its pain, agony, pleasure and humor…

Palliative Care Medicine for Bangladesh

Dr. Bimalangshu Dey, MD, PhD.
Associate Professor of Medicine
Harvard University, Boston, USA

Palliative Care Medicine focuses on the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious illnesses including cancers, advanced cardiorespiratory conditions, AIDS, strokes and diseases like diabetes, sickle cell anemia, thalassemia complicated by serious sequelae. Palliative care means patient-centered and family-focused care rather than disease and system-based care, that (1) optimizes quality of life by anticipating, preventing and treating suffering and (2) maxi

mizes dignity. Palliative Care Medicine focuses on the prevention and relief of suffering of any kind – physical, psychological, social, or spiritual – experienced by adults and children living with serious illnesses including cancers, advanced cardiorespiratory conditions, AIDS, strokes and diseases like diabetes, sickle cell anemia, thalassemia complicated by serious sequelae. Palliative care means patient-centered and family-focused care rather than disease and system-based care, that (1) optimizes quality of life by anticipating, preventing and treating suffering and (2) maximizes dignity.

Eventually we all will die. Throughout the world, in the medical and nursing colleges there has been little emphasis on how to treat patients who are suffering/dying from "incurable diseases". Death is a phase of life and "dying people are still living". There is no way we can "defeat the death", but with our imagination, love, compassion and persistence,

In 1960s, the first modern 'end-of-life care' program opened in the UK. But, in the developed countries over the past few decades, palliative care services have been increasingly incorporated into complex treatment for patients with "curable conditions", especially when these patients go through curative treatments (surgery, chemotherapy, radiotherapy) that may cause serious temporary sufferings.

We can dignify the "dying process", we can beautify the "transition into the next state of life (death).

Therefore,

while 'end-of-life care' is an important part of palliative care, "Palliative Care Service" is appreciably more than 'end-of-life care'. It not only improves quality of life; in some cases, it also may improve chances for a longer meaningful life.

Eighty three percent of world's 7.53 billion people live in low- and middle-income countries (LMICs) – 6.2 billion. Each year, an estimated 40 million people worldwide need palliative care, 78% of these patients live in LMICs, like Bangladesh. For children, 98% of those in need of palliative care live in LIMCs. There are 5.5 million terminal cancer patients per year in LMICs. On average, 70% of cancer patients in Bangladesh are diagnosed at a late, incurable stage. The only possible intervention for these seriously ill patients is palliative care. In 2015, The Economist published a research work named Quality of Death Index and Bangladesh got the 79th place out of 80 palliative care practicing countries. The score was 14.1 out of 100, where UK received the first position scoring 93.9 points. Pain is the most common cause of serious health-related suffering. Only 9% of world's total morphine consumption is consumed in LMICs. As per The Lancet-Palliative Care, 2017: morphine consumption for pain relief, in mg per patient with serious health-related suffering: Canada 68,194 mg, USA 55,704 mg, Australia 40,636 mg, Western Europe 18,316 mg, China 314 mg, Bangladesh 53 mg, India 43 mg.

In Bangladesh, hundreds of thousands of patients are in dire need of palliative care each year, but effective palliative care medicine, including end-of-life care, pain management resources and well-trained providers remain in critically short supply.

The government of Bangladesh and private sectors must start putting in concerted efforts, the sooner the better, to achieve the following primary goals:

1. To build high-quality palliative care services accessible at all levels of the healthcare system and in the home for all people in Bangladesh,

2. To assure that all medical college and nursing college graduates, all general practitioners, and all specialist-physicians have adequate training in palliative care, and

3. To train an adequate number of palliative care specialists / sub-specialists to be palliative care leaders, teachers, and implementers for Bangladesh.

Two Sisters

a true story of palliative care ward !

Dr. Nezamuddin Ahmad
FCPS, MD
Professor & Former Chairman
Department of Palliative Medicine
Bangabandhu Sheikh Mujib
Medical University (BSMMU)

I first met Fatima during one of my routine morning ward round and she was quietly lying on bed. I asked how she was feeling and she reluctantly opened her eyes and said "better, but I want to sleep now". I remembered, she had entered the ward on the previous day being referred from another hospital nearby, tossing around in the trolley, screaming in agonizing pain" Kill me, kill me, I can't take it any more". One of the residents and duty nurses had rushed to manage her immediately while I had completed the rest of the round and left the ward amidst lots of noises and in front of many worrying dissatisfied eyes. I knew she would be looked after alright. Now, today, the resident says" pain has come down from 10 to three by now and she slept well last night". We all were relieved, though we knew she was dying, she had advanced gall bladder cancer.

She was at best in her late twenties but already having two kids, a girl of eight and a boy much younger! One could easily see the less privileged socio economic class they belonged to. The husband, a young man, electric technician in a shop as he claimed to be, always complaining and remaining on her bedside despite being told that he couldn't remain in the female ward for long which he seemed to care very little. In next few days, we two, I and Fatima developed a funny communication style, as she always had a way of challenging us and me enjoying her attitude! It often went like "Who loves you most Fatima, Your mother!" No, no, it's not my mother, it's my husband! My mother loves her son most "! Another morning she says "You go and finish your round first and then come "! I said "Why, what's wrong now!" She answers "If its now, you will only

She told me in detail how she had lost her father, how much her father loved her when she was a child, why her mother could not come regularly to visit her because her mother had to look after her brothers children and she can't make them annoyed because of dependency on son ! One day, she challenged me asking why the doctors in other hospitals had allowed her to suffer with such horrible pain which almost killed her! Why they had not given the same medicine which relieved her pain in this place! She was saying in such a tone as if it was my fault and I had let her suffer unnecessarily! I didn't mind, I didn't say anything! She was never alone in her bed, always with at least her children and another teen age girl, she introduced as her only younger sister! One day they all were eating melon and she loudly called me to join them! She said "See, how stupid my husband is! I just wanted to have a little melon juice and he has brought such a big whole melon, now, which will finish it!

I can't eat this "Only on one occasion I saw her alone, lying in bed. She looked unusually quiet and a little sad. I sat with her and asked what was wrong! was the pain back !, she did not say much, touched my hand very lightly and as if talking to herself , said "why life is so short! Why it is often so painful and difficult! I remained quiet.

However, one day she went home smiling, saying that she had to go, 'because so many pending things back at home were waiting. Care of her husband, children's' education and what not!'Fatima visited us a few more times, mostly with some pain, due either for missing her regular pain tablet Morphine or had needed to increase the dose. Once we showed a little annoyance to her husband due to apparent negligence of her husband in collecting medicine from our store regularly. She retorted back "What funny medicine you prescribe for pain that he does not get in other pharmacies! How can he miss his duty at work just to collect that tablet without which I can't manage! Why it is not available everywhere "There was no point in talking about narcotic laws etc.

We all could see she was gradually deteriorating. She managed to survive few more months and one day her husband came alone, crying and giving us the news we knew would be coming. He then went to the bed which Fatima occupied during her last admission in our female ward, the bed no 8! Fatima's face gradually faded away from our mind as the new other Fatima's kept on occupying her bed and many others in other beds. We had almost forgotten her till about a year later when the husband once again appeared, this time with a young girl! I looked at the well made up face, wearing a new bright silk sari and ornament! He introduced me "My wife, Fatima's younger sister. So much she wanted to come here and to see you all today "! I didn't say anything, didn't even possibly smile or greeted! I murmured "Where are the children "! He says "I have sent them to village, to her grandmother"! I nodded my head and hurriedly left the place.

" ..there must be places for pain relief, some people to listen to their stories, there must be some arrangement for their children to grow and educated in a safe world. "

Life goes on, Life must go on! But, no one should suffer like Fatima with such horrible pain, there must be places for pain relief, some people to listen to their stories, there must be some arrangement for their children to grow and educated in a safe world. So, after a year and a half later, when I am reading the Lancet Commission report saying' serious health related suffering is a massive, appalling oversight in global health that must be remedied. Palliative Care and pain relief are some of the most neglected dimension of global health today', The same report says that 673000 individuals like Fatima, including males and females of all ages in this country are in need of suitable care known as Palliative Care. We all firmly believe that Palliative Care should be everybody's business. Nobody should ever be told that "there is nothing more that we can do for you".

Palliative Care
The new healthcare frontier

Laila Karim
Senior Advisor
AYAT Education

I came across the terminology 'palliative care' while conversing with a young couple sometime in late 2017. Being a non-medical person, I was unfamiliar with the term and other jargons that came up in that discussion. So, I sat with Google, and it was like opening Pandora's box… terms like hospice care, critical care, geriatric care, end of life care, quality and dignity of life —all were lined up with scientific explanations.

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The last two terms — 'quality and dignity of life' drew my attention. By the end of the year, the term palliative care had entered into my life with the failing health of my husband. Now, I can see the issue all around me with my relatives and other extended circles, in hospital beds, in the pale face of a child, or in the blank look of a person suffering from critical illness.

Now I know, palliative care 'is a multidisciplinary approach' with specialised medical and nursing care for people with prolonged illness. It focuses on providing people with relief from symptoms, pain, and physical and mental stress. The goal is to improve quality of life for both the patient and their family while they face problems associated with life-threatening illnesses.

It is about prevention and relief of suffering by early identification, impeccable assessment and treatment of pain and other problems, and also about dealing with the physical-psychosocial and spiritual aspects.

Besides cancer, palliative care is also referred to any kind of life-threatening diseases or sufferings associated with long-term critical illness like chronic heart, or renal failure and so on. Put simply, palliative care is easing the pain with the physical, mental, emotional and other supports, when someone's life has come to a crossroads.

Palliative care may be required at any stage of life of the patient suffering from critical illness. The life of an accident victim with serious physical illness along with the mental agony could not be minimised without appropriate palliative care.
Palliative Care (PC) targets on patient's comfort and care, with or without the presence of curative intervention. Hospice Care (HC) is for the people who are terminally ill or declared as dying within six months or so, while PC is for the patients who cannot take care of themselves and patients who no longer receive curative treatment.

HC is provided at a person's own home environment, or in nursing facilities. At a certain point, both HC and PC may merge into a compromised system, like balancing between the two with hospital care and home care. Palliative care is not only services and care by the medical professionals – physicians, nurses, or hospital facilities, but also a concerted effort with the family members, people from the community, and overall the state, for creating an enabling environment.

Today, with the advancement of medical science and health care facilities, life is extended beyond the earlier assumption about 'aging.'

Crossing the 50 plus bar was a big deal, termed as 'boyshoko,' or aged! Now life begins in the mid-30s, and the government has promised to raise the maximum age for applying for official positions to 35, from 32 years.

Retirement age has already been extended to 65 years by many organisations. Our active seniors are inspiring us every day — having a quality of life — with active participation as the mantra of celebrating life.

There will be illness and suffering on their path, but if it is supported well by the family members and required facilities, life becomes tolerable, despite the sufferings of the body. Once, tuberculosis was considered fatal; we heard 'cancer has no answer' too. Today, we can see that medical science has made remarkable developments. Now, tuberculosis is handled with vaccines. In my childhood, I remember one of my aunts lived a confined life in a single unit house – she was abandoned, and returned to her parents due to having TB.

We need to remember that in the next 10-12 years, the aging population with health complexities alone will be one in every five in Bangladesh, and today's youth volume will also fall into that.
It can be mentioned here that Bangladesh stands 79th on the Quality of Death Index and 80th on the Quality of Care Index and also the Quality of Health Workforce Index of the Economic Intelligence Unit of the Economist's report on 80 countries.
Therefore, it is time to come together in a 360 degree approach. All stake holders, state and non-state parties need to act in unison. In this regard, I just remembered the remarks of a Dr Bimalangshu Ranjan Dey, from Harvard University, published in The Daily Star.

"Our healthcare system is disease-centred, not patient-centred. We are competent at providing medical services as far as our medical knowledge advances. But there are conditions or diseases where our medical knowledge falls inadequate in helping the seriously or terminally ill patients. It is not just about offering them a pain-free existence, but also the opportunity to help them with the required comfort. The suffering can be both physical and emotional, and palliative care addresses both. We also need to note that end of life care is a part of palliative care, not the whole of it. "

The government has made us proud by achieving most of the Mid Decade Goals (MDGs), especially bringing down infant mortality and maternal mortality from healthcare issues. Now it is time to focus on the Sustainable Developing Goal (SDG to be achieved by 2030) to ensure healthy lives and promote wellbeing for everyone at all ages, with access to quality essential health care, increase and create a trained workforce under WHO guidelines with policy advocacy, capacity building, essential medicines, and coordination and collaboration at all quarters.

As a general citizen, my humble call to the Ministry of Finance and Health is to include palliative care in their sectoral plans and budget lines.

Recently, along with some state supported organisations like Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka Medical College and Hospital (DMCH), National Institute of Cancer Research & Hospital (NICRH), and private initiatives like ASHIK, Ayat Education, a social enterprise, have created extensive programmes on the issue of palliative care with a road map of engaging youth and community, and transfer knowledge and skills for the health professionals along with policy dialogues. This is one of the giant leaps taken to address the gargantuan task with the right slogan —'Dignify Life through Palliative Care.' Let's bring the term palliative care into our regular vocabulary of health care and services. Here the WILL comes first, alignment of the other issues like availability of human, financial, and other resource will follow.

Source: https://www.thedailystar.net/lifestyle/perspective/news/palliative-care-the-new-healthcare-frontier-1719739

Palliative Care

A systematic approach

Emily Erhardt, RN.
Massachusetts General Hospital

Nursing is a multi-dimensional and dynamic role. A nurse not only needs the knowledge to help treat patients and assist with managing their distress and symptoms, but also the empathy to support them and their family throughout the emotional and psychological distress that serious and chronic illness can have on individuals and their families. 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.

The concept of palliative care encompasses each of these aspects of nursing that I hold in such high regard, and amazingly, it is transforming healthcare systems across the world. To shift from a disease focused care model, to a patient focused care model, is the epitome of what palliative care is. 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. To have the ability to lessen patient suffering, to be able to lend them a hand to hold, an ear to listen to their fears and worries, and to share in their hope, is the greatest gift you can give to another human being, and can be given by all healthcare professionals and lay people alike. While these ideas are what drew me to nursing in the beginning, the effect it has had in my career is beyond powerful, and one I hope I have the privilege to continue to explore throughout the world.

To quote the movie Patch Admas,

"You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome is."

Journey of a Nurse

Jocelyn Hulbert, BS, RN
Massachusetts General Hospital

Relief of suffering is a human goal. As humanity continues to evolve intellectually, we evolve ethically and emotionally as well. We recognize the great advancements that have been made in medicine and technology and we recognize there must be advancements in comfort and dignity as well. Palliative Care examines what we can do to promote comfort and dignity when medicine can provide no further solutions. It aims to support the best quality of life a person can have when experiencing serious illness.

The need for Palliative Care and the desire to provide patients with the best quality of life are universal. This is why the concept of Palliative Care has become a popular movement in medicine.

The nurse is a trusted ally of the patient and the partnership is unique. As a nurse of critically ill patients for many years, I have watched many people suffer with severe illness and disease. Education in Palliative Care has been some of the most important education I have received. Understanding how to ease uncomfortable symptoms and have difficult conversations with patients and families leaves me satisfied that I have provided the best life or death that person can be experiencing. Without this knowledge, we feel helpless.

In Bangladesh I have met compassionate, passionate, and driven doctors and nurses. I feel that there is a deep kindness which is inherent to the Bangladeshi culture. I can't help but admire it and grow from it every visit I make. It was truly an honor to work amongst people who shared the same vision and heart. I am excited to share this valuable education with my fellow nurses in Bangladesh.

Why not safe death?

Need of Palliative Care

Lailatul Ferdous
Senior Staff Nurse
Department of Palliative Medicine
Bangabandhu Sheikh Mujib
Medical University

Rahima (pseudonym) was happy in her family life with her husband and a son. The happy and peaceful life of Rahima has suddenly turned into a great sorrow when she came to know that she had been suffering from an incurable life threatening illness. She belonged to a lower class family but there was no sorrow in her life for being poor. But after being diagnosed as a cancer patient everything had changed. Her husband tried to cure her with his limited income. After some time, he couldn't bear her treatment cost. When he came to know that his wife will never be cured from cancer then he left her.

Since then, Rahima only worried about her son all time because no one will be there to look after her son if she passed away. Rahima was in her village home at Khulna. And slowly her condition was deteriorating and her burdens also increased. She came at oncology department of BSMMU for her treatment. And from there physician referred her to center for palliative care for pain relief and symptomatic treatment. She got admitted in the palliative care unit with severe lower abdominal pain. She was suffering from cervical cancer. She had also a wound over her buttock. That was appeared after radiotherapy. After treatment was proceed her abdominal pain reduced by taking morphine and wound dressing was advised regularly to minimize the complication for example- malodor, bleeding, maggot etc. Our only goal was to increase her quality of life. At that time, we tried to understand her psychological condition also.

All the time she was, she worried about her only son and always said that what will happen to her child after she passed away. He was only 8 years. After a while we planned to discharged her as she felt better from before. We discharged her with pain relieving medication and as there will no one to look after her, we Teach her son how to take care of her wound. We wondered how a small child had the courage to look after the cancer wound. After somedays, she went back to her home. At her home she lived with her only son. Her husband never tried to look after her. Sometimes neighbors had helped her by providing small money and gave some food. Day by day life had become difficult for her. She made small paper packet to run the cost of family. But when she tried to sit in long time period, then her pain increased.

When she went home we provide her with morphine tablets for 15 days as morphine is not available to any other city. morphine is only available in Dhaka city and people have to come every 10 to 15 days to collect it. It wasn't possible for her come at Dhaka every 15 days for collecting her medicine. Sometimes she collected her medicine by her neighbor. When someone was come Dhaka, they brought the medicine for her.

It made her taking small and inadequate dose of morphine for early consume and pain increased every time. But after some days it was difficult to collect her medicine by someone. Then somehow we managed a Palliative care volunteer and send medicines to her. By this initiative of palliative care volunteer, she was relieved from pain. But day by day her condition became worsen. And slowly her movement decreased and she became immobilize. Her son did the dressing of her wound. But that time it was difficult for him also to move her mother from one place to another. Again, we became helplessness. What we could do to make rahima comfortable and peaceful before she died. Because staying in her own home is the another wish of rahima. Then, we provide her a wheelchair for temporary and this wheelchair was collected by her neighbor. That was a small thing we did but that made her happy. At least she had not depend on others to move around. After Someday she died at home. We knew about her last wish. Her only wish about her son's education that she thought after she passed away education may be stopped. We tried to fulfill it and provide her son the expenditure for study by dream project of Palliative Care. It is the story of one incurable disease in our country. But there are many more stories if we can read the stories. In community level, there are no morphine to treat the severe pain of cancer patient. Many people die with unbearable pain in their home. there is no quality of death across our country. There is a lack of training among health care professionals about palliative care. A lot of people need palliative care in Bangladesh. Besides the needs, the access of palliative care is very limited. In our country there are some scattered type of individual hospital based palliative care center and most of them are Dhaka based. Some home care program also run by different organization. But by these type palliative care individualized service couldn't be reached to every needy people in the country. Palliative care should have integrated in primary health care. For this huge policy making is needed and palliative care should be included in national guideline. If we can deserve safe birth, then why not safe death?

মা

Who changed the way I knew life

Rahat Hossain
Business Development Manager
AYAT Education

For me, the word of "মা" in English meaning Mother, has changed forever in 2005. That year, I was a 9th grader, and still did not anything about the fear of losing a parent.

This changed rapidly after news reached us that my mom, having undergone a surgery, had been tested positive of cervical cancer (Cervical cancer is abnormal cells growing uncontrolled in the lining of the female cervix, a part of the female reproductive system located in the lower womb.). My whole family's situation changed in effect of this terrible news, none of us had ever considered for facing the reality of losing a family member. My mother, such a kind person and being always good to others - how could we even begin to imagine that we might lose her?

Following the advice of family and relatives, we decided to take her to India for treatment. The Indian doctors advised her to come to India every 3 months for a year, to ensure her treatment. It was a terrifying time for me and for my older brother. Both of our parents used to go to India frequently for couple of weeks, leaving a feeling of uncertainty. Every time my mother left the house, I would burst into tears thinking this could be the last time would see her, that maybe this will be the last time I will call someone "maa.

And every time she would return back home, it would feel like a festival, and we used to celebrate the days of her return. Until 2010, my mother had gone through radiotherapy, chemotherapy and surgery. By that time, our whole family life had changed.

The realization that I could lose my mother improved my sense of love for my parents and made me value the relationship so much more. As a family, my father, my elder brother and me understood that the only thing we really could do was to keep my mother happy, give her peace and of course pray for her wellbeing.

To this day, we always keep in our mind that she needs our mental support and that she should have a life full of dignity. Even though we did not know anything about palliative care, realized as a family, how important it was to give her mental support, trying to make her days beautiful, ensuring that she would have many lovely memories with us.

It been 13 years now and we are still keeping the promise we made as a family, doing our best to be true supporters of each other. Every morning, I thank our Almighty keeping her in my life. My mother has been a true blessing in my life, teaching me the right values and principles. I carry the fear of losing her every day inside of me, but as a family we grew much closer to each other. Now, we as a family can talk openly about life and death. We all accepted that we all die one day, but that it is more important to go with peace in mind and a smile on your lips.

When a person learns that their life is limited, they deserve even more the best support and care. As a family, we need to understand that a person needs their family and that a family can make a dying person's last days memorable and peaceful.

Scan to know more about Cervical Cancer

Grief

An unfamiliar friend

Rubaiya Ahmad
Founder
Obhoyaronno Foundation

Lately, I have been thinking a lot about grief.

My father's death in 2015 debilitated me. I crawled into a hole that was my room and cut everyone out. My dog stayed by my side the whole time and that's all the social interaction I could manage. I stopped working and much to my mother's distress, I only wore my father's clothes and told myself that I would never wear anything else again. I mourned and grieved like any daughter would when she loses her father but there was an added layer of complexity, which felt very unique. My father was a very unusual man. He way away a lot when I was growing up and I wanted nothing more than having him around (because he was SO much fun!). As I grew older, I learned to curb my expectations and that changed my relationship with him. When I was abroad and he occasionally wrote me long letters, he signed off with his full name, and never as "abbu". The letters were also never about how I was doing in school or how much he missed me, but quotes from the Quran or Nietzsche.

His death felt like an amazing book whose last pages had been torn off. I will never know how the book ends and the longing would haunt me forever.

It took me a long time to return to the normal life after my father's death. What I didn't realize is that "normal" had forever changed for me by then.

My relationship with my mother was also very rocky. Growing up, I was a defiant child and she was a struggling, hard-headed mother. I never sought refuge in my mother when my father died. Her reaction to my father's death also seemed very strange to me. She refused to see my father's body when they took him away. She didn't cry a whole lot, and within a few weeks, she seemed to be back to her normal self, coping a little too well. My mother, who never wore nail polish in her life, got a pedicure and let me put dark nail polish on her. She no longer liked her old apartment, so she went and bought a brand new on a whim and set it up very nicely with help from my sister. It was as though she started her life anew. I felt betrayed.
My mother could not live in her new apartment. She moved into it to get away from my father's memories, but started to unravel as soon as she did and came running back to the very memories she wanted to forget. She didn't allow herself to grief, and her grief consumed her in the end.

My mother died two years later. I know now that she died of a broken heart.
I was in India at the time of my mother's death and her burial was completed before I came back. I had no "closure" so to speak. I was expecting another bout of self-imposed isolation and strange behavior, but to my surprise, I "bounced back" the next week and started work in full swing. I took on new projects and a part of me was also "relieved" to see that I was able to work. I thought that I had wised up since my father's death and had accepted death as a natural course of life. Everything was going fine. Until it wasn't.

With the passing of each week…month, I started growing more and more tired and irritable and started losing focus and interest in my work. I was picking fights with everyone around me and couldn't stand being in anyone's company. At one point, I even considered shutting my organization down, because it seemed pointless and a waste of time. I still remember the day of my mother's one year death anniversary. Both my sisters and their kids were in town. It was supposed to be a quiet evening with just family. We were sitting round the dinner table and I started nitpicking over the food that was served and lashed out over the rice the khichuri was made with. The evening was completely ruined. I stormed out thinking who makes khichuri with parboiled rice!?

It was never about the parboiled rice.

I left for India the next month. My cousin who lives in Bombay had told me about a great acupuncturist who had helped her a great deal with her body ache. My friend was also suffering from pain in his hands for quite some time, so I convinced him to go to this therapist with me. The therapist was a bit of a "witch" I heard. She could hold your hands and tell you what's wrong with you emotionally or otherwise. Being a non-Indian, I had immense faith in her "super natural" powers. Being an Indian, my friend rolled his eyes. The lady took my friend's hands, gave him a few tips on his physical and emotional health and pricked his fingertips with a few needles and asked him to wait outside. Off he went looking like a cousin of Edward Scissorhands. As I proceeded to leave as well, the lady looked at me and said "what about you"? I said "oh, I'm fine, I am not in any pain". I was cheery and confident when I said it. She kept staring at me. I hesitated for a minute, then sat down and stretched my hands out. She took my hands and said a few things to me that are too personal to share. What happened afterwards is what this write-up is all about. A minute or so after she pricked my fingertips with these needles, I started howling uncontrollably and could not stop. I was crying like I never cried before. There was no privacy. There was no preparation. There was no stopping me. I didn't know what to do with myself. This must be a normal phenomenon at that place, because no one seemed to be too bothered and my friend "held back my hair while I purged". I cried myself to sleep that night. Next morning, when I woke up, I started crying again. I was so perplexed that I called my cousin and asked to see her (howling on the phone). I walked over to her place, she ordered breakfast for us both, and I slowly calmed down. The whole ordeal lasted for almost 12 hours.

After coming back from this trip, I went to see my mother's grave for the first time. It's been two years since her death and I finally stopped fighting with her in my head. I stopped distracting myself with "work" when all I want to do is sit and cry. I started talking to her again and told her that I was sorry that I didn't understand her grief. I was sorry that we didn't cry together for abbu. I was sorry that I betrayed her. In my imaginary conversation, my mother looks very smug, but forgives me in the end.

There is probably no other emotion that is as complex as grief. No two people grieve the same way, so the journey is very lonely and personal for each person. Grief has a life of its own and if you are not careful, it can manifest itself in your life in the most destructive manner and leave you feeling like a stranger to your own self. Don't ignore it. Don't deny it. I saved the needles to remind myself what lurks within. Live through your grief and hope and pray that your friends and family would suffer you like mine did.

DIGNIFYING LIFE
THRU PALLIATIVE CARE

PALLIATIVE CARE & AYAT

PALLIATIVE CARE & AYAT

Palliative Care asks for a total approach by the state and non state parties - with policy, with proper planning – allocating funds and making the services accessible to people and patients; as well as for general public to know the issue and purpose, have the capacity to handle it beyond medical facilities at home and also be supported by community – especially the youth to undertake voluntary services.

In partnership with experts from Massachusetts General Hospital and Harvard University, USA, AYAT Education has taken up a program towards Dignifying Life through Palliative Care.

The Program includes

Youth and Community Mobilization through dialogue and awareness

আমান গ্রুপের সহযোগী প্রতিষ্ঠান আয়াত স্কিল ডেভেলপমেন্ট সেন্টারের উদ্যোগে ও ঢাকা ব্যাংকের পৃষ্ঠপোষকতায় সম্প্রতি রাজধানীর ঢাকা ক্লাবে আনুষ্ঠিত হলো 'ডিগনিফাইং লাইফ রোলস অব ফিজিসিয়ানস ইন রিলিভিং সাফারিং' শীর্ষক অনুষ্ঠান। এর উদ্বোধন করেন অর্থমন্ত্রী আবুল মাল আবদুল মুহিত। অনুষ্ঠানে উপস্থিত ছিলেন আয়াত স্কিল ডেভেলপমেন্ট সেন্টারের চেয়ারম্যান তাহসিন আমান, চিফ পেট্রোন নুসরাত আমান, বাংলাদেশ পেলিয়াটিভ অ্যান্ড সাপোর্ট কেয়ার ফাউন্ডেশনের চেয়ারপার্সন ডা. রুমানা দৌডলা, বোস্টনের হার্ভার্ড ইউনিভার্সিটির অ্যাসোসিয়েট প্রফেসর অব মেডিসিন বিভাগ ও আর দে। মাস জেনারেল হসপিটাল বোস্টন (এমজিএইচ), ওয়ার্ল্ড হেলথ অর্গানাইজেশন এবং সিমন্স কলেজ অব নার্সিং, ইউএসএ থেকে একটি এক্সপার্ট টিমও এ অনুষ্ঠানে অংশ নেয়। বিজ্ঞপ্তি

Media engagement for information dissemination.

Engagement of stake holders for policy inclusion and developing a Plan of Action towards a long term goal

Knowledge transfer and technical capacity building of health care professionals

DIGNIFYING LIFE

Programs of Dignifying Life:

ELNEC Certification course:
5 day-long training on palliative care provided by our international experts.

Multi-disciplinary Tumor Board and Surgery:
Partnering with many national and international health experts to study and discuss critical cases of different cancer presented in a multi-disciplinary board comprising of cancer clinicians, surgeons, radiologists, pathologists to reach diagnosis and treatment plan.

Seminar on Non-Communicable Diseases & Palliative Care.

Community Awareness & Wakhathon

Knowledge Transfer & Sharing:
Experience Sharing and Resource Mapping.

Round-table Discussion:
Discussion on Palliative Care by national and international experts and youth leaders.

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018
Dhaka | 5-12 Jan 2018

DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE SYLHET 2018
Sylhet | 6-11 Sept 2019

DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE DHAKA, 2019
Dhaka | 1-8 Feb 2019

DIGNIFYING LIFE THRU PALLIATIVE CARE
Dhaka | 16-21 Nov 2019

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DIGNIFYING LIFE THRU PALLIATIVE CARE

Dhaka NOV 19

Programs

4th ELNEC Nurses Training Program

16-19 November 2019 | 9:00am-5:00pm
AYAT College of Nursing & Health Sciences

Dignifying Life Thru Palliative Care: A Call for Public Awareness

20 November 2019 | 6:30pm-9:30pm
Ballroom, The Westin Dhaka

Elnec Alumni Night

21 November 2019 | 5:00pm-7:00pm
AYAT College of Nursing & Health Sciences

DIGNIFYING LIFE THRU CANCER & PALLIATIVE CARE

DHAKA, 2019

3rd ELNEC Workshop: Cancer and Palliative Care

1-5 February 2019 | 9:00am-5:00pm

AYAT College of Nursing & Health Sciences

Surgery on Women with Gynecology Cancers

4 February 2019 | 9:30am

National Institute of Cancer Research and Hospital

Multi-diciplinary Tumor Boards

5-8 February 2019

NIRCH, DMCH, BSMMU, Apollo Hospitals Dhaka

Round-Table discussion : Dignifying life through Youth Engagement & Leadership Role for Community Awareness on Palliative Care

6 February 2019

Prothom Alo


Multi-disciplinary Tumor Boards


DIGNIFYING LIFE
CANCER
& PALLIATIVE CARE


DIGNIFYING LIFE

DIGNIFYING LIFE THRU PALLIATIVE CARE

SYLHET 2018

Experience Sharing & Resource

Inauguration Ceremony & Meet the Press

6 September 2018

2nd ELNEC Nurses Training Program

7-10 September 2018

Surgery with Gynecological Cancer

7-10 September 2018

Multi-diciplinary Tumor Boards

7-10 September 2019

NEMCH, PMCH, SOMCH

Seminar on Cancer and Palliative Care for Sylhet

11 September 2019


International Conference
ON CANCER AND PALLIATIVE CARE


International Conference
ON CANCER AND PALLIATIVE CARE
Nurses' Workshop: Cancer & Palliative Care


DIGNIFYING LIFE
International Conference
AND PALLIATIVE CARE

DIGNIFYING LIFE THRU PALLIATIVE CARE DHAKA 2018

Walkathon: For A Cause
TV Talk-Show: Dignifying Life, Understanding Palliative Care
Dignifying Life - Right to Information and Knowledge
5 January 2018

Round Table Discussions with The Daily Star:
Dignifying Life, A Call For Public Awareness
Inaugural Program with policy maker & stakeholders
6 January 2018

Inauguration Of ELNEC And Physicians Training Program
7 January 2018

1st ELNEC Nurses Training Program
8-12 January 2018


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DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA, 2018
Dignifying Life - Nurses Call to Care


DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA, 2018
End-of Life-Nursing Education Consortium (ELNEC
rtificate Giving C


Roundtable Discussion on


DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA, 2018
WALKATHON
5th January 2018
7:30am - 9:30am
Hatirjheel
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DIGNIFYING LIFE
THRU PALLIATIVE CARE
DHAKA, 2018
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RESOURCE PERSONS

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.

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.

Dr. BimalangshuDey, MD, PhD.

Dr. BimalangshuDey, 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.

Jocelyn Hulbert, BS, RN

Jocelyn Hulburt is a registered nurse at Massachusetts General Hospital and an Advanced Practice Nurse at Newton Wellesley Hospital in Boston. She is a graduate of Simmons College of Nursing and has a Master's Degree from Boston College Connell College of Nursing. She has worked for 10 years as a nurse in the Burn Intensive Care, Surgical Intensive Care, and Emergency Medicine Unit of MGH. In these critical care environments, she has developed a passion for improving suffering and supporting end-of-life transition. In 2016, she was delighted to travel to Bangladesh as part of the Bone Marrow Transplant Oncology partnership between MGH and Dhaka Medical College. Since that trip, she became an ELNEC certified trainer and has returned three times now to share education to nurses in Bangladesh regarding Palliative and End-of-Life Care. She is honored to return again this year to share her passion for improving Palliative and End-of-Life care.

Emily Erhardt, 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 (MGH). She worked for 5 years in a surgical/trauma Intensive Care Unit where she cared for patients and families experiencing serious and frequently, life-limiting illnesses. During that time became involved with the nursing education initiatives in Dhaka, Bangladesh. She has traveled to Bangladesh numerous times, the first time in 2015 for 2 months where she delivered a comprehensive oncology curriculum to nurses chosen for the Enhanced Specialized Nurse Training Program at Dhaka Medical College Hospital. After delivering that curriculum, Emily felt the call to become an oncology nurse and so in 2016, she transitioned her nursing practice to the Outpatient Cancer Center Infusion Unit at MGH where she cares for seriously ill oncology patients and their families.

Her efforts in Bangladesh continued when she became a trainer for the End of Life Nursing Education Consortium (ELNEC) in 2017 and has returned many times to deliver the intensive 5-day train-the-trainer program throughout the country. The program includes a variety of topics pertinent to palliative care and is delivered by way of modules that focus on an introduction to palliative care, pain and symptom management, ethical considerations, culture, therapeutic communication, and the dying process. The purpose of the curriculum is to inspire and encourage nurses from around the world, including Bangladesh, to be an active participant in their patient's care, empower them to be patient advocates, and give them the knowledge base to ultimately becomes trainers and educate their colleagues on palliative care and its place in the healthcare system. A rewarding experience for both trainers and attendees alike, the reflections made upon completion of the program show the impact the course has on a nurse's daily practice, and how patient outcomes improve when quality palliative care is provided. It is an honor to be returning to Bangladesh again to continue to educate nurses on the ELNEC curriculum, learn from their practices, and continue to empower nurses throughout the world.

Nisha Wali, 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 educator for 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 fourth 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.

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