

# Initiating palliative care in developing countries

More than one billion people (85% of world population) live in the developing countries with 20% global gross resources only. Hence, most of the developing countries remain grossly inadequate in their healthcare systems. Ever since the independence of our country, we are struggling to develop a healthcare system. During the last two decades, a rapid progress has been witnessed in this field, but it largely remained confined to private sector health institutions, with limited progress made by public sector. Yet palliative care (PC) remained a highly neglected area and even big academic institutions, private or government, have no PC services or programs<sup>1</sup>.

Supportive care helps the patients and their families to cope with their condition and its treatment – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live with the after-effects of the disease. It is given equal priority alongside diagnosis and treatment. PC is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as: 'Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families<sup>1</sup>'.

Many aspects of PC are also applicable earlier in the course of the illness in conjunction with other treatments. PC is an emerging medical specialty which enhances the patient's overall quality of life by providing a wide range of services. In current modern practice the concept of PC has been changed. It does not mean the end-of-life care for a dying patient only, but rather it is an approach that improves quality of life for patients suffering from incurable chronic and life threatening illness and to provide support for patient's families<sup>2</sup>.

In many developed countries, due to an ever-increasing ratio of ageing population, more people are now suffering from serious chronic diseases towards the end of life e.g. chronic renal and liver diseases and cardiac failure etc. The World Health Organization (WHO) has recently highlighted the importance of PC in the developing world as many of them have limited or no PC settings. The level of funding required to provide PC are usually far beyond the available limited resources of these countries.

Over the last two decade these PC settings have steadily increased not in the developed world but also in many

resource-poor countries e.g. Mongolia, Poland, Romania, Serbia, India, Bangladesh, South Africa and Uganda. As the prevalence of chronic diseases and the cancer rises at an alarming rate worldwide, these PC programs play an extremely important role in reducing the overall disease burden in the society. Recently in Bangladesh the first PC setup was introduced with the huge financial support by the government. This setup is currently lead by anesthesiologists, who are supposedly expert in the symptomatic management.

The PC team is usually a multidisciplinary one and includes doctors of different disciplines, nurses, pharmacists, social workers, psychiatrists or psychologists, ethicists and religious scholars, who help patients in addressing several broad range issues. The ultimate goal of PC is to help the recipients lead a comfortable life, which can usually be achieved by controlling or managing symptoms such as pain, shortness of breath, nausea, vomiting, fatigue, anxiety and somnolence by a multidisciplinary team. Taking care of chronically ill and dying patients can cause several problems among family members, mental exhaustion, anxiety and depression being the most common ones<sup>3,4</sup>. In addition families are often not very well aware as how to provide physical care and to cope with the imminent loss of their near & dear ones. Many caregivers may develop some physical illnesses in themselves e.g. low back or neck pain, that may affect their ability to care for the patient<sup>5</sup>.

The National Consensus Project for Quality Palliative Care (NCP) has recently developed and published the Clinical Practice Guidelines for Quality Palliative Care<sup>6</sup>. This NCP report defines terms and identifies essential elements of PC to promote quality, foster consistency of practice and continuity of care across settings, expand access, and encourage performance measurement and quality improvement. The principles identified in this regard are as follows;

- The unit of care comprises a patient with his or her family.  
For clinical purposes, family can be considered to include the people who most matter to the patient and those for whom the patient matters.
- Symptoms must be routinely assessed and effectively managed. Symptoms management is a central goal and fundamental principle. Suffering from pain and other physical symptoms associated with advanced disease is not inevitable. It is

core practice in PC programs to assess each symptom and manage accordingly

- Decisions regarding medical treatments must be made in an ethical manner. Decisions regarding medical treatments should be made in ethical manner with all honesty and considering the patient's rights. Always ask the patients about their wishes after letting them know the overall prognosis.
- PC is provided through a multidisciplinary team. PC programs should be a multidisciplinary team of professionals and trained volunteers. Each member brings particular experience including knowledge and skills to this area.
- PC coordinates and provides for continuity of care. Coordination of care is a critical function of PC setting. Knowing the complexity of diagnostic workups and treatments in this population of patient this coordination is must to provide continuity of care.
- Dying is a normal part of life, and quality of life is a central clinical goal. Death of individuals is understood in PC as normal and indirectly acknowledges that death comes at the end of every life.
- PC attends to spiritual aspects of patient and family distress and well-being. The dying patients may have questions and concerns about the meaning of life which are not answered always through religious believe. It is a common observation that spiritual issues are central to the quality of patients' lives near the death.
- PC neither hastens death nor prolongs dying. It means to allow a patient to die of natural course while providing whatever PC is necessary for comfort and not to have intention of ending life.
- PC extends bereavement support to patients' families. This principle recognizes that the experience of illness does not end with the death of the patient and so PC also supports patient's relatives or close friends who are grieving.

PC is considered a major issue for public health all over the world .The importance of this emerging area will further expand with increasing number of ageing population and highly prevalent incurable chronic and cancer diseases<sup>6,8</sup>.

In developing countries, unfortunately lack of awareness or recognition of PC is the most important factor in addition to limited financial resources.

We need to raise public awareness and influence the policy makers of institutions and the government for their more proactive role in building basic infrastructure under this umbrella. Despite financial constraints, many national, international and non government organizations are willing to provide funding for PC in the developing countries with potential capacity. We need to move forward to identify our needs and approach national as well as international funding agencies to develop this service in developing countries. Larger healthcare institutions must take the initiative now and take appropriate steps to start PC programs within the sphere of their healthcare activities. We must realize that the need of PC will grow exponentially with the current trend of smaller families, meaning thereby that less and less caregivers will be available to chronically or terminally sick or aged population.

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