

'Palliative care is a human right'

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Abstract:

Palliative care is about achieving the highest quality of life (QOL) and promoting comfort and dignity for patients with incurable and life limiting diseases. Palliative care advocacy has been strengthened by pronouncing that 'the provision of palliative care is a human right'. International covenants have agreed upon this. There are huge unmet needs of patients with life-limiting illnesses in Bangladesh as well as in the world. The majority of countries have neither formal palliative care policies nor integrated palliative care services to meet basic standard guidelines in the provision of palliative care. The nature of the right in the context of international and Bangladesh perspective is discussed here.

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Introduction:

Treatment of the ill, irrespective of curability or life-limitation, has social, legal and medical sanction and may be considered an essential requirement of a civilized society.

'Palliative care is an approach that improves the Quality of Life (QOL) 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.' Palliative care is about achieving the highest possible QOL by promoting comfort and dignity¹

'Palliative care is a human right' was the global slogan of the 'World Palliative Care Day' in 2008. The powerful statement needs examination of foundations of legal rights before reaching this assertion.

The international Human right to Health Care

Health is a human right enshrined in numerous human rights instruments.^{2,3,4,5} The International Covenant on Economic, Social and Cultural Rights (ICESCR) specifies that everyone has a right 'to the enjoyment of the highest attainable standard of physical and mental health'. The right to health is considered a right of 'progressive realization'.

There is no expressed right to palliative care in these documents as such, but right to health understandably includes health during end of life

also. It would be artificial to separate a 'Right to palliative care from general right to health'

Palliative Care: International Statements

In 1992, Margaret Somerville, a scholar of medical law, wrote articles arguing that relief of suffering is a common goal of both medicine and human rights and that the relief of the pain and suffering of terminally ill patients is also a human right^{6,7}. Since that, several international statements have been made till date asserting provision of palliative care as a universal human right. These include Cape Town Declaration (2002)⁸, European Committee of Ministers⁹, International working group of European Medicine(2004)¹⁰, Standing Committee of the Canadian Senate (2005)¹¹, Pope Benedict XV1 (2006)¹², International Human rights to health care. All these organizations and institutions have asserted officially that palliative care is a human right.

Cape Town Declaration (2002) asserted four main propositions:

1. Palliative care is a right of every adult and child with a life-limiting disease.
2. Appropriate drugs, including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan country and all levels of care.
3. The establishment of education programs as necessary at all levels of the learning continuum.

4. Palliative care should be provided at all levels of care...While primary care is emphasized, secondary and tertiary level teams are needed to lead and foster primary level care.

The Korea declaration¹³ emerged from the 2nd Global Summit of National Hospice and Palliative Care Associations in 2005. It stated that governments must ‘make access to hospice and palliative care a human right.’

Montreal Statement on the Human Right to Essential Medicines (2005) has clear implications for the provision of palliative care. The statement linked the international right to health with the universal access to these essential medications.

Pope Benedict XVI, in his message for the 2006 World Day for the sick stated that an essential emphasis of palliative care was the preservation of human dignity. He also stated that the provision of palliative care services was a human right.

The ethics of the medical care of the patient with life-limiting illness has a deep humanitarian core. Palliative care is compassionate in approach, meticulous concentration on symptom control, clarity and sensitivity in communication to the patient and family which guide all through the unique journey of dying. So, if there is a clear ethical obligation to relieve suffering – an argument of right can spring from that obligation. WHO has promoted clear public health policies and recommendations for the rational implementation of pain relief and palliative care. So, Palliative care embraces human rights that are already recognized in a number of national laws, international human rights documents, and other consensus statements. Having recognized this, one must admit that the provision of care varies enormously around the world. Many countries do not have palliative care policies or integrated palliative care services.

What are the Palliative Care Rights!

Palliative care is the ‘active total care’ of patients with life-limiting disease and their families by a multi professional team. Ideally, the care is to be provided by physicians, nurses, physiotherapist, occupational therapist, social worker, religious workers and volunteers. The care encompasses four basic needs of the patients such as physical, psychological, social and spiritual aspects.

Palliative care rights include the right to:-

- Pain relief
- Symptom control for physical and psychological symptoms

- Essential drugs for palliative care
- Spiritual and bereavement care
- Family-centered care
- Care by trained palliative care professionals
- Receive home-based care
- Treatment of disease
- Information about diagnosis, prognosis, and palliative care services
- Not be discriminated in the provision of care because of age, gender, socioeconomic status, geographic location, national status, and prognosis.

What is the Basis of Rights to Palliative Care!

The Content of Obligation:

All the bodies mentioned earlier observed that irrespective of the resources, palliative care remains their core obligation. A further guide to minimum standard expected by the international community emerges from WHO recommendations. These include that all countries should adopt a national policy, ensure the training and education of health professionals and promote public awareness, ensure availability of morphine in all health settings and ensure that minimum standard for pain and palliative care are progressively adopted at all levels of care. Recognizing the widely diverging capacities of countries, WHO set out general recommendations for different resource settings. In countries with medium resources, services should be provided by the primary health care clinics and home based care. In high resource settings, there is variety of options, including home based care.

Synthesizing all these sources a consensus on the content of the obligation on individual governments in relation to palliative care appears to be emerging. The following countries or regions have already incorporated palliative care into their national or regional (state or provinces) health care policies. These are Canada, Catalonia, Kerala, Georgia, Mongolia, Ontario, Uganda, and United States.

Bangladesh Context:

Article 15A & 18(1) of Bangladesh Constitution enjoins on the state the provision of basic medical care for her citizens¹⁴.

Article 15 states that ‘It shall be a fundamental responsibility of the State to attain, through planned economic growth, a constant increase of productive forces and a steady improvement in the material

and cultural standard of living of the people, with a view to securing to its citizens-

- a) the provision of basic necessities of life, including food, clothing, shelter, education and medical care'

Article 18 (1) states that 'The State shall regard the raising of the level of nutrition and the improvement of public health as among its primary duties and in particular shall adopt effective measures to prevent the consumption, except for medical purposes or for such other purposes as may be prescribed by law, of alcoholic and other intoxicating drinks and of drugs which are injurious to health.

The concept of palliative care in Bangladesh so far remained limited to the compassionate tender loving care of the family members toward their loved ones with terminal illness. It would be fair to say that palliative care in Bangladesh is set at a most basic level, where some respite could be sought from the extended family care support system. Although this is being recognized as an essential element, lack of skilled medical attention with all its paraphernalia leaves a big gap in the total care of the suffering. Quality of life (QOL) issues are rarely thought, spoken or practiced in Bangladesh; this is truer for the elderly, especially, for the chronically ill, dying less privileged people. Symptom relief is attempted to be obtained from the local doctors or traditional healers. Besides, the health care system and the community also are driven by a cure oriented approach, where QOL issues are ignored. Regardless of the location, in the urban or rural, public or private setting, the health care service is not oriented towards an organized palliative care service - neither by word nor by philosophy.

Moreover, palliative medicine, in the context of total palliative care does not have its due recognition in this country. Palliative care is not really considered a part of our national, institutional or individual health care approach. Palliative care for patients requires total support from physicians, family and Government. The sick, like other citizens of Bangladesh, have a right to the preservation of health and well-being. The health policy, construction of hospitals and establishment of hospices all follow the same principle. It is the duty of the society to make drugs and arrangement available for the incurably sick members of the society so that the pain of sickness and suffering as a whole is made more tolerable.

Bangladesh with scarce medical resources has strong cultural and ritualistic community and cohesive family support system to tend their terminally ill citizens. These valuable components of care if properly blended with government policy driven medical care, then 'peaceful exit' of many people from a 'helpful society' can be ensured. Community involvement can also empower the family members to address symptom control, like bed sore prevention, appropriate food and basic hygiene etc. Finding ways to empower families and communities in such care is an urgently needed priority. Socioeconomic, cultural and spiritual measures may well be as important as medical ones in providing effective palliative care. But, for this care to reach most of the people there must be a national guideline. Effective program implementation requires clarification of the dimension of the problem and recognition that inexpensive solutions do exist. We must use the knowledge gained in past quarter century of delivering palliative care in a rational public health context. For palliative care to become available to many people who need it, several things must happen. These include effective advocacy and clear policies that support the pain relief and palliative care, education and training of health workers and volunteers, empowerment of family members and affordable drugs-especially oral morphine.

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. The total number of patients needing palliative care would be about 0.6 million per year¹⁵. These patients suffer from severe pain and other symptoms. These ill patients need palliative care as their right. The health care system of the country should help them to deal with their sufferings with importance.

Academic programs are lacking to train practitioners in palliative care for allied health professionals like physicians, nurses, pharmacists, social workers and others. Undergraduate and post graduate education as a symptom control, clinical use of opioids and end of life care remains relatively poor or absent. It is thus obvious that we are in acute need of an organized palliative care service, encompassing all the issues in it (policy, advocacy,

training, fund and ethical issues). Quality of life should be an issue elsewhere in the health service as in the terminally ill patient care.

Certain measures would help to assure the availability of end of life care to the people of Bangladesh. These are to establish a national palliative care policy specific for the country and culture, commitments to educate and train all health professionals by including palliative care in the curricula for physicians, nurses, pharmacists, social workers and others, develop advocacy and education for the public, define freedom from pain as a basic human right, ensure availability of affordable drugs for pain control and symptom management and their appropriate use by trained professionals, to ensure that pain and palliative care programs are incorporated into the country's health care system and to provide interdisciplinary and multi-disciplinary approaches to health care.

Palliative care tries to bring light into the dark world of the dying who are isolated physically and emotionally. While we are increasingly equipped to deal with the challenges presented to us as health professionals, many aspects of serious illness and death are beyond our control. The right to palliative care can only mean reasonable and proportionate response to the need of patients.

Conclusion:

There are huge unmet needs of patients with life-limiting illnesses in the world -obviously more in low resource countries. A human right to palliative care may be implied from even the usual right to health care. For the progressive fulfillment of a human right to palliative care, we need flexible and creative public policy, grater access to opioids for medical purposes, tireless advocacy, comprehensive education, professional leadership and continued call upon individual compassion for this most vulnerable group of people.

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