EDITORIAL

Changing wrinkles to smiles with palliative care for the Elderly!

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Over the past years, the conscious and collaborative efforts of Peoples and Planners world-wide have shown a reduction in mortality and increase in the life expectancy at birth. Thus, the world will be over loaded with aged people one century ahead; on the other hand, we in India have cheated this particular group for last 65 years by not providing any special care package for them – the Elderly: presenting them the "geriatric care"! The then Director-General of the World Health Organization, Gro Harlem Brundtland in 1999 had said "Population ageing is, first and foremost, a success story for public health policies as well as social and economic development". Thus, the WHO has aptly chosen the theme "Ageing and health: Good health adds life to years" for 2012. The focus is how good health throughout life can help older men and women lead full and productive lives and be a resource for their families and communities.[1] It is predicted that within the next five years, the number of adults aged 65 years and over will outnumber children under the age of 5 and by 2050, all children under the age of 14. Between 2000 and 2050, the proportion of the world's population over 60 years will double from about 11% to 22% with the most rapid and dramatic demographic changes being seen in low and middle income countries.[2]

Even as the 2012 theme aims at a lifetime of healthful living culminating in a healthy autumn of life, the concern for palliative care of the elderly retains its importance as a public health issue. Natural disasters, armed conflicts or even changes in lifestyles and employment requirements of families make elderly population increasingly vulnerable. Physical sufferings, isolation, loss of autonomy, physical and economic dependency compounded by marginalization can make the experience of ageing bitter and painful. Coming to life's end is an intensely personal experience and could be emotionally and physically challenging. The care of the elderly must focus on quality of life rather than on simply prolonging life. It is now time to be part of the overall health policy for older people and the services they receive. Medical and social needs of this group must be addressed to, by countries through targeted and customized health care services. In all countries and, more so, in developing countries, measures to keep older people healthy and active are a necessity, not a luxury.[3]

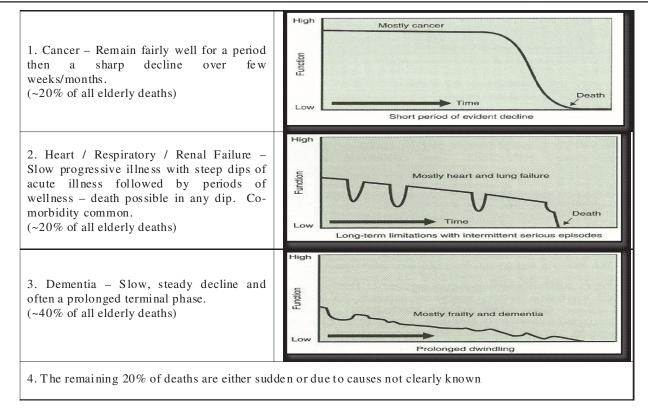
Palliative care was defined by the World Health Organization in 2002 as ".... An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Although the context in which 'palliative care' was defined was mostly restricted to terminal cancer pain alleviation, today it aims at providing relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, and intends neither to hasten nor to prolong death. It integrates the psychological and spiritual aspects of (patient and family) need-based patient care and offers a support system to help patients live as actively as possible until death ('active ageing') and to the family for coping during the patient's illness and in their own bereavement. Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age. It applies to both individuals and population groups. [3] Older people are more commonly affected by multiple medical problems of varying severity and epidemiological studies have pointed out that cumulative effect of these may be much greater than any individual disease, and typically lead to greater impairment and needs for care. Aged people have unclear trajectories to death and therefore the end-of-life journey is usually unpredictable. Three common trajectories to death in the elderly have been described by Lynn and Adamson as follows:[4]

In India, the National Cancer Control Programme in 1975-76 had enlisted palliative care in terminal stage as one of its goals. Even the working group on health research for 12th five year plan^[5] has also highlighted the need for specialized geriatric care.

As pain palliation acquires increased prominence, barriers to integration of effective palliative care into the health care delivery system (HCDS) of countries have also been identified viz., low skill mix and sparse medical support, avoidance of public discussion of death, complacency to fight pain and death which is usually the accepted norm for ageing people and medical model of HCDS with less emphasis on rehabilitative services. Anthony F. Jerant et al (2004) [6] have enumerated five fundamental flaws in the way end-of-life care is currently delivered:

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- The perception that palliative care is only terminal care instead of a longitudinal continuum.
- Palliative care and cure-directed-treatment being considered as mutually exclusive.
- Non-negotiation among patients, family members, and providers as regards palliation.
- Making treatment choices is given more importance than discussing the reality of life with a chronic debilitating illness.
- Palliative care is treated as an either/or decision instead of an integrated part of the treatment plan.

On a comprehensive note, the policy implications are huge! The upfront challenges have also been specified.

1. Epidemiological transition (The Double Burden of Disease) – The infectious diseases still prove to be a scourge to mankind while non-communicable diseases continue to expand in magnitude. This demands delicate balancing of focus on the part of policy makers and financers. India has also reacted actively to this dilemma. Even as our national health programmes continue to be operational at the grass roots under NRHM, the National Programme for Prevention and Control of Cancers, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) is a novel attempt under the same banner to counter the up rise of NCDs. Elderly in India are vulnerable to both infectious as well as non-communicable diseases.

- 2. Increased risk of disability viz., vision, hearing, mobility or even cognitive. The magnitude of disability is huge given the fact that adults over the age of 80 years are perhaps the fastest growing age-group world-wide.
- 3. Providing care for the ageing populations is also a challenge. Three dimensions of such care encompass self-care, informal support from family and friends, and formal care through the HCDS and social services.
- 4. It has also been seen that females tend to live longer than males. This feminization of ageing is sure to pose difficulties as women are prone to domestic violence, discrimination and lack of social security, economic and health dependency, etc.
- 5. Issues of ethics and inequities are also imminent which involve age-discrimination in resource allocations, human rights issues and those pertaining to fraudulent marketing (e.g., anti-ageing cosmetics and medical claims) and financing schemes. Concerns for social justice and aggravation of inequalities based on race, ethnicity or gender also need to be addressed to.
- 6. Ageing populations also warn of exceptional expenditures in terms of health care and social security (pensions). The WHO recommends 'fair financing' of health care that is equitable and accessible irrespective of age, sex or ethnicity. This financing has to be preferably, pre-paid (through insurances, taxes, etc).

7. It is also noteworthy that more and more people continue to remain economically productive, disease free and independent even beyond 60 years of age. This calls for forging a new paradigm that ensures an age-integrated society where the elderly are active contributors as well as beneficiaries of development.

Responses are expected from stake holders of geriatric palliative care which include policy and decision makers, health professionals, care-givers from the family and those funding research.

Policy and decision-makers need to recognize the needs of ageing populations and ensure provisioning of quality care towards end-of-life as an integral part of public health services. This has to engage multidisciplinary services with proper coordination, linkage and convergence. Creation of state-of-the art service units and personnel along-with quality auditing and information sharing is important. Palliative care training of medical people should be a core part. Sufficient palliative care specialists must be created and sustained to provide training to future man-power. Involving older people while designing services for them and generating awareness about the service-packages on offer are their onus. Health professionals have to ensure that their training is adequate and timely updated. Rajagopal has gone a step further to give a humane view of the attributes of effective palliation while calling for respect, empathy, relief from symptoms, companionship and encouraging life review as regards elderly care by trained professionals.^[7]

Old age is associated with increased emotional dependency as well. Bereavement and social isolation can be countered by sympathetic and respectful attitude of informal support providers which includes family members, friends and neighbors. It has been seen that this informal support group is of critical importance when the formal health service delivery system is well-equipped in order to ensure geriatric health care. There is also a preference for home care in case of the elderly for which this group's cooperation is vital. Supporting families and care givers with tolerant listening and appreciation by the organized service providers is also crucial to help them fight the depression and anxiety associated with an ailing dear one.

Research financers must not overlook the geographic variations within and between countries as far palliative geriatric care is concerned. Support for relevant research is most urgently needed for less developed countries. WHO has highlighted that low and middle-income countries despite having beyond 85 percent of the world's population and disease burden, received only a meager amount of the world's health research spending (WHO, 2000). Innovative researches between palliative and geriatric medicine must be encouraged through developmental funding, and consequently, translated into practice.

Several other aspects of geriatric palliation include spiritual and religious need-based support, psychological assistance and bereavement support. The iconic English novelist Mark Twain had said, "Wrinkles should merely indicate where smiles have been!" In this context, the people who have lived through their lives cannot be excluded. Thus, it is time to re-brush their wrinkles with smiles through well-concerted endeavors in palliative care. Even as the determinants of elderly suffering and seclusion and the spectrum of efforts that can be put in to ensure social security, inclusion and palliation open a Pandora's Box, it is time to realize that the old is an asset to the society. They have soaked themselves in the challenges of life and basked in the glory of successful experimentations. They have their wisdom to offer in harvest and it is up to us to save and savor. It is high time to learn from their experience and not deprive them through our ignorance.

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