The Importance of Integrating Palliative Care in Universal Health Coverage Discourse in India

Sir,

Ideally, Universal Health Coverage (UHC) is designed to provide full spectrum of health services which include health promotion, prevention and treatment, rehabilitation, and palliative care irrespective of economic or gender status.\(^1\) Palliative care is defined as an approach that improves the quality of life of patients and their families facing 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.\(^2\)

Globally, palliative care got included in the definition of UHC as a component in 2012 and palliative care resolution was adopted at the World Health Assembly in 2014 which calls on governments to “integrate palliative care services in the continuum of care, across all levels, with emphasis on primary care, community- and home-based care, and universal coverage schemes.”\(^3\)

**The myths and misconceptions**

Most of the UHC models restricts in providing a minimum package of health services and see it in the paradigm of medical care and not as a comprehensive primary health-care approach. Even in the basket of services provided under UHC, palliative care is the service which is often neglected even though it can be delivered at an affordable cost compared to any other set of health services. With regards to palliative care, it is also seen in the paradigm of medicine and usually get confined to cancer care and end of life care, even though many other diseases of all age groups come under its ambit.

In the western world, the traditional social support system has given way to a formal, rigid, and expensive medical system. This western perspective has culminated in the formation of a specialized branch called Palliative Medicine which clearly failed to extend to domains of social and financial aspects of the patient.\(^4\) This practice gets followed in many countries including India. The concept of “social care” which is the cornerstone of palliative care always gets diluted in this scenario, and the institutionalized medical approach has failed to reach the majority of those in need of palliative care. Palliative medicine should only be seen as a part of palliative care but should not be equated to palliative care since it includes all levels of care.\(^5\)

**Community-based palliative care approach**

The community-based model is generally patient-centric, takes into account cultural value systems and reduces the expenses associated with accessing health facility for follow-up visits and unnecessary investigations and treatments thus making it cost-effective and apt for any low- and middle-income country settings to follow.\(^6\)

Kerala was the first state in the country to formulate a palliative care policy in the year 2008 with home-based care as its cornerstone. The program works in a highly decentralized manner where local self-governments have taken the ownership of the program and volunteers are given a prominent place in service delivery, mainly in providing psychosocial care. Hence, being a resource constraint country, India should also focus more on adopting a community-based palliative care model which is financially sustainable and socially viable.

**Importance of integrating palliative care in universal health coverage discourse in India**

In India, all the existing UHC models operationalized across various states focus on a limited range of issues such as maternal and child health issues, family planning, and certain national health programs and palliative care services is never seen in the range of services. The recent Global Burden of Disease Report for India also clearly shows the change in epidemiological transition happening in the country and how the morbidity and mortality pattern are changing.\(^7\) Palliative care is not often available, accessible, and affordable to the needy in the country even though the people in need for the services are huge.

Since equity is considered as the central theme of UHC, palliative care services must be made an integral component of UHC models as it will mainly increase the quality of life and mitigate the sufferings of the poor and vulnerable, mostly patients at the end of life and reduces their financial burden.\(^8\)

There is no primary validated database in India to understand the palliative care needs of the people in the country. As per Kumar (2013), among the 9.8 million deaths happening in India every year, around 60% of them are in need of any palliative care services. However, only a meagre 2% of them receive any kind of palliative care. It is also a stark reality that among all the palliative care programs that exist in the country, 90% are available in the small State of Kerala, which accounts for nearly 3% of the country’s population.\(^9\) Hence, there is a clear demand-supply mismatch in the provision of palliative care services in the country.

Recently, the Government of India has introduced the idea of transforming Health Sub-Centres and Primary Health Centers into Health and Wellness Centers (HWCs) to expand the reach, coverage, and package of primary health care by placing a Mid-Level Health Provider (MLHP) who will be
Table 1: Organization of palliative care services - at various levels in a Health and Wellness Centers

| Services to be provided by MLHP (at Household and Sub-Center-HWC) |
|--------------------------------------------------------------|
| Basic Home care Nursing services such as catheterization, pressure sore cleaning, wound care, bowel care, lymphedema massage, colostomy care, eye care, bed bath, nasogastric tube insertion, and IV fluids. |
| Psychosocial support and empowering caregivers in basic patient management techniques |
| End of life care and bereavement support |
| Nutritional support and administration of medications prescribed |
| Generation of community volunteers and patient support groups |
| Enrolling eligible beneficiaries in welfare schemes with the help of community volunteers |
| Supply of commodities such as walkers and alpha beds |

**PHC-HWC**

| Services to be provided by MLHP (at Household and Sub-Center-HWC) |
|--------------------------------------------------------------|
| Outpatient services |
| Prescription of analgesics including oral morphine |
| Inpatient services |
| Certification of death |
| Supervisory role |
| Referral for specialty care |

**Higher referral centers**

| Services to be provided by MLHP (at Household and Sub-Center-HWC) |
|--------------------------------------------------------------|
| Inpatient services for patients requiring continued medical supervision |

Trained in public health and primary care. The HWCs are envisaged to provide a comprehensive set of 12 services which includes basic palliative care and geriatric care. As of now, the concept of government is to institutionalize the role of an MLHP. However, it should be noted that while including palliative care as part of the HWC concept, the approach needs to be community oriented as it is the only realistic model for achieving significant coverage of care for the most needy. The proposed model for the organization of palliative care service delivery at the HWC is represented in Table 1.

Palliative care is not a novel concept as far as Indian traditions are concerned. We have had an inbuilt social structure that respected and cared for the well-being of the aged and chronically ill patients. It is lost in the passage of times, though. We only have to rediscover it and assimilate it into our psyche.

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There are no conflicts of interest.

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