Review Article

Rural Elderly and Access to Palliative Care: A Public Health Perspective

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Abstract

In near future, the elderly population will increase to a high proportion. This will increase the burden of Age-Related Diseases (ARDs) to a significant level. Most of the ARDs need palliative care (PC) for a fairly long duration. Some statistical extrapolations are discussed to help in identifying this future burden. The existing PC centers are limited in numbers, situated mainly in urban areas, and mostly attached to cancer hospitals. Socioeconomic vulnerabilities of the elderly, especially in rural areas, are high, and access to health is also not optimal. In the coming decades, the number of needy people, as well as the demand for PC, will increase. Existing numbers indicate that exponential increment in quantum and quality of PC services is required to deal with the imminent burden. Specific suggestions are made to use existing public health programs to cater to the rural elderly.

Keywords: Access to health, elderly, palliative care, rural

Introduction

Although India is enjoying its demographic dividend, this window will close soon. The focus of public health interventions so far is around preventing deaths, and there is a fair improvement in life expectancy in the past two to three decades. Other socioeconomic improvements also contributed to it. The system is now grappling with the increasing trends of various age-related diseases (ARDs) and care burden of an ever-increasing number of elderly. People with age 60 years and above are defined as elderly and with age 80 years and above are called as eldest of the old.[1] Currently, the epidemiological transition is speeding toward the end of ARDs.[2,3] Many of the ARDs need palliative care (PC) due to their noncurable nature and prolong survival rates.[2,4] Access to PC is a major challenge, especially in rural areas. Access of the elderly to PC is a concern because along with higher disease burden, there are other socioeconomic vulnerabilities of the elderly as well. It is essential to understand and deliberate on the specific vulnerabilities of the elderly in the context of access to PC for better future interventions.

Demographic Changes and Trend of an Aging Population

The population of the elderly was 8.7% as per the 2011 census, and by 2050, it will be close to 19%, and in the same period, India's annual growth rate of the elderly will cross national annual growth rate.[5,6] The percentage may appear small, but the absolute number of elderly will be too high to handle for the health system. In the period 2000–2050, the total population of India will grow by 55%, but the elderly population will increase by 326% and those in the age group of 80 years and above by 700%.[1] One needs to understand that this demands a significant shift in public health priorities in the coming years, as longevity does not ensure a better quality of life or low prevalence of ARDs.

Life expectancy at the age of 60 years, in India, is 17 years for men and 19 years for women. This means that after the age of 60 years, on average, one elderly will live for an extended period in the stage of dependency. In the global ranking, India at present has low rank, but it will increase fast.[7] Old-age dependency ratio (OADR) is the ratio of older dependents (age 64+) to the working-age (15–64) population, and it is indicative of the burden related to the care of the elderly. India

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has OADR of 14.2 elderly (64+) for a working-age population of 100. It varies across the states with Kerala on the top with 19.6 and Delhi at the bottom with 10.4.[8] Such indices can be useful to identify priority areas for PC interventions.

Elderly Health Care: A Neglected Burden

Aging can be divided into multiple stages, depending on how much care and assistance is required. Even healthy elderly people need care and assistance, which increases with age. Moreover, when ARDs occur, along with care and assistance, medical intervention is also required. After all possible curative treatment, PC is the mainstay. In India, there are problems in support at all these stages and the level of assistance due to the absence of a public system for support. Global strategy and action plan of the World Health Organization (WHO) on aging and health 2016–2020 suggests countries to make provisions for the health and welfare of the elderly population.[9] The global burden of ARDs is very high.[10] The global picture indicates that among the needy people, the number of noncommunicable disease (NCD) patients is very high. As per the WHO global atlas on PC, cancer patients constitute 34.01%, cardiovascular patients: 38.47%, chronic obstructive pulmonary disease patients: 10.26%, and so forth. All most all of the major diseases are NCDs except for HIV (5.71%) and multidrug-resistant tuberculosis (0.80%).[11] Most of these NCDs are part of ARDs. This further indicates the importance of making PC services elderly friendly.

As life expectancy increases, the incidence of ARDs, including cancers, increases. For cancer alone, roughly one million new cases are diagnosed each year in India, and a major proportion of the patients are older than 60 years.[12] The burden of deaths due to other NCDs is also very high, contributing to 63% deaths per year, that is, 6.03 million of 9.57 million total deaths in India.[13]

As per the 2011 census, 71% of the elderly live in rural areas where access to quality health care is a significant concern. There is no reach of specialty services or PC in rural areas. About 64.8% of the elderly are suffering from some of the other chronic diseases, and they have huge health-care needs.[14,15]

The disability rate for the elderly was 51.8/1000 and 84.1/1000 for the above 80 population in 2011.[16,17] Out of a total of 26.8 million disabled people, 21% were elderly, and 76.19% of disabled elderly live in a rural area.[17] Every 20th elderly is disabled. For these elderlies, disability acts as a barrier to health access as well as an NCD risk factor apart from a social vulnerability. This additional factor needs to be at the back of the mind while making PC services elderly friendly.

The Situation at the Family Level

Elderly people are often ignored at family as well as policy spheres. The elderly have no control over resources or decision-making at a family level. There is no social support system for them, and their poverty laden families have other priorities. Around three-fourths of all Indian elderly are financially dependent on their families or others.[5] In rural areas, the migration rate of the younger population is very high. Family members often neglect the health needs of their elderly due to other competing priorities. Around half of the elderly face some form of abuse.[14,18] The modern processes for availing various government schemes are complicated for rural older people. Enrolment of the elderly in various government welfare schemes is limited for various reasons, including health insurance. All these factors affect access to health and PC, leading to low health-related quality of life of the elderly.

Even the families of the elderly who need PC face multiple problems which go unnoticed. In the absence of access to PC, these patients need to be taken to a specialty institutional care. These frequent visits are troublesome for both patients as well as caregivers. In-house caring and nursing a family member is a fulltime work, and it takes an incremental toll on caregivers as this period extends. Apart from the direct cost related to institutional care, there are multiple indirect costs that the family needs to bear. Emotional burnout is also significant.[19,20] Provision of PC at grassroots has a positive impact not only on the needy elderly but also on the family members and caregivers.[20]

Barriers to Access to Palliative Care

Access to health care is a broad concept which encompasses all the factors affecting an individual's ability to seek appropriate and quality health care. From the PC perspective, there are multiple barriers for the elderly. Unavailability of PC services is a key issue, especially in rural areas. Till 2018, there were only 159 centers in India except for Kerala. In Kerala, there are 316 centers.[21] Kerala is at a relatively advanced stage of demographic transition with a higher proportion of elderly. Furthermore, it has the most appreciated community-based PC model in India.[22] However, in most of the other states, there are minimal services, and community-based care model is a distant dream.[2] It will be a major challenge to incorporate PC in primary health-care services.

For most of the ARDs, including cancers, early diagnosis is crucial for better prognosis and reduction of further complications. Due to compromised access to health care and low awareness, there is a problem in the early diagnosis of ARDs. This delay, especially in rural areas, makes the elderly population further dependant on PC.

Disability is another aspect which poses challenges for the elderly. The disability rate among the elderly is 51.8/1000 and 84.1/1000 for the above 80 population. Furthermore, 76.19% of the disabled elderly are in rural areas.[7]

Another major challenge is the availability of trained human resource at grassroots. There are very limited training centers, and education in palliative medicine is not on the required scale.[2]

Future Burden and Palliative Care Provision at Grassroots

Among the sustainable development goals, the third one gives a target of reducing premature deaths due to NCDs to one-third by 2030.[23] However, this means in future, a higher number of people will need PC. As per the WHO, currently, 40 million patients need PC annually in the world, and only 14% have access to some form of care. In India, 60% of the dying population needs PC per year.[24] Unfortunately, only 1%–2% of needy people in India have access to PC.[25,26] As if now, the government structure for the provision of PC is not fully evolved in India. The existing facilities are around urban cancer treatment centers and in disaggregated status.[24]

India ranks 67 in the list of 80 countries for quality of death index with a total score of 26.8 of 100. India ranks below many low-income countries such as Ghana and Uganda. The highest-ranking country is the UK with 93.9, and Iraq ranks last with a score of 12.5.[27] There will be many variations across the Indian states, but this low average for such a vast population is worrying, and it is directly related to lack of access to PC.[4]

Rural areas are far from such services and the elderly take a huge burnt of it. It is crucial to plan now for providing PC in rural areas and understand the significant hurdles toward that. The need will be huge in future, and insufficient services may jeopardize the right to health and dignity of the needy elderly people.[28]

In India, the need for PC is increasing exponentially along with the rise in the elderly population. Some of the prominent reasons for the increase in future demand for PC are increasing paying capacity, better coverage by insurance, awareness due to digital knowledge sources, etc., Hence, the future generation will demand PC for their dying elderly, both in private as well as public sectors.

Some statistical extrapolations help to understand the future burden on the PC system due to cancers and other diseases. The current global cancer burden estimated was 18.1 million new cases and 9.6 million deaths. By 2040, the global cancer incidence will rise to 29.5 million per year.[29] In 2018, the incidence of all types of cancers was estimated 1,146,672 for India, and by 2040, this will reach to 1,891,621 per year and death burden due to cancer at present is 784,821, and it will be 133,434 by 2040.[30] The group called "Serious Health-Related Suffering" (SHRS) represents the needy group of patients for PC. It is estimated that by 2060, low- and middle-income countries (LMICs) will account for 83% of such patients.[31] India represents around 44% of the population from LMIC and will have a major portion of SHRS people in future. Even among the patients who reach tertiary level cancer centers, 96% do not have proper PC access.[32] An existing PC system is not enough for cancer patients alone. The current PC delivery structure is already in an overwhelmed status. Although conceptually experts agree that other noncurable and progressive diseases need PC intervention and patients should be handled based on palliative medicine principles, in reality, only a small section of noncancer, needy patients get PC.[24,26] Other ARD patients are not being focused on this perspective. At present, 63% of deaths occur due to NCDs in India and this number will increase in future.[13] Future projections indicate that 6 million people per year will need PC in India.[24]

Institutional Efforts and Policy

As per the World Health Assembly, health systems are supposed to provide PC as a part of primary health care. No needy person should be kept devoid of it, and it is an ethical responsibility of health systems.[33] The National Health Policy of India, 2017, for the first time, has included PC in the objectives related to primary health-care provision.[34] This is a positive policy change. Furthermore, the specialization cadre in PC, along with a specialty in higher medical education, has been started recently in India. These steps will prove crucial in laying down the foundation of a future system for better PC, but providing the care to such a huge and needy population is a challenge.

The National Programme for Health Care of the Elderly (NPHCE) was started in 2011 with 100 selected districts, and it is expected to expand to the whole nation. Under this program, infrastructure and health-care delivery centers are to be built from primary to tertiary level health centers and equip those with a trained medical cadre in geriatric care. More focus will be on primary health care and prevention of diseases or complications of ARD. There will be dedicated clinics for the elderly, and they will be linked to the system through community-based cadre with regular health monitoring of the elderly.[3] As per the National Health Policy, PC will be part of primary care, and this program can act as the leading provider, especially at grassroots. NPHCE is now based in the NCD cell of the respective district, which is an additional benefit as most of the ARDs fall in the NCD category. However, mounting the PC component on NPHCE will be a vital and challenging task. This will need additional training of the same human resource and better referral linkages to PC centers. In India, both these systems are in the nascent stage and marrying the two has its own challenges. However, if state governments could integrate PC component with primary care provision through NPHCE, it will benefit rural elderly to tackle with ARDs and improve their quality of life.

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Conflicts of interest

There are no conflicts of interest.

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