## Mainstreaming Ageing in to a Relevant Policy

## Introduction

Populations around the world are ageing, and more people are living with the effects of serious chronic illness towards the end of life. Meeting their needs presents a public health challenge. Patterns of disease in the last years of life are also changing, with more people dying from chronic debilitating conditions, such as cardiovascular disease, chronic obstructive pulmonary disease, diabetes, cancer and dementia.

Palliative care focuses on improving the symptoms, dignity and quality of life of people approaching the end of their lives and on the care of and support for their families and friends. This topic is often neglected, although it is relevant to everybody. Older persons are diverse in their needs, preferences, and opportunities throughout their life course. The emphasis is on improving quality of life and respecting human dignity to be available for all especially to older people in our State is a growing need.

## PAIN

Unnecessary suffering of older persons for lack of pain medicines and palliative care at the end of their lives

violates basic human rights. The lack of access to pain relief is a form of cruel inhuman and degrading treatment.

Palliative care is not only about lifting older persons out of needless pain and distress; it is an imperative to maintain their dignity at the end of their lives," the human rights experts said, noting that the number of older persons is expected to more than double globally from 841 million people in 2013 to more than 2 billion in 2050.

Research Studies explored that pain and other symptoms are under assessed, undertreated, and are associated with a number of negative outcomes in older adults (Gibby et al.,2002) and also several studies advocates that untouched pain is allied with depression, decreased socialization, sleep disturbance, impaired ambulation, and increased health care utilization in older adults (Ferrell et al.,2003)

Palliative Medications should be available, accessible and affordable and must be included in health financing schemes. States should promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use.

Healthcare systems which ignore the need to have accessible and good quality palliative care will never be able to effectively promote and protect right to health and related

human rights of their citizens. So each state have the responsibility to discuss and to identify the barriers to opioid availability and to develop national action plans.

## **Challenges faced by the elderly**

a) Restricted Social life

b) Mental torture

c) Denial of basic needs – medical attention, food,

clean clothes etc

d) Physical harassment

e) Emotional blackmailing, Humiliation

f) Elder Abuse

g) Isolation and loneliness

h) Poor access in rural areas- Rural populations have less access to services and activities and their situation may aggravate further when combined with poorer socio-economic conditions. This puts rural populations at a disadvantage compared to urban ones and can be particularly problematic for older people who may face a greater risk of social isolation, reduced mobility, lack of support and health care deficits as a result of the place in which they live.

**Ageing Status**

India's population (1.31 billion) is the second largest globally, contains 17% of the world's whole (United Nations, 2015) and the United Nations Population Division estimates that India's population will surpass China's population by 2028In the case of developing countries, the geriatric population is expected to be 840 million by 2025 (WHO, 2002).

Presently, the growth level of the figure of older individuals (age 60 and older) is three times greater than that of the population as a whole (Giridhar, Sathyanarayana et al. 2014). Population ageing is an imperative evolving demographic phenomenon in India, deserving a strong multi-sectorial policy and programme response (United Nations, 2011). In India, about 80% of the older persons are living in the rural areas and it denotes the in accessibility in seeking services. Female population is more than the male. Increase in the number of the oldest-old (persons above 80 years) is another challenge faced by the demography of India. About 30% of the elderly live below the poverty line makes it more complex. A combination of these features makes the elderly very vulnerable.

States with high share of ageing population is in the state of Kerala-12.6%. According to the census 2011, the whole

population comes around 121 Crore and the aged 60+ is about 10.39 Crore. So the share of the elderly population is 8.6 million. The proportion is increasing at an alarming pace as per the records.

**Situation in Kerala -2018**

Kerala is the first state to have state palliative care policy in India. In 2008, the state was able to launch the policy, which considers old age as an important group requiring palliative care. Elderly population was also acknowledged in the National Program for Palliative Care in 2012.

Kerala has got more than 150 palliative care centres across the state based on Recognized Medical Institution status, this is apart from government institutions with palliative care provisions. The same state has got 565 old age homes of which 225 with government grants. In 2017, these homes were found to be overcrowded with about 10,500 inmates, these old age homes are running without trained nurses, medicines as many of them are not registered under government schemes like Vayomithram and mental health is neglected to a large extend.

Elderly abuse is yet another problem, a survey by Help Age India found that 15% of elderly surveyed in one of the districts in Kerala reported abuse and 44% of participants

across India reported abuse from public. (HelpAge India, 2017)

**Actors and Context:**

It is the influence of palliative care fraternity including doctors, nurses and volunteers which began from Calicut – Pain and Palliative Care Society (PPCS) in 1990's, Indian Association of Palliative Care (IAPC), Pain Policy Study Group from Wisconsin, International Narcotic Control Board, interventions from courts and government officials / stakeholders resulted in the formulation of palliative care policy in the country and state. Civilian like Ravi Ghooi who filed a petition for accessing pain medications for his mother suffering from cancer pain in 1997 and a public interest litigation in 2007 also played crucial steps in the process.

All these were aimed at making available less expensive pain medications for patients in suffering. This ultimately led to the amendment of narcotic policy in 2014 and classifying six drugs as Essential Narcotic Drugs (ENDs) recognizing its medical use (Vallath N et al,. 2017).

**National policy 2017**

The primary aim of the National Health Policy, 2017, is to inform, clarify, strengthen and prioritize the role of the Government in shaping health systems in all its dimensions- investments in health, organization of healthcare services, prevention of diseases and promotion of good health through cross sectoral actions, access to technologies, developing human resources, encouraging medical pluralism, building knowledge base, developing better financial protection strategies, strengthening regulation and health assurance.

The policy envisages as its goal the attainment of the highest possible level of health and well- being for all at all ages, through a preventive and promotive health care orientation in all developmental policies, and universal access to good quality health care services without anyone having to face financial hardship as a consequence. This would be achieved through increasing access, improving quality and lowering the cost of healthcare delivery. The policy recognizes the pivotal importance of Sustainable Development Goals (SDGs).

On Feb13th, 2018 The Hindu Newspaper reported - The NITI Aayog's released report, ranking the states as per "Performance in Health outcomes" Index put Kerala on top as the overall best performing state and at the bottom, at rank 21,when the annual incremental progress was measured.

The NITI Aayog (National Institution for Transforming India) is a policy think tank of the Government of India started in 2005 with the aim to achieve sustainable development Goals and to enhance cooperative federalism by fostering the involvement of State governments of India.

In the National Budget of 2018,recommendations with commitment to Universal Health Coverage, strengthening of primary health care, linking new medical colleges to upgraded district hospitals, provision of free drugs and diagnostics at public health facilities, and stepping up financial protection for health care through a government funded programme that merges central and state health insurance.

**Palliative Care policy for Kerala**

The Government of Kerala declared a palliative care policy in April 2008. This is the first state in India having a palliative care policy among other states.

Arogyakeralam project - Health policy 2018 in Kerala- Kerala's new health policy focuses on improving and equipping the public health system to deliver affordable, accessible and quality care to the public at primary, secondary and tertiary levels.

Long-term Goals-

a) Public- funded free, Universal comprehensive health- care system.

b) Bring infant, child, and maternal mortality to levels in developed countries.

Recommendations

a) Medical auditing in hospitals to ensure transparency and quality care.

b) Setting up a Medical Recruitment Board.

C) Enactment of Kerala Public Health Act.

The state governments have the main responsibility of health service delivery and also need to bear the major share of the public expenditure on health. As a whole, in a federal polity with multiple political parties sharing governance, an all India alignment around the NHPS requires a high level of cooperative federalism, both to make the scheme viable and to ensure portability of coverage as people cross state boarders.

Community Based organizations (CBO) – For better coverage, community based volunteers can play a major role in addressing the psycho social, spiritual matters of the patients as well as the families.

**Budgetary Sources**

1) Centrally Sponsored Schemes

*a) National Rural Health Mission (NRHM)*
*b) National disease control Programme*
*(Cancer, AIDS, etc)*
*c) National Health Protection scheme (NHPS)*

2) State Sponsored Schemes

*a) Directorate of Health Services*
*b) Directorate of Medical Education*

3) Local Self Government Institutions (LSGIs) - Expected to work closely with CBO and NGOs under the coordination of LSGI.

## Analysis of National Policy on Older Persons

In view of the increasing need for intervention in area of old age welfare, Ministry of Social Justice and Empowerment, Government of India adopted 'National Policy on Older Persons' in January, 1999. The policy outlines 'senior citizen' or 'elderly' as an individual who is of age 60 years or above. The policy provides broad guidelines to State Governments for taking action for welfare of older persons in a proactive manner by devising their own policies and plans of action. It strives to ensure well-being of senior citizens and improve quality of their lives through providing specific facilities, concessions, relief, services etc. and helping them cope with problems associated with old age.

The Elderly in India, 2011 action on the part of Government Departments for ensuring that the existing public services

for senior citizens are user friendly and sensitive to their needs. It provides a comprehensive picture of various facilities and covers many areas like financial security, health care, shelter education, welfare, protection of life and property etc. key features of the policy are  Pension Scheme for old age; Subsidy in healthcare ,Tax Exemption for Senior Citizens; Make PDS to reach older people;, geriatrics care services, mental health services, counselling amenities and services ; Grants/Endowments, land grant at concessional rates to NGOs and private hospitals to provide cost-effective and specialized care for the older person; Allocating 10% of the houses in housing schemes and easy access to loans; Layout of housing colonies to be sensitive to the needs of the older persons; Quick disposal of cases of property-transfer, mutation, property-tax etc; Assistance for construction/ maintenance of Old-Age Home, Daycare Centers, Multi-service Citizens Center, outreach services, supply of disability related aids and appliances etc and setting up a welfare fund for older persons .(GK today,2016)

**Content Analysis**

The main problems recognized in this policy are with respect to upsurge longevity, the issues with social security, and the care of oldest old (80 years or above). The policy had identified gender related problems among aged women.

It identifies-economic problems, illiteracy, unemployment, property rights, social mental, Non Communicable Diseases, disability, and widowhood as the need for special attention areas among elderly women.

The policy of elderly is still young because most of the activities are not yet implemented properly. However, efforts needs to be there to develop a model of health and social care in tune with the changing need and time. The policy inspires voluntary organizations to supplement the care provided by the family and deliver care and protection to vulnerable elderly people but it felts like exact effort has not been initiated for the collaboration of private, NGO sector activities into the policy. Even though policy has succeeded in identifying many neglected zones like elderly women and the oldest old, objectives seems not time bounded and the activities need to be matched objectives. Policy is not sensitive to the needs of the elderly. The UN Principles (Rights) on older persons (Independence, Participation, Care, Self-Fulfillment and Dignity) needs to be incorporated. The rights perspective needs to be incorporated in the policy. Knowledge with the medical history of the elderly is vital for planning and implementation of policy related to healthy old age. Other emerging problems such as institutionalized elderly, abuse

of elderly, destitute, long term home based care, elderly living alone, are not there. The problem statement is blind towards many major emerging issues relating to the elderly. It also fails to address the differential needs of women as a problem and need. Regarding the rural elderly, the health care and related factors are not coming up. Considering the fact that more than 50% of the elderly are sick one or the other way, the aspects of problems relating to health and health care are uncovered. The availability, accessibility to different services including health care was not identified as a problem even when the policy identified many vulnerable areas. There is an emerging need to give greater attention to ageing-related issues and to promote holistic policies and programmes for dealing with the ageing society. The availability, accessibility to different services including health care, palliative care was not identified as a problem even when the policy identified many vulnerable areas. Policy lacks strategies to address issues of cognitively impaired elders.

**WHAT WE NEED TO DO**

As a basic human right issue, we have to develop a strategy to map out the plans and progress in Palliative Care development. There are four major components-

Appropriate policies, Adequate drug availability, Education of health care professionals and Implementation of plans.

**Suggested strategies /Policy options section**

To recognize and meet the needs of older persons, policies need to be flexible and sensitive to local variations in cultural and physical realities. They can best be designed and implemented at a local or regional level, and supported by higher levels of government.

Option 1)

A multi layered and multi skilled health workforce is needed to implement health care through out the country. Help to implement model programs that could be the focal point for change and the grass root efforts will make progress in regional and national level. Effective collaboration among Governments, Policy makers, private sector and non-governmental organizations.

To uphold the commitment to the United Nations 2030 Agenda and it's Sustainable Development Goals.

Option 2)

Developing modern policies for care as well as extending home-based services and furthering the integration of care into the local community are effective ways to react to social

changes and to respond to the desire of many older persons to live independently.

Developing volunteering and community-based initiatives to improve social integration of older people. Policies on health and welfare of older persons need to be complemented with measures aimed at empowering and safeguarding their dignity, and preventing all forms of discrimination, abuse, neglect and violence.

Integrated training programme – strengthening of primary health care system to enable and to meet the health care needs of older persons. Training and orientation to medical and para –medical personnel in health care of the elderly. Technological enhancement of active care through media is also an alternative for spreading the news in the community.

Option 3)

Recognizing the potential of older persons and promoting opportunities for them to participate in society and economy.

Provision of separate queues and reservation of beds for the elderly people in all the hospitals and thereby increase attention for older person's dignity and enjoyment of all human rights. In rural areas try to reduce inequities and

creating better opportunities for healthy ageing and well being for rural populations.

**CONCLUSION**

An urgent and sustainable response is needed to improve palliative care for older people and meet the growing needs of the world's ageing populations.

The expected result through this initiative is - Better quality of care especially for the elderly- from passive to active care- a paradigm shift.

Develop more comprehensive policy responses to secure or enhance the existing access of older persons to adequate social protection and well functioning systems of health and long-term care. The policies aims to provide better palliative care practices for older people to help those involved in planning and supporting care-oriented services most appropriately and effectively.

To stand together in reaffirming the commitment to implement policies for active and healthy ageing, where older persons are continuously recognized as an asset for a sustainable and inclusive society for all ages.

An extensive acceptance of palliative care approach from all health professionals, Connection between primary care, geriatric care, coordination with Palliative care physicians, development of hospital palliative consultative teams together with specialized units caring for more elderly with greater needs and legal rights adoption will help to achieve quality of life with good outcome for elderly population.

Governments around the world should ensure full access to palliative care of all terminally ill, including older persons, and overcome all obstacles that restrict availability to essential palliative care medications. States have an obligation to ensure that older persons can enjoy the last years of life without unnecessary suffering.

*N.B - Based on the reports and discussions, in collaboration with Pallium India, Kerala - we formed a working group under the leadership of Dr.M.R.Rajagopal. Based on the assessment and evidence, we have to implement the following steps - Stakeholders meetings with key policy makers, Health policy, Financing, Legal framework, Education and Drug policy in connection with the elderly people.*

**Check List**

| Tools and techniques | Purpose | Elements | Stakeholders |
|---|---|---|---|
| Strategic framework | Systematic considerationof ageing- related concerns in all areas | National action plan on Ageing | Government and other relevant stakeholders |
| Laws and policies | Evaluation of existing laws and policies | Guidelines on mainstreaming ageing | Legislative Bodies and governmental agencies |
| Data collection and Analysis | Availability of socio-economic data about ageing and different age -groups | Advocacy campaign on local, provincial and national level. | Governments and Research institutions |

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