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A REVIEW OF THE PROCESS OF FORMULATING THE PAIN AND PALLIATIVE CARE POLICY OF KERALA, INDIA

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ABSTRACT

The state of Kerala launched the Pain and Palliative Care Policy in April 2008. It was one of the most celebrated policies and Kerala became the first state in India, which formulated a policy for palliative care. The present paper is written primarily based on review of literature and primary data was also collected through key informant interviews. The present paper is a review of events and processes that led to the development of the Pain and Palliative Care policy of Kerala. It describes major events and roles played by important actors at the international and national levels that contributed to the development of 'palliative care services' in Kerala and later to the formulation of a policy.

KEY WORDS: *Pain and Palliative Care Policy, palliative care, hospice care, Kerala, India, World*

1. INTRODUCTION

The state of Kerala launched the Pain and Palliative Care Policy in April 2008. It was one of the most celebrated policies and Kerala became the first state in India, which formulated a policy for palliative care. This policy envisaged the scaling up of already existing, community-led and decentralized palliative care to the entire state incorporating local self-government institutions, government health centres, nongovernmental organisations (NGOs) and community-based organisations (CBOs) to provide palliative care to the neediest at primary, secondary and tertiary levels of health care. (Government of Kerala, 2008) The present paper is an attempt to portray the evolution of palliative care and the policy in Kerala from a historical perspective of palliative and Hospice care.

The paper is organized into four sections: -

1. Evolution of palliative care in the world
2. History of palliative care in India
3. Development of palliative care in Kerala
4. Process of formulating the Pain and Palliative Care Policy in Kerala

2. METHODOLOGY

The present paper is written primarily based on review of literature and primary data was also collected through key informant interviews. Both face-to-face interviews and telephonic interviews were done. Both published and grey literature were reviewed to get finer details on the various sections.

3. THE EVOLUTION OF PAIN AND PALLIATIVE CARE POLICY OF KERALA

3.1 Evolution of palliative care in the world

Palliative medicine is a recently developed medical specialty with a history of only six decades. The initial developments happened in the United Kingdom during 1950s. Three surveys on 'end-of-life care' conducted in 1952, 1960 and 1963 revealed that the 'sufferings of terminally ill patients remain unrelieved (C. Saunders, 2001). These three different surveys conducted by Marie Curie Memorial Foundation, Gulbenkian Foundation and John Hinton unveiled the pain and sufferings of patients dying of cancer at home, elderly who lived in charitable homes and those who were dying in the wards of a teaching hospital (C. Saunders, 2001; C. M. S. Saunders, 1967).

3.1.1 Contribution of Dr Cicely Saunders

The modern palliative care is indebted to Dr Cicely Saunders whose experiences with terminally ill cancer patients and their families inspired her to work for them. She was advised by her colleague to take medical degree to convince doctors who took care of the dying patients. Thereafter, from 1958 onwards, she had undergone medical training and research for 7 years at St. Joseph's Hospice centre, UK (C. Saunders, 2001).

Saunders' observations and research on pain management with small doses of oral morphine laid the first evidence for the modern palliative care (C. Saunders, 1963). During the same time, there were attempts to sensitize the world through compiling available research evidences. As a result, National Health services, UK came forward to find solutions to fill the proven gap in the system to address the problems of dying patients. As a result, St. Christopher's hospice started in 1967 with 54 beds, of which 16 residential beds for elderly. After two years, they started home care. Alongside, rigorous attempts were made to spread the message around the world through numerous visits to different foreign countries and establishing international links with medical and related fraternities (C. Saunders, 2001).

3.1.2 Other milestones at the international context

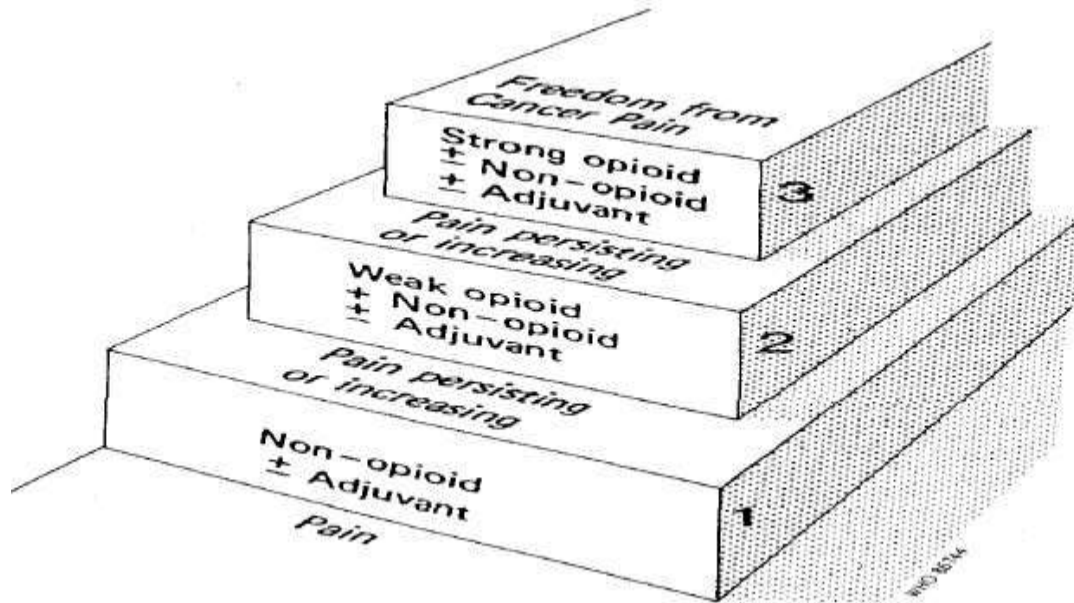
In 1969, Dr Elisabeth Kubler Ross in her book 'On death and dying' described five stages of grief while facing death. This book was a best seller and gained attention from all parts of the world ("EKR Biography," n.d.). These five stages of grief were denial, anger, bargaining, depression, and acceptance; that all people would experience even though not sequentially. Three basic concepts of modern palliative care i.e.; 'home care, hospital care and consultation teams' developed during this period (C. Saunders, 2001). Many international organisations and research centres formed during the period from 1990 to 2000 namely Worldwide Palliative Care Alliance (WPCA), European association of palliative Care (EAPC), International Palliative Care Resource Centre (IPCRC) etc. According to a joint study named 'Global Atlas of Palliative Care at the end of life' by Worldwide Palliative Care Alliance (WPCA) and WHO, 138 out of 238 countries started at least one palliative care initiatives (58%) by 2011 (Connor & Bermedo, 2014).

3.1.3 Role of World Health organization

During 1980s, palliative care gained momentum when World Health Organisation (WHO) accepted pain management as an important strategy in the cancer control. According to WHO, "*Palliative care is 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*" (World Health Organization, n.d.). From mid-1980s onwards, palliative care extended its arms to cover not only terminally ill cancer patients, but for patients living with HIV/AIDS also (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002).

In 1982, palliative care became an essential component of WHO's cancer control programme and in 1986, WHO came up with 3-step analgesic ladder for the management of pain among cancer patients. This model emphasizes the use of opioids for pain management in cancer patients (World Health Organization, 1986).

Figure 1 The World Health Organization analgesic ladder for treating cancer pain

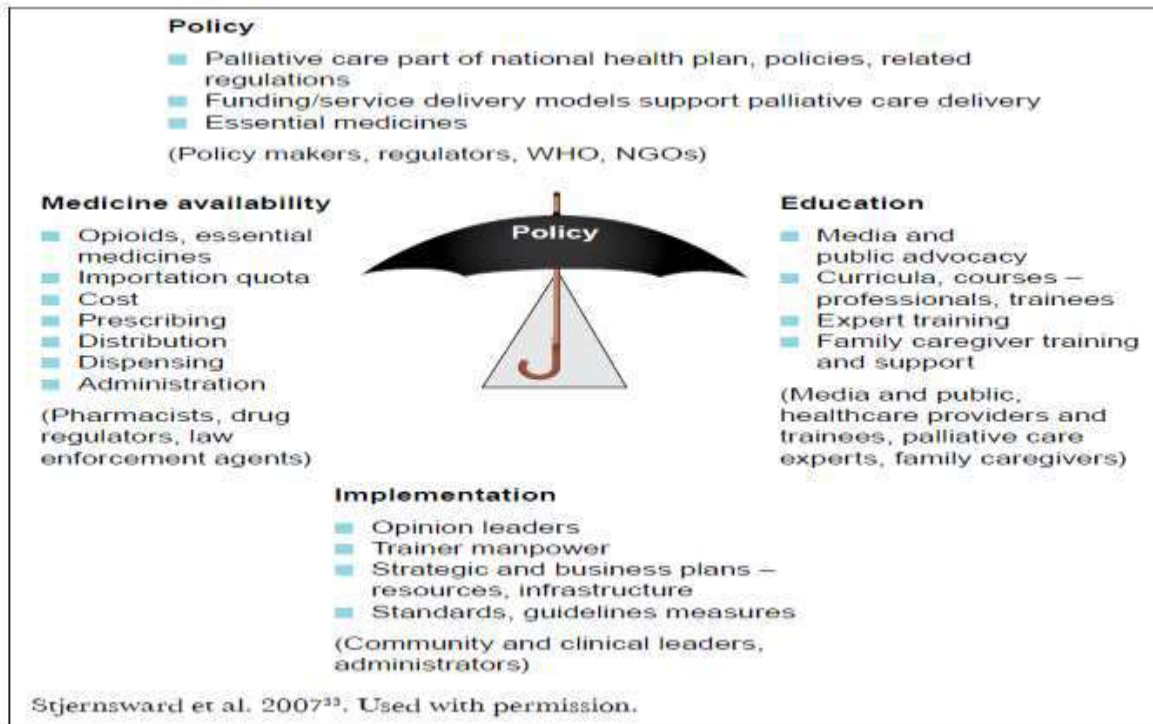


Source: (World Health Organization, 1986)

In 1990, for the first time, WHO proposed a Public Health Strategy for palliative care and encouraged member nations to formulate a palliative care policy (Stjernswärd, Foley, & Ferris, 2007). It also recommended for “early integration of palliative care into the disease trajectory” which means the palliative care should start from the time of diagnosis itself and

not based on the disease prognosis. This public health strategy has four main aspects: - policy, medicine availability, education and implementation. It recommends strong advocacy from governments and active involvement of media to create awareness among general population (Stjernswärd et al., 2007).

Figure 2 WHO Public Health Model



Source: (Stjernsward et al., 2007)

In 2002, WHO started two projects for Africa and Europe. In Africa the project aimed to provide palliative care to patients with HIV/AIDS along with cancer patients and in Europe the aim was to strengthen the existing palliative care interventions within the existing framework of cancer control programmes and integrating with the health systems (Sepúlveda et al., 2002).

Essential Drugs and Medicines Policy of WHO (EDM) deals with the regulation of narcotic drugs and psychotic substances including opioids. This department along with collaborating centres conducted workshops, developed guidelines and persuaded national governments to make necessary changes in their policies to make these drugs available for therapeutic use (Sepúlveda et al., 2002). In 2000, WHO issued a 16- item checklist to examine and evaluate the laws and regulations related to drugs especially narcotics in 22 languages and also, recommended for the integration of palliative care into the primary health care (Sepúlveda et al., 2002).

3.1.3.1 Role of Pain and Policy Studies Group (PPSG)

PPSG is a WHO collaborating centre at the University of Wisconsin Comprehensive Cancer Centre. They entered the domain when a group of Indian physicians seek their assistance to analyse the laws and regulations constraining the medical use of opioid drugs. PPSG studied and evaluated the international, national and state level policies and laws, conducted meetings with various stakeholders directly or indirectly related with opioid availability (World Health Organization, 2016).

3.2 History of palliative care in India

In India, the history of palliative care started with the National Cancer Control Programme in 1975. In 1984, the Government of India declared that the pain management in cancer should be incorporated into primary health care (Khanna & Lal, 2016). Though this was not implemented, thereafter many palliative care hospice centres started in India. The first of such kind was started in Gujarat Cancer and Research Institute, followed by Shanti Avedna Ashram, Mumbai, Regional Cancer Centre, Thiruvananthapuram and Kidwai Memorial Institute of Oncology, Bangalore (Singh & Harding, 2015). In 1985, Government of India brought strict regulations to prevent illicit

transactions of narcotic substances which made the legitimate use of these substances impossible. In addition, state governments also had their own laws so that the licensing of opioid drugs for therapeutic use became too complex (Anderson, Beletsky, Burris, Davis, & Kresina, 2009). To overcome this and being recognising the importance of opioid drugs in pain management, the PPSG was consulted. PPSG submitted the results with a proposal to reform the Indian policy in 1997 and consequently in 1998, the Government of India gave instructions to state governments to make the Narcotic drugs and psychotic substance policy flexible, enabling the legitimate use (Anderson et al., 2009). But many states ignored these except Kerala. The Indian Association of Palliative Care officially registered in 1994, which was a major mile stone (Anderson et al., 2009).

3.3 Development of palliative care in Kerala

Since 1990s, the history of palliative care in India is the history of the same in Kerala too. Palliative care has a successful story in Kerala for the last 20 years. Though localised in certain parts of Kerala, it was considered as an 'ideal model' in resource poor settings (Palat, 2014; Rajagopal, 2014).*

3.3.1 Pain and Palliative Care Society, Calicut

The period during 1990s was the golden era of palliative care in Kerala. A group of people with similar interests joined together and laid the first step for a 'revolution'. Dr M R Rajagopal, Dr K Suresh Kumar and Dr Ashok Kumar together started the Pain and Palliative Care Society (PPCS) in the campus of Government Medical College, Kozhikode in 1993. All of them were anaesthetists as well as colleagues in the medical college (Paleri & Numpeli, 2005; Rajagopal, 2014*). In 1996, they started home care by selecting and training volunteers from the community. In the same year, WHO conferred PPCS as their "demonstration project" to provide palliative care services in resource poor settings. By 1999, 30 similar community-based organisations (CBOs) were formed in northern Kerala, especially in Malappuram, Calicut and Wayanadu (Rajagopal, 2014).*

3.3.2 Neighbourhood Networks in Palliative Care (NNPC)

The domiciliary services provided by community volunteers were gaining attention from different parts of the world and in 1999 such small, decentralized networks in northern Kerala organized together to form the Neighbourhood Networks in Palliative Care (NNPC), which was the major paradigm shift in the Palliative care history of Kerala.¹⁵ NNPC was formed by four NGOs namely Pain and Palliative Care Society, Malappuram Initiative in Palliative Care, Alpha Charitable Trust and Justice Sivaraman Foundation. The aim was "to develop a sustainable "community led" service capable of

offering comprehensive Long-Term Care (LTC) and Palliative Care (PC) to those in need". This initiative evolved in the next few years to become World's largest palliative care network (Paleri & Numpeli, 2005).

Being inspired by the success of NNPC, Dr Suresh Kumar started a training institute for doctors, nurses and community volunteers. As a result, Institute of Palliative Medicine was formed in 2003 with basic certificate courses in palliative care. In the same year, Dr Rajagopal started Pallium India which was also primarily a training centre with in-patient facilities at Kochi, Ernakulam. Now both centres are WHO collaborating centres for promoting and developing palliative care strategies for low and middle-income countries ("About Pallium India | Pallium India," n.d.; "Institute Of Palliative Medicine," n.d.).

In Kerala, the media contributed immensely to promote palliative care. One of the most popular Malayalam newspapers started a new initiative known as 'we are with you' which was a great movement from the part of media (Kumar, 2013). Apart from this, all local, national and international media extensively spread the 'Kerala Model palliative care' across the world. WHO accepted it as the 'best model' for resource poor settings and conducted workshops inviting representatives from different countries to demonstrate this model before them (Kumar, 2013).

During the same period, PPSG conducted many workshops in Kerala and bring forth the complex licensing system of narcotics before the officials in 1998. The then health secretary agreed to simplify the narcotic rules and in 1999 the new rule came into action. The rule recognised institutions providing palliative care as recommended medical institutions (RMIs) which can procure, store and dispense opioid drugs. Thereby, the opioid drug use increased dramatically and the state with only 3% population became the largest consumer of (80%) of narcotic drugs in the country (Rajagopal, 2014).*

3.4 Process of formulating the Pain and Palliative Care Policy in Kerala

The last decade witnessed the evolution of palliative care from a humanitarian aspect to a fundamental human right to 'live with dignity'.¹⁷ Through active media involvement, the message was spreading faster across the state and it gained attention from various stakeholders like politicians, bureaucrats, religious leaders etc and very soon, palliative care became the 'felt need' of the community as a whole. Apart from this, decentralized governance system in Kerala delegates Local Self Government Institutions to take responsibility of the social welfare activities including health in the respective areas (Palat, 2014; Rajagopal, 2014).* In northern Kerala, the LSGIs were already taking part in the provision of palliative care services in various ways. However, in other parts

of Kerala, the services were either absent or rudimentary (Rajagopal, 2014).*

Before the state government, there was 'well-functioning, self-sustaining community-based model' of palliative care, extremely sensitive to the needs of the community. A window of opportunities opened at this time. The first was the demand for Kerala model from different parts of the world and from within the state as well. The second and the major one was the entry of National Rural Health Mission (NRHM) into the domain and the third one was the presence of a group of government bureaucrats with similar interests in the senior level administrative positions (Palat, 2014; Rajagopal, 2014).*

The pain and palliative care policy was formed as a 'response to the request'. There were many actors who played key roles in the process of developing the policy. Palat Mohandas IAS, then Chief Secretary noticed the increasing popularity of palliative care. His niece Dr Gayatri Palat was a colleague of Dr M R Rajagopal, the Director of Pallium India (Trust). They shared the idea of a policy for palliative care with Chief Secretary. He advised them to draft a policy and after 6 months, in August 2005, the first draft was submitted to the then Health secretary Dr Vishwas Mehta IAS. He called up several meetings with all stakeholders and discussed each item in the draft. During the course, many new items were added and some were deleted to the draft. The policy was finalized by Dr Mehta who championed the whole process. The final Pain and Palliative Care policy was announced in April 2008 by then health minister Smt. PK Sreemathi teacher. Dr. Rajan Khobragade, then deputy health secretary also played key role in the whole process (Palat, 2014; Rajagopal, 2014).*

When considering the context of Kerala, both the problem and its solution were already identified. The last step was to make it into a policy which was done by these actors. There was a consensus from all stakeholders about the need of a policy. But the conflict aroused regarding the implementation of the policy. The first draft emphasized on palliative care as a specialty of medicine and provision of government owned palliative care services whereas other stakeholders preferred community owned services. Later after so many meetings and discussions, an integrated approach was adopted for the policy (Palat, 2014; Rajagopal, 2014).*

4 CONCLUSION

The Pain and Palliative Care policy of Kerala is the best example of how a community initiative can successfully be changed into a policy. Within two years, the palliative care programme had been implemented as an integrated endeavour named as 'Arogya Keralam Palliative Care Project' incorporating NHM, Local Self Government Institutions, health

system, Nongovernmental organizations and volunteers from the community.

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