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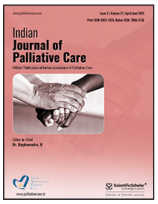

Original Article

Status of Palliative Care Services in Tamil Nadu – A Descriptive Report

Sathish Kumar Deenadayalan[1], Surendran Veeraiah[1], Vidhubala Elangovan[2], K. Sathyamurthi[3]

[1]Department of Psycho-Oncology, Cancer Institute (WIA), [2]Fenivi Research Solutions, [3]Department of Social Work, Madras School of Social Work, Chennai, Tamil Nadu, India.

ABSTRACT

Objectives: Advanced cancer patients attending tertiary cancer centres from rural places are referred back to local physicians for symptom management. Due to lack of networking with palliative care centres (PCCs), the referred patients do not receive appropriate palliative care (PC) services. Hence, an attempt was made to map the PCCs in Tamil Nadu to make the referral system efficient.

Material and Methods: PCCs in Tamil Nadu were identified from the National Health Mission directory, online sources and from morphine license annexure of drug control department. The details regarding nature of facility, PC model, service type, procedures, cost, morphine availability and type of personnel involved in their PCCs were collected from government and private centres. The data were analysed using descriptive statistics and geomapping of all the centres identified was created.

Results: A total of 371 PCCs were identified, of which 32 were government headquarter hospitals (GHQH), 281 were government community centres and 58 were private. Eighty-three of the 90 centres (including GHQH and private) were active and 60 responded to the survey. More than half of the centres were hospital-based (61.7%) and 28.3% were community-based. The majority of the PCCs had in-patient (75%) and out-patient (63.3%) facilities and 63.3% had regular home visits. Forty-six centres provide PC service free of cost. Nearly 80% provide morphine for pain management, wherein 41 have obtained a license. In total, ten centres had a social worker and four had a psychologist.

Conclusion: The number of PCCs is disproportionate, in which majority of the centres are clustered in urban areas. Integrating PC services into the existing health system is the way forward.

Keywords: Mapping, Palliative care services, Models of palliative care, Morphine availability, Community palliative care centres

INTRODUCTION

The increasing burden of non-communicable diseases and the ageing population warrant palliative care (PC) as a much-needed service.[1] It is estimated that every year, 56.8 million people need PC, globally, of which 76% of them belong to low- and middle-income countries.[2] One-third of those needing PC suffers from cancer.[3] PC services are being offered in India for more than 20 years; however, only <1% have access to the services at present. Moreover, the centres which are providing the services do not have adequately trained professionals.[4] This has been attributed to the non-inclusion of PC in healthcare policies and restrictions on access to opioids.[5]

Among countries with PC facilities, India provides generalised PC services, stating the development and utilization of PC facilities in the communities with local support who are independent of the health care system.[6] This indicates that there is a need for structured initiatives including policies and fund allocations, exclusively for PC.

Although the overall awareness about the PC is increasing, exclusive centres catering to the needs of PC patients in India are minimal.[7] At present, 284 PC providers have been identified in the country, with the ratio to the population being 1:4218.[6] However, there are no data on the availability of PC services in Tamil Nadu. Many hospitals are providing care to advanced cancer patients as an aspect of their regular clinical care; however, the extent of services offered to address the needs of patients is not yet understood.[8] The majority of the patients attending tertiary cancer centres are predominantly from rural places and are referred to local clinicians when the disease is in an advanced stage.[9] However, due to lack of knowledge about

***Corresponding author:** Sathish Kumar Deenadayalan, Department of Psycho-Oncology, Cancer Institute (WIA), Chennai, Tamil Nadu, India. sathishmsw@hotmail.com

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the facilities available in different districts, the oncologists are not able to give appropriate guidance and refer them to suitable centres based on the needs of the patients. When the patients are referred to local physicians, the caretakers become helpless and apprehensive about future care, and therefore, they are reluctant to take the patient back, which, inevitably, increases the burden on the tertiary centres. Therefore, it is essential to explore and map the PC services in Tamil Nadu and make the database available to healthcare professionals and the public.

Ethical approval

Ethical approval was obtained from the Institutional Ethics Committee, Cancer Institute (WIA), Chennai, Tamil Nadu (Ref No. IEC/2017/14).

MATERIAL AND METHODS

Study design

Descriptive research design was employed in the present study.

Study settings

The present study was conducted in Tamil Nadu, which is the 11th largest state, in terms of area and the sixth-largest state in terms of population; 7.2 crores, in India. It is divided into 38 districts.[10] In 2018, around 86,000 new cancer cases and 43,000 deaths were reported in Tamil Nadu. Furthermore, it has been reported that 70–80% of the patients seek treatment in an advanced stage of the disease in Tamil Nadu.[11,12]

Operational definition

PC

PC is defined as the service delivered by specialised staff who are trained with specific knowledge in symptom management, emotional, spiritual, practical and cultural care either at home or at specialised in-patient and out-patient units either individually or attached to hospitals. This focuses on managing symptoms, providing supportive care and assistance, thereby alleviating suffering and improving the quality of life of patients and families.

Measures

A semi-structured interview schedule was developed by the primary author to understand the nature and types of PC services available in the government and private centres across the state. The schedule consisted of 37 items, with a mix of closed, open-ended and multi-optional questions. These items were formulated based on existing literature and were focusing on the nature and models of PC, financial implications, regular procedures, home care facilities, morphine availability and type of personnel involved. The interview schedule was face validated with 12 experts in the field of PC.

Sources of data and data collection procedure

The availability of PC services offered in Tamil Nadu was obtained through the following sources: (i) The list of hospital and PC centres (PCC) licensed to store morphine was extracted from the morphine license annexure issued by the Director of Drug Controller, (ii) list of the headquarter hospitals and community centres under the government was obtained from the National Health Mission directory and (iii) the contact details of medical and paramedical professionals who had completed Certificate Course on Essentials of PC offered by Indian Association of PC from Cancer Institute (WIA) and Lakshmi PCC was collected. These professionals were contacted over the phone to obtain information regarding their PCCs and their practice and also contacts of other PC practitioners known to them (iv) PCCs attached to private hospitals, non-governmental organizations, government hospitals, and exclusive palliative and hospice care centres were identified through online search. In addition, the snowballing method was used to obtain data from other sources [Figure 1].

After identifying the sources, the person-in-charge from each government and private PCCs were contacted and briefed about the purpose of their study and a time of their convenience for data collection was obtained. Four different methods such as Google forms, email, telephonic surveys and in-person interviews were used for collecting data based on the convenience of the respondents. The in-person and telephonic interview was conducted using the interview schedule at the mentioned time. Those respondents to whom the interview schedule was either emailed or shared through Google form were followed up regularly until data were received.

Statistical analysis

The data were analysed using IBM Statistical Package for the Social Sciences version 20.0. Descriptive statistics including frequency and percentage were used to calculate the geographical details, categories, types, nature and models of the PCCs. Morphine availability, symptoms management, details of personnel involved and the advertisement methods of PCCs in government and private centres were also calculated using frequency and percentages. A geomapping of PCCs in Tamil Nadu was created using Quantum-Geographic Information System [Figure 2].

RESULTS

A total of 371 PCCs were identified in Tamil Nadu, of which 32 were government headquarter hospital (GHQH), 281 government community centres and 58 were private centres. Of these, only 90 centres including private and GHQH PCCs were included in the in-depth survey, whereas the government community PCCs were not reported due to practical reasons in this study and will be reported separately,

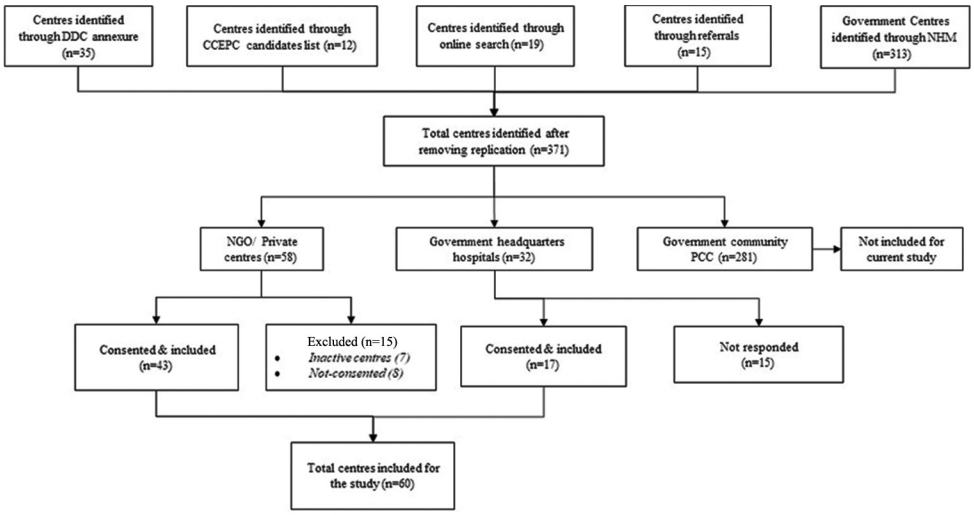

Figure 1: Sources and method of data collection.

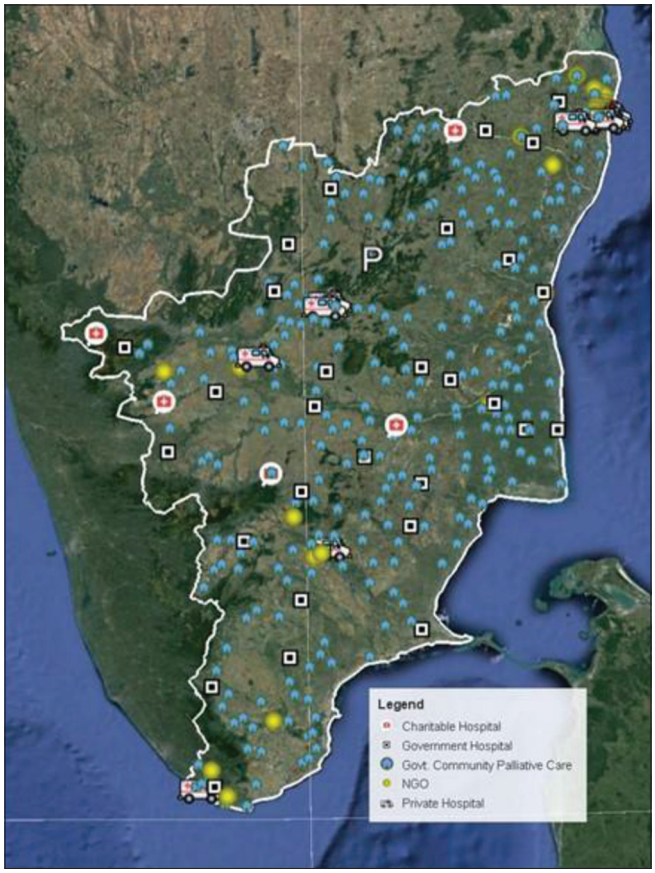

Figure 2: Geomapping of palliative care centres in Tamil Nadu.

in further studies. Eighty-three of the 90 centres were active, whereas the remaining were not functioning.

Of the 83 centres, 60 responded with a response rate of 72.2%. More than half of the PCCs (58.3%) were initiated between 2011 and 2020, whereas 15 (25%) centres were established between 2001 and 2010 [Table 1]. One-third of the PCCs were established by physicians (36.7%). At least one PCC was identified from 25 districts each. Of these, Chennai reported to have a maximum of 18 centres. Four centres were identified in Kanchipuram, Kanyakumari and Madurai districts, respectively, whereas Coimbatore and Dindugal districts were reported to have three centres, respectively.

Among the PCCs identified 33.3% function in rural areas and 66.7% function in urban areas. More than half of the centres (61.7.8%) were hospital-based, whereas only 17 (28.3%) were community-based. Twenty-nine centres (48.3%) were found to be offering exclusive PC services, of which 56.7% were established and managed by non-governmental organizations [Table 1].

Two-thirds (75%) of the PCCs have in-patient facilities, 38 (63.3%) centres provide out-patient facilities and 32 (53.3%) offer home care services. The centres providing care in the areas of advanced care management (66.7%) and bereavement support (65%) to caregivers are fewer than the proportion of centres providing care in symptom management [Figure 3]. Of all centres, 41 (68.3%) cater to all types of diseases, whereas 18 (30%) centres provide service to cancer patients alone [Table 2]. Thirty-eight centres provide home visits. On an average, 33,769 patients are enrolled for PC services in a year across Tamil Nadu [Figure 4]. Of the responded centres, 41 reported to have obtained a license for storing and dispensing morphine [Table 2]. Forty-five centres (75%) provide supportive care for patients and families free of cost.

Forty-one (68.3%) centres reported to have 57 full-time physicians in total, of which only 44 had undergone a PC training program. Among the physicians, 17 hold more than 5 years of experience. Moreover, 29 centres reported having 43 nurses in total, of which only 16 underwent PC training

Table 1: Centre-related demographic variables (*n*=60).

Category	Frequency (%)
Category of palliative/hospice centre	
Hospital Based	37 (61.7)
Community Based	17 (28.3)
Both	6 (10)
Year of establishment	
1981–2000	10 (16.7)
2001–2010	15 (25)
2011–2020	35 (58.3)
Type of service area	
Rural	20 (33.3)
Urban	40 (66.7)
Exclusive palliative/hospice care	
Yes	29 (48.3)
No	31 (51.7)
Nature of the palliative/hospice care centre	
NGO	34 (56.7)
Commercial/Private hospital	9 (15)
Government Hospital	17 (28.3)
Type of patients admitted	
Only Oncology	18 (30)
Other Diseases	41 (68.3)

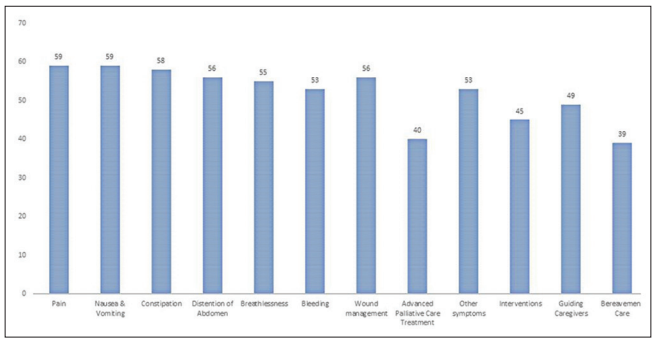

Figure 3: Symptom management and supportive care provided by palliative care centres in Tamil Nadu.

programs. Of these, only six nurses have more than 5 years of experience. Only ten centres reported to have social workers and four centres with psychologists to take care of the psychosocial needs of the patients.

DISCUSSION

The present study explored the availability of PC services, categories, models of centres, morphine availability, financial implications and personnel involved in the PC centres in Tamil Nadu. A major strength of this study is that it is the first of its kind to investigate and report the availability of PC services across Tamil Nadu along with the geographical location which is an essential factor in ensuring the availability and accessibility of PCCs to the patients and health-care professionals. However, one key limitation of the study is that the government community PCCs were not included as they were started recently. The pandemic restrictions posed challenges in collecting data from the said centres.

This study reveals an interesting finding that almost 90% of the centres were active and offering full-fledged services. However, this study also shows that the number of PCCs in rural districts of Tamil Nadu is considerably low in proportion to the population. While a previous study stated that there were only 12 centres overall in Tamil Nadu,[9] the present study has identified 364 active centres in the state. This increasing trend has been observed in urban areas, particularly in Chennai. However, the present study provides updated information that 83 centres are actively working at present widely spread over different districts in Tamil Nadu. This increasing trend in the number of centres could be attributed to the increased training programs on PC for medical and paramedical professionals. The significance of such training programs has been emphasised in the previous studies. Over 90% of all PCCs in India are placed in Kerala, a state with 3% of the nation's population, which is ascribed to the local and state policy emphasising the need to increase PC services, through training and awareness.[7] Tamil Nadu government has also recently implemented a similar policy for PC.[13]

Community-based PC is considered an effective and significant model in terms of making PC services accessible. Most patients at the end of life wish to spend their remaining life at their home surrounded by family members.[8] When a patient's health condition is manageable at home with the help of home visits by doctors, nurses and a multi-disciplinary team approach, it is advisable to enrol the patient for home care service. Providentially, most of the centres identified in the present study offer home care facilities.[8] This facility enables patients to have an improved quality of life as they will be in a familiar and comfortable environment, surrounded by their loved ones. Studies have also highlighted that home visits are significantly associated with less symptom severity and distress, lower depression scores, and better physical health and quality of life than those receiving inpatient care.[14] However, home visits are sometimes avoided by the families due to social stigma. Home care facilities are considered more expensive than in- and out-patient care.[8] However, this study identified that majority of the centres bear the cost of the home care facilities and thereby the financial burden for patients is reduced. Due to the availability of home care facilities, the cost incurred towards hospital admissions, transportation and accommodation is reduced by 45% of the total care cost for patients.[15]

Similarly, many centres identified in this present study also provide hospice care free of cost. Hospice care service is significantly vital in rural areas, where caregivers are generally not well equipped physically, informationally or

Table 2: Services offered by palliative/hospice centre (*n*=60).

Category	Frequency (%)
Models of palliative care	
In-Patients	45 (75)
Out-Patients	38 (63.3)
Home Care	32 (53.3)
Transport facility	
Available	36 (60)
Not Available	22 (36.7)
Home visits	
Yes	38 (63.3)
No	21 (35)
Specialty Consultants	
Yes	36 (60)
No	16 (26.7)
Morphine availability	
Yes	48 (80)
No	12 (20)
Mode of access to morphine	
Have license	41 (68.3)
Tied up with licensed	5 (8.3)
Purchasing from Narcotic drug suppliers	11 (18.3)
Refer patients to Narcotic drug suppliers	8 (13.3)

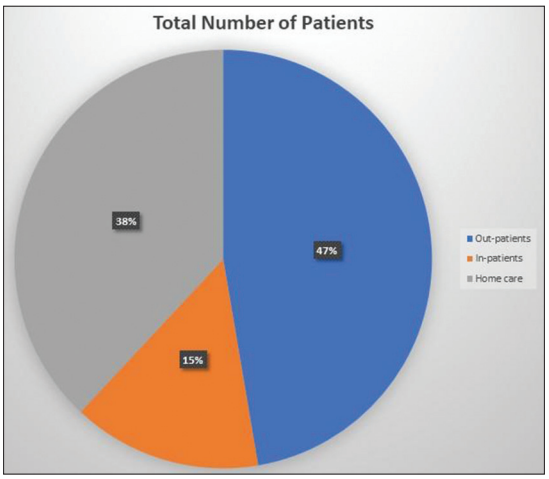

Figure 4: Total number of patients enrolled in palliative/hospice care centres per year (*n* = 33,769).

financially to care for patients at home at their end of life. However, in the present study, hospice care facilities in rural areas are deficient. People living in rural areas face problems including transportation, insufficient accessibility to health care, limited local information and community support services.[16] Even under manageable conditions, families in rural areas find it challenging to manage patients at home due to lack of knowledge, education, awareness and myths about the disease. This inadequacy of hospice and community PC services in rural areas can affect the quality of life of patients and their families. However, the government community PCCs in rural areas are yet to be studied to understand the services offered and their impact on patients' wellbeing.

Morphine is one of the most commonly used drug for the step 3 pain ladder, as described by the World Health Organization (WHO). Although the amendment of the Narcotic Drugs and Psychotropic Substances Act of 1985, in 2014, expanded the scope of the law to improve access and availability of opioids in India, it is still dreadful.[17] As only a few centres in this study were found to have obtained a license for morphine storage and distribution, other centres refer patients to morphine-licensed hospitals and drug suppliers. Moreover, it is unfortunate to find that majority of the morphine supplying centres are placed in urban areas, while patients in rural are deprived of adequate pain management.

Professional training on PC is needed to provide better care to the patients and their families. Inadequate training leads to a lack of confidence in providing care and poor communication which creates a gap between the professionals and patients.[18,19] This study shows that only physicians have undergone adequate training on PC. Most of the physicians were trained in recent years. This could be due to the increased number of training centres providing awareness on PC in TN. In recent times, the Indian Medical Council has included PC in undergraduate medical education and also has recognised PC as a postgraduate speciality since 2010. Along with symptom management, a holistic approach to the social, emotional and spiritual needs of the patients and their families is vital. Social workers play a crucial role in crisis management, social support network and financial assistance, while psychologists handle emotional needs and bereavement.[20] Regrettably, this study shows that less than five PCCs have social worker and psychologist in their multidisciplinary team.

CONCLUSION

Although the need for PC is growing fast in Tamil Nadu in recent years, it is disproportionate, wherein a majority of the centres are clustered in urban areas and rural populations are still deprived. Awareness and training among healthcare professionals and government policies are important factors for development of PC. The findings of the study suggest the implementation of major government policies for easy and improved access to PCCs. Furthermore, networking of the PCCs by government, non-governmental and private organisations would increase better service and care to patients and their families.

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Declaration of patient consent

Institutional Review Board (IRB) permission was obtained for the study.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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