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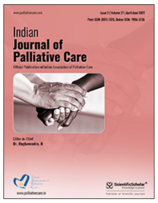

Original Article

Mapping of Palliative Care Services and Challenges in Implementation of National Program for Palliative Care in Puducherry

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ABSTRACT

Objectives: The purpose of this study was to map ongoing palliative care services and describe the characteristics of providers, recipients, level of care, and approach. Second, it seeks to investigate the difficulties encountered in implementing NPPC in the Puducherry district of UT Puducherry. This study aims to review the challenges in its implementation.

Material and Methods: The study using both quantitative and qualitative design, including geospatial mapping of organisations, describing service delivery characteristics and exploring challenges faced in implementing NPPC, was conducted from July 2021 to January 2022. In-depth interviews were conducted with seven healthcare providers, four patients and three caregivers, as well as key informant interviews with six doctors in administration.

Results: Thirteen organisations providing palliative care to population of Puducherry district of union territory Puducherry and neighbouring districts of Tamil Nadu were identified. Mapped organisations were primarily concentrated in urban areas. Morphine was available only at three medical colleges, providing outpatient palliative care services. Non-governmental organisations provided only home-based palliative care services and the hospices provided both in-patient and home-based services. Key barriers perceived by the health system were difficulty in procuring morphine, inadequate personnel and inadequate funding. Few barriers perceived by patients/family were stigma faced in community, psychological challenges and poor quality of care.

Conclusions: Palliative care services are mainly available in urban areas and through private hospices. There is a need to implement palliative care program through the public health system to improve the accessibility in the rural areas.

Keywords: Challenges, Mapping, National program for palliative care, Palliative care

INTRODUCTION

In recent times people are living longer and while doctors may be successful in extending patients' lives, both the sickness and therapy can cause pain and other unwanted effects. Palliative care is crucial because it allows patients to manage their pain, symptoms and quality of life while seeking curative approaches.[1] An estimated 40 million people each year require palliative care. It is required not only for cancer but for a wide range of chronic diseases. As per the study globally, hospice services are available in approximately half of the countries, whereas there was no palliative care activity observed in 33% of nations.[2]

Development of palliative care in India was initiated from Kerala. Services are delivered through regional cancer centres, hospices, private and government hospitals and home care services.[3] Union Territory (UT) of Puducherry has a population of around 12 lakhs, of which nearly 75% reside in urban areas.[4] Population of district is around 9.5 lakhs according to 2011 census, the district is divided into Puducherry, Villianur, Bahour and Ozhukarai taluks. The district has a network of 9 medical colleges, 4 community health centres, 39 primary health centres, 80 sub-centres, 14 ESI dispensaries and 17 disease specific clinics with bed to population ratio of 1:422, doctor to population ratio of 1:196.[5] The study was done from January 2021 to July

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2022 with data collection period from July 2021 to January 2022. Puducherry has well-developed and widely accessible healthcare facilities. However, the development of palliative care is still in early phases, with little evidence of interaction with the public health-care system.

As elucidated in the National Program for Palliative Care (NPPC), implementation of palliative care services requires planning involving a situational analysis as the first step. Mapping of the availability and the extent of palliative care services in Puducherry was planned to provide this information to the programme managers. Puducherry had taken a few steps toward implementing this programme 6 years ago, from training medical officers to planning implementation in district hospitals.[6] It is necessary to identify the barriers that have limited its full-scale implementation and the needs of the patients in need of palliative care, which are still unmet. Therefore, this study was undertaken to map ongoing palliative care services and describe the characteristics of providers, recipients, level of care and approach. Second, it aims to explore challenges faced in implementing NPPC in Puducherry district of UT Puducherry.

MATERIAL AND METHODS

Study included a cross-sectional mapping schedule, a questionnaire survey and in-depth interviews. For the first objective, all organisations delivering palliative care services were included using a universal sampling approach and for the second objective, all the stakeholders involved in the delivery of palliative care services were included using purposive sampling based on stakeholder's involvement in the program and willingness to discuss their perceptions.

Study procedure

After obtaining approval from ethics committee (Ref: JIP/IEC/2021/147, Date: 25/06/2021), a search and analysis was conducted of publicly available palliative care, hospice and related material, including grey literature (annual reports, technical papers), information from web-based sources and personal communication from those involved in providing palliative care. Once the list from the sources mentioned above was compiled, institutes were contacted, mapping was done and their characteristics were recorded. After careful evaluation, some questions were added to the minimum national standards tool developed by Pallium India[7] and used to describe the characteristics of the institutions involved in palliative care services. More than one visit was conducted whenever required to complete the data collection.

For the second objective, stakeholders from the government included representatives from the directorate of medical services, program managers and medical personnel involved in palliative care delivery. Non-governmental stakeholders involved Non-governmental organisations (NGOs), medical personnel including hospice staff. Twenty interviews were conducted among health-care providers (n = 7), patients (n = 4)/caregivers (n = 3) and doctors in administration (n = 6). The interviews were conducted in English/Tamil at place chosen by participants for 30–45 min. After gaining written consent, data were collected using a pre-designed interview guide and questions were added based on the responses provided by participants.

Data analysis

For the first objective, data were collected using Epicollect 5. Spatial data were analysed using Tableau Public version 2021.4. Data for the indicators were summarised as frequency and percentage wherever applicable. For the second objective, the transcripts of interviews were read thoroughly to generate codes. Manual content analysis was carried out using the framework approach. The analysis included reading each transcript and coding of text information. The codes related to similar areas were aggregated together to form sub themes and further were grouped to form themes.

RESULTS

Description of the palliative care services available in Puducherry

Thirteen organisations were identified as providing palliative care services in Puducherry during the study period. All these organisations participated in the data collection. [Figure 1] depicts mapping of organisations and their distribution. Private hospices were found to be more in number (n = 7, 54%), followed by an equal number of medical colleges (n = 3, 22%) and NGOs (n = 3, 22%). [Table 1] depicts the total number of palliative care organisations present in various taluks. Hospices were present around the odiansalai area. Most of the organisations providing palliative care services were concentrated in Puducherry taluk, which included six hospices, two NGOs and one medical college.

[Table 2] depicts characteristics of organisations following the minimum standard tool, it was observed that palliative care was not the main focus of work in 69% of the organisations. Personnel having more than 5-year experience in medical colleges, NGOs and private hospices were 68%, 40% and

Table 1: Total number of palliative care organisations present in various taluks of the Puducherry district (n=13).

S. No.	Area (Type)	Population	Palliative care organisations working
1	Puducherry (Municipality and Commune)	316,432	10
2	Villianur (Commune)	213,278	2
3	Bahour (Commune)	120,475	1
4	Ozhukarai (Municipality)	300,104	0

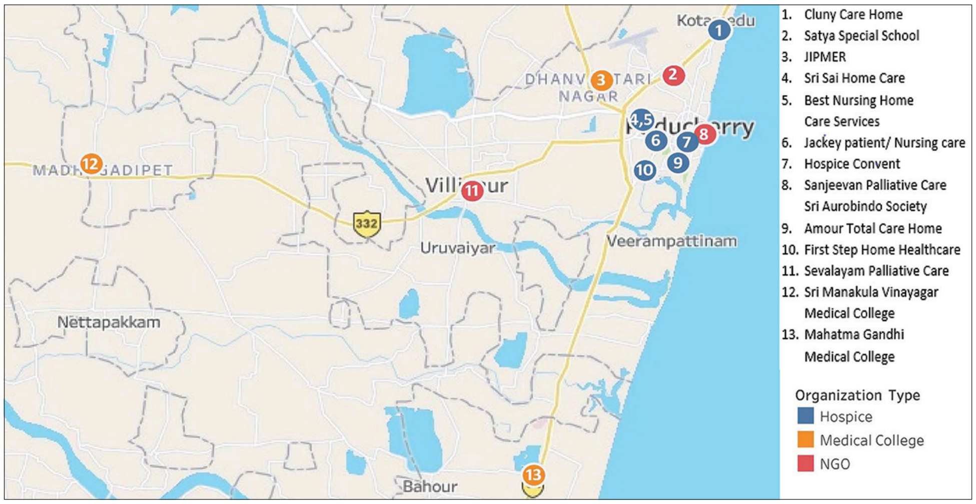

Figure 1: Map depicting organisations providing palliative care services in Puducherry district of UT Puducherry (map not-to-scale).

55%, respectively. [Table 3] depicts average patients catered by different organisations per day, two hospices served patients through in-patient facilities catering to three patients per day. Three medical colleges provided only outpatient services, with median of eight patients served per day by each college. Home-based care was provided by three NGOs and six private organisations with a median of 15 and 6 patients catered to per day, respectively, by each organisation. Medical colleges and NGOs provided palliative care services for free. Patients accessing palliative care services through hospice had to pay anywhere between ₹200 and ₹11,000, depending on the nature of services, duration and the qualification of personnel providing care. Charges were high if the services were provided by qualified nursing staff, they varied considerably with the involvement of home visits by doctors, with organisations also charging on a monthly basis.

Challenges in the implementation of NPPC

Challenges perceived by the health system

Majority of the opinions of the healthcare workers and doctors in administration were similar and were thus grouped together to resonate with perceptions of the health system. Fourteen sub-themes emerged for challenges faced by the health system. These challenges are presented under two headings: challenges within the health system and challenges faced in the community [Tables 4 and 5].

Challenges within the health system

i. Palliative care work being assigned to healthcare professionals in addition to their existing job responsibilities: *'I'm doing two jobs, working in palliative care and anaesthesiology. It is more stressful. So, there's going to be burnout in the team'* - Anaesthesiologist providing palliative care
ii. Participants perceived the absence of a structured palliative care programme:
'I feel the main challenge is that we have no models to follow. See, it has to be cost-effective, sustainable and done locally' -Program manager in NGO
iii. The complex procedure to procure and dispense morphine: Managers perceived that paying annual fees for obtaining a license, placing morphine in double lock systems, proper disposal and returning empty strips had become difficult. There was also concern that morphine would be misused and managers questioned whether morphine could be provided at the primary care level.
iv. Inadequate human resources: Managers in colleges mentioned a lack of specialised palliative care doctors, which led to rotational postings of other doctors in the department.
v. Low-paying jobs in the private sector:
'One of my best counsellors left and went to work at a shopping mall, where she was putting in more hours but also getting paid much more, whereas here I couldn't pay her more.' -Palliative care program in-charge at NGO
vi. Inadequate funding for palliative care programs: Programme Managers at NGOs felt that as no tangible result is obtained, spending on palliative care has to be limited.
'Unfortunately, there is no funding for palliative care programs maybe because there's no tangible result, except for ensuring that the person has dignity to life' -Doctor trained for implementation of a pilot project
vii. Lack of satisfaction for a cure, emotionally challenging job: Healthcare providers perceived that whatever services they provided failed to give them satisfaction as curing the patient was impossible.
viii. Inadequate training for communication: Health-care providers mentioned difficulty in communicating the diagnosis, prognosis and treatment plan to patients

Table 2: Adapted Indian minimum standards tool for palliative care services in Puducherry district.

Indicators for Hospice/palliative care program:		**Medical college (*n*=3)**	**NGO (*n*=3)**	**Private (*n*=7)**
Essential criteria				
	Has a system in place for patient assessment, documentation and management that includes at minimum			
1.	Assessment and documentation of pain, pain scale	3	3	7
2.	Assessment and documentation of other symptoms	3	3	7
3.	Regular review of pain and other symptoms and titration of medications	3	3	7
	Provides access to essential medications as demonstrated by:			
4.	An uninterrupted supply of immediate release oral morphine	3	0	0
5.	Access to essential medicines and equipment. (Essential Package)	3	3	7
6.	A system for documentation of step 3 opioids use including names of patient and identification number, quantity dispensed each time and balance of stock after each transaction	3	0	0
	A Palliative service should adopt a team approach. It should have at least:			
7.	Trained Doctor with a minimum of 10 days clinical palliative care training under supervision	3	2	4
8.	Trained Nurse with a minimum of 10 days clinical palliative care training under supervision	3	2	6
9.	Designated team members trained to deliver psychological, social and spiritual support	3	0	0
	The palliative care service engages the community and does not work in isolation.			
10.	There is evidence of interaction between the community and health care professionals in the establishment and ongoing operation of the services	3	3	7
	The palliative care service supports the health of the team through activities such as:			
11.	Regular team meetings	3	3	7
12.	Self-care training	3	3	5
13.	Debriefing	3	3	7
	The palliative care service has a programme of education and training			
14.	Ongoing continuing professional education for the palliative care team	3	2	0
15.	Educational programmes on palliative care for fellow professional	3	1	0
	Desirable criteria			
16.	Has sufficient access to free morphine (essential package for poor patients)	3	0	0
17.	Provides home care service directly/indirectly	2	3	7
18.	Provides after hours support directly/indirectly	0	0	0
19.	Has an institutional policy for Pain Management	3	3	3
20.	Has an institutional policy for End-of-life care	3	3	3
21.	Has access to ancillary services- Dietetics, Physical Therapy, Occupational therapy, Physical Rehabilitation	3	3	7
22.	Provides caregiver support including bereavement support	3	1	0
23.	Has significant contributions from volunteers	0	3	0
24.	Has support of other health-care professionals for palliative care work	3	0	0
25.	Conducts programmes to promote awareness, advocacy for palliative care work through media support, IMA, etc.,	3	1	0
	The palliative care service fosters a healthy organisational culture which includes:			
26.	Regular team activities that foster team building	3	3	7
27.	Conflict resolution	3	3	7
28.	Administrators are supportive of palliative care	3	3	7
	The palliative care service has in place a programme of education and training which includes:			
29.	Education programs on palliative care for medical/nursing students/social work students	3	1	0
30.	Education programs on palliative care for volunteers	0	1	0
31.	Awareness programs on palliative care for the public	3	1	0
32.	Access to teaching material, textbooks and journal	3	1	0
33.	Participation in conferences and CMEs	3	0	0
	The palliative care service has a commitment to continuous quality improvement though:			
34.	Ongoing audit	3	0	0
35.	Participation in research	3	1	0
	The palliative care service participates in institutional activities:			
36.	Integration with mainstream care	3	0	0
37.	Participation in Journal Club, Ethics Committee, Multidisciplinary team meeting etc.	3	0	0

NGO: Non-governmental organisation

Table 3: Mode of delivery and number of patients served by palliative care organisations per day in Puducherry district.

Mode of delivery/ Size of program	**Daily census**		
	Medical Colleges Median (Range)	**NGO Median (Range)**	**Private Organisations Median (Range)**
In-patient	0	0	3
Out-patient	8 (8–10)	0	0
Home based care	0	15 (7–20)	6 (1–15)

NGO: Non-governmental organisation

ix. Participants felt that palliative care delivery was hampered because the hospital focused on treating patients infected with COVID.

Challenges faced in the community

Barriers faced by health staff in providing community palliative care services were:

i. Difficulty in accessing patients: Nurses working with NGOs had to cover large areas, often on foot, as vehicles were unavailable.
ii. Patients' lack of awareness regarding the importance of palliative care: Participants mentioned that people are unaware of palliative care and associate it with cancer care.
iii. Lack of community involvement: It was perceived that people do not prioritise palliative care, making a self-sustaining model of care delivery difficult.
iv. Stigma against palliative care providers, as patients treated by palliative care providers always died. People did not understand that aim of care is to relieve patients from pain and discomfort

'Many people refuse to believe doctors and accept that there are certain diseases that cannot be cured, each with its code; we always aim to treat the disease, not cure it.' - Palliative care program manager at medical college

These challenges lead to poor implementation of palliative care services, such as inadequate counselling and support for patients and caregivers. Health-care staff including doctors, nurses, medico-social workers and program managers, came forward with recommendations such as establishing palliative care registry portals for patients enabling people to volunteer, introducing palliative care in the curriculum of medical graduates and increased funding for programmes.

Challenges perceived by patients/family

Challenges perceived by the patients and their families were categorised into nine sub-themes such as:

i. Poor access to morphine: The inability to obtain adequate pain management services forces patients and caregivers to travel to distant hospitals to receive these services.
ii. Facing stigma and discrimination from the community: *'People in my village do not understand that cancer is not communicable; they believe that we they touch them, they will also get cancer, making it extremely difficult for us.'* - Caregiver of a lung cancer patient
iii. Poor quality of care provided to the patients: This made it difficult to undertake daily tasks, causing a sense of dependency in patients and leading to isolation. There is also additional responsibility with regular jobs for caretakers so, burnout develops in caretakers, leading to less support for patients.
iv. Financial burden due to treatment: *'I don't have any children, so I take loans to get her treatment. I hope to pay off all the loans after she gets her treatment. I will work to repay all the loans' - Caregiver of a head and neck cancer patient*
v. COVID: Participants were unaware of how to support patients and they often had to self-medicate.

These difficulties lead to problems associated with poor implementation of palliative care services, such as pain management, physical management and psychological counselling for caregivers struggling to deal with suicidal tendencies in patients. Possible solutions suggested by the patients included priority-based appointments based on condition and medications dispensed from the nearest healthcare facilities after a check-up [Figure 2].

DISCUSSION

This study found that private hospices were located around the Odiansalai region, an urban area, with very few organisations working in rural areas. Out of seven medical colleges functioning in the district of Puducherry, only three provided palliative care services. NGOs had difficulty in maintaining services due to competing priorities for funding and fewer profits from palliative care.

NPPC envisages services through the existing system, but in the absence of adequate implementation, private hospices and NGOs are catering to most of the needs. Rural areas had less number of hospices due to low paying ability of patients/families and privately-owned organisations do not want to operate in settings with low-profit generation. According to information available in the public domain during 2016–2017, ₹171.6 Lakhs were sought to implement the NPPC in Puducherry,[6] whereas approximately one fourth was allocated.[8] Funding for NGO sector was also limited, as stated by manager of NGO, palliative care is not profitable

Table 4: Thematic analysis of perceived challenges faced by Health system in implementation of National Program for Palliative Care.

Theme 1: Challenges from health system perspective		
Subthemes	**Codes**	**Statement**
		Group 1: Challenges within the health system
Inadequate human resource	No dedicated doctor	No dedicated doctor posted in palliative care here. They keep rotating and every month some new person is posted -Medico social worker involved in palliative care delivery
		Such people who are trained in palliative care and can provide homecare to patients are lacking in Pondicherry -Human resource trained for implementation in a pilot project
	Burden on doctor	The doctors who see OPD are the same who see the palliative care patients. So, doctor has to manage all the cases, we can't say that you have to see this first. The patients have to wait till the doctor start seeing the palliative patients -Medico social worker involved in palliative care delivery
	Nodal officer responsible for several programs	We have appointed a nodal officer; he is in charge of certain programmes to see if they are on target. So, he is running several programmes, one of the programmes he is running is this palliative care -Bureaucrat (public health)
	No proper follow-up of patients	In PHC most of patients are lost to follow-up process for palliative medicine because the doctors forgot to contact them or they are not recorded the proper way as they should be -Human resource trained for implementation in a pilot project
Palliative care not part of job profile	Doing work of two jobs	I'm like doing two jobs, working in palliative care and working in anaesthesiology, so it is more stressful compared to just doing one job. Definitely there's going to be burnout in the team be it from the nurse to the entire team - Anaesthesiologist providing palliative care
		Nodal officer went because he was in medicine and was interested in palliative care but I don't think we have nominated anybody else for this -Bureaucrat (public health)
Lack of knowledge	Training is inadequate	Nowadays, the training is quite less. I was trained by available staff about all expected things in palliative care, there's a book by Pallium India that I was given and asked to read -Nurse providing palliative care
	Hard to help every patient	There's a way of functioning here, sometimes when you can't provide the help to every patient that you really want to provide on a human level, you can't give them. I do feel difficult -Nurse providing palliative care
	Often have to self-learn	I initially came into cancer care and palliation even I wasn't aware that there are so many aspects to palliation, which I have gone through the textbooks and learned -Medico social worker involved in palliative care delivery
	Confusion on palliative care	It is thought that palliative care is only related to pain management for cancer patients but we are also giving family support which also comes under palliative care -Nurse providing palliative care
	Palliative care beyond cancer	So, every time we say palliative care, we think only of cancer patients. No, it is not like that. We would like to include even these patients suffering from chronic illness -Anaesthesiologist providing palliative care
		Palliative care is one of the most important things and that is really needed. Because at the end of the day, whether you talk of anything which is under the sky, could be a malignancy, or could be old age disease, or you even talk of neurological problems, anything under the sky. At some point, every human being will have to go through palliative care -General surgeon involved in palliative care delivery
		understanding about the palliative care is still not clear among patients and also among medical fraternity who sometimes state that it is more likely related to the incurable cancer -Human resource trained for implementation in a pilot project
	Holistic care is not provided	We definitely provide some support, but moral support is not there. So, holistic support is not provided rather than a theoretical kind of support is provided -Human resource trained for implementation in a pilot project

(Contd...)

Table 4: *(Continued)*

Theme 1: Challenges from health system perspective		
Subthemes	**Codes**	**Statement**
Low paying jobs (staff demotivated)	Low pay for efforts	I lost one of the best counsellors, to a shopping mall. She left this and she went and joined at the mall and she was, putting in a greater number of hours, but she was getting paid much more, here I could not pay her more -Palliative care program in-charge in NGO
Absence of structured program	program is not structured	In state, we have not got ourselves into a structured system for palliative care delivery -Bureaucrat (public health)
	Little focus on palliative care in PHC	But to tell you frankly, our PHC medical officers are not really very much involved in palliative care, they will be involved in the sense they will be knowing who are the very chronically ill bedridden patients, because they know the families in the area. And probably whatever little help they can be doing, they will be doing only that -Bureaucrat (public health)
	Patients are only referred when there is need of monitoring	it takes some time for the patient to be referred and after the application they refer to palliative medicine, that too just for the sake of protocol not for palliative care but because they need some more time for monitoring the patients -Human resource trained for implementation in a pilot project
	Palliative care delivery is not streamlined	In Pondicherry, palliative care program is not streamlined, though we have a separate OPD for palliative care, we don't get the ideal patients -Human resource trained for implementation in a pilot project
	No dedicated program for palliative care it is merged it elderly care	Through government side a separate program for palliative care has not started, but they are providing program for care of the elderly. It is taking care of both the entity palliative care and elderly care. Even for the doctors in the training, elderly or dependent sessions are provided, I would just say training is conservatively possible for both the NCDs and the palliative care -Bureaucrat (public health)
Lack of satisfaction for cure	No satisfaction of cure	First of all, the satisfaction of curing a disease is different, it gives meaning and encourages to work, but that is not going to be here in palliative care. So, it is difficult -Anaesthesiologist delivering palliative care services
Inadequate funding	No funding for palliative care program	Unfortunately, there is no funding to palliative care programs. Absolutely no funding, maybe because there's no tangible result, except for ensuring this person has dignity of life -Doctor trained for implementation of a pilot project
Difficulty in procuring morphine	Difficult to procure morphine unless institute has own license	For narcotics, so what was happening is GH had the license. So, every quarter we had to indent from GH. So, we were getting from there, then at some point of time there was an acute shortage of morphine and we were unable to get and had to get our own license -Bureaucrat (public health)
	Procurement and reporting are complicated	The medical superintendent has the powers to store morphine, but the collector will mention how many vials can be purchased of what narcotics every year they will say you can buy only this many vials and we have to pay some annual fees and all that. And once you purchase a unit, they have given a lot of guidelines like you have to store vials in a double lock system then when it has to distributed to the wards also, sister have to follow some procedure, also they have to return back used vials, we have to keep account and destroy, with the consent of drugs department. So many procedures are there -Bureaucrat (public health)
	In case of shortage it is difficult to procure for palliative care	There was a shortage, we were really needing it for patients and anaesthesia department was also looking for it and then every month we had an issue with procurement. It was difficult to procure morphine -Bureaucrat (public health)
Emotionally challenging job	Caregivers demotivated on seeing suffering	We tend to get demotivated over time and you see more suffering, more death daily. We feel helpless over time -General surgeon involved in palliative care delivery
	Emotionally binding job	The job takes a lot emotionally, you have to speak, you have to listen you need to be okay to seeing somebody's wound oozing out. It takes a lot out of you to go through all that and there is risk of you having it, if it is contagious and it's depressing -Palliative care program in-charge in NGO

(Contd...)

Table 4: *(Continued)*

Theme 1: Challenges from health system perspective		
Subthemes	**Codes**	**Statement**
Inadequate training for communication	Hesitancy in telling diagnosis	We will say you have a tumour; they do not also ask. So basically, nobody speaks we are also worried for the patients -Medico social worker involved in palliative care delivery
	Communication is difficult for nurses	First time communication about diagnosis is very difficult, both to the patient and family. I don't know how to tell them -Nurse providing palliative care
	Explaining medical diagnosis is hard	I have to make patients understand who are not aware of any medical things, it becomes a difficult thing for us to break that myth that Palliative care is not just for end of life It can begin right away patient's life expectancy can improve with palliative care -Medico social worker involved in palliative care delivery
COVID	Difficult to provide home care during COVID	I'm telling we stick to people who come to us we go and those patients who are already there with us, we follow up we are not going inside and venturing new patients. Because in this scenario is pandemic situation, it's not possible -General surgeon involved in palliative care delivery
	No palliative care delivery	Post COVID. Since 1 year we have not done anything because all of us are busy. This is a COVID Hospital. So slowly we are changing the entire alignment and hope we will get to normal palliative care delivery soon -Palliative care program in-charge in a hospital
	Training could not be conducted	But unfortunately, during COVID time, we were very busy, that was super busy time, lots of COVID work was there. So, we were not able to spare the medical officers for the proposed training in palliative care -Bureaucrat (public health)
Group 2: Challenges faced by health system in the community		
Lack of awareness (Patients)	People don't know what is palliative care	Because of the lack of proper insight in the community they don't know what is palliative care and they think that if a patient is incurable and they have to suffer with the pain -Human resource trained for implementation in a pilot project
	People think palliative care is related to cancer	patients which require pain relief care only come and most of the people they feel that the palliative care is related to cancer rather than other disease conditions. -Human resource trained for implementation in a pilot project
Difficulty in access to patients	Accessing patient is difficult	It is difficult to reach to the patients because there are narrow streets and we are going in vehicle but not able to go near patients' homes -Public health nurse involved in palliative care delivery
Stigma	Palliative care not aligned to aim of medicine	Main motto of palliative care is not aligned with medicine, because we will accept death and we take death as part or, an extension of life, which in other field of medicine, we don't take because our aim over there is to cure the disease, but here it is not so -Anaesthesiologist providing palliative care
	Stigma in the community	There is a social stigma that if people work in palliative care, they really are not doctors. That kind of a feeling people get and there is one thing where if you go into the community, they will tell you that whatever you do, the patient dies, because they don't know that we are not there to cure the disease, but we are there to comfort the patient -Anaesthesiologist providing palliative care
Lack of community involvement	People contribute to fund only in time of disaster	Only if some disaster type or a natural disaster happens, they may be contributing to the relief funding otherwise there is no funding like Kerala palliative care program -Human resource trained for implementation in a pilot project
Group 3: Problems associated with poor implementation of palliative care services		
Inadequate counselling and support for patients and caregivers	Attenders loose interest in caring for patients	The attenders also lose interest in catering to their own patients and also same with patient relatives. So, the care is not provided at home -Anaesthesiologist providing palliative care

(Contd...)

Table 4: *(Continued)*

Subthemes	Codes	Statement
Theme 1: Challenges from health system perspective		
	Patients do not cooperate	Problem in community service is patient's cooperation and cooperative family members. Many times, patients do not cooperate they want to be left -Public health nurse involved in palliative care delivery Sometimes patient is not willing to take care or family is not willing, then we need more time for counselling and making them understand the importance of care -Nurse providing palliative care
	Unfavourable attitude	The patient also doesn't ask about what is wrong. I keep on asking to caregivers, don't you have communication at home? Don't they ask what is it? They say no, she doesn't ask so basically, nobody speaks -Medico social worker involved in palliative care delivery

NGO: Non-governmental organisation

Table 5: Thematic analysis of perceived challenges faced by patients/family in implementation of NPPC.

Subthemes	Codes	Statement
Theme 2: Challenges faced in implementation of NPPC in Puducherry (Patients/Family perspective).		
Group 1: Factors contributing to challenge in implementing palliative care services		
Poor access to morphine	Medicines can't be procured from nearby facility	I need morphine for pain and that is not available near my place there they keep telling me to come to JIPMER so I have no other options. -Patient with breast cancer We have to come here regularly to get medicines, if its possible we can call through a phone and if you can send medicines through courier or somewhat like that. If it is possible, because the only thing is patient coming every time. -Caregiver of a head and neck cancer patient We have to come here to get medicines, there is a nearby hospital to our place can there be a system so we can get medicines from there. -Caregiver of a lung cancer patient
Stigma	Discrimination	When I started taking chemotherapy then the hair fall started to happen. So, it was difficult for me and I shaved my head. People knew that this only happens when someone has cancer. So, people started doubting and they started maintaining a distance. -Patient with lung cancer
	Fear of disclosing diagnosis	Her side of family does not even know about her cancer because we do not want to tell them, as they might get worried, we stay with them and then we will have to move out. -Caregiver of a lung cancer patient
	Think it's communicable	In my village, they don't come to help us the people think that if they come and touch, they'll also get cancer. They talk behind our backs but they don't come, nobody comes to help us. They think we are cancer patients and if they come help us then other people will exclude them also, so nobody comes to help. -Patient with head and neck cancer
Lack of family support	Wish I had a boy child	If I had a boy then I think my problem would be solved but when I asked my daughter to come visit then she does not want to come. I don't know why. -Patient with metastasis
	If we had child it would be easy	It's very difficult because we do not also have a child, sometimes I feel that if we had a child then there would be someone to support us. -Patient with head and neck cancer
	Daughter refused to visit and take care	My daughter is married so there is no one to take care of me. I also asked her come and visit sometimes, but they denied. My wife also asked several times but she feels guilty now to come and help us. she is in her home and won't visit. -Patient with metastasis

(Contd...)

Table 5: *(Continued)*

Theme 2: Challenges faced in implementation of NPPC in Puducherry (Patients/Family perspective).		
Subthemes	**Codes**	**Statement**
COVID	Unaware how to take support	During COVID it was very bad for her because in starting we did not have any idea how to support her and she was in pain, everything was closed -Caregiver of a head and neck cancer patient
	Lack of service availability during COVID	During COVID, I didn't know what to do and where to go. See during that time if you go to emergency, if the patient is in a very serious condition, they are admitting them. If she's normal, they don't take her in. -Caregiver of a head and neck cancer patient
	Read and gave medications on own	During COVID, I read and asked, with my knowledge for almost all the 3 months I gave her medicines, first I gave one time then I gave three times, but no use at all she had a lot of it and finally, when everything, hospitals OPD got open, I came here. -Caregiver of a cervical cancer patient
Financial constraints	I wish 1 day I can repay all the loans	I do not have any children so my wife and I are childless couple, so I am only taking care of her every time. So, what I'm doing is I'm taking loans from finance companies in our village I take loans and we come here and I get her treatment. So that is how we finance we do not take money from any other relatives or any other person. I just take loans, but I just hope that 1 day I can pay all the loans back after she gets her treatment and I will work to repay all the loans. -Caregiver of a head and neck cancer patient
		Like get whenever I get time, I go for a job. I work as a coolie and I pick bags from here and there. Whatever money I make from that job, I give that money for repaying the loan whatever I can repay back. -Caregiver of a lung cancer patient
		We did not go to private as I know it takes very much money and we can't afford that -Caregiver of a cervical cancer patient
	Difficult to manage everything in little money	I am managing everything in my pension of Rs 1000/month. I have to get food, bus fare, medicine in pension only. I do not have any other support. It costs me Rs 200 to come here every time in bus fare then I have to wait but medicines are important for me. -Patient with head and neck cancer
	Loss of wages	I can't do farming because I'm taking care of my mother and she needs care so I can't go for work -Caregiver of a head and neck cancer patient
		I was supposed to be working today but I am taking leave so I won't earn anything -Caregiver of a cervical cancer patient
Quality of care provided	Poor patient management	Patient is waiting out there in wheelchair whole day and so if we can get the medicine early and then it would be great -Caregiver of a cervical cancer patient
		I want to tell, the security personnel who are standing there they are doing their duties, I don't mind, they need some kindness to tell they're just throwing out there go there, go there, what they can do is they can ask them to behave nicely. -Caregiver of a cervical cancer patient
		Main problem I face is distance and another is food. I cannot go anywhere till now I had only juice because I do not know when they will call me and I have to run, if my chance is over then I can't do anything -Patient with head and neck cancer
	Struggling with telemedicine	See I have passed 10th class so I can take appointments and all but they said that you can do video call and you can share. So, a person like me was struggling to like do video call and all, the person who is not educated, how can they do video call -Patient with head and neck cancer
Group 2: Problems associated with poor implementation of palliative care services		
Poor pain management	Can't tolerate pain	She was always in pain, so much suffering that in night and all she'll be knocking on the door and telling me 'give me something I will eat and die, I can't tolerate the pain' -Caregiver of a head and neck cancer patient
	Difficulty in doing work	From the past 4 months, I can't eat anything, do anything. Pain is so much that I get tears. I'm trying hard to do work but it gives me so much pain that I cannot even eat or drink anything -Patient with head and neck cancer

(Contd...)

Table 5: *(Continued)*

Theme 2: Challenges faced in implementation of NPPC in Puducherry (Patients/Family perspective).		
Subthemes	**Codes**	**Statement**
Poor physical/ support management	Unable to do daily tasks	Sometimes she becomes sad because she's not able to perform daily tasks and not able to go to work. -Caregiver of a lung cancer patient
	Difficult to travel in public transport	I live in Vellore district that is around 160 km from here. I have to wake up early then walk for an hour to get to bus stand then after getting a bus it takes me 5 h to get here. When the work is done from hospital, I leave till 5 pm and then I reach back home at 12 in the night so it is very tiresome -Patient with breast cancer
	Accessibility decreases with wheelchair	The wheelchair, we have to push everywhere because the patient cannot walk. That is the only problem that we have. Sometimes its crowded and it's very difficult to get wheelchair -Caregiver of a head and neck cancer patient
	Added responsibility for caretaker	I have to work, take care of my mother and I feel that there is little time because I have my children also and my daughter is getting married. I have to do work there also; I have to work to earn and I have to take care of my mother. So, it's it gets very tiresome -Caregiver of a head and neck cancer patient
Psychological challenges	Patient becomes suicidal that hurts	I can't leave her at home alone. Once I went home from hospital and found that she was ready to hang herself. Another time I got her here in hospital and she ran from here. She came to the hospital but she ran away so I had to search for her in the whole Pondicherry and then when I found her then I got her back to take treatment all these things hurt. -Caregiver of a lung cancer patient
	Emotional attachment to patient	Sir, mom is mom. In the world we can get anything but we can't get our mother. So right from 2014, I just take care of her, even now. See you know in an emergency we don't even have a place to sit. She is just laying down near OPD and once they call on speaker our name we have to rush and they will say go, go there, go there, get all these investigations and come. -Caregiver of a head and neck cancer patient
	Emotional after knowing the diagnosis	She was free from cancer but after hearing that, she is once again affected by metastatic cancer daily I feel pain, if I just talk more, I will be emotional. -Caregiver of a head and neck cancer patient
	Worries with the disease	I found my mother is affected by malignancy. In radiation department, I was told by them sir cancer is cancer. We can't say it won't come again. Even if a single stem will deposit somewhere it may come again or may not -Caregiver of a head and neck cancer patient
	Fear of chemotherapy	The doctor said, to go for injections and go for chemotherapy, but we did not take chemotherapy after operation because we were afraid -Patient with lung cancer
	Poor psychological support	My mother keeps saying that let me do suicide and I'm bothering you all, she thinks that she's a burden for everyone -Caregiver of a head and neck cancer patient
	Dependent on medications	I'm not able to do any work without medicines, now I think that she should have taken the injections and that would have helped. -Patient with head and neck cancer

NPPC: national program for palliative care

and so there is a cap on how much they can spend thereby limiting the services being provided by them.

Majority of the key standards were met by all mapped organisations, except the failure to procure an uninterrupted supply of morphine. The 2014 amendment to the Narcotic Drugs and Psychotropic Substances Act has made the system less complicated; however, the procurement system still had many procedural difficulties and continued advocacy is needed to ensure that the amended rules are implemented.[9] Managers in our study found the challenges faced in drug policy and opioid availability include overly excessive regulatory policies and restrictions on pain medications, particularly morphine as a challenge. The study's findings were consistent with the study done by Munday *et al*. in Uttar Pradesh, India, who found that adequate palliative care was being delivered except, for procurement of morphine supply. Even after amendments, many states had not changed their systems.[10] Participants interviewed in our study also perceived that the procedure to procure morphine is tedious and complicated. Despite a greater number of private organisations, medical colleges served more patients. The private organisations were hospices which provided in-

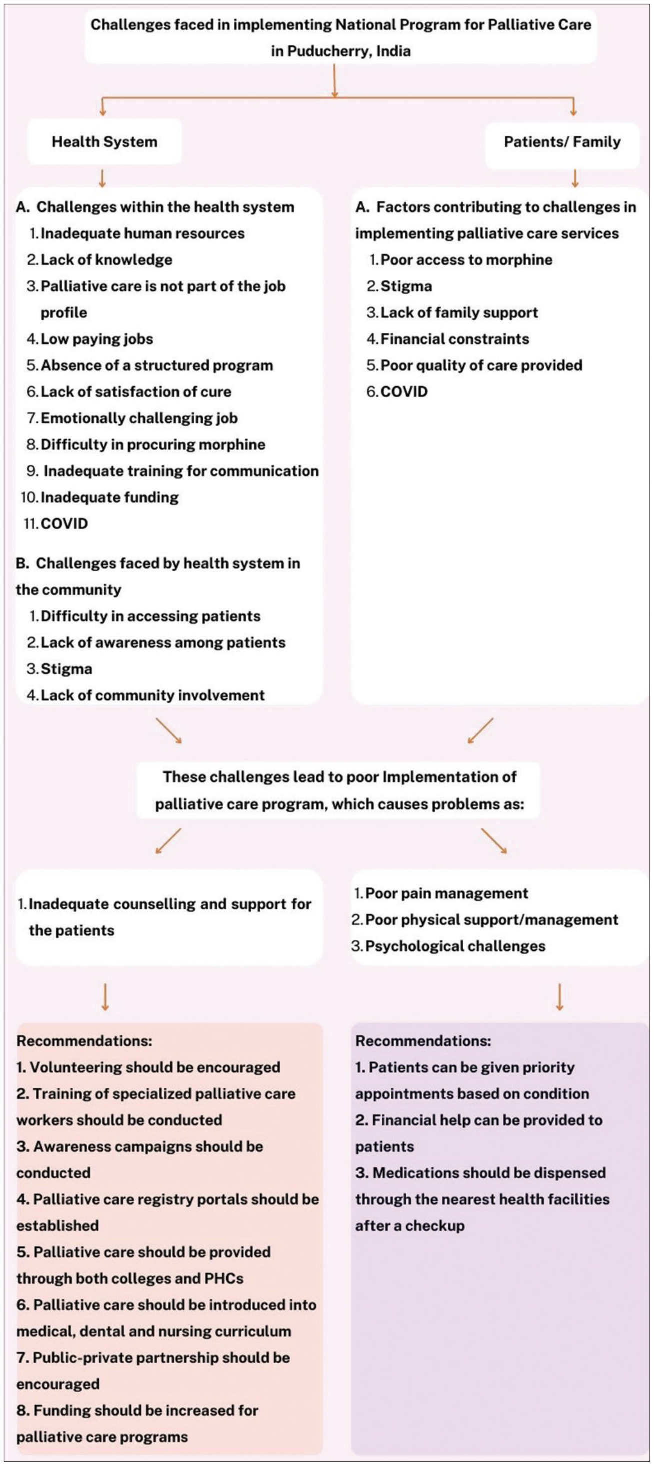

Figure 2: Conceptual framework depicting challenges faced in implementation of National Programme for Palliative Care in Puducherry.

patient and also home-based palliative care, whereas medical colleges mostly provided outpatient care. Hence, personnel providing palliative care were more in private institutes than medical colleges. According to the NPPC operational guidelines, challenges perceived by the health system can be classified as those related to the delivery approach, which could be through the public health system or the provision of services through specialised curo-palliative care centres, difficulties encountered due to opioid availability and difficulties encountered by healthcare providers.

Difficulties faced in the public health approach for palliative care delivery were doctors perceived lack of support and overburdened personnel as roadblocks at the primary level. Bureaucrats feared that misuse of morphine would increase and there was lack of confidence if personnel at primary level could prescribe morphine correctly. Challenges encountered in implementing home-based/community services included less trained personnel, nurses providing home-based care had to cover a vast rural area and often had troubles in accessing patients. This was consistent with a study done by Dharkar in Madhya Pradesh, India. They discovered that the dearth of manpower is due to the fact that palliative care is a specialisation that does not attract talent since it is not financially rewarding.[11]

The interdisciplinary approach for palliative care delivery faced a lack of integrated curo-palliative centres. Interviews revealed that misunderstandings on palliative care roles and objectives among doctors, as there was no dedicated staff, were one reason why this approach was still unpopular. The findings resonated with research by Dharkar in Madhya Pradesh, India, which discovered that the most significant issue was meeting the expenses of these centres.[11] Another issue was the scarcity of skilled individuals; healthcare workers required more training and encouragement to handle challenging symptoms. These barriers were similar to those found by Manna during a study in West Bengal, India, which highlighted that pain and other symptoms control were grossly inadequate due to a lack of adequately trained workforce in rural India.[12]

Few challenges that exist irrespective of the approach taken for palliative care delivery were inadequate coordination among healthcare providers, a paucity of funding, lack of palliative care registries and inadequate infrastructure. Most of participants also felt inadequate sensitisation to the undergraduate medical students regarding palliative care created difficulties, as a person who is very motivated to enter the field could only enter it. These findings were consistent with the studies conducted by Lynch *et al*.[13] and Centeno *et al*.[14] in Europe which found insufficient palliative care education and training programmes, limited availability of/knowledge about opioid analgesics, uneven palliative care coverage as few barriers in implementing palliative care program.

Challenges perceived by the patients/family were inadequate pain management another factor was patients had to travel great distances for treatment which lead to loss of wages for caretakers and difficulty for patients. Patients in the community also face stigma due to lack of awareness regarding palliative care. Financial constraints in the form of loss of wages and resource-intensive care were also felt as a difficulty. The findings were consistent with studies done by Wiles *et al*.,[15] Lynch *et al*.[13] in Europe and Ngwenya *et al*.[16] in South Africa which mentioned perceptions of roles and responsibilities of care providers, economical and practical problems, lack of recognition and awareness for palliative care, misconceptions regarding palliative care as few barriers faced in implementing palliative care program.

The strength of our study is that it uses both quantitative and qualitative study designs, parts of our study complement each other and provide a complete picture of the views and opinions including all stakeholders. Epicollect form was used, designed with inbuilt checks that minimise chances of data entry error and integrated with Google spread sheets, A comprehensive checklist designed for Indian organisations with a focus on each domain to find out the characteristics of services was used. Limitations include a minimal possibility that some facilities that would have opened up new and people involved in the provision of palliative care in Puducherry had not known about such facilities being missed in this study.

CONCLUSION

Thirteen organisations provided palliative care in Puducherry district, access to morphine was poor as procurement of morphine was found to be challenging by all those providing. The inequity in access to palliative care can be lessened only by implementation of the NPPC through the public health system. This study recommends increased and sustained financial support for palliative care training facilities, thereby motivating more personnel to be involved in provision of palliative care. Community awareness should be generated for better participation of the community in these services, which can only guarantee sustainability. Setting up of mobile palliative care services for home visits, identifying and training volunteers in the patients' immediate vicinity, building a palliative care registry containing details of people requiring palliative care and simplifying procedures for drug policy and opioid availability will help meet the palliative care needs of the population.

Declaration of patient consent

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

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Conflicts of interest

There are no conflict of interest.

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