



Needs of People Requiring Palliative Care in an Urban Area of Pondicherry, South India: An Exploratory Study

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ABSTRACT

Context: Diseases requiring palliative care are on rise and people suffering from these diseases experience pain, psychosocial distress and other symptoms which decrease their quality of life. The study was conducted to assess the needs of people requiring palliative care in terms of medical, social, psychological, financial and spiritual aspects in two selected areas in Pondicherry.

Materials and Methods: An exploratory descriptive study conducted among 3554 individuals in 1004 households in two selected areas under an Urban PHC in Pondicherry identified 22 people in need of palliative care and their needs were studied using Needs Assessment Tool: Progressive Disease (NAT: PD). Data was analysed using IBM SPSS Software version 20. Levels of concern for various domains were rated subjectively as none, some, significant and expressed in proportions.

Results: Major needs of the patients were in psychological domain followed by physical and financial domains. Common physical symptoms reported were sleep problems followed by fatigue or tiredness. Psychological problems reported were sustained lowering of mood followed by tearfulness. Financial problems reported were loss of income followed by costs of treatment and travel expenses.

Conclusion: Early identifications of these needs help to alleviate the problems of patients and their dependents to a great extent.

Keywords: Palliative care, urban, patients, Physical problems, Psychological problems

INTRODUCTION

Need for palliative care services are in an increasing pace globally. World Health Organization defines palliative care for adults as an approach that prevents and relieves the sufferings, improves the quality of life of people suffering from life-threatening illness and their families by identifying and assessing their sufferings at an earlier stage and treating their pain, other physical, psychosocial and spiritual issues¹.

Worldwide, every year nearly 20 million people are in need of palliative care services and among them 6% are children. Around 78%, of adults who

require palliative care live in low and middle-income countries¹. Demand for these services will further increase because of the rising burden of non-communicable diseases and increasing number of ageing population who are expected to live long and suffer from these life threatening conditions. Indian scenario is comparable with the situation prevailing globally. In India each year, around 9.8 million people are facing their death and around 60% of them would be in need of palliative care services². This will be further fuelled by the rising burden of non-communicable diseases contributing to 53% of total deaths³ and increasing

proportion of elderly population (≥ 60 years) in India. The 2011 census estimated 76 million (7.5%) elderly in the country and it is expected to attain 12.17% by 2026⁴. Despite the growing need there exists inadequate accessibility and availability to palliative care services, as only very few countries are providing palliative care services through a public health approach.

Assessing the needs of people requiring palliative care is a global humanitarian need to alleviate the sufferings of those patients and their families. Historically palliative care programmes have concentrated on the needs of the cancer patients who were known to suffer from high symptom burden. But there are other non-malignant conditions like HIV, drug-resistant TB, cerebrovascular disease, congestive heart failure, chronic respiratory diseases, neurodegenerative disorders, diseases of elderly¹ etc. which make the people suffer physically, psychologically, financially and socially making their end stage of life miserable.

Worldwide various studies have assessed the needs of people requiring palliative care in various domains. There is paucity of evidence in the current geographic region. So the present study was conducted to identify the people in need of palliative care in two selected areas in an urban PHC of Pondicherry, to assess the needs of patients in terms of medical, social, psychological aspects and needs of family caregivers in various domains.

MATERIALS AND METHODS

Study design and setting: An exploratory descriptive study was conducted in two areas, Senthamarai nagar and Thiruvalluvar nagar having about 500 households each, under Muthialpet Primary Health Centre (PHC), an Urban PHC in Pondicherry, selected purposively to represent the urban population of Pondicherry after discussion with the Deputy Director of Public Health, Govt. of Puducherry. Total of 1004 households with 3554 individuals were surveyed.

Study duration: Study was conducted for one year from Jan 2013 – Jan 2014

Study population and study tool: Twenty two people who were in need of palliative care were identified from the two selected areas using a standard questionnaire and needs of those people were studied using Needs Assessment Tool: Progressive Disease (NAT: PD)⁴. It is a tool developed by University of Newcastle, Australia for assessing the types and levels of needs of the patients eligible for palliative care and their caregivers. This tool allows detailed assessment of the needs of the patients and caregivers in the following domains –

physical, psychological, social, financial and spiritual. Level of concern for every item, was assessed using the response options: “none”, “some” or “significant”. There is no definite criteria to categorize as none, some and significant. The rating was done subjectively by the investigator after discussions with families on these issues.

Data retrieval and analysis: Data were entered in excel sheet and analysed using IBM SPSS Software version 20. Levels of concern for various domains were rated subjectively as none, some and significant and expressed in proportions. Content analysis was done for the qualitative data after translation and transcription.

RESULTS

Twenty two people were identified to be in need of palliative care and they were described as on table.1

Table 1: Disease conditions requiring palliative care (n=22)

Disease conditions	Male	Female	Total (%)
Age related weakness	-	9	9 (41)
Chronic heart disease	1	3	4 (18.5)
Paralysis due to cerebro-vascular accident	2	1	3 (13.5)
Post- polio residual paralysis	-	1	1 (4.5)
Cancer esophagus	-	1	1 (4.5)
Chronic kidney disease	1	-	1 (4.5)
Psychosis following head injury	1	-	1 (4.5)
Mild mental retardation	-	1	1 (4.5)
Filariasis (left) leg	-	1	1 (4.5)
Total	5 (23)	17 (77)	22 (100)

Among them age related weakness was the most common condition (9) identified followed by chronic heart disease (4) and paralysis due to cerebro-vascular accident (3). Other conditions noticed were post-polio residual paralysis, esophageal cancer, chronic kidney disease, psychosis following head injury, mild mental retardation and filariasis leg in one each. Physical symptoms of people requiring palliative care were described in Table.1

Table 2: Physical symptoms of people requiring palliative care

Physical symptoms reported	Frequency (%)
Sleep problems	22 (100)
Drowsiness/fatigue	20 (92)
Pain	14 (62)
Oedema in legs	8 (38)
Dyspnoea	8 (38)
Loss of appetite	5 (23)
Persistent cough	2 (7)

Physical health issues were observed among all the people in need of palliative care but the severity varied according to the disease condition. Among the physical symptoms reported sleep problems was most common followed by fatigue or tiredness and pain. All these physical health issues prevented most of them from continuing their job, and their family was facing severe financial constraints because of their unemployment and women among them even found it difficult to do their household chores.

Physical issues reported by the patients are stated as follows,

A patient suffering from esophageal cancer said,

"I couldn't swallow foods because of severe pain in my throat; I am having cough also...I am spending sleepless nights".

A middle aged married woman suffering from filariasis in left leg said,

"I can't walk like before...my legs are so edematous and it is very disgusting...it is difficult for me to walk without support, my daughter is with me always, she holds me while walking, I can't stand and cook also...my daughter is the one who is doing all household chores and looking after me".

A 45 year old widow suffering from chronic heart disease said,

"I was working as a maid six years back but when I developed this heart problem I left the job...because I am becoming breathless if I work for some time... I have to go by walk to reach my work place...it will take around 15 minutes... I couldn't walk that distance to reach the workplace; I am getting breathlessness, so I stopped working. Nowadays even I can't do the household activities, because already I am having cough and we are using firewood for cooking, so when I exposed to this smoke my cough gets aggravated".

Levels of concern for physical problems in people requiring palliative care

Concern for physical problems in relation to age and disease conditions

Levels of concern were categorized into none, some and significant subjectively by the investigator after discussion with patients on these issues. "None" and "some" levels of concern were clubbed into "some" category because of very less number in none category.

Among the individuals in need of palliative care, no one was in the pediatric age group. In the 20-39 years age group, the conditions observed were mild mental retardation and Post-polio residual paralysis and both had significant level of concern for their physical problems, in 40-59 years

age group the conditions observed were paralysis due to cerebro-vascular accident, Chronic Heart Disease (CHD), filariasis leg and psychosis following head injury. Among them all had significant level of concern for physical problems except one with CHD. In the ≥ 60 years age group, the common conditions observed were age related weakness, cancer esophagus, CHD, Chronic Kidney Disease (CKD) and paralysis due to cerebro-vascular accident and among them all had significant level of concern for their physical problems except those having age related weakness.

Overall almost all persons in the <60 years age group had significant level of concern for their physical problems except one having CHD and almost all conditions other than age related weakness had a significant level of concern.

Concern for physical problems in relation to marital status, education and socio-economic status

Among the 14 people with significant level of concern for physical problems, half (7) were widowed females. Among the 14 people having significant level of concern, 6 were in middle school level and 3 in high school level. Of all people requiring palliative care maximum, 8 were in lower middle class but among the 14 people with significant level of concern for physical problems, 5 were from lower class followed by 4 from lower middle.

Psychological problems in people requiring palliative care

Table 3: Psychological problems in people requiring palliative care

Psychological problems reported	Freq (%)
Requesting a hastened death	3 (15)
Guilt or irritability	3 (15)
Feeling of hopelessness	9 (43)
Loss of pleasure or interest in usual activities	9 (43)
Tearfulness	19 (86)
Sustained lowering of mood	20 (93)

The common psychological problems reported were sustained lowering of mood followed by tearfulness. Common reasons identified for these psychological symptoms are feeling of being burden to their family or caregiver, feeling of worthlessness because of their inability to fulfill their roles or responsibilities, and concern about the caregiver. Reasons for the psychological symptoms of the patients were stated in patients' words as follows,

Feeling of being a burden to the caregiver:

Few patients had a feel of being a burden to their caregivers mainly because of the economic impact of their illness over the caregiver or family.

An elderly widowed woman suffering from cancer esophagus said,

"I am a big burden to my son... he was so caring towards me, he left the job to take care of me and he is with me for the whole 24 hours, I feel so bad as his wasting his life for me" .

Concern about caregiver’s future:

A middle aged widowed woman suffering from CHD taken care of by her daughter said,

"My daughter’s husband died before three years and she was struggling with two small children. She is working as a maid in two families, after finishing her work she return back to home in a very tired state and then she has to manage our household chores also. I am more worried about her and about these children’s future...I am spending sleepless nights...when I lie down I am getting thoughts of these only..."

An elderly widowed female suffering from paralysis due to cerebro-vascular accident (in the same family the patient’s younger daughter was suffering from post-polio residual paralysis and both of them were taken care by the elder daughter) expressed feeling of both being burden and concern about the caregiver’s future,

"My elder daughter is providing care for both of us...she is not married till now. She is 40 years old...who will marry her after this age...her life is wasted because of us... sometimes I feel I should die soon, should not continue to be a burden for my daughter"

Feeling of worthlessness:

A middle aged widowed woman with CHD said,

"Previously I was working in a company and I earned a reasonable amount, now because of my illness I can’t go to work and now I feel that I was useless to my children...I can’t make them study in a good school...I can’t buy a new dress for them...my younger son is going by walk to the school...he is asking for a cycle since a long time...I couldn’t even buy that" .

Feeling of being isolated:

An elderly widowed female suffering from CHD who was staying alone said,

"Even though I have two daughters and many grandchildren...nobody visits my home regularly...they are staying in the next street only. I have a dog and my grandchildren are very fond of this dog. Sometime they visit my home to see this dog...but not for me... (Patient started crying)...I don’t deserve their love as even this dog deserves..."

Concern for physical health of the caregivers:

A middle aged woman suffering from filariasis leg provided care by her daughter said,

"My daughter is pregnant now, she provides care for me and she has to take care of her own family also. I can observe her getting tired and exhausted, I should have looked after her during this time, but she is looking after me (patient started crying)...I feel so guilty as I am a burden to her...I am not at all getting sleep nowadays..."

Concern for psychological problems in relation to age and disease conditions

All conditions other than age related weakness had significant level of concern for psychological issues. In <60 years age group, all had significant level of concern except one person with CHD. Among those ≥60 years of age with age related weakness, only 3 out of 9 had significant level of concern.

Concern for psychological problems in relation to marital status, education and socio-economic status

More number of men (4 out of 5) had significant level of concern for psychological problems. Among the 15 people with significant level of concern 7 were widowed females followed by 4 married (3 males and 1 female) and 3 unmarried females. Significant level of concern for psychological issues was more among the higher educated. Among the 15 people with significant level of concern for psychological issues, 8 had education more than primary level. Out of 15 people with significant level of concern for psychological issues, 5 were from lower class followed by 4 each from lower middle and upper lower.

Financial problems in people requiring palliative care

Table 4: Financial problems of people requiring palliative care

Financial problems	Frequency (%)
Travel expenses	13 (60)
Cost of treatment	20 (90)
Loss of income	22 (100)

The common financial problems reported by the people in need of palliative care were loss of income followed by costs of treatment and travel expenses. Loss of income was the common reason mentioned because people who were previously employed had quit the job because of their illness and not only the patients but also the caregivers had quit the job in many families for the purpose of caregiving. Concern regarding the costs of treatment was the second common reason, as many patients were worried about the consultation, medication and travel charges.

Financial issues related to loss of income:

A middle aged widowed woman with CHD said,

"Before my illness I was working as maid and was earning about rupees 1500 per month, now I have quit the job because of my illness. My daughter is working as maid in two houses and she will get around rupees 3000 per month...but this is not sufficient for us to lead a life...we are living in this hut for long years, this is also for rent only...most of the time we won't have even a small amount of money with us"

Financial issues related to costs of treatment and travel expenses:

A middle aged widowed woman with chronic heart disease said,

"I have to get few tablets from private health care facilities because I am allergic to some of the Government drugs...as I am unemployed now for getting these drugs, I have to borrow money from my relatives and neighbours...I don't know how I am going to repay it"

A patient with cancer esophagus said,

"I have to go to Chennai every month for my radiotherapy treatment and few drugs I am getting from Private facilities, because few of the drugs prescribed to me are not available in the government facilities and I am allergic to Government drugs, so for each time for travel and drugs we are spending a lot of money"

Concern for financial problems in relation to age and disease conditions

In the 20-59 years age group, all had a significant level of concern for financial issues except two; one with filariasis leg and one with chronic heart disease. In ≥ 60 years age group also one patient of CHD had some level of concern and 7 out of 9 people with age related weakness had some level of concern. Overall among the 12 people with significant level of concern for financial issues, major conditions observed are paralysis due to cerebrovascular accident, chronic heart disease and age related weakness, with 2 in each.

Concern for financial problems in relation to marital status, education and socio-economic status

More men (4 out of 5) had a significant level of concern for financial issues. Among the females, all the never married and 5 out of 13 widows had significant level of concern. Of the 12 people with significant level of concern for financial issues, 7 had more than primary level of education. Of the 6 with middle school education, 5 had significant level of concern. Related to socio-economic status, out of the 12 people with significant level of concern for financial issues, 5 were from lower class followed by 3 in lower middle and 3 in upper lower. Five out of the six in lower class had significant financial concerns.

Concern for spiritual issues:

Of the 22 in need of palliative care, 4 women had spiritual issues, two with chronic heart disease, one with cancer and other with paralysis due to Cerebro-vascular accident. Common spiritual issues observed were previous birth's karma, question of why it happened to them, loss of faith in God, hopelessness, few felt that their life has been wasted and had a negative attitude towards life.

Concern about sexual functioning or relationship:

Among the people requiring palliative care, 3 had significant level of concern for sexual functioning or relationship. All are observed in paralytic conditions; one was a woman with post-polio residual paralysis and two men having paralysis due to cerebro-vascular accident.

Concern for issues related to managing daily living activities:

Among the 22 in need of palliative care, 17 had problem with managing their daily living activities like bathing, toileting and food preparation and it was more among paralytic conditions followed by psychosis following head injury, CKD and filariasis leg.

Concern for difficulty in managing medication/treatment regimes:

Out of 22 people in need of palliative care, 8 were on medications for their illness, 4 among them were CHD patients, 2 with paralysis due to CVA, were on medications for hypertension and the others are one with esophageal cancer and one with CKD. People suffering from CHD were able to manage their medications; other patients suffering from paralytic conditions, cancer and chronic kidney disease were dependent on their caregiver for managing medications.

Concern for social issues:

Out of 22, 2 persons with conditions like filariasis leg and mild mental retardation had social issues. A patient suffering from filariasis leg said,

"As my legs are like this...I avoid going out to family functions or festivals, few of my relatives show sympathy towards me, but it is hurting me badly..."

Other patient with mild mental retardation since birth said,

"Except my mother nobody is speaking to me well, my neighborhood children never play with me"

DISCUSSION

Major needs of the patients were in psychological domain followed by physical and financial.

Physical health problems of people requiring palliative care:

Major physical problems identified among the people in need of palliative care were sleep problems like disturbed sleep during nights followed by drowsiness or fatigue, pain and other few have reported oedema in legs, dyspnoea, loss of appetite, persistent cough and incontinence. These symptoms were observed more among the people in younger and middle age groups, men, widowed females and the higher educated people with high concern for financial issues. The higher reporting of physical symptoms among these categories could be because they were suffering from more severe disease conditions like paralysis due to cerebro-vascular accident, post-polio-residual paralysis, cancer esophagus, chronic kidney disease, psychosis following head injury and filariasis leg. Among elderly widowed, with lesser level of education the common condition observed was old age related weakness which was considered to be a normal phenomenon and therefore more acceptable to the patients. So many of them didn't perceive a high level of physical problems.

It was observed by the investigator during the qualitative interviews that those who complained more physical problems also had inadequate social support, poor financial status, had left the job because of their illness and had high concern about loss of family savings. People with adequate social support and good financial status perceived very less symptoms, even though they had severe difficulties with their daily living activities.

Study done by Wijk et al in Sweden found out similar type of physical symptoms like pain, lack of appetite, fatigue and shortness of breath among cancer patients in Sweden but pain relief was the common need of those patients⁵. Similar to this study done by Raghavan et al in Kerala, India also found pain to be the common symptom among the terminally ill patients⁶. This was different because both these studies involved mainly cancer patients that require more pain relief.

Creutzfeldt et al found out the common physical problems among stroke patients as chronic pain, fatigue, incontinence, sexual dysfunction and sleep disorders⁷. These were similar to the symptoms observed among the paralysed patients in the present study. They have mentioned that urinary and fecal incontinence observed among stroke patients may not be always due to neural cause, it could be because of immobility and decreased ability of the patient to communicate. This was observed among a woman suffering from paralysis due to cerebro-vascular accident in our study. Moens et al⁸ based on their review expressed that physical symptoms like pain, fatigue, anorexia and dyspnoea are observed among both cancer and

non-cancer patients which was similar to the findings from this study.

Psychological issues of the people requiring palliative care:

Most needs of the patients were related to psychological domain. Reeve et al in their study among the cancer patients in UK⁹ and Akechi et al among cancer patients in Japan¹⁰ found out the prevalence of depression to be 4.1% and 6.7% respectively. This is similar to the finding of sustained lowering of mood observed in the present study but the prevalence in the present study is higher. Studies have reported similar psychological issues like depression, feeling of guilt for not fulfilling their roles or responsibilities, feeling of worthlessness and feeling of being burden among the terminally ill patients¹¹⁻¹⁴

Financial issues of the people requiring palliative care:

Financial needs were the third most common needs perceived following psychological and physical. The common financial problems reported by the people in need of palliative care were loss of income followed by costs of treatment and travel expenses. Few studies had showed similar finding of high financial issues among the patients. Study done by Rainbird et al in Australia reported that 10-30% had high needs in the financial domains¹⁵. Similar to this study done by Gupta et al in Rohtak, India¹⁶ and Slovacek et al in Europe¹⁷ had mentioned high financial constraints among the people requiring palliative care. As per disease conditions, financial issues were less among the people with age related weakness as they need lesser clinical management compared to other severe conditions.

Spiritual issues of the people requiring palliative care:

Spiritual well-being is associated with a greater ability to cope with illness and a positive attitude about life and illness can improve the health outcomes of the patients. Among the 22 people in need of palliative care, 4 (18%) had spiritual issues. It was observed people with higher psychological problems, even with adequate social support and from upper middle class had spiritual issues. Positive spiritual well-being was observed in a patient diagnosed with chronic heart disease with less psychological and financial issues, who was provided care by his son, expressed a positive attitude towards life and had a belief that God never let him down.

Muckaden et al found out the common spiritual issue as acceptance of their present situation as because of their previous birth's karma¹⁸ which was similar to that observed in the study.

Concern for Sexual life or relationships among people in need of palliative care:

Sexuality is often an area that is rarely addressed or often missed by the healthcare providers, because it is a sensitive issue and it is difficult to discuss for both the healthcare providers and patients but it is an important need for some patients at their end stage of life, because sexuality doesn't mean just a physical act between two persons, it is an emotional form of expressing the love towards a person that improves the intimacy and can relieve or reduce their sufferings and psychological issues to a great extent.

Among the people in need of palliative care three expressed significant level of concern for their sexual life; two were men suffering from paralysis due to cerebro-vascular accident. As per the statement of their caregivers (wife), it was noted that both the men were worried about their inability to involve in sexual life, which made them feel very inferior, irritable and they were showing their anger over their wife frequently and unnecessarily. Other one a female suffering from post-polio residual paralysis was worried about her personal life and was highly depressed about it. She started taking medications to get relieved of her depression, but as per the caregiver her depression is increased and recently she stopped communicating to others and was crying most of the time.

Blagbrough et al in their review regarding the importance of sexual needs assessment among terminally ill patients found out that loss of sexuality or sexual functioning could severely affect the health and relationships of the patients¹⁹. This is similar to the findings observed among the paralytic patients in the study.

Social issues of people in need of palliative care:

Social factors like education, employment, economic status and social support play an important role in coping with chronic disease conditions. Social isolation or lack of support can affect the patient psychologically which can also affect their physical well-being. Social issues are commonly missed during the treatment of patients. Knowledge of these factors can help in understanding the physical and mental health of the patients and can help in patient management.

In the present study, social issues was observed among two patients, one was a woman suffering from filariasis leg, who started avoiding going out or attending festivals because of the disfigured appearance of her limb. Other one was a woman suffering from mild mental retardation, social issues experienced by her was avoidance by children in her neighborhood. These things happened to her

during the childhood continue to cause emotional distress thus affecting her psychological health.

Study done by Yiengprugsawan et al²⁰ in Australia and Tsevat et al²¹ found out that lack of social support was associated with psychological distress which was similar to the finding observed in the study.

CONCLUSION

Major needs of the patients were in psychological domain followed by physical and financial domains. All these domains are interrelated and identifying these issues earlier and providing the essential support helps to alleviate the problems of patients and their dependents to a great extent. As the need for Palliative care services are growing rapidly imparting components of palliative care into medical curriculum is essential to improve the knowledge of medical students on these aspects. Palliative care services have to be a part of government health system to enable its accessibility to everyone in need.

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