

Original Research Article

Needs of the caregivers of people requiring palliative care in an urban area of Pondicherry, South India

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ABSTRACT

Background: There is an increasing need to provide palliative care services globally. All these chronic, life limiting diseases not only affect the patients but also affect their caregivers in various aspects. The aim of the study was to assess the needs of caregivers of people requiring palliative care in an urban area of Pondicherry, South India.

Methods: An exploratory descriptive study was conducted in 1004 households with 3554 individuals in two selected areas under an urban PHC in Pondicherry. Needs of the 21 caregivers who provided care for 22 patients 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. Content analysis was done for the qualitative data after translation and transcription.

Results: Caregivers faced physical, psychological, financial, social and spiritual issues related to care-giving. Physical issues reported were sleeplessness, fatigue and back pain. Common psychological issues reported were depression, hopelessness and getting tensed frequently. Financial issues of caregivers were related to loss of income and loss of family savings for the treatment charges of patients. Social issues observed were avoiding going out or attending festivals, lack of social support and lack of time to spend enough time with their spouse and children.

Conclusions: Caregivers are exposed to a long-term stress starting from the diagnosis of the patient's illness continuing even after the death of patient. So in this way the caregivers are exposed to higher level of stress than the patients, which needs to be addressed appropriately.

Keywords: Caregivers, Palliative care, Physical issues, Psychological issues

INTRODUCTION

There is an increasing recognition of unmet need to provide palliative care services globally and in India. In 2010 the major contributions to diseases requiring palliative care in India are from non-communicable diseases that account for 53% of all deaths in India. Among them cardiovascular diseases contribute to 24% followed by respiratory diseases (11%), injuries (10%), cancers (6%) and diabetes (2%).¹ In addition to these non-communicable diseases, wide availability of anti-

retro viral therapy has made HIV to be a chronic condition requiring palliative care; Experts estimated that 80% of people dying from cancer and AIDS will require pain relief at least for 90 days during their illness and all these patients would be in need of palliative care.²

All these chronic, life limiting diseases make the patients suffer from pain, other symptoms and psychosocial distress which decrease their quality of life significantly and these illnesses not only affect the patients but also affect their family or caregivers in physical and psycho-

social aspects. According to the National Alliance of Caregivers (NAC, 2009), “Caregivers are defined as those who provide unpaid care to an adult or to a child with special needs”.³ Caregivers who care for the patients with life limiting illnesses face a lot of challenges and experience a high burden of stress because of their increased responsibilities which drain their energy, time and patience. It can affect their physical, psychological and emotional health to a great extent. Very few studies have reported the needs and issues of caregivers who care for people in need of palliative care. So this study was done to assess the medical, social, spiritual, psychological and financial needs of the caregivers of people requiring palliative care.

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. This PHC was 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 January 2013 – January 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 the 21 caregivers who provided care for 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 was 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 in need of palliative care and they were provided care by 21 caregivers. The disease conditions of the people requiring palliative care are given in Table 1.

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

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

All the caregivers were family members of patients. In a same family the mother was suffering from paralysis due to CVA and the younger daughter was having post-polio residual paralysis and they were provided care by a single caregiver (elder daughter).

Table 2: Characteristics of caregivers (n=21).

Variables	Frequency
Gender	
Male	7
Female	14
Marital status	
Unmarried	5
Married	14
Widowed	2
Relationship with people in need of palliative care	
Daughter	8
Son	7
Spouse	3
Mother	2
Sister	1

All caregivers were in the 30-45 years age group. Of them, 9 were full time caregivers who provided care for the patients the whole day and remaining 12 were part-time caregivers who provided care for the patients along with managing their income generating activities. Among the caregivers, one who was providing care for a CHD patient was not staying with the patient and she used to visit the patient whenever the patient was in need. Among the caregivers who were employed, most of them were

housemaids, few were day wagers and factory workers. Other characteristics of caregivers are shown in Table 2.

Difficulty among caregivers in providing physical care

Caregivers of patients with all other disease conditions except age related weakness (2/9) and CHD (1/4) expressed a significant level of concern for difficulty in providing physical care. Caregivers with poor physical health and who are employed found it difficult to provide care for the patients and they expressed their concern as follows,

Caregiver (widowed mother) of a patient with psychosis following head injury said,

"I find it so difficult to take care of him...he is suffering a lot... nobody is there to look after him if I fall sick for some days, he is not oriented to the things happening around him... I have to be with him always...otherwise he will run away somewhere".

Caregiver (35 year old married, wife) of a patient with paralysis due to CVA said,

"I find it so difficult to provide physical care to him...after this incident he can't go to work...I have to go for work...we don't have any other support...what I will do?...I have to take care of him also, he needs me for his toileting and bathing...we don't have enough money to employ some person to look after him...if we employ also nobody can adjust with him...he used to drink alcohol and speak badly"

Difficulty of caregivers in coping with psychological problems of patients

Significant level of concern for difficulty in coping with the psychological problems of the patients was found among the caregivers of all disease conditions except age related weakness (2/9). Caregivers who had a significant level of concern for managing the psychological problems of the patients felt that the psychological issues of the patients were oriented mainly towards them and they expressed their concern as follows,

Caregiver (middle aged unmarried son) of a patient with esophageal cancer said,

"She is always feeling depressed and crying most of the time; she is more worried about my life than about her illness. She used to feel bad that if something happens to her, I will become an orphan."

Caregiver (middle aged mother living with spouse) of a patient with mild mental retardation who was significantly distressed about her daughter's condition said,

"She used to feel so bad as she is not like other persons of her age...once she asked me why nobody from the neighbourhood is playing with her...I can't reply anything to her...what I will say (caregiver started crying)."

Physical and psychological issues of the caregivers

Among the 21 caregivers, 11 had significant physical and psychological issues related to care-giving. This was observed more among the caregivers providing care for patients with all disease conditions except age related weakness. Common physical issues reported by them were sleeplessness, fatigue and back pain. Physical issues were mainly because of their poor physical status and because of heavy work burden due to managing the patients along with income generation and household activities.

Caregiver (30 year old widowed daughter with two children) of a patient with CHD said,

"I want to be with my mother always...but as I am going to work I can't stay with her all time. When I return back from my work I feel so tired and exhausted to do the household works along with managing her"

Caregiver of a patient with filariasis leg said,

"I don't find it so difficult to help her in bathing and toileting. I have never thought her to be a burden...as I am in my 7th month of pregnancy, I am feeling so tired and exhausted, my legs are edematous, I couldn't stand and cook for a long time...but I don't want to leave her to some maid or others...because they may not look after her as like me"

Reasons for psychological problems of the caregivers

Common psychological issues reported by them were depression, hopelessness and getting tensed frequently.

i. Related to physical health of the patient

Caregiver (middle aged unmarried son) providing care for the esophageal cancer patient had significant level of concern for psychological issues and he said,

"As my mother's condition is worsening day by day, I started feeling hopeless and most of the days I have disturbed sleep, during mid-sleep I used to wake up and sit. I don't know what to do further (romba manakavalaya irukku...enakku ena panrathune theriyala)".

Caregiver (middle aged mother) who provides care for her daughter suffering from mild mental retardation said,

“My daughter used to feel so bad as she is not like other persons of her age...she don't have any friends...after fifth standard her school teachers told she is not able to understand the lessons, so they asked me to take her away from the school, I felt so bad as my child couldn't study like others”

ii. Related to loss of income

Caregiver (middle aged married and working daughter) who provides care for her mother suffering from age related weakness was requesting a hastened death for the patient. She said,

“My husband is not going for work regularly, I too can't go to work regularly because of her and I am losing my only way of income because of her. I am expecting her to die soon. I will be happy, because she is already very old, how many days I can look after her, I need to take care of my family also”. The words “let her die soon were repeated several times in front of the patient (mother) during half an hour of the interview. High level of psychological issue of the caregiver affected the patient to a great extent. As per the caregiver's (daughter) statement, the patient (mother) had stopped speaking for past 6 months.

iii. Related to unaffordability of higher level of care for the patient

Caregiver (mother) of patient with mild mental retardation was worried about her inability to afford higher level of care to her daughter, she said,

“Doctors and her school teachers advised me to take her to some special schools meant for these type of children...but I can't afford that much...so I didn't do anything further...(caregiver started crying)”.

Financial issues of the caregivers

Significant level of concern for financial problems was found among the caregivers who provide care for patients with all other disease conditions except age related weakness (2/9), CHD (2/4) and filariasis leg.

Financial issues of the caregivers are mainly related to the loss of income and loss of family savings or selling of assets for the treatment charges of the patients. They expressed their concern as follows,

i. Financial issues related to loss of income

A caregiver (middle aged unmarried daughter) who was providing care for 2 persons in the same family (mother suffering from paralysis due to CVA and sister suffering from post-polio residual paralysis) said,

“I have to take care of two persons, I have to be with them the whole 24 hours, because both of them can't even stand or sit...I am not working anywhere. I have to take them to toilet, make them take bath...so after finishing all these works...I feel so tired to do even household works...how can I go to outside work...we are totally dependent on my brother for money...he is also married...sometimes his wife won't allow to give money...we feel so bad to ask money to him frequently”.

ii. Financial issues related to treatment charges

Caregiver of a patient suffering from cancer esophagus said, *“I quit the job to take care of my mother and few of her cancer drugs I am getting from private facilities, I don't have enough money and we are dependent on my brother and other relatives...I am having debts all around”*

Caregiver (middle aged unmarried son) of a patient with CKD said,

“Previously I was working in a private company and now I have left my job as I have to take care of my father. I don't want to employ any other persons to look after him. They may not take care like us. As he is undergoing dialysis, I have to spent more money for that...we are getting treatment in a private hospital.. So because of his dialysis and other treatment costs I have sold one of our lands and with that money we are managing till now”.

Social issues of the caregivers

Among the caregivers, three had significant level of concern for social issues. Social issues observed were avoiding going out or attending festivals, lack of social support and few had mentioned that they couldn't spend enough time with their spouse and children. It was observed more among the caregivers of patients with mental health related illness.

Caregiver (mother) whose daughter was suffering from mild mental retardation said,

“I am not attending any family functions because if somebody asks me why your daughter is like this...I used to feel so bad, so nowadays I started to avoid functions”

Caregiver of a patient suffering from psychosis following head injury was worried about the lack of social support for her, she said

“I find it so difficult to take care of him...he is suffering a lot...I can't take him to any good hospitals to provide treatment. I don't have any support from anybody...being a woman what I will do alone...”.

Caregiver (37 year old married woman) of a patient with age related weakness expressed her lack of time to socialize with her children, spouse and relatives, she said,

"I couldn't spend enough time with my children nowadays, because after returning back from work I have to manage all the household chores and I have to provide care for her also, by the time I finish all these works I felt so tired and my children fall asleep by that time"

Spiritual issues of the caregivers

Among the caregivers three had significant level of concern for spiritual issues and it was observed among the caregivers of patients suffering from paralytic conditions followed by psychosis following head injury. Spiritual issues observed among them were the question of why such things were happening to them and two also mentioned loss of faith in God. Caregiver (middle aged widowed mother without any social support) of a patient with psychosis following head injury said,

"I lost faith in God...previously I used to pray every day and used to go to temples every Thursday, but nothing I got out of that...people who are bad and make others suffer are happier and we people who have never thought of doing anything bad to others are suffering for the whole life, then why should we believe in God and other things?. Everything is happening as per our fate only...nobody can change anything"

Bereavement grief

Among the caregivers, 2 had bereavement grief. It was observed among conditions like esophageal cancer and CKD and it was mainly related to the caregivers thinking about things that will happen after the death of the patient.

Caregiver (son) of a patient suffering from esophageal cancer said,

"I will be an orphan if something happens to my mother... if I think of those things I will start crying."

DISCUSSION

In our study, most caregivers were females (72%) in the age group of 30-45 years similar to the findings by Piragglia et al among caregivers of HIV patients in USA who found that the mean age of the caregivers of was 42 years and more than half were females.⁵ But in our study, all caregivers were family members as compared to only 35% in the study by Piragglia et al.⁵ This may be due to cultural differences and unaffordability of paid caregivers in our study context.

Regarding difficulty in providing physical care, it was more among the caregivers who provided care for patients with conditions like paralysis due to CVA, post-

polio residual paralysis, CKD, psychosis following head injury, because these patients were totally dependent on their caregivers for their daily living activities like bathing, toileting, taking food etc. This was observed less among CHD patients, as most of them in the present study were able to manage their daily living activities and were not bedridden. For people with oldage related weakness, only those caregivers who were working and from low socio-economic status found it difficult to provide care for the patients in need of help for daily living activities. Because of their inability to afford a paid caregiver they were forced to provide care in addition to their occupational work. Few of these caregivers wanted to get relieved from the duty of caregiving, which was similar to the finding of studies done in India among caregivers of cancer patients by Joad et al and Kulkarni et al.^{6,7}

Common physical issues experienced by the caregivers in this study were sleeplessness, tiredness or fatigue and back ache. Study by Kulkarni et al among caregivers of cancer patients in Maharashtra, India found similar physical symptoms like fatigue and sleep problems.⁷ Study among caregivers of cancer patients by Sjoval et al in Sweden and Joad et al in Jaipur, India had showed a common finding of fatigue or tiredness similar to this study.^{6,8} Study by Carlsson et al among caregivers of palliative patients in Sweden have identified sleep problems similar to this study.⁹

In present study the psychological stress was observed more among female caregivers. Study by Yiengprugsawan et al among Thai caregivers identified high level of psychological stress among female caregivers with high work burden, because of managing the patient and other household activities similar to the present study.¹⁰ In contrast to this, study by Gupta et al among caregivers of psychiatric and cancer patients in India showed equal level of stress among male and female caregivers.¹¹

This study identified common psychological issues among caregivers as depression, hopelessness, getting tensed frequently and sleep problems which was commonly observed among the caregivers of patients with deteriorating conditions like cancer esophagus, CKD, paralytic conditions and among caregivers of patients with mental health related illness. Similar to this study done by Piragglia et al and Fujinami et al in US among caregivers of cancer patients showed high level of depression among the caregivers of terminally ill patients.^{5,12} Kulkarni et al in Maharashtra, India and Carlsson et al in Sweden identified sleep problems among the caregivers of palliative patients and they found it was more among the younger age and women caregivers which was similar to this study.^{7,9}

In our study caregivers of conditions other than age related weakness, perceived high stress because the sudden diagnosis of the patient's illness was unexpected

for their family and was not acceptable by the caregivers. It suddenly increased their role in the family leading to a higher emotional stress. Similar finding was observed in study done by Sjøvall et al.⁸

In the present study caregiver of a patient with psychosis following head injury was highly depressed, because in other disease conditions the patients were able to understand the stress of the caregivers and few were psychologically supportive to the caregiver, even though they were depressed themselves. But in case of psychosis following head injury the patient was not able to understand the stress of the caregiver and the caregiver was suffering without any social or moral support from anybody. This similar finding was reported by study done by Sharma et al in India among the caregivers of patients with mental health related illness.¹¹

Common financial issues observed among caregivers of our study were due to loss of income as many of them had quit the job because of caregiving and among those who were working were forced to take frequent leaves, missed many days of work. Other issues like daily costs of caregiving, travel expenses, medication, and consultation charges for the patients created financial crisis for them. Study by Fujinami et al in United States showed financial constraints among caregivers due to loss of income, which was similar to this study.¹² Present study found financial issues caregivers of poor socio-economic status and those who provided care for patients with illnesses like paralytic conditions, mild mental retardation, psychosis following head injury, CKD, cancer esophagus and chronic heart disease which was similar to findings observed in studies done by Covinsky et al among caregivers of palliative patients in United States and Kulkarni et al in India.^{7,13}

In our study three women caregivers who provided care for persons suffering from stigmatizing illness like mental health related illness experienced social issues like avoiding going out or avoiding attending festivals, lack of social support and lack of enough time to spend with their partners and children. Study by Sharma et al in India found that the caregivers of patients with mental health related illness experienced more distress, sadness, frustration and social isolation which was similar to that observed in this study.¹¹ Joad et al identified one of the social issues among the caregivers as lack of adequate time to spend with their children affecting the health of their children similar to this study.⁶

Our study identified spiritual issues among three women caregivers and it was more among caregivers with higher psychological problems, providing care for people with deteriorating illness, lacking social support and with poor financial status. Spiritual issues observed were the question of why such things were happening to them and they expressed a loss of faith in God. This led to a negative attitude in life for them and it could have affected the psychological health and physical health

thereby their ability of them to provide care. Study by Adams et al in United States among caregivers of cancer patients found out high level of spiritual issues like lower levels of meaning and peace among the caregivers of cancer patients and he also noted that these issues were noted among caregivers with less social support which was similar to this study.¹⁴

CONCLUSION

Caregivers are the one who can provide a major psychosocial support to the patients. Needs of the caregivers depends on the disease condition of the patients, socio-economic status of the family, social support and physical health of the caregiver. Caregivers in this study faced difficulties in providing physical care and coping with the psychological problems of the patients and also many physical, psychological and financial problems of their own, but related to the process of caregiving. Psychological issues observed among them can cause a serious effect on the health outcomes of the patients. Psychological issues like depression among the caregivers are known to be common and not provided separate care or attention at the health care facilities. But it has to be realized that caregivers are exposed to a long-term stress starting from the diagnosis of the patient's illness continuing even after the death of patient. So in this way the caregivers are exposed to higher level of stress than the patients, which needs to be addressed appropriately.

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