Original research article

Perceived needs and challenges of non-state caregivers in palliative care in Imphal West district Manipur: A Qualitative study

Annastasia A Sangma[1], Jyothi S[2], Pooja Akoijam[3], Brogen Singh Akoijam[4], H Sanayaima Devi[5]

[1,2]PGT, Department of Community Medicine, RIMS, Manipur University, India,[3]Senior Resident, Department of Community Medicine, RIMS, Manipur University, India .[4]Professor, Department of Community Medicine, RIMS, Manipur University, India, [5] Professor and Head of Department, Department of Community Medicine, RIMS, Manipur University, India

Corresponding Author

Dr Annastasia A Sangma
Post Graduate Trainee
Community Medicine Department
RIMS, Imphal 795004
Manipur
Phone number 9366955936
E-mail –annastasiasangma15@gmail.com

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Introduction: *There is a need for assessing caregivers' perceived needs and challenges in the private sector as their involvement in palliative care is the need of the hour, so that we can fill the gap between quality care and improved health.* ***Aim:*** *To explore the perceived needs and challenges of caregivers in palliative care in private sector, Imphal West district Manipur.* ***Methods:*** *A Qualitative study was conducted in Imphal West district in Manipur, India from December 2022 to January 2023 among Palliative care-givers and volunteers from private sector of Imphal-West district. Purposive sampling was done till theoretical saturation was reached. Data was collected using In-depth interview (IDI)/ Focus Group Discussions (FGDs) with voice recordings and transcribed verbatim. Transcribed data was translated into English language and coded. Thematic analysis was done using inductive approach. Ethical approval was sought from the Research Ethics Board, RIMS, Imphal.*

Results: *Themes identified were- physical challenges, psychological challenges, financial burden, personhood, working conditions, quality of care* ***Conclusion****: Majority of the caregivers discussed need for emotional and physical support. Financial burden, misuse during work hours, work- personal life imbalance, need for formal training were identified as challenges of the caregivers. Hence, necessary steps need to be taken to improve the overall skill and quality of life of palliative caregivers.*

Key words: *challenges; needs; non- state*

Introduction

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Through this the quality of life of caregivers also improves. Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care. Worldwide, only about 14% of people who need palliative care currently receive it. There is a huge gap in the demand and supply of palliative caregivers. Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may also require palliative care. Pain and difficulty in breathing are two of the most frequent and serious symptoms experienced by patients in need of palliative care.[1]

Negative attitudes toward palliative care among patients and caregivers are often cited by physicians as a reason for late referrals to palliative care services[2,3] and a change of name to "supportive care" has been roposed.[4] Approximately 90% of advanced or terminally ill patients prefer to be cared at home during their illness,[5] and 67% indicate home to be their preferred place to die.[6]Optimum home care for patients depends on adequate care for the caregivers to continue providing care.[7] Caregivers of patients receiving home palliative care have been shown to experience many physical,[8] emotional,[9] psychological,[10] [11]social[10, 12] and financial[12] difficulties as well as unmet needs for information.[13] Therefore, health care professionals (HCPs) need to acknowledge caregivers' ambivalence towards their identity as caregivers and consider them not only as providers but also as recipients of care, particularly as their needs may sometimes exceed those of the patient.[14] It is estimated that nearly 5.4% million patients need palliative care every year. However, it is accessible to only 1% of them.[15] In Manipur, in the year 2022, out of 30 lakh population more than 12,000 patients need palliative care at one point of time.[16] There is a need to assess the needs and perspectives of caregivers in palliative care thoroughly in our setting, so that we can fill the gap between quality care and improved health. Hence in our study we are concentrating on carers' needs and perceptions on palliative care. The present study is conducted to explore the perceived needs and challenges of non-state caregivers in palliative care in Imphal west district, Manipur.

Material and methods

Study tool: Study tools used was interview guide and audio recorder**.** Interview guide consisted of two parts: background characteristics like age, sex, religion, educational status, occupation, marital status, monthly family income, family size and the Perceived needs and challenges of non-state caregivers in palliative care in Imphal, West district of Manipur. The domains explored were physical challenges, psychological challenges, financial burden, personhood, working conditions and quality of care.

Data collection: Data was collected using in-depth interview (IDI) with the participants using a semi structured approach, which was conducted by two post graduate trainees of the Department of Community Medicine of a teaching hospital in Manipur and focus group discussions (FGDs) was conducted with one of the post graduate trainee as a moderator and the other as a notetaker . Our goal was to gather rich, detailed information about their experiences related to the research topic.

After explaining the purpose of the study, an informed written consent was taken from each participant with permission to voice record the interview**.** The participants were reassured about their anonymity at the time of IDIs and FGDs. Data analysis: Once we had collected all of the data, we began the process of thematic analysis. Through careful listening and cross-checking by the interviewer, all the IDIs and FGDs recorded were transcribed verbatim. Transcribed verbatim data were translated into English**.** Translated data was back translated into Manipuri language**.** Translated data was studied in detail, read multiple times to get a sense of the overall themes and patterns that emerged. and coded**.** Data was sorted and sub-themes were constructed**.** Themes were identified. Specifically we used Nvivo, which is a popular software program for qualitative data analysis. However, it's worth noting that we also did a significant amount of manual analysis and interpretation of the data. We were careful to maintain a high level of internal validity throughout the process.

Ethical issues: Approval was sought from the Research Ethics Board RIMS, Imphal. Information collected through IDIs and FGDs with voice recording was utilized only for the purpose of this study and was not disclosed to anyone outside the research team. Data collected was not linked to identify the individual in any way. All the recorded interviews were stored with secure password encryption. Confidentiality was maintained by limiting the access of data only among the investigators.

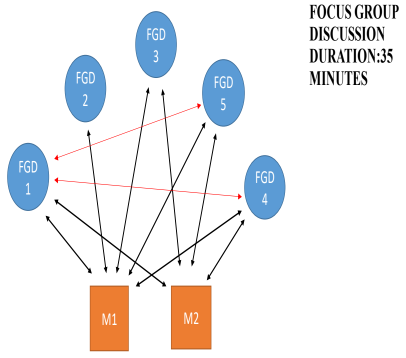

Fig no 1: Sociogram for group discussion

Results

Eleven in-depth interviews and onefocus group discussion were conducted. The focus group discussion consists of six participants. Out of seventeen participants who were included in the study,ten were married and seven were unmarried. Only three among the participants had received formal training on palliative care while the remaining fourteen had not received any form of training. Out of the seventeen participants, ten were family caregivers while seven were paid caregivers. Table 1 shows the socio- demographic characteristics of the participants.

Themes identified were: Physical challenges, psychological challenges, financial challenges, loss of social life, working conditions and quality care.

Physical challenges

a) **Feels exhausted**: The majority of the caregivers discussed being physically exhausted, since the patient completely depends on them for all their needs, they feel tired occasionally. The physical challenges faced by them while providing palliative care also affected their overall productivity.

"I have to give him medicines. But sometimes I am not able to do all that's needed for him as I am also tired and I fall asleep. Rarely once or twice I also missed his medicine…" -IDI 4

b) **Work-Life Balance**: Few of the participants shared their worry related to work, because of not having enough time for their career, their job or work was affected. They had a hard time balancing their job and their home caregiving schedules. One of the in-depth interviewees expressed his lack of sleep and his decreased time for his day job.

"Getting tired because of not sleeping at night and going for work without sleeping at night. Since my duty is also for the society as a lawyer, I need to read and since I cannot read for long at night, I find some problem." -IDI 3

2) **Psychological challenges**

a) **Mental fatigue**: Majority of the caregivers, both informal and formal caregivers commented that once in a while, they feel mentally tired and exhausted. While taking care of the sick person and if the severity of the illness increased, the level of tiredness also increased

"Once in a while mentally and physically I feel tired because I'm looking after a sick person. Sickness is not a good thing. If their illness gets worse, I feel mentally tired." -IDI 1

"While going for official work I have some bad feeling thinking about what might happen. Even inside the courtroom I don't switch off my mobile I keep it in silence thinking I might get call… so these things are always on my mind" - -IDI 3

b) **Change in temperament**: Some of the caregivers mentioned that once in a while they have felt annoyed because of the emotional stress and workload and they had no one to turn to in those situations.

"…. but I will calm myself down thinking that for what I am doing I can't get angry. It's human nature to get angry. Sometimes it's because of my profession, even if I am tired whom will I complain to? So, I just handle on my own." - FGD2

3) **Financial challenges**

a) **Increased out-of-pocket expenditure for the patient**: Majority of the family caregivers talked about the financial loss they are facing because of the increased expense while taking care of the sick patient. They also expressed the need to part with their assets just to cope up with the expenditure.

"I am the one who earns for the family, my mother is just a house wife, my father is weak now. All the money matter are done by me and also, I have to take care of the patient. ... but we have sold a part of our property." -IDI 4

"… We have money problem as the expenditure involved in the treatment is huge. Other than that there is not much of a problem." -IDI 8

b) **Cut in wages or salary**: Some of the participants mentioned about the financial loss they are facing because of increased time for caregiving, as they have to spend time off from their work for the patient.

"For that, I lost so much time on doing this. I mean as I am taking care of my brother, my work. My business is all affected. Before this I hardly used to stay at home." -IDI 4

"He is very happy when I take care of him instead of anybody else. When I go out for work, he is usually sad and tries to take care of himself only

Fig2 shows conceptual framework for addressing the possible recommendations for providing a better palliative care.

Fig: conceptual framework

Table 1: Socio demographic characteristics of participants (N=17)

Characteristics	n (%)
Gender	
Female	15 (18)
Age (in years)	39±12
Range (years)	21-60
Duration of palliative care services	
< 1 year	6
1- 2 year	5
3– 5 year	5
>5 year	1
Religion	
Hinduism	11 (65)
Sanamahism	4 (23)
Christianity	2 (12)
Family size(in numbers)	
≤5	6(35)
>5	11(65)
Education Qualification	
Primary	1(6)
Secondary	2(12)
Higher Secondary	7(41)
Graduate	7(41)
Occupation	
Unemployed	2(12)
Home maker	3(18)
Nurse	4(23)
GDA in palliative	2(12)
Others	6(35)
Family Income	
10000-30000	8(47)
30001-50000	4(23)
50001-100000	3(18)
>100000	2(12)

without bothering anybody else. But I can't help it... I have to go and earn money for us." -IDI 6

4) **Loss of Social life**: Majority of the family caregivers described the need/lack of social interactions since they were always pre-occupied with the patients.

"Saying it shortly, our personal work like going to church also, we cannot go regularly, for doing household work also we can't do it freely because someone has to stay with her." -IDI 5

5) **Unfavourable working conditions**

a) **Attitude of the beneficiaries**: Few of the palliative volunteers explained some of the challenges they faced while giving service, like yelling and shouting by both patients as well as their family members.

".... sometimes, they've shouted and sworn at us but when this happens, we don't feel like going to that house...Sometimes the family members in their urge to cure the patient faster also speak badly to us." -FGD4

b) **Lack of clarity of roles**: Formal caregivers complained about occasional bad experiences with the family members as they were asked to do work unrelated to palliative care during their home visits.

"Our work is only providing the nursing care but some people have also told us to do household activities/ chores. They have a mentality that since we are not hospital workers and providing care at home, they can ask us to do household activity to our work schedule. But we never get angry, we explain to them properly the jurisdiction of our work lies till taking care of the patient only……"-FGD 2

6) **Quality care**

a) **Training of the caregivers:** Most of the participants, both home caregivers as well as volunteers, emphasized the need for training in palliative care to provide quality care. They expressed that they needed more guidance as to face the difficult situations.

"…it will be better for us, getting guide from medical expert. Since we do not receive any guidance from expert it's very difficult sometimes." -IDI 3

b) **Improving logistics:** Many of the participants expressed the need to improve logistics and the difficulties faced by them

"umm like transportation problem, we could not afford the private vehicles often, so miss out on some health check-ups." -IDI3

"I mean patient needs to be taken care of and medicines are also required for relieving of pain. Both these are needed at the same time and some assistance from a trained person would be of much help." - IDI4

Discussion: The need for palliative care will continue to grow as a result of the ageing of populations and the rising burden of non-communicable diseases. Little is known about patients' and carers' experiences of palliative care in the home setting. Family members of people in need of palliative care suffer from heavy physical and psychological burdens, including financial instabilities and daily chores and limited social communication. The current support provided to them is insufficient. More financial support should be provided to people providing home based palliative care. To a certain extent, the increasing resources and support for patients and their family caregivers can relieve the burdens on family members taking care of the patients.

In our study, Majority of the family caregivers described thelack of social interactions since they were always pre-occupied with the patients, which was similar to the findings of Adejoh et al.[17] Also in this study, few of the volunteers explained some of the challenges they faced while giving services, like yelling and shouting by both patients and as well as their family members which was similar to the findings of the study conducted by Musondo et al.[18]

In a study conducted by Daya P et al.[19] the findings were similar to our study in the domain of social issues such aslack of social support and avoiding going out or attending festivals. Regarding financial issues also there were similarities such as loss of income and selling of family assets for the treatment charges of the patients.

Understanding the sources of palliative caregivers' burden has an impact on improving family intervention programmes, patients' outcomes and the caregivers' well-being as well. The six themes identified may serve as a structure for quality improvement tools in palliative care settings

Strength: This study bridges the gap in the knowledge of perception of palliative caregivers' service among the non-state caregivers and what we know.

Limitation: Most participants may not have felt free to share their views and may have given socially desirable answers.

Conclusion: Majority of the caregivers expressed the need for emotional support and physical support. The participants also talked about financial burden and loss of work- personal life balance and lack of social interactions. Few of them also talked about misuse during work hours as well as the need for awareness about palliative care.

Recommendations: Public awareness in the form of health talk on the importance and need for palliative care should be given. Proper training can be given to palliative caregivers to improve the quality of care. Financial aid to those undergoing palliative care as well as to the caregivers.A conceptual framework was developed to better understand the needs and challenges as well as recommendations for providing better palliative care.

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