Original Article

Experiences of Caregivers in a Home-Based Palliative Care Model – A Qualitative Study

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Abstract

Background: Family caregivers are of vital support to patients receiving home-based palliative care. **Aims and Objectives:** This study sought to identify and comprehend the challenges that caregivers face while taking care of a terminally ill patient in a home-based palliative care setting and the mechanisms that facilitated their coping. **Materials and Methods:** A qualitative approach was employed to understand the perceptions of primary caregivers through 3 focus group discussions and 4 in-depth interviews, across 3 socioeconomic categories and 3 geographic zones of Mumbai. **Results:** Caregivers expressed that they wished they had been introduced to palliative care earlier. Being trained on minor clinical procedures and managing symptoms, and receiving emotional support through counselling were found beneficial. Caregivers did not perceive the need for self-care as the period of active caregiving was often short. Bereavement counselling was felt to be of much help. **Conclusion:** The study helped understand the caregivers' perceptions about the factors that would help them in patient as well as self-care. Recommendations for designing interventions for future caregivers and recipients were also made.

Keywords: Bereaved caregivers, home-based palliative care, qualitative experiences

INTRODUCTION

Studies show that patients with advanced cancer prefer to be cared for and die at home instead of at an institution.[1-4] A study conducted by the Cipla Palliative Care Institute, Pune, India, in 2014 showed that 83% of people in India expressed a preference to die at home.[5]

With the single-minded purpose of delivering a home-based, multidisciplinary, efficient and compassionate, palliative care service to patients in the city of Mumbai, the Jimmy S Bilimoria Foundation was founded in January 2015 and launched its PALCARE service in December 2015. PALCARE became the first NGO to offer a multidisciplinary home-based palliative care service for cancer patients from any facility or even privately within Greater Mumbai. Since inception till the date of this report, PALCARE has looked after over 1000 advance-stage patients and provides services to 100–120 patients concurrently. Right from inception, the PALCARE medical team has witnessed how essential it is for any palliative care service to be supported by at least one caregiver, be it a family member or other individual like a nursing aide or friend, who diligently takes on the charge of looking after the patient after the palliative care team visits and does so in a responsible, compassionate, and efficient manner and is willing to be an adjunct to a multidisciplinary palliative care medical team.

A systematic review of the literature published between 2006 and 2014 that analyzed the various roles and tasks of family caregivers of patients in palliative care revealed that family caregivers are the "greatest support of patients in end-of-life care, especially when they wish to be cared for at home" and that they can be considered the "core structure for the continuity of care of these patients."[6] However, caregivers face a demanding and challenging role. The emotional and physical burdens that caregivers face in palliative care are a well-documented

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phenomenon.[7,8] Fatigue, stress, and burnout are also the issues that confront the persons tasked with caring for an ailing relative or friend.[9] Caregivers report higher rates of depression, lower overall life satisfaction, and poorer physical health than age- or gender-based population norms and noncaregiving control groups.[10,11] A direct relationship between burnout and depression among caregivers has also been reported.[8]

As the caregiver is such a critical aspect of delivering a top-quality service, it becomes important to gain a fuller understanding of the caregiver's role. This study, conducted in conjunction with the Tata Institute of Social Sciences (TISS), sought to identify and comprehend the challenges that caregivers face in a home-based palliative care setting and the mechanisms that facilitate coping by caregivers during the active caregiving phase, understand the caregivers' perceptions about the factors that would help them in caring for their patient as well as for themselves, and design interventions for future caregivers and recipients of PALCARE's service, based on their suggestions.

METHODS

This research study employed a qualitative approach to understand the experiences of individuals who had performed the role of primary caregiver to a now-deceased patient and had received support from PALCARE's home-based palliative care service in the city of Mumbai. For study purposes, a primary caregiver was defined as a person who, from among all the patient's relatives/carers, had spent the most time with the patient on a daily basis, had been responsible for taking care of a majority of the patient's physical and emotional needs, and had ensured that instructions provided by the home-based palliative care team were adhered to. A home-based palliative care service delivers care at home and offers multidisciplinary care with an integrated team that include physicians, nurses, social workers, and counselors who visit patients in their homes and offer tailored treatment plans focused on managing symptoms and improving the quality of life, so that the patient may live in dignity. Ethical clearance for this study was obtained from the TISSs Institutional Review Board.

Focus group discussion (FGD) was the primary method of data collection, which was used to explore the meaning held by several individuals on their caregiving experiences and the support received and support required. The FGD involves a "gathering of a group of people who are asked about their attitudes toward a concept, product, or idea." Regarding the process, a "set of open-ended questions" initiates the discussion, and the facilitator can, thereafter, "steer the participants back to the focus group questions or go along with the direction of the discussions, depending on the research questions posed."[12]

FGDs were supplemented by in-depth interviews (IDIs) with select caregivers who either made points that needed further investigation or had been a second-degree relative to the patient (e.g. grandparent, grandchild, aunt/uncle, cousin, in-law, or any other distant relation). In-depth interviewing is a qualitative research technique that "involves conducting intensive individual interviews with a small number of respondents,"[13] with the aim being to gather a more detailed and rich understanding of the topic of interest.[14] Through this method, "the participant's experience, behavior, feelings, and/or attitudes may be probed deeply" allowing the participant "to communicate much more freely and to provide more detailed descriptions."[14]

Potential participants were identified by TISS from PALCARE's database of patients and their caregivers and had to meet all of the following inclusion criteria: (i) at least 18 years of age, (ii) able to provide written informed consent, (iii) able to communicate in English, Marathi, or Hindi, and (iv) had performed the role of caregiver for at least 7 days with PALCARE. A PALCARE staff member then contacted the identified potential participant over the phone, briefed them about the study in a language they could understand and assessed their interest in participation. If they provided verbal consent, they were then invited to the PALCARE office for the FGD or met up with at a venue of their choice for the IDI. The TISS team obtained written informed consent from the participants before conducting the FGD or IDI.

Participants belonged to one of three socioeconomic groups: lower, middle, or upper and hailed from three geographical areas: South-Central Mumbai (Colaba to Mahim and Parel, Dadar to Wadala, Sion and Chembur), Western Suburbs (Bandra to Borivali), and Eastern Suburbs (Kurla to Thane, Dombivali, Kalyan). Three FGDs were held at the PALCARE office between September and November 2018, with a PhD scholar from TISS facilitating each. An FGD guide outlining questions for discussion was prepared in English, translated to Hindi and Marathi and then back-translated to English. FGDs were conducted in any of these three languages, based on the choice of the group. One FGD was held for each of the three socioeconomic groups, with six (upper), five (middle), and twelve (lower) participants, respectively. Over the same period, four IDIs were conducted with caregivers by the PhD scholars from TISS, across income groups: one (upper), two (middle), and one (lower) [Table 1].

All FGDs and IDIs were audio-recorded using a SONY audio-recording device (model ICD-UX560F) and transcribed. Data were extracted from the raw transcripts and tabulated into the following main categories: (i) a description of the (deceased) patient they cared for and the last days leading up to his/her death, (ii) choice of home-care service – advantages and disadvantages, (iii) role of home-care service – support received and required, (iv) self-assessment of efficacy in caregiving, (v) respite and coping mechanisms, (vi) bereavement, (vii) impact on the caregiver's life, and (viii) recommendations for future caregivers and PALCARE's service. The research teams from TISS and PALCARE analyzed the data independently. Major themes that arose from the data were identified and then discussed jointly in detail. Some caregivers had made similar statements or expressed the same concerns, and emerging patterns were looked at by the research team.

Table 1: Profile of the participants

Patient	Caregivers relationship to the patient	Date of death	Date of FGD/IDI	Income group	Place of death
1	Son	April 16, 2016	October 21, 2018	LIG	Home
2	Uncle	January 13, 2017	October 21, 2018	LIG	Hospice
3	Son	November 28, 2017	October 21, 2018	LIG	Home
4	Brother	April 12, 2018	October 21, 2018	LIG	Home
5	Father	April 15, 2018	October 21, 2018	LIG	Hospice
6	Sister and brother-in-law	April 20, 2018	October 21, 2018	LIG	Home
7	Husband	April 22, 2018	October 21, 2018	LIG	Home
8	Husband	June 26, 2018	October 21, 2018	LIG	Home
9	Husband	July 7, 2018	October 21, 2018	LIG	Home
10	Wife	July 23, 2018	October 21, 2018	LIG	Home
11	Son	March 20, 2016	September 8, 2018	MIG	Home
12	Son and daughter-in-law	June 9, 2016	September 8, 2018	MIG	Home
13	Daughter	August 25, 2016	September 8, 2018	MIG	Home
14	Cousin	September 12, 2016	November 22, 2018	MIG	Home
15	Husband	August 11, 2017	September 8, 2018	MIG	Home
16	Son	January 18, 2017	September 8, 2018	MIG	Home
17	Nephew	December 5, 2018	November 27, 2018	MIG	Home
18	Daughter-in-Law	May 7, 2016	September 9, 2018	UIG	Home
19	Sister-in-law	August 13, 2016	November 30, 2018	UIG	Home
20	Son	October 20, 2016	September 9, 2018	UIG	Home
21	Son	October 17, 2017	September 9, 2018	UIG	Home
22	Son and Daughter-in-law	December 19, 2017	September 9, 2018	UIG	Home
23	Daughter-in-law	April 1, 2018	September 9, 2018	UIG	Home
24	Wife	June 21, 2018	September 9, 2018	UIG	Home

All patients had been suffering from a type of cancer. MIG: Middle-income group, LIG: Low-income group, FGD: Focus Group Discussion, IDI: In-depth interviews

RESULTS

Inferences were drawn from 3 FGDs and 4 IDIs. At the time of the FGD/IDI, caregivers were bereaved anywhere between 4 and 32 months. Data gathered during the four IDIs either reinforced or supplemented the data gathered during the three FGDs, helping the research team gain a better understanding of what caregivers' needs are. IDIs allowed caregivers to express themselves more freely and in more detail about their experiences.

Referral to home-based palliative care

Caregivers wished that they had been introduced to palliative care earlier on. Apathy and lack of guidance at the treating hospital initially added to grief and confusion. Families strove to provide all medical care for their patients even if it was scarcely affordable.

> *"Whatever it was, the homecare team had told us clearly, but in the hospital, we were only asked to get more money, do this treatment-do that treatment, but they didn't tell us anything about what would happen."*

The treating oncologist/hospital or word-of-mouth (relative/friend) were the most common sources of referral to PALCARE. A declaration of futility of further treatment by the treating doctor was usually accompanied by sharing PALCARE's phone number, with a word of advice to contact them. Most families and patients were unaware about the patient's prognosis, leaving it to the palliative care team to break the bad news. Conversely, families were more reconciled to the situation and comfortable with palliative care, if advised so by a knowledgeable relative or friend.

> *"They came home and explained everything to us, we got the courage that somebody is there for us. Otherwise (in the hospital) the doctor would say 'no, take her home, there is nothing more that we can do.'"*

Interface with home-based palliative care team

Caregivers were unanimously satisfied with PALCARE's services and mostly seemed comfortable with providing patient care at home. For many, PALCARE had influenced their understanding about palliation and the quality of caregiving. It had either been the patient's or the caregiver's wish for the patient to not undergo hospital admission.

> *"The best part is that there are no visiting hours. The relatives can drop in anytime and they can spend as much time as they want."*

Caregivers appreciated PALCARE's competent multidisciplinary team and calming presence. The patient and family were kept informed of the pros and cons of all available care alternatives, with no compulsions to follow any particular one.

> *"They always give two suggestions: One is this, one is that. You decide what you want to do."*

Training caregivers on minor procedures such as giving subcutaneous injections, wound dressing, removal of urine bag, and doctors and/or nurses being accessible 24 × 7 for medical advice were considered practical. Being primed for end-of-life and emotional support through counseling were felt helpful. Families were grateful for access to medicines such as morphine, which were not available easily, and ointments, beds, and tubes for free. The tenacity with which the team repeatedly attempted to treat a patient's pressure sores and their willingness to manage fungating wounds without hesitation were lauded. Several caregivers felt reassured during emergencies when staff would text them the name of the medicine to be used and then follow up the same or next day.

> *"How many doctors can you call at 3 in the morning and they will sweetly pick up the call and attend to you?"*

Caregivers felt that not subjecting the patient to painful, unnecessary tests were an important aspect of care. Working holistically, the team provided emotional support and built such rapport that some patients would confide matters that they had not with their family caregiver.

> *"Even if the patient had pain, he would never tell me… but to those two nurses, he used to tell."*

Patient's insight

A certain level of collusion was evident within the families. In most cases, the patient was aware about their cancer diagnosis, and few even actively decided about the course of disease modifying treatment. Most families preferred not to inform their patient about being shifted to palliation for end-of-life care. Caregivers forced themselves to maintain emotional composure in front of their patient.

"I hid it from the patient that he was in the last stage"

"We used to go out and cry. Never in front of her."

Last stages

Some caregivers observed anhedonia in patients during the very last stages. There appeared to be a divide among patient's desires, with very few desperately wanting to be admitted to hospital and others not wanting to be taken to a hospital at all.

> *"In the last days, they lose all desire to do anything… They just lie in bed."*

Caregivers were grateful for PALCARE's constant guidance and reassurance during their patients' final hours, stating that the dying process itself was eased due to the presence of competent staff, in person or over phone.

> *"They prepare you very well for the end."*

Support systems

A few caregivers, particularly second-degree relatives, opted to shift their patient to a hospice for terminal care. All upper-income group (UIG) participants hired attendants to look after their patients, as opposed to only one middle-income group (MIG) family and no lower income group (LIG) families. In joint families (MIG), members took turns in caring for the patient, thereby reducing the caregiver burden on one individual. In the LIG, caregivers had to adjust their day jobs around their patient care routine. Most caregivers did not perceive the need for self-care, as they felt that the active phase of caregiving lasted only a short duration. Attending musical concerts (UIG), going on an outstation tour (MIG), and praying (LIG) were the exceptions. When decision-making lay mostly upon one individual, one caregiver felt depressed and resorted to exercising and taking Omega-3 supplements. Societal pressure to admit the patient in the hospital and be seen as "doing more" was strong in the UIG and MIG.

"We have social pressure too. Everybody asking 'why are you doing this, why are you keeping them at home, why haven't they been kept in hospital?'"

Bereavement

A sense of emptiness in the house pervaded through families for days following the death of a relative while some caregivers experienced a sense of relief. One caregiver stated that the caregiving experience had made him a better person. Caregivers shared that it was important not to be left by oneself and slip into depression during the immediate months following the patient's death and were grateful for the bereavement visits made by the counselor/full home-care team, calls on the patient's death anniversary, and memorial token (*diya*) sent on "Remembrance Day."

"We did not realize how time flew from one doctor to another. So now that there is suddenly no doctor to visit, you wonder what to do at home all day."

"It was not so much trouble after the patient was gone, as much as while the patient was alive."

DISCUSSIONS AND CONCLUSIONS

Based on the responses received, it is evident that a well-designed caregiver program should be made part of any home-based palliative care service. The following few domains would need to be addressed in such a program:

1. Awareness and comprehension: Often, caregivers and patients are unexpectedly informed by their treating physicians to discontinue curative treatments, and those physicians who are aware of the benefits of palliation may, thereafter, refer the patient to palliative care service for "further care." In such cases, either at the point of entry into the service, but normally a few visits later, after the palliative team has built a rapport with the patient and family, breaking bad news about the terminal nature of the illness becomes the responsibility of the palliative care team. Explaining the illness and its prognosis, as also the futility of further curative treatments and the scope of palliative care, needs to be conducted sensitively, in lay language, to patients and caregivers. Caregivers must be provided all relevant information by the palliative care team, so that they may make informed choices and be able to competently assist the team in ensuring that the patient is physically and emotionally cared for and can die in dignity
2. Collusion: Often, caregivers wish to shield their patients from hearing bad news about the terminal nature of their

illness and imminent death and collude with health-care professionals to hide these truths. However, this takes away the patient's right to autonomy. Caregivers need to be prepared by the palliative care team to allow the patient to state his/her treatment preferences, perform any last wishes, reconcile with persons if needed, and prepare their legal/financial arrangements, particularly before he/she becomes incapacitated. Moreover, patients who are aware of their prognosis are often able to reach a state of acceptance, and therefore comfort, quicker

3. Training in skills: For caregivers who opt to care for their patients at home, it is important that they are well informed of the nature of the condition, possible side effects that may occur, and how to handle these. Training on essential skills such as wound care, administering subcutaneous injections, changing urine bags, and cleaning stoma bags is desirable. As the caregiver is likely to be preoccupied providing active care to the patient, these skills need to be demonstrated at home as often as possible, and ideally by the caregiver carrying out the procedure under observation of the palliative care team. Creating a series of procedural steps with pictures may be explored that can be provided as handouts
4. Preparation for the patient's death: Caregivers are most anxious about what to expect while the patient is at end-of-life (as they may not have witnessed any home deaths before) and are fearful that the patient may suffer extreme pain or distress while dying, which can cause them to panic and rush the patient to a hospital/intensive care unit. Providing adequate information about what to expect during the dying process and simple procedures that they can perform at home to keep the patient as comfortable as possible will help assuage these fears. Leaving behind a box with the medicines that may be required at the end stage, and corresponding instructions for usage may help provide a sense of confidence to the family. A brief guidebook may come in handy at moments of panic. Information about the procedure for obtaining a death certificate must be given in advance, and contacts of funeral services may be provided
5. Self-care: Caregivers are likely to ignore their own physical, mental, emotional, and social trauma while they are engrossed in caring for a loved one. The palliative care team must emphasize the need for caregivers to take adequate time out to destress, without feeling guilty, explaining that this is essential for them to be more attentive at crucial times and hence be able to provide better patient care
6. Bereavement: One or more bereavement visits should be made to the home of the caregiver, by the counselor/team, within a reasonable time after the death of the patient, depending on the family's convenience. This can be supplemented by regular group bereavement meetings where caregivers can come together to share their experiences and memories. This platform can be used to ascertain potential volunteers for home visits, advocacy and testimonials, fundraising, data-entry/back-office, and other activities.

Besides the caregiver program, the following are further suggestions from the study participants that PALCARE may consider to improve its services: form a panel of general physicians to provide death certificates to patients residing within a given radius and keeping these doctors informed about the patients directly, rather than via the patient's relatives; making more frequent visits/phone-calls to homes of those imminently dying; initiating or providing links to services for dependents (elderly or children) who may require legal, financial or social services after the demise of the patient, keeping contact lists of trained nurses/attendants bureaus and funeral services handy, and liaising with treating oncologists and hospitals for earlier referrals.

A follow-up study to understand caregivers' experiences may be carried out after a caregiver program is initiated, particularly to study its impact on addressing collusion, self-care practices, and confidence in patient care.

Limitations

1. Potential participants for the study were contacted from PALCARE's patient database for the period December 2015 to August 2018. It was observed that a significant number of caregivers, mostly from earlier periods and particularly from the LIG, had moved on physically and emotionally and were either untraceable or not interested in recalling a painful past
2. This time factor might introduce some recall bias into the responses given by the caregivers, as the duration of being bereaved varied
3. Those who agreed to participate in the study mostly did so out of a sense of gratitude to PALCARE, which may also affect the responses given
4. As the objective was to understand caregivers' experiences in depth, the number of participants was small, thereby affecting the generalizability of the study.

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Conflicts of interest

There are no conflicts of interest.

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