The experience of family members caring for a dying loved one

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Abstract

Qualitative nursing research into the experience of family members caring for a dying loved one has been limited. This study used a phenomenological approach to explore this experience. The pattern of caring for a dying loved one and its intertwined dimensions were described. Caregivers felt a sense of helplessness that was associated with illness progression, their inability to relieve pain and discomfort, and decision-making related to patient admission to a palliative care unit. Lack of support from health professionals and having to face personal limits were found to accelerate the decision to admit a patient. The role of a support person involved with the caregiver was also considered and found to be an area worthy of further investigation. Health professionals must provide information and support tailored to the caregivers' needs as they change along a patient's illness trajectory.

Of all human experiences, death imposes the most painful and far-reaching adjustment for families (Walsh and McGoldrick, 1998). The demand for palliative care in Canada and elsewhere continues to rise as the population ages, life expectancies increase and illness trajectories lengthen. In response to this, home-based palliative care has grown. However, better appreciation of the complex nature of caregiving at home is needed (Jones et al, 1993). This qualitative study sought to explore the experience of caring for a dying loved one. Understanding the challenges and hardships associated with caregiving, and acknowledging the support provided by family or friends in the context of palliative care may have implications for how caregivers sustain the role.

Literature review summary

Laizner et al (1993) defined a caregiver as an individual responsible for the majority of caregiving tasks, including emotional support and supervision of the family member with cancer. In a study exploring family caregivers of people with a life-threatening illness, Scott et al (2001) identified the following challenges: stress experienced by caregivers; lack of control; lack of acknowledgement of role expertise; physical demands and information deficits.

Grande et al (1997) suggested that caregivers' support needs should be assessed independently of patients', as their perception of need may be different from the patient. Payne et al (1999) drew attention to the lack of literature addressing caregiving across different illness trajectories and on the levels of support needed to reduce caregiver stress.

According to Hinton (1994), the ability of the informal network to maintain the individual at home is dependent on the material, social and professional support available to the caregiver. The accessibility of services and timing of their introduction are therefore essential to ensure adequate support in the home setting (Grande et al, 1997).

Although the term support person is often used as a synonym for caregiver, the role may actually be different. A support person can be considered as someone who supports and guides the caregiver. The support person is part of the informal network, e.g. a family member or a close friend. In a study examining a group of spousal caregivers caring for persons with cognitive impairment, Campbell and Travis (1999) found that adult children were the most frequent informal support person available to provide respite for the spousal caregiver when day service centres were closed.

The literature describes the caregiving experience in terms of its impact on physical and emotional health problems, support and informational needs of caregivers, and the exhaustion felt by family members caring for a dying loved one. Researchers have demonstrated the negative impacts on the caregivers' physical and emotional health. However, there may be positive aspects to this experience, which need to be explored. The questions of how caregivers seek support, and from whom, also need to be better understood. The authors' review of the literature revealed a lack of research on the role of a designated support person for the caregiver.

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'Purposive sampling was used to recruit family caregivers and their support person.'

Social support has been identified as an important factor to help the caregiver and Hunt (2003) has described the need for research on supporting family caregivers to improve quality of care and quality of life for both patients and family caregivers. Schoenfelder et al (2000) stated that it could be hard for health professionals to tell if caregivers have the support they need to solve problems, to identify their abilities, resources and care options, and to prevent any negative effects on caregivers' health. Wilson and Daley (1999) stated that further research must include interviews with family members during the dying process and shortly after death. In order to capture the entire spectrum of caregiving for a dying loved one, the authors used a phenomenological approach to explore caregivers' experience.

Aim

This research aimed to reveal the experience of caregivers of a dying loved one at home and how they were sustained in that role, before admission of the patient to a palliative care unit. The focus of the study was therefore twofold:

1. To describe the experience of family members caring for a dying loved one at home
2. To understand the role of a support person in facilitating family caregiving.

Method

Design

A Heideggerian phenomenological approach was used to explore the lived experience of family members caring for a dying loved one. The purpose of a phenomenological interview is not to explain, predict or generate theory, but to understand shared meanings by drawing from the respondent a vivid picture of the lived experience, complete with the richness of detail and context that shape the experience (Sorrell and Redmond, 1995).

Research participants

Purposive sampling was used to recruit family caregivers and their support person. Phenomenological studies commonly use purposive sampling to select individuals based on their particular knowledge of a phenomenon (Streubert and Carpenter, 1995). The researcher recruited participants who were eager to share their experience of either caring for a dying loved one at home, or supporting the caregiver.

However, it should be noted that, at the time of the interviews, patients had been admitted to a palliative care unit in Ottawa in Eastern Ontario, Canada. It was on this unit that family members were initially approached to participate in this study.

The first step in the recruitment process was obtaining verbal permission from the patient to interview family members, as required by the ethics committee of the institution where the palliative care unit was located. The patients were asked to identify who provided care for them while they were living at home. In all cases, it was a family member who was identified by the patients. Family caregivers were then approached to participate in the study. The caregivers were asked to identify the most significant support person during the initial interview. Subsequently, the researcher contacted the support person. All support persons were also family members. Caregivers and support people eligible for this study were: adults (18 years or older); either the family caregiver (as confirmed by the dying patient) or the support person of the family caregiver (as identified by the family caregiver); emotionally capable of participating in an interview (based on the opinion of palliative care clinicians); and able to participate in an interview in either French or English.

Setting

Caregivers and their support persons were interviewed at the palliative care unit where the patient was admitted. At the time of the study the regional palliative care unit in Ottawa was divided into acute and chronic sections. Average length of stay in the acute section was 2 weeks versus 6–9 months in the chronic area. The caregivers had admitted loved ones to both these areas for end-of-life care. Both divisions of the palliative care unit had private family rooms where family members could rest quietly. All but one follow-up interview was conducted in the participant's home.

Data collection

Written consent was obtained from participants before each interview and participants were informed that they could withdraw from the study at any time. Two patients preferred not to give the researcher permission to talk to their families and one caregiver declined the invitation to participate, stating that she would not have a lot to say since everything had gone well at home.

Open-ended questions were used to explore the experience of family members caring for a dying loved one and the experience of supporting a caregiver (*Table 1*). All ten initial interviews were conducted in a family room on the palliative care unit. The average interview length was 64.5 minutes (range 45–95 minutes). This location provided participants with the opportunity to return to the loved one's room if there was a change in their condition. Interviews were conducted with seven different families. The researcher briefly followed up participants in person 24 hours after the initial interview to ensure they were not experiencing any unpleasant effects from the interview process. None of the participants had negative feedback regarding the research interview; conversely some expressed the cathartic effect of their participation.

Adhering to the phenomenological approach, eight out of the ten participants underwent a confirmation interview, which took place 8–12 months after the death of their loved one. It would have unduly burdened participants to conduct the second interview early on in the bereavement process. This interview allowed the participants to confirm that the research findings reflected their experience of caring for a dying loved one or supporting the caregiver. Initially, the researcher asked the participants to share how their life had been since the first interview. Then, the participants were invited to comment on the findings shown on a PowerPoint presentation. The average length of the confirmation interviews was 76.8 minutes. Some participants told the researcher that they had been looking forward to meeting again in order to finish the research process. The confirmation interview was one way of putting closure to their caregiving experience. Following the interview, participants felt they could start another chapter in their life.

Data analysis

Each tape-recorded interview was transcribed verbatim. The transcription of the entire narrative was checked by listening again to the taped interview (Giorgi, 1975; Colaizzi, 1978). The data were read and reread several times. A circular form of hermeneutic analysis was used whereby the researcher moved back and forth between an examination of the text of the transcripts as a whole, and then a piece by piece examination (Leonard, 1994).

A colour code system was used to highlight significant statements. Extraction of every expression directly associated with the experience of caring for a dying loved one was completed for each transcript (Colaizzi, 1978). Significant statements were grouped to form a category. Then, redundant categories were reduced to form the themes (Giorgi, 1975). Saturation of themes was reached when no more new categories emerged from the analysis.

Ensuring rigour

The researcher applied the four criteria of rigour in qualitative studies as described by Guba and Lincoln (1981): credibility, fittingness, auditability and confirmability To ensure the credibility of the analysis, the researcher documented her personal impressions of the interview process in a

Table 1. Interview questions

Interview questions for the caregiver	Interview questions for the support person
Tell me what it's been like for you since your loved one became sick?	Tell me about how you helped the caregiver of your loved one?
Can you describe a difficult period you have lived through while you have taken care of your loved one?	What does it mean for you to be the support person of the caregiver?
What does it mean for you to be the caregiver of your family member?	Can you describe a difficult period you have lived through while you were supporting the caregiver?
How do you think your other family members would describe what it has been like for you?	Can you explain to me what has helped you through this experience and kept you going?
Can you explain to me what supported you through this experience and kept you going?	Are there other aspects of your experience that you would like to share with me?
Are there other aspects of your experience that you would like to share with me?	

diary to facilitate the differentiation between the observations of the researcher and the data emerging from the participant's narrative. In addition, participants were consulted in a second interview to obtain their acknowledgement of the conclusions from the analysis of the first interviews (Oiler, 1982). All participants recognized their own experience in the analysis of the findings. An expert in qualitative research also verified the themes from the analysis.

Fittingness of the data was evident since participants repeated the same stories at both interviews. Furthermore, field notes were documented immediately after the interview in order to capture non-verbal communication, episodes of silence and the environmental context of the interview. Guba and Lincoln (1981) suggest that auditability should be the criterion relating to the consistency of qualitative findings. In this study, every decision related to the research process was documented in a succinct manner so that another researcher could follow the decision trail. Finally, selecting and integrating participants' quotes to describe the findings ensured the confirmability criterion, which confirms the neutrality of the results (Guba and Lincoln, 1981).

Findings

The sample consisted of ten family members of whom six were caregivers and four were the main support person identified by the caregiver. The relationships and the ages of the participants are shown in *Table 2*. Lack of availability and absence of a support person were the main reasons why the researcher was only able to interview two members of the same family on three occasions. The participants varied in age, gender and role so that the results might be more widely applicable to other contexts.

Table 2. Participant characteristics

Family	Dying loved one	Caregiver (age in years)	Support person (age in years)
1	Woman	Husband (63)	Daughter (30)
2	Woman	Husband (67)	
3	Woman	Sister (68)	Daughter (47)
4	Man	Wife (74)	
5	Man	Wife (74)	Son (53)
6	Man	Wife (72)	
7	Woman		Sister (39)
Mean age (in years)		**69.6**	**42.2**

All participants began the interview by describing, from the beginning, their caregiving journey or their supporting role. Some of the themes that arose also reflected their perspective on the end of life, as they were interviewed after the patient had been admitted to a palliative care unit. The pattern of caring for a dying loved one and its intertwined dimensions are shown in *Figure 1*.

Four main themes emerged from the analysis, which described what it was like for a family member to care for a dying loved one at home. Theses themes were associated with the illness trajectory from the diagnosis to the end of life. These were identified as:

- Phase 1. Making a commitment
- Phase 2. Caring and supporting
- Phase 3. Dealing with helplessness
- Phase 4. Balancing it out: the decision to admit.

In addition, four interconnected dimensions were identified that could be visualized as a four-blade propeller moving the caregiver or support person from one phase to the other. These four dimensions were essential to support, guide and nurture family members caring for their dying loved one. Participants described them as social support, giving all you have, impact on the family and sitting on the sidelines.

The dimension of social support is composed of the elements of practical help, information and emotional support. Giving all you have illustrates the physical demands associated with caring for a dying loved one. Impact on the family describes the emotional and financial cost. Finally, sitting on the sidelines represents a role transition for the family member, from being the caregiver to once again being the spouse or child, as care was now provided by health-care professionals. This dimension involves a reflection, for example on spiritual beliefs, as the family members are somehow getting ready for the death of their loved one. The position of the dimensions on the propeller can be changed as, for example, a family caregiver may need to draw on their spiritual beliefs to help them go on with their caregiving journey.

Phase 1: making a commitment

Participants described what it entailed to be the caregiver of a dying loved one. For

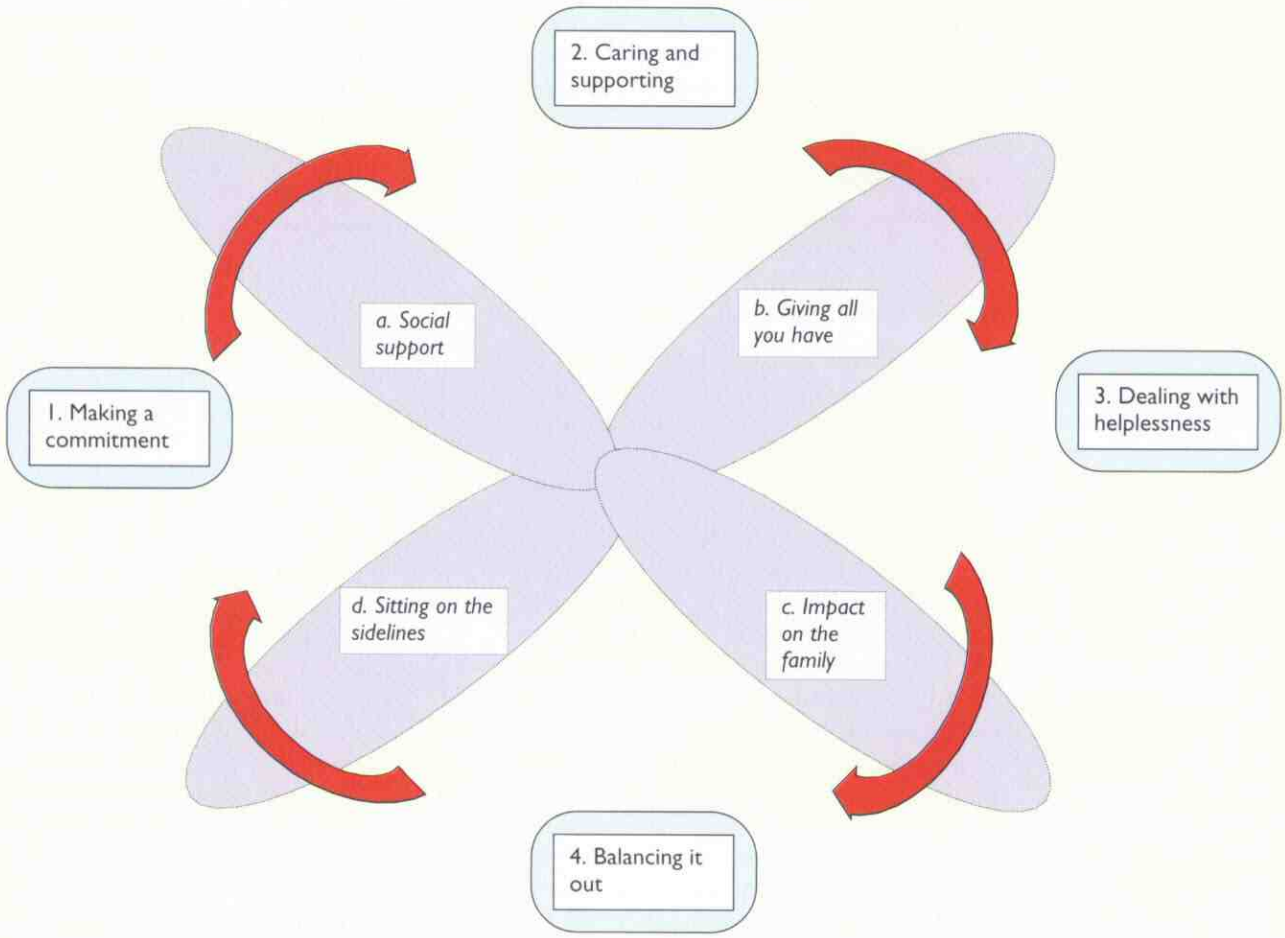

Figure 1. Pattern of caring for a dying loved one and its intertwined dimensions.

the majority, it came naturally and was driven by a sense of duty and responsibility.

> **'I'll be here for her till the very end.'**
> (*Caregiver*)

Family caregivers and their support persons identified the motivators that helped them to fulfil the caregiving demands: love; being there; providing help and support; and getting closer to the dying loved one. They felt a sense of accomplishment and satisfaction through helping family members and a sense of relief for having done everything they could.

Social support

Family and friends: Participants said that the best support that family or friends could provide was practical help, such as cooking a meal or doing the housekeeping. They also appreciated the opportunity to talk about their caregiving experience. One caregiver was greatly helped before the death of her husband by her widowed friends who were able to provide tangible support in relation to financial and legal issues.

> **'... other people when they know my kids are coming for the weekend and I'm exhausted, they simply bring around a huge stew... just knock on the door and say here!'**
> (*Caregiver*)

Support from health-care professionals: Five participants stated they received insufficient support from health-care professionals. For example, they felt they could have been provided with more assistance in terms of pain management. They also shared their disappointment regarding the lack of follow-up in the community after a visit to the emergency department. Although most of the participants affirmed that the emergency department remained the best way to access palliative care services when facing a crisis, such as pain, they identified that navigating the health-care system was difficult and time-consuming and they found miscommunication among professionals frustrating.

The majority of the family members had been caring for their loved one at home for many months before admission to the pal-

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liative care unit. In terms of the delivery of community nursing care, participants were satisfied with the services provided when the nurse was present, but the sporadic nature of the visits did not lighten the caregiving load. In addition, participants mentioned that there was a long waiting period for nursing services at night and in rural regions. Finally, participants mentioned that home care was provided only when their loved one had a very poor prognosis.

> **'Sometimes, I called them [the nursing agency] and said hurry up! but we had to wait... I felt uncomfortable... I saw him suffer and I could not do anything.'**
> (*Caregiver*)

Some families had access to community services only 2 weeks before the admission of their loved one to the palliative care unit. One support person had to advocate for the caregiver in order for them to access community nursing services in a timely manner. Some family members were under the impression that their loved one received good community nursing service while they were still receiving chemotherapy, but changing from the oncology to the palliative care programme entailed some delay in accessing palliative care services. Caregivers were mainly satisfied with support from their family physician but remarked that some were uncomfortable with pain management issues. Difficulties contacting specialists for advice increased when entering the palliative phase of the illness. Only a few participants had access to a specialist palliative care physician at home and usually only during the last week of living at home.

Phase 2: caring and supporting

In this study, caregivers' roles were mainly centred on physical tasks, such as mobilization, personal care, comfort and preventive measures, dealing with confusion, giving medications, maintaining activities of daily living, housekeeping, and transport to medical appointments. On the other hand, the support person took on a role with psychological and social tones that encompassed providing relief from care, listening, respecting silence, being present, sharing, being available for trouble shooting, advocating and caring for the caregivers. Some participants said that they would not have been able to continue as the caregiver without the contribution of the support person. This person was instrumental in providing the caregiver with respite away from responsibilities. For example, the presence of the support person allowed the caregivers to do some laundry or walk the dog or simply take some time for themselves.

> **'... taking over... which would help him cope with what will happen... for me it was important to support my father. I believe it lighten the burden a little bit... to know that you have someone that you can rely on if something happens...'**
> (*Support person*)

One support person described his role as organizing leisure activities for the dying loved one, creating joyful time or offering opportunity to review past life experiences that were pleasant for the ill family member:

> **'We went on a car journey visiting where he was coming from and saw his old friends.'**
> (*Support person*)

Another support person shared that the dying person had chosen her particularly because she was the only one who was willing to sit in a room with her and say nothing and allow her to choose to speak or not to speak. However, in some families, caregivers were disappointed in the lack of commitment and support provided by their peers or children.

> **'... not having anybody close by that could give you a hand...'**
> (*Caregiver*)

Giving all you have

During the phases of diagnosis and initial treatment, family members tried to survive their anxiety. As the illness progressed, the caregivers' responsibilities increased, leaving less time and opportunity for them to talk about their worries to their loved one. Participants also described that they would not share emotions in order to not burden the patient. Caregivers were sometimes left with many uncertainties in relation to the progression of the illness and their capacity to sustain the caregiving demands. This experience was described in terms of psychological fatigue.

> **'... I never had a dying husband before... I wasn't quite sure what to expect... I'm wondering if you can deal with it or how long you should deal with it on your own... it's mentally tiring.'**
> (*Caregiver*)

'Some would have continued caring at home a little longer if more professional help and support from family had been available.'

As one participant stated, giving all you have is providing care with heart during the longest period possible. However, caring for a dying loved one means also being confronted with one's own physical limit:

> **'I gave all I could honestly... at the end I could not take it any more... my strength failed me... '**
> (*Caregiver*)

Phase 3: dealing with helplessness

When participants were asked to describe a difficult moment as they were taking care of their loved one, none explicitly voiced their own suffering but rather described the impact of caregiving in terms of helplessness, which included witnessing deterioration, feeling isolated and waiting for the inevitable. Four participants expressed their sense of helplessness while taking care of their dying loved one and three participants shared that witnessing their loved one deteriorate was most poignant:

> **'... when he was at home and was in excruciating pain... I did not like to see that... it's tough to watch your father suffer like that... '**
> (*Support person*)

> **'... what can we possibly do to keep her from getting sick and she's losing her appetite over it... I realize now that a lot of it was because the cancer was going on... '**
> (*Caregiver*)

Some caregivers felt they were letting down their loved one with the possibility of admission to an institution even though the burden of care was taxing their own health. Some would have continued caring at home a little longer if more professional help and support from family had been available. For example, one participant was caring for her husband at home with minimal support and had a medical condition herself:

> **'I could probably have gone on further with more help... I would go to sleep on the dialysis machine... '**
> (*Caregiver*)

Impact on the family

Caring and supporting a dying loved one had an emotional cost attached to it. Participants shared that taking care of a dying loved one entailed a great deal of waiting. For example, family caregivers waited in the emergency room to have an elderly father assessed for a blocked catheter, or waited for an appointment with the specialist who would eventually explain that the end was near. Another difficult aspect for family members was waiting for the inevitable – the actual death of a loved one:

> **'I wished my sister to die to put an end to this process... '**
> (*Support person*)

Participants worried about how they would handle the actual death of their loved one at home or in an institution. In addition, limited social activities and the constant need to watch the dying loved one caused some participants to feel isolated. Many participants mentioned that their social network tended to diminish as their loved one's illness progressed to the palliative phase. Aware of the fact that their loved one was slowly withdrawing, caregivers limited friends and family visits when they would cause more burden than enjoyment.

Finally, another important issue raised by some support persons was the direct impact on their own family of being extremely involved in the care of their dying loved one. Some mentioned that they had to change their employment status or change planned holidays with family to become more available to their dying loved one. Another one felt that her own children went through a difficult period because of the time she spent at her loved one bedside:

> **'... my children have, I don't want to use the word suffered, it's the first one that came to my mind but, my children had to manage without me... it doesn't come without consequences.'**
> (*Support person*)

Phase 4: balancing it out: the decision to admit

For the majority of family members caring for their loved one at home, the understanding that their relative had reached the 'point of no return' was a major determinant in the decision to admit to the palliative care unit. The decision to admit was the defining moment in the caregiving journey. The final decision was the patients', but implied participation of both caregivers and health professionals. In one case, a husband mentioned in the interview that the decision to admit his wife to a palliative

'Participants used different beliefs to help them cope with the impending loss of their loved one.'

care unit was made by the physician during her clinic visit. Patients wanted to be admitted to a palliative care unit because they knew that their illness was progressing and that nothing else could be done to stop it. They were worried about the caregiving load of family members. Dying loved ones provided a multitude of insights to the caregivers on how they envisioned that the end was near. For example, participants shared that their loved ones felt they were dying, that they were losing hope and spirit, that they were experiencing pain and finally recognized that their bodies were 'taking a turn'. For caregivers, making this decision was difficult.

> **'Tough decision to come here... it's a place to die... his final home.'**
> (*Caregiver*)

> **'... balancing it out... pros and cons... it's hard to know when somebody is going to be better off in an institution.'**
> (*Caregiver*)

Sitting on the sidelines

Admission to the palliative care unit reduced the caregivers' worries in relation to the physical care they were providing. Family members obtained some respite and some noticed major improvement in their sleep habits. On the other hand, caregivers found it emotionally difficult to be on the palliative care unit where they witnessed the sorrow of other family members. Some felt isolated or described a lack of privacy. For others, parking expenses were a real issue. The admission of the dying loved one created a major shift in the role played by family members from being the caregiver to becoming the spouse or child again.

> **'Assisting around the edges like I was a visitor... of course it [role] changes I'm not the primary caregiver... I can concentrate on him when I'm here as I'm not as tired... and I've been getting done a lot of things at home... '**
> (*Caregiver*)

Participants shared how the admission impacted on their dying loved one in a positive way as they were, for example, surrounded by experienced professionals and specialized equipment that helped achieve prompt pain and symptom management. The imminence of the approaching death became clearer once the loved one was admitted to the palliative care unit where upon he or she moved into detachment and preparation for death. In addition, family members described how physicians shared information about poor prognosis and palliative treatments or prescribed additional medication to manage pain and symptoms. Family members interpreted these activities as a significant signal of the deterioration in the medical condition of their loved one. The realization that the loved one was going to die came gradually and over time.

> **'The total realization does not just hit you once and it doesn't hit you at all levels.'**
> (*Caregiver*)

Participants used different beliefs to help them cope with the impending loss of their loved one. Some reflected back on their loved one's life and recognized that the future would be different without them. Many wondered how they would adjust to living without their spouse, parent or sibling. Others mentioned that the deterioration of their family members' condition provided them with factual information to accept that dying would put an end to their difficulties.

> **'Watching my sister prepare her husband and children for her to leave... seeing where she is now... allowed me to accept that she needs to pass on... it's not a morbid thing... I have feeling of peace cause she will be at rest.'**
> (*Support person*)

Participants also mentioned that their spiritual beliefs and faith helped them to go on with their caregiver role and to come to terms with the future loss of their loved one. Others shared their belief that death was a human condition.

> **'I think that God gave me the strength to be able to do what I did... '**
> (*Caregiver*)

Discussion and recommendations

Family members' commitment to care for a dying loved one at home was initiated at the time of diagnosis. As the illness progressed into the palliative phase, caregivers had accumulated many sleepless nights, faced many challenges, and coped because of the support of family and friends and the sometimes-limited help from healthcare professionals. One family caregiver summarized her caregiving experience as having four dimensions: a physical side,

'One striking feature of the interviews was how family members did not focus on their own difficulties.'

which was the actual personal care provided to her loved one; a social side, which dealt with the support she had from her family and friends; and a financial side, which could be described as all the decisions around putting legal affairs in order. One additional dimension involved the spiritual aspect, which helped her ground her experience as part of being human.

One striking feature of the interviews was how family members did not focus on their own difficulties. They managed to put aside the distress they felt so it would not influence their loved one. However, participants shared stories of helplessness and isolation. Helplessness was represented in relation to particular events, such as facing illness progression, realizing their personal inability to relieve their loved one's pain and discomfort, and participating in the decision-making regarding admission to a palliative care unit.

The literature provides a comprehensive description of the multidimensional burden carried by the family caregivers of a dying loved one. Physical burden has been described in terms of fatigue, physical exhaustion (Yang and Kirschling, 1992), sleeplessness (Carter, 2002) and deterioration of health (Davies et al, 1996). Social burden encompasses limited time for self (Steele and Fitch, 1996), social stress related to isolation (Scott et al, 2001) that escalates as the physical aspect of caregiving increases (Weitzner and McMillan, 1999). Enyert and Burman (1999) mentioned that providing care is a multifaceted journey in which caregivers identified meaningfulness in their experience of caregiving but also had to learn how to provide routine and complex caregiving tasks, live through grief and loss and face financial burdens and multiple tragedies. Indeed, Kristjanson et al (1996) suggested that family members caring for the terminally ill should be considered pseudo-patients with their own needs.

Service provision

The heightened interest in promoting death at home may be futile if family members have only limited support from health-care professionals. For example, Llewellyn et al (1999) stated that services did not meet all the needs of dying patients and their families. In this current study, some family members would have cared for their loved one at home for a longer period if the caregiving load had not become so burdensome. Others simply respected the patient's choice to be admitted to the palliative care unit. Lack of support and lack of confidence have been found to be determinants contributing to hospital admission and the breakdown of informal caregiving for people with a life-threatening illness (Scott et al, 2001).

Caring for a dying loved one at home implies large responsibilities for the family caregivers. Some participants in this study demonstrated their perceived lack of support from the health-care system. For example, some families mentioned that palliative care services were provided only 2 weeks before patient admission to a palliative care unit. Some participants described difficulty with pain control at home. Others had difficulties in accessing nursing services at night or when living in rural region. This dissatisfaction has been recognized elsewhere (Wilkes, 1984; Blyth, 1990), as has the need to clarify the role of specialist palliative care nurses and improve communication between generalist and specialist physicians (Beaver et al, 1999). Acknowledging that availability and access to service is important, Stajduhar and Davies (1998) specified that care must be provided within a team context so families can benefit from a whole set of services needed to support death at home. In order to promote family involvement in the care of a dying loved one at home and empower caregivers, health professionals must provide information and support tailored to the caregivers' needs.

In developing support strategies, Scott et al (2001) suggested that consideration be given to caregivers' age, length of caring experience and gender. For example, Scott (2001) stated that reducing new caregivers' stress was feasible through the use of early interventions such as informational support and validation of emotional responses to caring. However, longer-term caregivers needed help with cognitive reappraisal of the stressfulness of caring and regular respite and socializing activities (Scott, 2001) and access to resources (Aranda and Pearson, 2001).

Admission

A difficult period in the participants' caregiving experience was the decision-making around the admission of the patient. Participants stated that this decision reinforced their sense of helplessness. However, positive aspects were identified. For example, caregivers said that they were less worried and slept

better after the patient was admitted to the palliative care unit. Participants found this transition to a palliative care unit changed their caregiver role into being simply a husband/wife, child, etc. again. They also mentioned that their loved ones appreciated being surrounded by professionals and benefited from specialized equipment and timely pain and symptom management. In a study measuring quality of life of patients following admission to palliative care units, Cohen et al (2001) found significant improvements in physical well being when pain became less problematic. In addition, patients in their study expressed being less anxious and demonstrated increased existential/spiritual wellbeing.

Social support

This study also revealed some bright sides to the caregiving experience. The presence of the support person and the unconditional guarantee of continued support from other family members and friends allowed the caregiver to sustain the role. The informal support network was extremely important given the lack of support from the formal health-care system. A key to the relationship between the caregiver, support person and others was an understanding and knowledge of the needs of both the caregiver and the patient, so helpful decisions were made about the amount and the timing of support provided. More research is needed into the support person in the process of caregiving so that interventions can be tailored to promote the various activities that this person fulfils.

The findings of this research study provide incentive to promote implementation of family-centred palliative care services, early on in the course of the illness trajectory, which are more supportive and sensitive to the needs and roles of the caregivers. Lohfeld et al (2000) mentioned that a broad-based set of services for both the terminally ill and their families are necessary. If family members become too stressed by the burden of care, the home-care arrangements may simply collapse (Weitzner and McMillan, 1999).

Conclusion

This research study allowed the participants to talk about their experience of caregiving and to identify what had been the most difficult time for them. The findings described a pattern of caring for a dying loved one that was composed of four phases. This process was supported by a four-dimensional propeller that supported the caregiver through this caring journey.

Participants described helplessness as the experience of witnessing their loved one deteriorate or suffer. Helplessness triggered the decision to admit the loved one to a palliative care unit when caregivers were confronted by their physical or emotional limits. Additionally, participants stated that lack of support from health professionals, and sometimes family, accelerated the decision to admit.

Professionals must be aware of the impact of caregiving, particularly when there is no solid social network. Professionals must be proactive in implementing family-centred palliative care services tailored to the changing needs and roles of the caregivers as the illness progresses. Furthermore, the structuring of a formal and informal support system early on in the illness trajectory may ease the caregiving experience, reduce the sense of isolation lived by family members, foster the sharing of caregivers' experiences, facilitate the transition to the palliative care unit and prevent difficult bereavement. In addition, the role of the support person to the caregiver was introduced. Further research is needed to highlight this person's activities and what he or she needs to sustain the role. The caregiver–support person interaction should be looked at in depth, as this might shed more light on interpersonal relationships and how they influence the experience of caring for a dying loved one at home. IJPN

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Key words

- Phenomenology
- Palliative care
- Caregivers
- Helplessness
- Support

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