The Experience of Hope for Informal Caregivers of Palliative Patients

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Abstract / This study explored the experience of hope for informal caregivers of palliative patients. Interviews were conducted with 10 caregivers living with and providing care to a palliative patient. The interview data were analyzed using grounded theory qualitative methods. "Eroding hope" was their main concern—a result of bad days, negative messages, and experiences with the health care system. The participants dealt with eroding hope by "hanging on to hope." Hanging on to hope had four subprocesses: a) doing what you have to do, b) living in the moment, c) staying positive, and d) writing your own story. The support of friends, family, and health care professionals, and spiritually connecting with something bigger and stronger were subprocesses. These findings have application for informal caregivers providing palliative care at home, as a basis for assessment and interventions. Health care professionals need to recognize and value the experience of hope for the informal caregivers of palliative patients.

Résumé / Cette étude a porté sur l’expérience de l’espoir telle que vécue par les soignants naturels de patients en soins palliatifs. On a interviewé 10 proches vivant avec un malade en phase terminale et s’occupant de ses soins. Les données recueillies lors de ces entretiens ont été analysées selon la méthode de la théorie ancrée. La principale préoccupation des soignants était de voir leur espoir érodé par des journées difficiles, par des messages négatifs et par des expériences pénibles avec le système de santé. Pour vaincre cette érosion, les participants ont dit devoir “s’accrocher à l’espoir”. Et comment s’y accroche-t-on? a) En faisant ce qu’il faut faire ; b) en vivant le moment présent ; c) en gardant une attitude positive ; et d) en écrivant sa propre histoire. Le soutien de la famille, des amis et des professionnels de la santé, de même que le recours à la spiritualité sont également d’une grande aide pour maintenir l’espoir. Les résultats de cette recherche ont des applications auprès des soignants naturels et peuvent servir lors de l’évaluation et des interventions. Les professionnels de la santé se doivent de reconnaître la valeur de l’expérience de l’espoir pour les aidants naturels qui s’occupent à domicile de patients en soins palliatifs.

INTRODUCTION

Caregivers describe providing palliative care at home as a challenging, exhausting, and difficult experience (1). They express concern about the patient’s symptom distress (2), the complexities and uncertainties of their role (3), and the significant personal cost involved (4). Hudson (5) found that 40% of palliative caregivers were unable to identify any positive aspects of caregiving. Hope has been identified as a psychosocial resource used by caregivers of palliative patients to deal with a difficult yet significant caregiving experience (6,7). How caregivers use hope as a resource and the processes involved is unknown. The purpose of this study was to explore the processes of hope in a sample of caregivers living with and providing care to a palliative patient.

BACKGROUND

Previous research with caregivers of palliative patients has identified hope as a key element (8–12). Caregivers have identified hope as a strategy that allowed them to continue day to day (8). Family members described “good” days as having hope; a lack of hope was a feature of poor palliative care (9). Hope was always present, whether for a miracle cure or in the preparation for death (10,11). “Hoping” was a type of meaningful “work” requiring energy, focus, positive attitude, and faith (12).

Only three studies have specifically addressed hope in caregivers of palliative patients. All of the studies suggest that hope is an effective and powerful tool for facilitating coping and quality of life (6,7,13). One of the studies was quantitative. Chapman and Pepler (13) found positive correlations between hope and constructive coping in a self-selected sample, of which 33 of 61 family members were caregivers. Only 50% were providing care, so it is unclear if these findings truly represent caregivers.
Two studies were qualitative and described hope as a dynamic inner power that allowed caregivers to move beyond the present and that fostered a positive awareness of themselves (6,7). Herth’s (7) longitudinal study with 25 caregivers concluded that hope was at lower levels at the beginning of the caregiving experience, then rose and remained stable. Borneman et al. (6) studied hope in 51 family caregivers. Hope evolved from faith, connections with God and others, and was reduced by caregiver fatigue and poor symptom management. These studies were descriptive, using content analysis methods, so did not uncover the processes of hope.

The overall purpose of this study was to build on these findings using a grounded theory approach to explore the processes of hope in a sample of caregivers living with and providing care to a palliative patient. The specific aims were: a) to describe the experience of hope in informal caregivers of palliative patients, b) to generate a theoretical analysis of their hope experience, and c) to develop statements about relationships between concepts of the basic social processes of the hope experience. Specific strategies to assist caregivers are more likely to emerge from a grounded theory approach to studying hope (14). Exploring the experience of hope adds to the understanding of how caregivers deal with a complex and stressful situation.

METHOD

The method used was Glaser’s grounded theory (15–17). Caregivers of palliative patients were interviewed in their homes using open-ended questions. Ethical approval for the study was received by an institutional ethics review board and the local health region.

Sample

The participants were informal caregivers, defined as any adult living with and providing care to a terminally ill family member. Purposive and theoretical sampling was used to recruit caregivers from two cities in western Canada. The palliative care coordinator contacted each participant, based on inclusion criteria of: a) English speaking, b) man or woman, 18 years of age or older, c) residing with and providing care to a terminally ill family member, and d) consenting to be a study participant.

Saturation was reached with 10 participants. A second interview was planned, however caregiver issues prevented this with two participants. A total of 18 interviews were completed. The average age of the participants was 55 years, with a range of 29 to 74 years. The length of caregiving reflected a wide range, from six months to six years. Fifty percent of the caregivers were female. Fifty percent of the participants said they had no religious preference, 30% said they were Protestant, 20% Catholic. Sixty percent of the caregivers were spouses of the patient, the rest were sons and daughter-in-laws. Ninety percent of the patients had a cancer diagnosis.

Data Collection

Data collection included obtaining a written informed consent, a demographic form, face-to-face interviews, and the writing of field notes and memos in a journal. Open-ended audiotaped interviews were conducted in the caregivers’ home; one participant chose to meet in another location. In four interviews, the caregiver preferred the patient to be present and this was accommodated. The first interview question was: “Tell me about hope.” All data was collected by the researcher, a palliative home care nurse, not providing care to any of the participants. This encouraged the participants to feel assured their care would not be affected, and that the researcher understood and was comfortable with their situation, while establishing credibility and trust.

Data Analysis

All interviews were transcribed verbatim. Data were managed using NUD*IST 6 software. The data were examined line by line, processes identified and coded, and underlying patterns conceptualized. Coding included: open coding, constant-comparative coding, and theoretical coding. Open coding was completed when the basic social process of hope was identified. Constant-comparative coding was then used to compare incident with category, and category with category or concept. Theoretical coding involved examining relationships between categories or concepts. Relevant literature was selected and integrated throughout to help fill in the missing pieces of the emerging theory.

Credibility, auditability, fittingness, and conformability are the specific criteria used to judge the scientific rigour of qualitative research (18). To establish credibility or the truth of the findings, audiotapes were transcribed verbatim and the participants’ language used to code, categorize, and write theory. Credibility was established by confirming the results of the interviews with participants at a second interview. Auditability was achieved by keeping raw data, field notes, and memos, providing an audit trail of the various steps from the raw data to analysis and interpretation. Grounding theoretical observations in the data, and cross-coding and
categorizing data ensured fittingness. The researcher and her supervisor independently coded selected transcripts throughout the study, and compared the results. Confirmability is ensured when the criteria of credibility, auditability, and fittingness are met (18,19).

FINDINGS

Caregiver’s Definition of Hope

Caregivers defined hope as inner strength. Hope gave them the courage and ability to go through a difficult situation. It was dynamic and a choice. One participant said, “It’s just inside you that you have that feeling...you’re going to keep on trying as long as you can.” Another said, “Hope gives you the courage and your courage gives you hope.”

The focus of the caregiver’s hope was for the patient, for themselves, and for their families. Caregivers hoped for minimal pain and suffering for the patient: “...we’re hoping she gets through this with the least amount of pain and the most dignity she can.” Some hoped for a miracle, not giving up their hope for a cure, or a remission: “I hope she stays healthy,” and “She’s defied so many odds.” Caregivers hoped they would be able to handle whatever the future would bring and to do a “good job” of caregiving without giving up: “Without hope it would be really hard to cope with looking after her. I think that you’d just completely give up.”

Eroding Hope

The main concern for caregivers was “eroding hope,” usually as a result of experiences with the health care system, bad days, and negative messages. Caregivers felt their hope was eroded when they had difficulty communicating with health care professionals, felt depersonalized, or received too many negative messages: “They use these big words...so you get frustrated.” Bad days meant the patients’ symptoms had become out of control. “Seeing the pain” and “knowing what’s ahead” caused the level of hope to flow downward, but all participants agreed there was always some hope remaining. One participant said, “You don’t survive without hope”. Caregivers faced the problem of eroding hope by using the basic social process of “hanging on to hope.”

Hanging on to Hope

Hanging on to hope meant “never giving up on hope.” A participant described the experience as “hanging on to hope, sometimes by a frayed thread.” Hope was seen as necessary to survive: “We all managed to hang on to hope...”

The subprocesses of hanging on to hope were linked together into a theoretical model of the experience of hope. Figure 1 is a diagram of the concepts, the basic social process of “hanging on to hope”, and its subprocesses.

THEORY OF THE PROCESS OF HOPE

The experience of hope was described by the participants as fluctuations and waves of hope: “Hope is never steady at all, it’s always kind of in between...it changes every day, even by the hour sometimes, it’s never steady at all, it’s up and down and around and curves.” A caregiver described the experience: “I call it a wave, up

Figure 1 / THE PROCESS OF HANGING ON TO HOPE IN INFORMAL CAREGIVERS OF PALLIATIVE HOME CARE PATIENTS
and down, up and down. How long can you stay in the valley? You want to stay there and be hopeless, but you can flow back up again, and say okay, building, there’s building."

The subprocesses of hanging on to hope included “doing what you have to do”, “living in the moment”, “staying positive”, and “writing your own story.” The support of family, friends, health care professionals, and “connecting with something bigger and stronger than you” were subprocesses that, together, directly affected movement within the other four subprocesses. The processes were not linear, often occurring simultaneously, circularly, and interchangeably, possibly resembling an upward spiral. For example, the caregivers used different processes depending on the experiences they were going through at the time. The upward spiral denotes a trend upwards within the subprocesses. "Doing what you have to do" was a starting point that allowed caregivers to progress to "living in the moment", "staying positive", and "writing your own story".

Doing What You Have to Do

All of the participants described this subprocess: "We just do what we have to do, and get through it." The ways of doing what you have to do were: "accepting the situation", "not giving up", and "recharging". "You have to accept what happens and then work your way through it." One caregiver said, "Not necessarily liking it, not being in denial, but owning what is and going back to the positive of saying 'Okay, that's the way it is. With the time we have, we're going to do well with it.'"

"Not giving up" was resolute determination to persevere through the experience. "You just never quit, keep putting one foot in front of the other, one way or another, things will work out." "Recharging" was needed to get through and not give up. One participant said, "I always kind of recharge my batteries at night, pray and read something." Another said, "It takes that sitting down...charging my batteries...helping me with the idea that I could muster up the hope I needed." Ways of recharging included getting outside, going for a walk, going to work, going away for the weekend, having respite, or just taking quiet moments of prayer, reading, or resting.

Living in the Moment

Caregivers refocused their thoughts and actions on "the very present", based on an uncertain future. "You change your focus from far ahead to right now." Looking too far ahead was described as "dangerous." Another said, "You don't look up, you don't hang a picture up of where you're going to be, you just have to deal with what you have to deal with that day." Living day to day was a strategy described by all of the participants, as looking too far ahead made caregiving seem too overwhelming.

Staying Positive

One participant said, "You look for something positive, and you carry on with that. Anything that isn't negative, any positive contribution is what is helping." Caregivers realized that hope allowed them to stay positive. "Without hope, you can't do all the good stuff" and "We're not grieving till we have to, not wasting time, the good time." The ways of staying positive were looking for the good things, putting away the negatives, and appreciating the situation. One caregiver's approach was: "I don't think 'Why me?' or 'Why us?' There are no answers, so I don't waste my time." Another said, "I don't want to wallow in it." Caregivers chose to "appreciate life."

Writing Your Own Story

This subprocess involved staying in control in difficult circumstances and making decisions about the future. Caregivers and patients worked together to find a way to handle their situation. "He's writing his own story, with a different ending than the one they have for him."

A caregiver described maintaining a locus of control: "Is part of being hopeful, I think, that you feel you're not prey to whatever comes along...if you feel that you have some modicum of control over how to deal with it." Another caregiver said, "We talk about them [the medical system] and then say, 'To hell with them, let's go on.'" "We all know that everyone's situation is different and no one can predict the future." Caregivers appreciated it when health care professionals allowed families to explore options and ideas, choosing to "work with you", rather than saying, "There's nothing we can do for you, go and make your wills."

Supporting and Connecting

The basic social process of hanging on to hope depended on both supporting relationships and spiritually connecting with "something bigger and stronger than you." All participants identified having support as extremely important. One participant said, "Lots of support from everywhere, it helps a lot, it actually is huge, otherwise I'd have gone crazy." "Having family in it together with you" was a source of security through difficult times and a hope for the future. "We're all on the same verse...they're in the
same mind with me. I always think, you're safe as long as you have family."

Support from caring, positive professionals was a source of hope. "Talking to the palliative team, once we got on track with them, then you know what you're doing, before you were blind." One participant said, "Home care is a terrific delivery of hope for me." Connecting with family, friends, and supportive professionals happened by "talking about it". One participant said, "When we talked about it, I felt better. We were in the same mind." Talking allowed caregivers to discover each other's feelings, frustrations, and hopes for the future, and build closer relationships that gave greater support.

**Connecting With Something Bigger and Stronger**

Participants approached this process in many different ways such as "having deep, deep beliefs", "simple prayer", "connecting with a higher power", or "something that's larger than yourself". One participant said, "I have it inside me...deep, deep beliefs. I think you wouldn't have hope if you didn't have that." Caregivers described "simple prayer before you go to sleep", "a small prayer at night...what are we thankful for today...that's a builder." Many participants discussed connecting with nature. "Nature is very close, we're fortunate here for the beauty of it." "It's just the knowledge that the world is a big place...you find you're looking for a context of some sort that's larger than just you and your problems, that you fit into it as one element."

**DISCUSSION**

Some findings of this grounded theory study are new when compared to previous research, although similar individual concepts were found in research with palliative caregivers exploring the experience of caregiving.

**Caregiver's Definition of Hope**

The caregivers' experience of the fluctuations of hope is similar to the findings of Herth (7), Kyölä et al. (20), and Miettinen et al (9). The participants' definition of hope as inner strength that gave them the courage and ability to go through a difficult situation is different from the findings of Borneman et al. (6), and Herth (7). Both Herth and Borneman et al, defined hope as transcending the current situation. The *Canadian Oxford Dictionary* (21) defines “transcend” as “to go beyond, or to be above”, which is different from the experience of the study participants who described “going through” a difficult situation. This may be explained by the use of grounded theory methodology, whereas Herth and Borneman et al. applied content analysis. Their findings may have been influenced by administering the Herth Hope Index prior to the interviews, thus informing the participants and positively affecting their level and descriptions of hope.

**Eroding Hope**

The participants in this study described their main concern as "eroding hope." The caregivers did not describe feelings of hopelessness. Kyölä et al. (20) described the fluctuations of rising towards hope, and away from despair and hopelessness in caregivers of HIV/AIDS patients. Hopelessness was part of the cycle. Social stigma relating to AIDS/HIV may have affected the caregiver's level of hope. This was also reported by Herth (7).

**Hanging on to Hope and Its Subprocesses**

Hanging on to hope has not been reported as a basic social process by any grounded theory research studies of hope. The *Canadian Oxford Dictionary* (21) defines “hang on” as “to continue or persevere, especially with difficulty." Mok et al. (11) described the concept of “holding on to hope" in a qualitative study of 24 bereaved caregivers of palliative patients. The *Canadian Oxford Dictionary* defines "hold on" as to "keep one's grasp on something" (21). The difference could be explained by the sample used, as the participants in the research by Mok et al. were bereaved caregivers reflecting back on their experience of caregiving, whereas the sample for the current research was interviewed during the experience of caregiving.

As in previous studies of hope and palliative caregivers (6,7), denial did not emerge in the findings of this study. "Hanging on to hope" was not suggesting denial, as the participants described their hope as subjective. This is similar to the findings of Jevne (22), who describes hope as situational and subjective, an orientation towards life where individual hopes can be disputed rather than being labelled false hope or denial.

There are no reported studies that have described the subprocesses of hanging on to hope as described in Figure 1. However, when the subprocesses and their mechanisms are viewed as individual concepts, there are similar findings in the literature.

**Doing What You Have To Do.** The ways of doing what you have to do as accepting, not giving up, and recharging have not been described by other researchers examining caregivers of palliative patients. However, the need for recharging
or finding personal energy for caregiving was described by Herth (7), Hudson (5), and Stajduhar and Davies (23).

**Living in the Moment.** Borneman et al. (6), Davies et al. (24); Herth (7), Martens and Davies (12), and Thulesius et al. (25) reported findings similar to "living in the moment".

**Staying Positive.** Looking for the good things in the situation, putting away negatives as much as possible, and appreciating the situation have been reported in previous research (7,12,26,27).

**Writing Your Own Story.** The participants described "writing their own story"—a process that has not previously been identified with palliative caregivers. Similar concepts to staying in control and making decisions are evident in the literature in studies by Gelling (28) and Proot et al. (29).

**Supporting Relationships.** The relationship between hope and support is clearly evident in the literature (6). Relationships as sources of hope were described by Bland and Darlington (30), Gelling (28), and Rose et al. (31). Participants in the current research discussed their experiences with the health care system as either a source of hope or a cause of an erosion of hope, similar to the findings of Proot et al. (29), Strang and Koop (32), and Mok et al. (11).

**Connecting With Something Bigger and Stronger.** Previous research has linked the concepts of hope and spiritual connections in populations of palliative caregivers (20,26,27,30). In Herth's study (7), having a spiritual belief system empowered hope. Borneman et al. (6) described an "outer source" that enabled caregivers to find hope through faith.

**Discussion Summary**

The findings of the current research are new. By interviewing caregivers during caregiving and using grounded theory methodology, the main concern of eroding hope and the basic social process of hanging on to hope emerged from the data. The research has attempted to capture the inner workings of hope for palliative caregivers going through a difficult situation. The subprocesses of hanging on to hope have been theoretically linked into a model that resembles an upward spiral, picturing the upward momentum of hope that caregivers were able to achieve using the subprocesses of hanging on to hope.

**Limitations**

The limitations of this study include the sample and the methodology. The sample was from two cities in western Canada with active palliative care programs. Religious affiliation and ethnicity may have influenced the results of the study. The participants included only English-speaking caregivers. Ninety percent of the patients had a diagnosis of cancer, limiting the results for other diagnoses. The sample was limited to individuals available and willing to participate in the study. Caregivers who were too busy, too stressed, or not interested in speaking to a researcher about hope were not included in the study. The results might have been different if a friend or neighbour had been the caregiver. The differences in length of caregiving or having the patient present for four of the interviews may also have affected the results. Saturation was reached with 10 participants. According to Glaser (17), the small sample size is not a concern as long as saturation of the categories is achieved.

**Implications for Practice and Research**

The health care provider can apply these findings by specifically considering each of the subprocesses in the theoretical model and their interrelatedness in exploring multiple hope-fostering strategies. The well-being of the caregiver is essential to successfully providing palliative care at home.

The subprocesses of doing what you have to do, living in the moment, and staying positive can be applied by commending caregivers for accepting their role, teaching strategies such as time refocusing, and encouraging a positive approach. Writing your own story can be facilitated by giving options to families, and working with them to understand their values, priorities, and wishes. Being aware of the impact of bad days, negative messages, and "seeing the pain" may prevent an unnecessary erosion of hope.

Caregivers need to be encouraged to make the most of every opportunity for family closeness and relationship building, sometimes just by talking about it and getting fears and issues out into the open; offer counselling for families. Connecting to something bigger and stronger should be encouraged. Helping caregivers to look at their situation within a larger context can bring a reassuring comfort and foster hope.

This study provides a tentative framework for future research to explore hope in caregivers from other cultural groups, with noncancer patients, at different geographic locations, and with caregivers who are bereaved or not giving direct care. These findings add to our understanding of the relationships between the subprocesses of hope and how they are linked in an upward spiral. Specific interventions for
caregivers may be developed and tested based on the findings of this study.

CONCLUSION

The findings of this study relate to a quote by Cicely Saunders: “For the family, we have to be aware of the whole group and the understanding and support they need if they are to find and use their own resources and strengths” (33). Supporting caregivers’ hope is an essential aspect of providing compassionate and effective care to families going through the experience of palliative care.

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