

Caregivers' Perception of Time in Palliative Care: A Meta-synthesis of Qualitative Studies

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Abstract

Background: The lack of time in palliative care implies a greater focus on its protection by caregivers and nurses. Understanding the time perception of family members and professionals taking care of patients in palliative care is important to build a dignified and respectful care of the patient's little time left to live.

Aim: This was a systematic review aimed to conduct a meta-synthesis of available qualitative literature on caregivers' perception of time.

Design: Meta-synthesis is a useful method for synthesizing qualitative studies and for developing models that can interpret the findings. Articles were scanned by two reviewers. Six studies met the inclusion criteria, as they used qualitative methods to explore the formal and informal caregivers' perception of time in palliative care. Articles were coded independently according to Joanna Briggs Institute's guidelines, and the results of qualitative research were grouped through a manual coding method that involved the aggregation of results.

Data sources: CINAHL (EBSCOhost), Scopus, Pubmed, Embase, PsycINFO and Cochrane Library (10/06/2015 – 16/07/2015).

Results and Conclusion: The perception of time by caregivers of patients in palliative care was described through two main themes: 'Borrowed Time' and 'The control of present time'. This study gives some new perspectives on time in palliative care.

Keywords: Time perception, Palliative care, Caregiver, Qualitative research

Background

In the U.S. the estimated prevalence of caring for an adult is 16.6%, or 39.8 million Americans. Approximately 34.2 million Americans have provided unpaid care to an adult age 50 or older in the prior 12 months [1]. The 65+ aging population will be more than doubled between the years 2000 and 2030, increasing to 71.5 million from 35.1 million in 2000. For the American Cancer Society caregivers are sometimes called informal caregivers or lay caregivers. In most cases, the main (primary) caregiver is a spouse, partner, or an adult child. When family is not around, close friends, co-workers, or neighbours may fill this role. Primary caregivers help patients significantly and guide them in respecting the rhythm of therapy, in reducing stress and generally in every aspect of daily life.

Caring for a terminally ill relative is a complex, time-consuming experience [2]. Time is the crucial issue in determining how caregivers feel about looking after patients; therefore the meaning of time is vital in palliative care [3].

In addition, depression is one of the common negative effects of caregiving and of a negative perception of time [4] and also hope in caregivers is a phenomenon that changes over time, evolving in different ways depending on circumstances [5].

Hospitals and caregivers play an important role in end-of-life care, they 'make the time' for patients. Giving good and reliable caregiver support is therefore crucial to the physical and emotional well-being of people with cancer, so healthcare and researchers should also focus their studies on the caregiver, in order to lead a healthy therapy and assistance, and to promote the welfare not only of the patient but of those around him as well.

Comprehensive insights into caregivers' perspectives across different contexts can be gained by synthesizing multiple qualitative studies. Qualitative research can

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generate theories and hypotheses to explain the experience and the caregivers' perceptions related to time, so it can let us understand the whole caring experience of disruption of life, practically and emotionally [6].

In conclusion, in a time of limited resources, more research is needed on what intervention we can enact without excessive economic efforts, to have positive outcomes for patients and their caregivers. Good care is possible only by analyzing the caregivers' time perception and this is the key of an ethical approach.

Aim

The aim of this study was to synthesize qualitative studies in order to understand the meaning attributed to time by formal and informal caregivers in palliative care settings.

Design

This metasynthesis was based on a review of primary qualitative studies that explore time perception of caregivers

who assist patients in palliative care. This review considered studies which reported qualitative data, including descriptive qualitative studies that describe the experience or its effects, and used designs including, but not limited to, phenomenology, grounded theory, ethnography, and action research.

The research was built as a meta-synthesis, according to the Joanna Briggs Institute guidelines, in order to identify, select, and critically appraise relevant research, and to collect and analyze qualitative data from the articles included. Studies taken in consideration were conducted at any time period, in any geographic place, in any language and with no age limit in the period from the 10/06/2015 to the 16/07/2015. Different terms were considered in order to include both formal and informal caregivers (care giver, caregiver, carer, caretaker, and primary caregiver) (Table 1).

The meta-analysis was done following the integrative approach or meta-aggregation proposed by JBI guidelines. Using standardized critical appraisal instruments from the

Table 1: Characteristics of included studies.

Authors/ Title	Aim	Design	Sample/Setting	Findings
Pesut B, McLeod B, Hole R, Dalhuisen M, Rural Nursing and Quality End-of-Life Care, Palliative Care... Palliative Approach...or Somewhere In-Between?, in Advances in Nursing Science, 35, No 4, 288-304	Better understand how a nursing palliative approach influences quality outcomes at end-of-life.	Secondary analysis of transcript from 2 studies examining palliative care in rural areas.	72 interviews: 26 interviews with nurse and 46 interviews with family caregivers of deceased palliative patients.	2 primary findings were constructed: the nature of rural contexts that require particular skills and competencies from nurses to ensure high-quality care and nurses' ways of being that connect and comfort at end-of-life. The nature of the rural context. With its geography, relationships, and lack of resource could be seen as dialing up the intensity on end-of-life care.
Angelo JK, Edgan R, Reid K Essential knowledge for family caregivers: a qualitative study. International Journal of Palliative Nursing, 2013, Vol 19, No 8	To uncover the information that palliative care teams routinely provide to family caregivers	The methodology used was the normal group technique, a type of focus group.	17 health professionals from three community PCTs	Three themes emerged as dominant priorities for caregiver needs: caring for oneself physically, emotionally and spiritually; learning practical skills; and knowing what to expect and plan as the family member's health declines.
Harding R, Epiphaniou E, Hamilton D, Bridger S, Robinson V, George R, Beynon T, Higginson IJ What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention Support Care Cancer, 2012, 20: 1975-1982	The aim was to generate evidence to inform a subsequent appropriate intervention based on caregivers' experience.	Cross-sectional qualitative study	20 informal cancer caregivers of home cancer palliative care	Carers reported the need to be prepared for their caring role, to be visible to professionals, to receive clear and specific information about the patient's condition, and to be emotionally supported. They described challenges as uncertainty, distress at witnessing disease progression and the daily struggle with financial issues, personal time, own health and sleep problems
Peacock S, Duggbley W, Koop P The lived experience of family caregivers who provided end-of-life care to persons with advanced Dementia Palliative and Supportive Care, 2014, 12, 117-126	The present study begins to address the paucity of research regarding end-of-life caregiving experience with dementia	Munhall's methodology for interpretative phenomenology. In-depth, open-ended, audiotaped interviews.	Four wives, three husbands, three adult daughters, and one adult son. Spouses' ages ranged from 65 to 89 years; children's age ranged from 49 to 63 years.	Findings reveal two essential aspects of end-of-life dementia caregiving: being-with and being-there. Examination of the life worlds demonstrates that 1) spatiality provided a sense or lack of feeling welcome to provide end-of-life care; 2) temporality was an eternity or time melting away quickly, or the right or wrong time to die; 3) corporeality revealed feelings of exhaustion; 4) relationality was felt as a closeness to others or in tension-filled relationships.
Draper A, Day E, Garrod E, Smith P Patients and carers experience of living with a complex neurological and palliative diagnosis Mortality, 2013, vol 18, No3, 270-289	To improve patient experience and satisfaction of care for those diagnosed with rare and rapidly progressive neurological conditions.	Secondary data, originally collected as part of a service development evaluative of the "My Needs Now" project.	Five patients and five carers.	A number of themes emerged namely, Professional Knowledge and Understanding, Time and Progression, The Family, and Coping Strategies
Dalgaard MK, Delmar C The relevance of time in palliative care nursing practice International Journal of Palliative Nursing 2008, vol 14, No 10	To contribute to an empirical understanding of connections between time and the quality of palliative caring practices.	Explorative and qualitative study inspired by grounded theory methodology.	Six concrete death courses, comprising individual and family interviews with patients and spouses, and individual interviews with nurses witnessing the actual death course.	Two scenarios are presented: one in which clock time is insufficient and another in which clock time is sufficient. Each scenario outlines how nurses relate to time in different ways, according to whether clock time is insufficient or sufficient, respectively.

Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI), the selected papers were assessed by two independent reviewers for methodological validity prior to inclusion. Any disagreement that raised between the reviewers was solved through discussion, or with a third reviewer.

Qualitative data were extracted from the papers included using the standardized data extraction tool from JBI-QARI. The data extracted were specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review. The researchers read the articles carefully several times to extract the results. Then the level of consistency between the results and the data that can support them was classified as level "unequivocal", "credible" or "unsupported", according to the quality appraisal module of JBI-QARI, to identify the credibility of the studies.

Qualitative research findings were collected using both JBI-QARI and manual aggregation of findings with similar meaning. This aggregation or synthesis of findings generated a set of statements that represent the category. Two or more categories were then subjected to a meta-aggregation in order to produce a single comprehensive set of synthesized findings, which can be used as a basis for evidence-based practice. The findings of qualitative research were grouped through a manual coding method that involved the aggregation of results and the subsequent generation of a set of themes, which represent the perception of time by nurses and caregivers who assist patients in palliative care units, with the creation of two themes (Table 2).

Data Sources

The context of this review included Hospices, Palliative Care Community, and home. It considered researches on perception of time and the effectiveness of programs/strategies that are

designed to decrease its prevalence or mitigate its negative effects in palliative care, where caregivers give practice.

A three-step search strategy was utilized. An initial limited search of MEDLINE and CINAHL was undertaken, followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe articles.

A second search using all identified keywords was then undertaken across all included databases.

Thirdly, the reference list of all identified articles was searched for additional studies. The articles were searched on the electronic databases CINAHL (EBSCOhost), Scopus, Pubmed, Embase, PsycINFO and Cochrane Library. The reference list of all included studies was analyzed to search for the "related articles" in PubMed and for any type of document that could quote all the results seen or key words relevant to our research (for example, through citations research). For this purpose we used the "Cochrane Qualitative Research Methods Group" guidelines.

Specificity and sensitivity of each search were obtained by reasonable use of Boolean operators "AND", "OR" and of the asterisk (Table 3).

Results

Borrowed Time

Time in palliative care does not have the traditional meaning. It is not marked in hours and days that follow one another, there is no temporality. Time in palliative care is a collection of moments, each of them is fundamental.

"A day is an eternity in palliative care" [7]

The uniqueness of the moment, which might be the last, is

Table 2: JBI-QARI flow diagram.

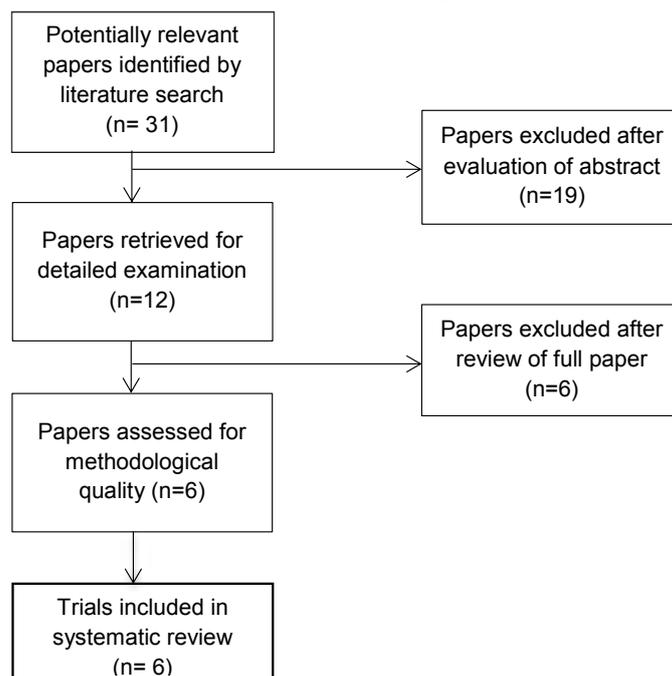


Table 3: Findings, Categories and Synthesised findings.

Findings	Categories	Synthesised findings
Paradoxical time Time Temporality	time remaining is essential for caregivers of palliative care, it is heavy, anguished, infinite and finite but granted the family to stay close to the patient	Borrowed time
Clock time Waiting Paradoxical time	Organizing time and waiting for care and treatment creates a need in caregiver	The control of the present time

invested by a greater importance: each unique moment should be spent with the patient. It is time lent by the caregiver to the patients in order to stay close to them.

“The time that I was with my family, with her, was very meaningful” [8]

Suddenly time becomes real, almost concrete and it is possible to feel its burden. Time has a new dimension: one day is an eternity and paradoxically the caregiver starts to lose control over it, starts to feel both the presence and the responsibility of creating a good time for the patient. The perception of limited time arises needs, needs that relate to the patient.

The distressing question that needs an answer is always the same: how much time do I have left? The patient asks himself how much time he has left *to live*, while the caregiver is asking how much time he has left *to be with* his loved one.

“No, no not at the moment it’s just what’s going to happen in the future more than anything else, I just worry about what’s going to happen” [4]

From the articles it appears clearly that caregivers are lending their time.

The time spent for the patient, cut off time to the wellbeing of the caregiver, it seems like the clock time is replaced by the interior time of the patient. Caregiving is a time-consuming experience and the time left is not enough for caregivers’ resting.

“If someone came for some time to look after the patient and give the caregiver a rest, if they could stay there for a day and the caregiver can go out, go shopping, just to go out then, that could give them a real break...” [9].

The caregiver’s personal time is cancelled. He can’t be separated from the patient and he can’t have autonomy because his concern about his loved one is bigger than his real need to separate himself from him.

“If I had a day off I will have a day off but I am still worried about her and I want to get home. So I can’t go for long because I can’t leave her too long” [9].

The simplicity and the generosity of giving time truly show a lack of personal time that could lead for example to depression, back pain, poor mobility, ulcers and cardiac problems, if not treated adequately. [1,9].

To return in harmony with time the caregivers need to know how much of it is left, because it is in the frame of time that we can make decisions with respect to spending time with the patient.

Providing care for a family member in need is an act of kindness, love, and loyalty. Regardless of all the burdens that

come from the illness, caregivers are glad to do this and feel rewarded by it.

“The time spent with my family with her was really meaningful” [8].

However, to return in harmony with time, caregivers need to know how much time is left, because it is within the frame of time that they can make decisions with respect to spending time with the patient. For them it is necessary to know the quantity of time left to live, in order to synchronize themselves with it.

“From family caregiver’s perspectives, important aspects of time were the need to have in some sense of the amount of the time left so that informed decisions could be made and the need to have timely attention to care so that the time left could be optimized” [7].

Providing care for a family member in need is an act of kindness, love, and loyalty. Regardless of all the burdens that come from the illness, caregivers are glad to do this and feel rewarded by it. For them it is necessary to know the quantity of time left to live, in order to synchronize themselves with it.

The Control of Present Time

The forthcoming death, the lack of time, the anxiety of leaving interrupted something important are all aspects that bring the caregiver to feel the need to control time. It is all a rush towards the end of the time left. It’s obstinacy.

“The need to plan life around death was an important factor for families. Family members are conscious of the limited time available to them and have important needs in relation to having some control within the time left” [7].

“He would say, “How much time do I have left?” And the response from the physicians was always “We can’t tell you. Every person is different.” It wasn’t until M said, “You have weeks not months.” And that was when it really hit P that’s where he was” [7].

By caregivers’ words we can understand the definition of clock time, like the punctual and exact time, which it is really important to follow. Whenever the clock time is adequate or inadequate, the time is right or wrong.

One other point of view described in the articles is the “waiting”: the act of waiting throws the person in a future dimension that seems as a preview of a perception. What is awaited is by essence, something that will be perceived. (Husserl)

“It’s like...it’s so slow, you can’t just put a handle on it and you just wonder how long it’s going to go on for” [4].

During this waiting caregivers start to hope for a daily plan, a program that they can plan and actually manage every day. To realize this program, in the end, means to realize the caregivers’ mission.

Discussion

The right to the respect of time is one of the many definitions of cure humanization. In this study, after dealing with the topic of “Perception of time” regarding the patient [6], it felt necessary to focus on the caregiver as well. The originality of this work lays in the concept of addressing personalised care, a care that is ever

closer to the patient and their family and that is also closer and personalised to the caregiver as well. The caregiver plays the main character in the patient's care, especially in palliative care. It is then important to take into consideration the caregiver's time perspective and therefore to know the results of this research to build a good communication between health professionals and patients, to guarantee the best possible outcome and management of the care.

Conclusion

The aim of this metasynthesis was to synthesize available qualitative literature on the caregivers' perception of time in palliative care. This study can contribute to the understanding of time from the caregivers' perspectives.

The goal of palliative care resides in the patients' and caregivers' experience of care, and is concerned with the quality of the time left to live that should enrich the whole person day to day [4].

Time's perception generates needs in caregivers, therefore it is fundamental to recognize that everybody is living in an environment where time is coming to an end: the chronological and the inner one, the one of the caregiver and the one of whom is assisted. In sharing this moment there is a sharing of time left. No one knows how much time remains, but all agree that the quality of this time should stay high until death comes. Time is a gift especially if that time is well spent by the patient and the caregiver.

The first result was 'The Borrowed time'. This synthesized finding arises from the lack of time due to the incoming death. From Heidegger's point of view (1927) the impending death means an authentic perspective of time, which is why the time described by the caregiver is perceived as "eternal, paradoxical and heavy".

It is difficult to find out references to past time in caregivers' quotes, or any reference to a future time, because there is none. The living time is locked in the present, which seems to be an eternal *present*. The possibility and the uncertainty of the situation, added to the value of the lived moment, creates a sense of borrowed time, because it is connected to the possibility of both the patient and the caregiver realizing their last wills; the possibility given to the caregiver to be next to his loved one and live with him his last life moments.

The second synthesized finding was the control over the present or the attempt to control the future. Organizing is an automatic mechanism which is triggered by the fear that something important might escape. On the other hand, the term control, which implies the concepts of custody and guardianship, sums up the deep meaning of care. Moreover, the similarity between the organization of time and care is going to mean a therapy that the caregiver wants to implement.

These issues generate a perception of time donated. Both the borrowed time and the organized present are gifts, presents, offerings and contributions.

Jacques Derrida, in one of his most famous pieces, describes the time as a gift.

"The gift is not a gift, the gift only gives to the extent it gives time. The difference between a gift and every other operation

of pure and simple exchange is that the gift gives time. There where there is gift, there is time. What it gives, the gift, is time, but this gift of time is also a demand of time. The thing must not be restituted immediately and right away. There must be time, it must last, there must be waiting—without forgetting [l'attente-sans oublil.] [The thing is not in time; it is or it has time, or rather it demands to have, to give, or to take time-and time as rhythm, a rhythm that does not befall homogeneous time but that structure it originally. The gift gives, demands, and takes time."

Time seems to be one important aspect of caring as well. Knowing and studying the time perception of the caregiver can help the health professionals to understand what the caregiver is asking and subsequently act in a more efficient way.

"While the clock marks the passage of time, our personal experience of time is not always in sync with it "[10].

Moreover what the studies show is that the majority of caregivers in palliative care units feel the need of being useful and caring for their relatives on a time dimension.

"Time is the center of our way not only of arranging life, but also to live life" [10].

Palliative care is the context where patients and caregivers have the chance to know the definition of time and to comprehend the importance of it. It is also possible for them to meditate on the meaning of "limited time": time is stolen just because its dimension is limited. But the relevance of it is strictly related to its limitedness. As a consequence, time in this new perspective becomes an opportunity to enforce relations, and to get the most out of every day; time becomes care [11-15].

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