Original Article

Using a Reflective Attitude when Meeting Older Chronically Ill Patients' Care Needs in Home Care Nursing

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Abstract

Background: Current demographic developments have resulted in an increased focus on home care nursing, which can be defined as any form of assistance to a sick person (the patient) in her/his home by family and members of the community in cooperation with a qualified healthcare professional who provides advice and support.

Aim: To describe what nurses take into account in order to meet the care needs of older chronically ill patients in home care nursing.

Methods: Fourteen nurses with home care service experience employed at four different units in two municipalities in Norway participated in a qualitative study. Semi-structured interviews were conducted, transcribed verbatim and analysed by qualitative content analysis.

Results: Four categories emerged from the analysis: Getting to know the patients, Helping patients to live their own life, Involving next of kin, and Making time for and comforting lonely patients.

Conclusion: The nurses reflected on the importance of reading the patients' faces as they expressed themselves. Following patients over time helped the nurses to understand their personal wishes for life and expectations of care.

Keywords: content analysis, older chronically ill patients, home care nursing, involving next of kin, making time, qualitative method

Introduction

Current demographic developments have resulted in an increased focus on home care nursing. The proportion of the population that is older is increasing and consequently, more people will be care-dependent in the near future (World Health Organization, WHO, 2015). In Norway, the government has emphasized that the key values and goals of nursing provided by the home care services should be to support the patient and meet her/his basic needs while respecting each individual's self-determination, self-esteem and way of life, thus enabling the patient to live at home for as long as possible (Ministry of Health and Care Services, 2017).

Most patients supported by home care nurses are older and chronically ill, and either live with family members or alone (Ministry of Health and Care Services, 2005-2006). Home care nurses are expected to focus on helping patients feel safe in their daily life and promote their well-being (Birkeland and Flovik, 2011; Fjörtoft, 2012). The quality and organization of care for older chronically ill patients is a palliative pathway for dealing with complex illness, loss of physical functions and the need for nursing care (Ministry of Health and Care Services, 2007, 2012, 2015). The Norwegian Kaupang Report (2012) presents a more comprehensive pathway for patients in the Coordination reform (2008-2009). This resulted in increased pressure on the home care nurses due to older chronically ill patients' early discharge from hospitals and the reduction of time allocated to each patient. As a consequence, the responsibility placed on the home care service nurses increased, leading to a request for more training in home care nursing (Sæterstrand, Holm and Brinchmann, 2015).

Tönnessen, Nortvedt and Förde, (2011) describe the difficulties when caring is linked to a written reform, which makes it harder to adapt the care to the needs of each individual patient. Caring often becomes something stationary that does not take into account that needs change from day to day and are constantly in motion. That means that the nurse is either guided by the patient's personal needs or by written instructions (Tönnessen, Nortvedt and Förde, 2011). The issue of nurses' ethical character then becomes important. According to Kirkevold (1998), the character of caring nurses involves their responsibility to pay close attention to the patient's facial expressions, based on their intuition and ethical knowledge. Nurses should encounter the patients or their next of kin in their suffering, in order to understand their plea for relief as described by the philosopher Lögstrup (1962), who inspired Martinsen's (2003) theory of caring.

Caring for patients and their families is a way of describing good nursing care, because even in need of home care nursing a person is still a member of her/his family (Åstedt-Kurki 2010). On the other hand, the next of kin also need support and help to reduce the feeling of guilt and sorrow (Dorell, Östlund and Sundin, 2016). Caring for the whole family gives the family hope and helps each member to cooperate better (Pusa, et al., 2015; Sundin, et al., 2016). Benzein and Saveman (1998), revealed that hope is a dynamic experience, important for both a meaningful life and a dignified death for patients suffering from a chronic disease. The nurse's effect in terms of bringing hope to patients in difficult situations is a significant feature

described by Rudolfsson, et al., (2003). Furthermore, when responsibility for patients is handed over to nurses, a comforting atmosphere can be created for both patients and their families (Rudolfsson, von Post and Eriksson, 2007).

Many of the patients cared for by nurses in their own home are older with a chronic illness of a more or less serious nature and some of them live alone. The aim of this study was therefore to describe what nurses take into account in order to meet the care needs of older chronically ill patients in home care nursing.

Methods

The study has a qualitative design as the overall methodological structure (Polit and Beck, 2016). The qualitative approach involved individual indepth interviews that were analysed using qualitative content analysis (Graneheim and Lundman, 2004). According to Graneheim, Lindgren and Lundman (2017), the ontological assumptions of content analysis are open and vary according to the researchers' standpoint. During the analysis process the two authors made an effort to be aware of their personal and professional standpoint and how it could influence the analysis. Their standpoint was based on a caring science perspective (Eriksson, 2006), comprising a psychiatric nurse's and a surgical nurse's knowledge, experience and commitment to patients.

Participants

The research context was four home care nursing teams with 20 employees in each team in two municipalities (A and B) in Northern Norway. Fourteen nurses (13 women and one man) aged 35 to 65 years were interviewed. The sample included home care nurses from all four teams in order to capture work experience varying from three to 20 years. The nurses cooperated in cancer palliation for 55 patients a year in municipality A and 50 patients in municipality B. Older patients made up 80% of their workload. Seven were specialist nurses, one in diabetes, one in intensive care, one in health promotion, three in cancer palliation and one in dementia and elder care. Four of the nurses worked as team leaders. which involved spending one day per week on administrative duties in addition to home care nursing together with their team.

Each team was responsible for about 100 patients ranging in age from 20 to 95 years, mainly older chronically ill patients either living alone or with their next of kin. Both municipalities have a nursing home. Two local hospitals are located approximately 10-30 kilometres away and university hospitals can be reached by air in about 30 minutes to one hour. The nurses had to drive many kilometres each day to visit the patients two to four times a day.

Data collection

Semi-structured interviews were conducted. The interviews, which lasted between 50 and 60 minutes, were audio-taped and transcribed verbatim. The participants were allowed to decide the time and place for the interview. The interviews took the form of a formal conversation between the researcher and each participant and were conducted in a quiet office at their workplace, in a hotel room and in the nurse's own home. The main questions were about the patients' vulnerability and suffering and the necessity of being aware of the different phases of the patients' life. Questions were also asked about bodily discomfort and needs. Probing questions such as "could you explain more", or "what do you mean by that" were used to deepen the interviews.

Analysis

The transcribed text was analysed using qualitative content analysis inspired bv Graneheim and Lundman (2004). The analysis started by reading the text to gain a sense of the whole. The intention was to remain close to the text and find contextual meaning. The text was divided into meaning units, which were condensed without losing the core meaning. The condensed meaning units were abstracted and labelled with a code. The coded meaning units were then compared and sorted into four categories. The categories were compared with the whole text by moving back and forth between the whole and the meaning units until consensus was achieved. An example of the analysis process is provided in Table 1. Quotations from the interviews are presented to strengthen the credibility of the analysis.

| Table 1. | An | example | of the | analysis | process |
|----------|----|---------|--------|----------|---------|
|----------|----|---------|--------|----------|---------|

| Meaning unit | Condensed meaning unit | Code | Category |
|--|--|---|------------------------------|
| For us the first home visit is important. We look at their photos, we talk about children, about travels and about the person's life. | First home visit is important, we look at photos, talk about children, travels and the person's life. | Listening to the patients' own history. | Getting to know the patient. |

Ethical approval

Ethical approval was granted by the Regional Ethics Committee and the Norwegian Social Science Data Services accepted the project. Contacts were established with the leaders of the home care service, who recruited and informed the nurses about the project. The first author then verbally informed each participant about the study and gave her/him written project information, after which the participants signed the declaration of consent.

To ensure confidentiality the interviews were given a number that only the researcher knew and no names or team references were used in the transcribed interviews. The participants were informed about their right to withdraw from the study at any time without any consequences. The ethical principles for research set out in the Declaration of Helsinki (2008) were followed throughout the entire study.

Results

The findings consist of four categories that emerged from the analysis: Getting to know the patients, Helping patients to live their own life, Involving next of kin and Making time for and comforting lonely patients.

Getting to know the patients

The nurses expressed their desire to get to know the patients by listening to each patient's own story. They explained that the first encounter with a patient was very important for establishing a relationship:

> "For us the first home visit is important. We try to get to know the patient by being there. We look at their photos, we talk about children, about travels and about the person's life." (B)

By being there, communicating with and following the patients over time they became aware of changes in the patients' mood and felt that they could understand their needs because they knew them better.

The nurses explained that by knowing the patient and her/his next of kin well they could see what was needed by both their facial expressions and body language. They reflected on how important it was to read the patients' faces as they expressed themselves.

Helping patients to live their own life

The nurses reflected on the importance of hope for the patients and their families who in just a few weeks or months could lose their loved ones:

> "It is important to help the person make plans, even if she/he doesn't live to see them happen." (A)

The nurses described how patients might want to make plans for their birthday in a few weeks. They plan and discuss it together, even though the nurses themselves thought that because of their illness the patients would be unable to celebrate it. Sometimes time is short and the nurses tried to mediate hope in hopeless situations:

> "I want to help them by giving time and hope, so that they can live as well as they

possibly can. I believe that in order for the patient to be able to live her/his life, I have to be aware of and help her/him put the concerns and challenges into words." (F)

By listening to the patients the nurses understood their wishes for life and their expectations of the care.

Involving next of kin

The nurses described their reflections on and experiences of how they involved the next of kin in caring for the patient. Among other things, this meant managing nutrition and intravenous treatment because some cancer patients had been discharged from hospital very quickly. The nurses taught them the procedures so that the patients could remain at home. The winter conditions in this Arctic region and the fact that some patients lived quite a distance from the home care service office worried the nurses, but in one case they had cooperated with and involved the patient's wife:

> "I thought of their need to feel secure. I had problems sleeping myself because of the storms outside, thinking I might not reach their home, and therefore I had to teach the wife how to manage the IV. I phoned her and we agreed that she could reduce the drop-count as I had taught her earlier." (K)

Because of stress and crisis in the patients` family, the nurses experienced that they often had to take care of the whole family. There was not enough time allocated for this in the care contract, but nevertheless the nurses understood that the family also needed care and to be involved:

> "It is good for the patients and their next of kin that we can talk about what they have experienced. Sometimes the families help them express this in addition to caring for them." (D)

They had to spend more time than what was set out in the care contract because many patients did not live alone and the nurses naturally included their family. The nurses realised that they could include next of kin by involving them in nursing procedures:

> "I want the next of kin to be with us during home visits because they have questions

about the future, what the symptoms are and about CVC, IV and analgesia. We can tell them what to expect and that we will support and teach them." (J)

Making time for and comforting lonely patients

Some patients lived alone and the nurses reflected on how they made time for and comforted lonely patients. When the nurses made home visits they experienced that the patients had just been sitting there awaiting their arrival:

> "It is only a few minutes and I do not think that the person I am visiting got any help from the allocation unit. They are sitting there waiting for me and I make time to be there for them as this extra time keeps them going." (N)

The nurses found it difficult to leave old and lonely patients:

"She was so lonely, lying in bed all alone the whole day. I want to give her time. She was unable to speak because of her illness, but I could see her eyes looking at me and she always wanted to lie facing the door so that she could see people coming and going." (F)

The nurses reflected on how it would be to feel lonely and how they felt concern and love for their patients. They experienced that they had gained competence in listening, respecting and communicating with patients while trying to do their very best for them.

Discussion

The aim of this study was to describe what nurses take into account in order to meet the care needs of older chronically ill patients in home care nursing. The results show that the nurses met the patients' care needs by getting to know them, helping them to live their own life, involving next of kin, as well as making time for and comforting lonely patients. Looking at the patient's face was a way to meet the other person's vulnerability and face her/him in her/his suffering, described by Lévinas (1969) as the responsibility of the face, which touched the nurse's heart. For Lévinas (1969), the responsibility of the face reflects our humanity as a natural representative of all human beings and constitutes us all as persons. When the face of the patient was understood as an etic appeal, it touched the

nurses because the appeal represented patients' rights and nurses' duty

The nurses' actions in the present study can be understood as the impact of their own values and how this influenced the relationship with patients. Similar findings are described by Suzuki, Tatsumi and Otsuka (2010), illustrating the nurses' ethical standpoint when they build relationships with patients. From the present study it can be understood that the nurses' touch in combination with reading the patient's face was important for their subsequent relationship. The results show that the nurses tried to help patients to live their own life, respect their expectations of life and give them hope. In the words of Benzein, Hagberg and Saveman, (2008a) and Benzein, et al., (2008b), nurses' relationships with patients, are of importance for acknowledging patients on how to lead their own lives, helping them to be the person they were and go on with their life.

The present study is also supported by Öresland, et al., (2011), who focus on the metaphors that describe the norms and values nurses use in the context of home care nursing. The metaphor "an endless journey" is used by Öresland et al., (2011) to describe how patients find themselves travelling to an unsafe destination, while the nurses take care of the control and planning of the journey. This situation was revealed in the present study, where a male patient planned for his birthday, whereas the nurse was aware that he probably would not live to celebrate his birthday. However, keeping hope alive was more important and the reason why they participated in planning the event, which can be seen as a universal act of humanity.

In the context of the long distances between each patient it became necessary for the nurses to involve the next of kin in the care. This situation is described by Benzein, Hagberg and Saveman, (2008a) as seeing the family as a resource and a conversational partner.

The results revealed that the nurses made time for and comforted lonely patients. When they became aware of the patients' loneliness they offered more time and stayed longer than planned (Sæterstrand, Holm and Brinchmann, 2015). This meant that the nurses' actions were contrary to the briefness of their time allocation (15 minutes for dialogue). Despite providing extra time, they

felt sad when leaving the lonely patient and wished they could stay longer. Loneliness has been described metaphorically by Kitzmüller, et al., (2018) as "an empty waiting room" and defined as the experience of desiring relationships, intimate attachment and reciprocal empathic understanding. The nurses' understanding of and involvement in the patients' needs show that they let things, "die Sache", come forward on their own terms (Gadamer, 1975/1989). Their actions in practice are supported by the nurse philosopher Martinsen (2003), who points out that the alleviation of suffering involves having consideration for and being concerned about the other. According to Eriksson (1992; 2006), existential suffering is the most basic form of suffering.

According to Milne and McWilliam (1996), "caring time" was spent by "being with" and "doing for" the patient. The nurses' thoughtful acts of compassion in practice required time and represented value for those who participated, which can be described as an invisible element of caring. Although it might have been invisible to others, it was an everyday situation and brought value into the patient's life.

The nurses described how they involved the next of kin in caring for the patients. This adds value in nursing interventions because it is possible to identify individual and family strengths and soften the grim experience of terminal illness (Bell, 2013). Bell's (2009; 2013) ideas represent an orientation that includes interaction, reciprocity and relationship by involving the whole family in the patient's situation. It also represents the larger system or context in which the family lives; where the goal is to maintain health and promote healing. According to Lazarus and Folkman (1984), illness is a crisis for the whole family.

We believe that the nurses' understanding of the patient's needs determines the decisions they make in different situations. Gadamer (1975/1989), states that there is a presumption before the understanding of a situation. By relating his thoughts to how the nurses consider the situation in a compassionate manner when meeting the patients' needs, it is clear that the nurses evolved through experience, which gave them a presumption of what was about to happen, before it happened. An example was how the

nurses' previous experiences made them more capable of meeting patients in all kinds of situation and understanding the situation they found themselves in. Nurses' experience was based on what they had already learned, which allowed a new understanding to evolve that strengthens their intuition.

Methodological considerations

The aim of this study was to describe what nurses take into account in order to meet the care needs of older chronically ill patients in home care nursing. The participants consisted of only one male nurse. Despite this our data can be considered representative and rich due to all the participants' eagerness to discuss the topic. Open-ended questions were posed during the interviews to follow up the participants' statements in order to obtain varied data. In accordance with the Declaration of Helsinki (2008), the ethical principles for the whole research process were reflected on. As we have tried to researchers maintain trustworthiness in order to ensure transferability. Analysing the text from the interviews and trying to present new knowledge requires the researchers to be true to what the nurses communicated, because it offers an in-depth understanding of what it means to meet the care needs of older chronically ill patients in the context of the home care service. According to Graneheim and Lundman, (2004), data analysis is dependent on how the researcher helps the reader to follow the steps of the qualitative analysis. We have strived to make the differences between the categories clear and discern "the red thread" of content as described by Graneheim, Lindgren and Lundman, (2017).

Conclusion

The findings revealed that the nurses met each patient's care need in a reflective manner by getting to know the patient, helping the patient to live her/his own life, involving next of kin and making time for and comforting lonely patients. They reflected on the importance of reading the patients' faces as they expressed themselves. The patients' personal wishes for their life and expectations were understood. Future research should further deal with how to find organizational models to enable nurses to place the needs of patients and next of kin in focus.

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