What will happen to my mom? A grounded theory on nurses' support of relatives' end-of-life decision-making process for residents living with dementia in long-term care homes

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Abstract
Background: Relatives of an older person living in a long-term care home with advanced-stage dementia must often make important and difficult decisions, including ones that impact the resident's end-of-life. Healthcare professionals must support them in this decision-making process. The aim of this study was to propose a theory on nurses' support of relatives who make end-of-life decisions for a resident living with dementia in a long-term care home.
Method: A constructivist grounded theory approach was used, with a theoretical sample of nine nurses and 10 relatives whom we met for face-to-face interviews. Three documents on end-of-life

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care, which were available in the study setting, were also included. The analysis was carried out using the method proposed by Charmaz.

Findings: The findings highlight the importance of building a strong and trusting relationship between nurses and relatives. Furthermore, exploring the refusal of palliative or end-of-life care, supporting relatives' need to witness firsthand the condition of the person living with dementia, and education at a "good" time are useful interventions that nurses can make to support relatives' decision-making.

Conclusion: Better support of relatives in end-of-life decision-making improves the well-being of relatives and older people living with dementia alike.

Introduction

Dementia is an increasingly common health problem around the world (World Health Organization, 2019). In many European and North American countries, most people with dementia live in long-term care homes when they reach the advanced stages of the disease and this is also where they are likely to die (Reyniers et al., 2015). Advanced-stage dementia is generally associated with residents being incapable of decision-making (Chambaere et al., 2015), thus forcing relatives to take responsibility for the residents' consent to care (Government of Québec, 2020).

This responsibility is sometimes complicated for relatives, especially when the decisions to be made may influence the resident's end-of-life (Gjerberg et al., 2015). These decisions include, but are not limited to, cardiopulmonary resuscitation, level of care, antibiotic administration, symptom investigation, and artificial nutrition or hydration (Daneau et al., 2020). Relatives rely on the healthcare team, including nurses, to initiate end-of-life conversations and guide them in the decision-making process, but nurses are sometimes uncomfortable in this role (Livingston et al., 2012). Few studies have focused on the support nurses provide in this situation; however, it is essential to know the nature of this support to better guide practice and research on how nurses can guide relatives through their decision-making process. Palliative and end-of-life care would also be improved by enhancing the support received by relatives who find themselves faced with making end-of-life decisions for an older person living with dementia in a long-term care home.

To fill this gap in knowledge, the aim of the study was to propose a theory on nurses' support of relatives making end-of-life decisions for an older person living with dementia in a long-term care home.

Method

A constructivist grounded theory approach (Charmaz, 2014) was used. This qualitative research method uses an inductive and comparative approach to build an interpretive theory of a given social process. This type of theory draws relationships between concepts to explain or understand a phenomenon (Thornberg & Charmaz, 2012). Like the well-known Glaserian or Straussian approaches of grounded theory, the constructivist approach elaborates an inductive theory with an iterative process but is based on data generated by a more flexible method. This allows the development of a co-constructed theory by which each hypothesis about the theory in question is discussed with the other participants.

Sample and setting

The study took place in long-term care homes in Montréal, Quebec, Canada, with nurses and relatives of residents. Once admitted to long-term care homes in Quebec, residents have a life expectancy of about 27 months (Health and Welfare Commissioner, 2017). Nurses were recruited with the help of the local administrative coordinator of all the long-term care homes in the region, as well as with assistance from each home's head nurse. Also, some relatives volunteered to take part in the study after presentations of the project at various conferences. Other relatives were recruited with a snowball approach (Sadler et al., 2010). The inclusion criteria specific to nurses and relatives are found in Table 1. The participants were also required to understand and speak French. A total of nine nurses and 10 relatives were recruited to reach theoretical saturation, which, according to Charmaz (2014), is when "gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories" (p. 213).

Data collection

A questionnaire was used to collect participants' sociodemographic data, while an interview guide was used to conduct semi-structured interviews. Participants were met individually for one interview, except for three relatives from the same family who, at their request, were interviewed together in a single interview. The interviews, which lasted an average of 47 min, were audio-recorded and then transcribed. The first version of the interview guide was developed based on a literature review previously conducted on the subject (Daneau et al., 2020). One version of the guide was designed for nurses and another for relatives. The questions were on the same themes, but their wording differed to ensure the relatives' version was easy for them to understand. Each subsequent interview helped us adjust the interview guide to explore the concepts, as well as the similarities and contradictions identified. Finally, the end-of-life documents available in the study setting were also collected and analyzed ($n = 3$; one document about the end-of-life was aimed at relatives and residents, and two addressed healthcare professionals). A journal was also used by the principal researcher, who conducted the interviews. It contains field notes including, among other things, her report on how the interviews were conducted, her observations in the role of interviewer, and memos.

Table 1. Inclusion criteria.

Nurses
- Providing direct care to residents as part of their daily practice or being in regular contact with these nurses during management, teaching, or supervision activities;
- Holding a regular position in the long-term care home for at least one year;
- Having provided end-of-life care in the past 12 months to at least one older person living with dementia (for direct care nurses).

Relatives
- Currently experiencing or having recently experienced the end-of-life of a person aged 65 or over who is living or lived with dementia in a long-term care home;
- Having or recently having had to make decisions related to the end-of-life for that person or being involved in the discussions around decisions to be made.

Data analysis

Sociodemographic data were analyzed using descriptive statistics. The interviews were transcribed in full before being analyzed in Excel. The two iterative steps described by Charmaz (2014) guided the analysis: initial coding, used to assign an action term to each data segment; and focused coding, which organizes the data according to the initial codes with a view to ascribing a more conceptual value to the analysis. During these two steps, the constant comparison method and the writing of memos were used. Although interviews were conducted with two types of participants, no distinction was planned in the analysis. All categories of the theory came from both nurses' and relatives' data. In accordance with the grounded theory methodology, potential categories were always explored with both groups of participants. Relatives and nurses often expressed things differently, but the analysis at a higher level of abstraction demonstrated that it resulted in the same themes. Since nurses and relatives were involved in the same process, the integration of data from both groups allowed for the development of a theory rich in nuance and for the understanding of each conceptual category. In addition, data from the end-of-life documents were extracted using a flexible grid inspired by Charmaz (2014) that included all aspects relevant to end-of-life decision-making. These data were then integrated with the interview data for the analysis. Finally, field notes and analytical memos from the journal supported data analysis (Charmaz, 2014). Data analysis was conducted by the first author (SD) and confirmed by the second (AB).

Ethical considerations

This study was approved by the Institutional Review Board of the Research Centre of the Institut universitaire de gériatrie de Montréal (# CER VN 18-19-04) and we obtained written informed consent from all participants. Participant confidentiality was ensured. Because the research topic could be a sensitive one, relatives were contacted 48 h after their interview and asked about their well-being. All participants' mental health was comparable to its pre-interview status and none felt the need for additional support.

Findings

The nurses interviewed (seven women and two men) had a mean age of 34.3 years (range: 24−44 years), had been working in a long-term care home for an average of 6.2 years (range: 2−18 years), and mostly held a full-time position. They came from six different long-term care homes. Relatives (eight women and two men) were on average 61.5 years old (range: 42−85 years). Six participants were a relative of a person who had died between eight and 60 months before the interview, while the other four were relatives of a resident who was still alive. Seven relatives were making decisions for a parent, two for a spouse, and one for a parent-in-law. Except for the three relatives of the same family, the participants' relatives all lived in different long-term care homes. The sociodemographic characteristics of the study participants are shown in Table 2.

The developed theory on nursing support of relatives making end-of-life decisions for a person living with dementia in a long-term care home (Figure 1) starts with discussion triggers that lead to four supporting actions.

According to this theory, nurses initiate support for relatives around the decision-making process following one or more triggers that prompt discussion. Subsequently, this support mainly draws on the trust between nurses and relatives. This trusting relationship gives nurses a solid foundation for intervening in other ways, namely by exploring the refusal of palliative or end-of-life care if it arises,

Table 2. Sociodemographic characteristics.

Nurses (*n*=9)		
Gender	N	%
Female	7	77.8
Male	2	22.2
Age (years)		
24–29	3	33.3
30–35	1	11.1
36–41	3	33.3
42–47	2	22.2
Education		
Technical diploma	7	77.8
University degree	2	22.2
Experience in long-term care home (years)		
1–4	5	55.6
5–9	2	22.2
10 and +	2	22.2
Work schedule		
Day	6	66.7
Evening	3	33.3
Night	0	0
Work status		
Full-time	8	88.9
Part-time	1	11.1
Relatives (*n*=10)		
Gender	N	%
Female	8	80.0
Male	2	20.0
Age (years)		
40–49	2	20.0
50–59	1	10.0
60–69	5	50.0
70–79	1	10.0
80 and +	1	10.0
Occupation		
Retired	5	50.0
Part-time worker	3	30.0
Full-time worker	2	20.0
Religious affiliation		
Catholic	2	20.0
Non-practicing Catholic	4	40.0
None	4	40.0
Resident's type of dementia diagnosis		
Alzheimer	7	70.0
Mixed dementia	2	20.0
Unknown by relative	1	10.0

Table 2. (continued)

Relatives (*n*=10)		
Time since relative's death (years)		
Alive	4	40.0
0–1	2	20.0
2–3	3	30.0
4–5	1	10.0
Relative's length of stay in long-term care home (years)		
0–1.5	8	80.0
1.6–3	1	10.0
3.1–4.5	1	10.0
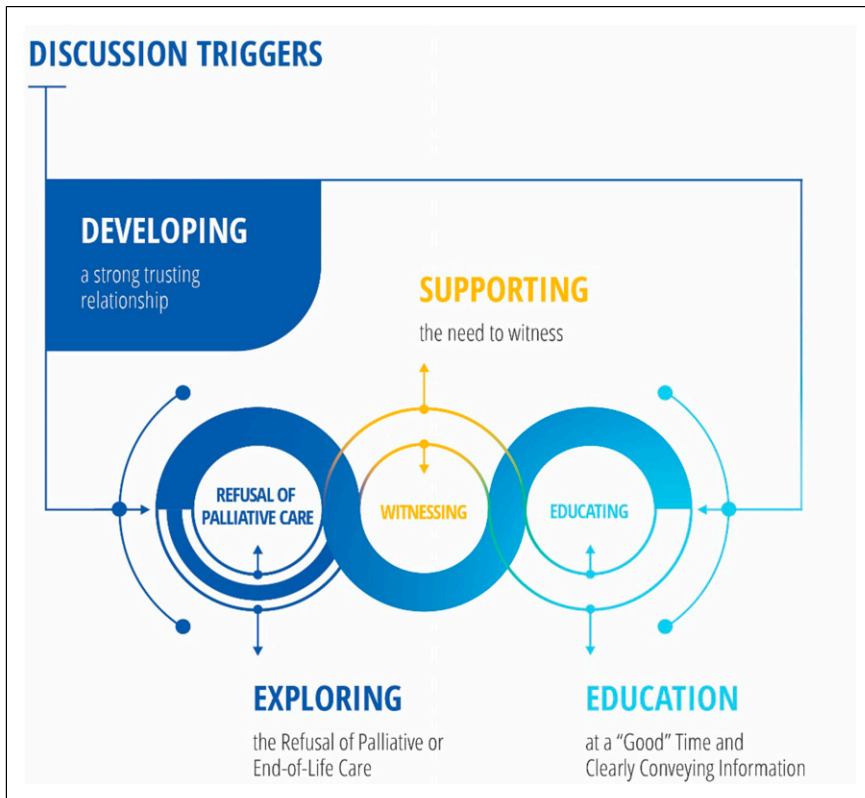
Figure 1. Theory of nursing support of relatives making end-of-life decisions for a person living with dementia.

Table 3. Components of the theory.

Triggers	- Admission
	- Onset of specific signs or symptoms
	- Decrease in quality of life
Developing and maintaining a strong trusting relationship	- Technical skills and clinical judgment
	- Transparent and proactive behavior
	- Genuine interest in residents and their relatives
	- Recognition of relationship difficulties
Exploring the refusal of palliative or end-of-life care	- Fear of abandonment or poor quality of care
	- Uncertainty, guilt, and hope
Supporting the need to witness	- Importance for relatives to witness the resident's clinical condition for themselves
	- Relatives' mistrust of the healthcare team if they have not witnessed the condition
Educating at the right time and using plain language	- Aspects to be addressed
	- Timing
	- Use of clear language, no euphemisms
	- Repetition, patience, and staying grounded in the present

supporting relatives' needs to witness firsthand the deterioration of the older person's clinical condition, and educating relatives at the right time with the information needed, using plain language. These different components of the theory are summarized in Table 3 and described in the following sections.

Triggers: When do we have to talk about the inevitability of my mom's death?

Although the decision-making process does not have a definite beginning or end, some events are more likely than others to lead nurses to initiate discussion with relatives about the end of the resident's life and its related decisions. The triggers identified in the data were the admission into a long-term care home, the onset of specific signs or symptoms, and a decrease in quality of life.

Admission. The protocols in place in the long-term care homes indicated that the level of care should be discussed and established shortly after admission. Participants confirmed that the weeks following admission were generally the first opportunity to discuss the interventions to be carried out once the resident's clinical condition deteriorated. Practices varied between long-term care homes, but it was generally head nurses or assistant head nurses who initiated these discussions before the physician officially prescribed a level of care. As required in the health system, this level of care was usually reviewed annually for each resident by the interprofessional team in collaboration with residents and their relatives.

Onset of specific signs or symptoms. For nurses, the onset of specific clinical signs or symptoms was an important indicator of disease progression and of the need to initiate discussion with relatives. Examples of fairly reliable signs of deterioration were a loss of muscle tone resulting in dysphagia, or a significant decrease in walking ability or tolerance. These signs indicated the need to discuss end-of-life decisions with relatives.

Almost all the time, it starts with food. Actually, with the muscle tone, [the resident] needs a geriatric chair, loses muscle tone and, with the loss of tone, dysphagia sets in. And with dysphagia, the patient eats less. Already, as soon as the person begins having dysphagia problems and uses a geriatric chair, we start talking with the family, talking about the [end-of-life] process. (Nurse 3, line 92)

Rigidity, drowsiness, anorexia, apathy, or repetitive infections without other apparent cause are other signs of deterioration in residents' clinical condition that trigger nurses to broach the subject of end-of-life with relatives.

Decrease in quality of life. Finally, both nurses and relatives mentioned the residents' deterioration or lack of quality of life as a turning point in the disease trajectory and an essential aspect to consider for end-of-life care. The definition of a "still acceptable" quality of life varied greatly among participants. However, one common element was relatives seeing that the older person could still recognize them, and both relatives and nurses pinpointed the moment when this was no longer possible as pivotal in the disease trajectory. Indeed, this turning point where they felt there were no more quality of life often prompted end-of-life discussions. One relative shared, with emotion, the moment he realized his mother no longer recognized him:

(...) we'd go to see our mother, take her hand when we arrived. '*Hello Mom, how are you?*' Her eyes would sparkle! But the morning I got there, took her by the hand, saying '*Hi Mom, how are you?*' as usual and, when she opened her eyes, … no reaction. That's when I said to myself, '*Oh my god*' (...) I felt … like she was cold, a dead person still alive. (...) She was already dead. (Relative 6, line 278)

For others, the loss of their relative's quality of life was associated with an inability to eat, a lack of awareness of their environment, or signs of discomfort the majority of the time.

Developing and maintaining a strong trusting relationship: Are you good enough to take care of my mom?

Nurses and relatives all brought up the central role trust plays in supporting the decision-making process. Indeed, a trusting relationship was key to relatives' acceptance of nurses' support. Regardless of the decisions made, the process was smoother when relatives trusted the healthcare professionals. Nurses were more comfortable in their interventions to guide relatives through the decision-making process. Relatives were also able to better reflect with nurses on residents' clinical condition and the interventions to be favored, since they were convinced that the healthcare professionals only sought residents' well-being and comfort. This trust then allowed nurses to implement effective support strategies.

To develop and maintain strong trusting relationships with relatives, nurses had to display several attitudes and skills, which are described below, and the healthcare team as a whole had to be stable—that is, the same professionals had to take care of the same resident as often as possible. These were conditions *sine qua non* for optimal nursing support in the decision-making process.

Demonstrating technical skills and clinical judgment. Relatives' capacity to develop an initial trusting relationship stemmed in part from their perception of nurses' technical skills (e.g., dressing a wound or administering an injection) and clinical judgment (e.g., interpreting vital signs or reacting to the onset of a new symptom and then intervening appropriately). Initially, relatives had a limited interest in assessing nurses' relational skills. They wanted to ensure that their nurses had the technical skills

and clinical judgment that would lead to a quick and efficient response in the event of clinical deterioration. Once this initial trust was built, relatives then assessed nurses' bedside manner.

Being transparent and proactive. To foster a trusting relationship with residents' relatives, nurses had to adopt a transparent and proactive approach. For instance, this could be achieved by immediately disclosing any unusual situation, such as incidents or accidents, and reaching out to explain the reasons why a particular treatment or intervention had not been done. This contact reassured relatives that the resident had not been forgotten. Instead, it informed them that temporary circumstances justified leaving a specific need unmet that day, as one relative explained: "They'd tell me '*today, we didn't have time*' or '*your father didn't want to,*' so I would understand." (Relative 12, line 195)

Trust was also built when nurses had a proactive attitude when a problem occurred, responding quickly and without relatives having to intervene. For example, one participant was relieved that after her mother had fallen into a closet when walking, as she frequently did, a nurse placed a foam mattress there. Being promptly informed of the situation and seeing the nurse intervene immediately to mitigate the consequences of a potential subsequent fall significantly increased the trust in this relationship. Moreover, this relative was convinced that the team's suggestion to start end-of-life care was the appropriate decision during her mother's pneumonia: "Because they always took great care of her and they always set the record straight and I trusted them and she [my mother] did too." (Relative 11, line 253)

Relatives mentioned nurses taking the time to answer their questions or to follow up if they did not know the answer as being important to trust-building. This was also the case with problems needing to be addressed or special requests: relatives' trust in the healthcare team was greater when relatives did not have to reiterate their position.

Demonstrating a genuine interest in residents and their relatives. The nurse-relative relationship was positively influenced when nurses demonstrated genuine interest in the resident and their relatives. This was manifested when nurses knew the residents and their habits, interests, and life story, and adapted their interventions accordingly. The relationship also benefited when nurses gave importance to the relatives who were present. A relative explained that this was why she trusted the healthcare team:

Their empathy, their kindness to my mother. They knew her very well. Empathy to want to help us, too. Then, when my father came to see her, the empathy for my father, wanting to chat with him and get to know him, too. (Relative 12, line 187)

Another way nurses confirmed their genuine interest was by recognizing the relatives' knowledge of the resident's needs. This recognition was demonstrated by involving relatives in discussions about daily care and the best ways to provide it to residents, as evidenced by the same study participant:

Sometimes I'd say, *'You know, my mother, this problem...' and she [the nurse] would answer, 'What do you think if we bathed her in bed instead? It would be less trouble for her' 'Ah, yes, I agree.'* Things like that, you know, being involved in the decisions. (Relative 12, line 31)

Recognizing relationship difficulties. Despite all the efforts invested, the trusting relationship was sometimes difficult to establish for healthcare professionals. For a variety of reasons, including difficult prior experiences in the healthcare system, some relatives displayed mistrust of the professionals and of the care they provided. Sometimes, nurses acknowledging the friction or

precariousness of the trusting relationship was enough to defuse the situation and foster relatives' openness, thus forging a bond and establishing communication with these relatives:

> I recognized that the trusting relationship was weak, so I told [the relative] '*I know you don't trust us*' and then I actually reflected it all, *'You think we drug her too much that it keeps her from eating. I know you don't trust us'* and just to acknowledge the lack of trust there, already, I think then we made a lot of headway. (...) Just naming it already repaired something. (Nurse 3, line 12)

Therefore, technical skills, transparency, proactive attitude, and genuine interest for residents and their relatives proved to be essential components in establishing a trusting relationship, which, in turn, allowed nurses to effectively support the decision-making process that guides the end-of-life of people living with advanced neurocognitive disorders in long-term care homes. The relatives who were convinced that the nurses worked for the residents' well-being expressed greater trust in the healthcare team.

Exploring the refusal of palliative or end-of-life care: Why give up on my mom?

Exploring the refusal of palliative or end-of-life care for a resident was also an essential part of the nurses' support of relatives' decision-making process. This exploration focuses on perceptions or beliefs that, in turn, could lead to interventions. Indeed, the fear of abandonment and of poor quality of care, feelings of uncertainty and guilt, and a need to maintain hope were all aspects related to relatives' refusal of palliative or end-of-life care.

Fear of abandonment and of poor quality of care. Some relatives associated end-of-life care with abandonment in two ways. First, relatives felt that, by accepting this type of care, they were giving up and thus abandoning the resident. For some participants, agreeing to palliative or end-of-life care was synonymous with provoking the resident's death or at least being responsible for it, as one nurse testified: "The family, [all the siblings], told me '*if we stop [the treatment], we kill her right there,'* [...] then, '*we're going to have killed our mother, you know*'" (Nurse 15, line 121).

Second, yet other relatives perceived professional suggestions to treat the resident's various symptoms with a palliative approach as abandonment by the healthcare team. In their view, not to intervene curatively was the same as not intervening at all. Similarly, some relatives felt that palliative or end-of-life care was poor-quality or limited care. These beliefs caused some study participants to fear that their relatives would experience significant suffering when cared for with a palliative, rather than curative, approach.

Thus, relatives' perception of abandonment—be it by the relatives themselves or the healthcare team—and the fear of poor quality of care were essential aspects that nurses explored when relatives expressed reluctance about palliative or end-of-life care. To work through these perceptions, nurses supported relatives by listening and validating the emotions they expressed. They then educated families by defining palliative or end-of-life care, the rationale behind the need to provide such care for the resident, and the care and supervision that were provided when a resident received palliative or end-of-life care.

Uncertainty, guilt, and hope. End-of-life decisions stirred a great deal of uncertainty and guilt among relatives. These latter doubted the resident really was "there" at the end of their life. They also feared making the wrong decision and living with regrets after the relative's death. A nurse described relatives' reactions:

> They feel guilty. They do not know if they are making the right decision and they wonder (...) "*Is that what my mother would have wanted, is that what my father would have wanted?*" So, they question and then... "*Could I do more if I asked for it? And if I don't, I'll feel guilty forever,*" so it is a lot... (Nurse 18, line 23)

To guide relatives through this uncertainty and the guilt that may ensue, nurses used the same strategies as for perceptions of abandonment or the fear of subpar care: they focused on educating relatives. By providing a better understanding of the resident's current medical state and the usual trajectory of the disease, they helped reduce relatives' uncertainty.

However, even when rationally acknowledging that the resident was at an advanced stage of the disease and their likelihood for improvement was poor, some relatives sometimes maintained hope that the situation would improve, if even slightly. Conversely, accepting palliative and end-of-life care or refusing a potentially curative treatment reduced hope that the condition would improve or that the resident's life would go on. One nurse said the following about relatives: "When we offer [end-of-life care], they are very reluctant because it means really giving up all possibilities of saving their relative, so for them it's very complicated" (Nurse 4, line 82). Thus, uncertainty may persist despite cognitive recognition of the resident's condition.

In these situations, nurses tried to instill a different hope, based on the family's beliefs. Turning the hope of healing into a hope of life after death, a return to God, a cessation of suffering or a peaceful death, for instance, allowed relatives to cope better with the situation and adjust their expectations for care.

Witnessing: But what have you done to my mom?

The importance of witnessing the relative's clinical condition was identified by all participants. Nurses mentioned this explicitly, and relatives, implicitly. To be able to accept a shift to palliative or end-of-life care, relatives had to be able to observe for themselves the resident's signs of deterioration. Moreover, the decision-making process was often more difficult when relatives were infrequently or not all present, since the resident's deterioration took them by surprise.

For some relatives, the inability to witness the resident's signs of deterioration or behaviours resulted in a significant mistrust of the healthcare professionals. For example, witnessing an episode of choking, even if minor, had a very different impact on relatives than being told by a healthcare professional that the resident had choked when eating. In some cases, relatives associated the deterioration of the resident's health with the care or medication administered by the nurses, rather than with the disease progression. A nurse described a situation in which the relatives persisted in their belief that their mother had little or no real agitation and that her current condition was due to the care provided:

> They blamed us for the situation, saying "*If she is in this condition, it is because you don't feed her. If she's in this condition, it's because you give her too many medications and things she doesn't like and so she doesn't eat.*" Even when we showed them the medical evaluations or met with the nutritionist... it was very difficult, the process was difficult. The situation changed when the patient's daughter saw her mother being agitated (...). She was really traumatized by this event, but then, from this point onwards, we were able to start talking [about end-of-life]. She witnessed the agitation, she saw it, when we said that her mother was agitated, it wasn't just that her mother got up and walked around a little, it was really 'She is agitated'! (Nurse 3, line 12)

However, even after witnessing residents' condition and behavior, some relatives were still unable to interpret the signs they observed or to associate them with the end-of-life. A relative, whose spouse had died in her absence, mentioned this non-recognition: "I didn't think he was going to die that night. I would have stayed!" (Relative 2, line 40). Yet, the husband's signs in the days leading up to his death, which the wife had witnessed, clearly indicated that he was in a precarious state and death was impending. Relatives do not systematically recognize the signs of end-of-life, thus underscoring the need for healthcare professionals to help them make sense of what they are witnessing.

Educating at a "Good" time and clearly conveying information: What is happening to my mom?

Participants explained the aspects to address when educating relatives, the importance of having a sound clinical judgment so as to be able to choose the ideal time to deliver this information, and the use of plain language by the nurse. Also, nurses' understanding of the decision-making process as non-linear and dynamic was necessary to effectively support relatives' decision-making process. This understanding was reflected in nurses' patience and respect of the need to repeat the same information to relatives again and again, for instance.

Aspects to be addressed. The essential information that needed to be shared with relatives related to the disease, how it manifests at different stages, and its expected trajectory. It was also important for nurses to address the impacts and risks of each of the treatment options available to the resident. For example, not adapting the resident's diet or "forcing" a specific diet on a resident who does not wish to eat or drink runs a risk of causing aspiration pneumonia. Nurses therefore had to explore the benefits of each potential decision, but also its risks, with relatives.

Ideal timing. Participants did not identify the same ideal timing for education about the disease trajectory: while some felt it was better to teach early on in the journey, others considered it to be more appropriate to focus on the signs and symptoms that the resident presented in the moment. All agreed, however, that moments of crisis, such as acute symptoms of pneumonia being displayed, were undeniably inappropriate times for education. Given the uniqueness of each relative and situation, nurses mentioned the importance of exercising their clinical judgment to determine the best time to initiate or continue educating relatives.

A relative, whose mother had been admitted to a long-term care home a few months before, also mentioned her current need to protect the hope she maintained and to live day to day, without looking too far ahead. She said that, for now, she did not want education:

> In the beginning, if we see too far ahead, if we know too much, it's too difficult ... if we go back to one day at a time, well, we say today, it's a good day and we will cross that bridge when we come to it. (Relative 13, line 63)

Plain language. The interviews highlighted the importance of clear communication when nurses provided education or information to relatives. Indeed, it was essential that they use simple but accurate terms when sharing information and, above all, that they avoid the use of euphemisms that might exacerbate misunderstanding in relatives. A relative, whose father had survived pneumonia in the months preceding his death from a second bout of pneumonia, reported this misunderstanding of the nurse's message about her father's condition just prior to his death:

> The evening nurse (...) said '*Oh you know, your father is not doing well at all.*' So, I thought, he's really not well, but they had already telephoned [during the first episode of pneumonia] to say that he wasn't doing well. (Relative 1, line 49)

This relative expressed surprise at her father's death since, although she had understood that he was "not well," she took this to mean that his condition was similar to that of the first episode of pneumonia, from which he'd recovered. She was not expecting him to die, even though the clinical signs reported during the interview clearly indicated her father's impending death and the care provided by the healthcare team was indeed end-of-life care. The choice of terms used by nurses to discuss residents' condition is therefore fundamental to relatives' understanding.

Repetition, patience, and keeping things grounded in the present. It was crucial for nurses to understand that decision-making is, in fact, a non-linear and dynamic process. For optimal understanding, certain relatives needed to receive education or information on a specific topic several times over a more or less extended period of time. It was essential for nurses to recognize this need and to respect relatives' pace whenever possible. Depending on the residents' health, some situations did not allow unlimited time for reflection. In these cases, nurses relied on the strategy of supporting relatives' need to witness the residents' condition, while ensuring that they reflected on their perceived well-being. Questions such as "*Do you feel that your relative is comfortable right now?*" "*Do you consider that he still has a quality of life?*" "*How do you find her compared to yesterday?*" (Nurse 17, line 31) allowed some relatives to better understand the resident's current condition and to see the suffering or deterioration.

Discussion and implications

The aim of this study was to propose a theory on the support of relatives who find themselves making end-of-life decisions for a resident living with dementia in a long-term care home. Considering the distinct culture and rules characterizing long-term care homes, the fact that advanced-stage dementia causes older people to be incapable of decision-making (Brody, 2016; Chambaere et al., 2015), and the prolonged end-of-life trajectory of dementia (Brody, 2016; Cohen-Mansfield et al., 2018), these findings are specific to the context of relatives making end-of-life decisions for an older person living with dementia in a long-term care home.

The proposed theory emphasizes the fundamental nature of the trusting relationship in the nursing support of relatives in this context. It was easier for relatives to accept the support from the nurses once this trusting relationship was established. Nurses also felt more comfortable in their role of supporting the decision-making process when they qualified the trusting relationship with relatives as a good one. This then allowed nurses to explore the refusal of palliative or end-of-life care and to support relatives' need to witness residents' clinical condition, as well as to educate at the best time by clearly conveying the information relatives needed.

Although the importance of a trusting relationship is not new, the findings of the study establish its powerful impact on the support of relatives' end-of-life decision-making process. In addition, they have made it possible to concretely identify the specific dimensions influencing the trusting relationship in this context. The literature clearly demonstrates several positive impacts of a trusting relationship with the healthcare team when discussing goals of care for dying patients (Rosemond et al., 2017). These positive impacts have also long been recognized in the various health professions, particularly in medicine where trust has an impact on the very well-being of the patient (Finniss et al., 2017), in psychology where it is strongly associated with the effectiveness of

psychotherapy (Lecomte et al., 2004), and in physical rehabilitation where it increases the adherence to treatment and the satisfaction rate (Hall et al., 2010). However, its effects on the continuum of end-of-life decision-making for people living with dementia in a long-term care home is an innovative aspect of this study. It implies the need for nurses to work actively to develop and maintain this trusting relationship with relatives.

Participants identified fear of abandonment as a reason for refusing palliative care, a reality already introduced by the existing scientific literature. Relatives faced with end-of-life decisions for a resident living with a major neurocognitive disorder at an advanced stage associate palliative care with poor-quality care (Lopez, 2009), limited care (Mann et al., 2013), or abandonment of the resident by the healthcare team (Gessert et al., 2006). The findings of our study provide a better understanding of this feeling of abandonment by specifying that it can indeed be associated with abandonment by the healthcare team, but also with abandonment by the decision-making relatives.

Scientific literature demonstrates that the allusion to palliative care in itself is sufficient to cause fear, anguish, sadness (Lefaucheur et al., 2019), and despair (Zimmermann et al., 2016). The fears associated with death and palliative or end-of-life care have been widely explored in oncology patients (Back et al., 2009) and their relatives (Odagiri et al., 2018). Our study confirms that relatives of a resident living with dementia have similar fears, often regardless of their relative's health status or age. Merrow (2016) affirms that "*when palliative care becomes invisible because it is completely ubiquitous in our practices and the system, our mission will have been achieved*" (p. 973). It could be argued that a better integration of palliative care in long-term care homes could lessen the fears and negative feelings experienced by relatives when making end-of-life decisions.

A significant contribution of our study is its finding that it is important for relatives to witness firsthand the signs of the older person's disease progression. This specific element is rarely addressed in the literature and, when it is, it has been related to family presence in the context of cardiac resuscitation or pediatric critical care (McAlvin & Carew-Lyons, 2014; McGahey-Oakland et al., 2007). In these situations, having seen maneuvers or interventions firsthand (rather than being told about them) reassured the parents that everything that could have been done had indeed been done. The nurses in our study pointed out that relatives who were unaware of the resident's signs of discomfort and disease progression had trouble grasping the situation and comprehending their relative's actual health status. Some such relatives even blamed the care provided by the healthcare professionals for the deterioration in their relative's health. To make informed decisions, relatives should ideally be present to witness firsthand the resident's clinical condition, while receiving support from health professionals.

In addition, the need for timely education and, especially, for information presented clearly by nurses without use of euphemisms is another important finding of our study. The findings show that relatives are not always able to make sense on their own of the information received or of the events experienced, even when the situation seems obvious to healthcare professionals. Professionals are therefore responsible for repeating education as needed, helping relatives interpret the information received, and ensuring relatives' understanding.

Lastly, it is important to develop better understanding of the phenomenon of relatives attributing residents' deteriorating health to the care provided, rather than to the progression of the disease. In the same vein, a better understanding of the impact of power relations and hierarchical issues would make it possible to further develop knowledge on supporting relatives.

Limitations

The main limitations of this study are the absence in the sample of relatives who had conflictual relationships with the healthcare team, and the homogeneity of the ethnic and cultural origins of the relatives who took part in the study. These limitations, however, were partially offset by the participation of nurses in the study, who described conflictual situations and cultural considerations in the decision-making process. Another limitation concerns the lack of participation of other members of the healthcare team, such as licensed practical nurses, nurse's aides, social workers, and physicians, which could have helped better delineate the nursing role from an interprofessional standpoint.

Conclusion

This study contributed to the development of knowledge on the support of relatives who find themselves making end-of-life decisions for an older person living with dementia in a long-term care home. Nurses and other healthcare professionals can guide relatives' decision-making process by actively developing a trusting nurse-relative relationship, exploring the refusal of end-of-life care, and supporting relatives' need to witness firsthand the signs of the resident's deteriorating health condition. When nurses better support relatives in their decision-making, the well-being of both relatives and residents in this last stage of life can only be improved.

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