

Table 38: Caron 2005⁸⁵

Study	Caron 2005 ⁸⁵
Aim	Examine the experience and preoccupations of family caregivers about end-of-life issues, and more specifically, about treatment decision-making processes in the context of advanced dementia.
Population	<p>FAMILY:</p> <p>Research sample consisted of 24 family caregivers involved in the care decisions for an older family member with late-stage dementia, as documented in the person’s medical record.</p> <p>A total of 20 care givers (4 spouses, 5 sons, 8 daughters, 2 nieces and a widowed daughter-in-law) agreed to be interviewed. The adult children and nieces ranged in age from early 40s to mid-70s. Among the caregiving spouses were 1 wife in her 60s, 2 women in their 70s and an 83-year-old man. At the moment of interview, 3 sons arrived with their wives and 1 wife requested that her son be present for their interview, resulting in interviews with 24 caregivers (17 women and 7 men) for 20 relatives with late-stage dementia.</p> <p>Regarding people with dementia, 15 women and 5 men aged from 63-96 years were receiving care in the long-term care facilities. Of these, 16 had died within the year prior and 4 were still alive at the time of the interview. The presence of dementia varied from 2 to 22 years and the period of institutionalisation ranged from 1 month to 16 years.</p>
Setting	Canada. Two types of long-term care facilities were involved in the study – a university geriatric institute and a group of publicly funded long-term care centres.
Study design	Grounded theory method of qualitative research was used. This allows a substantive theory to be generated that depicts the actions of individuals in a given social context.
Methods and analysis	<p>The recruitment strategy sought to interview the principal caregiver, as identified by two types of long-term care facilities involved in the study. Following the imperative of theoretical sampling, the selection criteria in this study evolved with the development of the theory as key factors appeared, including differing relationships (spouses, children, nieces) and genders.</p> <p>Each caregiver dyad participated in one in-depth interview, lasting approximately 1 hour and was recorded on audiotape in order to collect data in narrative form. The audiotapes were subsequently transcribed for analysis. IN the grounded theory approach, the questions posed during the early interviews were open-ended questions. As the research progressed through an iterative process, the analysis of each interview prompted questions for subsequent interviews. The constant-comparative method and line-by-line/dimensional analysis were used to code each interview. To ensure that personal beliefs of research team members were not imposed on the subject matter and to allow cross-validation in the interpretation of the interviews, at least two members of the research team participated in the data analysis sessions.</p>
Themes with findings	<p>One dimension that has an important influence on the decision-making process was the context of the interactions that caregivers had with healthcare providers. The 4 elements of this dimension are quality of the relationship, frequency of contact, values and beliefs and level of trust.</p> <p>Quality of the relationship:</p> <p>Family caregivers seek a personalised relationship with the care providers; personalised in the sense that the care team both understands the needs specific to the caregiver’s situation and displays empathy. In the absence of a personalised relationship, it was more difficult for family caregivers to have a sense that their experience was understood and considered important by healthcare providers, and thus more difficult to</p>

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	<p>promote their viewpoint regarding care of their loved one.</p> <p>‘The first meeting [with the care team] was quite formal. I mean, we had forms that we had to fill out. It seemed pretty routine to them. I think that those people are really pressed for time. It would be nice to take the time with them, just to talk and get to know each other a little more, it would make a difference. But they just don’t have time for that. If they’d taken the time, I think it would have changed everything. I mean you can’t just put people in categories A B C D. You know, mark here and she’s coded. C’mon, she’s a human being! Each case needs to be looked at individually and each case analysed ... according to what the family wants, who the person is, their past , how we will think tomorrow and then after her death ... that would be really personalised, I think.’ Niece 01.</p> <p>‘What I find with them [the care team], it’s that they are a bit cold towards us, as if these things happen every day, and they have built up a shell to deal with all the complaints. I got that feeling, I felt a wall there. “Hey, say what you like but we did our best.” For sure, I agree that they did their best, but I say to them “Just the same, you can’t put all the patients in the same basket.” Then they said “It’s all in your head, because you are aware of it, but your mother, she isn’t aware of it”. Hey, just a minute! It’s not as true as all that. So, it was difficult. From the first day I asked for a transfer.’ Daughter 08.</p> <p>Frequency of contact:</p> <p>One of the greatest dissatisfactions expressed by the family caregivers who participated in this study relates to the limited contact between themselves and the providers working with their family members. Certain families met with the care team or the doctor at the time of their relative’s admission to the centre in order to clarify family expectations with regard to treatment and to answer any questions about the person and his or her living conditions, whereas other families had no such meetings. Certain caregivers wished that regular meetings with the healthcare providers could have been planned.</p> <p>‘Well, for me, I think that in terms of the relationship [with the] family, it might have been good to have meetings with the staff, to see what is going on with [my relative], treatments, the evolution of the disease as well as getting to know each other a little bit. It would reassure us. When we can see that they really are interested in the patients and in us as well. But sometimes we get the impression that we are important but when it comes to the care of the patients, we don’t have a lot of say. Perhaps if we met regularly, we’d have a little more say in the decisions being made.’ Niece 01.</p> <p>‘It would have been good if, once a year, someone who really know what was going on with [my relative living in the long-term care setting] would have said to us “well, such and such a thing happened, things are like this now but we’re expecting this to happen.” Maybe we could get like an update once a year. It wouldn’t be a bad thing. And if we wanted to know more, we could phone the doctor. But rather than having to do this ourselves, and there are certain people at certain times, who have trouble reaching the doctor ... it would be ... perhaps a good suggestion to have someone meet with us once a year. Anyway, it would be a minimum, if you will.’ Son 05.</p> <p>It is important to note that nearly all the caregivers who took part in this study expressed the need to meet more often with the care team, in a formal manner. The caregivers do not specify a particular type of professional. In their view, such meetings would provide an understanding of the evolution of the condition or illness of their relative, an opportunity to receive answers to their questions from knowledgeable professionals, reassurance with doubts dispelled and a sense of being involved. Few care givers were fully aware of their role as decision maker.</p> <p><i>Interviewer:</i> ‘So you’re saying that it was important for you in those last moments, first of all, to be sure that she was not in pain?’</p>

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	<p><i>Family caregiver:</i> ‘yes, and to have someone answer our questions. Like, for us, they answered our questions. We asked them if we give her this, do you think that...?’” and they told us “She will be more comfortable, but we can’t give her more than 1 dose. They explained why and that was fine. We have to have answers to our questions. We’re suffering too, but we need to know what is going on.’ Spouse 03.</p> <p>Values and beliefs: Another dimension in the context of interaction with the healthcare providers that influences decision making, in terms of considering a medical treatment, is the concordance of values and beliefs between caregiver and the professional. The results of this study indicate that concordance of values facilitates decision making.</p> <p>Level of trust: ‘Pre-existing trust’ is an implicit trust accorded on the basis of the professional status and medical knowledge of the care team. Some caregivers did not feel the need to participate in care decisions because they did not see themselves as competent in this area. ‘So for me, I let them do their job. It is completely beyond my ability, I don’t know how [to administer oxygen]. They are the ones who know how to do that. We leave it in their hands because they know what they are doing.’ Son 05. Caregivers with pre-existing trust are the least likely to feel the need to participate in medical decisions, delegating these decisions to the professionals. However, for many caregivers, trust is built through interactions with the care team in the long-term care setting – referred to as ‘acquired trust’. ‘It’s not easy to abandon someone we love to other hands, many other hands. And the personnel is changing all the time. It’s not easy, it’s not obvious. And then, at one point we all become like a little family. We can trust them more. But they were being tested. And they passed. There was even an orderly who remarked to me “oh I’m so happy that I passed your test”.’ Daughter 02. ‘Myself, I like to be consulted. After all, she’s a member of my family, someone I love, and before treatment, I would like to be consulted before making a decision. So that I can ask questions, afterward, well, I tell myself that I can let them go ahead as they see fit ... because in the end, how can I trust them if they do whatever they want, as soon as my back is turned, without talking to me about it? I might lose confidence. I find that, trust is really important for the family to be able to trust these people, because we aren’t there every minute of the day. And if we know that they have consulted us it’s because they take our feelings into account, that’s really good.’ Daughter-in-law 02. A number of elements facilitate enabling trust: regular contact with the family, providing patient information on the progression of the disease as well as treatments to control symptoms, advising families of changes in the loved one’s condition, establishing a personalised approach and considering the family as a partner in the care of the person.</p>
Limitations	Serious limitations- Small sample size from a limited geographical area.
Applicability of evidence	Indirect evidence. Not all people had end of life decision making experience as 4 were still alive at time of interview. Results are not transferrable to all family caregivers, as participants in this study had a good relationship with their older family member with dementia and sought to be involved in the care of their loved one. Results may not apply to families with a long history of family conflict.