Table 39: Caron 2005B[86]

Study (ref id)	Caron 2005B[86]	
Aim	To explore the meaning attributed by family care givers to the end of life experience of a loved one with dementia.	
Population	Family care givers involved in the care decisions for an elderly relative with late stage Alzheimer's disease or a related dementia who was either alive or had died within the previous year, although no less than 3 months prior to the interview. These were recruited from long term care facilities, 1 with more medical input available and 1 with less. n=24. 16/24 of the participants loved ones had died within the last year, 8/24 were still alive. Of those who died, 1 died suddenly without intervention from septic shock. The remaining were treated with morphine, and some had oxygen, and antibiotics given in the last days of life as well.	
Setting	Canada in care home facilities.	
Study design and methodology	In-depth interviews were undertaken, these were then transcribed. Open ended questions were posed examples included: • Tell me about the last few weeks of your relatives life • What were (are) your concerns about the care of your loved one? • What were some of the decisions that you had to make about the care of your loved one? • How did making these decisions go? • How difficult was it to have a sense of what your (relative) was experienced? How did this influence the decisions you made? These questions became more narrowed as the interviews progressed and initial themes were analysed helping shape further questioning.	
Analysis methods	Each interview was coded using the constant comparative method and line by line/dimensional analysis. Particular attention was paid to the conditions under which the decision making process occurred and the consequences of this process for the caregivers their loved ones and other affected by the decision making process. Between 2-03 members of the research team participated in the data analysis sessions.	
Themes with findings	Facilitators	Barriers
		Ambiguity in the role of the surrogate decision maker: *"To know what I should do, what my role is. In the end we get so that we don't know any more"* *"oh they keep them alive as long as they can. It should be the family that decide or the person himself, he should decide. Instead of dragging things on… for a long time even. They should hold a meeting with the family and ask everyone if they agree or not".*
		Lack of medical understanding on part of surrogate decision maker: *".. For sure I want to be told about major changes in medication. I have no way of evaluating whether it's necessary for her to have it or not, so what could I say about it? I don't see it".*

Study (ref id)	Caron 2005B[86]	
		"… Leave it in their hands as they know what they're doing".
		Unavailable for support/discussion *"It seems to me that, when there is something, a, a decision to be made, they make it among themselves in their office. Why we are not included in what is going on… It becomes such a routine to them that they don't think to let us know. So we, we no longer know what is going on".*
Limitations	Serious limitations. Not all the barriers and facilitators listed in the discussion are supported by the quotes or results described.	
Applicability of evidence	Indirect population. 33% of those interviewed relative had not died, and was not in the last days of life. Canadian setting.	