

Table 52: Vig 2007⁴⁴⁹

Study (ref id)	Vig 2007 ⁴⁴⁹
Aim	To gain an understanding of the experience and challenges of surrogate decision making.
Population	n=50, Surrogate decision makers of older, chronically ill, veteran people. Eligibility criteria included being identified as a surrogate decision maker by the veteran, being fluent in English, being able to participate in a telephone interview, being free of moderate to severe cognitive impairment (as determined by fewer than 5 errors on Short Portable Mental Status Questionnaire) and previous experience with surrogate decision making (as determined by asking potential participants if they had ever made a medical decision for someone who was too ill to make their own decisions). 76% of those included had made end of life decisions, 10% surgical management decisions and 14% medical management decisions. 68% of those included were spouses, 14% adult children, 8% other family, and 10% friend.
Setting	USA.
Study design and methodology	Participants were identified from an additional study on veterans. Semi structured telephone interviews were conducted asking participants to tell the story of their loved ones illness, to describe their experiences making medical decisions for others and to reflect on what made decision-making easier and harder for them. Interviews were recorded and transcribed. Further participants were recruited until data saturation was reached.

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Analysis methods	A content analysis of surrogate's reports of barriers and facilitators was undertaken- the research team independently read 3 of the transcripts and then met to draft coding schemes, and continued coding until consensus was reached. Remaining transcripts were then coded by 2 of the researchers with quality assurance in place- the percentage agreement ranged from 68%-75%.		
Themes with findings	Theme	Facilitators to decision making	Barriers to decision making
	Surrogates characteristics and life circumstances	Previous decision making experiences <i>"I had lost both parents of the same thing, so I had been through it before. And so I knew how to talk to him and bring up stuff that I knew that I'd been through and so it did help a lot".</i>	Physical distance between surrogate and the patient <i>"I wasn't there with him to really talk to him person to person"</i>
		Positive coping strategies /managing stress/hobbies <i>"I think my own strength [helped me make the decision], because to not do something that someone has asked to me would be a harder thing to live with than not doing it".</i>	Competing responsibilities (aging parents, or surrogates own health).
		Religious community support/spiritual beliefs.	
		Decision the surrogate can live with.	Financial barriers.
	Surrogates social networks	Support and others to talk to and working towards consensus.	Family conflict <i>"Family's family and when they're dying they want to have their say... it was a hard time... But [my brother] and I finally came to an agreement because I found some sort of a way to wait for him to come to terms with losing our mother".</i>
	Surrogate – patient relationship and communication	Responsibility, keeping a promise to the patient <i>"I had made a promise to him. It was that simple... You make that kind of commitment and you've got to do what you've got to do to see that its fulfilled... he was helpless, there was nothing more he could do".</i>	Not being able to follow the patients preferences <i>" I think the only thing that made it difficult was that I did know his wishes... to have his demise here at home, and we couldn't do it for him. We had to make the decision to take him into the hospital so that he would be more comfortable in his last hours".</i>
		Decision will result in a good outcome (that is, reduced suffering).	Emotions or attachment to the patient.
		Being involved- keeping up on the patients' medical condition <i>" I don't think I could've made those [decisions] if we hadn't</i>	Weighing a person's preferences against their quality of life.

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Surrogate- clinician communication and relationship		<i>discussed it</i> ".	
	Clinician availability		Too many involved clinicians
	Frank information from clinicians in lay terms (prognosis, chances of recovery, how a person would die after withdrawal of ventilator support)		<i>"There was just too many people: there were too many different stories. I was being told one thing and when another team would come through, they'd tell me something else. I was so confused during that time, I didn't know what was going on. At that point I said 'I want to speak to one person and one person only. I can't take in all this stuff'".</i>
	Recommendations from clinicians <i>"I talked to the doctors, and they all were very helpful in giving me proper information, and telling me that he probably wouldn't come out of it because his cancer had spread and plus he'd had pneumonia on top of it"</i>		
	Positive reinforcement for decision making Respect from clinicians <i>"Dr f. was fairly new to me, but when a doctor treats the spouse with a lot of respect and answers questions like they're important, they give you the feeling of competence. And I think Dr F made me feel like a very important part of the team"</i> .		
Limitations	No limitations. Well designed and analysed study.		
Applicability of evidence	Indirect population. Only 76% had made end of life decisions, unclear if there were themes directed towards this particularly or in general. Unclear if the patients had died or where in the last days of life in the study. Setting outside of the UK.		