

Table 43: Lind 2013²⁹⁰

Study	Lind 2013 ²⁹⁰
Aim	To explore to what extent and in what ways can family members of alert and assumed competent people be involved in information and decision-making processes regarding possible termination of treatment.
Population	<p>n=11, inclusion criteria: age over 18 years old of both the patient and the family member, daily visits by the family member. The family member was invited to interview within a year of the person dying, the person was alert and had assumed competence in the decision making process. Multiple members of the family who met the criteria were included, ranging from single participants to a 1 group of 3.</p> <p>This was part of a larger study which looked at 27 family members of 21 hospital patients. This study is also included in the report, but it is unclear</p>

	whether these patients' data were reused in this study.
Setting	An ITU in Norway
Study design	Focus groups for each family were undertaken by two researchers. One researcher was an ITU nurse and it was unclear whether they had a prior relationship with the participants during the person's stay in ITU. A semi structured interview guide was used but not provided for extraction, but questions related to the interaction with healthcare professionals, experiences of the communication in the end of life discussions and the content of the conversations. The participants were also asked their experiences of how the clinicians assessed the person's autonomy and decision-making capacity. The starting questions was ' <i>Can you tell me what happened?</i> '
Methods and analysis	The interviews were transcribed from digital recording and analysed using thematic narrative analysis, each analysed separately using hermeneutic approach. Emergent themes were then compared across the other interviews. Unclear who was involved in this process.
Themes with findings	<p>Transparency in communication- Due to the alert condition of the person's condition, some of these 6 families experienced less attention paid to their informational needs, which then had ethical implications for their ability to support and protect the patient. The family members were often informed separately to the dying person. This led to confusion over the information that had been given to the dying person, and concern from the family members that they were adequately informed to make decisions:</p> <p><i>"The doctor said he knew everything. That he got the same information as us. But he had great difficulty in talking. he had a tight mask on and was dependant on it. He had trouble making clear enough signs for us to understand him"</i></p> <p>There were also concerns raised by family members on how the competence of the patient had been assessed.</p> <p>Participation in the end of life decision making process, patient consent and the role of the family- the family members described a desire to be involved with the decision making process. There were 3 different experiences described:</p> <ol style="list-style-type: none"> 1. Shared decision making- Between the patient family and critically ill person of a person who had given the decision making responsibility to her daughters <i>"It is was absolutely crucial for us that we were included and we knew she was taken care of like that"</i> 2. Acceptance of the physician's decisions- this included examples of uniformed participation in decision making, where not enough information had been provided to the family member and yet they were asked to make a decision on the dying person's behalf. 3. Information of the physician's decision- some families reported being informed of the physician's decision without any evidence of shared decision with the patient or themselves. These situations were described as offensive and these families struggled with the memory of the ways this was done. Nurses did not participate in these talks. <p>Responsibility in the decision making, a matter of ethical intertwinement- When a person had capacity the family members main role was reported as supportive to facilitating decision between the patient and the healthcare provider. When the family members acted as surrogate decision makers their responsibility was firmly justified by acting in the person's prior informed wishes. When the family were not adequately informed or involved in the decision making they often felt responsible for the decision:</p> <p><i>"I've thought a lot about this. Did I do the right thing? Did I do the wrong thing? I understood that we were asked consent and I feel responsible for this. There and then, if I'd been asked there and then, I'd have said no. She seemed so much, much better. She was quite alert with bright eyes."</i></p>
Limitations	Serious limitations – Analysis process not fully described, no information given on theme saturation.
Applicability of	Indirect setting outside UK.

evidence