

Table 42: Lind 2011²⁸⁹

Study (ref id)	Lind 2011 ²⁸⁹
Aim	To examine family members' experiences of end-of-life decision-making processes in Norwegian intensive care units (ICUs) to ascertain the degree to which they felt included in the decision-making process and whether they received necessary information.
Population	Family: Twenty seven bereaved family members of 21 former ICU patients 3-12 months after the person's death.
Setting	Norwegian ICU.
Study design	A constructivist interpretive approach to the grounded theory method of qualitative research.
Methods and analysis	<p>A constructivist interpretive approach to the grounded theory method of qualitative research was employed, with interviews of 27 bereaved family members of 21 ICU patients who died after a decision to withhold or withdraw life support.</p> <p>Three university hospitals and 1 district hospital participated in the study. Hospitals were selected based on their ICU size (>8 beds) and type of unit (general ICU). A sample size of family members was selected from each IC's patient database by local research coordinators. Inclusion criteria were age greater than 18 years for both the person and the family member. The decision to withdraw treatment was documented in the patient records. Families who had been asked to consent to organ donation were excluded.</p> <p>Most interviews took place in the participant's home. Due to long distances, two interviews were conducted via telephone.</p>

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	<p>The interviews were held within 3-12 months after the person's death, with an average of 9 months. The interviewer used an interview guide as a background tool to ensure relevant topics were covered in the dialogue. The interviews lasted about 1 hour and were digitally recorded and transcribed verbatim. The data were organised using NVivo.</p> <p>First, individual interviews were thoroughly analysed by two researchers (G.F.L and R.L.) with relevant episodes then isolated and arranged into themes. Using the interpretive grounded theory method, the themes were coded and named. The concepts emerged within single interviews and between interviews, although the emphasis remained on the whole, as in a hermeneutic circle. In organising the data, initial codes were chosen to facilitate analysis. The cases were then labelled based on the participant's experience of inclusion in the decision-making process and then divided into two groups. The underlying assumptions of the different cases were compared. A common key concept emerged: 'wait and see.'</p>
Themes with findings	<p>Most participants were not included in end-of-life decision-making. The expression 'wait and see' was experienced by participants from both groups and it was related to communication with both physicians and nurses. Five subthemes demonstrate the variety in this main concept; unavailability, ambivalence, disparate comprehension, delayed communication, shared decision-making.</p> <p>Unavailability:</p> <p>Few participants experienced regular physician communication. The physicians often seemed busy, did not keep appointments and left the family waiting for hours. When family members did succeed in meeting a doctor, they found they were rarely given enough time for proper dialog. One daughter, who was with her father for 1 week in the ICU state: 'There was little ... very little communication. The only time we talked with doctors was that time the two doctors sat down with us. We had no contact apart from what we heard from the discussion when they arrived on their rounds.' (no. 8).</p> <p>Many families felt that they needed more frequent discussions concerning the perspectives of the treatment. One family member said: 'There were ... lots of questions I could ask, but I would not get an answer (from nurses). A doctor had to answer them ... But then ... then It seems a bit of an uphill path to get information and arrange a meeting with a doctor ...' (no. 18).</p> <p>Nurses rarely participated in meetings between families and physicians.</p> <p>Ambivalence:</p> <p>In retrospect, many felt that uncertainty was hidden behind a focus on continued full treatment and the hope for improvement. A wife said that 'they never actually said it would not work out, to start with. They had hope and we clung to it.' (no. 9).</p> <p>Disparate comprehension:</p> <p>In retrospect, the families realised that 'wait and see' was in fact used to convey treatment termination at a given time, unless there were unexpected signs of improvement. Others had previously understood it as meaning that the doctors were uncertain about the outcome. However, several family members felt that the end-of-life discussion after the 'wait and see' period was over came up too abruptly.</p> <p>Delayed communication:</p> <p>The 'wait and see' period sometimes delayed the important part of the discussion regarding the decision-making process and made it difficult for the family to recognise their role as surrogates for the patient. Some family members were relieved to discover that the physicians are responsible for decisions, but still had a perception of the importance of their own contribution. One woman, married for more than 30 years, said: 'My</p>

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	<p>husband and I were very conscious of wanting to be the closest relatives and part of this was to be confident that the spouse made the best decision'. (no. 1).</p> <p>Despite the fact that few people had previously discussed end-of-life goals within their family; the relatives believed they knew the end-of-life wishes of the patient. They based this on their previous generalised conversations on moral values and end-of-life goals. This carries with it a strong feeling of responsibility to communicate this knowledge to the clinicians.</p> <p>Several family members, while presuming that the correct decision had been made, would still have preferred greater involvement in the decision-making process. Looking back, 1 son said: 'Her quality of life was not part of the discussion ... no, in fact it was not ... They should have discussed it with me ... that is what I think. It is actually a moral question. It is really difficult.' (no. 18).</p> <p>Several family members recall the situation as emotionally charged. Some were left with unanswered questions, leading to doubt about whether the correct decision had been made. They were unsure whether they had received all necessary information or if there were other aspects to be considered.</p> <p>Shared decision-making:</p> <p>For a few family members the 'wait and see' period worked as a preparation phase for the decision-making process. These families experienced early family meetings in which clinicians made efforts to establish a relationship and provide family with emotional support. In later meetings, the person's preferences were discussed and treatment goals were revised. Nurses sometimes took part in family meetings. An elderly man who lost his wife said: 'In a way, I was prepared by the process which went on continuously and the talks with those two fantastic professionals. And it was obvious to me that it was her life it was all about, and on the doctor's recommendation I saw no reason to continue the treatment.' (no 12).</p>
Limitations	Serious limitations. Recall bias: impossible to know if participants recollect ion exactly describe their thoughts and feelings at the time of the decision.
Applicability of evidence	Indirect setting. (Norwegian ITU).