

**Table 51: Tilden 1995<sup>432</sup>**

Study	Tilden 1995 <sup>432</sup>
Aim	<p>To describe how families reason about a decision to withdraw life support.</p> <p>To describe the positive and negative effects of physicians' and nurses' behaviours on families during the process</p>
Population	<p>Family members (n=32) of people (n=12) without advance directives whose deaths followed a stay in the intensive care unit and withdrawal of treatment.</p> <p><b>PATIENTS:</b></p> <p>Eligibility criteria of patients: aged 21 years or older, unable to make decisions at the time of death, had been hospitalised at least 3 days before death, were without formal advance directives and had family who participated in a decision to withdraw life support.</p> <p>The deceased people whose families participated were all white, 2 thirds were male, half had private insurance and half had public sponsorship or were without payment coverage. Although the length of hospitalisation before death varied widely (range: 5-79 days, mean 24.9 days, SD 24.6 days), half of the patients were hospitalised for 12 days or less. Diagnoses included cancer, gastrointestinal disease, cardiac disease, heroin overdose and motor vehicle accident trauma. Half the patients were on the medical service and half were on the surgical service. All patients spent at least a brief period of time in the ICU, although half of all deaths occurred in the acute treatment unit. Although the mean age was moderately advanced (64.3 years, SD 16.03, range 41-94), three quarter of patients were between 41-69 years.</p> <p><b>FAMILY MEMBERS:</b></p> <p>More than half the family members were adult children of the dead people, about a quarter were spouses and the rest were parents, adult siblings or extended kin. The mean age of family subjects was 50.4 years.</p>
Setting	USA Tertiary hospital in a major university medical centre and level I trauma centre.
Study design	Semi structured interviews.
Methods and analysis	<p>Families were contacted 2 to 6 months following the death of the eligible person. Informed consent was obtained from 55% of the families who were contacted.</p> <p>Intensive 1- to 2-hour-long individual interviews were conducted using a semi-structured interview protocol and focused on the family's decision to limit life support and their experiences of the person's final days. Demographic information of participant was also collected at the beginning of the interviews. The majority of family members were interviewed individually in their homes or places of work. About a quarter of participants lived a long distance from the hospital and were interviewed by telephone.</p> <p>None of the authors were directly involved with any of the patients or their family members. Interviews were conducted by 1 author.</p> <p>Interviews were tape recorded and transcribed verbatim, producing more than 700 pages of narrative data. Content analysis was used to analyse the data. Multiple readings of the first 5 interviews by the authors led to an agreement of 10 main categories of data, which were further divided using 38 codes. Each transcript was then read and coded separately by 2 of the authors. Comparison of the 2 sets of coded data indicated 90% inter-rater reliability on codes independently selected from data segments. The 2 raters then jointly reviewed and discussed each code transcript until full agreement was achieved on the selection of codes for the data. Once all data were in final coded form, a computer software program (Ethnograph) was used to cut and sort the data by code and category.</p>

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Themes with findings	<p><b>Dawning awareness:</b></p> <p>Subjects said that physicians and nurses usually eased the family gradually toward the understanding of the possibility of withdrawing life support through tentative and cautionary statements that laid the ground work for patient’s death. Subjects reported that clinicians typically used phrases such as “he’s starting to fail”, “it doesn’t look good” and “I think he’s not fighting anymore.” The idea of withdrawal followed soon after, typically preceded by statements from physicians such as “let’s try another day of treatment and then see” and “we’ll try one more test and see what it shows us.” Acknowledgement of withdrawal as an option came from either the nurses or the physicians or both more or less simultaneously. Typically, phrasing at first was cautious, diplomatic and open-ended, for example “we’ll probably have to make some sort of decision ...” Most families realised a time for decision-making of some kind was approaching but felt it was up to the clinical team to lead the way. For example: ‘I can’t remember which nurse brought it up but they did it very diplomatically and of course I knew it was going to have to be done. But it was nice that someone else could sort of start the process for me. And I think then I talked to Dr X and he said, “You know, that is one option” and they were very, very careful about it.’</p> <p>Most families greatly appreciated the thoughtful and unhurried approach to withdrawal taken by staff, for example: ‘The doctors brought the subject up just a little bit, and of course I think they knew that I was aware, but sometimes it’s a little hard to say. I thought they handled it very well.’</p> <p><b>Framing the question:</b></p> <p>In some families, being asked the question lead to feelings of burden, while in others it led to feelings of inclusion in the care-giving team and empowerment to look after their family member’s interests. A subject said that the feeling she remembered when the physician asked the question was “Oh my god, you know, then <i>we’re</i> deciding life and death here ...?” Families who experienced being asked the question as indicative of inclusion and empowerment spoke of being an active and contributing part of the clinical team and not having to fight to be heard. One husband said that he feared he would have to fight the physicians for what he thought his wife would want and was relieved to find the physicians completely open and honouring of his input.</p> <p><b>Reasoning about the decision:</b></p> <p>Some families wondered about legal constraints (“We didn’t know ... what was legal or not legal about how far to go”) and needed to be told that withdrawal of life support was legally permissible before they were able to further reason about decision options.</p> <p><b>Families’ interactions with physicians and nurses:</b></p> <p>Subjects described overwhelmingly positive opinions of providers. Physicians and nurses were described with great feeling by families as inclusive and involved.</p> <p>Supportive behaviours:</p> <p>Many families noted how well staff included them in both the day-to-day care of the person and the decision-making processes about the person’s</p>

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	<p>treatment. The fact that staff gave both expert medical care <i>and</i> sensitive emotional care was valued highly. As 1 daughter said: ‘They treated him [the patient] as if he were their own father. They treated me as if I were part of the healing team.’</p> <p>Even as prognosis worsened and staffs’ efforts shifted toward comfort care, families felt tremendous support rather than abandonment. ‘we just can’t say enough about the hospital and the nurses and the care. They never lost their cool or never gave up. They were fighting just as hard as she [the patient] and we were.’</p> <p>Families valued physicians especially for their effectiveness in communication, which they described as timely, frequent, unhurried, honest, compassionate and available. Families were hungry for information, even small details and spoke warmly of physicians who: ‘...answered every question we ever wanted to ask without acting like it was foolish or they didn’t have time...’</p> <p><b>Burdening behaviours:</b></p> <p>Although positive experiences predominated and were more often described spontaneously by subjects, with further questioning families described a variety of experiences with staff that led to feelings of burden and exclusion. The experiences most often related to problems with attitude, communication, timing of withdrawal and dealing with family conflict. Regarding attitude, several families commented negatively about some physicians (interns, residents) who seemed to view the person’s death as a failure and who acted defensively or who distanced themselves. A few families noted that some physicians do not seem comfortable saying ‘I’m sorry’ after the death:</p> <p>‘... doctors just don’t say I’m sorry, and I don’t know why, except that perhaps they feel that they have lost a patient and they would be admitting a failure.’</p> <p>Problems with communication were not common but when they occurred they were distressing. Occasionally families did not understand staffing rotations and found it confusing to talk with different staff members who provided different information or perspectives.</p> <p>‘You got different messages, depending on what particular doctor it was and what that doctor was looking at. So sometimes that might be positive and then the next doctor would come in and say well, this isn’t so good” and so that was real confusing ...’</p> <p>Two families were upset that information regarding prognosis and the possibility of withdrawal was presented to them at the person’s bedside. A granddaughter said: ‘The one doctor, the way he was talking in front of [the patient], I felt like hitting him over the side of the head and saying “wait a minute, this is a person here ...”’</p> <p>Regarding timing of withdrawal, several problems occurred. One family, for whom the withdrawal of the ventilator from the person had been postponed several times for reasons unclear to them, blamed the staff for the emotionally difficult delays, saying the staff were afraid of the responsibility and:</p> <p>‘... wanted the patient to live at least a few hours after they took it off to save their own nerves so they wouldn’t feel like they were killing him.’</p> <p>Another family felt that the staff waited too long before coming to grips with withdrawal. When the family brought up withdrawal of the ventilator because they thought that the patient was suffering, the intern on duty quickly dismissed the idea:</p> <p>‘The young ones are gung ho and they’re going to save his patient no matter what. The doctor’s position was “As long as there’s life there’s hope.” And we thought, well, hum, yeah, but this is painful, you know, for him and for us to watch him being in pain ... as long as there’s true hope, that’s</p>

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	great, but if there isn't ... so that was frightening.'
	<b>Communication and information transmission:</b> Families were, as 1 man said, 'starving for information.' Many families spoke of the need for more information, more timely information and better coordination. Although they appreciated, on the whole, that clinicians are understandably reluctant to give information prematurely that may later change, many subjects appealed for early and direct talk. Families wanted physicians to be honest about poor prognosis as soon as possible so that they could be prepared. Families requested more reading material in lay language about the person's condition and hospital policies, and more specifically directions about ICU expectations (for example, appropriate length of visits, best timing of visits, how to touch the person, how they could participate in the person's care, where to wait during procedures).
	<b>Families in conflict:</b> Significant conflict was found in several families regarding who exactly compromised the family or who had decision-making authority. These families advised physicians and nurses to take more time to clarify the composition of family, to provide a private setting for discussions so that conflicts within the family can surface and to limit the involvement of others peripheral to the decision.
Limitations	Serious limitations. Only 55% of those included in the study participated in interviews
Applicability of evidence	Indirect setting, outside of the UK.