

**Table 28: Anselm 2005**

Study (RefID)	Anselm 2005 <sup>28</sup>
Aim	To determine the barriers to communication regarding end-of-life care
Population	n=67 healthcare professionals (10 attending physicians, 24 residents, 33 nurses)
Setting	General medical unit at a tertiary referral unit in Canada
Study design	Focus groups
Methods and analysis	<p>Participants were segregated into 11 homogenous (in terms of training, status and experience) focus groups to facilitate open and frank discussions. Each group was led by 1 or 2 interviewers with experience in qualitative research in medical settings. Sessions were approximately 1 hour in duration. Participants were paid a small honorarium.</p> <p>Interview schedule designed to elicit information on 1) who was responsible for initiating end-of-life discussions 2) perceived institutional, patient and family barriers to discussion 3) personal difficulties in initiating and participating in such discussions 4) views on what should happen during such decision making 5) personal and institutional problems encountered 6) how hospital management could help facilitate the resolution of these difficulties 7) suggestions on interventional strategies for educating providers on approaching end-of-life discussions.</p> <p>Qualitative analysis of content.</p> <p>Audiotapes of interviews were transcribed verbatim. Six analysts with qualitative research experience independently reviewed the transcriptions and identified word clusters that corresponded to discrete ideas related to barriers. A list of themes describing these ideas was developed by each analyst, then themes were distilled using the Delphi method.</p>
Themes with	<b>Recipient barriers</b>

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findings	<ul style="list-style-type: none"> <li> <p><b>• Exclusion by family of patients or their wishes</b>                      “I’ve had a couple of instances where the patient himself/herself was very calm and could appreciate the discussion and could carry on a reasonable conversation but the family didn’t want this discussion with the patient. Quite often we tell them that that’s inappropriate because where they can, the patient is still in charge of his or her own decision making. On occasion the family is the biggest barrier”</p> </li> <li> <p><b>• Difficulty in designating a decision maker or reaching consensus</b>                      Families have difficulty either determining who the decision maker is, or what the family’s consensus is regarding the desired level of intervention.</p> <p><b>Family tensions</b>                      Coping mechanisms of individuals increase family tension and make it difficult to establish communication. These feelings include feelings of intense guilt, relieving stress through confrontation and distancing themselves from the discussions.  <i>“The family wanted us to do everything despite realising that it was futile and that this patient was going to suffer and so we felt that there was some inner guilt in the family members. They just wouldn’t let the patient pass on and they would let us use the right to make the decision not to resuscitate”.</i></p> </li> <li> <p><b>• Differences in culture or values</b>                      Certain cultures religions or other sources of deeply held values may conflict with those of providers</p> </li> <li> <p><b>• Variable capacity to understand and appreciate discussions</b>                      Patients or family incapacity to understand or appreciate these discussions limits communication  <i>“Quite often the family is confused and although you have an idea about how you want to manage the patient and what would be appropriate actions, the family doesn’t necessarily understand you”.</i></p> </li> <li> <p><b>• Appropriate timing</b>                      A poorly timed discussion may raise anxiety in or alienate people who are relatively well, young, insufficiently informed about their condition, afraid of death, unprepared for death or who have not achieved closure in a personal relationship.</p> </li> <li> <p><b>• Temporal lability of appropriateness of resuscitation</b>                      The appropriateness and desirability of resuscitation might be different at different times for either the patient or provider.</p> </li> </ul> <p><b>System barriers</b></p> <ul style="list-style-type: none"> <li> <p><b>• Suboptimal coordination of information exchange</b>                      Providers in teaching hospitals do not communicate optimally with each other or with other institutions regarding end-of-life discussions even if these have occurred previously. The system for sharing information is inefficient. The resultant uncertainty regarding optimal management can delay initiation of communication.</p> </li> <li> <p><b>• Impersonality of large teaching hospitals</b>                      Teaching hospitals are large impersonal institutions care is typically short-term with minimal involvement of community providers.</p> </li> </ul>

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	<p><i>"It's not easy, Decisions for us are different from those made by long term care physicians; our usually short term relationship with patients can pose a barrier... my willingness is reflected by my not really knowing the patient on a long term basis"</i></p> <ul style="list-style-type: none"> <li>• <b>Providers unskilled in discussions as a result of specialization in certain areas</b> In teaching hospitals care is specialty-based; certain specialties are unskilled at conducting (or recognising the need for) these discussions.</li> <li>• <b>Scheduling difficulties</b> Busy work schedules of providers and the physical environment of hospitals make it difficult to arrange for private discussions.</li> <li>• <b>Lack of external support</b> External factors work against providers to create barriers to discussion: fear of legal action, lack of effective policy documents, and lack of institutional resources including education programs, better staffing or 24-hour support for ethical decision making by resource people.</li> <li>• <b>Risk of abandonment for "DNR" patients</b> "DNR" labels the patient and leads to abandonment or less aggressive care by others <i>"One of the problems that I've come across is that when you do put a DNR on a patients chart they frequently do not get the sake care that they should get up until the point where they have to be resuscitated, It does brand them...that's the one barrier that I have to the idea of DNR"</i></li> </ul>
	<p><b>Provider barriers</b></p>
	<ul style="list-style-type: none"> <li>• <b>Inadequate expertise in prognosticating and leading discussions</b> A lack of expertise due to inadequate training or inexperience makes providers feel uncomfortable about leading these discussions</li> <li>• <b>Discomfort with emotion involved</b> Identification with the person and/or other emotions, makes these discussions difficult <i>"Some doctors have difficulty...we had 3 physicians recently who, no matter how hard we tried, they never would talk with the patients and family about this... they themselves had difficulty dealing with it... they couldn't come to grips with it"</i></li> <li>• <b>Role ambiguity</b> Providers' roles and responsibilities in this domain are not well outlined; they fear reprimand due to overstepping the boundaries of their position</li> <li>• <b>Prognostic uncertainty</b> Providers prefer not to discuss end-of-life care until they are certain that the patient's prognosis is dismal. <i>"Often you don't know with 100% certainty that there's no hope... It's awkward but I guess you can say that the chance is unlikely or less likely. However, people often want you to be more specific and that's hard because again, you just don't know"</i></li> </ul>
	<p><b>Dialogue barriers</b></p>
	<ul style="list-style-type: none"> <li>• <b>Nature of "DNR" that may be perceived as nonsensical or defeatist</b> Discussing or ordering "DNR" is either nonsensical (because it specifies things not to do which is unique) or inappropriate because it is seen as being defeatist</li> </ul>

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	<ul style="list-style-type: none"> <li>• <b>Societal values surrounding death</b> Society does not generally recognise or appreciate death as a natural and acceptable part of life this is reflected in expectations of unrealistically high survival rates from CPR due to media portrayal.</li> <li>• <b>Lack of trust in providers commitment or competence</b> Recipients of care lacked trust in providers. They questioned providers' commitment or competence by charging that issues such as resource allocation were interfering with acting in their interest or by simply not believing their diagnosis or prognosis.</li> </ul>
Limitations	Serious limitations – unclear what precisely is encompassed by the phrase “end-of-life discussions”.
Applicability of evidence	<p>Context not specific to discussion of likelihood of entering last days of life but appears, from themes elicited, to be part of issues discussed within focus groups.</p> <p>Setting outside UK, therefore system barriers may not be appropriate for UK context.</p>