

Table 30: Gutierrez 2012

| Study (RefID) | Gutierrez 2012 ¹⁹¹ |
|----------------------|--|
| Aim | To describe the experiences and needs of family members surrounding prognostic communication for people at high risk of death in an ICU. |
| Population | n=20 family members of people with a greater than 50% chance of in-hospital mortality on the basis of clinical criteria. Female: 70%, white: 90% |
| Setting | 22 bed adult medical/surgical ICU in a community hospital in the USA |
| Study design | Semi-structured interview. |
| Methods and analysis | Purposive sampling used; families were interviewed (either in the family waiting room in the ICU or in the patient’s own room) until data saturation occurred. An iterative content analysis data process was implemented. |
| Themes with findings | <p>Experiences with prognostic communication.</p> <ul style="list-style-type: none"> Hearing and recalling information Family members described cognitive difficulties and feeling overwhelmed by the situation. This was greatest for those who did not anticipate hospitalisation, when events happened unexpectedly. Their ability to think and process information was perceived as being much slower than usual. <i>“Communication is difficult for two reasons. One, as a family member you are so overwhelmed by what’s just taken place especially if it’s in a situation like this where it was so unexpected. There’s not been a process of she’s getting worse. This was a sudden thing...Cause you’re so overwhelmed that you forget everything that has been in place (discussion of patients wishes) before this crisis happened”.</i> Accessing information Family members perceived a need to gather information regarding the person’s condition, treatment plan and prognosis throughout the stay, representing a significant form of work. While easy access to nurses was appreciated it was noted that they were often too busy to sit down and talk with families. Most family members described wanting to talk to a physician. They described frustration with the amount of time waiting to talk to a physician as well as difficulties knowing who to ask questions of and knowing who was “in charge” of decisions (due to a number of specialities being involved) |

| Study (RefID) | Gutierrez 2012 ¹⁹¹ |
|---------------|--|
| | <p>in care). Rotation of healthcare staff also provided difficulties to family members, having to get to know different providers in order to develop a relationship upon which to access information.</p> |
| | <p>• Interpreting information</p> <p>Once they were able to access and “hear” information, family members often struggled with making sense of it. Family members found it difficult to clarify their understanding since they did not possess a foundation of knowledge in order to be able to identify appropriate questions. If they did have questions many either did not know who to ask or did not want to ask due to a fear of “looking stupid”. If information was unclear many family members formed interpretations based on assumptions or simply “wondered” about possible interpretations. Some families turned to the internet for clarity.</p> <p><i>“I have seen nurses in different hospitals talk to my dad and explain information to him and he keeps nodding his head and no one ever asks “can you repeat back to me what I just told you? And I wish they would because I am sure my father did not understand anything he was just told. People just don’t want to look unintelligent, so they don’t always ask questions even though they don’t understand the information being presented to them. Sometimes you don’t know who to ask and you don’t know what to ask”.</i></p> <p><i>“It’s difficult to interpret simple words like ‘good’. Physicians say the patient is ‘doing good’ and that means ‘doing good this hour’, whereas the families interpret this as ‘hooray he’s recovering let’s have a party’ and then when the patient gets worse, they get really blown away”.</i></p> |
| | <p>• Retaining new information</p> <p>Most family members described significant difficulties retaining information even after then initial shock of admission had passed. Families often coped with this difficulty by utilising memory aids such as keeping notes.</p> |
| | <p>• Utilising information for decision making</p> <p>The availability of healthcare directives helped to decrease family members’ perceptions of anxiety and burden in making decisions, but did not always fully obviate the cognitive struggle regarding the appropriateness of decisions, which was frequently ongoing. Often families’ worries focused on the response of the person to the decisions if the person survived, especially how decisions might impact their relationship with the person and the person’s quality of life after discharge. Thus, utilizing information for decision-making and on-going evaluation of decision-making was a significant type of information-related work for family members, which was perceived as extremely stressful. Families of 2 people who were very concerned with goals of quality of life for the person and following the person’s wishes, which conflicted with the critical care physicians’ goal of patient survival. Both families wanted to withdraw life support because they perceived it was what their loved ones would have wanted based on their healthcare directives, previous discussions with the people before they became ill, and past actions on the part of the person (for example, making themselves Do Not Resuscitate in previous hospitalisations). However, in both of these situations the people were showing signs of improvement, so the physicians were reluctant to withdraw support at that time.</p> |
| | <p>Needs related to prognostic communication</p> |
| | <p>• Content</p> <p>“There was a consistent message conveyed by families, which said, “You have to hear the hard news but it is not easy to hear.” Only one family member did not want to hear any “bad news” for the first 2-3 days after her husband was admitted to the ICU. She was a registered nurse and</p> |

| Study (RefID) | Gutierrez 2012 ¹⁹¹ |
|---------------------------|---|
| | <p>knew from the information communicated by the physician that her husband was dying. She stated her way of coping with this devastating news was to deny it was happening. Thus, she stayed in the family waiting room, would not go into her husband’s room, and refused to listen to any “bad news”. Instead, the rest of the family communicated with the providers on her behalf. Besides this exception, all family members interviewed described a desire to receive honest, realistic information first and foremost, tempered with hope only when appropriate. They wanted both the good news and the bad news in order to get a “perspective” of the situation, a “reality check,” so they could use this information to prepare themselves for possible outcomes. Consistency of information provided was also important and influenced the level of trust family members perceived towards providers.</p> <ul style="list-style-type: none"> • Style of communication “Families wanted information communicated in a manner that was respectful, compassionate, and caring. Family members described that it was much easier to hear and cope with bad news when it was communicated in a caring, sensitive, compassionate manner. For some, the desire and need to perceive that providers genuinely cared extended beyond the manner of verbal communication to include communication via body language, actions, and even the perceived type and level of energy of providers when they were around patients and families. Most families wanted to know that providers genuinely cared for both the person and family and that “it’s not just your job””. • Communicator of prognostic information: who is saying it? Families suggested that being able to develop a relationship with only 1 or 2 healthcare providers would have facilitated families feeling “heard”. |
| Limitations | No limitations |
| Applicability of evidence | Population of intensive care unit not representative of review population, but, many aspects explored in the analysis may be applicable to the wider population. |