REVIEW ARTICLE

Communication with relatives on prognosis of critically ill patients

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Abstract

Most patients admitted to the intensive care unit are unable to participate in decisions relating to their care. Therefore, physicians have to inform relatives on the condition of the patient, his evolution and the estimated prognosis. Numerous studies have shown that relatives commonly have inaccurate expectations of the patient's prognosis, due to either misunderstanding of oral information by the physicians and/or overly optimistic beliefs. This may lead to undue prolongation of an ICU stay in the case of a poor prognosis. Several methods have been proposed in order to align relatives with the estimation of the patient's prognosis by the physicians. The use of visual tools, added to oral information seems beneficial. Moreover, communication with relatives on the prognosis has to convey support and empathy.

Key words: Critically ill patients, prognosis, relatives, visual aid.

1.Introduction

Communication with relatives is an essential part of caring for critically ill patients. Indeed, most patients in the intensive care unit (ICU) are unable to receive a clear information on their condition, because of the severity of illness, frequent use of sedation, and /or delirium. Therefore, physicians have to inform relatives on the condition of the patient, explaining the diagnosis, therapeutic measures ongoing, and prognosis.

It is crucial that relatives have a clear understanding of the patient's prognosis. Indeed, the process of decision making on

therapeutic issues for the patient, notably on life-sustaining therapies, is collaborative combining physicians, patients and relatives. To be well-informed participants in decision-making when the patients are unable to make decisions for themselves, relatives need a clear understanding of the patient's prognosis.[1] Furthermore, families who are too far from the reality of the prognosis will not be sufficiently prepared for the eventual death of their loved one.[2]

This review will describe how the information on prognosis of critically ill patients is usually delivered by physicians, how this information is received and interpreted by relatives, and the methods proposed to improve the estimation by relatives of the patient's prognosis.

2. Delivery of information on prognosis to relatives

Information on prognosis is usually delivered orally by physicians during family meetings. One study showed that more than 50% of time was spent to explain prognosis.[3] The language used to discuss prognosis in ICU is variable,[4] using direct or indirect statements,[5] with quantitative or qualitative estimations (Table 1). For example, for a patient with a high probability of death, some physicians will use direct assessments focusing on the individual patient. They may use numeric probabilities, such as "your loved one has about 70% risk of death"; or qualitative statements either probabilistic like "your loved one probably won't survive" or not probabilistic like "his prognosis is poor". Others will use indirect assessments. Some will refer to a group of patients, using statistics like "7 out of 10 as severely ill as your loved one do not survive", or qualitative terms like "many patients such as your loved one don't survive this severe illness"; others will describe the worsening of the condition of the patient; and others will guide the conversation towards patient values and future decisions to take.[5]

Table 1. Language used to convey prognostic information to relatives in the ICU

Type of statement	Quotation
Direct	
Numeric probabilities	« Your loved one has about 70% risk of death »
Qualitative probabilities	« Your loved one probably won't survive »
Non probabilistic	« His prognosis is poor »
Indirect	
Refering to other patients	
Using percentages	« About 70% of people as severely ill as your loved one don't survive »
Using frequencies	« About 7 out of 10 as severely ill as your loved one don't survive »
Qualitative	« Many people like your loved one don't survive this severe illness »
Refering to physiologic deterioration	« Things don't look good, we are concerned that we might not be able to maintain his organs alive »
Refering to future decisions to take	« There is possible that we will be in a situation where we might have to make some decisions regarding the pursuit of ongoing treatments »

3. Family members in the ICU commonly have inaccurate expectations of patient's prognosis.

Numerous studies have shown a discordance of 50% or more in prognosis estimates between physicians and family members of critically ill patients.[6-10] Physicians' estimates of prognosis are more accurate than relatives' estimates regarding hospital survival.[11] This implies that relatives often have a wrong assessment of patients' prognosis. Relatives

often have overly optimistic expectations about prognosis.[7,8,10,11,12,13]

When focusing on prognostic expectations of relatives more optimistic than those of the physicians,[10,14] the discordance arose mainly from the relatives misunderstanding the estimation of prognosis delivered by the physician: when the relatives were asked to record, on a 0% to 100% probability scale, what they perceived to be the physician's assessment of prognosis, they quoted a higher probability of survival than the actual assessment of the physician. In some cases, relatives when asked to record their own assessment on patient's prognosis, held more optimistic beliefs than what they perceived to be the physicians' assessment.[10,14] These relatives believed that maintaining an optimistic attitude, even unrealistic, would influence and improve the outcome of the patient.[10,11]

Optimistic expectations of relatives are problematic because they are associated with a longer duration of ICU stay among non-survivors.[14]

4. Different types of interventions have been proposed in order to improve the estimation by relatives of patient's prognosis and align physician and family prognostic perceptions:

4.1. Optimize the oral information on prognosis

First the communication with relatives, whatever the subject is, diagnosis, therapeutics or prognosis, should follow some rules on organization of the meetings with relatives and interaction with them.[15] Notably, relatives should have enough time and occasions during family-staff meetings to ask all the questions they wish, this may improve their comprehension.[16] Conversely, guiding relatives by providing them a list of important questions they could ask to the physicians didn't improve their comprehension on day 5, especially on prognosis.[16]

The best language to express prognosis is debated. Some experts argue that qualitative expressions of risk may be interpreted in different ways by patients, suggesting better to provide numeric estimates.[17] However, numerical expressions may also be problematic. Percentages may be misinterpreted.[15,18] For example when the physician says "70% risk of death" the relative may focus only on the 30% chance of survival. Moreover, percentages refer to populations and not to individuals.

A randomized trial comparing numeric and qualitative statements to convey news of a poor prognosis failed to show any difference in relative's prognosis estimate.[12] Concerning numerical estimates one study showed that using frequency (for example "1 out of 5 will die") to convey a prognosis will result in a more pessimistic assessment by relatives than using percentage ("20% will die").[19]

A recent study suggests that it is preferable to use direct assessments rather than indirect assessments which are perceived more optimistically by family members.[5]

Finally, it is recommended that physicians check whether relatives have understood the information provided on the patient's prognosis.[1,20]

4.2. Information tools

Information leaflets are widely used, personalized according to each ICU. They improve the comprehension by family members of the diagnosis and treatments delivered to the patient, but not of the prognosis when dichotomized as "grave" or "not grave".[21]

An Italian group developed an information brochure and website dedicated to relatives, and designed to cover all aspects of an ICU stay: equipment and devices, monitoring, procedures, rules, communication, family engagement.[22] This tool improved the

understanding by relatives of the information on prognosis delivered by physicians.

4.3. Decision aids

Decision aids are tools designed to help patients to choose between different options of treatment or care. They provide evidence-based information on the options proposed, their benefits and harms, and are personalized. Decision aids increase patients' perceived probabilities of outcome.[23] Cox and colleagues developed a decision aid[24] designed here for relatives to help them to align with what their loved one would want if he could tell us. This concerned patients under mechanical ventilation for at least 10 days and the decision aid focused on long-term survival at one year. The first part of the decision aid presented with graphics an estimation of one-year survival of the patient using a prediction model; the data were numerical, referring to 100 patients under mechanical ventilation in the same condition as the patient: "it would be expected that x would be at home, y in a nursing home and z had died". Then the options of treatment were detailed, and the relative clarified patient values to help finding the best option of treatment. Finally the relative chose the option of treatment that he thought to be the best for his loved one. This decision aid failed to improve the concordance between physicians and relatives in the estimation of survival at one year, when compared with usual information.[25] However, this decision aid was not just an aid to better evaluate prognosis, but incorporated other aspects of decision-making process.

4.4.Visual support of the patient's evolution

Graphical presentation may improve communication of risk.[18] Indeed, for some people visual memory is more effective than oral communication. Therefore we developed a visual support tool, dedicated to family members, available in the room of the patient and depicting day by day the evolution of his condition.[9] Every day in the morning physicians assessed global, hemodynamic, respiratory, renal and neurological conditions of each patient and put a point on the 5 related curves of the visual aid (Figure 1). The addition of new points allowed to visualize curves illustrating the clinical state of the patient during his intensive care unit stay. A controlled study showed that adding the visual support to classic oral information allowed the patient's family to have an estimate of the prognosis more concordant with the estimate of the physician.[9] It seems that the support may better align the perception of patient's prognosis by relatives to the real evolution of the condition of the patient, partly avoiding unrealistic optimism if an unfavorable trend was to occur. The support may act as a reference for family members, when faced with the dispersion of the information delivered by numerous caregivers, physicians or nurses. Moreover it is dedicated to them, emphasizing the attention they need.

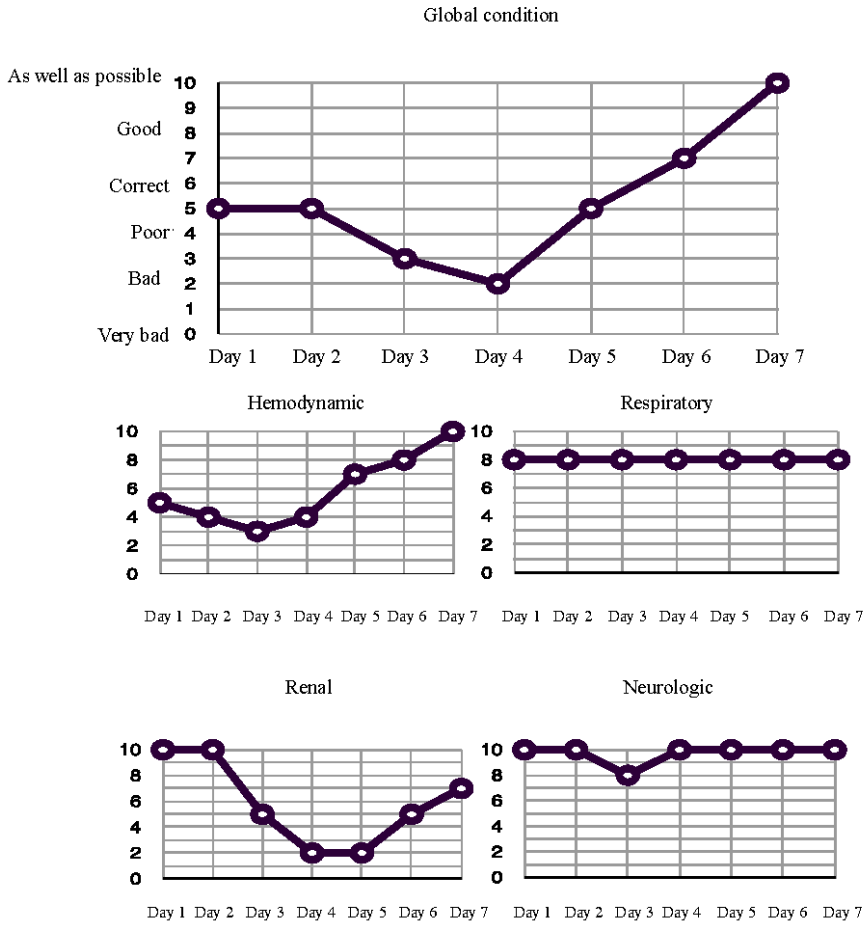

Figure 1: An example of the visual support for relatives.

5. Communication on prognosis has not only to be clear but also supportive

The intensive care unit is a stressful environment, where relatives have to deal with the uncertainty on the vital prognosis of the patient[26] and the lack of understanding of the techniques and therapies used in the ICU. The prevalence of symptoms of anxiety and/or depression, evaluated by HADS score, is high in family members, reported at 60-80% during the first week.[22,27,28,29] We found that the profile of the evolution of the patient – stable, worsening or improving – didn't significantly impact HADS score of relatives at day 5 after patient's admission.[29] In other words the level of stress was high even when the patient improved. Therefore, it seems that the uncertainty on vital prognosis of the patient is a major factor of stress.

Paradoxically, the uncertainty is for relatives, a reason for keeping some hope. Family members report the need that physicians help them to deal with their ambivalence between receiving bad news and preparing for the worst on one hand, and keeping some hope on the other hand.[30] When interviewing relatives who were more optimistic than physicians in their prognosis estimates, they report that keeping

hope may protect themselves from emotional distress,[11] and would improve the patient's outcome.[10,11] Optimistic beliefs were all the more frequent when the prognosis estimate by physician was poor.[13] Moreover, when a decision aid based on prognosis estimate and patient values suggested comfort-focused care, most relatives chose more aggressive care focused on survival.[25] These data show the importance of optimistic belief of relatives as a coping mechanism and question whether it is realistic to fight this attitude.

Now, when discussing prognosis, physicians have to integrate this behavioral aspect, to go beyond their role of information provider, and to show compassion.[31]

Moreover, it is important to verify that strategies designed to align relatives with a clear and realistic appreciation of the prognosis, won't be harmful and traumatic for them.[29]

6. Conclusion

Discordance between physicians and family members on estimation of the patient's prognosis remains frequent, mainly characterized by an overly optimistic expectation from relatives. This may be detrimental for the patient. Physicians have to take this into account when discussing prognosis with relatives. Visual tools are useful to help relatives to have a more accurate estimation of the patient's prognosis.

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