Shared Decision-Making With Patients and Families

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7.1 Introduction

Patients and families generally wish to be involved in important medical decisions through a process known as "shared decision-making." Shared decision-making (SDM) is a process of communication between clinicians and patients or family members that involves the following steps: (1) discussing the nature of the decision to be made; (2) exchanging relevant medical information and information about the patient's values; (3) checking for understanding of information; (4) discussing preferred roles in decision-making; and (5) achieving consensus about the treatment course most consistent with the patient's values and preferences [1]. This approach to decision-making is different to paternalism, in which the physician makes the clinical decision with mere patient or family assent, and to informed choice, in which the physician only provides information and the patient or family makes the

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final decision after receiving this information. In this chapter, we will see that involving patients and/or family members in SDM in the emergency department (ED) and the intensive care unit (ICU) can be a challenging task, specifically when patients lack decision-making capacity, when family preferences for decision-making vary, and when emotional distress is high. We also describe strategies to help clinicians to better involve patients and families in decision-making. Interprofessional shared decision-making within the team is the focus of Chap. 6.

7.2 The Relevance of Shared Decision-Making

SDM is a central component of patient-centered care in the ED and the ICU. SDM must be consistent with ethical principles and with patients' and surrogates' preferences. The American College of Critical Care Medicine defines shared decision-making as "a collaborative process that allows patients, or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values, goals, and preferences" [2]. In the ED and the ICU, difficult choices arise, and important decisions are made. Clinicians offer their expertise, scientific knowledge, and experience to improve their patients' health status, yet they still need to involve the patients and/or their families to ensure that the decisions made are respectful of the patients' values, goals, and preferences.

7.3 Shared Decision-Making in Critically Ill Patients

Patients in EDs and ICUs are some of the most vulnerable in any acute hospital. The change from a healthy individual occurs prior to the patient's arrival in an ED or an ICU and marks a fundamental change. The traditional consent model for medical treatment is often shortened, and ED or ICU physicians may have to adopt a paternalistic approach. The issues surrounding this area are discussed in Chapter 4 of this book.

Shared decision-making in critically ill patients can be challenging because patients and ED/ICU physicians usually have no established relationship, and decisions can be time critical. Achieving agreement as to the extent of treatment requires a balance of respect for autonomy and beneficence and/or management of resources. The emotional stress of the emergency situation on the patient and the fact that the baseline mental status is unknown to the clinicians often make it difficult to determine competency for decision-making, especially in cases of refusal of treatment [3].While patient autonomy is central, physicians may sometimes give priority to their own professional judgment to achieve the best possible outcome for patients. In the specific context of the ED, recent qualitative research shows specific emotional and logistical challenges to SDM, such as difficulty building trust, the challenges of uncertainty, lack of follow-up care, and the physical space of the ED [4].

7.4 Families in the ED and the ICU: Shared Decision-Making in a Context of High Emotional Distress

Patients in the ED and ICU very often lack decision-making capacity, and clinicians must turn to their families to learn about their values. Thus, families are no longer simple visitors in the hospital: They play important roles and should be considered by the ED and ICU teams as active partners. As defined by the American College of Critical Care Medicine [2], the term "family" should be used in its broadest sense to include "all individuals whom the patient considers family, whether related or unrelated to the patient, including those with whom the patient has a significant relationship and those who provide support to the patient." Ideally, the patient should choose which of his relatives should be involved. When this is not possible, the surrogate will help clinicians identify those individuals.

As all families are unique, there is a spectrum of role preferences, ranging from letting the physician decide to assuming responsibility for the final decision. Families often describe one of their roles in the ED or the ICU as being the patient's "historian" (inform the team of the patient's prior medical status, history, and wishes) and "facilitator" (translating, explaining, and interpreting information for both the patient and the team) [5]. Families can help the team understand the patient as a person and thus help the team respect that person by proposing adapted care. Sharing valuable information with the team is perceived as an important role, sometimes as the only role they want/are able to endorse.

Preferences for decision-making can vary. Some families may want to leave the physician decide independently, and this choice must be honored. For others, participating in the deliberation process is important: listening to the team's expertise and recommendations, sharing their opinion, asking questions, but leaving the decision to the medical team. Indeed, some families do not want to share the burden of decision-making with the clinicians. Others however may want to feel part of the decision itself, sometimes going as far as actually making the decision.

Cultural context impacts on these possible roles: For example, family responsibility for the decision to withdraw life-sustaining treatment is possible in the United States, whereas in France, this responsibility can only be the physician's. In a study from the United States [6], concerning value-laden decisions (resuscitation preferences), 10% of surrogates preferred to decide independently, 45% preferred to decide after considering the physician's recommendations, 40% preferred shared responsibility, and 5% preferred the physician decides either after considering the family's opinion or independently. A study from France shows that only 39% of ICU physicians had actually involved family members in decisions. A desire to share in decision-making was expressed by only 47% of family members, and only 15% of family members actually shared in decision-making [7].

Adapting the decision-making process to the family's preferences is thus fundamental, and guidelines must be adapted in order to have meaning in each specific cultural context.

7.5 Impact of Shared Decision-Making on Families' Well-Being

A qualitative study investigated which physician and nurse behaviors families find supportive and which behaviors increase the family's burden. Timely communication, open discussion about families' roles, facilitating family consensus, and providing adapted emotional support are helpful. Behaviors that made families feel excluded or increased their burden included postponing discussions about treatment withdrawal, delaying withdrawal once scheduled, placing the full burden of decision-making on one person, withdrawing from the family, and defining death as a failure [8].

In many studies, participation in care, discussions, and decisions is listed among the factors that increase family satisfaction [9]. For some families, however, sharing in decisions can result in substantial psychological burden: In a study from France, families involved in ICU end-of-life medical decisions presented higher risk of developing posttraumatic stress symptoms 3 months after the patient's death [10]. A systematic review found that at least one-third of the surrogates report negative emotional effects lasting months, and sometimes years, after making treatment decisions for others, including stress, guilt, and doubt about whether they made the right choice [11]. These results raise questions as to how family members are involved and what specific factors during the SDM process are associated with increased psychological distress. Future research is necessary to develop ways to increase support and reduce this burden [12].

Involving the family in the decision-making process raises further complex challenges. First, in the ICU, families suffer from high levels of emotional distress, such as symptoms of anxiety, depression, and acute stress [13]. They may experience feelings of vulnerability and guilt as well as daytime sleepiness that can impair their ability to make decisions that are in the patient's best interests. Second, not all patients discuss their wishes with their family. Family members may feel at a loss and not able to correctly describe their loved one's goals and preferences. Third, the family members may have difficulty shifting their perspective from what they want to what they believe the patient wants. This can also be true in other decisional contexts, such as organ donation. Families may defend their own best interests rather than the patient's [14, 15]. Fourth, obstacles to shared decision-making include difficulties experienced by families in understanding the information they receive: Studies have shown that families only understand half of the information given by the physician [15], and they may also unconsciously make decisions without clearly understanding what is at stake. Last, clinicians may sometimes be concerned that families pressure the patient to adopt their own preferences, thus violating the patient's autonomy. In situations of potential coercion or manipulation, clinicians may need to discuss with patients in private their goals and family dynamics in order to adapt decision-making to the patient's preferences: Some may wish to be free of family influence, while others may prefer to adjust to their family's position, thus requiring that clinicians consider the patient's *and* the family's mutual interests [16].

An interesting qualitative study shows that SDM can be a struggle for families [17]. Indeed, they may experience significant emotional conflict as they wish to act in accordance with their loved one's values but without feeling responsible of the patient's death. They fear that their lay involvement may be a barrier to a chance of recovery. Additionally, they have their family's well-being at heart, and involvement can increase the risk of tensions or conflicts [18].

7.6 Team-Centered Challenges

SDM challenges are not only family-centered. Other challenges remain and concern the ICU team. Research has shown the importance of quality communication. The manner in which the physician conveys the information may influence the choices made by the patients and the families. Shared decision-making assumes that the ICU staff can convey their knowledge in a simple and readily understandable manner that nevertheless allows the patient or family to grasp the nuances and consequences of each decision, without feeling any pressure. Among others, timing of the decision is also important. Rapid progression of a life-threatening illness can lead to rapid decision-making and insufficient time to build a trusting relationship with the family members.

7.7 Strategies to Improve Shared Decision-Making

7.7.1 Family Conferences: The VALUE Approach

Discussing end-of-life issues can be testing. The Society of Critical Care Medicine family-centered guidelines recommend that "routine interdisciplinary family conferences be used in the ICU to improve family satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members" [19].

Using a structured approach to communication, such as the "VALUE" mnemonic, will help enhance clinician-family communication [20]. This proactive communication strategy encourages clinicians to prepare the meeting beforehand, as interdisciplinary and interprofessional involvement in family conferences is important and all clinicians have a role to play. During the conference itself, clinicians are encouraged to:

- value family statements
- acknowledge family emotions
- listen to the family
- understand the patient as a person
- elicit family questions

This strategy includes active listening, expressions of empathy, and making supportive statements around nonabandonment and decision-making [21]. This mnemonic was used as part of an intervention to improve clinician-family communication in the ICU and, combined with a bereavement brochure, has been shown to significantly decrease family symptoms of anxiety, depression, and posttraumatic stress 3 months after the patient's death [22].

Effective communication with family members not only provides support for families and decreases their stress but will also improve decision-making for the critically ill patient. Once again, clinicians should tailor their approach to communication to each family's preferences by multiplying informal conversations and organizing formal conferences. This will enable families to experience SDM not as a "one-shot" but rather as a process that is responsive to their needs and emotions.

As communication is both complex and fundamental, the family-centered guidelines [19] also recommend that "ICU clinicians receive family-centered communication training as one element of critical care training to improve clinician self-efficacy and family satisfaction."

7.7.2 Support for the Family

The primary aim for facilitating a shared decision approach should be team collaboration [23]. When all invested parties – including, but not limited to physicians, nurses, social workers, and psychologists – are involved in SDM, the burden of decision outcomes is dispersed among those collaborating and does not fall on one person. Better collaboration between members of the ICU team encourages the development of collective competence and enhances job satisfaction, logically producing improved care and subsequently improving patient and family outcomes.

Family/patient-orientated facilitating techniques include developing confidence and trust (e.g., through patient activation), rapport with providers, and a trusting and positive patient-provider relationship. Language concordance between the provider and the patient is also imperative. Different professionals could intervene as facilitators, such as chaplains [24], social workers, nurses and physicians – as long as they are familiar with the ICU environment and have benefited from advanced training in communication.

In fact, the intervention of an ICU communication facilitator or specifically trained nurses can help to specifically reduce family distress and intensity of end-of-life care. Facilitators' roles are to support communication between clinicians and families, to adapt communication to family needs, and to mediate conflict. In an American study [25], families who benefited from the intervention of a facilitator experienced decreased symptoms of depression at 6 months, while families who didn't had increased symptoms. Symptoms of posttraumatic stress disorder were also lower with the intervention at 6 months. For decedents, the intervention was associated with reduced length of stay in the ICU and hospital. Facilitators may be a valuable resource and can help clinicians address issues that might be overlooked or unaddressed in the busy hospital setting. In another American study [26], a family-support pathway was instituted in which the trained nurses met with families in the interventional group on a daily basis (emotional support and communication needs) and arranged clinician–family meetings within 48 h after enrollment and every 5–7 days thereafter. The study showed that this family-support intervention did not significantly affect the surrogates' psychological distress; however, the surrogates' ratings of the quality of communication and the patient- and family-centeredness of care were better and the length of stay in the ICU was shorter with the intervention than with usual care.

7.7.3 Dealing With Discordance and Conflict

Discussing uncertainty about prognosis can be challenging for clinicians, although it is a central part of their work. Disagreement, and moreover conflict, between physicians and families over end-of-life decisions can lead to significant stress for everyone involved and can considerably hinder SDM. Research had revealed that such conflicts are prevalent in the ICU. In a multicenter international study [27], 27% of clinicians reported at least one conflict between themselves and families in the preceding week. Conflict is harmful in that it is associated with adverse outcomes both in clinicians (burnout) and in families (anxiety, mistrust). However, when correctly identified and managed, conflict can have positive effects, such as helping families move forward through a distressing experience.

Discordance about prognosis can be problematic in the context of SDM, and it is important to understand its causes. In a multicenter American study [28], physician-family discordance about prognosis occurred in over 50% of situations. Interestingly, discordance was related to misunderstandings by families about physicians' assessments of patients' prognoses and differences in beliefs about patients' prognoses. It is thus important that physicians regularly check with families about their perceptions of prognosis before engaging in SDM. Providing adapted emotional support (aimed to alleviate guilt, for example) and discussing religious or spiritual beliefs are strategies that have shown to be beneficial.

7.7.4 Mediation

Mediation is the process by which someone tries to end a disagreement by helping the two sides talk. It is a new area for clinical disputes, although has widespread use in other areas of conflict resolution. In the United Kingdom, the National Health Service Resolution (website resolution.nhs.uk) uses mediation to resolve clinical negligence claims. The results include nonfinancial remedies, which otherwise would not have been available to the claimant. In the recent case of Charlie Gard – a controversial case about an infant boy born with mitochondrial DNA depletion syndrome for whom the medical team and the parents disagreed about whether experimental treatment was in the best interests of the child [29] – the judge stressed repeatedly how he considered that the parties should have tried mediation first. International experience is there, with a Canadian Elder Law report demonstrating that 90% of participants found the process of mediation helpful, even if the dispute was not settled. Overall, mediation has been found to be cheaper, faster, and with a high chance of success (60–90%) [30]: It allows for the preservation of relationships rather than the destructiveness of litigation.

7.8 Conclusion

Throughout this chapter, it has been shown that shared decision-making is a complex personalized process that necessitates constant adaptation to the patients' as well as to the family members' needs and preferences. High-quality communication is a prerequisite to SDM, focused on the patient's and family's understanding of the medical situation, evaluation, and re-evaluation of the family's preferred role for decision-making and, last but not least, adequate emotional support. Some families may choose to formally be part of decision-making, thus taking on decisional responsibility, whereas others may choose to remain at a distance of medical decisions. R. J. Curtis and R. Burt have developed an alternative approach called "informed assent" that avoids putting family members in the difficult position of feeling responsible for the outcome [31].

Communication strategies have been tested, and recommendations have been published that are valuable tools for clinicians. However, one size does not fit all, and within every individual clinical circumstance, clinicians must strive to develop an approach to SDM that is adapted to each specific patient and each specific family. Last, one must remember that actively listening to the patient and the family is, without doubt, the first step to SDM.

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