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Communicating with families of critically ill patients about continuing or discontinuing life-sustaining treatment

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General introduction

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In 2021, the podcast ‘Op leven en dood’ (‘On life and death’) was launched. This podcast is part of the FamICom-project (Family Communication) which is aimed at (1) collecting scientific knowledge about how doctors communicate with families about major treatment decisions in the ICU and how they involve families in this, and at (2) translating these insights into tools for doctors and for the general public. The 10-part podcast shows what precedes the decision to stop life-sustaining treatment of a critically ill patient in the intensive care unit.

It can happen to anyone that a loved one ends up in an intensive care unit. Sometimes so many complications arise that the treatment options become limited and the question arises what is in the best interest of the patient: continuing or discontinuing life-sustaining treatment? Critically ill patients are often sedated and unconscious, and are therefore not aware of their situation. As a consequence, family members are confronted with all kinds of questions. “What can I do for my partner, parent, or child?”, “What will be the quality of life if my loved one survives this period?”, “What would he or she have wanted?”, and “What will doctors decide to do, and do I also have a say in this decision?” In five fictional stories, based on real conversations, and five interviews with intensive care doctors, the podcast shows which challenges doctors and family members face in the intensive care unit and how they communicate about these challenges with each other.

In their interviews, two doctors formulate these main challenges as follows:

“How does one arrive at a well-considered decision about what is best for the patient [ed.], while the patient [ed.] cannot participate in the decision-making process?”

Dutch original:

“Hoe kom je nou tot een afgewogen besluit over wat het beste is voor de patiënt [red.] terwijl de patiënt [red.] zelf niet kan meebeslissen?”

Prof. dr. Eduard Verhagen, Pediatrician-in-Chief,
Beatrix Children’s Hospital, University Medical Center Groningen,
Professor of Pediatrics

“Decisions are made under great pressure. Which means that careful considerations are sometimes also under great pressure. That does not always benefit the quality of the discussion about it.”

Dutch original:

“Beslissingen staan onder hoge druk. Wat betekent dat zorgvuldige afwegingen soms ook onder hoge druk staan. Dat komt niet altijd ten goede aan de kwaliteit van de discussie die je erover kunt voeren.”

Prof. dr. Matthijs de Hoog,
Director Pediatric Intensive Care Unit,
Erasmus MC-Sophia

“At the end of a trajectory in the ICU it is often no longer black and white, but has mainly become gray: ‘it might still be possible’, ‘maybe we can do something’, and so on. And then it is extremely important that you sit together with the parents to hear from them whether they think it is appropriate, whether they would still want it. Usually it’s about something about which no one knows exactly whether it could or couldn’t be effective and about which one might as well say ‘we’ll do it’ or ‘we won’t do it!’”

Dutch original:

“Vaak aan het einde van een traject op de IC is het niet meer zwart-wit, maar is het vooral grijs geworden: ‘het zou nog kunnen’, ‘misschien dat we nog iets’, enzovoort. En dan is het ontzettend belangrijk dat je bij elkaar gaat zitten ook met de ouders om van hen te horen of zij dat passend vinden, of zij dat nog zouden willen. Meestal gaat het over iets waarvan niemand precies weet of het nog iets zou kunnen doen of niet zou kunnen doen en waarvan je net zo goed zou kunnen zeggen ‘we doen het wel’ of ‘we doen het niet.’”

Prof. dr. Eduard Verhagen, Pediatrician-in-Chief,
Beatrix Children’s Hospital, University Medical Center Groningen,
Professor of Pediatrics

“As a parent, you also have to be able to interpret the technical information that is being discussed.”

Dutch original:

“Je moet als ouder ook in staat zijn om de informatie die technisch bediscussieerd wordt te kunnen duiden.”

Prof. dr. Matthijs de Hoog,
Director Pediatric Intensive Care Unit,
Erasmus MC-Sophia

In short, the podcast shows that medical decision-making in intensive care units involves many aspects and is always a challenging process, due to characteristics specific for this context, such as time constraints and pressure, the absence of preexisting relationships with patients and their families, uncertainty, complex ethical dilemmas, and the fact that in most cases family members must act as the patient’s surrogate decision-maker.

Medical decision-making

According to the literature, three prominent prototypical models for medical decision-making can be distinguished. These models are based on the degree and type of information exchange between doctor and patient, the degree of mutual deliberation, and the degree of patients' or surrogates' involvement in the decision-making itself. These models are paternalism, informed decision-making, and shared decision-making [1]. Paternalism has been the preferred approach to medical decision-making for a long time. It is characterized by a dominant role for doctors in treatment decision-making. The doctor sets the agenda for the consultation [2]. During that consultation, the information exchange is largely one way from the doctor to the patient – or the surrogate decision-maker in the case when a patient is incapacitated and therefore unable to make decisions for themselves. The doctor has to provide the legally required minimum amount of information and has to obtain the patient's or surrogate decision-maker's informed consent [1-2]. The exchange only concerns medical information, such as information about the disease and its natural history, a description of various treatment options and the associated procedures, and the potential benefits and risks of the treatment options. The doctor deliberates alone or with other doctors and is also the one to make the decision [1]. From the 80s on, the paternalistic approach began to be questioned. In response to that, both the informed models and the shared models were developed [1]. Informed decision-making is similar to the paternalistic model with regard to the information exchange being one-way and concerning medical information only. However, in informed models, doctors provide all information relevant for the decision-making – they cannot limit their information provision to the legally required amount of information as is the case in paternalistic models. The models also differ in the facts that the patient or surrogate decision-maker makes the final decision after deliberation with potential others or alone [1]. Finally, shared decision-making can be regarded as offering a potential middle between paternalism and informed decision-making. Shared decision-making has been defined in various ways [3]. What these descriptions have in common is that the information exchange is two way and involves not only medical information but also personal information, such as information about the patient's lifestyle, social context, preferences, and values, but

also about knowledge obtained by the patient or surrogate decision-maker about the disease and treatment options [3]. The doctor and patient or surrogate decision-maker deliberate together – potentially with others – and come to a decision together [3]. In short, shared decision-making can be defined as a mutual process in which doctors and patients or surrogate decision-makers participate actively, share information, and collaborate to come to a mutually agreed upon treatment decision [3]. Patients, healthcare professionals, healthcare organizations, and policy makers increasingly endorse shared decision-making as a decision-making model in the Western world. By way of illustration, the Netherlands has an active policy to promote participation in decision-making, as is incorporated in the new version (version 2020) of the Dutch Medical Treatment Act (WGBO) [4]. The key goal of shared decision-making is to reach a patient-centered, informed, conscious, high quality decision about one or several treatments [5-6]. It enables treatment decisions that best fit the individual patient's situation, preferences, and values [7]. Shared decision-making is advocated for various reasons. First, shared decision-making is regarded as the pinnacle of patient-centered care [8-10]. Second, accumulating evidence suggests that shared decision-making may improve patient outcomes, increases patients' and surrogate decision-makers' satisfaction with both the decision and the decision-making process, improves patients' understanding and trust, and increases treatment adherence in patients [11-15]. Lastly, evidence suggests that patients generally prefer to be involved in the decision-making process even though they vary in their preferred level of involvement [16-18]. Research shows that surrogate decision-makers too have varying preferences regarding their level of involvement in the decision-making process [19-22]. These preferences are not only related to personal characteristics, coping style or socio-cultural background of the patient or surrogate decision-maker, but also to the severeness and complexity of the situation at that moment and the type of decision at hand [21, 23-26]. It is therefore important that doctors and patients or surrogate decision-makers discuss their preferences and expectations regarding their role and involvement in the decision-making process. This act of determining roles in the decision-making process forms a component in various shared decision-making models [3].

Decision-making in intensive care units

In intensive care, decisions about the continuation or discontinuation (e.g., withholding or withdrawing) of life-sustaining treatment are made nearly daily [19, 27]. These decisions have to be made within a challenging context characterized by time constraints, the absence of preexisting relationships with patients and their families, and ethical dilemmas [28]. These challenges often concern decisions in the “gray zone” in which there is incomplete knowledge about the relative harms and benefits of the remaining options and no best option exists [29]. It is commonly advocated that patients’ values and preferences should be leading, especially when making decisions in the gray zone [28, 30-31]. Yet, most intensive care patients are not able to communicate their wishes themselves [32-33]. In these cases, doctors have to rely on family members, acting as the patient’s surrogate decision-makers [27, 34-35].

The position of surrogate decision-makers may differ between the three intensive care settings because these settings fundamentally differ in two main respects. First, in adult intensive care units the average age of patients is considerably higher than in pediatric intensive care units and certainly higher than in neonatal intensive care units. As an effect, doctors and families in adult intensive care units may be more likely to accept the death of a patient, albeit reluctantly. Moreover, due to the fact that patients in neonatal and pediatric intensive care units are (relatively) at the beginning of their lives, consequences of decision-making may be perceived as carrying even more (ethical) weight and as requiring even more family involvement than in adult intensive care units [36]. Second, the relation between the surrogate decision-maker and the patient differs between the intensive care settings [37]. In neonatal and pediatric intensive care units, the surrogate decision-makers usually are the parents, whereas the surrogate decision-makers in adult intensive care units often are the partners, children, or siblings of the patient. As parents carry formal responsibility for their child, the responsibility for making medical decisions on behalf of their child is more self-evident for them than it is for families of patients who up till now were always capable to decide for themselves [36, 38].

The approach to surrogate decision-making has been formally defined in the Dutch Medical Treatment Act (WGBO) as informed consent. In the Netherlands, the role of sur-

rogate decision-makers in the decision-making process is formally described as follows: doctors are obliged to inform legal representatives of minor and adult patients and to ask them for consent [39]. According to the Dutch Medical Treatment Act, this information obligation also includes the obligation to consult with the legal representative in time, whereby the patient is also invited to ask questions if possible. In addition, the representative must be informed about the possibility of refraining from treatment, about other examinations and treatments by other care providers, about the implementation period of the treatment and the expected duration thereof.

In line with this description of the situation in the Netherlands, most European countries and Asian, Middle-Eastern, and South-American countries are formally characterized by a relatively paternalistic view on making end-of-life decisions [40-49]. By contrast, families of incapacitated patients are considered the primary decision-makers in the United States, Canada, and Australia, based on prevailing moral and legal traditions [46, 50-52]. Despite these cultural differences, countries experience similar challenges of whether, in how far, and how to involve families of patients in the decision-making process [36]. In this regard, we see a shift in approach towards shared decision-making in the Western world. The Netherlands, for example, has an active policy to promote participation in decision-making.

A second relevant shift within intensive care is the fact that technical innovations increasingly enable intensive care teams to keep patients alive. In this light, the patient’s quality of life in the short and long term remains a relevant – if not paramount – factor in making decisions regarding life-sustaining treatment [53]. However, the assessment of the remaining quality of life is prone to subjectivity and uncertainty [53]. This may well add to conflicting views about what the expected quality of life is, how to assess this, and who has a say in this, especially when patients are not able to communicate their views on this matter [54-58]. The discussion about assessing and interpreting expected quality of life and its weight in the decision-making process is increasingly relevant in light of the significant costs and resource utilization involved in life-sustaining treatment and – especially relevant for adult intensive care – the ageing global population [59-61].

A final important contextual change is the ongoing growth in cultural diversity in the modern Western world [62-65]. This diversity unavoidably also leads to an increase in cultural diversity of the patient population in the hospitals. However, cultural diversity within the medical staff is increasing slower and the doctor in the consultation room often has a very different background as compared to the patient, which means that the values and worlds of experience can differ considerably from each other [66]. This situation can lead to more difficult communication processes compared to those between healthcare providers and patients belonging to the same cultural group [62, 65, 67-68]. Despite the contextual changes to which the intensive care setting is subject, some characteristics of intensive care remain relatively the same. It always remains to involve complex decision-making [19, 27, 69]. Argumentation in the sense of solid reasoning is one of the intrinsic parts of this decision-making process [70-77]. Even though argumentation- and decision-making processes are ideally aimed

at arriving at a mutually agreed upon treatment decision, conflicts between doctors and surrogate decision-makers commonly occur in the intensive care setting [78-83]. Such conflicts can be difficult to manage and may well hinder the decision-making process. Another lasting characteristic of the intensive care setting is that it often involves uncertainty, for example about the (expected) quality of life of the patient. Doctors find it difficult to discuss such uncertainties, despite the growing evidence suggesting that discussing uncertainties enhances the decision-making process [84-93]. Finally, decision-making in the intensive care setting involves complex medical information. Understandable information allows patients or their surrogate decision-makers to be involved in the decision-making process [94-96]. Comprehensible information can also lower the chances that conflicts will arise [81, 97]. In short, the intensive care setting remains to involve complex decision-making which requires good communication between doctors and families.

Rationale and aim of the FamICom-project

A good communication and decision-making process with families requires special communicative skills. This certainly applies to decisions about whether or not to continue life-sustaining treatment. In essence, these decisions concern the choice between (letting) live or die. These are decisions that can only be made once and this responsibility weighs heavily on both families and doctors. Awareness of the burden of decision-making keeps neonatologists, pediatric intensivists, and adult intensivists looking for the best way to involve each family member in the decision-making process, ranging from the parents to the partner, sibling, or child of a critically ill patient. This requires tailoring. Such a tailored approach may well enhance family satisfaction and can reduce families' later uncertainty, regret, or blaming the medical team for undesired outcomes [98-100]. Doctors learn this act of tailoring 'on the job', by trial and error. Learning from good and less good examples by watching each other's conversations and relistening one's own recorded conversations in order to learn from that and to further develop certain skills is an uncommon practice. This is due to the hectic of everyday life in intensive care units and to the fact that such exercises are not offered in the current training system.

The FamICom-project (Family Communication) aims to provide in depth insight into communication and decision-making practices in actual conversations in intensive care units. For this purpose, we collected scientific knowledge about how doctors deal with challenges in actual conversations with families in the neonatal, pediatric, and adult intensive care unit. By doing so, the FamICom-project aims to contribute to concrete improvements in the communication and decision-making process with families. With this aim in mind, the FamICom-study was devised and developed within a partnership of the neonatal, pediatric, and adult intensive care units of 6 Dutch university medical centers, including the Amsterdam UMC. The project started in 2017. Over a period of five years, we explored by in-depth research how doctors communicate with families in Dutch intensive care units and how they reach crucial treatment decisions with these families. We also focused on decisions in the gray zone in which there is incomplete knowledge about the relative harms and benefits of the remaining options and no best option exists [29]. The FamICom-project was supported by ZonMw [project number 844001316]. ZonMw is the Dutch organization for healthcare research and innovation.

Thesis outline

We recorded, transcribed, and analyzed audio-recordings of actual conversations between doctors and families in the neonatal, pediatric, and adult intensive care unit. Based on an initial thorough analysis of all transcripts, we determined what the most complex communicative challenges were in these conversations. This dissertation describes the extensive qualitative exploration of the following main challenges:

- how to involve families in decisions to continue or discontinue life-sustaining treatments;
- how to exchange arguments pro and con decisions to continue or discontinue life-sustaining treatments;
- how to deal with conflicts that arise between the medical team and families during the decision-making process;
- how to provide understandable information to families;
- how to discuss uncertainty with families.

In **chapter 2**, we explore how doctors involve families in the decision-making process regarding life-sustaining treatment on the neonatal, pediatric, and adult intensive care. For this purpose, we coded and analyzed 101 conversations by means of inductive thematic analysis to identify types of communicative behavior by which doctors involved families in the decision-making process [101]. This type of analysis is performed without any expected outcomes. It involves deriving meaning and identifying themes from data without preconceptions.

Chapter 3, presents the outcomes of a qualitative explorative study which focused on the real-life argumentative practices of both doctors and families regarding the decision to partly or fully continue or discontinue life-sustaining treatment. We coded and analyzed 101 conversations from the neonatal, pediatric, and adult intensive care. We used inductive thematic analysis to get a complete overview of all arguments doctors and families of critically ill patients used in support of their standpoints and to explore how doctors and families structured their argumentation.

In **chapter 4**, we prospectively explore team-family conflicts, including their main topics, complicating factors, doctors' conflict management strategies, and the effect of these strategies. For this purpose, we again coded and analyzed the 101 conversations from the neonatal, pediatric, and adult in-

tensive care now using a qualitative, deductive approach. In this top-down approach, we based our codebook on existing ideas and theories and applied that codebook on our data.

In **chapter 5**, we identify the best-practice recommendations doctors use to enhance the understandability of their oral information in conversations with families about decisions to continue or discontinue life-sustaining treatment and the strategies doctors use to check if families have understood the information provided in these conversations. For this purpose, we coded and analyzed 95 conversations from the neonatal, pediatric, and adult intensive care, again by means of a qualitative, deductive qualitative analysis.

Chapter 6 presents the outcomes of a qualitative explorative study into how doctors discuss uncertainty with parents. We coded and analyzed 29 conversations from the neonatal and pediatric intensive care by means of explorative analysis to investigate which topics doctors' discussion of uncertainty pertained to, which communicative strategies doctors used to discuss uncertainty with parents, and how the discussion of uncertainty developed over time.

Chapter 7 is a summary of our findings and overall conclusions.

Finally, in **chapter 8**, we put the findings of this dissertation in perspective in a general discussion and discuss future perspectives.

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