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

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General discussion and future perspectives

General discussion

This thesis is a collection of studies in diverse aspects relevant to the communication with families about crucial treatment decisions in intensive care units. We addressed how doctors involve families in the decision-making process, how doctors and families exchange arguments, how doctors manage conflicts, how doctors provide medical information to families in an understandable way, and how doctors discuss uncertainty with parents. This chapter places the findings in context and presents suggestions for future research.

Decision-making with families in intensive care units

It is commonly advocated that patients' values and preferences should be leading in medical decision-making, especially when making 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 [1-3]. Yet, because most intensive care patients are not able to communicate their wishes themselves [4-5], doctors often have to rely on family members, acting as the patient's surrogate decision-makers [6-8]. The involvement of surrogate decision-makers is challenging because surrogate decision-makers can have varying preferences and needs. Furthermore, it can be challenging for doctors to speak with multiple people, particularly when family members within one family have diverse backgrounds and health literacy levels [9-12]. In addition, the multidisciplinary team may be composed of numerous healthcare professionals, resulting in variations in who communicates information, when, what, and how [13]. Considering these challenges, it is important that doctors and family members 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 decision-making models [14]. Doctors in our studies involved families in different ways, ranging between shared and physician-driven approaches. Doctors also went back and forth between approaches within one and the same conversation or suddenly switched

approaches. Doctors more often displayed a physician-driven or a vacillating approach than a shared approach, especially in the adult intensive care unit (chapter 2). This is in line with research suggesting a discrepancy between what is being advocated and aspired regarding decision-making and clinical practice [15-17]. Furthermore, from informal conversations with various doctors and also from the podcast 'Op leven en dood' ('On life and death') it became apparent that not all intensive care doctors are eager to implement shared decision-making in their own practice. Doctors also explained that the doctor bears final responsibility for medical decisions in the Netherlands. Furthermore, doctors describe that the patient's best interests should always be the main concern in decision-making processes – also in those with families. Lastly, relative consensus exists that shared decision-making is not suitable when all active treatment options have been exhausted and a patient has no chance of survival or when only one treatment option is available. Doctors' cautious approach towards shared decision-making may also well be because of a belief that making end-of-life decisions – especially if it concerns a decision for a loved one – is too burdensome for family members of critically ill patients [18-19]. These decisions confront families with often limited medical knowledge with moral questions to which no one knows the right answers and with feelings of uncertainty, powerlessness, injustice, and regret [5, 20-37]. The FamICom-project affirmed that shared decision-making can be burdensome for families. Finding the right balance in involving families but not burdening them too much requires a tailored approach [1, 38]. That is, doctors should preferably adjust their approach as much as is reasonably possible based on family's preferences. Even though it is advocated that doctors tailor their communication to families' preferences, this does not seem to be integrated to the full into actual practice yet (chapter 2). Future research is needed to map out facilitators and barriers to a tailored communication approach.

Cognition- and affect-oriented skills in decision-making in intensive care

Decisions about whether to continue life-sustaining treatment are complex and challenging. In essence, these decisions concern the choice between life and let 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. This requires special communicative skills. These skills can be divided in two types of skills. The first type of skills is aimed at enhancing family-related outcomes that are cognitive in nature (i.e., cognition-oriented), such as their understanding and recall of information [39-43]. Cognition-oriented skills are especially relevant with regard to the more rational aspects of decision-making in intensive care units. The second type of skills is aimed at conveying empathy, compassion, or emotional engagement (i.e., affect-oriented) and can reduce emotional distress [44-48]. These skills are especially important regarding the emotional and psychological complexity associated with intensive care. Both types of skills are necessary in tackling challenges in medical communication. Cognition-oriented and affect-oriented skills support each other [49].

In order to paint a complete picture of the context of decision-making in the intensive care, we have studied both types of skills within the FamICom-project. This dissertation focused mainly on cognition-oriented skills, whereas doctors' affect-oriented skills are the main focus of other studies within the project [50-51].

Differences and similarities between neonatal, pediatric, and adult intensive care units

Doctors in different intensive care settings (i.e., neonatal, pediatric, adult intensive care) communicate differently with families in some regards. This was also suggested in the findings of our explorative studies. First, we observed a dichotomy between the adult intensive care unit on the one hand, and the neonatal and pediatric intensive care units on the other regarding the strategies (i.e., both premeditatedly and intuitively shown behaviors) used by doctors to involve families (chapter 2). That is, some strategies were more common in the adult intensive care unit than in the neonatal or pediatric intensive care unit (e.g., 'stressing that the medical team needs the family's input and advice' and 'pointing out that making the decision is a medical responsibility'), or vice versa (e.g., 'pointing out doctors' preference or obligation to make the decision together with families', 'explicitly asking families to share their opinion regarding the decision at stake', and 'proposing a decision to continue or discontinue life-sustaining treatment'). Second, we observed a similar dichotomy regarding lingering conflicts. These were found to be more frequent in conversations in the neonatal and pediatric intensive care unit than in the adult intensive care unit. Third, we observed some striking differences between the intensive care settings regarding doctors' use of best-practice recommendations to enhance the understandability of their information provision. However, we could not uncover a clear pattern in those differences (chapter 5).

We found no straightforward explanations for the differences found in our explorative studies. We described three hypothetical explanations. First, the adult intensive care unit fundamentally differs from the neonatal and pediatric intensive care units in the following respects: the average age of patients, the relation between surrogate decision-maker and patient, and the 'grayness' of the decision at stake. Second, the specific nature of the parent-child relationship and – consequently – parents' highly felt responsibility for their child's well-being. Third, the fact that prognoses tend to carry more uncertainty in critically ill babies and children than in adult patients. Further research is needed to validate these hypothetical explanations.

Regardless of these differences, with regard to the following aspects we found only slight differences between the intensive care settings – which could also be coincidental – or no differences at all: doctors' approach to family involvement in

the decision-making process, doctors argumentation practices, the frequency of occurrence of team-family conflicts, and how doctors discuss uncertainty with families (chapters 2-4, 6). These findings suggest that the neonatal, pediatric, and adult intensive care units are potentially more similar than is sometimes presupposed. After all, all intensive care settings involve decisions about the continuation or discontinuation (e.g., withholding or withdrawing) of life-sustaining treatment and each of the settings is characterized by time constraints, the absence of preexisting relationships with patients and their families, uncertainty, ethical dilemmas, and family members, acting as the patient's surrogate decision-makers [1, 6-8].

In short, neonatal, pediatric, and adult intensive care units have essentially comparable contexts, yet some of the communication strategies of doctors differ between the settings. The comparability of the contexts offers the opportunity to learn from each other's strengths. For example, during discussions in the context of the educational program 'complex communication in the ICU' for fellows and staff members of the three intensive care settings that is now being piloted within Amsterdam UMC, adult intensivists indicated that they have learned from the neonatologists and pediatric intensivists that sometimes more can be shared with loved ones than they usually considered possible. Neonatologists and pediatric intensivists, on the other hand, indicated that they noticed that they can sometimes be more vigorously than they generally are in conversations with parents. Our comparisons should be interpreted with caution, as differences have not been tested since the nature of the studies did not lend themselves to this. Therefore, our comparisons mainly have a hypothesis generating function. To the best of our knowledge, research comparing the neonatal, pediatric, and adult intensive care units is scarce. More comparative research is needed to enable doctors to learn from each other. The studies in this dissertation are a first step in building bridges between the different intensive care settings. This endeavor should be continued in future research.

Looking beyond national borders

The data on which the present dissertation is based were gathered in seven intensive care units in three Dutch university medical centers. In view of the cultural differences between intensive care units in different countries, this limits the international generalizability of our findings. Interestingly, during our data collection we noticed cultural differences between the Dutch intensive care units as well. These differences may result from differences in the patient population of the unit – both age-related and region-related –, as well as from management style. This means that the national generalizability of our study is also not self-evident. Most European countries and Asian, Middle-Eastern, and South-American countries are formally characterized as more paternalistic than the United States, Canada, and Australia [60-72]. At the same time, there is still international controversy about the degree to which (predicted) quality of life should be taken into account in decisions to continue or discontinue life-sustaining treatment [73-74]. For example, some studies suggest that low- and middle-income countries are in general less likely to withdraw life-sustaining treatment than high-income countries [75]. In low- and middle-income countries withholding new life-sustaining treatment is more commonly practiced than withdrawing treatment [73-75]. This could well be because intensive care is hardly available in low-income countries. When it is available, people must pay for intensive care themselves. As a result, both doctors and families must estimate in advance how successful an admission to an intensive care unit is likely to be and what it would mean for the patient's remaining quality of life. Sometimes families are so poor that they cannot afford intensive care at all and do not have the luxury of thinking about potential effectiveness and remaining quality of life. This international variation is reflected by international guidelines, which give contradictory recommendations regarding the level of involvement and authority of patients and their families [3, 76-89]. Despite these contradictory recommendations, countries experience similar dilemmas of whether, in how far, and how to involve families of patients in the decision-making process [74]. As a result, several international guidelines recommend that doctors should tailor their communication to the preferences and needs of individual families [1-2, 39]. Relative international consensus exists that life-sustaining

treatment may be withheld or withdrawn when all active treatment options have been exhausted and a patient has no chance of survival [3, 75-89]. Furthermore, national and international guidelines prescribe that the patient's best interests should be the main concern in decisions about the continuation or discontinuation of life-sustaining treatment [3, 75-94]. Nevertheless, discussions about what exactly is the patient's best interest and how this should be determined remain to exist [95-97].

Due to the basic similarities between international guidelines, the exploration in the present dissertation can be regarded internationally relevant. Nonetheless, considering the differences between international guidelines and the hypothesis that nation-specific cultural and religious traditions are key factors for communication and decision-making styles, it would be relevant to expand this research to intensive care units in other (not-Western) countries. This will enable investigating contextual and cultural influences on the communication and decision-making practices of healthcare staff and families. For example, factors other than religion, such as diagnostic and prognostic uncertainty, families' strong negative emotions, limited health literacy, and burden of responsibility, have significantly more influence on how a decision-making process proceeds – whether conflicts arise and whether they can be resolved [98]. Results from future research could enable learning about and from each other. This could in turn result in more input for doctors to tailor their communication to families of patients within a context of ongoing growth in cultural diversity.

Nurses in the intensive care unit

All conversations in our studies took place with health care providers and family members being seated around a table in one of the conference rooms in the intensive care unit. During most conversations, at least one nurse was present. However, their (verbal) engagement in these conversations was minimal. Therefore, the five individual parts of this study each focused solely on the communication between doctors and families. However, this does not mean that we consider the role of nurses communication and decision-making about life-sustaining treatment unimportant. In fact, we have seen in the intensive care units and heard from families that nurses play an important role in these processes. For instance, by having informal conversations with families at the bedside of the patient – conversations we did not record.

Recent studies show that nurses can contribute to the communication and decision-making about life-sustaining treatment in many ways. They can make things easier to understand by clarifying information and by painting the whole picture for families [91]. But also by talking through and checking understanding about what has been discussed in the formal conversation with the doctor [92-93]. In this endeavor, nurses can also translate what the doctor had said into simple language if necessary [91]. Furthermore, nurses can ask questions to explore families' values and preferences [94]. Due to these qualities, them being an integral member of the medical team and their proximity to family members, nurses can act as intermediary between the doctor and the family [95]. They can also fulfill such a role in the other direction. For example, by helping doctors in recognizing communication preferences and needs from individual families and families' values and perspectives [91, 93]. In short, nurses can check the quality of a decision, complement the decision-making process, and facilitate the decision-making process through their communication [94].

As previously mentioned, it is important that doctors tailor their communication to specific family members. We have seen in our data and have heard from doctors that different family members participating in the same conversation can differ in their preferences, needs, wishes, values, cognitive and social-emotional level, and communication skills. Doctors indicated to us that they experience tailoring to individual family members within one consultation as particularly

difficult, especially when complicated family dynamics are at play. An example of the latter is a case within the neonatal intensive care in which the father and mother with a mild intellectual disability showed very different needs – in terms of cognitive and communicative skills – in the conversation than the grandfather (and the social workers) involved. Nurses can play a key role in the act of tailoring by sharing with the doctors their knowledge and impressions of the family's values, preferences, and needs [91, 93]. More awareness and recognition of this important role of nurses by both nurses themselves and doctors is needed to identify and target intensive care nurses' involvement. To enhance this involvement, it may be helpful to give structural attention to timely and qualitative transfer of information between healthcare professionals and to education and training for nurses [94]. These preconditions also enable cooperation between all healthcare professionals (e.g., doctors, nurses, spiritual caregivers, social workers, and psychologists) and provide the opportunity to utilize the professional's knowledge and skillset which best fits the particular needs of family members at a specific time point [96]. To enable nurses to adopt and improve their role in the decision-making process, it is essential to provide them with skills training and supervision [94, 97]. Future research is needed to gain more insight into the most fruitful ways to involve intensive care nurses in the communication and decision-making process, especially regarding the continuation and discontinuation of life-sustaining treatment.

The intensive care doctor of the future

Being a 21st-century doctor is characterized by challenges such as an increase of chronic diseases, rising life expectancy, increasing administrative tasks, and medical workforce shortages [98]. The latter has been a serious problem for years, but raises even more concern now, with severe burn-out and demographic factors contributing to this shrinking workforce [99]. As a consequence of workforce shortages, medical care becomes less accessible. Concurrently we see that access to medical knowledge keeps becoming increasingly easy and that digital health technology keeps evolving [100-101]. These developments have consequences for the world of medicine as a whole and for subspecialties – including intensive care.

Due to technological developments the amount of data about patients grows [98]. Artificial intelligence can be incorporated into healthcare systems, supporting the healthcare professionals' decisions. First, by running artificial intelligence algorithms on these data of patients predictions can be made in intensive care units it can be predicted which patients run which risks, who have the best chances of survival, etcetera [102]. This way doctors can better determine which patients to admit and which patients not, and which patients to continue to treat and which patients not. Second, because of these data, and again with the aid of artificial intelligence, bedside models of machine learning models are being developed [103]. These models can be used to retrieve clinically relevant information and can help intensive care doctors to provide patient-centered care [103]. These two developments are also relevant for the decision-making process with families, because the doctor will have to explain that and how an 'algorithm thinks along' to involve the family in this process. For the presentation of predictions from artificial intelligence models also goes that doctors preferably tailor it to the level of understanding, the health literacy, and the individual preferences and needs of families [104].

A drawback of the growing amount of data is that vast amounts of data can lead to cognitive overload of patients and their family members [105]. Therefore, guidance from health care professionals, particularly nurses, in how to manage and interpret these data will become even more important in the future [106].

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Even when technology will play a bigger role, the human factor will remain to play a big (or even bigger) role than it already does [106]. This is because technologies are assumed to take over repetitive components of doctors' jobs, which will subsequently allow doctors to deal with patients or their surrogate decision-makers more [98, 106]. Technological advances are predicted not to replace doctors, but to require more from doctors' soft skills [106]. The Society of Critical Care Medicine's Future of Critical Care Taskforce foretells that innovations will be meaningful only if medical outcomes are optimized while patients and their families are treated humanely, affectionately, and coequally [105]. Concurrently with rapid technical innovations, we see an ongoing growth in cultural diversity in the modern Western world [107-110]. This diversity unavoidably also leads to an increase in cultural diversity of the patient population in the hospitals. Concerns have been raised that the current medical workforce does not reflect the diversity of our patients [111]. Building a more diverse medical workforce should be a priority for the future. Another shift in population is that there are increasingly more elderly patients [98-112]. The changing patient population results in intensive care doctors progressively have to deal with more diversity of both patients and families regarding their cultural background and health literacy. Because of this, sufficient communication skills become increasingly important [98]. This dissertation confirmed the importance of an effective communication and decision-making process in conversations with family members of critically ill patients. The intensive care doctor of the future is required to tailor their communication to the communication preferences and needs of individual patients and/or their family members – even more so than is currently the case.

Limitations and strengths

This dissertation is unique in performing several studies on one dataset from three hospitals. The dataset includes data from several neonatal, pediatric, and adult intensive care units from three hospitals. It furthermore involves both doctors and families of critically ill patients who discuss highly sensitive topics in their conversations. This complexity made the data collection a time-consuming endeavor which led to a rich data set. Within this dataset we have selected recurring themes and identified cross-links between those. The latter was an iterative process involving analysis before and during the writing process. Our method resulted in findings which come straight from the data (i.e., our findings are based on what actually happened in doctor-family conversations).

The main limitation of the studies in this dissertation is that the generalizability of our findings is limited as selection bias may have occurred, even though we have pushed for maximum variation regarding the participating patients, their families, and their doctors. Another limitation is that we only audio-recorded conversations to minimize the intrusiveness of our data collection. This precluded the analysis of non-verbal communication. Finally, the generalizability of our studies is not self-evident because due to the logistical demand of the studies we included the audio-recordings of conversations from three Dutch medical centers only. It would be relevant to expand this study to other intensive care units in the Netherlands and, preferably, to intensive care units in other countries, thereby also multiplying the number of cases. This will enable investigating contextual and cultural influences as well.

Future perspectives

Future research

The FamICom-project is unique in terms of its focus on family-integrated care and the dataset collected. To the best of our knowledge, the studies on family-integrated care that have been performed thus far focused mainly on the domain of pediatrics [113-115]. Family-integrated care should be focused on more in future research, as it is a key element of the job of an intensive care doctor. Also unique about our dataset is our collection of audio-recorded doctor-family conversations in three intensive care settings – the neonatal, pediatric, and adult intensive care unit. As such, this dissertation is a first step in connecting these different intensive care settings. This endeavor should be continued in future research by including and comparing data from neonatal, pediatric, and adult intensive care units. Moreover, it would be relevant to expand this research to intensive care units in other (not-Western) countries. This could provide doctors with more input on how to tailor their communication to families of patients within a context of ongoing growth in cultural diversity.

Future research could additionally focus on validating our findings by presenting them to a representative group of healthcare professionals (e.g., doctors, nurses, social workers) linked to neonatal, pediatric, and adult intensive care units. This could be done by organizing mixed focus groups in which the key findings of the FamICom-project are presented to and discussed with the focus group participants. Next, based on our explorative research into doctors' communication, future research could aim at gaining more insight into the effectivity of doctors' communication strategies. This effectivity study could focus on various family outcomes, such as: understanding, participation in the decision-making process, trust, distress, information recall, acquiescence in the decision, and satisfaction with the communication and decision-making process [32, 116-126]. Such research could be performed in different ways, for example through interview studies, questionnaire studies, intervention studies, or experiments [127-129]. A mixed methodology would also be appropriate for further investigating of the causal effects of doctors' strategies. An example could be a study in which analyses of conversations would be combined with before- and after measurement [130]. Participating families would receive a baseline questionnaire

before the conversation, a checklist immediately after the conversation, and a follow-up questionnaire after the conversation. The conversation could be recorded and analyzed by means of a content analysis. The before- and after measurements could then be related to the results from the content analysis resulting in insights about how doctors' strategies effect family outcomes. Provided that the study power is high enough and a heterogeneous group of participants is included, a study like this could yield generalizable longitudinal results from actual practice. A potential drawback of such a study design could be that it burdens families with questionnaires in an already emotional, difficult, and demanding time. Moreover, drawing firm conclusions about causal relations between doctors' strategies and patient outcomes remains challenging. A video vignette study can offer a solution here.

A video vignette experiment offers the opportunity to systematically vary doctors' communication strategies without manipulating doctors' communication in actual clinical practice [131-141]. Doctors' communication is manipulated within so called video vignettes (i.e., videos of scripted, hypothetical scenarios of actual (medical) conversations) [131-141]. The main advantages of vignette experiments are that communication strategies can be manipulated in an ethically responsible manner and that causal relationships can be established [131-141]. However, achieving high clinical (ecological) validity and generalizability are a main challenge of this methodology due to the artificial nature of the experiments [142]. To enhance realism in a future video vignette study, scripts for the video vignettes could be written on the basis of the audio-recorded data collected within the FamICom-project and of observations of conversations. These scripts could consequently be manipulated for the experiment. During this process, doctors can be consulted in order to maximize realism [142]. During the experiment, analogue family members (i.e. persons who are not acting as surrogate decision-makers at that time) would be asked to watch and evaluate filmed and edited video vignettes while pretending to be the family member in the vignettes [132, 140]. Analysis of the results would not only offer more insight into the effects of various cognition-oriented and affect-oriented skills and strategies but also into the interplay

between these strategies. Despite the challenges regarding clinical validity and generalizability, such an experiment would allow a further description of effective strategies and combinations of strategies. This could be helpful in improving doctors' conversation practice and medical training in that regard.

Yet another research method is conversation analysis. Conversation analysis is an inductive method involving the close analysis of actual interactions [143]. It is a precise method, including nuances, such as silences, sounds (e.g., sniffing or laughing), and stammering, which provides detailed data [144]. Conversation analysis focuses on the analysis of the actual text rather than on psychological factors [146]. The analysis itself concerns the micro-level of conversation [147]. This type of analysis enables researchers to qualitatively study very specific phenomena in detail. However, when considering a conversation analytic approach, one should be aware that the transcription and analysis of data are very time consuming.

Lastly, future research could focus on developing a skills training and on evaluating the effectivity thereof. For example, a systematic review study could provide insight into which relevant skills trainings exist and into the effectivity of these trainings. Subsequently, a skills training can be developed for the context of doctor-family communication in intensive care unit. The effectivity of these trainings could then be evaluated through a one-group pre-posttest design [97].

Future education

Effective communication and decision-making processes are important. Doctors (in training) learn many skills by experience and by watching their colleagues. However, they have indicated that this experience should be accompanied by formalized training [148]. Therefore, communication skills are an important area to address in training and education [95]. Training and education should preferably focus both on cognition- and affect-oriented skills [149].

There is a need for evidence-based training and education with careful skill measurements afterwards [150]. Ideally, two levels of evaluation would be used: (1) participating doctors' satisfaction with the training and their development and (2) changes in communicative behaviors in real-life conversations [151]. The majority of educational interventions include simulation training in which actors play the role of family members [150]. To allow for true tailoring, doctors' awareness regarding their communicative behavior is key. For this purpose, developing reflection skills could also be made a part of training programs. Three simple questions can be helpful:

- “Which communicative strategies do/did I use in this particular situation?”
- “Why do/did I use these strategies?”
- “Does/did my approach fit this family's communication preferences and needs?”

We know that doctors prefer a tailored approach towards training and education. That is, they prefer training programs which can be enrolled when it fits their agendas and which focus on their individual learning questions. We also know that neonatologists, pediatric intensivists, and adult intensivists can and want to learn from each other. We therefore recommend offering joint training and education in which neonatologists, pediatric intensivists, and adult intensivists improve their communication skills together. A tailored communications skills program is currently being piloted within the FamICom-project. In this program, 4 knowledge and reflection sessions are alternated by 5 simulation training sessions. Before each session, the participating doctors are asked what specific questions they have, what scenarios they want to submit and what skills they want to develop.

Clinical practice

Doctor-family communication consists of several challenges: how to communicate with families, when to communicate with families, and what to communicate with families [152]. This dissertation focused especially on the how. We hope that our findings will help to further raise doctors' awareness. The next step for doctors is to try to turn this awareness into actions to improve their communication. For this purpose, we presented several hands-on recommendations for doctors in the chapters of this dissertation. In addition, based on the research findings within the FamICom-project, we developed a tool (i.e., a conversation guide) for conversations in intensive care units. This conversation guide is published on three national informational sites, those of Palliaweb (intended for all healthcare professionals involved in palliative care inside and outside the hospital), Pharos (intended for all healthcare professionals who deal with patients with limited health literacy or a migration background and with their immediate relatives) and the Kenniscentrum Kinderpalliatieve Zorg (i.e., Knowledge Center for Palliative Care for Children) (intended for healthcare professionals who are involved in palliative care for children, inside and outside the hospital, and for the parents of these children) [153-155]. Figure 1 presents the conversation guide.

Overarching conclusions

This dissertation shows that communicating with families of critically ill patients can be challenging for doctors in intensive care units and the patients and families involved. Our research shows that much is going well. Nevertheless, progress can be made on several aspects. The first step for this progress is awareness, which we have tried to raise. Now it is up to the neonatologists, pediatric intensivists, and adult intensivists (in training) to further improve their communication skills in collaboration with nurses. They have to do so in a rapidly changing context involving technological advancements and a diversifying patient population which reshape the doctor-family relationship. We believe that tailored communication is key in establishing satisfying communication and decision-making processes with families. Tailoring is only possible if families reveal more about themselves, their preferences, and their needs than seems to be the case now. They can be stimulated to do so by the doctor, but more awareness on the part of the family may also be necessary. Awareness about that it can happen to anyone that a loved one ends up in an intensive care unit and about the possibilities of peer support and family education [156].

Gesprekswijzer voor familiegesprekken over ingrijpende behandelbeslissingen

Gebaseerd op uitkomsten uit de FAMICOM-studie

Amsterdam UMC
Onderspor Medische Centra

ZonMw

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ALGEMENE HANDVATTEN:



Bereid je voor

- Zet de behandelmogelijkheden op een rij.
- Weet wat eerder besproken is met de familie.
- Bepaal je doel van dit gesprek.
- Bedenk welke informatie je wilt geven en hoe je dat gaat doen.
- Bedenk welke informatie je wilt krijgen.



Bouw een vertrouwensband op

- Laat je niet storen tijdens het gesprek.
- Vraag de familie naar eerdere moeilijke situaties en wat hen toen hielp.
- Overleg hoe je hen wilt informeren en betrekken.
- Veronderstel niet maar vraag door.
- Houd regie over het gesprek.



Communiceer op maat

- Stem je woorden af op de taalvaardigheid van de familie.
- Leg helder uit wat je zeker weet en wat (nog) niet.
- Praat niet te lang achter elkaar.
- Bied tussendoor ruimte voor vragen en reacties.
- Stel tijdens het gesprek open vragen om te checken of de familie je begrijpt.



Heb oog voor emoties

- Geef emoties de ruimte zonder de familie erin te laten verzanden.
- Reageer ook op impliciete uitingen van emoties.
- Ontdek waar zij angstig of boos over zijn en hoe je daarin kunt helpen.
- Stei misconcepties invoelend bij.

AFGESTEMD OP DE BESLUITVORMING:



Bespreek concrete behandelopties

- Zet voor- en nadelen van de overgebleven behandelopties overzichtelijk op een rij.
- Vraag de familie welke voor- en nadelen zij zien.
- Als één behandelroute ontgeenzeggelijk de beste is, beargumenteer deze dan concreet.
- Leg uit dat de bestrijding van pijn en andere symptomen nooit stopt.



Wissel wensen en waarden uit

- Vraag de familie naar de behandelwensen van de patiënt.
- Vraag hen wat voor de patiënt het leven tot een goed leven maakt.
- Vraag wat zij een goede toekomst vinden voor de patiënt.
- Vraag waar voor hen de grens van lijden ligt.
- Leg uit dat goede zorg is in jouw ogen.



Ga invoelend om met verschillen van inzicht

- Heb oog voor de unieke omstandigheden van de familie.
- Onderzoek waar het verschil van inzicht in de kern om draait.
- Kijk onbevooroordeeld naar hun standpunten.
- Oefen geen morele druk uit.
- Blijf naast hen staan.



Kom via dialoog uit op een gezamenlijk gedragen beslissing

- Vat samen waar je nu met elkaar staat.
- Toets of de familie zich kan vinden in die weergave van de situatie.
- Bespreek de volgende concrete stappen in behandeling en zorg.
- Reageer op signalen dat de familie zich onvoldoende gehoord of te zwaar belast voelt.
- Als een beslissing onontkoombaar is, leg uit waarom dit zo is.



Bereid de familie voor op het sterven van de patiënt

- Vraag naar hun wensen rond het afscheid.
- Ondersteun hen bij de uitvoering van deze wensen.
- Bereid hen voor op hoe het stervensproces zal gaan.
- Leg uit wat je gaat doen zodat de patiënt zo vredig mogelijk overlijdt.

Figure 1. The conversation guide developed within the FamCom-project

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