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

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Best-practice recommendations doctors use to enhance the understandability in their information provision in neonatal, pediatric, and adult intensive care

Abstract

Purpose

Understandable information provision by doctors is a prerequisite to enable family involvement in the intensive care unit (ICU). Previous research has resulted in best-practice recommendations to enhance the understandability of medical information. To the best of our knowledge, doctors' information provision in the ICU has not yet been studied. This study aimed to explore (1) which best-practice recommendations doctors in the ICU use to enhance the understandability of their oral information in conversations with families about decisions to continue or discontinue life-sustaining treatment, (2) which best-practice recommendations doctors use to check if families have understood the information provided, and (3) how families respond to best-practice recommendations used by doctors.

Method

A qualitative deductive analysis of 95 audio-recorded team-family conversations.

Take-home message

Doctors in intensive care units use several best-practice recommendations to enhance the understandability of the information they provide. However, there are also some missed opportunities; using more of the best-practice recommendations and using those to the fullest can help doctors in explaining complex medical information in a way that fits family's capabilities.

Results

Seventy-one doctors and the families of 34 patients from the neonatal, pediatric, and adult ICU of a large university-based hospital participated. Doctors frequently used best-practice recommendations intended to improve the understandability of their exchange of medical information. Yet, they less frequently structured their conversations, or used visual aids. To check understanding, doctors used teach-back in less than half of their conversations and rarely used summaries. Regardless of the use of best-practices, families mostly showed no response or reacted with a back-channel.

Conclusion

Doctors frequently used best-practice recommendations to improve the understandability of their exchange of medical information and to check families' understanding. Nevertheless, room for improvement remains. Doctors' best-practices sometimes yielded explicit responses from families, but families mostly showed no response or reacted with a backchannel.

Keywords

Intensive care, Communication, Critical care, Information provision, Understandability, Comprehension

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Introduction

Conversations in neonatal intensive care units (N-ICUs), pediatric intensive care units (P-ICUs), and adult intensive care units (A-ICUs) involve complex medical information. An exchange of information about the patient's current situation, test results, prognosis, and the (still) possible treatments – each with their own pros and cons – often precedes decisions about the continuation or discontinuation of life-sustaining treatment (LST). As most ICU-patients are not able to communicate, doctors usually inform the patient's family members, who act as surrogate decision-makers [1-5]. Studies have shown that an adequate exchange of information will enhance family satisfaction and the quality of the decision-making process [6-18]. A prerequisite for family involvement is to provide information in such a way that people with varying backgrounds and levels of health literacy can understand the key messages of the information provided [19].

Comprehensible information is especially relevant in the context of decisions regarding LST in ICUs. If the family is involved in decisions, understanding the information provided is key to also understand the doctors' reasoning. A good understanding is also necessary to respond to that argumentation [20]. Moreover, comprehension can decrease the risk that conflicts will arise later. Indeed, in a previous study, we noticed that a lack of understanding of the information provided added to the complexity of conflicts between doctors and families [21]. Last, informing families about uncertainties in an understandable way can enhance the decision-making and wellbeing of patients and their families [22]. In sum, it is important that doctors communicate medical information in a way that families can understand the gist of the message as needed for their decisional role and psychological wellbeing.

Information provision in the ICU-context is complex because it usually involves technical and biomedical knowledge. Furthermore, the ICU-context, especially regarding decision about LST, can cause emotional distress as it involves ethical dilemmas, fear of loss, high risks, and far-reaching consequences [3-5, 23]. This emotional distress can cause difficulty in processing and consequently understanding medical information [24]. Finally, doctors in especially the N-ICU and A-ICU often have no pre-existing

relationships with patients nor their families and have therefore no knowledge of patients' and families' preferences. Over the last decades, more scientific attention is being given to how complex medical information can be explained in a way that fits the patient's or family's capabilities. This research has resulted in best-practice recommendations to enhance the understandability of written, audio-visual, and – to a lesser extent – oral patient information [19, 25-38]. Yet, to the best of our knowledge, it is unknown whether and how this has affected doctors' information provision in the ICU. This qualitative study aims to answer the following questions:

1. Which best-practice recommendations do doctors in the ICU use to enhance the understandability of their oral information in conversations with families about decisions to continue or discontinue LST;
2. Which best-practice recommendations do doctors use to check if families have understood the information provided in these conversations;
3. How do families respond to best-practices for understandable information used by doctors?

In answering these questions, we will also look into differences and similarities between the three ICU-settings.

Methods

Design and setting

This explorative, qualitative study focused on doctors' information provision in conversations about LST with families of patients in the N-ICU, P-ICU, and A-ICU. A deductive approach was chosen to be able to build on the results of previous research which yielded best-practice recommendations for enhancing the understandability of written and oral information in different medical contexts [19, 25-59]. Data were derived from audio-recordings of team-family conversations in ICUs of the Amsterdam UMC.

Population and sampling

Families of patients were eligible to participate from the moment when doubts were expressed by the medical team and/or the family whether continuing LST was in the patient's best interests. 'Families' refers to the parents, relatives and/or close friends who were present during these conversations. We strived for maximum variation regarding patients' age, gender, diagnosis, disease progression, and course of treatment, families' ethnic background, and doctors' gender, medical specialty, and role within each ICU.

Recruitment

Prior to data collection, all doctors and nurses from the participating units received oral and written information and were asked for their consent to participate. The attending doctor or nurse introduced the study to eligible families. Families who were interested in participating were further informed and then asked for their oral and written consent by a member of the research team or the attending doctor.

Data collection

The inclusion period lasted from April 2018 to December 2019. From the moment of inclusion of a family, all conversations between the medical team and families were audio-recorded until a final decision was reached to continue or discontinue LST. Only conversations in which all participants spoke Dutch were included in the present study.

Data analysis

The audio-recordings were transcribed verbatim and anonymized. The transcripts ($n=95$; N-ICU: $n=51$; P-ICU: $n=28$; A-ICU: $n=16$) were then uploaded to MaxQDA 2022 for analysis [60]. Coding and analysis consisted of four phases, as illustrated in Figure 1. Our initial codebook was based on literature describing best-practice recommendations to enhance the understandability of written, audio-visual, and oral patient information [19, 25-59]. Coding consisted of determining the frequency of the occurrence of best-practices. During coding, it became apparent that not all best-practices for written and audio-visual information could be assessed in or were relevant for oral information. To illustrate, we had first included using short sentences and limiting the sequence of sentences in the codebook. We later removed these two codes because these could not be reliably coded due to the less streamlined nature of oral communication (e.g., less clear punctuation), as compared to written text. Table 1 describes the best-practice recommendations from the literature which could reliably be applied in the coding phase and therefore were included in the final codebook. With regard to families' responses to best-practices, we focussed on families' immediate responses after a doctors' best-practice and used inductive analysis to categorise families responses.

Ethics

The Amsterdam UMC institutional review board waived approval of this study (W17_475 # 17.548). All participants could withdraw their consent at any time.

Results

Seventy-one doctors and the families of 34 patients participated in our study. Table 2 lists patients, relatives, and doctors' characteristics. All doctors and all but one nurse from the N-ICU gave their consent and participated. All but one of the approached families agreed to participate, the latter because they found participation too burdensome at that moment.

Table 3 shows the number and percentage of conversations in which doctors used each of the best-practice recommendations described in Table 1.

Theme 1: Doctors' best-practices to enhance the understandability of their oral information

Doctors used various best-practices to enhance the understandability of their information in conversations with families about decisions to continue or discontinue LST, including: (1) word choice and style, (2) structuring the conversation, (3) stimulating questions, and (4) visual aids. Families' immediate responses to best-practices were of four types: (1) no response, (2) backchannel (e.g., "yeah", "hmm", "right"), (3) asking questions, and (4) substantive response. Regardless of which best-practice doctors used, families mostly showed either no response or provided a backchannel only.

Phase 1 Preliminary codebook

We based our preliminary codebook on relevant studies in which best-practice recommendations were presented to enhance the understandability of medical information.

Together with 6 experts in the field of medical communication (MZ, AA, MdV, ES, GB, AL) we thoroughly discussed the best-practice recommendations identified in the literature and consequently excluded those practices that were only relevant for written or audiovisual information and not for oral information.

The remaining practices formed the basis of our preliminary codebook.

Phase 2 Final codebook

Two researchers (MZ, MdV) coded 12 randomly chosen transcripts in MaxQDA 2022 using the preliminary codebook.

We refined the codebook by adjusting it whenever deemed necessary. Most importantly, we distinguished between best-practice recommendations to enhance the understandability of their oral information and best practices to check if families have understood the information provided.

Codes were removed when those could not be assessed in or were not relevant for the oral information in our data set.

The final codebook was again discussed with four experts (MZ, AA, MdV, AL) and refined.

Phase 3 Coding

One researcher (MZ) coded all transcripts ($n=95$) in MaxQDA 2022 by means of the final codebook. This included the transcripts already coded in Phase 2. Table 3 describes how the codes were applied.

The coding was randomly checked by three researchers (AA, MdV, AL).

The codes about which there was no immediate agreement were discussed by four researchers (MZ, AA, MdV, AL) until they reached consensus.

Phase 4 Analysis

All codes were extensively discussed during three rounds of analysis by the team of researchers (MZ, AA, MdV, AL) and three experts in the field of medical communication (ES, GB, JN) to identify discerning patterns regarding the three research questions:

- Which best-practices from the literature do doctors use to enhance the understandability of their oral information in conversations with families about decisions to continue or discontinue LST?
- Which best-practices from the literature do doctors use to check if families have understood the information being provided in these conversations?
- How do families respond to best-practice recommendations used by doctors?

With regard to the third research question, the researchers focussed on the immediate responses of families after a doctor used a best-practice recommendation. The researchers focussed solely on those best-practice recommendations where an explicit verbal response from the family could be expected: explaining medical jargon, using metaphors, explaining or contextualizing numeric information, summarizing the information provided, explicitly stimulating families to ask questions themselves, using visual aids.

During the analysis, the researchers also looked into differences and similarities between the three ICU-settings.

These outcomes were extensively discussed by all co-authors in three discussion rounds to sharpen them and to minimize bias and unclarity.

Figure 1. Four phases of coding and analysis

Practices	Description
Theme 1: Doctors' practices to enhance the understandability of their oral information	
Category 1: Word choice and style	
Using plain language	It is important to use simple, familiar language and to avoid jargon as much as possible as at times of distress people may struggle more than usual to take in information [33, 36, 43, 59, 61]. Studies suggest that utilizing plain language has the potential to enhance patients' knowledge across the continuum of health literacy [44]. Also according to patients themselves, information should be provided in plain language [32].
Explaining or substituting medical jargon	In healthcare conversations, it is well known that a range of jargon is used. This is unfamiliar to patients and their families, and difficult to understand [25, 43, 59]. This means that when medical terms are used, these should be defined (i.e., explaining medical jargon) or accompanied by an alternative term for explanation (i.e., substituting medical jargon). The explanation of a medical term should also be easy to understand [43].
Using metaphors	Metaphors can be used by healthcare professionals for promoting understanding, for example by explaining complex information through a metaphor [52, 62-63].
Not using double negatives	Double negatives are often difficult to understand, especially because of the ambiguous nature of double negatives [64]. Therefore, it is important to avoid those.
Explaining or contextualizing numeric information	Many patients and their families have difficulty understanding numeric information, making it imperative that numbers, fractions, and percentages should be used only as needed [41]. When numeric information is used, it should be clear and easy to understand. It can be helpful to explain or contextualize the numbers alongside the number (e.g., very few patients – 1 out of 10,000 patients in a similar situation – will fully recover) [36, 41]. Comprehending the information provided should not require families to perform calculations [41].
Category 2: Structuring the conversation	
Explaining the purpose of the conversation	It is important to make the purpose of the conversation completely evident. This will help the doctor to deliver clear and consistent messages and enables patients or their families to interpret the information provided in terms of this purpose and to remain focused [19, 25, 39].
Categorizing the information provided	In medical conversations, there is often much information to be discussed. Furthermore, doctors often have to discuss more than one concept. Patients and their families can struggle to comprehend such complex information [56]. To enhance the understandability, the doctor could break down the information into sections or categories. Discussing these relatively short sections prevents information overload, makes the content easier to understand, and enables doctors and patients or their families to discuss questions and check understanding regarding a certain category of information right away instead of at the end of the conversation [27, 36, 40, 56].
Summarizing the information provided	Each conversation should have a summary of what is discussed in the conversation (so far) as such a summary can aid accuracy of information [25, 40, 55]. It furthermore creates structure, facilitates patients' or their families' responses, and aids building relationships [25, 40, 55].
Category 3: Stimulating questions	
Explicitly stimulating families to ask questions themselves	Patients or their families may have questions as things are being discussed with them. If the information is provided all together and doctors do not explicitly provide room for questions, patients or their families may hold these questions until the end or don't ask them at all, meaning their understanding may be affected [25, 51, 56]. By providing information based on questions asked, doctors can be sure that their information meets an information need [65-69]. The answer is therefore likely to be better processed and understood.
Category 4: Visual aids	
Using visual aids	Spoken word is often misheard or misunderstood. Visual aids can be used to assist and support explanations. The use of appropriate visual aids can be effective in improving understanding and can support recall [31, 33, 42, 44, 48, 50-51, 58, 70].
Theme 2: Doctors' practices to check if their information provision was understandable for families	
Teach-back	The teach back method is a useful way to check understanding by asking families to state in their own words what has been discussed in the conversation or their current understanding of the issue. If comprehension is not demonstrated, doctors can modify their explanation [26, 38, 49, 53, 57, 71]. Evidence supports that the teach-back method adds to maximizing understanding [26]. All patients and families with limited (health) literacy can benefit from the teach-back method, especially people with limited health literacy [49].

Table 1. Description of the best-practice recommendations included in the present study

Setting	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Neonatal intensive care unit	11 (32)	30 (30)	22 (31)
Pediatric intensive care unit	11 (32)	28 (28)	35 (49)
Adult intensive care unit	12 (35)	41 (42)	14 (20)
Age (y)	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Premature	10 (29)		
0–1	6 (17)		
1–4	–		
4–12	2 (6)		
12–16	2 (6)		
16–21	2 (6)		
21–35	–		
35–50	3 (9)		
50–65	5 (15)		
65+	4 (12)		
Gender	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Male	16 (48)	39 (39)	28 (40)
Female	17 (52)	60 (61)	43 (60)
Main diagnosis	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Prematurity	4 (12)		
Prematurity + congenital disorder + acute illness	1 (3)		
Perinatal asphyxia	4 (12)		
Congenital disorder	13 (35)		
Acute illness	11 (32)		
Cancer + acute illness	2 (6)		
Neurological damage	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Yes	24 (65)		
No	12 (33)		
Total duration of care in the intensive care unit	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
0–24 h	5 (15)		
1–7 days	9 (26)		
1–4 week	15 (44)		
1–3 months	5 (15)		

Table 2. Main characteristics of included patients, family members, and doctors

Relation to the patient	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Parent			42 (42)
Grandparent			7 (7)
Partner			7 (7)
Child			9 (9)
Sibling			8 (7)
Brother in law/Sister in law			2 (2)
Aunt/Uncle/Cousin			10 (10)
Friend			4 (4)
Other			5 (5)
Unknown			5 (5)
Ethnic Background	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Dutch			86 (87)
Moroccan			4 (4)
Syrian			1 (1)
Surinamese			1 (1)
Turkish			2 (2)
Ethiopian			2 (2)
Unknown			3 (3)
Medical specialty	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Neonatologist			14 (20)
Pediatric intensivist			9 (13)
Pediatrician			15 (21)
Pediatric neurologist			7 (10)
Pediatric cardiologist			3 (4)
Metabolic pediatrician			2 (3)
Pediatric pulmonologist			1 (1)
Intensivist			9 (13)
Anesthesiologist			4 (6)
Internist-hematologist			1 (1)
Neurosurgeon			3 (4)
Neurologist			1 (1)
Unknown			2 (3)
Role	Patients (N = 34), n (%)	Family members (N = 99), n (%)	Doctors (N = 71), n (%)
Resident			20 (28)
Fellow			13 (18)
Staff			36 (51)
Unknown			2 (3)

Table 2. (Continued)

Practices	Coding	Number of conversations in which doctors used a specific strategy		
		N-ICU (51 conversations included) (n/%)	P-ICU (28 conversations included) (n/%)	A-ICU (16 conversations included) (n/%)
Theme 1: Doctors' practices to enhance the understandability of their oral information				
Category 1: Word choice and style				
Using plain language	We determined the frequency of the occurrence of doctors' use of plain language.	45 / 88%	11 / 39%	9 / 56%
Explaining or substituting medical jargon	We determined the frequency of instances in which doctors explained or substituted medical jargon.	34 / 67%	10 / 36%	13 / 81%
	Explaining medical jargon	28 / 55%	9 / 32%	8 / 50%
	Substituting medical jargon	18 / 35%	7 / 25%	6 / 38%
Using metaphors	We determined the frequency of the occurrence of doctors' use of metaphors.	40 / 78%	25 / 89%	13 / 81%
Not using double negatives	Avoiding double negatives is the only best-practice based on what does not happen. We nevertheless counted the frequency of double negatives.	5 / 10%	1 / 4%	3 / 19%
Explaining or contextualizing numeric information	We determined the frequency of instances in which doctors explained or contextualized numeric information.	19 / 37%	3 / 11%	4 / 25%
	Numbers	15 / 29%	3 / 11%	3 / 19%
	Percentages	5 / 10%	1 / 4%	1 / 6%
Category 2: Structuring the conversation				
Explaining the purpose of the conversation	We determined the frequency of instances in which doctors explained the purpose of the conversation.	12 / 24%	10 / 36%	7 / 44%
Categorizing the information provided	We determined the frequency of instances in which doctors categorized the information.	9 / 18%	5 / 18%	4 / 25%
Summarizing the information provided	We determined the frequency of summaries doctors provided about the discussed information.	3 / 6%	2 / 7%	1 / 6%
Category 3: Stimulating questions				
Explicitly stimulating families to ask questions themselves	We determined the frequency of instances in which doctors explicitly stimulated families to ask questions.	42 / 82%	4 / 14%	10 / 63%
Category 4: Visual aids				
Using visual aids	We determined the frequency of verbal signs that the doctor used a visual aid.	2 / 4%	0 / 0%	0 / 0%
Theme 2: Doctors' practices to check if their information provision was understandable for families				
Teach-back	We determined the frequency of instances in which doctors used teach-back.	23 / 45%	5 / 18%	7 / 44%

Table 3. The number and percentage of conversations in which doctors used each best-practice recommendation

When providing medical information, doctors mainly used plain language. Doctors more commonly used plain language in conversations in the N-ICU (88%) as opposed to those in the P-ICU (39%) and A-ICU (56%). Doctors also used medical jargon, but when they did, they mostly explained the terms they used and/or substituted those by everyday language, for example:

"The breathing was compromised, the respiration was not good anymore. For that we had to intubate her, as it's called in our jargon. Had to put a tube in her throat that allows us to ventilate her."

In most conversations, doctors appeared to avoid double negatives (e.g., "No, I don't think, that it didn't go well"). More so in conversations in the N-ICU (10 % double negatives) and P-ICU (4% double negatives), as compared to the A-ICU (19% double negatives). Doctors mentioned and explained or contextualized numeric information more often in the N-ICU (37%) and the A-ICU (25%), as opposed to the P-ICU (11%). To illustrate, a doctor in the A-ICU first told the partner of a patient a percentage chance of waking up and immediately provided a qualification of this percentage:

“Well, that chance is about 5% [partner: “okay, yes”] and, uh, so that chance is very small.”

In response to doctors' explanation of numeric information, families sometimes asked questions. These questions in most cases were about what the information meant for specific situation at hand.

Doctors only to a limited extent structured conversations to enhance the understandability of their information (category 2). Doctors explained the purpose of the conversation most often in the A-ICU (44%), followed by the P-ICU (36%), and the N-ICU (24%).

“Of course we will discuss what the current state of affairs is. Where we are now standing and how we will proceed, right?”

Doctors categorized the information provided by enumerating, for example:

“those medicines fall within two groups. The first group is the reset group...” or “there are three important things I wish to discuss with you. The first is the brain”.

Doctors categorized their information in about a fifth to a quarter of all conversations in the different ICU-settings. Finally, doctors only incidentally summarized the information provided (N-ICU: 8% of all conversations; P-ICU: 7% of all conversations; A-ICU: 6% of all conversations). If they did, they always provided this summary at the end of a conversation, in all ICU-settings. Families in most cases responded to those summaries. They either asked questions about the content of the summary or next procedural steps or responded substantively by confirming what the doctor said. In one conversation, families responded substantively by explicating how they appreciated the doctor's overarching summary:

“We've had three important conversations and we have to tie those together, even though ... Well, I think we understand a lot of it, but sometimes we cannot get to the required level of understanding and then it is great when one of the three doctors ties the three conversations together. So that we get an overall summary of the conversations.”

Doctors also explicitly stimulated families to ask questions themselves (category 3). As with the summary, such encouragements most commonly occurred at the end of conversations and either focused on questions families had at that particular moment (e.g., “Do you still have any questions?”) or on future questions (e.g., “If you any questions come up, you are always welcome to ask those.”). Additionally, doctors commonly encouraged families to write down questions, so that they would not forget and could ask those in a follow-up conversation. Doctors frequently stimulated families to ask questions in conversations in the N-ICU (82%) and they quite commonly did so in conversations in the A-ICU (63%), whereas they infrequently did so in conversations in the P-ICU (14%). Families responded by asking questions they had or with a substantive response in which they explicated that they did not have any questions at that point. In only two conversations, both in the N-ICU (4%), doctors used visual aids to support the information they provided, by drawing the anatomical situation. In both instances, families responded substantively, discussing the situation together with the doctor.

Theme 2: Doctors' best-practices to check if their information provision was understandable for families

Doctors used teach-back to check if families had understood their oral information in nearly half of the conversations in the N-ICU (45%) and A-ICU (44%) and in only about a fifth of the conversations in the P-ICU (18%).

Doctors generally posed teach-back questions at the start of a conversation; broad, open-ended questions in which they checked families current level of understanding, such as:

“And, I wanted to know from you all, what do you know at this point?; How he's doing, what have you all been told so far?”

Doctors sometimes provided the family with some guidance in answering the question posed, for example by specifying subjects of importance:

“Maybe you could start by telling me what you know about the ventilation”.

Discussion

When the answer of a family member suggested a mismatch between the family's comprehension of the information and what the doctor had actually intended to tell, the doctor then elaborated on relevant aspects and corrected misunderstandings. For example, in one conversation, a family member responded to the question whether he knew what dialysis is: "I think so but I'm not sure if what is in my head is right". In response the doctor explained dialysis as follows: "dialysis is a treatment of flushing a person's kidneys for a large part of the day when these do not work well". In none of the conversations, doctor used the teach-back method at the end of a conversation.

Doctors frequently used best-practice recommendations intended to improve the understandability of their exchange of medical information, including using plain language, explaining or substituting medical jargon, using metaphors, not using double negatives, explaining or contextualizing numeric information, and explicitly stimulating families to ask questions themselves. Yet, they less frequently structured their conversations, or used visual aids. To check understanding, doctors used teach-back in less than half of their conversations and rarely used summaries. Regardless of the use of best-practices, families mostly showed no response or reacted with a backchannel. Doctors' summaries and direct questions were most likely to elicit a content-related response from families.

In all ICU-settings, doctors very commonly used metaphors. Indeed, metaphors can be used to enhance the understandability of the information provided [52, 62-63]. Yet, a metaphor and its explanation have to match people's knowledge, abstraction level, and requires processing time as it involves an interaction between the metaphor and its meaning [45-46]. Furthermore, metaphors carry a risk of misinterpretation and therefore require repeated checking. This is especially important in intercultural communication, because concepts can be represented differently in different cultures [72]. Therefore, it is important to handle metaphors with care. Unfortunately, in our study, we could not verify whether metaphors were in tune with families cognitive skills. Yet, we did observe that doctors did not verify either. Many of the recommended practices were used by the ICU-doctors in our data set. However, some were not or only incidentally used. First, doctors in only two conversations explicitly used visual aids although we cannot rule out that aids were used more often, because we could not watch the conversations. Not using visual aids is a missed opportunity as using visual aids (e.g., pictographs, icon arrays, booklets) is likely beneficial for people with low health literacy and potentially for everyone [70], it can increase understanding [47, 70, 73-76], and doctors and families at a NICU indicated visual aids to be helpful [77]. It is important to consider a family's visual literacy when using visual aids [70]. Second, doctors only incidentally summarized the information provided, and if they did, they always provided the summary at the end of a conversation. As summarizing

appears to facilitate families' responses, can aid accuracy of information, creates structure, and aids building relationships it would be recommendable for doctors to provide summaries more often during a conversation rather than only incidentally at the end of the conversation [25, 40, 55]. Likewise, families can be more often invited to pose questions.

Our analysis showed that doctors only to a limited extent used structuring practices in their conversations. This is unfortunate because doctors can build the information step-by-step, taking families by the hand by delivering the information in categorized chunks. This also enables doctors to provide processing time between different chunks, and by doing so to prevent information overload. Moreover, doctors can check families' comprehension and stimulate them to ask questions between chunks of information [19, 25, 27, 36, 39-40, 55-56].

Doctors used teach-back in less than half of these complex conversations, and only at the beginning of the conversation. The latter suggests that these doctors checked whether the family had understood the information from earlier conversations – potentially with another doctor – more so than their own information provision during the ongoing conversation. It would be recommendable to more frequently check understanding as the conversation unfolds, either using teach-back, direct questions, or response solicitations [78]. It is fitting to use teach-back at least once in the conversation, preferably after sharing an important piece of information or at the end of the conversation in order to make sure that the family has understood and remembered the most important information from the conversation [26, 57, 79].

We observed some striking differences between the ICU-settings, but could not distill a clear pattern and have no straightforward explanations for the variations. Therefore, the differences between the ICU-settings require further investigation.

Limitations, strengths and recommendations for future research

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. Moreover, we cannot rule out a Hawthorne effect as a result of audio-recording conversations [80], although such an effect appears unlikely [81]. Finally, the generalizability of our study is not self-evident because due to the logistical demand of the study we included the audio-recordings of conversations from one medical center only. It would be relevant to expand this study to other ICUs in the Netherlands and, preferably, to ICUs in other countries, thereby also multiplying the number of cases. This will enable investigating contextual and cultural influences as well.

There are few qualitative assessment tools specifically developed for the assessment of oral information provision behavior [82-83]. We therefore had to develop our own. During coding, it became apparent that not all best-practices for written and audio-visual information could be applied to the coding of oral information. Oral information provision concerns two-way traffic between doctors and families. Assessment instruments for oral information should preferably account for this. The Verona Coding Definitions of Emotional Sequences (VR-CoDES) – developed to analyze emotional communication in provider-patient encounters – forms an example of an instrument in which an attempt has been made to take this sequentiality into account [84-85]. This could be an interesting startingpoint for future research into assessment tools for oral information.

A strength of this study is that we collected a large dataset of transcripts of real-life, highly sensitive conversations from three different ICUs which we meticulously analyzed. The results of this study are very relevant as these provide in depth insight into the use of practices to enhance and check understanding of information provision in the ICU and into existing room for improvement regarding those practices.

Conclusion

In this study, we have explored which best-practices doctors do use to enhance the understandability of their information provision and which practices they do not or only infrequently use. We can conclude that much is going well. Nevertheless, progress can be made on some aspects. Based on our findings we present some specific hands-on recommendations for doctors to enhance the understandability of their information provision in Figure 2.

Recommendations for conversations

Visual aids

Make use of visual aids to assist and support explanations. Preferably visual aids which are part of a relevant flyer which can be given to the family to take home. Always consider a family's visual literacy when using visual aids.

Structuring

Explain the purpose of the conversation. Structure your information by breaking it up in sections and by categorizing it. Also provide structure by summarizing sections of information during the conversation.

Processing time

Provide the family with enough time to process the information provided and to respond to it. In light of this processing time, it could help to have more short conversations instead of fewer longer conversations.

Checking understanding

Check families's understanding in a subtle and natural manner. In order to do so, not only use teach-back at the start and end of a conversation, but also during the conversation. If a family does not respond or in a very short manner, then ask further questions to check if they really have understood the information.

Recommendations for reflection

Video reflection

Videotape your conversations and reflect on those. Looking to your conversations without being part of it enables you to see more.

Good examples

Watch and discuss good examples from and with other doctors.

Reflection with others

Reflect on your the conversation with the family or a nurse to also include their perspective in your reflection. This way you can minimize bias.

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Author contributions

AA and MdV had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. AA, MdV, MZ, ES, GB, AL contributed substantially to the study design, data analysis and interpretation. AA, MZ, GB, MS, TC, JvW, MvH, AvK, MvdL, ES, and MdV contributed substantially to the writing of the manuscript. The first draft of the manuscript was written by AA and all authors commented on the previous versions of the manuscript. All authors read and approved the final manuscript.

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Data management and sharing

Data are available upon request.

Figure 2. Recommendations for doctors to enhance the understandability of their information provision

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