How matters

End-of-life communication with family members of critically ill neonates, children, and adults

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CHAPTER 5

HOW INTENSIVE CARE FELLOWS EXPERIENCE FAMILY COMMUNICATION, AND HOW THEY (WISH TO) LEARN IT: A SURVEY IN THE NETHERLANDS

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ABSTRACT

Background

Effective communication is crucial to ensure high-quality intensive care, particularly when physicians and families need to make end-of-life decisions on the patient's behalf. However, communication skills training is often not formally included in education programs for intensive care fellows. This study aimed to obtain insight into how intensive care fellows experience their communication with families of critically ill patients, and how they currently and preferably develop their communication skills.

Method

In 2021, a survey was sent to all 34 neonatal-, 15 pediatric-, and 75 adult intensive care fellows in the Netherlands. The answers to the open-ended questions were qualitatively coded and analyzed. Descriptive statistics were predominantly used to analyse the answers to the closed-ended questions. Chi-squared tests were employed for group comparisons.

Results

Sixty fellows (48%) responded ($N_{NICU} = 21, N_{PICU} = 10, N_{ICU} = 29$). Fellows identified managing disagreements between families and themselves to be the greatest communicative challenge. In general, they felt less proficient in their affect-oriented communication skills compared with cognition-oriented communication skills. Regardless of specialty, fellows primarily acquired their communication skills through learning on-the-job rather than through formal training. Fellows preferred to improve their communication skills through a combination of learning methods, including simulation training, on-the-job learning, and structured feedback.

Conclusions

Our findings underscore the necessity of structured communication training within intensive care medicine education, complementing fellows' on-the-job learning. Fellows emphasized the need to particularly improve their affect-oriented communication skills. Education programs could be improved by tailoring it to fellows' individual educational needs.

Keywords

Intensive care, Communication, Education, Fellows, Decision-making, Families

INTRODUCTION

Effective communication is a fundamental component of intensive care, ensuring both sensible and high-quality care. Healthcare providers (HCPs) are required to engage in clear and structured communication (i.e., cognition-oriented) as well as in empathetic communication (i.e., affect-oriented) with patients and their families.[1–4] This becomes even more important in conversations in which decisions about the (dis)continuation of the patient's life-sustaining treatment (LST) have to be dicussed.[5–7] Studies have shown that effective communication significantly influences the decision-making process and may have a stronger effect on patient- and family care satisfaction than medical outcomes.[8–11] Effective communication can also have a positive impact on HCPs themselves by enhancing their comfort in handling difficult conversations and reducing moral distress.[12,13]

Despite the importance of communication, training in communication skills is often not a formal part of education programs for residents and fellows, including the fellowship programs for neonatal -, pediatric -, and adult intensive care fellows in the Netherlands.[14–16] While intensive care fellows are highly trained in technical skills, studies show that they mostly learn how to communicate with patients and their families 'on-the-job'.[14,17] However, on-the-job learning appears to be an insufficient learning method if it is not combined with supervised training and structured feedback.[12,18–21] A lack of training and feedback may even hamper effective communication between physicians and families.[15,22]

While fellows' communication experiences shape their professional identity and direct their learning preferences,[24] little is known about how intensive care fellows experience and evaluate their own communication, specifically about end-of-life decisions, with families of critically ill patients in neonatal- (NICU), pediatric- (PICU), and adult (ICU) intensive care units. Furthermore, it is still unknown which specific communication skills fellows wish to improve and which learning methods they prefer. This information is pivotal to enhance the quality of intensive care medicine (ICM) education programs.

Therefore, we performed a survey study among all intensive care fellows in the Netherlands. We aimed to obtain insights into NICU, PICU, and ICU fellows' (1) personal experiences and evaluations of their communication with families of critically ill patients, and (2) their evaluation of their current training in communication skills and their preferences for future training, specifically regarding conversations in which decisions to continue or discontinue the patient's LST have to be discussed with families.

METHOD

Study design

A comprehensive survey was developed and on August 1, 2021, sent electronically to all NICU, PICU, and ICU fellows in the Netherlands who were enrolled in their fellowship at that point in time. For each specialty, the survey included an identical set of questions, with one exception. In the survey for ICU fellows the terms 'families' and 'patients' were used. In the survey for NICU and PICU fellows the terms 'parents' and 'children' were used. A definition was added to these terms for clarification.

The survey ensured anonymity and privacy and was accompanied by a cover letter. The survey was available for four months. Reminders were sent after two and three months.

A university's institutional review board approved the study and provided a waiver for informed consent (W17_475 # 17.548).

Survey development

A comprehensive survey was developed based on literature on medical education,[17,25–29] and revised and finalized in three rounds (see Supplemental File 1, Survey Development). The final version of the survey consisted of five sections and contained 11 closed-ended questions and 9 open-ended questions (see Supplemental File 2, Questionnaire in Dutch).

Data analysis

To analyse fellows' answers to the open-ended questions, two researchers (SP, MdV) inductively coded these answers in an iterative process. The researchers discussed inconsistencies in the applied codes to ensure consistency of categorization, thereby minimizing bias and measurement error.

In one section, a list of 14 communication skills was presented. An exploratory factor analysis (principal axis factoring, direct oblimin rotation) was then performed to gain insight into underlying properties of these skills. Two factors were identified (see Table 1). To assess the internal consistency, a reliability analysis was conducted by calculating the Cronbach's alpha. A reliable scale for cognition-oriented communication was constructed, including six items (α = .76). A reliable scale for affect-oriented communication was constructed as well, including eight items (α = .78).

No assumptions were made regarding missing data. The data are presented as numbers and percentages, and occasionally as median and interquartile range. Mostly, descriptive

statistics were used. If possible in terms of power and assumptions, significant differences were calculated between the three groups of fellows (NICU, PICU, and ICU) by using chi-squared test, or Fisher's exact test where appropriate. Paired sample t-test was used to compare fellows' assessment of their cognition- versus their affect-oriented communication. All tests were two-tailed and a *p-value* less than 0.05 was considered statistically significant. Statistical analyses were performed in SPSS 28.0 (SPSS Inc, Chicago, IL).

Table 1. Factors identified for the 14 communication skills

Factor	% of variance		Factor loadings[a]	Mean item score
1. Cognition-oriented communication *(α = 0.76)*	**Skills**	18.8		3.74
	A. Providing clear information about diagnosis and prognosis		.730	
	B. Providing clear information about available treatment options		.886	
	C. Giving clear advice if there is one best available treatment option		.643	
	D. Exchanging arguments pros and cons of different treatment options		.304	
	E. Summarizing the conversation		.573	
	F. Leading the conversation		.147	
2. Affect-oriented communication *(α = 0.78)*	**Skills**	28.3		3.38
	G. Providing space for families' reactions and questions		.403	
	H. Eliciting treatment preferences of the patient		.861	
	I. Eliciting treatment preferences of the family		.686	
	J. Discussing religious beliefs		.237	
	K. Bridging differences in perspectives		.427	
	L. Preparing for the dying process		.504	
	M. Dealing with the emotions of family members		.409	
	N. Offering psychological support		.808	

[a] Most items have an acceptable loading score of >3. Some factor loadings are relatively low; items are included due to theoretical reasoning and statistical considerations.[30]

RESULTS

Demographics

All 124 intensive care fellows in the Netherlands ($N_{NICU} = 34$, $N_{PICU} = 15$, $N_{ICU} = 75$) received the survey, including the fellows who had provided feedback in the survey development phase. Sixty (48.4%) fellows returned the survey, per specialty this concerned 38.7% (29/75) ICU fellows, 66.7% (10/15) PICU fellows, and 61.8% (21/34) NICU fellows. Variations in respondent counts occurred due to item nonresponses. All 10 PICU fellows fully completed the survey, followed by 79.3% of the ICU fellows, and 71.4% of the NICU fellows. Of the completed surveys, 83.3% (40) of the respondents were female. The median age of fellows who completed the survey was 37 [35-39] years, and 58% were in the first or second year of their training.

Experiences in communicating with families of critically ill patients

Difficult

In answer to the question of what makes family conversations especially difficult, fellows reported the following five main difficulties: disagreements, emotions, end-of-life decisions, differences in religious/cultural background and language barriers.

Over half of all fellows (33/60; 55.0%) experienced conversations in which families disagreed with the proposed treatment plan or decision to be the most difficult. This was often due to families being more optimistic or pessimistic regarding the patient's condition or prognosis, and/or families' inability to accept the provided bad news or the severity of the patient's situation.

One-third of all fellows (20/60; 33.3%), and mostly NICU fellows (11/21; 52.4%), experienced conversations in which families expressed intense emotions to be the most difficult. These emotions not only hindered information provision and the decision-making process but also had a personal impact on them.

Another one-third of all fellows (20/60; 33.3%) experienced conversations in which end-of-life decisions had to be discussed to be the most difficult, especially if these decisions were surrounded by uncertainties.

Almost one-third of all fellows (19/60; 31.7%), but significantly more ICU fellows (12/29; 41.4%) ($p = 0.037$), experienced conversations with families who had a different religious or cultural background, and/or who did not speak Dutch fluently, to be the most difficult. These differences added even more complexity to conversations in which disagreements had arisen and/or end-of-life decisions had to be discussed.

Additionally, only a few ICU fellows (4/29; 13.8%) perceived conversations about organ donation procedures to be difficult, due to the high amount of 'technical' information that should be given at a time that families experienced intense grief.

Rewarding

Fellows of all specialties (18/59; 30.5%) reported "harmonious" conversations in which a decision was reached in close cooperation with the family to be the most rewarding. Conversations in which they had been able to provide certainty, for instance in a situation where the patient's death had become inevitable, were also experienced as rewarding (17/59; 28.8%).

Significantly more NICU fellows (9/21; 42.9%) mentioned building trust with parents as a rewarding aspect, compared with PICU fellows (1/10; 10.0%) and ICU fellows (4/28; 14.3%) ($p = 0.042$). PICU fellows (5/10; 50.0%) mentioned family members expressing their thankfulness to be a rewarding aspect significantly more often than NICU fellows (1/21; 4.8%) and ICU fellows (4/28; 14.3%) ($p = 0.009$). ICU fellows (9/28; 32.1%) reported being able to provide good end-of-life care as a rewarding aspect. They named this aspect significantly more often than NICU fellows (0/21; 0%) and PICU fellows (1/10; 10.0%) ($p = 0.005$).

Evaluation of family communication

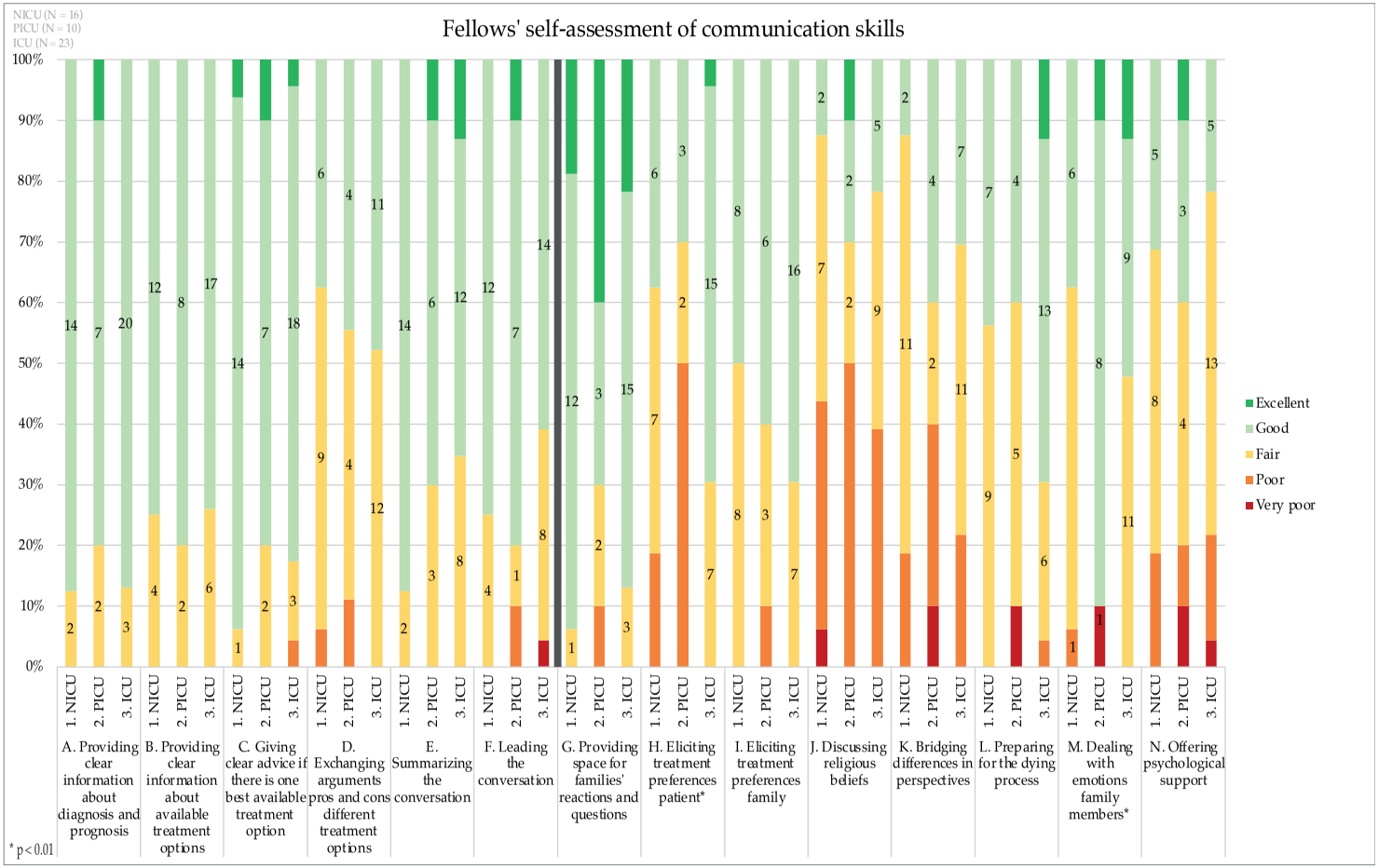
Self-assessment communication skills

Overall, fellows of all specialties rated the extent to which they mastered cognition-oriented communication significantly higher ($M = 3.74$, $SD = .36$) than the extent to which they mastered affect-oriented communication ($M = 3.38$, $SD = .47$) ($p < 0.001$).

Of all 14 communication skills, the affect-oriented skill 'providing space for reactions and questions of families' was rated the highest ($M = 4.08$, $SD = .67$), with 86% of all fellows assessing this as good to excellent (see Figure 1). The skill 'discussing religious beliefs' was rated the lowest ($M = 2.78$, $SD = .85$), with 80% of all fellows assessing this as poor to fair. Ratings of other affect-oriented communication skills differed between the specialties. For instance, most NICU fellows (10/16; 62.5%) rated the skill 'dealing with the emotions of family members' as poor to fair, whereas most PICU fellows (9/10; 90%) rated this skill as good to excellent ($p = 0.008$).

Of all cognition-oriented communication skills, the skill of 'exchanging arguments' was rated the lowest by all fellows ($M = 3.43$, $SD = .61$).

Figure 1. Fellows' self-assessment of communication skills

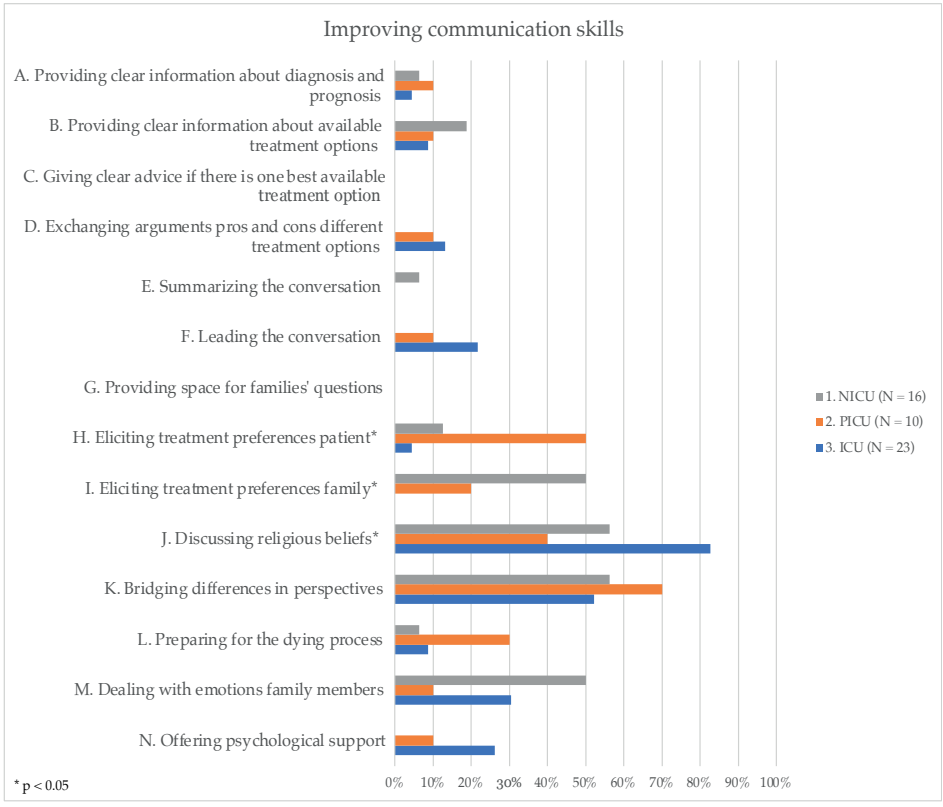


Improving communication skills

In answer to the question which specific communication skills fellows would like to improve, fellows of all specialties particularly named affect-oriented skills, including 'discussing religious beliefs' (32/49; 65.3%), 'bridging differences in perspectives' (28/49; 57.1%), and 'dealing with family members' emotions' (16/49; 32.7%) (see Figure 2).

Notably, cognition-oriented communication skills were selected to a lesser extent by fellows of all specialties as skills they wished to improve.

Figure 2. Improving communication skills



Experiences with and evaluations of learning methods

Table 2 shows fellows' experiences with and assessment of different communication learning methods.

All fellows had conducted difficult family conversations themselves and had observed colleagues conducting difficult family conversations. All but one fellow found these methods somewhat helpful to very helpful in becoming more proficient in communicating with family members of critically ill patients. Fellows also felt that the learning methods 'receiving feedback from families' and 'communication trainings with training actors' (i.e., simulation training) are 'very helpful'. However, nearly half of all fellows had no experience with one or both methods.

In asking fellows to prioritize their preferred learning methods to become more proficient in complex communication with families, most listed simulation training first. This was followed by conducting difficult conversations themselves, observing colleagues, and receiving feedback from families and supervisors. A significantly lower percentage of ICU fellows (4/23; 17.4%) expressed a preference for receiving feedback from families, compared with NICU fellows (8/16; 50.0%) and PICU fellows (6/10; 60.0%) ($p = 0.026$).

Table 2. Experiences with communication learning methods and evaluations

Learning method	Offered in fellowship (n = 49)	Felt the learning method was very helpful[a]	Preferred learning method (n = 49)
Conducting family conversation(s) yourself	49 (100%)	46/49 (93.9%)	23 (46.9%)
Observing others conducting family conversation(s)	49 (100%)	40/49 (81.6%)	18 (36.7%)
Asking colleagues for advice	48 (98%)	43/48 (89.6%)	2 (4.1%)
Receiving feedback from supervisors	45 (91.8%)	35/45 (77.8%)	15 (30.6%)
Taking part in multidisciplinary team meetings	44 (89.8%)	17/44 (38.7%)	1 (2%)
Receiving feedback from colleagues	43 (87.8%)	35/43 (81.4%)	3 (6.1%)
Lectures	33 (67.3%)	7/33 (21.2%)	7 (14.3%)
Communication training without training actors	31 (63.3%)	8/31 (25.8%)	10 (20.4%)
Group discussions	30 (61.2%)	7/30 (23.3%)	7 (14.3%)
Peer-to-peer coaching	29 (59.2%)	9/29 (31%)	7 (14.3%)
Receiving feedback from families	29 (59.2%)	16/29 (55.2%)	18 (36.7%)[b]
Communication training with training actors	27 (55.1%)	19/27 (70.3%)	26 (53.1%)
Personal coaching	10 (20.4%)	4/10 (40%)	3 (6.1%)

[a] Number (percent) of fellows who had experience with these learning methods and assessed it as 'very' or 'very much' helpful in becoming more proficient in communicating with family members of critically ill patients

[b] *p = 0.026*

Conversations about decisions to (dis)continue LST

In the past year, all fellows had participated in conversations in which decisions regarding the (dis)continuation of the patient's LST had to be discussed with families, although between and within each specialty the frequencies differed ($M \pm SD_{NICU}$ = 11.48±6.77; $M \pm SD_{PICU}$ = 10.60±5.40; $M \pm SD_{ICU}$ = 38.00±25.98). On average, fellows themselves had led about three-quarters (73%) of these conversations and had been a participant or observer in the other conversations.

Evaluation of communication

In looking back on their communication with families about decisions to either continue or discontinue LST, most fellows positively evaluated how they had explained the patient's situation and available treatment options, and how they had provided space for families' perspectives and emotions.

In response to the question what fellows in retrospect wished they had done differently, the following answers were frequently given: providing clearer information, and exploring families' perspectives and emotions to a larger extent. Notably, fellows also frequently reported that there was "nothing" they would have done differently.

Evaluation of supervision and feedback

Most fellows (43/55; 78.2%), regardless of their specialty, reported that a supervisor was never, or only sometimes, present in the family conversations they had led regarding decisions to (dis)continue LST. More than half of the fellows (24/45; 53.3%) reported that when a supervisor was present, they never or only sometimes gave feedback. Yet, when feedback was given, this was highly valued by fellows. It specifically helped them to better dose their information in following conversations, to better explore family members' emotions and perspectives, and to be silent more often.

Many fellows (41/55; 74.5%) also reported that they never or only sometimes received feedback from families on conversations in which the fellow had discussed these difficult decisions. Some fellows who had received feedback from families indicated that this had helped them to provide clearer information and to better listen to families' concerns. Some other fellows reported that the feedback had not resulted in any changes in their communication. They reported two contrasting reasons for this: either families had only provided positive feedback, or fellows considered the feedback families had given to be insincere or unfair.

DISCUSSION

Difficult family conversations, also regarding the decision whether to continue or discontinue the patient's LST, take place on a daily basis in the NICU, PICU and ICU. These conversations require specific communication skills.[14,24,28,31] The findings of this national survey confirm that leading such end-of-life conversations is not uncommon among intensive care fellows. Our results show that fellows perceive conversations in which disagreements arise with families to be especially difficult. Overall, they feel less competent in their affect-oriented communication skills than in their cognition-oriented communication skills. Fellows of all specialties primarily acquire their communication skills through learning on-the-job rather than through formal training, whereas most prefer to receive simulation training. Fellows rarely receive feedback from supervisors and families on their communication, including communication regarding crucial treatment decisions.

Fellows' higher level of confidence regarding their cognition-oriented communication skills compared to their affect-oriented communication skills may be explained by the fact that within the limited time and resources available to train fellows in communication, affect-oriented skills are even more challenging to translate into concrete educational initiatives.[14,32–34] However, families particularly remember and appreciate relational and caring communication with HCPs.[11,35] Therefore, it is important that the learning of affect-oriented skills, such as helping families deal with uncertainty and offering emotional support, is prioritized.[25,36–42]

Most fellows, regardless of their specialty, perceived conversations involving disagreements between families and themselves as the most difficult, whereas conversations characterized by harmony were perceived as the most rewarding. This is in line with the deeply rooted idea in medical practice that harmony is 'normal' and that disagreements should be minimized, as these might lead to conflicts.[43] However, disagreements between families and the medical team about treatment decisions occur regularly, and may not necessarily be harmful to the provider-family relationship.[44,45] When handled adequately, disagreements can even improve the quality of the relationship, because families feel better understood, as well as improve the quality of the decision-making process, because alternative treatment options on what is best for the patient are more thoroughly explored.[46,47] Instead of viewing disagreements as complicating factors, fellows may learn to appreciate them and see their hidden value.[44]

Our findings show that fellows were especially content with the way they informed families and gave them space to elaborate on their perspectives and express their emotions.

Some acknowledged in hindsight the potential for providing clearer information and exploring families' emotions to a larger extent. Prior interview studies with families of critically ill patients underlined that many families experienced the communication with physicians to be poor, including an unclear, late, and contradictory provision of information, and a lack of empathy.[48–54] In contrast, a remarkable finding of our study is that fellows frequently reported that in retrospect they would not change anything in their communication. In other words, that they feel completely confident with how they handle end-of-life conversations. This contrast raises the question whether fellows' positive self-evaluation accurately reflects the actual quality of conversations and families' perceptions of these conversations. Several studies indicate a disparity in how physicians and families perceive communication.[51,55,56] Also, people tend to overestimate their own abilities, which hinder awareness of one's own shortcomings.[57] Engaging in reflective practices, for instance by video-based learning and briefings or debriefings, can be helpful.[58,59] Paradoxically, if fellows enhance their communication skills through reflective practices, this will create more awareness,[57] and may prompt them to better explore families' informational and emotional needs.[60]

Our findings confirm the conclusion of previous research that fellows of all specialties primarily acquire communication skills through learning on-the-job rather than through formal training.[14,17] Learning on-the-job can both promote and inhibit fellows' development of certain communication skills, especially because it highly depends on the workplace environment and the role models that one observes.[61–63] In this respect, learning in a predominantly white, sometimes male-dominated, work environment poses challenges.[64] The extent to which one can observe non-white role models is limited and it can cause implicit bias.[64] Studies have for instance shown that white physicians communicate less affectively with ethnic minority patients than with white patients.[65–67] Our important finding that fellows perceive the communication with families with a different religious and cultural background to be especially challenging, illustrates the necessity to pay more attention to this crucial aspect in future ICM education programs. This especially holds true in multicultural countries like the Netherlands.

In line with other studies (e.g.,[17,28,68,69]) our findings show that fellows rarely receive feedback from supervisors and families on the conversations they led. Yet, receiving feedback is indispensable not only to be able to evaluate one's communication, but also to be coached and receive appreciation.[70–72] When feedback is not the standard practice, residents and fellows may hesitate to ask questions about their performance, due to uncertainty, frustration, or fear of embarrassment.[63] In turn, this may result in a reluctance to share concerns and mistakes and to seek emotional support. This reluctance may be

further reinforced by a strong hierarchical structure within a department and/or a lack of psychological safety.[62,63] A self-protective behaviour of not asking questions and admitting mistakes may also start to hamper an open communication with families. Especially in an on-the-job learning environment, fostering psychological safety is therefore paramount. This safety will allow fellows to share their true concerns and receive valuable feedback, coaching and appreciation from supervisors and colleagues and to proactively ask for feedback.[63,73] Ultimately, this will shine through in their communication with families.[63]

Limitations and strengths

There were several limitations to this study. Out of all intensive care fellows in the Netherlands, 48% responded, with a higher representation of NICU - and PICU fellows compared to ICU fellows. This could be attributed to the COVID-19 outbreak at the time of data collection which placed a considerable burden on fellows, particularly in the ICU. Moreover, only 39% of all fellows fully completed the survey. Because of the strict privacy regulations in the Netherlands regarding data collection, respondents could not save their answers while filling in the survey to complete it at a later point in time. Although respondents who partially completed the survey did not significantly differ in their responses compared to those who fully completed it, the demographic data were collected at the end of the questionnaire, and thus this information remains unknown for a fifth of the respondents. Furthermore, this national study only included Dutch fellows, which limits the generalizability of our findings to other countries, especially since end-of-life practices, as well as communication trainings, vary among intensive care units worldwide.[74,75] Lastly, despite conducting thorough testing and gathering feedback on our survey, certain limitations exist in the questions posed. Specifically, we asked which learning methods had been offered to fellows, but we lacked information on the extent to which they received this. Follow-up research is needed to enhance our survey and its validity.

The main strength is that by conducting a comprehensive survey among all intensive care fellows in the Netherlands, we were able to draw the bigger picture of communication and education, including fellows' experiences, evaluations, needs, and preferences. The results of this study can be used to improve the ICM communication education programs by tailoring it to fellows' perceived difficulties and specific needs. In the continuing search to accomplish effective provider-family communication, future longitudinal studies are needed to determine if and how different learning methods improve the actual communication of fellows and whether these effects can be sustained over time.

Conclusions

Our findings illustrate that fellows experience the greatest communicative challenges with regard to affect-oriented communication, especially when harmony with the family is undermined, whereas they feel particularly proficient in their cognition-oriented communication. Fellows primarily acquire communication skills through learning on-the-job. To enhance their communication skills, they prefer a combination of learning methods. The results of this nationwide survey study among intensive care fellows can be used for further improving the communication education programs in ICM. Future research should explore the extent to which a tailored communication training program truly improves fellows' communication skills and by effect the actual communication with families.

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Author contributions

Drs Prins conceptualized and designed the study, collected, analyzed, and interpreted the data, and drafted and finalized the initial manuscript and figures; Dr Linn analyzed and interpreted the data, and finalized the initial manuscript and figures; Drs Roskam-Mul conceptualized and designed the study, and collected, analyzed, and interpreted the data; Dr Lemson conceptualized and designed the study, analyzed and interpreted the data, and drafted the initial manuscript; Dr de Vos conceptualized and designed the study, coordinated, and supervised the data collection, collected, analyzed and interpreted the data, and finalized the initial manuscript and figures; All authors reviewed and revised the manuscript, approved the final manuscript as submitted, and agreed to be accountable for all aspects of the work.

Declaration of conflicting interests

The authors have indicated they have no conflicts of interest relevant to this article to disclose.

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Data management and sharing

Data are available upon request.

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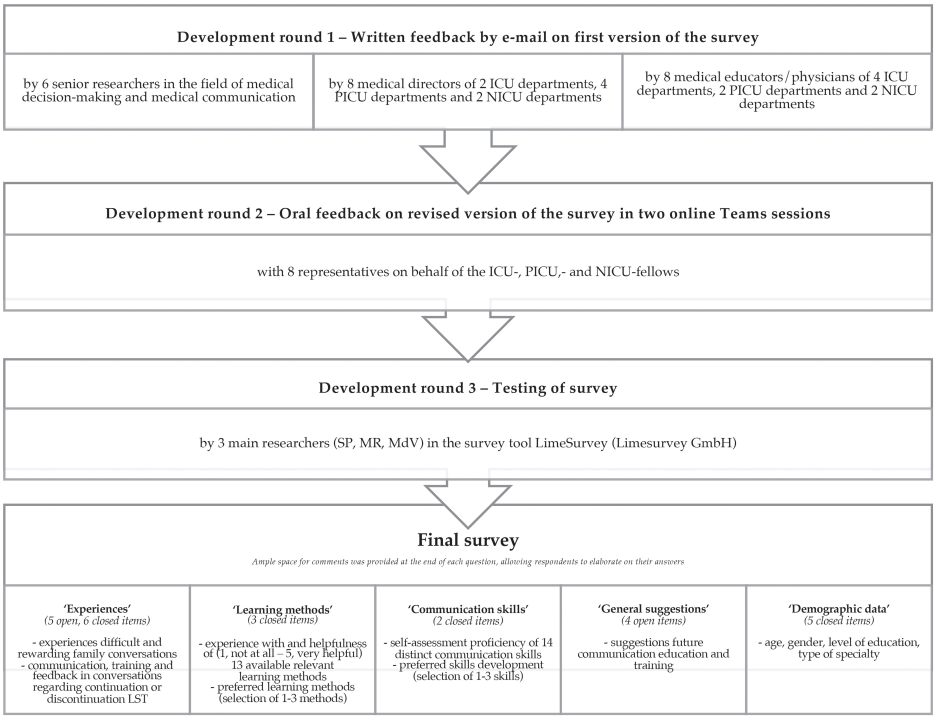
APPENDIX

Supplemental File 1. Survey development

Supplemental File 2. Questionnaire (in Dutch)

Supplementary 1. Survey development



Supplementary 2. Questionnaire

"Beter in gesprek met de directe naasten van ernstig zieke patiënten"

Versie I

Voor fellows Neonatologie

A. Eigen ervaringen

Als medisch specialist voer je verschillende soorten gesprekken met de ouders van ernstig zieke kinderen[d]

1.a. Welke gesprekken ervaar jij persoonlijk als de meest moeilijke gesprekken?

…

1.b. Wat maakt deze gesprekken moeilijk?

…

2. Welke gesprekken geven je de meeste voldoening?

…

De vragen 3 tot en met 12 hebben betrekking op familiegesprekken over ingrijpende behandelbeslissingen voor een ernstig zieke patiënt die (op dat moment) niet zelf kan beslissen.

*Met **ingrijpende behandelbeslissingen** bedoelen we beslissingen om een of meerdere levensondersteunende behandelingen te gaan staken of niet meer in te stellen. Het staken of niet meer instellen van deze behandeling(en) zal in de meeste gevallen resulteren in het overlijden van de patiënt binnen afzienbare tijd.*

*Terugkijkend **op de achterliggende 12 maanden**:*

3. Bij hoeveel gesprekken ben je aanwezig geweest waarin met ouders werd gesproken over ingrijpende behandelbeslissingen voor hun ernstig zieke kind?

Circa ……. gesprekken over …….. patiënten

[d] Met kinderen bedoelen we alle kinderen tussen 0 en 18 jaar, **inclusief te vroeg geboren kinderen.**

4. Hoeveel van deze gesprekken heb je zelf geleid?

Circa ……. gesprekken over …….. patiënten

5. Hoe vaak zat er een staflid/supervisor bij de gesprekken die jij leidde?
Kies het toepasselijke antwoord voor elk onderdeel:

Nooit - Soms - Regelmatig - Vaak - Altijd

5.a. Hoe vaak kreeg je na afloop feedback van deze stafleden/supervisoren op hoe je het gesprek voerde?
Beantwoord deze vraag alleen als aan de volgende voorwaarden is voldaan: Antwoord was groter dan 'Nooit' bij vraag 5 (Hoe vaak zat er een staflid/supervisor bij de gesprekken die jij leidde?).

Kies het toepasselijke antwoord voor elk onderdeel:

Nooit - Soms - Regelmatig – Vaak – Altijd

5.b. Hoe heb je deze feedback in het algemeen ervaren?
Beantwoord deze vraag alleen als aan de volgende voorwaarden is voldaan: Antwoord was groter dan 'Nooit' bij vraag 5.a. (Hoe vaak kreeg je na afloop feedback van deze stafleden/supervisoren op hoe je het gesprek voerde?).

- Positief, want…..
- Negatief, want…..
- Anders, namelijk….

5.c. Wat ben je daardoor anders gaan doen?
Beantwoord deze vraag alleen als aan de volgende voorwaarden is voldaan: Antwoord was groter dan 'Nooit' bij vraag 5.a. (Hoe vaak kreeg je na afloop feedback van deze stafleden/supervisoren op hoe je het gesprek voerde?).

…

6. Hoe vaak kreeg je in de afgelopen 12 maanden feedback van ouders op de gesprekken die je leidde?
Kies het toepasselijke antwoord voor elk onderdeel:

Nooit - Soms - Regelmatig - Vaak - Altijd

6.a. Hoe heb je deze feedback in het algemeen ervaren?

Beantwoord deze vraag alleen als aan de volgende voorwaarden is voldaan: Antwoord was groter dan 'Nooit' bij vraag 6 (Hoe vaak kreeg je in de afgelopen 12 maanden feedback van ouders op de gesprekken die je leidde?).

- Positief, want…..
- Negatief, want…..
- Anders, namelijk

6.b. Wat ben je daardoor anders gaan doen?

Beantwoord deze vraag alleen als aan de volgende voorwaarden is voldaan: Antwoord was groter dan 'Nooit' bij vraag 6 (Hoe vaak kreeg je in de afgelopen 12 maanden feedback van ouders op de gesprekken die je leidde?).

*We willen je vragen om terug te denken aan **een concreet gesprek** dat je in de achterliggende jaren met ouders hebt gevoerd over een ingrijpende behandelbeslissing en dat je het meest is bijgebleven.*

7. Om welke reden(en) is dit gesprek je bijgebleven?

…

8. Wat ging goed tijdens dit gesprek?

…

9. Wat had je anders willen doen?

…

10. Had je dit gesprek met anderen voorgesproken?

- Ja, namelijk met…..
- Nee

11. Heb je dit gesprek met anderen nabesproken?

- Ja, namelijk met….
- Nee

B. Opleiding en training

Als medisch specialist bekwaam je je op verschillende manieren in het voeren van moeilijke gesprekken met ouders van ernstig zieke kinderen. Hieronder hebben we de belangrijkste onderwijsvormen op een rij gezet.

Wil je per onderwijsvorm aangeven:

1. of je deze aangeboden hebt gekregen?

2. hoeveel je aan deze onderwijsvorm hebt gehad om je (verder) te bekwamen?

	1. Aangeboden? Ja/nee	**2. In welke mate heb je hier iets aan gehad?** **1. niets** **2. weinig** **3. redelijk** **4. veel** **5. heel veel**
Communicatietraining zonder (simulatie)patiënten		
Communicatietraining met (simulatie)patiënten		
Kennisoverdracht tijdens regulier onderwijs (plaatselijk en/of landelijk)		
Discussie en reflectie tijdens regulier onderwijs (plaatselijk en/of landelijk)		
De kunst afkijken bij (ervaren) collega's		
Vragen stellen aan (ervaren) collega's		
Het zelf doen en ervaren		
Feedback van supervisor/opleider		
Feedback van andere collega's		
Feedback van ouders		
Multidisciplinaire overleggen		
Intervisie		
Persoonlijke coaching		

Ruimte voor opmerkingen

2. Hoe wil je je het liefst verder bekwamen in het voeren van moeilijke gesprekken met ouders?

	Vink maximaal 3 opties aan *Kies tussen de 1 en 3 antwoorden*
Communicatietraining zonder (simulatie)patiënten	
Communicatietraining met (simulatie)patiënten	
Kennisoverdracht tijdens regulier onderwijs (plaatselijk en/of landelijk)	
Discussie en reflectie tijdens regulier onderwijs (plaatselijk en/of landelijk)	
De kunst afkijken bij (ervaren) collega's	
Vragen stellen aan (ervaren) collega's	
Het zelf doen en ervaren	
Feedback van supervisor/opleider	
Feedback van andere collega's	
Feedback van ouders	
Multidisciplinaire overleggen	
Intervisie	
Persoonlijke coaching	

Ruimte voor opmerkingen

C. Specifieke communicatieve vaardigheden

In de literatuur worden een groot aantal gespreksvaardigheden genoemd die bijdragen aan ***een goed gesprek met ouders*** *van ernstig zieke kinderen. Deze staan hieronder opgesomd.*

1. Als je jezelf zou moeten beoordelen, in welke mate vind je dat je deze vaardigheid beheerst?
Kies het toepasselijke antwoord voor elk onderdeel:

	Onvoldoende	**Matig**	**Voldoende**	**Goed**	**Uitstekend**
Ouders op een heldere en begrijpelijke wijze informeren over de diagnose en prognose van hun kind					
Ouders op een heldere en begrijpelijke wijze informeren over de (nog) aanwezige behandelopties en hun voors en tegens					
Uitvragen van de behandelwensen van het kind (indien mogelijk) en wat voor hem/haar belangrijk is					
Uitvragen van de behandelwensen van de ouders en wat zij belangrijk vinden voor hun kind					
Bespreken van religieuze overtuigingen van ouders					
Uitwisselen van argumenten voor en tegen de verschillende behandelopties					

1. Continued

	Onvoldoende	Matig	Voldoende	Goed	Uitstekend
Geven van helder advies indien er duidelijk één beste behandeloptie is volgens de geldende professionele standaard					
Actief ruimte bieden voor vragen en reacties van ouders					
Overbruggen van verschillen van inzicht met ouders					
Ouders voorbereiden op het stervensproces van hun kind					
Exploreren van emoties van ouders					
Bieden van psychologische ondersteuning aan ouders					
Regie houden tijdens het gesprek					
Samenvatten van gesprek en maken van vervolgplan/vervolgafspraak					

2. In welke drie **gespreksvaardigheden** zou je je als eerste (verder) willen bekwamen?

	Vink maximaal drie opties aan *Kies tussen de 1 en 3 antwoorden*
Ouders op een heldere en begrijpelijke wijze informeren over de diagnose en prognose van hun kind	
Ouders op een heldere en begrijpelijke wijze informeren over de (nog) aanwezige behandelopties en hun voors en tegens	
Uitvragen van de behandelwensen van het kind (indien mogelijk) en wat voor hem/haar belangrijk is	
Uitvragen van de behandelwensen van de ouders en wat zij belangrijk vinden voor hun kind	
Bespreken van religieuze overtuigingen van ouders	
Uitwisselen van argumenten voor en tegen de verschillende behandelopties	
Geven van helder advies indien er duidelijk één beste behandeloptie is volgens de geldende professionele standaard	
Actief ruimte bieden voor vragen en reacties van ouders	
Overbruggen van verschillen van inzicht met ouders	
Ouders voorbereiden op het stervensproces van hun kind	
Exploreren van emoties van ouders	
Bieden van psychologische ondersteuning aan ouders	
Regie houden tijdens het gesprek	
Samenvatten van gesprek en maken van vervolgplan/vervolgafspraak	

D. Aanbevelingen

1. Heb je concrete suggesties hoe het (beter leren) voeren van moeilijke gesprekken met ouders ingebed kan worden in je opleiding?

- Ja, namelijk…..
- Nee

2. Kun je mensen aanbevelen die nu al onderwijs, training of coaching geven in het voeren van moeilijke gesprekken?

- Ja, namelijk…..
- Nee

3. Kun je mensen aanbevelen die je dit graag in de toekomst zou zien doen?

Ja, namelijk…..

Nee

4. Wil je zelf bijdragen aan het verder vorm en inhoud geven van dit thema binnen het opleidingscurriculum?

- Ja

…

- Nee

E. Persoonlijke gegevens

1. Wat is je leeftijd?

- 25-29 jaar
- 30-34 jaar
- 35-39 jaar
- 40-45 jaar
- > 45 jaar

2. Wat is je geslacht?

- Man
- Vrouw
- Anders, ……

3. Welke specialisatie(s) heb je afgerond? (meerdere antwoorden mogelijk)

- Interne geneeskunde
- Anesthesie
- Cardiologie
- Neurologie
- Longziekten
- SEH
- MDL
- Kindergeneeskunde
- Kindercardiologie
- Kinderneurologie
- Anders, namelijk……

4. Met welke (sub)specialisatie ben je op dit moment bezig?

- Neonatologie
- Intensive Care Kinderen
- Intensive Care Volwassenen
- Anders, namelijk…….

5. In welk opleidingsjaar zit je?

- Eerste jaar
- Tweede jaar
- Derde jaar
- Vierde jaar
- Anders, namelijk….

Einde van de survey. Bedankt voor deelname aan deze enquête.