Measuring satisfaction with general and end-of-life care in the intensive care unit

Gerritsen, Richard

Publication date:
2018

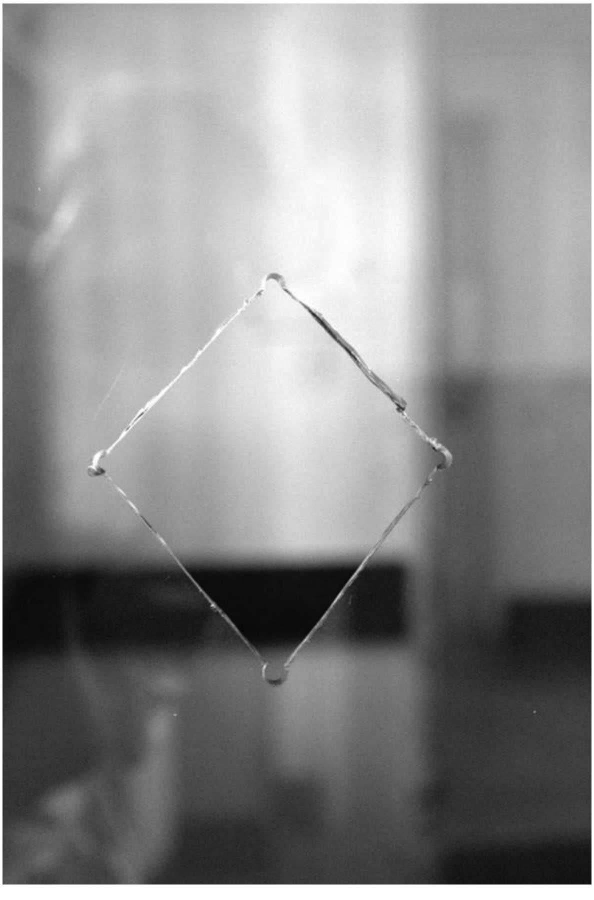
Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):
Gerritsen, R. T. (2018). Measuring satisfaction with general and end-of-life care in the intensive care unit: The euroQ2 project [Groningen]: Rijksuniversiteit Groningen

Measuring satisfaction with general and end-of-life ICU care

The euroQ2 project

Rik Gerritsen



Colofon

Measuring satisfaction with general and end-of-life ICU care;
the euroQ2 project

Thesis University Groningen with summary in Dutch

ISBN: 978-94-034-0494-3

Printed by
Dekker Drukwerken, Leeuwarden
Cover image
Communication with families “African style”;
photo by Ralph Lenior
Cover design
M. Vaartjes en Linda Dost
Layout and Graphical design
Libbe Hoekstra, Medisch Centrum Leeuwarden

Het onderzoek voor dit proefschrift is financieel mogelijk gemaakt door de Stichting Intensive Care Onderzoek Friesland. De stichting en de MCL academie hebben ook een bijdrage geleverd in de drukkosten.

rijksuniversiteit
groningen

Measuring satisfaction with general and end-of-life care in the intensive care unit

The euroQ2 project

Proefschrift

ter verkrijging van de graad van doctor aan de
Rijksuniversiteit Groningen
op gezag van de
rector magnificus prof. dr. E. Sterken
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
woensdag 30 mei 2018 om 16.15 uur

door

Richard Theodorus Gerritsen

geboren op 15 mei 1962
te Amsterdam

Promotor

Prof. dr. J.G. Zijlstra

Copromotor

Dr. P.E. Spronk

Beoordelingscommissie

Prof. dr. P.H.J. van der Voort

Prof. dr. J.E. Tulleken

Prof. dr. E. Azoulay

Wat niet kan, is nog nooit gebeurd!

Daniël Lohues 2013

Contents

Section I Introduction

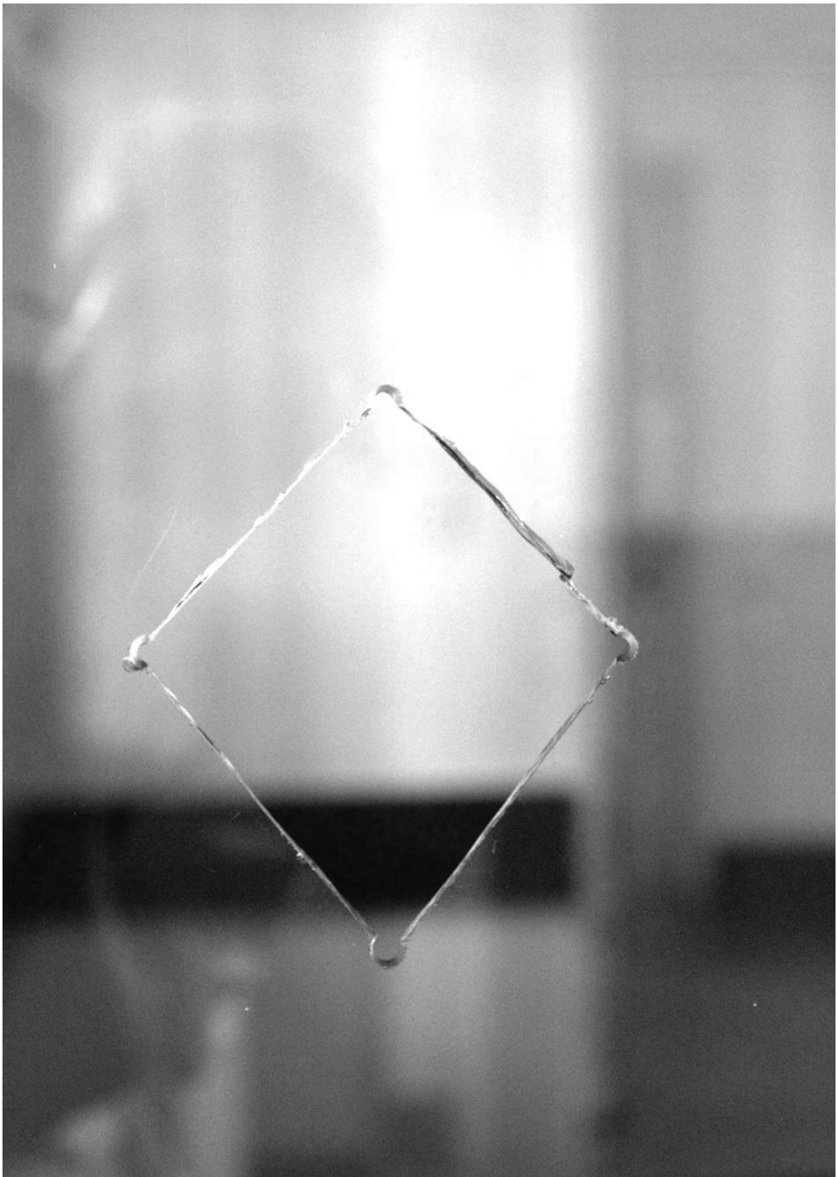
Section II Family Centered Care

Section III Quality of dying and death (QODD)

Section IV The euroQ2 questionnaire

Section V Summary and perspectives

Section VI Appendices



Prologue

If you would have told me ten years ago that not only I would have start doing research but also wrote a thesis I would have considered you slightly confused. My ambition next to being a clinician was much more administrative than scientific. But things have turned out more or less different. I increased my administrative tasks but also started to do research. The combination made it possible to use my time in an efficient and flexible way. Leading to being active in the management of my hospital as well as producing this thesis.

From my first steps in the clinic, intensive care appealed to me. At first it was the heroism and the impressive machinery that made it attractive to me as a young physician. The fact that you were really able to make a difference.

Soon thereafter it became clear to me that there are so much more aspects of intensive care that made it the most interesting field of medicine for me. In the intensive care department the treatment is always a team effort, with physicians but also with nurses and allied health care professionals. One cannot function without the other but also the team is much more than the sum of the individuals. Working together makes it possible to deliver the right care at the right moment to the right patient. With all the technical possibilities and staff facilities it is tempting to do everything for everybody. But I realised quite early in my professional career that delivering good care to a specific patient is not the same as hooking up every machine you have got.

With experience came doubt. Am I delivering good care? And is the family satisfied with the way I take decisions to withhold or withdraw care.

From this doubt came the urge to find answers to the question: ‘do I deliver good care” ? And even more interesting to me “ are the relatives happy with the decision-making process in which I am grateful for their input but I take the decision and communicate clearly that taking that decision is my responsibility”?

Having this contemplation about my behaviour and performance made me start doing research. Not that I wanted to add to the body of knowledge as such, but I want to answer my own question: am I doing the right thing in the right way?”

1

General Introduction

Introduction

Intensive Care is often thought to be focussing on machines and heroism. This statement cannot be farther from the truth. The essence of intensive care medicine is about making choices. It is about trying to provide the right care to the right patient at the right time.

Recent papers have addressed this important issue trying to define "potentially inappropriate treatment" formally known as "futile care" (1). Deciding which treatment is offered to a patient may be challenging. It brings together the basic bioethical principles of autonomy, beneficence, non-maleficence and distributive justice (2).

Together with the patient and his or her loved ones, trying to make the right choices might be the most difficult, but also the most important and rewarding part of intensive care medicine. The joined efforts of the ICU team members, taking into account the patient's and families' preferences, results in the right decisions, thus delivering good quality of care. A secondary gain of making joined choices is that it may benefit the team itself. It might help to maintain team satisfaction, thereby playing a positive role in the prevention of burnout within the team (3,15).

Delivering the best care can sometimes be withholding non-beneficial technical care and supplying comfort care or mere support to a patient (4).

For health care professionals, the high-technology therapies and environment quickly tends to become commonplace. However, the ICU is probably a place full of fear and uncertainty for the families of the ICU patients(1,5,6). In this potentially terrifying environment, family members face a real possibility of losing a loved one. Out of all the patients admitted to an Intensive Care Unit (ICU) 10-15% will die during that same admission period (7, 8). During that ICU admission period the family members frequently perceived their role as guardian and protector of the patient. Indeed we try to involve the family members in the decision making process in these difficult and straining conditions. Involving patients and families in decision making is quite common in the ICU nowadays (20). Nevertheless, most intensive care patients lack decision making capacity, which bares another dilemma that is encountered every day in the ICU, i.e. surrogate decision making: decision making by the relatives on behalf of a loved one(17, 18).

Supporting families in decision-making is one part of family centered care. Professionals in the ICU should recognize that family members also have more needs of their own. They may need support to cope with the uncertainty of the situation and need complete, honest and consistent information to be able to understand what is going on with their loved one and in the unit (6).

Half of the family members of critically ill intensive care patients suffer from excessive daytime sleepiness associated with functional impairment (9). The strains experienced by families during an ICU stay of their loved ones may subsequently lead to posttraumatic stress syndrome (PTSD) and depression (10,11,12,13). The needs of families should therefore also be taken into account by ICU teams. To be able to offer tailored family centered care it is necessary to obtain knowledge of families' experiences and needs during ICU treatment and sometimes dying, of their loved one(9).

Understanding families' experiences is obligatory for health care professionals working on quality improvement of care for patients (14). Although patients' experiences can usually not be obtained from ICU patients, family experience can be a substitute marker of quality of care delivered (11). Validated measures of family satisfaction with the care for all critically ill patients, and more specifically of quality of care for the dying could be used to evaluate interventions designed to improve this care and outcomes as well as provide benchmarking for ICU quality. The concept of family centered care is generally accepted. Recently a multi-disciplinary international group published a guideline on behalf of the Society of Critical Care Medicine (SCCM) (15).

What is good quality of delivered care?

The perceived quality of care as perceived by professionals, doctors and nurses on the one hand, and the perceived quality of care as reported by patients and family members may differ markedly. Consequently, “good care” is hard to define and measuring it may be almost impossible. The answers one gets will depend on the instrument used(3). One could define good care as care that satisfies the patient and the family, although this not necessarily means technically good care. We could then use instruments that measure satisfaction as a tool. If the patient and relatives are satisfied we probably delivered at least one aspect of good care.

In end-of-life care obviously the family members are the only source of feedback available for identifying opportunities for improving the specific but very important part of ICU care.

Several instruments are available for measuring satisfaction and quality of care in the ICU. These were designed to be completed by family members of ICU patients (16). Two well validated instruments are the “Family Satisfaction in the ICU” questionnaire (FS-ICU) looking at satisfaction with the whole ICU process and the “Quality of Dying and Death” questionnaire (QODD) looking at quality of care at the end of life specifically(13,16,17,18). The latter instrument was originally developed in a hospice setting but subsequently also validated in an ICU population. Both were developed and validated in North America. Cultural differences exist between North America and Europe and within North America and within Europe that might influence validity (19) .

In recent years it has become increasingly clear that the decisions we take as ICU physicians are not based on straight forward algorithms. Many subjective feelings and ideas are in play in both patients, family members, as wells as within the ICU team(20). The culmination of integrating all these feelings, ideas and past experience in optimal communication amongst all involved will ultimately determine the satisfaction of all parties with the decision-making process.

Making the right choices together with the patient or his loved-one, and if necessary providing the best possible end-of-life care for patients and also for families have become my main professional interest and ultimately the subject of this thesis. More specifically measuring satisfaction with, and subsequently find options to improve this process are the subject of this endeavour.

In more detail:

Chapter 2
This paper describes in summary the development of a guideline on family centered care. Recommendations to improve family centered care are given and areas that need future research are identified (21).

Chapter 3
This paper tries to answer the question "How is the quality of the end-of–life care delivered in three Dutch ICU's?" as perceived by family members and by professionals. In this paper that question is partly answered. But new questions were raised. Does the instrument used, the validated questionnaire on Quality of Dying and Death (QODD) pose the right questions to this Dutch population of family members and professionals (22) ?

Chapter 4
The second paper studied the same questions but compared these in two different settings, the original American population and the Dutch cohort. It showed that family members from different countries vary slightly in the reported perceived quality. But interestingly the professionals differed much more. The Dutch professionals had less trouble answering the questions in the QODD than the family members had. Several items from the original instrument were judged irrelevant by European family members (23).

After these papers evaluating the QODD questionnaire it became clear that the quality of care in Dutch ICU's as perceived by family members might be measured better by a questionnaire adapted for this population. The same conclusion was reached, at that time, in a Danish population.

This has led to a joined initiative to develop a European instrument to measure quality of ICU care in general and of end-of-life care in particular. Because decision-making is an important part of end-of-life care, questions about decision making were added to measure the perceived role and the desired role in the decision-making process. Free text fields were also provided, to capture information subjects could not express by answering the closed questions.

Chapter 5

This paper describes the development and qualitative validation of the euroQ2 questionnaire. This questionnaire is based on the American Family Satisfaction in ICU (FS-ICU) and the QODD. This was done in close cooperation with the original developers (24).

To develop the instrument further a large quantitative validation in two countries simultaneously was done. The relatives of patients from eleven Danish and ten Dutch ICU's were questioned. More than thousand questionnaires were filled out and returned. As the euroQ2 was based on the FS-ICU and QODD, the psychometrics and results are reported along that line. One paper describes the "euroFS-ICU" and one the "euroQODD". Together constituting the "euroQ2"

Chapter 6

This paper describes the validation of the first part of the euroQ2. That part focuses on perceived quality of general ICU care as reported by families. The psychometrics of the questionnaire is extensively reported. The results of over 700 filled out questionnaires are the source of this data(25).

Chapter 7

This paper describes the validation of the second part of the euroQ2. That part focuses on quality of end-of-life ICU care as reported by families and on the decision-making process. The validation and the factor analysis are reported in depth. Of course also the results from the part of the questions on quality of end-of-life care are reported. The questions on actual perceived and preferred role in decision-making reveal interesting information and add new knowledge of the shift towards shared decision-making in Denmark and the Netherlands.

This thesis gives some insights in the perceived quality of ICU care. It also describes the development and validation of an instrument. With this instrument clinicians can measure the perceived quality of care they deliver and find areas in which improvement is possible and needed.

The instrument "the euroQ2" is available for anyone to use, free of charge. It can be downloaded from the website www.euroQ2.org.

References

1. Bosslet GT, Pope TM, Rubenfeld GD, Lo B, Truog RD, Rushton CH, et al. An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units. Am J Respir Crit Care Med. 2015 Jun 1;191(11):1318-30.

2. Beauchamps TL CJ. Principles of Biomedical Ethics. Sixth Edition. Oxford University press 2009. 2009.

3. Vet H, Terwee C, Mokkink L, Knol D. Measurement in Medicine. Cambridge University Press; 2011.

4. Frontera JA, Curtis JR, Nelson JE, Campbell M, Gabriel M, Mosenthal AC, et al. Integrating Palliative Care Into the Care of Neurocritically Ill Patients: A Report From the Improving Palliative Care in the ICU Project Advisory Board and the Center to Advance Palliative Care. Crit Care Med. 2015 Sep;43(9):1964-77.

5. Alonso-Ovies A, Heras La Calle G. ICU: a branch of hell? Intensive Care Med. 2016 Apr;42(4):591-2.

6. Agard AS, Harder I. Relatives' experiences in intensive care--finding a place in a world of uncertainty. Intensive Crit Care Nurs. 2007 Jun;23(3):170-7.

7. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA. 2003 Aug 13;290(6):790-7.

8. Jensen HI, Ammentorp J, Ording H. Withholding or withdrawing therapy in Danish regional ICUs: frequency, patient characteristics and decision process. Acta Anaesthesiol Scand. 2011 Mar;55(3):344-51.

9. Verceles AC, Corwin DS, Afshar M, Friedman EB, McCurdy MT, Shanholtz C, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med. 2014 Aug;40(8):1124-31.

10. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005 May 1;171(9):987-94.

11. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010 Feb;137(2):280-7.

12. Sundararajan K, Martin M, Rajagopala S, Chapman MJ. Posttraumatic stress disorder in close Relatives of Intensive Care unit patients' Evaluation (PRICE) study. Aust Crit Care. 2014 Nov;27(4):183-7.

13. Wall R, Engelberg R, Downey L, Heyland D, Curtis J. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. American journal of respiratory and critical care medicine. 2007;35(1):271-9.

14. Pochard F, Darmon M, Fassier T, Bollaert P, Cheval C, Coloigner M, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. American journal of respiratory and critical care medicine. 2005;20(1):90-6.

15. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, et al. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. Crit Care Med. 2017 Jan;45(1):103-28.

16. Broek J, Brunsveld-Reinders A, Zedlitz A, Girbes A, Jonge E, Arbous M. Questionnaires on Family Satisfaction in the Adult ICU; A systemic Review Including Psychometric Properties. Critical Care Medicine. 2015.

17. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage. 2002 Jul;24(1):17-31.

18. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. J Pain Symptom Manage. 2010 Jan;39(1):9-22.

19. Moselli NM, Debernardi F, Piovano F. Forgoing life sustaining treatments: differences and similarities between North America and Europe. Acta Anaesthesiol Scand. 2006 Nov;50(10):1177-86.

20. Rostami S, Esmaeali R, Jafari H, Cherati JY. Perception of futile care and caring behaviors of nurses in intensive care units. Nurs Ethics. 2017 Jan 01:969733017703694.

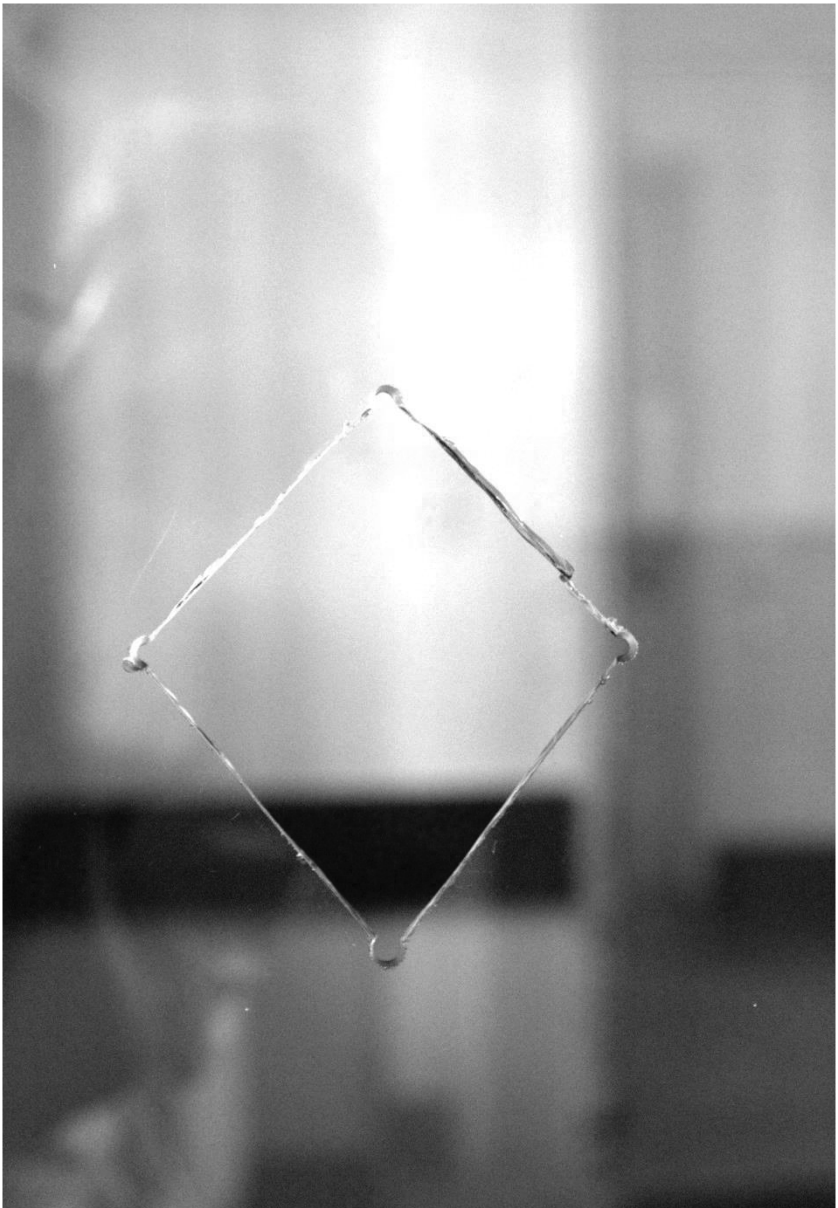
21. Gerritsen RT, Hartog CS, Curtis JR. New developments in the provision of family-centered care in the intensive care unit. Intensive Care Med. 2017 Jan 25.

22. Gerritsen RT, Hofhuis J, Koopmans M, van der Woude M, Bormans L, Hovingh A, et al. Perception by Family members and ICU staff of the Quality of Dying and death in the ICU - A prospective multi-center study in the Netherlands. (1). Chest. 2013;143(2):357.

23. Gerritsen RT, Koopmans M, Hofhuis JG, Curtis JR, Jensen HI, Zijlstra JG, et al. Comparing quality of dying and death perceived by family members and nurses for patients dying in US and Dutch ICUs. Chest. 2016 Sep 19.

24. Jensen HI, Gerritsen RT, Koopmans M, Zijlstra JG, Curtis JR, Ording H. Families' experiences of intensive care unit quality of care: Development and validation of a European questionnaire (euroQ2). J Crit Care. 2015 Oct;30(5):884-90.

25. Jensen HI, Gerritsen RT, Koopmans M, Downey L, Engelberg RA, Curtis JR, et al. Satisfaction with quality of ICU care for patients and families: the euroQ2 project. Crit Care. 2017 Sep 7;21(1):239,017-1826-7.



2

New developments in the provision of family-centered care in the Intensive Care Unit

Gerritsen RT, Hartog CS, Curtis JR
Intensive Care Med 2017Apr;43(4)550-553

There is increasing recognition of the important role of family members in the ICU and there are four compelling reasons that ICU clinicians should incorporate family members into the provision of critical care. First, critical illness of a loved one has enormous effects on family members of the patient with approximately one-quarter to half of family members of critically ill experiencing significant psychological symptoms, including acute stress, post-traumatic stress, generalized anxiety, and depression both during and after the critical illness of their loved one (1-3). The combined impact on family members may result in what has been termed “Post-Intensive Care Syndrome-Family” (PICS-F) (3, 4). Importantly, clinician communication behaviors are associated with these psychological symptoms, highlighting the importance of supporting family members during critical illness (1). Second, family members are often placed in the position of acting as surrogate decision-makers for critically ill patients and support for and effective communication with family members will facilitate high quality and ethical shared decision-making in the ICU (5) . In addition, being involved in surrogate decision-making is associated with higher levels of distress among family members and matching family preference for role in decision-making may reduce this stress (5,6) Third, patients often want family members involved in decision-making about their care and most patients with chronic illness report that their family members’ perspectives should take precedence over their own advance directives (7). Finally, there is some evidence outside the ICU that supporting family members may improve patient outcomes by allowing family to be more effective caregivers (3,8). For all these reasons, high quality family-centered care should be considered a basic skill for ICU clinicians.

A recent clinical practice guideline about family-centered care in the ICU was produced and published the Society of Critical Care Medicine (9). These guidelines were developed by an international multidisciplinary team of 29 members with expertise in guideline development, evidence analysis, and family-centered care. Family was defined as individuals identified by the patient to be family (not necessary following a legal or genetic definition) or, in the case of minors or those without decision-making capacity, identified by their surrogates. Furthermore, family-centered care was defined as an approach to healthcare that is respectful of and responsive to individual families' needs and values. The guideline development process was designed according to up-to-date standards for guideline development. Importantly, individuals who had been critically ill in the past and their family members were involved in reviewing the domains for the guidelines, prioritizing the outcomes to be considered, and validating the recommendations of the guidelines committee. The group performed a systematic review of the literature using the methodology of Grading of Recommendations, Assessment, Development and Evaluations (GRADE), which yielded 236 studies that were used to make 23 recommendations. All 23 of the recommendations, however, were graded as weak recommendations, reflecting the relatively low quality of evidence. Of the 23 recommendations, 2 were based on moderate quality evidence, 12 on low quality evidence, and 9 on very low quality evidence. Table 1 shows the 14 recommendations based on moderate or low quality evidence, excluding those based on very low quality of evidence.

The five domains that were covered in these guidelines include such important areas as supporting family presence in the ICU; activities that explicitly support family members such as informational leaflets and ICU dairies; strategies to improve communication with family members; use of consultants or ICU team members such as ethics or palliative care consultants or family navigators, psychologists or social workers; and operational and environmental issues such as ICU policies supporting family-centered care and standardized protocols for withdrawing life support. The guidelines committee also developed tools to enhance implementation of the research highlighted in these guidelines into clinical practice and a gap analysis tool to support translation of recommendations into practice (available at www.sccm.org).

There are two key take-home messages from these guidelines. First, the level of evidence supporting interventions to improve family-centered care is relatively weak. However, there are important interventions that can be recommended based on the existing evidence. Second, no ICU could simultaneously implement all 14 recommendations supported by moderate or low quality evidence let alone the 23 supported by the guidelines committee. Instead, individual ICUs will need to review the recommendations and evidence, as well as their own processes of care and family-centered outcomes, to decide which interventions make the most sense given their current practice, current outcomes, the interests of the ICU team, and the resources available.

Family-centered care should be considered an important part of high quality care in every ICU. Many of the recommended strategies are based on common sense and can be implemented without significant financial investments or special equipment. However, it is important to note that some randomized trials of “common sense” interventions designed to improve family outcomes – such as a palliative care-led family conference or a condolence letter to family members of patients who died in the ICU from the ICU team – have been associated with increased psychological symptoms among family members (10,11). Furthermore, some changes in clinical practice may carry the risk of increasing clinician burnout (12), as shown in an Italian pre-post study of extending family visiting hours (13). In the future, research is needed to develop and validate more specific and responsive outcomes which can quantify benefits of improving partnerships with families and evaluate interventions designed to improve the diverse domains of family-centered care (14). Furthermore, we need more and higher quality evidence to help identify the effective and cost-effective interventions that improve all ICU care, including family-centered care. These recent guidelines document the best available evidence to improve care for the families of critically ill patients and clearly document the need for additional research and quality improvement projects to improve this important aspect of ICU care.

Table 1. Recommendations supported by moderate or weak quality of evidence

Category	Recommendations	**Quality of evidence** (B=moderate C=low)
1. Family presence in the ICU	Family members of critically ill patients be offered the option of participating in interdisciplinary team rounds to improve satisfaction with communication and increase family engagement.	**C**
	Family members of critically ill patients be offered the option of being present during resuscitation efforts, with a staff member assigned to support the family.	**C**
2. Family support	Family members of critically ill neonates be offered the option to be taught how to assist with the care of their critically ill neonate to improve parental confidence and competence in their caregiving role and improve parental psychological health during and after the ICU stay.	**B**
	Family education programs be included as part of clinical care as these programs have demonstrated beneficial effects for family members in the ICU by reducing anxiety, depression, post-traumatic stress, and generalized stress while improving family satisfaction with care.	**C**
	ICUs provide family with leaflets that give information about the ICU setting to reduce family member anxiety and stress.	**B**
	ICU diaries be implemented in ICUs to reduce family member anxiety, depression, and post-traumatic stress.	**C**
	Among surrogates of ICU patients who are deemed by a clinician to have a poor prognosis, clinicians use a communication approach, such as the “VALUE” mnemonic (Value family statements, Acknowledge emotions, Listen, Understand the patient as a person, Elicit Questions), during family conferences to facilitate clinician-family communication.	**C**
3. Communication with family members	Routine interdisciplinary family conferences be used in the ICU to improve family satisfaction with communication and trust in clinicians and to reduce conflict between clinicians and family members.	**C**
	Healthcare clinicians in the ICU should use structured approaches to communication, such as that included in the	**C**

	"VALUE" mnemonic, when engaging in communication with family members, specifically including active listening, expressions of empathy, and making supportive statements around nonabandonment and decision making. In addition, we suggest that family members of critically ill patients who are dying be offered a written bereavement brochure to reduce family anxiety, depression, and post-traumatic stress and improve family satisfaction with communication.	
4. Use of specific consultations and ICU team members	Proactive palliative care consultation be provided to decrease ICU and hospital length of stay among selected critically ill patients (e.g., advanced dementia, global cerebral ischemia after cardiac arrest, patients with prolonged ICU stay, and patients with subarachnoid hemorrhage requiring mechanical ventilation).	**C**
	Ethics consultation be provided to decrease ICU and hospital length of stay among critically ill patients for whom there is a value-related conflict between clinicians and family.	**C**
	Family navigators (care coordinator or communication facilitator) be assigned to families throughout the ICU stay to improve family satisfaction with physician communication, decrease psychological symptoms, and reduce costs of care and length of ICU and hospital stay.	**C**
5. Operational and environmental issues	Protocols be implemented to ensure adequate and standardized use of sedation and analgesia during withdrawal of life support.	**C**
	Hospitals implement policies to promote family-centered care in the ICU to improve family experience.	**C**

References

1. Lautrette A, Darmon M, Megarbane B, Jolly LM, Chevret S, Adrie C, Barnoud D, Bleichner G, Bruel C, Choukroun G, Curtis JR, Fieux F, Galliot R, Garraouste-Orgeas M, Georges H, Goldgran-Toledano D, Jourdain M, Loubert G, Reignier J, Saidi F, Souweine B, Vincent F, Barnes NK, Pochard F, Schlemmer B, Azoulay E (2007) A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 356:469-478

2. Davidson JE, Jones C, Bienvenu OJ (2012) Family response to critical illness: Post intensive care syndrome-family. *Crit Care Med* 40:618-624

3. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS Caregiver burden (2014) A clinical review. JAMA 311(10):1052-1060

4. Kon AA, Davidson JE, Morrison W, Danis M, White DB(2016) American College of Critical Care Medicine.; American Thoracic Society. Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement. Crit Care Med. Jan;44(1):188-201.

5. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B; FAMIREA Study Group(2005) Risk of post-traumatic stress symptoms in family members of intensive care unit patients._Am J Respir Crit Care Med 1;171 (9):987-94.

6. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, Curtis JR (2010) Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU._Chest 137(2):280-7.

7._Puchalski CM, Zhong Z, Jacobs MM, Fox E, Lynn J, Harrold J, Galanos A, Phillips RS, Califf R, Teno JM (2000) Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project**.** J Am Geriatr Soc 48(5 Suppl):S84-90.

8. Lynn J (2014) Strategies to ease the burden of family caregivers. JAMA 311(10):1021-1022

9. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, Netzer G, Kentish-Barnes N, Sprung CL, Hartog CS, Coombs M, Gerritsen RT, Hopkins RO, Franck LS, Skrobik Y, Kon AA, Scruth EA, Harvey MA, Lewis-Newby M, White DB, Swoboda SM, Cooke CR, Levy MM, Azoulay E, Curtis JR (2017) Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU Crit Care Med 45(1):103-128.

10. Carson SS, Cox CE, Wallenstein S, Hanson LC, Danis M, Tulsky JA, Chai E, Nelson JE (2016) Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness: A Randomized Clinical Trial. JAMA 5;316(1):51-62

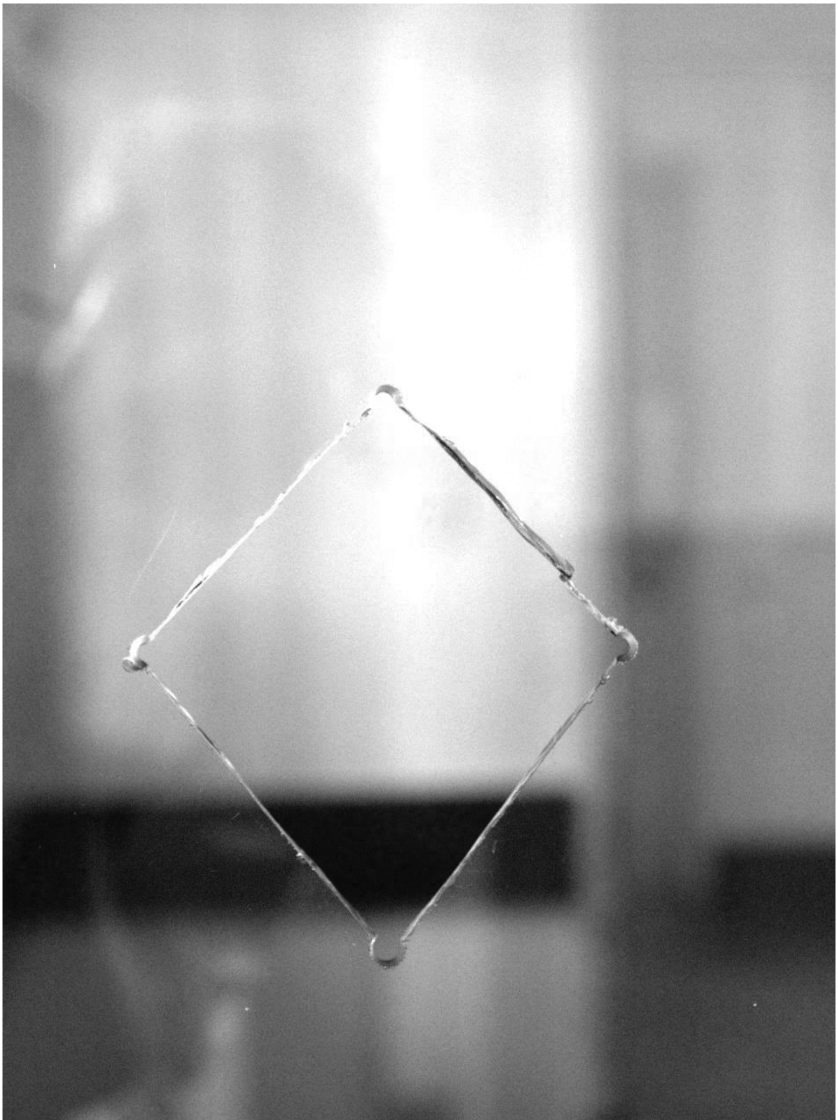
11. Kentish-Barnes N, Chevret S, Champigneulle B, Thirion M, Souppart V, Gilbert M, Lesieur O, Renault A, Garrouste-Orgeas M, Argaud L, Venot M, Demoule A, Guisset O, Vinatier I, Troché G, Massot J, Jaber S, Bornstain C, Gaday V, Robert R, Rigaud JP, Cinotti R, Adda M, Thomas F, Calvet L, Galon M, Cohen-Solal Z, Cariou A, Azoulay E; Famirea Study Group. Effect of a condolence letter on grief symptoms among relatives of patients who died in the ICU: a randomized clinical trial.Intensive Care Med. 2017 Apr;43(4):473-484

12. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN, (2016) A Critical Care Societies Collaborative Statement: Burnout Syndrome in Critical Care Healthcare Professionals. A Call for Action. Am J Respir Crit Care Med 194: 106-113

13. Giannini A, Miccinesi G, Prandi E, Buzzoni C, Borreani C, Group OS, (2013) Partial liberalization of visiting policies and ICU staff: a before-and-after study.

Intensive care medicine 39: 2180-2187

14. Curtis JR, Downey L , Engelberg RA (2016). The importance and challenge of measuring family experience with end-of-life care in the ICU. Intensive Care Med.42(7):1179-81.



3

Perception by Family members and ICU staff of the Quality of Dying and death in the ICU

A prospective multi-center study in the Netherlands

Gerritsen RT, Hofhuis JGM, Koopmans M,
van der Woude M, Bormans L, Hovingh A, Spronk PE

Chest 2013 Feb 1;143(2)357-363

Abstract

Objective

Admission to the intensive care unit (ICU) is a major event in a patient's life, and also for family members. We tried to elucidate how family members and ICU care-givers experience the dying process of their patients.

Design

The prospective study took place in three Dutch ICUs. Patients who had stayed>48 hrs and died in the ICU were eligible. The Quality of Dying and Death (QODD) was used with addition of items pertaining to the patient's autonomy. Values indicate median and interquartile range.

Measurements and results

We included 100 consecutive patients. ICU stay before death was 8 [3-16] days. APACHE-II score at admission was 24 [19-31]. Family response rate was 89%.

Families were satisfied with over-all QODD (score 8 [7-9]) and felt supported by the ICU care-givers (8[7-9]). Pain control was scored lower by family members (8[5.75-8.25]) than by nurses and physicians (9[8-10]; p=0.024) Almost always, physicians discussed the patient's end-of-life wishes with family members, although families rated the quality of the discussion lower 7 [5.5-8.5] than physicians 9 [6.5-10] (p=0.045). The majority of the families (89%) felt included in the decision making process. More than half of the family members (57%) felt that the physician took the final decision alone after giving information, while 36,8% felt they had participated in taking the decision. Family members rated the QODD questionnaire as difficult 6[5-8] and several items were not answered by a majority of family members. .

Conclusions
Quality of dying and death is generally perceived good by family members and caregivers of patients who die in Dutch ICUs. There is a need for modification of the QODD for the European ICU population.

Introduction

Admission to the intensive care unit (ICU) is a major event in a patient's life, also for the family members (1). The aim of every ICU admission is to do good and to cure the underlying illness. However, during ICU treatment a situation may evolve where the perspective of a reasonable recovery with expected well-being is no longer achievable. Than the aim of doing good changes from cure to care, i.e. trying to deal with the patient's symptoms and burden of disease. Indeed, most ICU deaths are preceded by withholding or withdrawing of life-sustaining treatment (2-7). Communication with families is of utmost importance in that phase of ICU stay (8). Indeed, previous studies have shown that the family will be better able to cope with the loss of a loved one if the ICU professional can provide high quality end-of-life care. However, if the family perceives suffering by their loved one while dying, this may induce feelings of distress (9,10).

To provide a good death, the question: "what is a good death?" should be answered first. This may in part depend on the patient's and family's religious and social background and setting (11-13). To standardize this issue in the ICU environment quality of dying and death experiences were studied by Patrick (10) and Curtis (11,14) who characterized several conceptual domains and developed an instrument called Quality of Dying and Death (QODD) with good reliability and validity characteristics (15,16) reflecting the perception of different family members in a reliable way (16). Since dying in an ICU is different from dying elsewhere in the hospital, a hospice or at home, the QODD was modified for use in the ICU (17) (15).

In the present study, we tried to elucidate the experience of families of patients dying in ICU, and also experiences of ICU care-givers the Netherlands. Additionally we looked at the participation of the family in decision making with regard to withholding and withdrawing therapies and particularly their satisfaction with their role in that process.

Patients and Methods

Design and Setting

This prospective study was performed in three non-academic teaching hospitals in the Netherlands during 8 months, i.e. the Medical Center Leeuwarden (MCL) with 800 beds and a 22 bed ICU , the Gelre Hospitals (GH) with 650 beds and a 12 bed ICU, and the Heerlen Medical Center(HMC) with 715 beds and a 21 bed ICU.

The Institutional review board (IRB) of the GH, approved the study (TCO 10.19), which was acknowledged by the IRB's of the MCL (TPO706) and HMC (10-N-61).

Measuring instrument

The previously published and validated Quality of Dying and Death (QODD)(15,17,18) questionnaire was translated to Dutch and back-translated from Dutch by a native English speaker (19). The QODD consists of twenty five questions, each question has two parts. The first part evaluates the frequency of occurrence of an item using a five point scale, while the second part is related to the perceived burden for the patient of that specific item. The QODD score is a summation of available zero to ten ratings, divided by the number of items completed, and then recalibrated to a zero to hundred scale, with higher score indicating higher quality of dying and death. The questionnaire we used was modified by translating it to Dutch, the exact text was maintained. Several items pertaining to the patients autonomy regarding decision making in the period directly preceding death were added (table 3). For this part we used part two of the Family Satisfaction with care in the ICU questionnaire (FS-ICU34).(20,21) The same translation procedure with the Family Satisfaction in Intensive Care Units FS-ICU was used (17).The FS-ICU 34 contains domains addressing general satisfaction with care and the satisfaction with the process of decision making . We used the six questions that related to end of life decision making.

Study participants

Adult patients who died in the ICU after a treatment period exceeding 48 hours were eligible for study participation, we included consecutive patients. The by the patient appointed representing family member, or if not present the one according to the hierarchy stated in Dutch law, was asked for consent to participate. Their contact details were stored and both the attending nurse and ICU physician who were treating the patient immediately before and during patient's death completed the questionnaire independently and individually within 24 hours after the patient's death. Three weeks after the patient's death the designated family member was sent the QODD-questionnaire by regular mail. One week later they were contacted by phone by consistently the same research nurse, in each center. During the telephone interview the QODD was completed both by the family member and the research nurse simultaneously. The family member was asked to sent his or her copy back to the hospital.

Data analysis and statistics

Frequency tables were made of all data. Items scored most frequently, (arbitrarily defined as those items scored by more than 25% of participants) were subsequently analysed in more detail. We used this approach because the items scored most frequently are probably most relevant for family members and ICU staff. Data of the three sites were analysed separately and in total. All data are expressed as median and interquartile range (IQR; P_{25}-P_{75}) where appropriate Comparison between frequencies in groups was tested by X^2 analysis or with Friedman test and Wilcoxon signed rank test whenever appropriate. Differences between groups were tested with Mann-Whitney-U test. $P<0.05$ indicated statistical significance. The significance level was adjusted by Bonferroni correction according to the number of related tests conducted. Data were analyzed using the Statistical Package for the Social Sciences (SPSS Inc, Chicago IL, USA, version 14).

Results

Patients and setting

In a period of 8 months, 197 patients died in the three ICUs and were screened for study participation (figure 1). Of those patients, 112 fulfilled the inclusion criteria Of those 112 patients the family of 100 consented in study participation. Ten families refused consent and two were excluded because of language problems, which resulted in an inclusion rate of 89%. In all cases where the family consented to participate, we were able to obtain questionnaires from the family member, the nurse and physician.

Median patient age was 73 [65-80] years, with 66% males, median ICU stay before death was 8 [3-16] days. Median APACHE-II score at admission was 24 [19-31]. The admission reason was mainly medical, 70%. 86,5% of the patients died after some form of withholding or withdrawing therapy. CPR was been performed in 3% of deaths (table 1).

QODD items

We used a translated QODD. Answers related to frequency of occurrence completed by family members are presented in table 2. Family members rated the difficulty of the questionnaire on a 0-10 scale with a median of 6 [5-8] (table 1)

Perceptions of family members and care-givers

The perceptions of the family members compared to those of the physician and nurse are shown in table 2. The perceived overall quality of death showed a median score of 9 [8-10] out of a 0-10 scale for all the three groups. The quality of care by the physician as perceived by the family was good, on a 1-10 scale a median score of 8 [7-9]. Where the professionals judged themselves with a median score of 8 [8-9](physician) and 9 [8-10] (nurse). Also the other questions in table 2, the scores in on almost all questions are high and showed few differences between the groups. The results to the important question about pain control showed a significant difference between physicians 9 [8-10] and family 8 [5.5-8.5] (p<0.001) whereby the doctor rates the control of pain higher than the family, while nurses rated pain not different 8 (6-10) There was also a difference reflecting the appraisal of the question asking whether the patient was feeling at peace with dying (family score 7 [5-8] lower than. physicians 8 [7-9]; p=0.001). Almost always, physicians discussed the patient's end-of-life wishes with family members, although physicians (9 [6.5-10]) rated the quality of the discussion higher than the families (7 [5.8-8.5])(p=0.032) . Subgroup analysis using Mann-Whitney test showed no differences in answers in different subgroups evaluating medical versus surgical reasons for admission, sex, older age, ICU length of stay, duration of mechanical ventilation and type of relationship with the patient. We did not find differences between the answers from the three different centers.

Autonomy regarding decision making

The results of the questions evaluating the decision making process are reported in table 3. The majority of the families felt somewhat (27%) or very (62%) included in the decision making process. 39% of families felt very supported , 43% felt supported by the team. The majority of family members had enough time for questions (89%). Half of the family members (58%) felt that the physician took the final decision almost always after incorporating the families input without asking consent . While 37% of the family members felt that they had participated in taking the decision on end of life care. A small minority felt that they took the decision to limit or stop care themselves after being informed (5%). No one reported that they felt solely responsible for these decisions.

Discussion

We showed that families are generally satisfied with the quality of dying and death of their loved one in Dutch ICUs. One third of the relatives reported that they had actively participated in making end of life decisions.

Although several authors report incomplete QODD items, there are no reports on the perceived difficulty of the questionnaire. We showed that family members rate the difficulty of the questionnaire as 6 on a scale of 1-10, while 9 items were left blank in more than half of the forms received. We have no further information about these non answered items. These data suggest that for Dutch families the translated QODD questionnaire is not easy to answer and many questions may be judged irrelevant or unclear. We have no data on the perceived difficulty for the professionals to complete the questionnaire.

Previous studies looking at QODD show that nurses and residents reported consistently lower scores than families and physicians on all items asked (15) (22). However, we could not confirm this finding, although some differences did occur We also could not confirm the previously reported difference in the appreciation of pain control between families and nurses, nor the difference in perceived patients control over himself. Nevertheless, there seems to be a difference between the rating of pain control as judged by physicians when compared to the pain control judged by family members (22,23) This may be related to insufficient implementation of objective and reliable pain-scores like the CPOT (24)

On the other hand, professionals in American and Dutch ICUs may have different roles in the eyes of families.. We conducted the survey in a setting where the physician is directly available at the bedside, which is comparable to the nurses availability in ICUs in the USA. Other differences that we found, either between families and professionals, or between physician and nurses, may be explained by the fact that the families scored the burden of therapies as ventilation and dialysis higher than the professionals who consider these treatment modalities as daily routine. The problem in interpretating the QODD by family members and ICU care givers may not be related to perceived differences in quality of end of life care, but may be due to different experiences and expectations of critical care..(25).

The overall high rating of the QODD might be explained by the fact that continuity in caregivers and clarity in appointing a contact family member, either by the patient him or herself or according to the hierarchy stated under Dutch law are standard practice in Dutch ICUs. Those factors were previously shown to be related to the perceived quality of care (26). This was recently corroborated by the results of the APPROPRICUS study (27) . They showed that perceived appropriateness of ICU care is for a large part determined by the communication between the caregivers and the role they can play in determining the extent of care delivered. The high rating of QODD results are different than the findings in a recent large intervention trial as part of a quality improvement intervention (25) They measured the quality of end of life care before and after the intervention, which. was lower than in our study. Their relatively low response rate might play a role, but other factors may be more important ,e.g. differences in roles of nurses and physicians between the USA and the Netherlands, differences in culture and legislation related to communication(28).Also it is not clear how Dutch and US family members differ in terms of their expectations thereby influencing the results., In our study only a very small minority of patients died under full support. Transition to comfort measures when clinically required and adequately communicated is known to improve the perceived quality of end of life care (25) . Next to the QODD, we studied how family members perceived their involvement in the decision making process related to end-of-life of their loved one. Most of the literature dealing with this dilemma originates in the USA. Most American families prefer a shared decision –making approach in which they are involved in the decision (29). In addition, a passive role in decision making is associated with a higher prevalence of post traumatic stress syndrome (PTSS) (26). In Europe the opposite was reported, i.e. sharing the decision about withdrawing or withholding therapy may induce PTSS (30). This might be explained by the cultural differences between Europe and the USA (31-33). Acting in contrast with what is considered the norm may be associated with increased stress and risk for developing PTSS. In the Netherlands, like in Italy and Tunisia , physicians usually use a paternalistic approach to end of life care (31,32,34). According to Dutch law, after only informing the family members physician can withhold or withdraw treatment.. Our results indicate however that the Dutch approach is gradually changing from a paternalistic approach to shared decision making. Similar findings were reported in Norway (33). It is interesting to see that change seems to occur in the USA to, where pure autonomous decision making seems to be replaced by a more shared decision making process(35)

Several important strengths and weaknesses of our study should be pointed out. Strengths of our study are the multicenter character of the design and the fact that perceptions of physicians, nurses and family members are analyzed in the same patient, and as such can be directly compared on an individual level. However, only three centers in The Netherlands were involved in the study. Nevertheless, we think the data reflect the current Dutch situation,. Although the religious background is different, HMC is in catholic area, GH is protestant and MCL has no specific religious population, no differences in QODD results were apparent. Second, results of perceived QODD may markedly differ in other parts of the world. Local adaptation of the QODD in future studies may help address this problem. Third, we only asked one family member per patient. However, we aimed to contact the family member who was appointed as primary contact by the patient and thus probably best able to respond in line with patient’s perceptions. We did not separately validate our version of the QODD being an exact translation of the original text. The FS-ICU we used was also carefully translated but we used only the part of the second domain related to end of life care. We did not change the original text but did not validate our selection of questions in the studied population.

In conclusion, we showed that QODD is generally perceived as being good by family members and caregivers of patients who die in ICUs in The Netherlands. There is a need for revising the QODD to the local setting in view of the differences in culture and setting. The historic difference between the USA and the Netherlands seems to be diminishing as both countries are increasingly adopting a shared decision-making approach with incorporation of the patient's and family's autonomy as well as a role for the physician in the decision-making process.

Table 1. Patient characteristics in participating centers

	All	MCL	GH	HMC	P-value
Number of patients	100	37	21	42	
Age	73 [65-80]	72 [64-79]	77 [68-85]	71 [66-79]	0.200
Male %	66 [66%]	26 [70%]	12 [57%]	28 [67%]	0.594
APACHE-II score	24 [19-31]	30 [21-35]	20 [16-27]	23 [19-28]	0.01
SAPS 2 score	58 [48-68]	67 [54-82]	47 [42-59]	57 [49-64]	0.003
LOS-ICU (days)	8 [3-16]	6 [3-14]	12 [3-30]	10 [4-22]	0.344
Ventilation (days)	7 [3-16]	6 [3-13]	8 [4-21]	9 [2-18]	0.602
Admission type					
Medical	70 [70%]	28 [76%]	15 [71%]	27 [64%]	0.014
Emergency surgery	17 [17%]	2 [5%]	6 [29%]	9 [21%]	
Elective surgery	13 [13%]	7 [19%]	0	6 [14%[	
DNR orders	64 [64%]	12 [32.4%]	18 [86%]	34 [81%]	<0.001
Withdrawal therapy		32 [86.5%]	21 [100%]		
Vasopressors		26 [70.3%]	17 [81%]		
CPR performed	3[3%]	3 [8.1%]	0	0	
Type of proxy					
Partner	31%	9 [24.3%]	9 [45%]	10 [31%]	
Child	68%	28 [75.7%]	11 [55%]	22 [69%]	
Common household	51%	21 [57%]	5 [25%]	19 [59%]	
Known for years	45 [42-54]	45 [41.5-54]	46 [41-56]	45 [43-50]	
Difficulty in questionnaire	6 [5-8]	7 [6-9]	5 [2-7]	6[3-9]	

MCL= Medical Centre Leeuwarden, GH=Gelre Hospitals, HMC=Heerlen Medical Centre Values are indicated as median [P_{25}- P_{75}] unless stated otherwise

Table 2. comparison of median scores for part B QODD answers for three groups of raters

	Family	Physician	Nurse	F vs Ph	F vs N	Ph vs N	ALL	number of items scored by family members (%)
Number of questionnaires filled out	100	100	100					
Questions								
Had control of pain	8[5.75-8.25]	9[8-10]	8[6-10]	0.001			0.024	55
Had control over what was going on around him/her	7[4.5-8]	0[0-5]	1[0-5]	0.001			0.075	57
Was able to feed him/herself	6[3-8]	0[0-0]	0[0-0]	<0.001	<0.001		<0.001	65
Breathing comfortably	6[4-7]	7[3-8]	6[4-7]				0.138	64
Felt at peace with dying	7[5-8]	8[7-9]	9[5-9.5]	0.001			0.018	31
Was unafraid of dying	8[5-9]	8[7-8]	7[3.5-8.5]				0.175	31
Laughed and smiled	5[2-7]	2[0-5]	0[0-3]				0.058	43
Maintained dignity and self-respect	7[3-8.25]	8[7-9]	8[5-9]				0.166	38
Spent time with family	4.5[2-7]	2[0-8]	6[0-8]				0.269	39
Bad feelings spoken out	5[2-7.5]	0[0-1]	0[0-5]				0.017	34
Spent time alone	4[2-6]	0[0-7]	1.5[0-0.5]				0.692	30
Was touched and hugged by loved ones	8[8-9]	10[8-10]	9[8-10]	<0.001			<0.001	83
Said goodbye to loved ones	5[3-8]	1[0-7]	0.5[0-7]				0.013	51
Had visits from spiritual advisor	8[5.5-9]	0[0-8]	0[0-10]					65
Spiritual service or ceremony before death	8[6.5-9]	0[0-6]	0[0-7]					65
Had funeral arrangements in order	8[6-9]							74
Discussed end-of-life wishes with doctor	7[5.5-8.5]	9[6.5-10]	8[5-10]	0.032			0.045	41
Experience of mechanical ventilation as an aspect of dying	7[3-8]	9[7-10]	8[6-9.75]	<0.001	0.002		0.002	80
Experience of dialysis	8[5-9]	10[8-10]	9[7-10]	<0.001			<0.001	43
Was anyone present at the moment of death?	9[8-10]	9[9-10]	10[9-10]	<0.001	<0.001		<0.001	84
Overall Quality of dying	9[8-10]	9[8-10]	9[8-10]				0.166	86
Quality of care	8[7-9]	8[8-9]	9[8-10]				0.085	89

F: family member; Ph: physician; N: nurse

Median [P_{25}- P_{75}], All groups: Friedman test, F vs Ph, F vs N, Ph vs N Wilcoxon test **; X and # P value significant after Bonferroni correction.

Table 3. Patients autonomy in decision making

		all
Involved in decisions		N=100
	Felt very excluded	4 (4,6%)
	Felt somewhat excluded	2 (2,3%)
	Neither included nor excluded	3 (3,4%)
	Somewhat included	24 (27,6%)
	Very included	54 (62,1%)
Decisions made together		
	By physician	10 (11,5%)
	By physician after information	40 (46%)
	together	32 (36,8%)
	By me after information	5 (5,7%)
	By me alone	0 (0%)
Supported by team		
	Totally overwhelmed	4 (4,6%)
	Slightly overwhelmed	7 (8%)
	Neither overwhelmed nor supported	4 (4,6%)
	Felt supported	37 (42,5%)
	Very supported	34 (39,1%)
	No answer	1 (1,1%)
In control of situation		
	Really out of control	6 (7%)
	Somewhat out of control	22 (25,6%)
	Neither in or out of control	15 (17,4%)
	Some control	25 (29,1%)
	Good control	18 (20,9%)
Enough time for questions		
	Could use more time	8 (9,2%)
	Had adequate time	77 (88,5%)
	No answer	2 (2,2%)

Table ESM-1. Quality of dying and death as perceived by family members

		all
Number of questionnaires		100
Had control of pain		
	0= never	6 (6,7)
	1= a little bit of the time	4 (4,5)
	2= some of the time	5 (5,6)
	3= a good bit of the time	6 (6,7)
	4= most of the time	14 (15,7)
	5= all of the time	21 (23,6)
	6= I don't know	33 (37,1)
Had control over what was going on around him/her		
	0= never	28 (31,5)
	1= a little bit of the time	6 (6,7)
	2= some of the time	15 (16,9)
	3= a good bit of the time	3 (3,4)
	4= most of the time	3 (3,4)
	5= all of the time	3 (3,4)
	6= I don't know	31 (34,8)
Was able to feed him/herself		
	0= never	70 (78,7)
	1= a little bit of the time	6 (6,7)
	2= some of the time	1 (1,1)
	3= a good bit of the time	0
	4= most of the time	1 (1,1)
	5= all of the time	2 (2,2)
	6= I don't know	9 (10,1)
Breathed comfortably		
	0= never	24 (27)
	1= a little bit of the time	11 (12,4)
	2= some of the time	8 (9)
	3= a good bit of the time	6 (6,7)
	4= most of the time	11 (12,4)
	5= all of the time	8 (9)
	6= I don't know	21 (23,6)
Felt at peace with dying		
	0= never	8 (9)
	1= a little bit of the time	5 (5,6)
	2= some of the time	1 (1,1)
	3= a good bit of the time	4 (4,5)
	4= most of the time	8 (9)
	5= all of the time	7 (7,9)
	6= I don't know	56 (62,9)

Was unafraid of dying		
	0= never	11 (12,4)
	1= a little bit of the time	3 (3,4)
	2= some of the time	2 (2,2)
	3= a good bit of the time	3 (3,4)
	4= most of the time	2 (2,2)
	5= all of the time	9 (10,1)
	6= I don’t know	59 (66,3)
Laughed and smiled		
	0= never	52 (58,4)
	1= a little bit of the time	7 (7,9)
	2= some of the time	11 (12,4)
	3= a good bit of the time	4 (4,5)
	4= most of the time	1 (1,1)
	5= all of the time	0
	6= I don’t know	14 (15,7)
Maintained dignity and self respect		
	0= never	10 (11,2)
	1= a little bit of the time	3 (3,4)
	2= some of the time	3 (3,4)
	3= a good bit of the time	4 (4,5)
	4= most of the time	5 (5,6)
	5= all of the time	13 (14,6)
	6= I don’t know	51 (57,3)
Spent time with spouse/ partner		
	0= never	54 (60,7)
	1= a little bit of the time	6 (6,7)
	2= some of the time	3 (3,4)
	3= a good bit of the time	5 (5,6)
	4= most of the time	5 (5,6)
	5= all of the time	4 (4,5)
	6= I don’t know	12 (13,5)
Spent time alone		
	0= never	54 (60,7)
	1= a little bit of the time	4 (4,5)
	2= some of the time	3 (3,4)
	3= a good bit of the time	1 (1,1)
	4= most of the time	0
	5= all of the time	0
	6= I don’t know	27 (30,3)
Was touched and hugged by loved ones		
	1= yes	85 (95,5)
	2= no	3 (3,4)
	3= I don’t know	1 (1,1)

Said goodbye to loved ones		
	1= yes	27 (30,3)
	2= no	58 (65,2)
	3= I don't know	4 (4,5)
Clearing up bad feelings		
	1= yes	7 (7,9)
	2= no	66 (74,2)
	3= I don't know	13 (14,6)
Had visits form spiritual advisor		
	1= yes	20 (22,5)
	2= no	66 (74,2)
	3= I don't know	3 (3,3)
Spiritual service or ceremony before death		
	1= yes	21 (23,6)
	2= no	68 (76,4)
	3= I don't know	0
Receiving mechanical ventilation		
	1= yes	86 (96,6)
	2= no	3 (3,4)
	3= I don't know	0
Receiving dialysis		
	1= yes	36 (40,4)
	2= no	52 (58,4)
	3= I don't know	1 (1,1)
Had funeral arrangements in order		
	1= yes	32 (36)
	2= no	56 (62,9)
	3= I don't know	1 (1,1)
Discussed end-of-life wishes with doctor		
	1= yes	21 (23,6)
	2= no	61 (68,5)
	3= I don't know	7 (8,9)
Was anyone present at the moment of death		
	1= yes	83 (93,3)
	2= no	5 (5,6)
	3= I don't know	1 (1,1)
State at moment of death		
	1= awake	6 (6,7)
	2= sleeping	15 (16,9)
	3= coma	68 (76,4)

References

1. McAdam J, Puntillo K. Symptoms experienced by family members of patients in intensive care units. Am J Crit Care. 2009;18(3):200-9.

2. Prendergast TJ, Puntillo KA. Withdrawal of life support: intensive caring at the end of life. JAMA. 2002;288(21):2732-40.

3. Halpern S. Perceived Inappropriateness of Care in the ICU. JAMA: The Journal of the American Medical Association. 2011;306(24):2725-6.

4. Cohen S, Sprung C, Sjokvist P, Lippert A, Ricou B, Baras M et al. Communication of end-of-life decisions in European intensive care units. (1). Intensive Care Med. 2005;31(9):1215-21.

5. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Crit Care Med. 2000;28(8):3044-9.

6. van der Klink MA, Heijboer L, Hofhuis JGM, Hovingh A, Rommes JH, Westerman MJ et al. Survey into bereavement of family members of patients who died in the intensive care unit. Intensive Crit Care Nurs. 2010;26(4):215-25.

7. Spronk PE, Kuiper AV, Rommes JH, Korevaar JC, Schultz MJ. The practice of and documentation on withholding and withdrawing life support: a retrospective study in two Dutch intensive care units. Anesth Analg. 2009;109(3):841-6.

8. Valks K, Mitchell ML, Inglis-Simons C, Limpus A. Dealing with death: an audit of family bereavement programs in Australian intensive care units. Aust Crit Care. 2005;18(4):146, 148-51.

9. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA. 2003;290(6):790-7.

10. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. J Pain Symptom Manage. 2001;22(3):717-26.

11. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. Journal of general internal medicine. 2001;16(1):41-9.

12. Hales S, Zimmermann C, Rodin G. Review: the quality of dying and death: a systematic review of measures. Palliat Med. 2010;24(2):127-44.

13. Albers G, Echteld MA, de Vet HCW, Onwuteaka-Philipsen BD, van der Linden MHM, Deliens L. Evaluation of quality-of-life measures for use in palliative care: a systematic review. Palliat Med. 2010;24(1):17-37.

14. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage. 2002;24(1):17-31.

15. Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR. Factors associated with nurse assessment of the quality of dying and death in the intensive care unit. Crit Care Med. 2004;32(8):1648-53.

16. Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the Quality of Dying and Death. J Pain Symptom Manage. 2004;28(4):306-15.

17. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. Chest. 2005;127(5):1775-83.

18. Ferrand E, Lemaire F, Regnier B, Kuteifan K, Badet M, Asfar P et al. Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. Am J Respir Crit Care Med. 2003;167(10):1310-5.

19. McDermott MA, Palchanes K. A literature review of the critical elements in translation theory. Image J Nurs Sch. 1994;26(2):113-7.

20. Heyland DK, Tranmer JE, Kingston General Hospital ICU Research Working Group. Measuring family satisfaction with care in the intensive care unit: the development of a questionnaire and preliminary results. J Crit Care. 2001;16(4):142-9.

21. Heyland DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ et al. Family satisfaction with care in the intensive care unit: results of a multiple center study. Crit Care Med. 2002;30(7):1413-8.

22. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. Chest. 2005;128(1):280-7.

23. Kjerulf M, Regehr C, Popova SR, Baker AJ. Family perceptions of end-of-life care in an urban ICU. Dynamics. 2005;16(3):22-5.

24. Gélinas C, Fortier M, Viens C, Fillion L, Puntillo K. Pain assessment and management in critically ill intubated patients: a retrospective study. Am J Crit Care. 2004;13(2):126-35.

25. Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE et al. Effect of a Quality-Improvement Intervention on End-of-Life Care in the Intensive Care Unit: A Randomized Trial. Am J Respir Crit Care Med. 2011;183(3):348-55.

26. Anderson WG, Arnold RM, Angus DC, Bryce CL. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. J Crit Care. 2009;24(2):249-54.

27. Piers R, Azoulay E, Ricou B, Ganz F, Decruyenaere J, Max A et al. Perceptions of Appropriateness of Care Among European and Israeli Intensive Care Unit Nurses and Physicians. JAMA: The Journal of the American Medical Association. 2011;306(24):2694-703.

28. Fuertes N. End-of-life decisions in Argentina. Lancet. 2012;379(9811):105.

29. Vincent JL. Ethical principles in end-of-life decisions in different European countries. Swiss medical weekly. 2004;134(5-6):65-8.

30. Azoulay E, Pochard F, Chevret S, Adrie C, Annane D, Bleichner G et al. Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. Crit Care Med. 2004;32(9):1832-8.

31. van der Werf TS, Zijlstra JG, Ligtenberg JJM, Tulleken JE. [Decisions around the end of life on Intensive Care: making the transition from curative to palliative treatment]. Ned Tijdschr Geneeskd. 2005;149(14):742-6.

32. Bertolini G, Boffelli S, Malacarne P, Peta M, Marchesi M, Barbisan C et al. End-of-life decision-making and quality of ICU performance: an observational study in 84 Italian units. Intensive Care Med. 2010;36(9):1495-504.

33. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. Intensive Care Med. 2011;37(7):1143-50.

34. Ouanes I, Stambouli N, Dachraoui F, Ouanes-Besbes L, Toumi S, Ben Salem F et al. Pattern of end-of-life decisions in two Tunisian intensive care units: the role of culture and intensivists' training. (1). Intensive Care Med. 2012;

35. White D, Braddock C, Bereknyei S, Curtis J. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. Arch.Intern.Med. 2007;167(5):461-7.

4

Comparing quality of dying and death perceived by family members and nurses for patients dying in US and Dutch ICUs

Gerritsen RT, Jensen HI, Koopmans M, Curtis JR, Downey L,
Hofhuis JGM, Engelberg RA, Spronk PE, Zijlstra JG
J Crit Care 2017 Dec 26;44:376-382

List of abbreviations

ANOVA:	analysis of variance
FS-ICU:	Family Satisfaction in the Intensive Care Unit
ICU:	intensive care unit
IQR:	interquartile range
NL:	Netherlands
PTSD:	post traumatic stress disorder
QODD:	quality of dying and death
SD:	standard deviation
SPSS:	statistical package for social sciences
US:	United States of America

Financial support

The American part of the study was supported, in part, by a grant from the Robert Wood Johnson Foundation and a grant from the National Institute of Nursing Research (R01NR05226).

Abstract

Background

The Quality of Dying and Death (QODD) questionnaire is used as a self-reported measure to allow families and clinicians to assess patients' quality of dying and death. We evaluated end-of-life (EOL) experiences as measured by the QODD completed by families and nurses in the United States (US) and the Netherlands (NL) to explore similarities and differences in these experiences and identify opportunities for improving EOL care.

Methods

Questionnaire data were gathered from family members of patients dying in the ICU and nurses caring for these patients. In NL, data were gathered in three teaching hospitals; in the US from 12 sites participating in a randomized trial. The QODD is consists of 25 items and has been validated in the US.

Result

Data from 446 patients were analysed, (346 in US; 100 in NL). Dutch patients were older than those in the US (72 ±10.2 vs. 65 ±16.0, $p<0.0025$). The family-assessed overall QODD score (medians [IQR]) was the same in both countries: NL 9 [8-10], US 8[5-10]. US family members rated the quality of two items higher than NL families: "time spent with loved ones" and "time spent alone". Nurse-assessed QODD ratings varied: the single-item QODD summary score was significantly higher in NL (NL 9 [8-10] vs US 7 [5-8]; $p<0.0025$), while the QODD total score was higher in the US (NL 6.9 [5.5-7.6] vs US.7.1 [5.8-8.4]; $p=0.014$), although not meeting our criteria for statistical significance. Of the 22 nurse-assessed items, 10 were significantly different between NL and US with 8 higher in the US and 2 higher in NL.

Conclusion

The QODD was rated similarly by family members in the US and the Netherlands but varied when assessed by nurses. These differences may be due to organizational or cultural differences between the two countries or to expectations of respondents.

Introduction

Admission and treatment in the intensive care unit (ICU) has a major impact on the lives of both patients and their loved ones and, despite significant efforts by the clinical team, a considerable proportion of patients do not survive ICU care.[1] A patient's death affects both families and clinicians. For family members, poor end-of-life (EOL) care may lead to difficult bereavement and post-traumatic stress disorder (PTSD), while clinicians caring for dying patients in the ICU may be at increased risk for burnout and moral distress.[2-4]

Previous studies have shown that family members are likely to have less psychological symptoms after the loss of a loved one in the ICU if the patient has received high quality EOL care.[5-7] Interventions to improve quality of communication and quality of care have been associated with reduced psychological symptoms in some studies, although other studies suggest that such interventions had no effect or can actually increase psychological symptoms in some setting.[8-12] Given the heterogeneity of results with interventions to improve end-of-life care, further studies are needed to help guide interventions to improve end-of-life care as well as experiences of patients, family members, and clinicians. Furthermore, since family members' and clinicians' social and religious background as well as the cultural and organizational context of care, influence both care and assessments of that care, understanding differences in care across different countries and organizations may provide insights into methods to improve care.[13-15]

In an effort to study the perceived quality of dying and death, the Quality of Dying and Death (QODD) questionnaire was developed through qualitative research and review of the literature identifying several conceptual domains with acceptable reliability and validity.[16-20] An instrument like the QODD may be useful in detecting and understanding differences in care between settings. For example, QODD scores are higher for patients dying at home as compared with patients dying in the hospital.[17] It may also be useful for comparing differences between countries in which features of care including organizational and cultural differences may be important to consider. For instance, when comparing the US and Europe, a higher proportion of patients in the US die in an ICU setting than in Europe.[15,21] In addition, previous authors have speculated that EOL care in Europe is characterized by more paternalism and less focus on autonomy than in the US.[22,23] The use of specialty palliative care teams in hospitals and ICUs also differs between Europe and the US, which may influence EOL care in the ICU.[23] Finally, the ways in which EOL care is delivered and interpreted are influenced by cultural norms and practices.[13,15] Understanding the nature of differences in EOL care across different countries may provide an opportunity to identify targets for interventions to improve care in each country.

We previously showed that the family-assessed QODD score was high in several Dutch ICUs, suggesting a good quality of dying and death. Families assessed these experiences differently from ICU clinicians.[24] Others have also shown that families and ICU nurses provided significantly different assessments of the QODD.[25] Examination of international differences in ratings of the quality of dying and death for patients dying in the ICU, from the perspective of families and nurses, may provide insights into areas of relatively high and low quality care that suggest specific targets for improvement. In the current study, we hypothesized that assessments of the QODD would differ between NL and the US for evaluations completed by both families and nurses. We also aimed to identify the specific experiences of the quality of dying and death, as measured by the individual QODD items, that were different in NL in comparison to the US where the QODD was originally developed.

Patients and Methods

Design and Setting

The NL sample included 100 consecutive patients dying in the ICU after an ICU-stay of 48 hours or longer. Data were collected from three non-academic teaching hospitals over 8 months in 2012. All Dutch family members filled in the QODD assisted by a member of the study team during a telephone call three weeks after their loved one had died. Family members were also asked to return the filled-in questionnaire by regular mail. Nurses completed their questionnaire within one or two days after they finished the shift in which they cared for that patient. The method was described in detail previously.[24]

US data were collected as part of a multifaceted, interdisciplinary quality improvement intervention implemented as a randomized trial in 12 hospitals in Seattle, Washington[26] and as a before-after trial at one hospital.[27] Eligible patients were those who died in an ICU or within 30 hours of transfer to another hospital location. In the US studies, questionnaires were provided to families by mail 4-6 weeks after a patient's death and self-administered. Nurses caring for the identified patients at the time of death and during the previous shift were identified and provided a self-administered questionnaire within 72 hours of the patient's death.[26,27] For the current study, only decedents with ICU lengths of stay >= 48 hours were included in the analyses. Both studies were approved by their respective institutional review boards (R-TPO 706).

Measures

The 25-item version of the validated Quality of Dying and Death (QODD) questionnaire was translated to Dutch by a native Dutch speaker and back-translated from Dutch to English by a native English speaker to confirm accuracy. The QODD includes questions assessing the quality of experiences that patients may have encountered at the end of life. Each question has two parts: 1) "report" items in which the frequency of an experience/event is provided; and 2) "rating items" in which the respondent evaluates the quality of the experience/event on an 11 point scale ranging from 0 "Terrible" to 10 "Almost perfect". If families answered "I don't know" for the report items, they were directed to skip the rating item. For the 25-item nurse version, nurses were asked to rate the first 15 items, and were asked for both reports and ratings for the remaining 10 items. Both the family and nurse versions have shown good internal consistency and validity.[16-20,28-31] For this study, we have analysed only the rating items and used 22 of the 25 items that were collected from both countries. Omitted items included: "health care costs", "overall health care" and "doctor's care last days". We also compared the individual QODD items across the two countries to understand the specific components of quality of dying that were different or similar in these settings.[18]

We used two summary measures, a single-item overall score and the summed total score on all items. The single-item QODD overall score (QODD-1) asks respondents the following question: "Overall, how would you rate the quality of your loved one's dying?" The QODD total score (QODD) is a summation of all available zero to ten ratings for the 22 QODD items, divided by the number of items completed, with higher scores indicating higher quality of dying and death.

Patient demographics were derived from chart abstraction (both US and Netherlands samples) and death certificates (US sample only). Family characteristics and demographics were self-reported. Nurse characteristics were only available for the US sample and therefore are not included for analysis.

Statistical Analyses

Using descriptive statistics, we analysed the QODD's rating items and overall scores for each country, providing % valid responses, means

(SD) or median (IQR) according to distribution. For differences in patient demographics a p<0.05 was considered statistically significant. To test for differences between countries, we examined individual QODD items and overall scores using both unadjusted and adjusted approaches. For unadjusted comparisons, we used the Mann Whitney test, a non-parametric statistic appropriate for the non-normal distributions that characterized the QODD items and overall scores. When base-line differences in demographics between groups were identified with a p<0.20, multivariate regression analysis was performed, controlling for those differences. We used an analysis of variance (ANOVA) with backward stepwise method.

We present both unadjusted and adjusted analyses because the unadjusted analyses provide evidence of the actual differences encountered in these ICUs in the Netherlands and the US while the adjusted analyses examine the differences that are more likely due to the country, adjusting for measured confounders. In order to control for the number of analytic comparisons, we adjusted the significance level (p<0.0020) using a Bonferroni correction for the number of tests.

In the US database, 20 nurses completed surveys for multiple patients. Clustered analysis revealed no effect on studied parameters of this clustering and we therefore report the results of the unclustered analyses. Data were analyzed using the Statistical Package for the Social Sciences (SPSS Inc, Chicago IL, USA, version 18).

Results

Sample

Four hundred and forty-six patients with both family and nurse questionnaires (NL: N=100; US.: N=346) were included in the study. The overall response rate was 89%. The two samples varied (p<0.01)on the following patient and family characteristics: 1) patient age with patients from the NL being significantly older (72 years ±10.2, (p<0.01)) than patients in the US (65 years ±16.0); 2) family members age with respondents from the NL being older than family members in the US (NL 61 years ±13.7 vs. US 57 years±14.3;(p<0.01)); and 3) length of patient-family relationship with longer relationships in the NL sample than in the US sample (NL 45 years±12.9 vs.US 40 years± 5.8;(p<0.01)). The two samples did not differ by sex of patients (65% males), mean length of ICU stay (7 days), and the proportion of patients that were ventilated (NL 97% vs. US 91%). (Table 1)

Single-item Summary QODD Scores and Total QODD Scores

We examined two summary measures for family members, the single item summary rating (QODD-1) and the average total score for all items of the QODD-22. Both summary measures were similar when comparing assessments by family members from NL compared to the US: single item QODD-1 medians (IQR) were NL 9 (8-10) US 8 (5-10) and the 22-item QODD total scores were NL 6.6 (5.3-7.6) and US 6.6 (4.9-8.0). (Table 2)

We also examined these same two summary measures for nurse assessments. In contrast to the findings from the family-assessed QODD, the nurse-assessed single item QODD-1 score was significantly higher in the NL (NL 9 [8-10] vs. US. 7 [5-8]; p<0,0020). However the QODD total score based on 22 items was higher in the US, although it did not achieve our definition of statistical significance (NL 6.9 [5.5-7.6] vs. US.7.1 [5.8-8.4]; p=0.014).

Family Members' Scores on Individual Items

In unadjusted analyses of the 22 individual items, 4 items were significantly different (all p<0.0020) between the US and NL with three higher in the US: 1) spending time with family and friends (US 8.5 [5-10] vs. NL 4.5 [2-7] days); 2) spending time alone (US 7 [4-9]) vs. NL 4 [2-6]) days); and 3) being touched and hugged by loved ones (US 9 [8-10]) vs NL 8 [8-9]). The item that was higher in NL was saying goodbye to loved ones (US 4[0-8] vs NL 5[3-8]. In adjusted analyses including those variables that differed significantly by country (i.e. patient age, family age, length of relationship), the items, “patient was touched and hugged by loved ones” and “saying goodbye to loved ones” were no longer significantly different (Table 2).

Nurses’ Scores on Individual QODD Items

Out of the 22 items, 12 were significantly different in unadjusted analysis between NL and the US, with 8 items rated higher in the US and 4 items rated higher in NL. Items that were rated as having significantly higher quality for nurses in the US included ratings about the patient having control, feeding him/herself, laughing or smiling, spending time alone and with family, saying goodbye, and the presence of a spiritual advisor or service (Table 3). Ratings that were significantly higher when rated by the nurses in the NL included having had discussions about EOL wishes with a physician, being on a ventilator, having someone present at the moment of death, and the single item QODD-1 ($p < 0.0020$). In the adjusted analyses in which we controlled for patient’s age, the items “discussed end-of-life wishes with doctor” and ”experience of mechanical ventilation” were no longer significantly different. The significance of the other ten items remained.

Discussion

To the best of our knowledge, this is the first study reporting on the similarities and differences between family and nurse ratings of the quality of dying and death for patients dying in the ICU in the Netherlands and the US. We examined responses from families of 446 ICU patients and found that, despite organizational, cultural and social differences between these countries, family-assessments were similar across the two countries. Only 3 of the 22 answered items were significantly different between countries and overall ratings, whether assessed with a single rating item or a total score, did not vary. This similarity persisted independent of whether analyses were adjusted for differences in patient and family demographics that have been linked to differing QODD ratings. Importantly, family ratings of experiences that were identified as critically important to a good death, like good symptom control and the delivery of timely and accurate information,[32,33] did not differ between the two countries. There was a difference between family ratings of the quality of "patient time spent with his/her loved ones", which was rated higher by families in the US. This is an important finding since previous studies have suggested the importance of this item when evaluating EOL care.[32,33] This may be an area in which the Dutch ICUs have room for improvement by increasing or facilitating family presence, such as with more open visiting policies.[34] On the other hand, the families from the NL scored higher on the item "saying goodbye to loved ones" suggesting this might be reflection of a cultural difference but maybe also a target for interventions in the US by stimulating family members to express their feelings.

We used an instrument validated in the US to measure quality of dying in the Netherlands. The similarities between the answers of the family members in the US and NL suggests the applicability of the instrument in the NL, although we have previously shown that Dutch family members judged the questionnaire difficult and a few items as irrelevant. This finding has led to an initiative to adapt the questionnaire for European use. A joint Danish-Dutch project called "the euroQ2" is currently developing and validating such an adaption of the QODD and also of the family satisfaction with ICU care (FS-ICU).[24]

In this study, we also examined nurse ratings of the quality of dying and death for patients. In contrast to family assessments, nurse scores varied significantly between the two countries. To our knowledge, few data are available assessing nurses' experiences in different countries except for a study of differences in the quality of nurse handover.[35] The current differences in QODD ratings may be associated with organizational differences. For example, in the Netherlands, an intensivist is always present in the ICU, which might help address symptoms earlier. Indeed, higher symptom control ratings may reflect this responsiveness.[33] Additionally, nurses in Dutch ICUs may play a more active role in the decision-making process including EOL decisions.[36] A prior report from Sweden found that nurses' experiences of inappropriate care, a known stressor for nursing staff, may occur less often with this direct involvement of nursing staff in decision making.[37,38] There may also be important differences in expectations of nurses in different countries that may influence ratings.[39] Lastly, the QODD differences may reflect a cultural difference between the two countries, in either the care delivered or the expectations of nurses about the care delivered.[40]

We report two approaches to providing an overall rating of the quality of dying, a single item summary score and a total score using the average of 22 items. Interestingly, these two approaches yielded different summaries of the differences in nurse ratings between the Netherlands and the US. There may be important limitations in using an average score for multiple items if those items don't have a unidimensional domain structure.[16,39] The single item rating may provide a more reliable summary rating, but further work is needed before this measure is ready for use as a primary outcome of intervention studies.[16]

Our study has several limitations. First, data collection was not specifically planned for the purpose of comparing the quality of dying and death between these two countries, and therefore was not collected in identical ways. For example, family members from the US independently filled out a mailed questionnaire without assistance whereas family members in the NL were offered assistance by telephone when filling in their questionnaires. The questions asked were the same, but some research suggests that response mode, particularly regarding sensitive topics, may alter response patterns.[41,42] Despite these cautions, we think a comparison between the data from the US and NL is feasible since our sample criteria and measures were the same. Second, in the US sample, nurses graded the quality of care for more than a single patient. However, clustered analysis showed that findings were robust. Third, we did not look at several factors that may have influenced QODD scores such as admission from the emergency department versus the acute care hospital,[43] and attending physicians' specialty.[44] These factors may have influenced the QODD, and we cannot rule out that these factors may have played a role in our findings. Fourth, the differences in timing of administering the questionnaire to families, three weeks in the NL and four to six weeks in the US, and, to a lesser extent, a one day difference in time given to nurses might have biased our results. It was shown previously that timing of interviewing bereaved people affects the obtained results.[42] However, a randomized trial suggests no difference between 2 and 6 weeks and the similarities between family ratings in NL and US make this less of a concern.[45] Fifth, the QODD has been validated in the US but not in the Netherlands, so some of the differences we found may reflect differences in validity of the tool in different cultures, as well as the difference end-of-life care, such as availability of palliative care consultation in ICUs between US and NL. An European initiative to establish the use of palliative care consultation in ICUs is starting this year. Finally, some of the items had a high number of missing data, which introduce the risk of non-responder bias.[24]

In conclusion, the quality of dying and death as perceived by families of patients dying in ICUs in the Netherlands and the US is similar, and seem to be rated relatively high. In contrast, nurses from these two countries provided significantly different ratings, which might be attributed to organizational or cultural differences between countries and may also reflect differences in perceptions and expectations. Further studies are needed to understand differences between countries in ratings of quality of end-of-life care. In the meantime, this study identifies some potential targets to improve EOL care in both US and NL. These targets could be used to explore and evaluate interventions to improve end-of-life care.

Table 1. Patient and family characteristics in participating centers

	All	NL	U.S.	P-value
Number of patients	446	100	346	
Age, mean (SD)	66 (15.2)	72 (10.2)	65 (16)	<0.01
Male, n(%)	286 (64.1)	66 (66.0)	220 (63.6)	0.72
LOS-ICU (days) median[IQR]	6 [3-13]	8 [3-16]	6 [3-12]	0.228
LOS-hosp (days)median [IQR]	9 [5-18]	11 [4-26]	9 [5-16]	0.282
Living together, n(%)	257 (59.6)	61 (68.5)	196 (56.6)	0.09
Years known, mean (SD)	41 (15.4)	45.2 (12.9)	40 (15.8)	<0.01
Family age, mean(SD)	57 (14.3)	61 (13.7)	57 (14.3)	<0.01

Data presented as mean (SD), numbers (%) or median [IQR] according their distribution
$p<0.05$ considered statistically significant
LOS=length of stay, ICU=intensive care unit, hosp=hospital
Differences between groups are tested with Student t test, X^2 test or
Mann Whitney U test whenever appropriate.

Table 2. Family responses of patients who stayed ≥ 48 hours in the ICU

Questions (% valid responses)	**All (n=446) Median [IQR]**	**Netherlands (n= 100) Median [IQR] (% valid responses)**	**U.S.(n=346) Median [IQR] (% valid responses)**	**Unadjusted P ***	**Adjusted P ****
Had control of pain (81%)	8[6-9]	8[5.75-8.25](87%)	8[6-9](89%)	0.813	
Had control over what was going on around him/her (81%)	7[3-9]	7[4.5-8] (87%)	7[3-9](88%)	0.956	
Was able to feed him/herself (78%)	5[2-8]	6[3-8](74%)	5[1-9](82%)	0.535	
Breathing comfortably (84%)	5[2-8]	6[4-7] (84%)	5[1-8](89%)	0.373	
Felt at peace with dying (52%)	7[3-9]	7[5-8](86%)	7[3-9](57%)	0.919	
Was unafraid of dying (50%)	7[4-9]	8[5-9](88%)	7[3-9](56%)	0.621	
Laughed and smiled (77%)	5[1-7]	5[2-7](79%)	4[1-7.5](80%)	0.178	
Maintained dignity and self-respect (84%)	7[3-9]	7[3-8.25](89%)	8[3-9](80%)	0.243	
Spent time with family (77%)	8[5-10]	4.5[2-7](82%)	8.5[5-10](88%)	**<0.001**	**<0.001**
Bad feelings spoken out(60%)	5[2-9]	5[2-7.5](73%)	5[2-9](61%)	0.074	
Spent time alone (78%)	6[3-9]	4[2-6](83%)	7[4-9](85%)	**<0.001**	**<0.001**
Was touched and hugged by loved ones (89%)	9[8-10]	8[8-9](88%)	9[8-10](89%)	0.010	0.650
Said goodbye to loved ones (78%)	5[1-8]	5[3-8](85%)	4[0-8](77%)	0.007	0.030
Had visits from spiritual advisor (72%)	8[5-10]	8[5.5-9](68%)	8[5-10](81%)	0.086	
Spiritual service or ceremony before death (68%)	8[5-10]	8[6.5-9](64%)	8[5-10](75%)	0.173	
Had funeral arrangements in order (83%)	7[4-9]	8[6-9](75%)	6[3-9](85%)	0.078	
Discussed end-of-life wishes with doctor (75%)	7[4-9]	[5.5-8.5](74%)	6[4-9](78%)	0.941	
Experience of mechanical ventilation as an aspect of dying (88%)	7[2-9]	7[3-8](87%)	6[2-9](88%)	0.799	
Experience of dialysis (54%)	8[5-10]	8[5-9](56%)	7[5-10](54%)	0.983	
Was anyone present at the moment of death? (86%)	9[8-10]	9[8-10](85%)	9[7-10](86%)	0.134	
State before death (83%)	8[5-10]	8[5-9](87%)	8[4-10](82%)		
Single item QODD-1 (93%)	8[6-9]	9[8-10](89%)	8[5-10](95%)	0.309	
Total QODD***	6.6[4.9-8.0]	6.6[5.3-7.6]	6.6[4.9-8.0]	0.390	

Differences tested by Mann Whitney U

P for significance: <0.0020

*univariate analysis

**multivariate regression analysis (ANOVA, backward method) including the following confounders: patient age, family age, length of relationship .

*** total QODD is numeric sum of scores of all questions administered in both countries divided by number of questions answered

Table 3. Nurses’ responses of patients who stayed ≥ 48 hours in the ICU

Questions (% valid responses)	All (n=446) Median [IQR]	Netherlands (n= 100) Median [IQR] (% valid responses)	U.S.(n=346) Median [IQR] (% valid responses)	Unadjusted P *	Adjusted P **
Had control of pain (86%)	8[7-9]	8[6-9](73%)	8[7-9](90%)	0.535	
Had control over what was going on around him/her (69%)	5[1-7]	1[0.5-8](63%)	5[2-7.5](71%)	**<0.001**	**<0.001**
Was able to feed him/herself (59%)	2[0-5]	0[0-0](69%)	4[0-5](57%)	**<0.001**	**<0.001**
Breathing comfortably (87%)	7[5-9]	6[2.5-7.5](71%)	7[4-9](92%)	0.301	
Felt at peace with dying (51%)	8[5-9]	9[5-9](39%)	8[36-9](55%)	0.706	
Was unafraid of dying (41%)	8[5-9]	7[3.5-8](33%)	8[5-9](43%)	0.015	0.020
Laughed and smiled (53%)	3[0-5]	0[0-5.5](50%)	4[1-6](54%)	**<0.001**	**<0.001**
Maintained dignity and self-respect (74%)	8[5-9]	8[5-8](53%)	8[5-9](80%)	0.623	
Spent time with family (78%)	9[7-10]	6[0-8](39%)	9[7-10](90%)	**<0.001**	**<0.001**
Bad feelings spoken out(30%)	2[0-5]	0[0-5](34%)	3[0-5](28%)	0.009	0.020
Spent time alone (61%)	7[4-9]	1.5[0-5](30%)	7.5[5-9](69%)	**<0.001**	**<0.001**
Was touched and hugged by loved ones (91%)	9[8-10]	9[8-10](88%)	9[8-10](91%)	0.315	
Said goodbye to loved ones (60%)	5[0.25-8]	0.5[0-7](52%)	5[1-9](62%)	**0.001**	**0.001**
Had visits from spiritual advisor (67%)	8[4-10]	0[0-8](71%)	8[6-10](65%)	**<0.001**	**<0.001**
Spiritual service or ceremony before death (59%)	7[1-10]	0[0-7](80%)	8[5-10](54%)	**<0.001**	**<0.001**
Discussed end-of-life wishes with doctor (47%)	6[3.5-9]	8[5-10](41%)	5.5[3-9](49%)	**0.002**	0.009
Experience of mechanical ventilation as an aspect of dying (85%)	7[5-9]	8[6-9.75](80%)	7[5-8](87%)	**0.002**	0.010
Patient kept alive too long, yes N(%)***	77(24%)	64(30%)	13(13%)	**<0.001**	0.021
Experience of dialysis (40%)	8[5-9]	9[7-10](43%)	8[5-9](39%)	0.022	0.110
Right amount sedation (95%)	9[7-9]	9[8-10](81%)	8[7-9](98%)	0.240	
Was anyone present at the moment of death? (80%)	9[8-10]	10[9-10](95%)	9[8-10](76%)	**0.001**	**0.001**
State before death (96%)	9[8-10]	9[8-10](94%)	9[7-10](98%)	0.004	0.040
Single item QODD-1 (99%)	7[6-9]	9[8-10](99%)	7[5-8](99%)	**<0.001**	**<0.001**
Care health professional (98%)	9[8-9]	9[8-10](99%)	9[8-9](98%)	0.110	
Care doctors (98%)	9[8-9]	9[8-10](99%)	9[7-9](98%)	0.200	
Total QODD****	6.9[5.7-8.3]	6.5[5.7-8.3]	7.1[5.8-8.4]	0.013	0.014

Differences tested by Pearson Chi-Square or Mann Whitney U when applicable

P for significance: <0.0020

* univariate analysis

** multivariate regression analysis (ANOVA, stepwise backward method) including the following confounder: patients’ age

*** kept alive too long is a yes/no question, so a Median(IQR) cannot be reported

**** total QODD is numeric sum of scores of all questions administered in both countries divided by number of questions answered

References

1. McAdam JL, Puntillo K. Symptoms experienced by family members of patients in intensive care units. Am J Crit Care 2009;18(3):200-9; quiz 10.

2. Connor SR, Teno J, Spence C, Smith N. Family evaluation of hospice care: results from voluntary submission of data via website. J Pain Symptom Manage 2005;30 (1):9-17.

3. Connor SR, Tecca M, LundPerson J, Teno J. Measuring hospice care: the National Hospice and Palliative Care Organization National Hospice Data Set. J Pain Symptom Manage 2004;28(4):316-28.

4. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. Chest 2005;127(5):1775-83.

5. van der Klink MA, Heijboer L, Hofhuis JG, et al. Survey into bereavement of family members of patients who died in the intensive care unit. Intensive Crit Care Nurs 2010;26(4):215-25.

6. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med 2007; 35(2):605-22.

7. Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. Chest 2008;133(3):704-12.

8. Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med 2007; 356(5): 469-78.

9. Curtis JR, Treece PD, Nielsen EL, et al. Randomized Trial of Communication Facilitators to Reduce Family Distress and Intensity of End-of-Life Care. Am J Respir Crit Care Med 2016 ;193(2):154-62.

10. Carson SS, Cox CE, Wallenstein S, et al. Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness: A Randomized Clinical Trial. JAMA 2016(1);316:51-62.

11. Curtis JR, Back AL, Ford DW, et al. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. JAMA 2013;310(21):2271-81.

12. Azoulay E, Pochard F. Communication with family members of patients dying in the intensive care unit. Curr Opin Crit Care 2003;9(6):545-50.

13. Sprung CL, Cohen SL, Sjokvist P, et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA 2003;290(6):790-7.

14. Sprung CL, Carmel S, Sjokvist P, et al. Attitudes of European physicians, nurses, patients, and families regarding end-of-life decisions: the ETHICATT study. Intensive Care Med 2007;33(1):104-10.

15. Bekelman JE, Halpern SD, Blankart CR, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. JAMA 2016;315(3):272-83.

16. Curtis JR, Downey L, Engelberg RA. The quality of dying and death: is it ready for use as an outcome measure? Chest 2013;143(2):289-91.

17. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002;24(1):17-31.

18. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. J Pain Symptom Manage 2010;39(1):9-22.

19. Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. Annals Intern Med 2003;139(5Pt2):410-5.

20. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. J Pain Symptom Manage 2001;22(3):717-26.

21. Wunsch H, Linde-Zwirble WT, Harrison DA, Barnato AE, Rowan KM, Angus DC. Use of intensive care services during terminal hospitalizations in England and the United States. Am J Respir Crit Care Med 2009;180(9):875-80.

22. Vincent JL, Berre J, Creteur J. Withholding and withdrawing life prolonging treatment in the intensive care unit: a current European perspective. Chron Respir Dis 2004;1(2):115-20.

23. White DB, Curtis JR. Care near the end-of-life in critically ill patients: a North American perspective. Curr Opin Crit Care 2005;11(6):610-5.

24. Gerritsen RT, Hofhuis JG, Koopmans M, et al. Perception by family members and ICU staff of the quality of dying and death in the ICU: a prospective multicenter study in The Netherlands. Chest 2013;143(2):357-63.

25. Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR. Factors associated with nurse assessment of the quality of dying and death in the intensive care unit. Crit Care Med 2004;32(8):1648-53.

26. Curtis JR, Nielsen EL, Treece PD, et al. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: a randomized trial. Am J Respir Crit Care Med 2011;183(3):348-55.

27. Curtis JR, Treece PD, Nielsen EL, et al. Integrating palliative and critical care: evaluation of a quality-improvement intervention. Am J Respir Crit Care Med 2008;178(3):269-75.

28. Engelberg RA. Measuring quality of dying and death: Methodological considerations and recent findings. Curr Opin Crit Care 2006;12(5):381-7.

29. Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the Quality of Dying and Death. J Pain Symptom Manage 2004;28(4):306-15.

30. Mularski RA, Dy SM, Shugarman LR, et al. A systematic review of measures of end-of-life care and its outcomes. Health services research 2007;42(5):1848-70. 2254566

31. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. Chest 2005;128(1):280-7.

32. Heyland DK, Rocker GM, , O'Callaghan CJ, Dodek PM, Cook DJ. Dying in the ICU: perspectives of family members. Chest 2003;124(1):392-7.

33. Clark K, Cain J, Campbell L, Byfieldt N. Caring for people dying in acute hospitals: A mixed-methods study to examine relative's perceptions of care. Palliat Support Care 2015;13(2):335-43.

34. Kodali S, Stametz RA, Bengier AC, Clarke DN, Layon AJ, Darer JD. Family experience with intensive care unit care: association of self-reported family conferences and family satisfaction. J Crit Care 2014;29(4):641-4.

35. Ganz FD, Endacott R, Chaboyer W, et al. The quality of intensive care unit nurse handover related to end of life: a descriptive comparative international study. Int J Nurs Stud 2015;52(1):49-56.

36. Yaguchi A, Truog RD, Curtis JR, et al. International differences in end-of-life attitudes in the intensive care unit: Results of a survey. Arch Intern Med 2005;165(17):1970-5.

37. De Villers MJ, DeVon HA. Moral distress and avoidance behavior in nurses working in critical care and noncritical care units. Nurs Ethics 2013;20(5):589-603.

38. Fridh I. Caring for the dying patient in the ICU--the past, the present and the future. Intensive Crit Care Nurs 2014;30(6):306-11.

39. Curtis JR, Downey L, Engelberg RA. The importance and challenge of measuring family experience with end-of-life care in the ICU. Intensive Care Med 2016;42(7):1179-81.

40. Ramos KJ, Downey L, Nielsen EL, et al. Using Nurse Ratings of Physician Communication in the ICU To Identify Potential Targets for Interventions To Improve End-of-Life Care. J Palliative Med 2016;19(3):292-9.

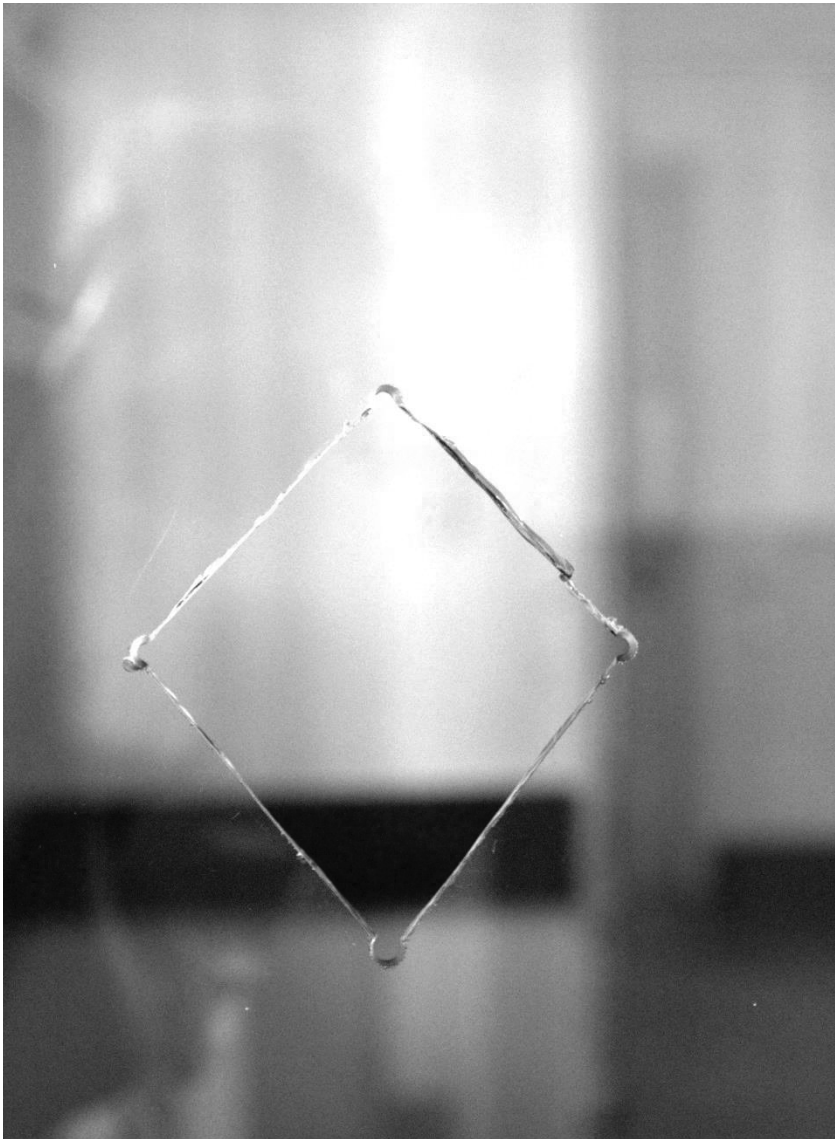
41. Gwaltney CJ, Shields AL, Shiffman S. Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. Value Health 2008;11(2):322-33.

42. Bentley B, O'Connor M. Conducting research interviews with bereaved family carers: when do we ask? Journal of palliative medicine 2015;18(3):241-5. PMC4348368

43. Long AC, Kross EK, Engelberg RA, et al. Quality of dying in the ICU: is it worse for patients admitted from the hospital ward compared to those admitted from the emergency department? Intensive Care Med 2014;40(11):1688-97. PMC4350659

44. Kross EK, Engelberg RA, Downey L, et al. Differences in end-of-life care in the ICU across patients cared for by medicine, surgery, neurology, and neurosurgery physicians. Chest 2014;145(2):313-21.

45. Casarett DJ, Crowley R, Hirschman KB. Surveys to assess satisfaction with end-of-life care. Does timing matter? J Pain Symptom Manage 2003;25(2):128-32.



5

Families' experiences of ICU quality of care: development and validation of a European questionnaire

The euroQ2 project

Jensen HI, Gerritsen RT, Koopmans M, Zijlstra JG,
Curtis JR, Ørding H

J Crit Care 2015 Oct; 30(5):884-890

Abstract

Purpose

To adapt and provide preliminary validation for questionnaires evaluating families' experiences of quality of care for critically ill and dying patients in the ICU.

Materials and Methods

This study took place in two European ICUs. Based on literature and qualitative interviews we adapted two previously validated North American questionnaires: "Family Satisfaction with the ICU" (FS-ICU) and "Quality of Dying and Death" (QODD). Family members were asked to assess relevance and understandability of each question. Validation also included test-retest reliability and construct validity.

Results

A total of 110 family members participated. Response rate was 87%. For all questions a median of 97% (94-99%) were assessed as relevant and a median of 98% (97-100%) as understandable. Median ceiling effect was 41% (30-47%). There was a median of 0% missing data (0-1%). Test-retest showed a median weighted kappa of 0.69 (0.53-0.83). Validation showed significant correlation between total scores and key questions.

Conclusions

The questions were assessed as relevant and understandable, providing high face and content validity. Ceiling effects were comparable to similar instruments, missing data low and test-retest reliability acceptable. These measures are promising for use in research, but further validation is needed before they can be recommended for routine clinical use.

Introduction

Most patients admitted to ICU are critically ill, and 10-15% of the patients die in the unit [1, 2]. For health care professionals, the high-technology environment becomes commonplace, but for families this is a new and uncertain world [3]. Families often see their role as guardian and protector of the patient, but they also have needs of their own. They need support to cope with the uncertainty and need complete information to be able to understand what is going on and how to navigate in the ICU [4]. The strains experienced by families during an ICU stay may subsequently lead to posttraumatic stress syndrome (PTSD) and depression [5-8]. Care that also takes the needs of families into account is therefore very important, but to be able to offer family-centered care it is necessary to understand families' experiences [9].

A Canadian questionnaire (FS-ICU) which examines families' general satisfaction with intensive care [9, 10] and an American questionnaire which examines families' rating of the quality of dying and death (QODD) [11, 12] have been developed and validated. The QODD questionnaire has been used in a Dutch study [13], but a high percentage of not-relevant or missing responses suggested that the questionnaire is not automatically transferable to European ICU environments.

The overall goal of this study was to adapt and validate a questionnaire to evaluate families' experiences of quality of care for critically ill and dying patients in the ICU based on the FS-ICU and the QODD and adapted to Northern European environments. The questionnaire, combining both a European FS-ICU and a European QODD, was named "euroQ2" (European Quality Questionnaire). Our specific aims were to a) pilot-test the instrument with family members, intensivists, ICU nurses, and questionnaire experts and then to b) examine the responses from family members of patients in the ICU to assess the distribution of response, the proportion of missing values, the content validity, and the construct validity of the euroQ2.

Materials and Methods

The euroQ2 incorporates issues identified as the most important by family members as well as an opportunity to add qualitative comments about issues not addressed in the questionnaire. The euroQ2 consists of two components: Satisfaction with care measured with the adapted FS-ICU for family members of all patients in the ICU and quality of dying and death measured with the adapted QODD for family members of patients who died in the ICU. The adapted questionnaires will be referred to as euroFS-ICU and euroQODD, respectively.

Setting

The study took place in two ICUs. The Danish ICU was a general ICU from a 300 bed regional hospital with 8 ICU beds, 1 intermediary care bed and 14 recovery beds and receives mainly patients from medical and surgical specialities. The Dutch ICU was a medical-surgical ICU from an 800 bed university affiliated hospital with 22 ICU beds and admits surgical, trauma, medical and cardiothoracic patients.

Study design

The study included a pilot-test phase and a validation phase. Prior to pilot-testing, we adapted the FS-ICU and QODD based on results from the Dutch pre-study [13], results from serial, semi-structured interviews with 8 family members of Danish ICU patients, and previously published research on the experiences of the family of critically ill patients. This adaptation phase was conducted from January to August 2013 and resulted in an initial draft of the euroQ2 in English. An overview of the adaptions can be found as supplementary material.

Inclusion criteria

Family members of patients admitted to the ICU for 48 hours or more. Up to three family members per patient could participate. Family members were defined as the persons closest to the patient (as defined by the patient), including partners, siblings, children, parents and friends. If there were more than three family members who wanted to participate the family members themselves decided who it should be, based on who had spent most time in the ICU.

Exclusion criteria

Family members under the age of 18, family members with cognitive impairment, and family members not able to read or write Danish or Dutch.

Pilot-testing phase

The initial draft of euroQ2 was reviewed by 2 family members, 5 nurses, 4 intensivists, and 2 questionnaire experts from both Denmark and The Netherlands. For each item feedback was obtained about the clarity, relevance, and acceptability (is the question phrased in an acceptable way or is it e.g. condescending or value-laden). After adjustments (please see supplementary material for details) based on the feedback, the final draft was discussed with and approved by one of the developers of the FS-ICU and QODD (JRC) and then translated into Danish and Dutch. In both countries the translation process consisted of two-way translations (the questionnaire was translated from English to Danish (and likewise to Dutch) by 2 persons fluent in both languages and then back from Danish by two others fluent in both languages but without knowledge of the original English version), discussion of the different versions in a research group and consensus decision on which phrasings were correct in Danish (and likewise in Dutch). The questionnaire was then evaluated qualitatively in both Denmark and The Netherlands by family members (six from each country). The family members filled in the questionnaire, assessed for each question whether they found it relevant and/or understandable, and were interviewed subsequently about overall assessment of the questionnaire: if there were important areas missing, if the information was adequate, and how they understood each question. After the pilot-testing phase the euroFS-ICU consisted of 20 questions and 2 options for providing comments (compared to 27 questions and 3 options to provide comments in the FS-ICU) [9]. Ten of the questions were identical, 5 were partially different, and 5 were completely different from the FS-ICU. The euroQODD consisted of 15 questions and 1 option for providing comments (compared to 47 questions in the QODD) [11]. Six questions were almost identical; the others different from the QODD. The pilot-testing phase was conducted from February to November 2013. A copy of the euroQ2 (euroFS-ICU and euroQODD) is available as supplementary material.

Validation Phase

The aim of this phase was to quantitatively validate the euroQ2 in regard to distribution of responses, the proportion of missing values, the content validity (do the questionnaires reflect the areas that are essential to clarify the purpose of the questionnaires), and the construct validity (the extent to which the questionnaires measure the expected concepts) of the two measures. In this phase 55 family members from the Danish ICU and 55 family members from the Dutch ICU participated. As in the pilot-testing phase the participants were asked to assess relevance and understandability for each question. They also filled in the Hospital Anxiety and Depression Scale (HADS) [14] and the revised Impact of Event Scale (IES-R) [15]. There already existed validated Danish and Dutch versions of the HADS and a Dutch version of the IES-R. A two-way translation with consensus discussion (as described above) was conducted for a Danish IES-R version. While still at the ICU the families were asked by the patients' nurse or physician whether they wanted to take part in the study and were provided with written information (please see supplementary material). If the family members agreed to participate they were asked to fill in a form with name, address and phone number. Three weeks after the patient either died or was discharged from the ICU the questionnaire (together with an accompanying letter and a prepaid envelope) was mailed to family members. If the questionnaire was not returned after two weeks the participants were contacted by phone and asked to return the questionnaire. All returned questionnaires were included in the analyses independently of when they were returned. To get an indication of test-retest reliability, questionnaires were sent two weeks after a questionnaire was returned until 10 completed questionnaires were collected in each country. For the participating families the following patient data were obtained from the medical record: gender, age, medical or surgical speciality of the admitting physician, diagnosis, length of stay in the ICU, any withholding or withdrawal decisions, APACHE II (Acute Physiology and Chronic Health Evaluation) [16], SAPS (Simplified Acute Physiology Score) [17] and SOFA (Sepsis-Related Organ Failure Score) scores [18]. The validation phase was conducted from December 2013 to July 2014.

Scoring

For correlation analyses Likert scale responses in the euroFS-ICU were transformed to a 0-100 scale according to the FS-ICU scoring [9, 10] and one single question. “When major decisions were made, did you have adequate time to have your concerns addressed and questions answered?” were transformed as 100 for yes and 0 for no. A total score for the euroFS-ICU was calculated as means of individual item scores provided that the respondents had answered more than 70% of the items included [9]. The euroQODD consists of more diverse response categories and therefore correlation analyses were based on a single item response of overall assessment of care (scale from 0-10) transformed to a 0-100 scale and a key question: “End-of-life care according to wishes" transformed as 100 for yes, 50 for partially and 0 for no.

HADS scores were divided into four categories: none (0-7), mild (8-10), moderate (11-15) and serious (16 or above) [14] and the IES-R scores into averages of three domains (intrusion, avoidance and hyper-arousal) on a scale from 0 to 4, where 4 is the worst possible. The IES-R has no cut-off points [15].

Data analyses

Statistical analyses were conducted using Stata 13 and SPSS 18. For comparing background characteristics of Danish and Dutch family members and patient data we used Students T-test, Chi2 or Fischers exact test, or Mann-Whitney U-test as appropriate. Descriptive statistics were used to present distribution of responses, proportion of missing data and content validity. Weighted kappa was used for test-retest reliability analysis. Total score of the euroFS-ICU and single item overall care score from the euroQODD were not normally distributed. Correlation analyses were therefore conducted based on the non-parametric Spearman's rank correlation coefficients. Cluster effect was checked by conducting Spearman's rank correlation analyses with one family member per patient and with Pearson's correlation with cluster option (adjusting for more than one family member per patient). Based on FS-ICU and QODD literature [9, 12] we hypothesised that higher total euroFS-ICU score would correlate with higher scores on two key questions (Concern and caring by ICU staff and overall quality of information). For the euroQODD we hypothesised a higher score of overall assessment of care would correlate with higher scores of key question (End-of-life care according to wishes) and with higher total euroFS-ICU score. Furthermore we hypothesised that higher total euroFS-ICU scores and higher euroQODD overall care score would correlate with lower levels of anxiety, depression and posttraumatic stress symptoms. $P < 0.05$ was considered significant for all analyses.

Ethics

In Denmark, the project was registered with the Danish Data Protection Agency and permission to register patient data without consent from the patients was obtained from the Danish Health and Medicine Authority (3-3013-353/1/1/). In The Netherlands the IRB (RTPO-MCL) approved the study and granted a waiver of informed consent (TPO 706).

Results

Pilot-testing phase

All participants in the qualitative pilot test had understood all of the items, all considered the questions relevant, and none identified domains or items that were missing. No items were removed, but we made some adjustments to phrasing according to suggestions from the participants, especially for questions about involvement in decision-making, and, after discussion of these results, two questions about the role the families experienced they had and wanted to have had in end-of-life decision-making were added. These two questions were pilot tested among 4 family member and 10 staff before the validation phase.

Validation phase

Of the total 110 responses (55 from each country), 37 were from family members of patients who died in the ICU. Participation rate was 87%; for the euroFS-ICU questionnaire only (family members of discharged patients) the rate was 83% and for the combined euroFS-ICU and euroQODD (family members of patients who died in the ICU) the rate was 95%. Figure 1 shows participation rates from both countries

Table 1 provides an overview of background characteristics of participating family members and their relatives (the patients). Due to the ICU differences (regional versus university affiliated), the reasons for admissions differed between the ICUs, and the Dutch patients had significantly higher SAPS and SOFA scores and a higher percentage of patients being mechanically ventilated.

Distribution of responses

Table 2 shows main results regarding the quality of care from the euroFS-ICU. The areas getting the lowest scores were connected with symptom management, information (consistency and overall quality), and decision-making. Of family members who felt that inclusion in the decision-making process was not good, 11 had answered the question about why. Forty-three % felt they had been included too much (all from Denmark) and 64% felt they had not been included enough.

There was a tendency for family members of patients who died in the ICU to assess quality of care higher than those of patients who survived. There were no significant differences between the two groups except for “Presence at bedside” (p=0.02) and “Consistency of information” (p=0.02).

Table 3 presents results from the euroQODD. These items were only completed by family members of patients who died in the ICU and show lower ratings for “Comfort on the ventilator” and for “Discussion of preferences before and in the ICU” than for other categories.

The median ceiling percentage (the percentage of responses in the highest category for ordinal response scales (“Excellent” and “All the time”)) for both measurements was 41 (30-47)median floor percentage was 0 (0-1). Median percentage of missing data for all questions was 0 (0-1).

Content validity and Test-retest reliability

For the euroFS-ICU, the median assessments of the questions being relevant and understandable were 98% (96-99%) and 98% (97-

99%), respectively. For the euroQODD, the median assessments of relevance and understandability were 97% (92-100%) and 97% (94-100%), respectively. The average test-retest agreement for the Likert scale responses in the euroFS-ICU was 0.69 (0.53-0.83).

Construct validity

The median total euroFS-ICU score was 82.9 (69.7-92.1); for family members of discharged patients 81.9 (65.8 – 90.8) and for family members of patients who died in the ICU 86.8 (73.6-92.1) (p=0.37). The median overall quality of care euroQODD was 90 (80-100).

Table 4 presents correlation analyses. The euroQODD was significantly correlated with the euroFS-ICU. The euroFS-ICU key questions correlated significantly with total score, as did the overall care euroQODD, but the euroQODD key question (end-of-life according with wishes) did not significantly correlate with overall rating of care.

With limitation of the analyses to include only one family member for each patient, results were essentially the same suggesting that the results were not affected by a lack of independence of observations.

A total of 21% of family members had moderate/serious symptoms of anxiety and 10% had moderate/serious symptoms of depression 3 weeks after ICU discharge or death. Median levels of posttraumatic stress symptoms were 1.3 (0.6-2) for intrusion, 0.6 (0.3-1) for avoidance, and 0.7 (0.2-1.5) for hyper-arousal. No significant correlation was found between the overall euroFS-ICU score or the euroQODD score and levels of anxiety, depression or posttraumatic stress symptoms.

Discussion

The present study describes the initial validation of two measures adapted for a European context and provides information about both European families' satisfaction with ICU care and their ratings of the quality of dying in the ICU. The total euroFS-ICU score was similar to prior studies using the FS-ICU [9, 19]. The median overall euroQODD care score was higher than in a North American intervention study [19] but similar to the Dutch pre-study [13].

Overall, family members assessed the quality of care fairly high, but there is room for improvement especially regarding symptom management, information (consistency and overall quality), and the decision-making process. As found in other studies [20], families of discharged patients seemed less satisfied with ICU care and had a tendency to higher level of anxiety after the ICU stay compared to families of patients dying in the ICU. This shows that focus on the needs of all family members, not only family of dying patients, is mandatory in order to improve quality of care and decrease negative impact on post-ICU quality of life.

Questionnaire methodology experts recommend that response scales are balanced with equal positive and negative options [21]. Most of the scales in the FS-ICU range from Excellent, Very good, Good, Fair, Poor, and Not Applicable and are therefore not balanced [10]. Nonetheless, we kept the 5 category responses because it is the standard response scale in the satisfaction and health status literature and because the "poor" category is rarely chosen. The median floor effect in this study was 0 showing that the “Poor” category was rarely used and the need for a “Very poor” category seems low. Also, very dissatisfied family members have the option of expressing their assessment in the open-ended questions.

The level of ceiling effect (table 2 and 3) in both the euroFS-ICU and the euroQODD were similar to other instruments [22, 23] but higher than recommended [21]. The high ceiling effect may entail less ability to discriminate and thereby less applicability for detecting improvements of interventions.

The low percentages of missing data in both the euroFS-ICU and the euroQODD support the questionnaire’s face and content validity in a European setting. For comparison, nine items were being left blank in more than 50% of the returned questionnaires when the original QODD was used in a Dutch setting [13]. Likewise, medians of 97-98% of questions being assessed as relevant and understandable in both the euroFS-ICU and the euroQODD emphasise a high content and face validity.

Our hypothesised correlations were found between key questions and the total euroFS-ICU score and between the euroFS-ICU and the euro-QODD, indicating construct validity. However, this needs to be tested in a larger sample. The lack of significant correlation between overall euroQODD score and end-of-life care according to wishes may be due to the small sample size or the question may not be applicable for testing construct validity. If for example the patient's wishes were to die at home, dying in an ICU would not be according to the patient's wishes, but overall rating of care could still be high. This correlation needs to be tested in a larger sample.

As shown in other studies [6, 7, 24], a substantial number of family members had symptoms of anxiety and depression and post traumatic stress-like symptoms 3-5 weeks after ICU death or discharge. Being a family member to an ICU patient makes a substantial impact also post-ICU, and this underlines the necessity of ICU care that also takes the needs of families into account. The hypothesised correlation between experiences of ICU care and level of symptoms were not found in this study, although a study by Azoulay et al [6] found a significant correlation. This may be due to the general high level of satisfaction in this study, to post-ICU symptoms of anxiety and depression and post-traumatic stress-like symptoms being influenced by a number of other factors, to cultural differences between France and Denmark/The Netherlands, or to the relatively small sample sizes in this study.

One of the differences between North America and Europe is the roles family members play in regard to decision-making [25]. In the US, family members are more likely to be involved in decisions about withholding and withdrawal of life sustaining treatment. This is less common in most European countries, where physicians are the legal decision-makers [25], even though also here there is a movement towards shared decision-making in Europe [26]. In the euroQ2 the questions about involvement in decision-making, both generally and in connection with end-of-life, have been those most commented on. Decision-making questions were rephrased to capture the families' experiences and wishes regarding involvement in major decision-making without leaving them with the impression that they had responsibility for the decisions themselves.

Strengths of the study included the high response rate, participation of family members from two countries, and the adaption based on two well-validated North American questionnaires.

The study had several limitations. First, there may be limitations in generalisability. This study was performed in areas where the majority is wealthy, Caucasian, protestant and well educated. The study was conducted at a single center in each of two countries and may not be representative for all Danish and Dutch family members. In addition, our results may not be generalisable to other regions such as Eastern or Southern Europe and adaptability to other regions will require further study. Second, although almost all family members being asked to participate did so, a substantial number of family members were not asked to participate in the study. When asking ICU staff why families had not been approached, the most common answer was that the staff had forgotten about the study. If this was the main reason, the risk of non-responders being different from the responders is probably less. If the ICU staff intentionally or unintentionally only invited family members who seemed satisfied, the results would be positively biased. However, in regard to the validation there is no plausible reason to believe that the level of satisfaction influences how the participants assessed the relevance and understandability of the questions. The test-retest was based on 20 participants which is less that the recommended 50 test-retest participants [27] and the results are therefore just an indication of the reliability of the euroQ2. Finally, further psychometric validation including item-response and factor analyses on a larger sample is needed for verification.

Conclusion

The euroQ2 (composed of euroFS-ICU and euroQODD) was assessed as relevant and understandable by family of critically ill patients, suggesting high face and content validity. Ceiling effect was high but comparable to similar instruments, the percentage of missing data was low, and test-retest reliability was acceptable. We identified significant correlation with constructs we hypothesized would be related to the euroFS-ICU and the euroQODD, suggesting construct validity. These findings suggest that these measures are promising for assessment of family satisfaction with care and family ratings of quality of dying in research. Further validation is needed before these measures are ready for use for quality assessment or clinical practice.

Funding

The study was founded by The Region of Southern Denmark and the Frisian ICU Research Fund. The funding bodies had no influence on the study or the paper.

References

1. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA 2003;290:790-7.

2. Jensen HI, Ammentorp J, Ording H. Withholding or withdrawing therapy in Danish regional ICUs: frequency, patient characteristics and decision process. Acta Anaesthesiol Scand 2011;55:344-51.

3. Agard AS, Harder I. Relatives' experiences in intensive care--finding a place in a world of uncertainty. Intensive Crit Care Nurs 2007;23:170-7.

4. Linnarsson JR, Bubini J, Perseius KI. A meta-synthesis of qualitative research into needs and experiences of significant others to critically ill or injured patients. J Clin Nurs 2010;19:3102-11.

5. Verceles AC, Corwin DS, Afshar M, Friedman EB, McCurdy MT, Shanholtz C, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Med 2014;40:1124-31.

6. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med 2005;171:987-94.

7. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest 2010;137:280-7.

8. Sundararajan K, Martin M, Rajagopala S, Chapman MJ. Posttraumatic stress disorder in close Relatives of Intensive Care unit patients' Evaluation (PRICE) study. Aust Crit Care 2014;27:183-7.

9. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Crit Care Med 2007;35:271-9.

10. Heyland DK, Tranmer JE. Measuring family satisfaction with care in the intensive care unit: the development of a questionnaire and preliminary results. J Crit Care 2001;16:142-9.

11. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002;24:17-31.

12. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. J Pain Symptom Manage 2010;39:9-22.

13. Gerritsen RT, Hofhuis JG, Koopmans M, van der Woude M, Bormans L, Hovingh A, et al. Perception by family members and ICU staff of the quality of dying and death in the ICU: a prospective multicenter study in The Netherlands. Chest 2013;143:357-63.

14. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale--a review of validation data and clinical results. J Psychosom Res 1997;42:17-41.

15. Weiss DS. The Impact of Event Scale: Revised. In: Wilson JP, Tang CS (ed) Cross-cultural assessment of psychological trauma and PTSD. New York: Springer; 2007, p 219-38

16. Campbell NN, Tooley MA, Willatts SM. APACHE II scoring system on a general intensive care unit: audit of daily APACHE II scores and 6-month survival of 691 patients admitted to a general intensive care unit between May 1990 and December 1991. J R Soc Med 1994;87:73-7.

17. Schuster HP, Schuster FP, Ritschel P, Wilts S, Bodmann KF. The ability of the Simplified Acute Physiology Score (SAPS II) to predict outcome in coronary care patients. Intensive Care Med 1997;23:1056-61.

18. Moreno R, Vincent JL, Matos R, Mendonca A, Cantraine F, Thijs L, et al. The use of maximum SOFA score to quantify organ dysfunction/failure in intensive care. Results of a prospective, multicentre study. Working Group on Sepsis related Problems of the ESICM. Intensive Care Med 1999;25:686-96.

19. Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE, et al. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: a randomized trial. Am J Respir Crit Care Med 2011;183:348-55.

20. Wall RJ, Curtis JR, Cooke CR, Engelberg RA. Family satisfaction in the ICU: differences between families of survivors and nonsurvivors. Chest 2007;132:1425-33.

21. Bowling A. Research Methods in Health. Investing Health and Health Services, 3 ed. Maidenhead: Open University Press; 2009, p 300-38.

22. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? Qual Life Res 1995;4:293-307.

23. Jensen HI, Ammentorp J, Erlandsen M, Ording H. End-of-life practices in Danish ICUs: development and validation of a questionnaire. BMC Anesthesiol 2012;12:16. doi: 10.1186/1471-2253-12-16.

24. McAdam JL, Dracup KA, White DB, Fontaine DK, Puntillo KA. Symptom experiences of family members of intensive care unit patients at high risk for dying. Crit Care Med 2010;38:1078-85.

25. Moselli NM, Debernardi F, Piovano F. Forgoing life sustaining treatments: differences and similarities between North America and Europe. Acta Anaesthesiol Scand 2006;50:1177-86.

26. Carlet J, Thijs LG, Antonelli M, Cassell J, Cox P, Hill N, et al. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. Intensive Care Med 2004;30(5):770-84.

27. Terwee CB, Bot SDM, de Boer MR, van der Windt DAWN, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007,60:34-42.

6

Satisfaction with quality of ICU care for patients and families

The euroQ2 project

Jensen HI, Gerritsen RT, Koopmans M, Downey L, Engelberg RA,
Curtis JR, Spronk PE, Zijlstra JG, Ørding H
Crit Care 2017 Sep 7;2191)239

Abstract

Background

Families' perspectives are of great importance in evaluating quality of care in the Intensive Care Unit (ICU). This Danish-Dutch study tested a European adaption of the "Family Satisfaction in the ICU" (FS-ICU). The aim of the study was to examine assessments of satisfaction with care from a large cohort of Danish and Dutch family members and to examine the measurement characteristics of the euroFS-ICU.

Methods

Data were from 11 Danish and 10 Dutch ICUs and included family members of patients admitted to the ICU for 48 hours or more. Surveys were mailed three weeks after patient discharge from the ICU. Selected patient characteristics were retrived from hospital records.

Results

A total of 1,077 family members of 920 ICU patients participated. Response rate for approached family members was 72%. "Excellent" or "Very good" ratings on all items ranged from 58-96%. Items with the highest ratings were concern toward patients, ICU atmosphere, opportunities to be present at the bedside, and ease of getting information. Items with room for improvement were management of patient agitation, emotional support of the family, consistency of information, and inclusion in and support during decision-making processes.

Exploratory factor analysis suggested four underlying factors, but confirmatory factor analysis failed to yield a multi-factor model with between-country measurement invariance. A hypothesis that this failure was due to misspecification of causal indicators as reflective indicators was supported by analysis of a factor representing satisfaction with communication, measured with a combination of causal and reflective indicators.

Conclusions
Most family members were moderately or very satisfied with patient care, family care, information and decision-making, but areas with room for improvement were also identified. Psychometric assessments suggest that composite scores constructed from these items as representations of either overall satisfaction or satisfaction with specific sub-domains do not meet rigorous measurement standards. The euroFS-ICU and other similar instruments may benefit from adding reflective indicators.

Keywords
Quality of care; ICU; family; satisfaction; questionnaire survey; FS-ICU

Background

In order to improve quality of care, the involvement of patients and their families in health care is a focal point in many countries (1). This involvement may extend to a variety of health care components, from participation in informed decision-making to the provision of feedback on care provided (2-4). In the Intensive Care Unit (ICU), although both patients' and families' experiences are of great importance (5), patient involvement is complicated by the patient's critical condition. Approximately 10-20 % die in the ICU (6-8) and a substantial percentage of surviving patients are too sick to be actively involved during their ICU stay, with many unable to remember their ICU experience altogether (9;10). Family members often spend considerable time in the ICU and their assessment of the quality of patient care correlates well with patients' assessments, making it reasonable to use family members to assess care for both the patient and family (11).

Families' assessments can be obtained in a number of ways, the most common being through interviews and self-administered questionnaires (12). Open-ended interviews and cognitive de-briefing techniques provide valuable, detailed information about individual experiences but generally rely on small samples. (12). By contrast, self-administered questionnaires that use a set of standard items allow a larger number of respondents to provide information, but they do not allow the same in-depth exploration as is afforded by qualitative methods. If such questionnaires are to provide accurate assessments of respondents' experiences, they must show evidence of strong psychometric characteristics, such as reliability, validity and responsiveness, to ensure that the items and the constructs they represent are appropriate for the populations with whom they are used (12).

A number of instruments are available to measure satisfaction and quality of care in the ICU and are designed to be completed by families of ICU patients (13). Two of the best known and well validated are the "Family Satisfaction in the ICU" (FS-ICU), looking at general satisfaction (13;14), and the "Quality of Dying and Death" (QODD), looking at quality of events that occur at the end of life (15;16). However, both were developed and validated in North America and, as cultural differences exist between North America and Europe (17), use of the instruments without cultural adaptation may decrease validity. Gerritsen and colleagues conducted a Dutch QODD study and found a high prevalence of "not applicable" responses and other missing data, suggesting a need for cultural adaptation (18). Therefore, in 2012, a Danish-Dutch study aimed at developing a European adaptation of both the FS-ICU and the QODD in a combined "European quality questionnaire" (euroQ2) was undertaken in collaboration with some of the North American developers of the FS-ICU and QODD (19). The first qualitative and quantitative components of the study showed high face and content validity, suggesting that the instrument may be promising for capturing European ICU families' experiences and assessments (19).

The goal of this component of the study was to examine assessments of satisfaction with care from a large cohort of Danish and

Dutch family members and to conduct a detailed examination of the measurement characteristics of the euroFS-ICU.

Methods

Settings

Participants came from 21 ICUs (11 from Denmark and 10 from The Netherlands) including both university affiliated and regional ICUs from different parts of the two countries.

Inclusion criteria

Family members of patients admitted to the ICU for 48 hours or more, independent of ICU outcome, were eligible for participation. Up to three family members per patient could participate. Family members were defined as the persons closest to the patient (as identified by the patient), including partners, siblings, children, parents and friends. If more than three family members wanted to participate, the family members themselves chose the participants based on who had spent the most time in the ICU.

Exclusion criteria

Family members were excluded who met the following criteria: 1) under age 18; 2) with cognitive impairment; or 3) unable to read or write Danish or Dutch.

Recruitment of participants

We asked that family members who fulfilled the eligibility criteria by approached during the patient’s ICU stay by either ICU nurses or physicians; most family members were approached although sometimes ICU nurses and physicians forgot to do so. Family members received oral and written information about the study and, if they agreed to participate, they provided their name and home address. Three weeks after patient discharge from the ICU, family members received the questionnaire by mail, together with written information and a pre-paid envelope. In Denmark, the individual ICUs were responsible for sending out the questionnaires, and the cover letter was signed by the local investigators. In the Netherlands, all questionnaires were sent out by the investigators. In both countries, the completed questionnaires were returned to the investigators. If the questionnaire was not returned, one reminder with a new questionnaire was sent.

Patient and respondent data

For participating families, the following patient data were obtained from the medical record: gender, age, medical or surgical speciality of the admitting physician, diagnosis, length of stay in the ICU, and decisions about withholding or withdrawing life-sustaining treatments. APACHE II (Acute Physiology and Chronic Health Evaluation) and SAPS (Simplified Acute Physiology Score) were also included when available (from 12 and 13 ICUs, respectively). Data on family respondents included age, gender and relationship to the patient.

Instrument

The euroQ2 questionnaire (see Supplementary Materials 1), consists of two sections: the euroFS-ICU, which all participating family members completed, and an extra section containing the euroQODD, which was completed only by family members of patients who died in the ICU. In this paper, we present results for the euroFS-ICU portion of the questionnaire.

Statistics

Statistical analyses were conducted using Stata 13 (20) and Mplus 7.4 (21). For comparing background characteristics of Danish and Dutch family members and patients we used χ^2 or Fishers exact test and Mann-Whitney U-test as appropriate. To compare family members' responses between countries, we used clustered regression models with country as predictor and the five-point satisfaction items as outcomes. We tested associations of family and patient characteristics with family members' responses on the family satisfaction items with clustered single-predictor probit regression models (family respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values were based on Wald's test. Clustered analyses were used to adjust for participation of more than one family member for some of the patients.

Earlier analysis of the North American version of the FS-ICU had suggested that the questionnaire encompassed two domains (care and decision-making), resulting in a recommendation for computing composite scores for those two domains and for total satisfaction (14). However, that analysis was based on exploratory factor analysis (EFA), with indicators defined as normally distributed continuous variables, and without the use of strict tests of empirical fit. More recent analyses, based on exploratory factor analysis within a confirmatory factor analysis framework (E/CFA) (22) and using a larger sample, with indicators defined as ordered categorical variables, have suggested that the instrument likely encompasses four domains of family satisfaction: (a) communication with the family, (b) empathy shown to the family; (c) support of the family during decision making, and (d) management of patients' symptoms (work by LD, JRC and RAE). [See supplement 2]. Although the euroFS-ICU is an adapted version of the 24-item FS-ICU, many of the items in the two instruments are identical. Therefore, we hypothesized that the euroFS-ICU would encompass dimensions that are conceptually similar to the four domains identified previously in the North American questionnaire.

Examination of the measurement characteristics of the euroFS-ICU included four aspects: (a) positing a conceptual framework for the domain structure of the euroFS-ICU; (b) using exploratory factor analysis (EFA) to simplify the conceptual structure by removing items that contributed to statistically significant misfit (i.e., a χ^2 test of fit with $p<0.05$) to data from the combined samples; (c) investigating whether the simplified structure was equally appropriate for Denmark and the Netherlands, considered separately; and (d) assessing whether a set of "pure" factors (i.e., each indicator contributing to the measurement of only one factor) could be identified, with the resulting factors having equivalent meaning in the two countries. Evidence supporting equivalent meaning between countries required that a model in which the loadings and thresholds for each indicator were constrained to equality between countries produced non-significant misfit to the observed data (i.e., a χ^2 test of fit with $p>0.05$). Equivalent meaning must be established in order to provide legitimacy for between-country comparisons of mean levels on the factors. Detailed descriptions of the analyses are presented in the supplementary material.

Results

Characteristics of patients and family members

A total of 1,077 family members participated, 573 from Denmark and 504 from The Netherlands, representing 920 ICU patients. In Denmark, 185 of the 573 participants were second and third family members of the same patient. In The Netherlands, six of the 504 participants were second and third family members. The overall response rate was 72% among family members approached and reportedly willing to participate, 75% in Denmark and 68% in The Netherlands.

The Dutch and Danish participants differed significantly on a number of demographic and clinical characteristics such as age, relationship to patient, reason for admission and level of therapy (Table 1).

Table 1. Background Characteristics of Participating Family Members and Patients

	Total Sample		Denmark		The Netherlands		*p*[1]
	Valid n[2]	Statistic[3]	Valid n[2]	Statistic[3]	Valid n[2]	Statistic[3]	
Family Member							
Age, median years (IQR[4])	1055	57 (22)	553	54 (22)	502	60 (20)	<0.001
Female	1056	724 (69)	554	399 (72)	502	325 (65)	0.01
Relationship to patient, n (%)	1061		559		502		<0.001
Spouse or partner		499 (47)		209 (37)		290 (58)	
Child		372 (35)		235 (42)		137 (27)	
Sibling		64 (6)		32 (6)		32 (6)	
Parent		60 (6)		37 (7)		23 (5)	
Other		66 (6)		46 (8)		20 (4)	
Patient							
Age, median years (IQR)	894	69 (16)	408	70 (15)	486	68(17)	0.33
Female, n (%)	894	340 (38)	408	144 (35)	486	196 (40)	0.12
Days in ICU, median days (IQR)	893	8 (10)	406	9 (11)	487	7 (10)	0.16
Level of therapy, n (%)	856		408		448		<0.001
Full		630 (74)		315 (77)		315 (70)	
Life-sustaining therapy withheld		123 (14)		38 (9)		85 (19)	
Life-sustaining therapy withdrawn		103 (12)		55 (13)		48 (11)	
Discharge, n (%)	895		408		487		<0.001
Planned		658 (74)		266 (65)		392 (81)	
Dead		178 (20)		88 (22)		90 (18)	
Other[5]		59 (7)		54 (13)		5 (1)	
Reason for admission, n (%)	894		407		487		<0.001
Respiratory		311 (35)		142 (35)		169 (35)	
Sepsis		152 (17)		52 (13)		100 (21)	
Cardiovascular		274 (31)		119 (29)		155 (32)	
Other		157 (18)		94 (23)		63 (13)	
Mechanical ventilation, n (%)	894	783 (88)	408	346 (85)	486	437 (90)	0.02
APACHE II, median score (IQR)	509	21 (10)	59	24 (12)	450	21 (10)	0.01
SAPS II, median score (IQR)	638	50 (24)	277	51 (22)	361	48 (26)	0.09

1. The Mann-Whitney U-test or χ2/Fisher exact test as appropriate
2. Different n due to missing data
3. Except where noted, the statistics provided are n (%).
4. Interquartile range (p75 – p25)
5. “Other discharge” includes patients who were transferred to other hospitals or who were discharged because of a lack of available beds in the ICU

Between-country comparisons of responses to individual family satisfaction items

Except for inclusion in decision-making processes, the Danish ratings were significantly higher than the Dutch ratings (Table 2). Items with the greatest number of “excellent” endorsements were concern and caring towards patient, dyspnea management, atmosphere of the ICU, presence at the bedside and ease of getting information. Items with fewer “excellent” endorsements and suggesting the need for improvement were management of agitation, emotional support, consistency of information and inclusion in decision-making (Table 2)

In addition to the questions presented in Table 2, the euroFS-ICU contains three items that do not use 5-point Likert Scale response options. 1) Those who chose “Fair” or “Poor” when asked about inclusion in the decision-making processes were subsequently asked why they gave these responses. A total of 114 family members responded to this question (Denmark, n=65, The Netherlands, n=49), with 9% stating that they were involved too much, 63% that they were not involved enough, and 28% that their low satisfaction was due to other reasons. The participants were also asked whether they felt they had adequate time to have their concerns addressed and questions answered when major decisions were made, with 72% answering that they had enough time and 9% that they could have used more time. For these two questions there were no statistical differences between the two countries. 3) Finally, the participants were asked to assess overall satisfaction with the care the patient had received from all doctors, nurses and other healthcare professionals. The assessment was made on a scale from 0 to 10, with 0 being worst care possible and 10 best care possible. The median assessment was 9 (Inter-quartile range 8-10) with significantly higher scores in Denmark (9 [9-10]) than in The Netherlands (9 [8-9]) (p<0.001).

Associations of respondent characteristics with responses on individual family satisfaction ratings

Whereas there was a significant difference between the two countries for almost all ratings, the respondents' age, gender and relation to the patient had only a small impact on level of satisfaction. Respondent age influenced six of the items, with higher ratings as age increased. These items were: agitation management, atmosphere of the ICU, emotional support, opportunity to be present at the bedside, consistency of information and overall satisfaction with care. The respondents' gender had significant associations with four items, with female respondents providing higher ratings, on average, than their male counterparts. Two of the items were about symptom management (management of pain and dyspnea) and two concerned staff communication (willingness to answer questions and provision of understandable explanations). The respondent's relationship to the patient was not associated with any of the satisfaction ratings.

Associations of patient characteristics with responses to individual family satisfaction ratings

SAPS scores were significantly associated with satisfaction, with higher scores associated with higher family satisfaction. The SAPS score was associated with 15 items. The items not associated with SAPS scores were symptom management (pain, breathlessness and agitation) and adequate time to have concerns addressed. Death in the ICU was associated with higher ratings on seven items including consideration of family needs, emotional support and overall satisfaction with care. The remaining patient characteristics (i.e. gender, age and hours in the ICU) were associated with few or none of the satisfaction items (see Table S2a-f for details).

Domains of family satisfaction underlying the euroFS-ICU instrument

The first step in investigating the structure of the euroFS-ICU items was to assign each of the 20 items *a priori* to one of the four conceptual domains (Communication, Empathy, Patient Care and Symptom Management, and Decision-making) that have been identified in the North American version of the instrument. To achieve acceptable fit to data from the combined Danish and Dutch samples (please see supplementary material 2, p. 1 for details), we generated a series of EFA models, using modification indices that eliminated nine items (five from the communication domain, one from empathy, two from patient care and symptom management, and one from decision-making) from the *a priori* structure. This produced a four-domain model with strong primary loadings, relatively weak cross-loadings, and good fit to the observed data from the combined countries.

Table 3. Exploratory Factor Analysis, Four-Factor Eleven-Indicator Model, Merged Data from Denmark and the Netherlands (n=1,077): Indicator Loadings and Factor Correlations

Indicator	Communication	Empathy	Symptom Management	Decision-Making
Provision of understandable explanations	**0.848***	0.013	-0.021	0.038
Honesty of information	**0.839***	-0.010	0.015	0.043
Overall quality of information from nurses	**0.765***	0.083*	0.068*	-0.005
Appreciation for family presence	0.195*	**0.720***	0.065*	-0.050*
Consideration of family needs	0.029	**0.976***	-0.059*	0.037
Emotional support of family	-0.029	**0.766***	0.038*	0.165*
Pain management	0.028	0.063*	**0.811***	0.012
Breathlessness management	0.053	-0.076*	**0.897***	0.017
Agitation management	-0.031	0.067*	**0.856***	0.012
Inclusion in decision-making processes	0.134	-0.009	-0.031*	**0.785***
Support during decision-making processes	-0.007	0.038	0.102*	**0.873***
	Factor Correlations			
Communication	----			
Empathy	0.774*	----		
Symptom Management	0.736*	0.730*	----	
Decision-Making support	0.793*	0.689*	0.667*	----

* = statistically significant at or beyond *p*=0.05.

However, although analysis of this EFA model within countries showed acceptable fit to the within-country data, the countries were dissimilar in their pattern of loadings, portending difficulties in establishing a factor structure where the factors had equivalent meanings in the two countries (see see supplementary material 2 p 11 for details). Moreover, a confirmatory factor analysis (CFA) in which each indicator was allowed to load on only one of the four factors required further elimination of indicators in order to obtain adequate fit to data from the separate countries, and even this model failed when indicator loadings and thresholds were constrained to equality between countries (see supplementary material 2, pp. 12-14). As a result of this failure, we could not conclude that the euroFS-ICU contains elements supporting a four-factor structure for which the factors can be legitimately compared between countries.

Correcting A Source of Model Misspecification

All of the models tested with these data use a methodology that is widely reported for similar instruments. However, it is based on an important type of model misspecification: the modeling of factor indicators as reflective (or effect) indicators, when they are more appropriately modeled as causal indicators (23-25). Reflective indicators are indicators that are caused by (i.e., reflect) a construct, with an individual's position on all of the indicators tending to rise or fall in concert with that individual's position on the underlying construct. By contrast, causal indicators are variables that contribute to, rather than reflect, the construct; an individual's position on some, but not necessarily all, of the causal indicators is expected to rise and fall in concert with the individual's position on the construct. The difference is in the direction of causation: reflective indicators are caused by the construct; causal indicators contribute to the construct. To achieve statistical identification, modeling a construct with causal indicators requires that there be at least two additional variables that can be used as outcomes of the construct. Ideally, these would be reflective indicators, but they may alternatively be more distal outcomes of the construct. Although the euroFS-ICU includes only one hypothesized domain (the “Communication” domain), for which there are, arguably, reflective indicators, the existence of reflective indicators for this one domain allowed us to test an alternative measurement method.

Figure 1. Quality of ICU Communication, Measured with Causal and Reflective Indicators

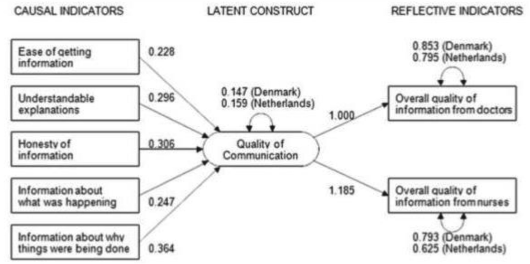


Fig. 1 Quality of ICU communication, measured with causal and reflective indicators. Measurement invariance imposed between Denmark and The Netherlands. Unstandardized coefficients are shown

Figure 1 shows a model in which quality of ICU Communication is measured with a combination of causal and reflective indicators with the additional imposition of between-country measurement invariance. In this model the regression coefficients for the causal indicators and both the factor loadings and thresholds for the reflective indicators were constrained to equality between the two countries. This model provided good fit to the data (*p* for χ^2 test of fit = 0.4147), thereby providing evidence that the combination of causal and reflective indicators measure a latent communication construct that has equivalent meaning in the two countries and on which the two countries can be legitimately compared.

The remaining hypothesized domains were not represented by a sufficient set of variables for use as outcomes (either as reflective indicators or as more distal outcomes) to allow causal-indicator tests of those domains.

Discussion

This study was based on a large sample of family members of patients treated in a variety of ICUs in two countries. All questions were assessed as understandable and relevant in the first qualitative and quantitative analyses (19) and, as single items, provide important information about families' experiences. Overall, family members rated the care provided by ICUs moderately highly, with a large majority of respondents from both countries rating each aspect of care as either excellent or very good, but with respondents from Denmark typically providing higher ratings than were offered by respondents from the Netherlands. Similarly, family members from both countries provided high marks on a single-item rating of overall care provided to patients, but Danish respondents gave higher ratings, on average, than respondents from the Netherlands. However, if the goal is to provide care rated as "excellent", many of the items were rated as excellent by only a third to a half of family members. Areas with the highest scores were concern and caring toward patient, dyspnea management, ICU atmosphere, opportunities for family members to be present at the bedside, and ease of getting information. Areas with most room for improvement were management of patients' agitation, emotional support of the family, consistency of information, and inclusion in and support during decision-making processes. Similar levels of satisfaction have been found in a number of ICU family satisfaction studies (14;26-28). Furthermore, areas for improvement are similar to results from a recent German FS-ICU study (26). The reasons for Danish ratings being higher than Dutch ratings are unknown. A generally higher nurse-patient ratio (1:1-1.4 patients) in Denmark versus 1:1-2.5 patients in The Netherlands could be a contributing factor.

Earlier studies have identified needs of ICU families, including honest and consistent information (5;29;30), possibilities to support, protect and advocate for the patient (29;30) and emotional support

(29;31). The development of the euroFS-ICU part of euroQ2 is based on the substantial work demonstrating domain validity conducted with the FS-ICU (14), interviews with Danish families (19), and both qualitative and quantitative tests of whether the questions were relevant, understandable and comprehensive (19). The literature and our preliminary research therefore support the four hypothesized domains (communication with the family, empathy shown to the family; support of the family during decision making, and management of patients' symptoms) as highly relevant for ICU families.

Although exploratory factor analyses identified a set of four domains potentially underlying family satisfaction, successive confirmatory factor analyses (aimed at producing a model in which each indicator measured only one factor) retained only a few indicators from the original set of 20 and failed to fit the data when between-country measurement invariance was imposed. The analyses suggested that the the euroFS-ICU instrument does not measure a unidimensional construct representing overall family satisfaction, nor does it measure four constructs that are comparable between countries. We posited that an important misspecification related to our definition of the component indicators as reflective indicators (i.e., indicators that are caused by a construct), when most of the variables in this instrument function conceptually as causal indicators of their respective constructs (i.e., variables that contribute to, rather than reflect, the construct). Analysis of a single construct (satisfaction with communication) for which the euroFS-ICU instrument includes both causal and reflective indicators provided evidence in support of this hypothesis. One potential approach for the next phase of development of the euroFS-ICU instrument is the addition and testing of a set of reflective indicators of overall satisfaction with the ICU experience, and the addition and testing of at least two reflective indicators for each of the four hypothesized domains. Based on results from this study, we have begun development of extra items that can be used as true reflective indicators. These items will be pilot tested in future research and added to the euroQ2.

Strengths and limitations

Strengths of the study include enrollment of more than 1,000 family members from two countries, affiliated with patients who were treated in a large number of ICUs of different types and located in several geographic areas. The response rate among family members approached by ICU staff and willing to consider participation was relatively high (72%), and respondents left few questions unanswered. Despite this high response rate, it was lower than that experienced in an earlier phase of the study (87%), perhaps because the earlier phase included phone contacts to respondents, whereas the current phase used mailed reminders. In addition, the analytic approach in this study was more rigorous than that used for most other measures of family experience. The analyses show the importance of using newer statistical approaches to ensure that multi-item constructs are unidimensional and meet quality standards, as we suspect that other measures may encounter similar challenges of model misspecification in the measurement of latent constructs.

There are also important limitations. SAPS scores were only available for approximately 70% of the sample and from 62% of the ICUs, and the generalizability of these findings may therefore be limited. Additionally, SAPS scores may not discriminate and describe disease severity as well as the APACHE-III scoring and APACHE-IV prediction model, but these scores were not available. If an ultimate objective is to construct multi-item constructs of overall satisfaction and its subdomains, an important limitation is the absence of reflective indicators of those constructs in the current instrument. Modification of the instrument is already in progress and may allow an exploration of whether such constructs exist and are consistent between countries, or whether contributors to satisfaction vary by country. The validity, reliability, and responsiveness of such measures remain to be determined. Because the current instrument consists primarily of casual indicators, most future analyses with this data set, except for satisfaction with communication, are best limited to the use of single-item measures. A second limitation is the omission of some eligible family members during the study period, owing to ICU staff forgetting to mention the study to them. However, there is nothing to indicate that these omissions were other than random. Likewise, exact numbers of families who refused to participate when approached is missing, but is estimated at less than 10%. A third limitation is that the effect of ethnicity is not examined. As the vast majority of patients in both Denmark and The Netherlands are Caucasians, groups of non-Caucasian family members would be too small for analyses. The lack of ethnic subsamples reduces the generalizability of the study. A fourth limitation is the fact that both of the countries represented in the study are from Northern Europe. Although we identified a model of satisfaction with communication that was invariant for these two countries, it may not fit data provided by ICU families from other parts of the Europe or the world. Addition of data from other European countries and other regions of the world will be important for future studies.

Conclusion

The euroFS-ICU part of the euroQ2 provides information about families' experiences with ICU quality of care. Areas with the highest scores were concern and caring toward patient, dyspnea management, atmosphere of the ICU, family members' opportunity to be present at the bedside, and ease of getting information. Areas with most room for improvement were management of patients' agitation, emotional support of the family, consistency of information, and inclusion in and support during decision-making processes.

Rigorous psychometric assessments showed that it is problematic to measure overall satisfaction with a composite score or latent construct based on items in the current euroFS-ICU, although a latent construct of one domain (satisfaction with communication) appears to be possible, using a combination of causal and reflective indicators. In the future, this and other instruments may benefit from adding reflective indicators that will allow measuring overall satisfaction, as well as the three other hypothesized satisfaction sub-domains (satisfaction with symptom management, empathy, and decision-making) as multi-indicator constructs.

Declarations

Ethics approval and consent to participate

In accordance with Danish law, the study did not need permission from the Regional Ethics Committees, but permission to access patient files was obtained from the Danish National Health Authorities (3-3013-353/1/) for all participating centers, and the study was registered with the Danish Data Protection Agency. In The Netherlands, the Leeuwarden IRB (R-TPO) nr. nWMO 21a approved the study and provided a waiver for patient consent according to Dutch law, valid for all participating centers.

Availability of data and material

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Funding

The study was supported by The Region of Southern Denmark, The Novo Nordic Foundation, Denmark (11415), The Augustinus Foundation, Denmark (14-2421), and The Frisian ICU Research Fund, The Netherlands. The funding bodies had no influence on the study or the paper.

Acknowledgements

The authors thanks all participating families and ICUs.

References

1. Haywood K, Brett J, Salek S, Marlett N, Penman C, Shklarov S, et al. Patient and public engagement in health-related quality of life and patient-reported outcomes research: what is important and why should we care? Findings from the first ISOQOL patient engagement symposium. Qual Life Res 2015 May;24(5):1069-76.

2. Wiering B, de BD, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. Health Expect 2016 Feb 18.

3. Kurtzman ET, Greene J. Effective presentation of health care performance information for consumer decision making: A systematic review. Patient Educ Couns 2016 Jan;99(1):36-43.

4. Boothroyd LJ, Lambert LJ, Ducharme A, Guertin JR, Sas G, Charbonneau E, et al. Challenge of informing patient decision making: what can we tell patients considering long-term mechanical circulatory support about outcomes, daily life, and end-of-life issues? Circ Cardiovasc Qual Outcomes 2014 Jan;7(1):179-87.

5. Curtis JR, Vincent JL. Ethics and end-of-life care for adults in the intensive care unit. Lancet 2010 Oct 16;376(9749):1347-53.

6. Adhikari NK, Fowler RA, Bhagwanjee S, Rubenfeld GD. Critical care and the global burden of critical illness in adults. Lancet 2010 Oct 16;376(9749):1339-46.

7. Azoulay E, Metnitz B, Sprung CL, Timsit JF, Lemaire F, Bauer P, et al. End-of-life practices in 282 intensive care units: data from the SAPS 3 database. Intensive Care Med 2009 Apr;35(4):623-30.

8. Jensen HI, Ammentorp J, Ording H. Withholding or withdrawing therapy in Danish regional ICUs: frequency, patient characteristics and decision process. Acta Anaesthesiol Scand 2011 Mar;55(3):344-51.

9. Thompson BT, Cox PN, Antonelli M, Carlet JM, Cassell J, Hill NS, et al. Challenges in end-of-life care in the ICU: statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary. Crit Care Med 2004 Aug;32(8):1781-4.

10. Aitken LM, Castillo MI, Ullman A, Engstrom A, Cunningham K, Rattray J. What is the relationship between elements of ICU treatment and memories after discharge in adult ICU survivors? Aust Crit Care 2016 Feb;29(1):5-14.

11. Stricker KH, Kimberger O, Brunner L, Rothen HU. Patient satisfaction with care in the intensive care unit: can we rely on proxies? Acta Anaesthesiol Scand 2011 Feb;55(2):149-56.

12. Bowling A. Research Methods in Health. Investing Health and Health Services. 3 ed. Buckingham: Open University Press; 2009.

13. van den Broek JM, Brunsveld-Reinders AH, Zedlitz AM, Girbes AR, de JE, Arbous MS. Questionnaires on Family Satisfaction in the Adult ICU: A Systematic Review Including Psychometric Properties. Crit Care Med 2015 Aug;43(8):1731-44.

14. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Crit Care Med 2007 Jan;35(1):271-9.

15. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002 Jul;24(1):17-31.

16. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. J Pain Symptom Manage 2010 Jan;39(1):9-22.

17. Moselli NM, Debernardi F, Piovano F. Forgoing life sustaining treatments: differences and similarities between North America and Europe. Acta Anaesthesiol Scand 2006 Nov;50(10):1177-86.

18. Gerritsen RT, Hofhuis JG, Koopmans M, van der Woude M, Bormans L, Hovingh A, et al. Perception by family members and ICU staff of the quality of dying and death in the ICU: a prospective multicenter study in The Netherlands. Chest 2013 Feb 1;143(2):357-63.

19. Jensen HI, Gerritsen RT, Koopmans M, Zijlstra JG, Curtis JR, Ording H. Families' experiences of intensive care unit quality of care: Development and validation of a European questionnaire (euroQ2). J Crit Care 2015 Jun 16.

20. Stata. StataCorp LP, Texas, USA 2016 April 18 [cited 2016 Apr 18];Available from: URL: http://www.stata.com/

21. Mplus. Muthén & Muthén, Los Angeles, USA 2016 April 18 [cited 2016 Apr 18];Available from: URL: https://www.statmodel.com/index.shtml

22. Brown TA. Confirmatory Factor Analysis for Applied Research. 2nd Edition ed. NY: The Guilford Press; 2015.

23. Edwards JR, Bagozzi RP. On the nature and direction of relationships between constructs and measures. Psychol Methods 2000 Jun;5(2):155-74.

24. Bollen KA, Bauldry S. Three Cs in measurement models: causal indicators, composite indicators, and covariates. Psychol Methods 2011 Sep;16(3):265-84.

25. Jarvis CB, Mackenzie SB, Podsakoff PM. A critical review of construct indicators and measurement model misspecification in marketing and consumer research. Journal of Consumer Research 2003;30:199-218.

26. Schwarzkopf D, Behrend S, Skupin H, Westermann I, Riedemann NC, Pfeifer R, et al. Family satisfaction in the intensive care unit: a quantitative and qualitative analysis. Intensive Care Med 2013 Jun;39(6):1071-9.

27. Wright SE, Walmsley E, Harvey SE, Robinson E, Ferrando-Vivas P, Harrison DA, et al. Family-Reported Experiences Evaluation (FREE) study: a mixed-methods study to evaluate families' satisfaction with adult critical care services in the NHS. Health Services and Delivery Research 2015 Dec.

28. Sarode V, Sage D, Phong J, Reeves J. Intensive care patient and family satisfaction. Int J Health Care Qual Assur 2015;28(1):75-81.

29. Linnarsson JR, Bubini J, Perseius KI. A meta-synthesis of qualitative research into needs and experiences of significant others to critically ill or injured patients. J Clin Nurs 2010 Nov;19(21-22):3102-11.

30. Lind R, Lorem GF, Nortvedt P, Hevroy O. Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. Intensive Care Med 2011 Jul;37(7):1143-50.

31. Stricker KH, Kimberger O, Schmidlin K, Zwahlen M, Mohr U, Rothen HU. Family satisfaction in the intensive care unit: what makes the difference? Intensive Care Med 2009 Dec;35(12):2051-9.

Table S2a. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 1

	Female			Age			Hours in ICU		
Outcome	n[b]	b	*p*	n[b]	b	*p*	n[b]	b	*p*
Concern and caring toward patient	1042/888	-0.049	0.536	1042/888	0.003	0.277	1040/887	0.000	0.726
Pain management	984/841	-0.152	0.058	984/841	0.002	0.521	983/841	0.000	0.939
Breathlessness management	905/775	-0.184	**0.024**	904/774	-0.002	0.417	903/774	0.000	0.431
Agitation management	945/816	-0.002	0.980	944/815	0.001	0.572	943/815	0.000	0.672
Atmosphere of the ICU	1047/893	-0.135	0.080	1047/893	0.004	0.095	1045/892	0.000	0.329
Consideration of family needs	1038/886	-0.148	**0.046**	1038/886	0.004	0.108	1036/885	0.000	0.781
Emotional support	1006/862	-0.136	0.072	1006/862	0.004	0.139	1004/861	0.000	0.906
Opportunity to be present at bedside	1048/893	-0.004	0.962	1048/893	0.003	0.268	1046/892	0.000	0.367
Ease of getting information	1043/888	-0.071	0.340	1043/888	0.003	0.278	1041/887	0.000	0.622
Understanding of information	1042/887	-0.032	0.672	1042/887	0.001	0.834	1040/886	0.000	0.600
Honesty of information	1042/887	-0.091	0.254	1042/887	-0.001	0.656	1040/886	0.000	0.271
Completeness of Information									
What was happening	1038/884	-0.087	0.247	1038/884	0.001	0.803	1036/883	0.000	0.305
Why things were being done	1036/882	-0.109	0.147	1036/882	-0.002	0.397	1034/881	0.000	0.744
Consistency of information	1030/880	-0.082	0.266	1030/880	0.003	0.234	1028/879	0.000	0.978
Overall quality of information									
By doctors	1017/871	-0.061	0.406	1017/871	-0.001	0.763	1016/871	0.000	0.099
By nurses	1039/886	-0.114	0.140	1039/886	0.000	0.871	1037/885	0.000	0.696
Inclusion in decision-making processes	883/771	-0.096	0.206	882/770	0.001	0.742	882/770	0.000	0.401
Support during decision-making processes	820/715	0.020	0.810	819/714	-0.001	0.618	818/714	0.000	0.945
Adequate time to have concerns addressed	760/670	0.190	0.156	759/669	0.000	0.937	759/669	0.000	0.598
Overall satisfaction with patient care	1032/879	-0.107	0.185	1032/879	0.002	0.438	1029/877	---[c]	---[c]

---

[a] All associations were tested with clustered single-predictor probit regression models (respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

[c] The joint distribution was too sparse to allow computation of this coefficient.

Table S2b. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 2

	Received MV			Apache Score			SAP Score		
Outcome	n[b]	b	*p*	n[b]	b	*p*	n[b]	b	*p*
Concern and caring toward patient	1042/888	0.127	0.236	525/508	0.005	0.388	738/634	0.007	**0.008**
Pain management	984/841	-0.027	0.810	480/467	0.006	0.301	695/599	0.004	0.144
Breathlessness management	904/774	-0.049	0.697	440/428	0.004	0.553	630/546	0.004	0.138
Agitation management	944/815	0.114	0.352	470/459	0.001	0.922	666/582	0.004	0.139
Atmosphere of the ICU	1047/893	0.209	0.052	525/508	0.013	**0.022**	743/637	0.009	**0.000**
Consideration of family needs	1038/886	0.172	0.104	519/502	0.018	**0.001**	737/633	0.011	**0.000**
Emotional support	1006/862	0.140	0.180	501/485	0.020	**0.000**	712/613	0.009	**0.000**
Opportunity to be present at bedside	1048/893	0.079	0.486	525/508	0.007	0.232	743/637	0.008	**0.003**
Ease of getting information	1043/888	0.163	0.145	522/505	0.013	**0.020**	739/633	0.007	**0.005**
Understanding of information	1042/887	0.276	**0.011**	523/506	0.012	**0.040**	739/633	0.008	**0.001**
Honesty of information	1042/887	0.202	0.060	523/506	0.014	**0.014**	739/633	0.008	**0.002**
Completeness of Information									
What was happening	1038/884	0.159	0.123	520/503	0.009	0.108	738/632	0.008	**0.001**
Why things were being done	1036/882	0.191	0.068	518/501	0.008	0.155	734/628	0.008	**0.001**
Consistency of information	1030/880	0.048	0.656	519/502	0.007	0.226	731/629	0.008	**0.001**
Overall quality of information									
By doctors	1017/871	0.173	0.104	514/498	0.014	**0.011**	720/621	0.009	**0.000**
By nurses	1039/886	0.125	0.231	521/504	0.009	0.090	737/632	0.009	**0.000**
Inclusion in decision-making processes	882/770	0.061	0.572	451/436	0.018	**0.001**	629/550	0.009	**0.001**
Support during decision-making processes	820/715	0.009	0.942	415/400	0.013	**0.046**	579/505	0.007	**0.020**
Adequate time to have concerns addressed	759/669	0.010	0.960	382/369	0.006	0.582	531/470	0.003	0.621
Overall satisfaction with patient care	1032/879	0.004	0.966	519/502	---[c]	---[c]	732/627	---[c]	---[c]

---

[a] All associations were tested with clustered single-predictor probit regression models (respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

[c] The joint distribution was too sparse to allow computation of this coefficient.

Table S2c. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 3

Outcome	Death in ICU			Reason for Discharge				
					Planned	Death	Other	
	n[b]	b	*p*	n[b]	b	b	b	*p*
Concern and caring toward patient	1070/915	0.060	0.547	1043/889	0.000	0.069	0.140	0.589
Pain management	1008/864	0.060	0.542	982/839	0.000	0.073	0.167	0.422
Breathlessness management	928/797	0.002	0.984	904/774	0.000	0.028	0.271	0.168
Agitation management	970/840	0.103	0.269	944/815	0.000	0.114	0.166	0.307
Atmosphere of the ICU	1075/920	0.099	0.293	1048/894	0.000	0.088	0.049	0.637
Consideration of family needs	1066/913	0.191	**0.036**	1039/887	0.000	0.184	0.061	0.135
Emotional support	1034/889	0.312	**0.001**	1007/863	0.000	0.315	0.163	**0.003**
Opportunity to be present at bedside	1076/920	0.052	0.553	1049/894	0.000	0.063	0.182	0.436
Ease of getting information	1071/915	0.145	0.126	1044/889	0.000	0.136	0.026	0.366
Understanding of information	1070/914	0.143	0.134	1043/888	0.000	0.142	0.093	0.307
Honesty of information	1070/914	0.080	0.383	1043/888	0.000	0.068	0.003	0.762
Completeness of Information								
What was happening	1065/910	0.156	0.075	1039/885	0.000	0.145	0.007	0.264
Why things were being done	1063/908	0.185	**0.037**	1037/883	0.000	0.187	0.173	0.076
Consistency of information	1057/906	0.115	0.171	1031/881	0.000	0.115	0.212	0.167
Overall quality of information								
By doctors	1045/898	0.202	**0.017**	1018/872	0.000	0.186	-0.004	0.090
By nurses	1067/913	0.140	0.118	1040/887	0.000	0.140	0.147	0.240
Inclusion in decision-making processes	906/793	0.289	**0.001**	883/771	0.000	0.274	0.054	**0.012**
Support during decision-making processes	839/734	0.261	**0.006**	822/717	0.000	0.234	-0.095	**0.029**
Adequate time to have concerns addressed	776/686	-0.116	0.414	762/672	0.000	-0.194	-0.634	**0.005**
Overall satisfaction with patient care	1060/906	0.229	**0.013**	1033/880	0.000	0.220	-0.020	0.054

[a] All associations were tested with clustered probit regression models (respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). The models with death in the ICU as a predictor were single-predictor models; those with reason for discharge as a predictor were two-predictor models, with death and other discharge reasons modeled as dummy indicators, and using planned discharge as the reference category. *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

Table S2d. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 4

		Treatment Limitations			
		Full Tx	Ltd Tx	Tx W/D	
Outcome	n[b]	b	b	b	*p*
Concern and caring toward patient	1004/850	0.000	-0.138	-0.015	0.498
Pain management	947/804	0.000	-0.104	0.024	0.655
Breathlessness management	870/740	0.000	-0.107	-0.031	0.662
Agitation management	909/780	0.000	-0.120	0.015	0.584
Atmosphere of the ICU	1009/855	0.000	-0.058	0.103	0.584
Consideration of family needs	1000/848	0.000	-0.113	0.148	0.214
Emotional support	968/824	0.000	-0.020	0.255	0.080
Opportunity to be present at bedside	1010/855	0.000	-0.059	0.065	0.713
Ease of getting information	1005/850	0.000	-0.084	0.063	0.620
Understanding of information	1004/849	0.000	-0.043	0.026	0.898
Honesty of information	1004/849	0.000	-0.063	-0.032	0.850
Completeness of Information					
What was happening	1000/846	0.000	0.111	0.070	0.571
Why things were being done	998/844	0.000	-0.069	0.101	0.527
Consistency of information	992/842	0.000	-0.101	-0.029	0.669
Overall quality of information					
By doctors	980/834	0.000	0.030	0.158	0.330
By nurses	1001/848	0.000	-0.161	0.079	0.241
Inclusion in decision-making processes	846/734	0.000	0.078	0.175	0.259
Support during decision-making processes	790/685	0.000	0.022	0.194	0.254
Adequate time to have concerns addressed	734/644	0.000	0.099	-0.030	0.838
Overall satisfaction with patient care	995/842	0.000	-0.074	0.181	0.210

---

[a] All associations were tested with two-predictor clustered probit regression models (dummy indicators for limited and withdrawn treatment, with full treatment serving as the reference category; respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

Table S2e. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 5

		Specialties						
		Med	Surg	Trauma	Onc	Neuro	Other	
Outcome	n[b]	b	b	b	b	b	b	*p*
Concern and caring toward patient	1043/889	0.000	-0.001	0.478	0.819	0.163	0.424	**0.044**
Pain management	985/842	0.000	-0.121	0.404	0.359	-0.178	0.966	**0.012**
Breathlessness management	905/775	0.000	-0.263	0.154	0.384	-0.223	0.784	**0.002**
Agitation management	945/816	0.000	-0.152	0.450	0.472	-0.043	1.087	**0.003**
Atmosphere of the ICU	1048/894	0.000	-0.118	0.389	0.238	-0.232	0.664	0.064
Consideration of family needs	1039/887	0.000	-0.135	0.092	0.438	-0.027	0.154	0.253
Emotional support	1007/863	0.000	-0.158	0.382	0.578	-0.089	0.430	**0.040**
Opportunity to be present at bedside	1049/894	0.000	-0.173	0.137	0.223	-0.189	0.301	0.139
Ease of getting information	1044/889	0.000	-0.044	0.217	0.205	-0.041	0.019	0.872
Understanding of information	1043/888	0.000	-0.120	0.316	0.122	-0.201	0.269	0.352
Honesty of information	1043/888	0.000	-0.162	-0.068	0.613	0.073	0.633	**0.029**
Completeness of Information								
What was happening	1039/885	0.000	-0.060	-0.009	0.334	-0.100	0.621	0.394
Why things were being done	1037/883	0.000	-0.104	0.208	0.386	-0.059	0.591	0.206
Consistency of information	1031/881	0.000	-0.125	-0.198	0.545	-0.168	0.337	0.084
Overall quality of information								
By doctors	1018/872	0.000	-0.148	0.054	0.621	0.029	-0.027	**0.009**
By nurses	1040/887	0.000	-0.059	-0.042	0.730	-0.128	0.777	**0.029**
Inclusion in decision-making processes	883/771	0.000	-0.176	0.115	0.298	-0.103	0.204	0.201
Support during decision-making processes	820/715	0.000	-0.280	0.152	0.480	-0.194	0.617	**0.004**
Adequate time to have concerns addressed	760/670	0.000	-0.027	0.012	-0.173	-0.325	-0.586	0.731
Overall satisfaction with patient care	1033/880	0.000	-0.136	0.115	0.502	-0.226	0.634	0.078

---

[a] All associations were tested with five-predictor clustered probit regression models (dummy indicators for five specialties, with medical serving as the reference category; respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

Table S2f. Unadjusted Associations between Patient Characteristics and Separate Family Satisfaction Items[a], Part 6

		Primary Reason for Admit							
		Resp	Cardio	Gastro	Trauma	Sepsis	Metab	Other	
Outcome	n[b]	b	b	b	b	b	b	b	*p*
Concern and caring toward patient	1042/888	0.000	0.030	0.099	0.073	0.136	0.187	0.327	0.804
Pain management	984/841	0.000	0.003	0.193	0.121	0.076	0.111	0.345	0.770
Breathlessness management	904/774	0.000	-0.031	-0.135	-0.082	0.010	0.405	0.559	0.229
Agitation management	944/815	0.000	0.071	-0.052	0.045	0.127	0.298	0.484	0.500
Atmosphere of the ICU	1047/893	0.000	0.129	0.134	0.049	0.117	0.526	0.198	0.322
Consideration of family needs	1038/886	0.000	0.050	0.168	-0.123	0.189	0.514	0.143	0.176
Emotional support	1006/862	0.000	0.096	0.137	-0.055	0.178	0.639	0.139	0.109
Opportunity to be present at bedside	1048/893	0.000	0.052	0.084	-0.037	0.092	0.715	0.234	0.080
Ease of getting information	1043/888	0.000	0.021	0.204	0.046	0.054	0.440	0.116	0.579
Understanding of information	1042/887	0.000	0.024	0.124	0.134	0.075	0.524	0.277	0.276
Honesty of information	1042/887	0.000	-0.048	0.250	0.083	0.034	0.709	0.175	0.060
Completeness of Information									
What was happening	1038/884	0.000	-0.056	0.116	0.065	0.052	0.599	0.173	0.168
Why things were being done	1036/882	0.000	0.046	0.109	0.170	0.093	0.284	0.405	0.614
Consistency of information	1030/880	0.000	-0.041	0.104	-0.092	0.053	0.845	0.321	**0.003**
Overall quality of information									
By doctors	1017/871	0.000	-0.026	0.123	0.014	0.068	0.787	0.269	**0.026**
By nurses	1039/886	0.000	-0.005	0.125	-0.039	0.013	0.437	0.170	0.502
Inclusion in decision-making processes	883/771	0.000	-0.126	0.096	-0.153	0.020	0.269	0.125	0.319
Support during decision-making processes	820/715	0.000	-0.047	0.087	-0.221	0.054	0.659	0.410	0.063
Adequate time to have concerns addressed	760/670	0.000	0.076	-0.098	0.276	0.138	0.003	-0.127	0.931
Overall satisfaction with patient care	1032/879	0.000	-0.040	0.208	-0.091	0.012	0.361	0.279	0.307

---

[a] All associations were tested with six-predictor clustered probit regression models (dummy indicators for six reasons, with respiratory condition serving as the reference category; respondents nested under patients; outcomes defined as ordered categorical variables) estimated with weighted least squares with mean and variance adjustment (WLSMV). *P*-values (statistically significant values presented in boldface) were based on Wald's test.

[b] Sample with valid cases is presented as #respondents/#patients.

7

Quality of dying and death in the ICU

The euroQ2 project

Gerritsen RT, Jensen HI, Koopmans M, Curtis JR, Downey L,
Hofhuis JGM, Engelberg RA, Spronk PE, Zijlstra JG

J Crit Care 2017 Dec 26;44:376-382

Abstract

Purpose

Knowledge of families' perspective of quality of intensive care unit (ICU) care is important, especially with regard to end-of-life (EOL) care. Adaptation of the US-developed "Quality of dying and death questionnaire" (QODD) to a European setting is lacking. The aim of the study is to examine assessments of EOL care in a cohort of Danish and Dutch family members, and to examine the measurement characteristics of the newly developed euroQODD, part of the euroQ2.

Methods

Family members of patients dying in an ICU after a stay of at least 48 hours were sent the euroQODD three weeks after the patient died. Selected patient characteristics were obtained from hospital records. A total of 11 Danish and 10 Dutch ICU's participated.

Results

217 family members completed the euroQODD part of the euroQ2 questionnaire. Overall rating of care was high, a median of 9 in Netherlands and 10 in Denmark on a 0-10 scale ($p<0.001$). The Danish were more likely to report adequate pain control all or most of the time (95% vs 73%; $p<0.001$). When decisions were made to limit treatment, the majority of family members agreed (93%). Most (92%) reported some participation in the decision-making, with half (50%) making the decision jointly with the doctor. About 18% would have preferred greater involvement. Factor analysis of the euroQODD showed two constructs; quality of end-of-life care and quality of dying and death. The quality of dying and death included physical comfort, mental comfort, and dignity.

Conclusions
The majority of family members were satisfied with the quality of EOL care and quality of dying and death. They agreed with decisions made to limit treatment and most felt they had participated to some extent in decision-making, although some would have preferred greater participation. Psychometric assessments showed two constructs measured by the euroQODD: quality of end-of-life-care and quality of dying and death.

Funding
The study was supported by The Region of Southern Denmark, The Novo Nordic Foundation, Denmark (11415), The Augustinus Foundation, Denmark (14-2421), and The Frisian ICU Research Fund, The Netherlands.

Introduction

Caring for the dying patient is part of critical care, and the quality of that care affects not only the patient but his/her family. As the primary goal of treatment switches from cure to comfort, families often experience stress as they may be asked to participate in making difficult decisions to guide care and as they anticipate the loss of their loved one [1,2]. As ICU clinicians, we have an important responsibility for providing good end-of life care to patients and their families. Reliable measurement of the quality of end-of-life care is crucial to identify what goes well and where improvements are needed.

Due to the severity of their illness, ICU patients are rarely able to provide assessments of the care they are receiving, and family members become surrogates for these assessments. Family members' assessments of the quality of patient care have been found to correlate well with patient assessments in non-terminal care, providing support for their use in evaluating end-of-life care provided to critically ill patients [3]. Instruments designed for families to complete include those used to measure the perceived quality of ICU care in general such as the Family Satisfaction in the ICU (FS-ICU) [4]. Others focus on end-of-life care such as the Quality of Dying and Death (QODD) questionnaire developed in the US [5]. The QODD has previously been tested in the Netherlands [6]. Several items had a high rate of missing values, and some items were not seen as relevant by family members. Therefore, we conducted a Danish-Dutch study to develop a new measurement tool, more suitable for our population. The new questionnaire was based on both the FS-ICU and the QODD. This was done in close cooperation with the original developers. Because decision-making is a very important part of end-of- life care, we added questions about the family perceptions of the decision making process. We also included a question about the role family members wanted to play in decision-making. With these new questions, the euroQODD might add to the body of knowledge about family preferences.

This combination of the euroFS-ICU and the euroQODD is called the "European Quality Questionnaire" (euroQ2). Earlier quantitative validation showed high content and face validity [7], This is again briefly explained in the methods section. In this study we report the results of perceived quality of end-of life care based on the euroQODD part of the euroQ2 questionnaire. We also report on a detailed examination of the psychometric characteristics of the euroQODD.

Methods

Instrument

The euroQ2 questionnaire (available as supplemental material) consists of two sections: the euroFS-ICU, which was completed by all participating family members; and the euroQODD, which was completed by family members of patients who died in the ICU. In this article, we report on the 14 questions that compose the euroQODD questionnaire.

Design and setting

Participants were from 21 ICUs in The Netherlands (n=10) and Denmark (n=11). ICUs in both countries included university-affiliated and regional ICUs, with the centers situated in different parts of the countries. This prospective study was performed during a 10-month period from October 2014 until June 2015.

Inclusion and exclusion criteria

Family members of consecutive patients who died in an ICU after a stay of at least 48 hours were eligible for study participation. Up to three family members per patient (including partners, children, siblings, parents and close friends) were identified by the patient (if able) or staff during the patient's hospitalization and received invitations to participate. Family members under the age of 18, those with cognitive impairment and those who were unable to read or write Dutch or Danish were excluded.

Recruitment of participants

Family members received oral and written information about the study and were asked for consent to participate after their loved one died. Three weeks after the patient died in the ICU, family members were sent the euroQ2 questionnaire by regular mail, together with written information and a pre-paid envelope. In the Netherlands all questionnaires were sent out by the investigators; in Denmark the individual ICUs distributed the questionnaires. In both countries, all the completed questionnaires were returned to the investigators. If the questionnaire was not returned, a reminder with a new questionnaire was posted once after two weeks.

Patient and respondent data

Patient data were obtained from medical records and included gender, age, reason for admission (respiratory illness, cardiovascular illness, sepsis, or other condition), length of stay in the ICU, SAPS (Simplified Acute Physiology Score), SOFA (Sepsis-Related Organ Failure Score) and whether the patient received mechanical ventilation. SAPS and SOFA were available only if these scores were collected routinely by the patient's ICU. Characteristics of family members were provided by respondents in the initial section of the euroQ2 questionnaire and included age, gender and relationship to the patient (spouse/partner, child, or other relationship).

The euroQODD consisted of 14 items. Two had binary (no/yes) response options: did the patient discuss preferences for end-of-life treatment with a doctor before ICU admission, or during the ICU stay. An overall rating of end-of-life care was measured with a pseudocontinuous response scale (0 “worst care possible” to 10 “best care possible”) but only one respondent provided a rating below 5. Therefore, we merged this value with the rating of 5, and modeled the result as an ordered categorical variable with six values (5-10). The remaining items were ordered categorical variables. Five response categories described how often the patient appeared to have pain under control, to be comfortable on the ventilator, and to retain dignity: none of the time, a little bit of the time, some of the time, a good bit of the time, most of the time, all of the time. Five responses were also used to describe the extent to which the respondent agreed with decisions to limit treatment: not at all, mostly not, partially, mostly, and totally. Questions about the participants’ role in decision-making regarding continuing or limiting life sustaining treatment, had five response options: doctors without family involvement, doctors after discussion with family, joint doctor/family decision, family after discussion with doctors, family without doctor involvement. Five variables offered three ordinal response options (no, partially, yes): whether the patient received the needed emotional support, whether the patient received the needed spiritual support, whether end-of-life care was concordant with the patient’s wishes; whether the patient’s life was prolonged unnecessarily; and whether the family member had a chance to say goodbye to the patient.

Statistics

In reporting descriptive statistics for continuous measures, we used mean and standard deviation if the Shapiro-Wilk test for departure from normality had *p*-value ≥ 0.05; median and interquartile range (IQR) if the *p*-value was <0.05. All inferential statistics were based on regression models. To account for the non-independence of respondents for the same patient, all models of family data clustered family respondents under patients.

Between-country differences in patient and family characteristics were tested with single-predictor regression models: probit regression, estimated with weighted mean- and variance-adjusted least squares (WLSMV), for binary characteristics (gender, mechanical ventilation); linear regression, estimated with restricted maximum likelihood, for continuously-scored characteristics (age, ICU days, SAPS II, SOFA); multinomial logistic regression, estimated with restricted maximum likelihood, for nominal-scale characteristics (relationship to the patient, reason for admission). *P*-values for binary and continuous items were based on Wald's test; those for nominal-scale variables on likelihood ratio tests.

When between-country differences in patient or family characteristics had $p<0.20$, we adjusted for these characteristics in regression models examining between-country differences in responses to the euroQODD items. In order to control for the number of euroQODD items compared, we used a Bonferroni correction for the number of tests (0.05/14), adjusting the level required for a judgment of statistical significance to $p<0.004$ for the between-country tests of the euroQODD items.

Theoretical constructs measured with multiple indicators facilitate the estimation of measurement error. Although a single interval-scale item can be used as the sole indicator of an underlying construct, this requires *a priori* estimation of its measurement error (a statistic that is frequently unavailable to researchers). Moreover, such estimation is unavailable, using currently-available software, with items such as those in the euroQODD, where response options are ordered categories. Absent an error estimate, single items can be used only under the questionable assumption that they were measured without error [8]. Because of these limitations related to the use of single items, one of the analysis goals for this study was to determine whether the euroQODD included items that could be combined into multi-item constructs related either to the quality of dying and death or to the quality of end-of-life care. To investigate this question, we used factor analytic and structural equation modeling techniques. We evaluated the fit of the resulting models with the χ^2 test of fit, requiring $p>0.05$ for a determination of non-significant misfit of a model to the observed data. Because of the relatively small sample size, all of these models were based on merged data from the two participating countries. Preliminary exploratory factor analyses (EFA) that included 12 euroQODD items (excluding two items measuring actual and preferred roles in decision-making), ruled out the existence of either a univariate or multi-factor model that made use of the full set of items. EFA with subsets of the items improved fit, but produced factor loading patterns that made the factors difficult to name, suggesting that analysis techniques other than EFA were more appropriate for the investigation of multi-item constructs.

One such construct of interest was the overall quality of patients' dying and death. Our explorations of this construct were based on exploratory factor analysis in a confirmatory analysis framework (E/CFA) [9]. Beginning with a unidimensional confirmatory factor analysis (CFA) model in which a single construct (i.e., factor) was measured with the 12 euroQODD items from the initial EFA, the E/CFA procedure involved a series of steps, each resulting in a modification of the model to enhance fit. Modification indices produced at each step guided the procedure and suggested the following types of alteration: introducing additional factors into the model, based on evidence of correlated residuals between pairs of indicators; moving indicators from one factor to another; or removing indicators from the model altogether. Once the model was expanded to encompass more than one factor, each item was allowed to measure only one of the factors, with its loading on other factors constrained to zero. The sequential modeling continued until there emerged a multi-factor model that had acceptable fit to the data. Ultimately, this multi-factor model was extended to include a second-order construct representing the quality of dying and death.

After identifying a multi-item construct representing the quality of dying and death (QODD), we turned attention to the possibility of a multi-item construct representing the overall quality of end-of-life care. We began this search with a focus on theoretical considerations. The instrument developers selected two items as the optimal indicators of the overall quality of end-of-life care: (1) family members' ratings, using a 0-10 scale, of the overall care the patient received from all doctors, nurses and other health care professionals during the last several days of life in the ICU, and (2) their indications of whether end-of-life care matched the patient's wishes (no, partially, yes). Although a two-indicator construct is not statistically identifiable in a confirmatory factor analysis (CFA) measurement model, we used the two-indicator quality-of-care construct as a predictor of the previously-identified QODD construct, to produce a testable structural model, using structural equation modeling techniques.

Sample descriptives were conducted with the Statistical Package for the Social Sciences (SPSS) (IBM, version 21). Between-country comparisons of patient and family characteristics and of euroQODD responses, as well as factor analyses and structural equation models, were done with Mplus7.4.

Validity

In our previous paper on the validation of euroQ2 questionnaire we reported the clinimetric properties of the instrument [7]. A brief summary is repeated here for clarification.

Content validity

In the validation phase, relevance and understand ability were overall very high. For the euroQODD, the median assessment of relevance was 97% (92-100%) and the median assessment of understand ability was 97% (94-100%). Test-retest reliability The average test-retest agreement for the Likert scale responses in the euroQODD was 0.71 (0.53-0.83). Most of those who had changed responses from test to retest within the Likert scale had moved only one "step" up or down the scale or had moved to or from a "Not relevant" response.

The median total euroQODD score patients who died in the ICU 86.8 (73.6-92.1) (p=0.37). The median overall quality of care euroQODD was 90 (80-100).

Ethics

In accordance with Dutch law, the study was approved by the IRB (nWMO 21a) of Medical Centre, which was acknowledged by the institutional review boards of all participating ICU's. In Denmark the study did not need permission from The Regional Committees on Health Research Ethics for Southern Denmark, but permission to assess patient files was obtained from the Danish National Health Authorities (3-3013-353/1), and the study was registered with the Danish Data Protection Agency.

Results

Sample

We sent the euroQ2 to 1,485 family members, of whom 1,077 completed and returned the questionnaire (response rate 72.5%). Of these, 217 family members (representing 174 patients) completed the euroQODD. Respondents included 126 family members from Denmark and 91 from The Netherlands. Table 1 summarizes the characteristics of the responding family members, and demographic and ICU information about their associated patients. Family members were, on average, middle-aged, and the majority were women. Most were the patient's child (46%) or partner (37%). Patients were typically older than the family respondents, and most were men. The median length of stay in the ICU was 8 days, with a majority of the patients receiving mechanical ventilation during ICU treatment.

Table 1. Patient and Family Characteristics[a]

	TOTAL		Netherlands		Denmark		Between-Country Difference[b]
Characteristic	Valid n	Statistic[c]	Valid n	Statistic[c]	Valid n	Statistic[c]	*p*
Family (total n)	217		91		126		
Age, mean (SD)	212	56.1(14.0)	90	57.9(13.8)	122	54.7(14.0)	**0.102**
Male	212	75(35.4)	90	34(37.8)	122	41(33.6)	0.526
Relationship to patient	213		90		123		**0.037**
Spouse or partner		79(37.1)		42(46.7)		37(30.1)	
Child		99(46.5)		34(37.8)		65(52.8)	
Other		35(16.4)		14(15.6)		21(17.1)	
Patient (total n)	178		90		88		
Age, median (IQR)	174	73.0(13.0)	86	73.5(16.0)	88	72.5(13.0)	0.939
Male	174	102(58.6)	86	46(53.5)	88	56(63.6)	**0.174**
Days in ICU, median (IQR)	173	8.2(12.0)	86	7.5(10.0)	87	9.0(13.5)	0.281
Reason for admission	174		86		88		**0.135**
Respiratory		76(43.7)		37(43.0)		39(44.3)	
Sepsis		27(15.5)		17(19.8)		10(11.4)	
Cardiovascular		48(27.6)		25(29.1)		23(26.1)	
Other		23(13.2)		7(8.1)		16(18.2)	
Mechanical ventilation	174	160(92.0)	86	81(94.2)	88	79(89.8)	0.287
SAPS II, mean (SD)	125	59.9(16.8)	67	59.1(18.5)	58	60.9(14.6)	0.551
Admission SOFA, mean (SD)	48	9. (3.6)	43	9.1(3.6)	5	9.2(3.1)	0.965

a *P*-values shown in boldface signify variables that were used as covariates in tests for between-country differences in family respondents' answers to the euroQODD questions.

b The tests for between-country differences were based on regression models: clustered models for characteristics of family members (family members clustered under patients) and unclustered models for patients' characteristics. Each regression model included country as the only predictor and the row variable as the outcome. The following regression types and estimators were used: for continuous outcomes (age, days in the ICU, SAPS II, and SOFA scores) linear regression with restricted maximum likelihood estimation; for unordered categorical outcomes (relationship to patient and reason for admission) multinomial logistic regression with restricted maximum likelihood estimation; for binary outcomes (gender and mechanical ventilation) probit regression with weighted mean- and variance-adjusted least squares estimation (WLSMV). *P*-values for continuous and binary variables were based on Wald's test; those for multinomial regressions were based on likelihood ratio tests.

c Unless otherwise noted, the descriptive statistics presented are n(%). For continuous measures an initial test for normality was done, using the total sample; if the p-value for the Shapiro-Wilk test was <0.05, the median and interquartile range are presented as the descriptive statistic; if the p-value was $\geq$0.05, the mean and standard deviation are presented.

IQR = interquartile range SD = standard deviation n = sample size

Table 2 summarizes responses to the euroQODD questions. In general, family members were highly satisfied with the emotional support provided to the patient, the concordance between the patient's preferences for end-of-life care and the care that was provided, and the possibilities to say goodbye to their loved one, with positive ratings from more than 80% of the respondents. In addition, a large majority (86%) indicated a feeling that the patient's life had not been unnecessarily prolonged. Although preferences regarding end-of-life care were discussed more frequently after ICU admission than before admission, such discussions occurred in a minority of cases at each time point, and 57.5% of the family members with valid responses to both questions indicated that such a discussion had never occurred: 50.0% in the Netherlands, and 63.8% in Denmark (data not shown). After adjustment for the family respondent's age and relationship to the patient and for the patient's gender and reason for admission, there were significant between-country differences on only two items: pain control and the overall rating of care, with family members from Denmark giving higher ratings on both aspects ($p \leq 0.001$).

Table 2. euroQODD Questions

	TOTAL		Netherlands		Denmark		Between-Country Difference[a]	
QODD Aspect	Valid n	n (%)	Valid n	n (%)	Valid n	n (%)	p^b	p^c
Pain under control	190		70		120			
All the time		102(53.7)		27(38.6)		75(62.5)	**<0.001**	**<0.001**
Most of the time		63(33.2)		24(34.3)		39(32.5)		
Good bit of the time		16(8.4)		12(17.1)		4(3.3)		
Some of the time		4(2.1)		2(2.9)		2(1.7)		
A little bit of the time		3(1.6)		3(4.3)		0(0.0)		
None of the time		2(1.1)		2(2.9)		0(0.0)		
Comfortable on ventilator	173		70		103		0.431	0.474
All the time		60(34.7)		26(37.1)		34(33.0)		
Most of the time		63(36.4)		18(25.7)		45(43.7)		
Good bit of the time		21(12.1)		11(15.7)		10(9.7)		
Some of the time		13(7.5)		6(8.6)		7(6.8)		
A little bit of the time		8(4.6)		4(5.7)		4(3.9)		
None of the time		8(4.6)		5(7.1)		3(2.9)		
Keeping dignity	185		73		112		0.347	0.287
All the time		94(50.8)		37(50.7)		57(50.9)		
Most of the time		55(29.7)		17(23.3)		38(33.9)		
Good bit of the time		14(7.6)		6(8.2)		8(7.1)		
Some of the time		15(8.1)		9(12.3)		6(5.4)		
A little bit of the time		6(3.2)		3(4.1)		3(2.7)		
None of the time		1(0.5)		1(1.4)		0(0.0)		
Emotional support for patient	159		65		94		0.837	0.918
Yes		129(81.1)		52(80.0)		77(81.9)		
Partially		27(17.0)		12(18.5)		15(16.0)		
No		3(1.9)		1(1.5)		2(2.1)		
Spiritual support for patient	133		60		73		0.023	0.048
Yes		105(78.9)		42(70.0)		63(86.3)		
Partially		24(18.0)		15(25.0)		9(12.3)		
No		4(3.0)		3(5.0)		1(1.4)		
Discussed preferences								
Before ICU admission	169		80		89		0.091	0.126
Yes		50(29.6)		29(36.3)		21(23.6)		
No		119(70.4)		51(63.7)		68(76.4)		
In ICU	94		41		53		0.422	0.342
Yes		39(41.5)		19(46.3)		20(37.7)		
No		55(58.5)		22(53.7)		33(62.3)		
Care concordant with wishes	154		71		83		0.953	0.614
Yes		133(86.4)		62(87.3)		71(85.5)		
Partially		16(10.4)		5(7.0)		11(13.3)		
No		5(3.2)		4(5.6)		1(1.2)		

	TOTAL		Netherlands		Denmark		Between-Country Difference[a]	
QODD Aspect	Valid n	n (%)	Valid n	n (%)	Valid n	n (%)	*p*[b]	*p*[c]
Life prolonged unnecessarily	204		87		117		0.925	0.878
Yes		9(4.4)		4(4.6)		5(4.3)		
Partially		20(9.8)		8(9.2)		12(10.3)		
No		175(85.8)		75(86.2)		100(85.5)		
Chance to say goodbye	210		89		121		0.692	0.659
Yes		185(88.1)		78(87.6)		107(884)		
Partially		17(8.1)		6(6.7)		11(9.1)		
No		8(3.8)		5(5.6)		3(2.5)		
Overall rating of care (0-10)	214		90		124		**0.001**	**0.001**
10		97 (45.3)		31(34.4)		66(53.2)		
9		62 (29.0)		23(25.6)		39(31.5)		
8		43 (20.1)		28(31.1)		15(12.1)		
7		5(2.3)		4(4.4)		1(0.8)		
6		2(0.9)		1(1.1)		1(0.8)		
3,5		5(2.3)		3(3.3)		2(1.6)		
Decision Making								
Agreed with decision to limit LST	202		86		116		0.318	0.529
Strongly agreed		144(71.3)		66(76.7)		78(67.2)		
Agreed		44(21.8)		14(16.3)		30(25.9)		
Neither agreed nor disagreed		12(5.9)		5(5.8)		7(6.0)		
Disagreed		1(0.5)		0(0.0)		1(0.9)		
Strongly disagreed		1(0.5)		1(1.2)		0(0.0)		
Actual decision-maker(s)	187		78		109		0.449	0.441
Doctor alone		15(8.0)		10(12.8)		5(4.6)		
Doctor after discussing with family		66(35.3)		20(25.6)		46(42.2)		
Joint decision: doctor/ family		94(50.3)		47(60.3)		47(43.1)		
Family after getting information from doctor		11(5.9)		1(1.3)		10(9.2)		
Family alone		1(0.5)		0(0.0)		1(0.9)		
Preferred decision-maker(s)	192		80		112		0.361	0.345
Doctor alone		3(1.6)		2(2.5)		1(0.9)		
Doctor after discussing with family		61(31.8)		18(22.5)		43(38.4)		
Joint decision: doctor / family		117(60.9)		57(71.3)		60(53.6)		
Family after getting information from doctor		11(5.7)		3(3.8)		8(7.1)		
Family alone		0(0.0)		0(0.0)		0(0.0)		

a All variables were defined as ordered categorical variables, with the tests for between-country differences based on probit regression estimated with weighted mean- and variance-adjusted least squares (WLMSV) and the *p*-values based on Wald tests. All models clustered family members under patients.

b These *p*-values are for models containing only the country indicator as predictor and the QODD aspect as the outcome. Values in boldface are those that met the cutoff for statistical significance using the Bonferroni-corrected value.

c These *p*-values are for models that adjusted the association between country and the QODD aspect for possible confounding by the family respondent's age and relationship to the patient and for the patient's gender and reason for admission. Sample sizes for the adjusted model were reduced by 3 to 9 cases, depending upon the outcome, because of cases with valid outcome responses but missing data on one or more of the covariates. Values in boldface are those that met the cutoff for statistical significance using the Bonferroni-corrected value.

LST = life-sustaining treatment

Of the 217 respondents, 212 indicated that decisions were made to limit care, and 187 gave valid responses to a question attributing the decision to doctors and/or the family. The majority (92.0%) of these respondents felt that they had been included to some extent in the decision-making process, with over half (50.3%) perceiving truly shared decision making. Of the 177 respondents who stated both their actual and preferred role, 132 (74.6%) were happy with their actual role, 32 (18.1%) would have preferred more involvement, and 13 (7.3%) would have preferred less involvement than they experienced. Almost no one (1.6%) wanted the doctor to make the decision without involving the family, and no respondents reported wanting to make the decision themselves, without the doctor's input. A large majority (93% of those who provided ratings and for whom the question was applicable) indicated either agreement or strong agreement with the decision that was made to limit treatment.

By and large, family members had little difficulty answering the 14 euroQODD questions. In the combined samples, 81.8% of the questions received valid responses, and only 18.8% were excluded from analyses because of missing data (primarily the result of questions that were inapplicable for a family member or to which the family member didn't know the answer). However, there were four questions for which more than 25% of the responses were unusable: (1) patient discussion of end-of-life care preferences after ICU admission (56.7% missing, with 39.6% inapplicable [patient couldn't communicate]; 14.3% don't know, 2.8% no response), (2) provision of adequate spiritual support (38.7% missing, with 35.5% don't know and 3.2% no answer), (3) concordance between patient's care preferences and care provided (29.0% missing, with 25.3% don't know and 3.7% no response), and (4) provision of adequate emotional support (26.7% missing, with 24.0% don't know and 2.8% no answer). There were significant between-country differences in the amount of missing data on two items: pain control (23.1% missing in The Netherlands; 4.8% in Denmark) and patient discussion of care preferences before ICU admission (12.1% missing in The Netherlands; 29.4% in Denmark).

Multi-item Construct Measuring the Quality of Dying and Death (QODD)

E/CFA analysis yielded a second order quality-of-dying-and-death construct (Figure 1), using data from 208 family members representing 171 patients. The measurement model fit the observed data well (p for the χ^2 test of fit = 0.4235). The underlying QODD construct exerted a causal influence on two first-order latent constructs (physical comfort and mental comfort) and on an additional directly-measured indicator (patient dignity). The two first-order constructs, in turn, exerted causal influences on four measured indicators: physical comfort influencing pain control and ventilator comfort, and mental comfort influencing emotional and spiritual support. All factor loadings were significant at $p<0.001$. QODD accounted for virtually all of the variance in physical comfort (estimated residual variance = 0.082, $p=0.167$), although significant unexplained variance remained in the mental comfort construct (estimate =0.239, $p=0.001$). All standardized loadings had high magnitude (0.779 to 0.957), and R^2 estimates (all with $p<0.001$) indicated that the model accounted for the following percentages of variance in the directly-measured items and latent constructs: 66.1% in patient dignity, 86.5% in physical comfort, 67.3% in mental comfort, and 60.6% in pain control, 67.0% in ventilator comfort, 73.2% in emotional support, and 91.5% in spiritual support (Table 3). Although it would have been useful to test the model for measurement invariance between countries, thus providing evidence that the quality of dying and death construct, so measured, had equivalent meaning in the Netherlands and Denmark, between-group measurement invariance tests have not yet become available for second-order constructs.

Figure 1. Measurement Model of a Second-Order Construct Representing the Quality of Dying and Death, Based on Merged Data from the Netherlands and Denmark (Unstandardized Loadings and Variances)

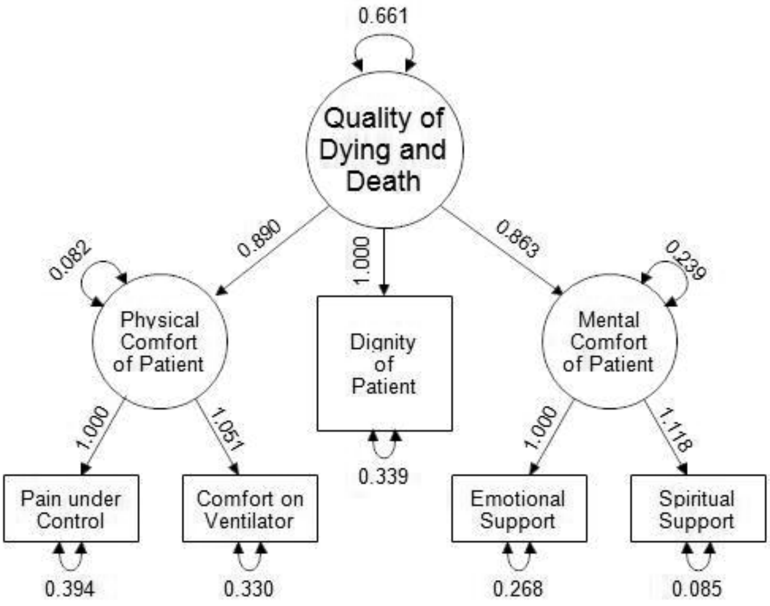


Table 3. Measurement Model of a Second-Order Construct Representing the Quality of Dying and Death, Based on Merged Data from Denmark and the Netherlands (Standardized Thresholds, Loadings, and R^2 Values)

	Thresholds	Loadings		R^2	
Variable		β	*p*	Estimate	*p*
Dignity (Manifest Variable)		0.813	0.000	0.661	0.000
1	-2.549				
2	-1.776				
3	-1.180				
4	-0.861				
5	-0.020				
Physical Comfort (Construct)		0.930	0.000	0.865	0.000
Control of Pain (Manifest Variable)		0.779	0.000	0.606	0.000
1	-2.307				
2	-1.938				
3	-1.671				
4	-1.119				
5	-0.092				
Comfort on Ventilator (Manifest Variable)		0.818	0.000	0.670	0.000
1	-1.682				
2	-1.326				
3	-0.964				
4	-0.556				
5	0.394				
Mental Comfort (Construct)		0.820	0.000	0.673	0.000
Emotional Support (Manifest Variable)		0.855	0.000	0.732	0.000
1	-2.078				
2	-0.883				
Spiritual Support (Manifest Variable)		0.957	0.000	0.915	0.000
1	-1.880				
2	-0.805				

Multi-item Construct Measuring the Overall Quality of End-of-Life Care

Evaluation of the fit of a two-indicator construct measuring the overall quality of end-of-life care required modelling the construct as a predictor of the second-order QODD construct (Figure 2). This structural model, using data from 216 family members of 178 patients, produced a good χ^2 test of fit with $p = 0.1640$. Factor loadings and the structural path linking the quality of end-of-life care to QODD, were all significant at $p<0.001$. The quality-of-end-of-life-care construct accounted for virtually all of the variance in QODD (estimated residual variance = 0.168, *p*=0.201). The quality-of-care construct exerted much stronger influence on family members' measured ratings of overall ICU care at the end of life than on their assessments of concordance between patients' care preferences and the care actually provided, although both loadings (0.897 and 0.532) were statistically significant at p<0.001 (Table 4). R^2 values suggested that the two-indicator quality-of-end-of-life-care construct explained the following percentages of variance: 80.5% in the measured ratings of overall ICU care in the last days of life (*p*<0.001), 28.3% in concordance of care with the patient's wishes (*p*=0.027), and 73.0% in QODD (*p*<0.001). Percentages of variance explained by the QODD construct on its effects were similar to those estimated by the earlier QODD measurement model. Because there were only two indicators, thus precluding evaluation of a pure measurement model, we were unable to test the quality-of-care construct for measurement invariance between countries.

Figure 2. Structural Model of the Second-Order Quality-of-Dying-andDeath Construct, Regressed on a Two-Indicator Construct Representing the Overall Quality of End-of-Life Care, Based on Merged Data from the Netherlands and Denmark (Unstandardized Loadings and Variances)

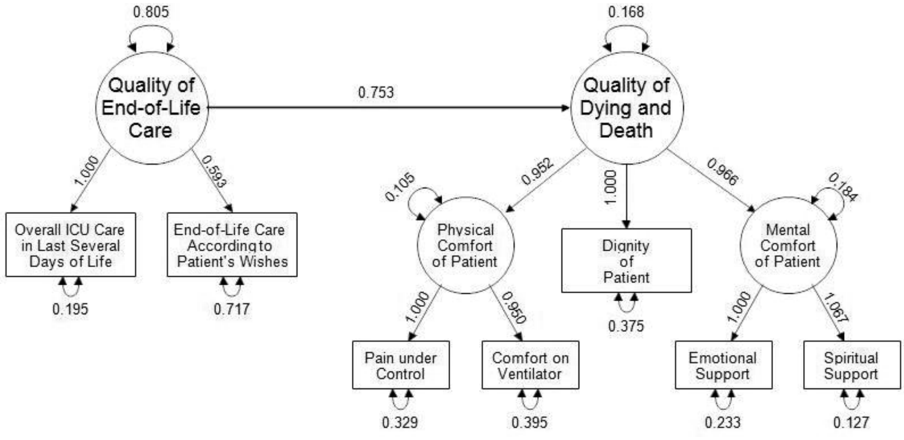


Table 4. Quality of End-of-Life Care as Predictor of Quality of Dying and Death, Based on Merged Data from Denmark and the Netherlands (Standardized Loadings, Path Coefficients, and R^2 Values)

Ultimate Latent Construct	Indicators	Loadings β	Loadings *p*	R^2 Estimate	R^2 *p*
Quality of End-of-Life Care	Overall ICU Care	0.897	0.000	0.805	0.000
	Care According to Patient's Wishes	0.532	0.000	0.283	0.027
Quality of Dying and Death	Dignity	0.790	0.000	0.625	0.000
	Physical Comfort (Latent)	0.918	0.000	0.843	0.000
	Control of Pain	0.819	0.000	0.671	0.000
	Comfort on Ventilator	0.778	0.000	0.605	0.000
	Mental Comfort (Latent)	0.872	0.000	0.760	0.000
	Emotional Support	0.876	0.000	0.767	0.000
	Spiritual Support	0.934	0.000	0.873	0.000
Structural Path					*p*
QODD on Quality of Care		0.490	0.000	0.730	0.000

Discussion

In this study, the euroQODD questionnaire provided relatively high overall ratings of end-of-life care for patients dying in Danish or Dutch ICUs by their family members, with very few significant differences between countries. In general, family members perceived that care was in line with patients' wishes, and only a small minority reported that life was prolonged unnecessarily. These findings are similar to those from studies that have been conducted in other countries, including the US [10,11]. Two items varied significantly between Denmark and the Netherlands with Danish participants providing higher endorsements and ratings: 1) perceived pain control; and 2) overall rating of care. This finding suggests possible opportunities for improvement in care in the Netherlands. Prior studies have identified the importance of symptom control for patients and family members [12,13], and overall assessments have been used as a reliable measure of quality of care [14-16]. However, when considering differences between countries, it is important to take into account how expectations for healthcare and healthcare providers may vary and the effect of this variability on assessments is unknown [17-20].

The high scores correlated well with previously published research on end-of-life care in general [10,11]. Previous studies suggest that support for shared decision-making may be an important factor contributing to high scores of end-of-life care [21]. Our data support this hypothesis. Both Denmark and the Netherlands have legislation and a tradition whereby the medical team make important decisions if patients do not have decision-making capacity. Families cannot make decisions on behalf of the patient but may contribute information about patients' wishes and values. Interestingly, families' perceptions did not reflect this legislation. In the Netherlands, more than 60% of the family members perceived they had participated equally with doctors in decision-making while another 26% perceived that the doctor made the decision after consulting them. In Denmark, the portion of the families that felt they shared in decision-making was somewhat smaller (43%), with an additional 42% perceiving that the doctor made the decisions after consulting the family. Importantly, the majority of family members in both countries reported preferring a shared decision-making approach (slightly higher in the Netherlands at 71% compared to 54% in Denmark.) Our findings suggest that relatives would like to be more involved in decision-making than they currently are. These findings support the hypothesis of an ongoing transition towards shared decision-making [22,23]. This may mark a societal shift towards shared decision-making in Denmark and the Netherlands that is not currently reflected by the laws in these countries.

We also used our data to test whether the euroQODD measures a single unidimensional construct representing the quality of dying and death, or includes a subset of items that measure such a construct. We discovered that instead of measuring a single construct, the QODD includes five items that measure three theoretically-meaningful lower-level domains (physical comfort, mental comfort, and dignity), which in combination measure a second-order construct that can be interpreted as representing the overall quality of dying and death. In addition, two items from the QODD instrument measure quality of end-of-life care, a construct that predicts a significant amount of the variance in the quality-of-dying-and-death construct. The original US-developed QODD survey was designed to measure six theoretical domains: symptom and personal care, preparation for death, moment of death, family, treatment preferences and whole person concerns. However, a six-factor model representing these six domains did not provide adequate fit to data from the US. Although a four-factor model using a subset of the original QODD items provided adequate fit to community data from the[24], several of the items in that study had significant missing data in a study from Denmark and the Netherlands. Our proposed instrument may, therefore, represent an advance in the measurement of quality of dying and end-of-life care in the ICU. Further studies are necessary to confirm these findings, but results from the current study are encouraging.

Recently, a French 15-item CAESAR questionnaire was developed and validated for use among family of critically ill patients who died in the ICU. The authors report one overall score from CAESAR with three domains: patient, interaction with and around the patient and family needs, and satisfaction [16]. Eleven of the questions are similar to the euroQODD. In addition, CAESAR includes questions about communication which we did not include in the euroQODD, although such items were included as a measure of satisfaction with care in the euroFS-ICU. In the euroQODD, questions about decision making are included which are not part of CAESAR. Low CAESAR scores were shown to correlate with higher levels of complicated grief or PTSD.

We did not find an association between low scores on euroQ2 and PTSD or depression, as reported previously [7]. Further studies are needed to assess whether the overall score provided by the CAESAR is unidimensional and how CAESAR and the euroQODD or euroFS-ICU compare in order to address the call for the development of robust quality metrics to improve end-of-life care for critically ill patients [25].

Additional testing of the euroQ2 questionnaire in countries from other regions, including Southern and Eastern Europe, is currently underway. This is important for future development. Also adaptation of the questionnaire with additional questions might improve the psychometric characteristics of the instrument.

Strengths and limitations

A relative strength of this study was the enrollment of more than 1,000 family members from two countries, of which 217 completed the euroQODD. Furthermore, family members were related to patients who were treated in 21 ICUs of different types and located in several geographic areas, a diversity that increases the generalizability of results. The high response rate and small number of unanswered questions are additional strengths.

There are also important limitations. Despite the high number of participants in the overall study, far fewer respondents were eligible for completing the QODD portion of the questionnaire. This smaller sample, drawn from two relatively limited geographic areas, decreases one's confidence in the generalizability of the result. Moreover, we were unable to test for between-country measurement invariance in either the QODD construct (because of its complexity) or the quality-of-care construct (because there were only two available indicators), so we cannot be certain that the latent constructs have the same meaning in both countries.

Conclusion

The euroQODD part of the euroQ2 project provides information about families' experiences with dying and death of their family member in the ICU. The perceived quality of end-of-life care is relatively high, and a majority of participants believed that care at the end-of-life was in accord with patient wishes. However, we identified some areas for improvement. Importantly, family members desired a higher level of participation in decision-making than they perceived occurring. There was also room for improvement in pain and symptom control. A small group of relatives found that the patient's life was unnecessarily prolonged, which may also represent an area for improvement. Psychometric assessment suggests that this version of the euroQODD warrants additional study as an outcome for palliative care interventions in the ICU. The euroQ2 – a pairing of the euroFS-ICU and the euroQODD -- provides a promising new instrument to assess ICU care and identify areas for improvement.

References

1. Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med*. 2001;29(10):1893-7.

2. Pochard F, Darmon M, Fassier T, Bollaert P, Cheval C, Coloigner M, et al. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *American journal of respiratory and critical care medicine.* 2005;20(1):90-6.

3. Stricker KH, Kimberger O, Brunner L, Rothen HU. Patient satisfaction with care in the intensive care unit: can we rely on proxies? *Acta Anaesthesiol Scand.* 2011 Feb;55(2):149-56.

4. Heyland DK, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ, et al. Family satisfaction with care in the intensive care unit: results of a multiple center study. *Crit Care Med.* 2002;30(7):1413-8.

5. Patrick DL, Curtis JR, Engelberg RA, Nielsen E, McCown E. Measuring and improving the quality of dying and death. *Ann Intern Med.* 2003 Sep 2;139(5 Pt 2):410-5.

6. Gerritsen RT, Hofhuis J, Koopmans M, van der Woude M, Bormans L, Hovingh A, et al. Perception by Family members and ICU staff of the Quality of Dying and death in the ICU - A prospective multi-center study in the Netherlands. *Chest.* 2013;143(2):357.

7. Jensen HI, Gerritsen RT, Koopmans M, Zijlstra JG, Curtis JR, Ording H. Families' experiences of intensive care unit quality of care: Development and validation of a European questionnaire (euroQ2). *J Crit Care.* 2015 Oct;30(5):884-90.

8. Kline R. principles and Practice of Structural Equation Modeling. 4th edition ed. New York: *Guilford press*; 2016.

9. Brown TA. Confirmatory Factor Analysis for Applied Research. New York: The Guilford press; 2006.

10. Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage.* 2002 Jul;24(1):17-31.

11. Levy CR, Ely EW, Payne K, Engelberg RA, Patrick DL, Curtis JR. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. *Chest.* 2005 May;127(5):1775-83.

12. Clark K, Cain J, Campbell L, Byfieldt N. Caring for people dying in acute hospitals: A mixed-methods study to examine relative's perceptions of care. *Palliat Support Care.* 2014 Mar 13:1-9.

13. Hartog CS, Schwarzkopf D, Riedemann NC, Pfeifer R, Guenther A, Egerland K, et al. End-of-life care in the intensive care unit: A patient-based questionnaire of intensive care unit staff perception and relatives' psychological response. *Palliat Med.* 2015 Apr;29(4):336-45.

14. Heyland DK, Tranmer JE, Kingston General Hospital ICU Research Working Group. Measuring family satisfaction with care in the intensive care unit: the development of a questionnaire and preliminary results. *J Crit Care.* 2001 Dec;16(4):142-9.

15. Wall R, Engelberg R, Downey L, Heyland D, Curtis J. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. *American journal of respiratory and critical care medicine.* 2007;35(1):271-9.

16. Kentish-Barnes N, Seegers V, Legriel S, Cariou A, Jaber S, Lefrant JY, et al. CAESAR: a new tool to assess relatives' experience of dying and death in the ICU. *Intensive Care Med.* 2016 Jun;42(6):995-1002.

17. Huibers L, Moth G, Andersen M, van Grunsven P, Giesen P, Christensen MB, et al. Consumption in out-of-hours health care: Danes double Dutch? *Scand J Prim Health Care*. 2014 Mar;32(1):44-50.

18. Huibers LA, Moth G, Bondevik GT, Kersnik J, Huber CA, Christensen MB, et al. Diagnostic scope in out-of-hours primary care services in eight European countries: an observational study. *BMC Fam Pract.* 2011 May 13;12:30,2296-12-30.

19. Lewis-Newby M, Curtis JR, Martin DP, Engelberg RA. Measuring Family Satisfaction with Care and Quality of Dying in the Intensive Care Unit: Does Patient Age Matter? . *J Palliat Med.* 2011:111122115038009.

20. Jackson J, Derderian L, White P, Ayotte J, Fiorini J, Hall RO, et al. Family Perspectives on End-of-Life Care. *Journal of Hospice & Palliative Nursing.* 2012;14(4):303-11.

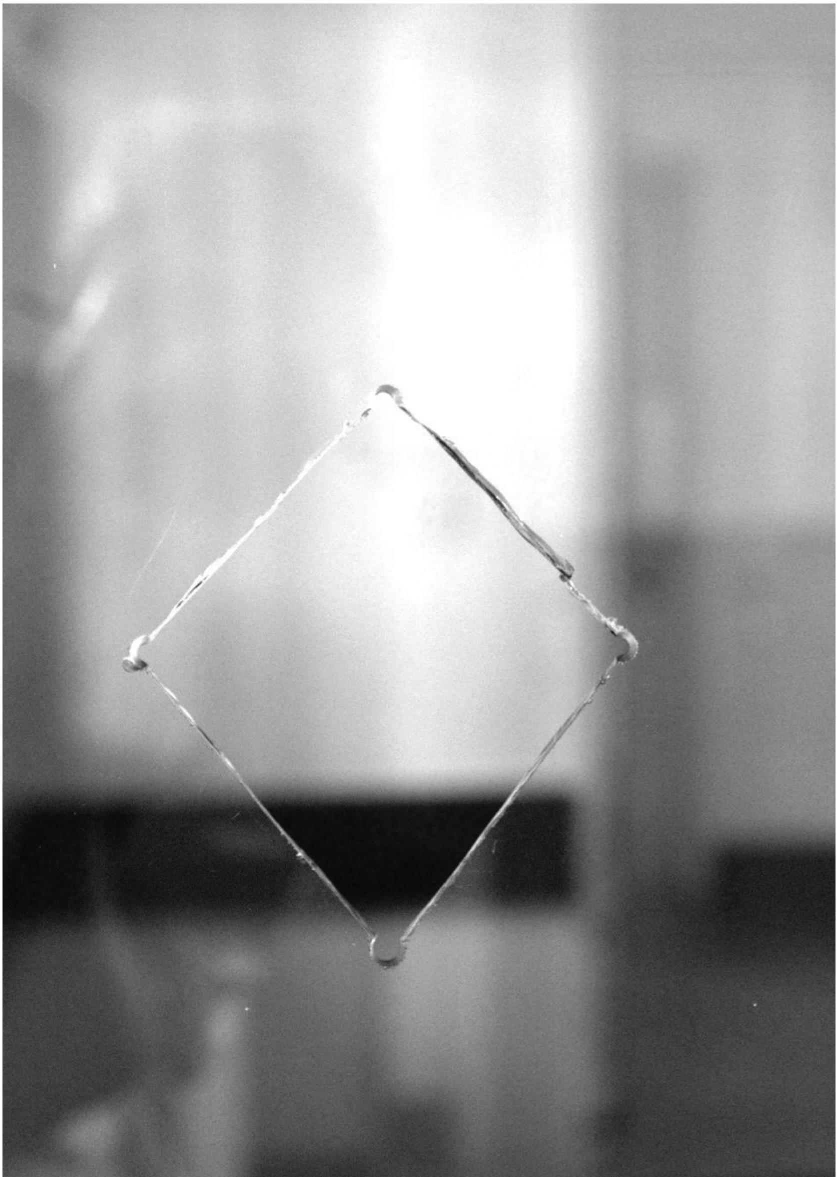
21. Hinkle LJ, Bosslet GT, Torke AM. Factors Associated With Family Satisfaction With End-of-Life Care in the ICU: A Systematic Review. *Chest*. 2015 Jan 1;147(1):82-93.

22. White DB, Braddock CH,3rd, Bereknyei S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Intern Med.* 2007 Mar 12;167(5):461-7.

23. Curtis JR, Tonelli MR. Shared decision-making in the ICU: value, challenges, and limitations. *Am J Respir Crit Care Med*. 2011 Apr 1;183(7):840-1.

24. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. *J Pain Symptom Manage.* 2010 Jan;39(1):9-22.

25. White DB, Ernecoff N, Billings JA, Arnold R. Is Dying in an ICU a Sign of Poor Quality End-of-Life Care? *Am J Crit Care. 2013;22(3):263-6.*



Summary

Intensive Care is often thought to be focussing on machines and heroism. The essence of intensive care medicine is about making choices. It is about trying to provide the right care to the right patient at the right time. Deciding on what treatment is offered to a patient is challenging. In brings together the basic ethical principles of autonomy, beneficence, non-maleficence and distributive justice. Because most ICU patients lack decision making capacity due to the nature of their illness, the dilemmas of surrogate decision making is often added. Involving families in the care in general but especially in decision-making is part of the daily tasks of an ICU professional. Medical challenges, ethical dilemmas and providing care for the patients and the families of that patients makes the intensivists job complicated but also very rewarding. To provide good care for the patients and his loved-ones is a wonderful task. To be able to do that, the ICU professional has to be aware of the needs of patients and families. Trying to get to know these needs and answer to them has become my main professional interest and ultimately the subject of this thesis. **Chapter one** elaborates on above named dilemmas in an introduction.

In **chapter two** reasons for providing family centered care (FCC) are given. Also practical advices to improve FCC are listed. Allowing family members to be present at the bedside without restriction, providing tools and education to improve communication between the family and the ICU-team and calling for external professionals like ethicist to join the care-team if needed are examples. These evidence based recommendations are derived from the guideline on family centered care recently published by the Society of Critical Care (SCCM).

Although most patients are discharged alive after ICU treatment, a number of patients die in the ICU. Providing good end-of-life care for the patient en his or her family is an integral part of ICU care.

In **chapter three** *w*e try to elucidate how family members and ICU care-givers experience the dying process their patients. This prospective study took place in three Dutch ICUs. The Quality of Dying and Death questionnaire (QODD) was used as a tool with addition of items pertaining to the patient's autonomy. Values indicate median and interquartile range. We included 100 consecutive patients. ICU stay before death was 8 [3-16] days. APACHE-II score was 24 [19-31]. Family response rate was 89%. Families were satisfied with over-all QODD (score 8 [7-9]) and felt supported by the ICU care-givers (8[7-9]). Pain control was scored lower by family members (8[5.75-8.25]) than by nurses and physicians (9[8-10]; p=0.024). Almost always, physicians discussed the patient's end-of-life wishes with family members, although families rated the quality of the discussion lower 7 [5.5-8.5] than physicians 9 [6.5-10] (p=0.045). The majority of the families (89%) felt included in the decision-making process. More than half of the family members (57%) felt that the physician took the final decision alone after giving information, while 36.8% felt they had really participated in taking the decision. Family members rated the QODD questionnaire as difficult 6[5-8] and several items irrelevant. There seems to be a need for revising the QODD to the local setting.

In **chapter four** we evaluated end-of-life (EOL) experiences as measured by the QODD completed by families and nurses in the United States (US) and the Netherlands (NL). We aim to explore similarities and differences in these experiences and identify opportunities for improving EOL care. The QODD questionnaire is used as a self-reported measure to allow families and clinicians to assess patients' quality of dying and death. Data were gathered from family members of patients dying in the ICU and nurses caring for these patients. In NL, data were gathered in three teaching hospitals; in the US from 12 sites participating in a randomized trial. The QODD is consists of 25 items and has been validated in the US. Dutch patients were older than those in the US (72 ±10.2 vs. 65 ±16.0, p<0.0025). The family-assessed overall QODD score (medians [IQR]) was the same in both countries: NL 9 [8-10], US 8[5-10]. US family members rated the quality of two items higher than NL families: “time spent with loved ones” and “time spent alone”. Nurse-assessed QODD ratings varied: the single-item QODD summary score was significantly higher in NL (NL 9 [8-10] vs US 7 [5-8]; p<0.0025), while the QODD total score, score per item added divided by the number of items answered, was higher in the US (NL 6.9 [5.5-7.6] vs US.7.1 [5.8-8.4]; p=0.014), although not meeting our criteria for statistical significance. Of the 22 nurse-assessed items, 10 were significantly different between NL and US with 8 higher in the US and 2 higher in NL. Some of these are because the patients ‘severity of illness may differ, like “being in control be able to feed himself”’. But most of the differences may be due to organizational or cultural differences between the two countries or to expectations of respondents.

As previously stated the QODD needs local adaptation to maximize its usefulness in a European population. In **chapter five** the first steps are described to adapt and provide preliminary validation for a questionnaire evaluating families’ experiences of quality of care for critically ill and dying patients in the ICU. This paper reports a study that took place in two European ICUs. Based on literature and qualitative interviews we adapted two previously validated North American questionnaires: “Family Satisfaction with the ICU” (FS-ICU) and “Quality of Dying and Death” (QODD). Family members were asked to assess relevance and understandability of each question. Validation also included test-retest reliability and construct validity. A total of 110 family members participated. Response rate was 87%. For all questions a median of 97% (94-99%) were assessed as relevant and a median of 98% (97-100%) as understandable. Median ceiling effect was 41% (30-47%). There was a median of 0% missing data (0-1%). Test-retest showed a median weighted kappa of 0.69 (0.53-0.83). Validation showed significant correlation between total scores and key questions. These measures are promising for use in research, but further validation is needed before they can be recommended for routine clinical use. This process is described in chapter six.

Families' perspectives are of great importance in evaluating quality of care in the Intensive Care Unit (ICU). In **chapter six** we describe a Danish-Dutch study tested a European adaption of the "Family Satisfaction in the ICU" (FS-ICU). The aim of the study was to examine assessments of satisfaction with care from a large cohort of Danish and Dutch family members and to examine the measurement characteristics of the euroFS-ICU.

Data were from 11 Danish and 10 Dutch ICUs and included family members of patients admitted to the ICU for 48 hours or more. Surveys were mailed three weeks after patient discharge from the ICU. A total of 1,077 family members of 920 ICU patients participated. Response rate for approached family members was 72%. "Excellent" or "Very good" ratings on all items ranged from 58-96%. Items with the highest ratings were: concern toward patients, ICU atmosphere, opportunities to be present at the bedside, and ease of getting information. Items with room for improvement were management of patient agitation, emotional support of the family, consistency of information, and inclusion in and support during decision-making processes.

Exploratory factor analysis suggested four underlying factors, but confirmatory factor analysis failed to yield a multi-factor model with between-country measurement invariance. A hypothesis is that this failure was due to misspecification of causal indicators as reflective indicators. The euroFS-ICU and other similar instruments may benefit from adding reflective indicators.

The euroFS-ICU as described in chapter six reports the perceived satisfaction with general ICU care. Because end-of-life care is an important part of ICU care a special part of the euroQ2 questionnaire focusses on the perceived quality of the care for the dying (part 3). This includes satisfaction with the decision-making process and also the perceived quality of care for the relatives themselves. The aim of this study, described in **chapter seven,** is to examine assessments of EOL care in a cohort of Danish and Dutch family members and to examine the measurement characteristics of the euroQODD. Family members of patients dying in an ICU after a stay of at least 48 hours were sent the euroQODD questionnaire by regular mail three weeks after the patient died. A total of 11 Danish and 10 Dutch ICU's participated, 217 family members completed also the euroQODD part of the euroQ2 questionnaire. Overall rating of care was high, a median of 9 in Netherlands and 10 in Denmark on a 0-10 scale ($p<0.001$). The Danish were more likely to report pain control all or most of the time (95% vs 73%; $p<0.001$). When decisions were made to limit treatment, the majority of family members agreed (93%). Most (92%) reported some participation in the decision-making, with half (50%) making the decision jointly with the doctor. About 18% would have preferred greater involvement. Factor analysis of the euroQODD showed two constructs; "quality of end-of-life care" and "quality of dying and death". The construct quality of dying and death included physical comfort, mental comfort and dignity.

The **conclusion** of this thesis is that the perceived quality of general ICU care and especially end-of-life care in Danish and Dutch ICU's is good. Although there are distinct areas in which improvement is called for. With the development and validation of the *euroQ2 questionnaire* a useful tool for the Danish and Dutch intensivist is added to their armamentarium. The instrument needs to be adapted further and validation in other European countries is necessary before it can be recommended for routine use in evaluation of quality of care in ICU's in general.

Future perspectives

With the research about family centered care and family satisfaction presented in this thesis a start is made with the acknowledgement of the role of family members and measuring of the perceived opinion of families of ICU patients and with this, getting insight in areas for improving care for relatives and for patients.

A change in paradigm is clearly present in many ICU's around the world. The staff has stopped talking about a disease in a bed and now sees a person with a problem. This movement has evolved even further and now the family, in its broadest sense, is receiving attention as part of the care for the patient. Of course the needs of the patient come first but needs of the family are to be noticed and cared for. With relatives being present not only during limited visiting hours they can become an important source of information for the team but also for the patient sometimes. The family can translate it for the patient in understandable information and repeat the information for confused patients. Taking into account that ICU patients often lack possibilities for communication, family should be regarded as "the expert of normal" explaining to the team who the patient is as a person and what his or hers preferences and goals of care are. But the role of families can be taken even further during longer periods that relatives are present. They can become an actual part of the care team, practically participating in the bedside care.

This paradigm shift is initiated by families and endorsed by many professionals. In the coming years it has to be established if it really adds value for the patients and for the families themselves. In the future we might not only judge ICU quality by objective parameters as mortality or length of stay but more by subjective ones like patient and family reported outcome or experienced measures.

There also needs to be attention for the costs and benefits for the ICU professionals. Practicing family centered care can by rewarding but it can also have a negative effect e.g. on workload or privacy.

In addition to research establishing the benefits for patients and families, there has been more attention to the well-being of the professionals of the ICU team. There is a need for studies looking at the effect of the shift to more family centered care in stead of disease centered care on threats like burn-out of members of the ICU team, workload and safety. The broadening view of what care for a critically ill patient means can benefit but also harm professionals working in a stressful environment as an intensive care unit.

With the development of the euroQ2 questionnaire we have started to develop a tool to get structural input from family members in a quantitative and qualitative way, but the instrument has been shown to be far from perfect at this stage.

As most quality measuring questionnaires we encountered a considerable ceiling effect. Modifying the positive answer categories by adding e.g. answer category "perfect" might be able to extract more information from the same questions. Specific issues in translation have to be dealt with.

The construct validity, especially of the domain overall satisfaction, might be improved by adding some more reflective questions at the end of each part of the euroQ2 questionnaire. To prevent "questionnaire fatigue" adding questions that look almost similar needs to be accompanied by clear explanation and instructions otherwise it might result in getting less information from relatives instead of more.

The initiative to adapt the existing American questionnaires is a joined effort from Danish and Dutch investigators with great support from the authors of the original questionnaires. The ambition, that is why the questionnaire is named "euroQ2", is to make it applicable in other European countries. To achieve this a validation pilot, like the ones in Denmark and the Netherlands was conducted in Belgium, Spain, and Germany. A pilot is planned in Norway and with the extra questions added in the United Kingdom. An online tool: www.euroQ2.org is in place to help new investigators with instruction materials and a data collection tool. With this tool the data from the various pilots will fill one uniform database to facilitate comparison and international research in the future.

The questionnaire might help to create input for quality improvement in ICU care. The focus on patient reported experience measures is a widespread and contemporary way to look at outcome in adjunction to more exact outcome measures like mortality. With the euroQ2 we might help to find, in this case family reported, experience measures for ICU care and especially end-of-life care.

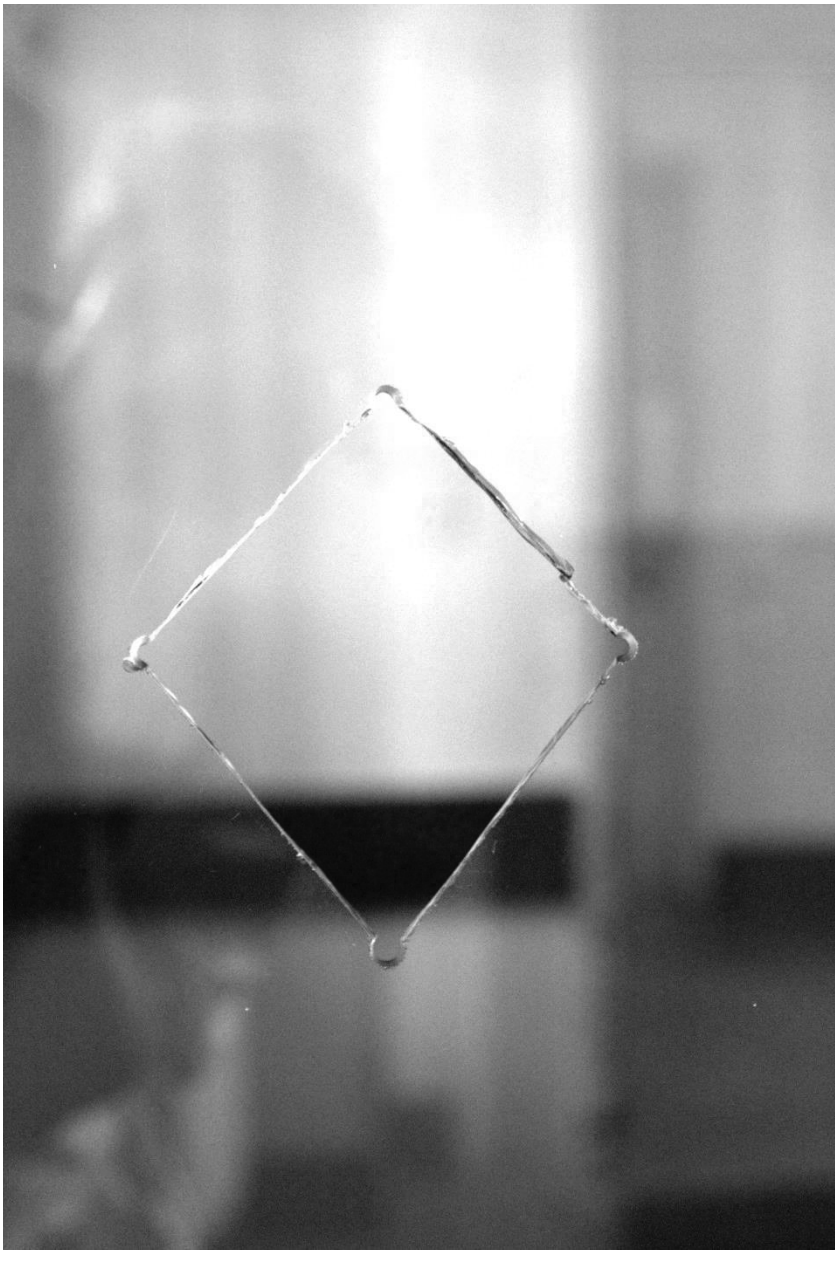
The input form the questionnaire gives quantative information, but the free text items are an opportunity to get directions for quality improvement strategies with the highest priority or highest added value. They provide specific items that can improve family satisfaction when taken care of. A paper analysing the free text answers in the euroQ2 in a qualitative way is to be published in the near future.

With the combination of quantative and qualitative data from the euroQ2 project a source of information is now available for intensive care professionals looking for ways to critically appraise their work.

A domain that the euroQ2 showed needs attention is communication. Communication has to be understandable, honest and consistent. There have been numerous studies looking at communication between professionals and patients and relatives in ICU’s studying strategies or communication aids, but still more work is needed. Communication between professionals is also extremely important. There are very few proven effective strategies. The ethic section of the ESICM has made inter-professional communication a special focus and several research projects looking at this are initiated and endorsed.

With the broadening of the view of professionals from disease to a human with surrounding family, the ICU professional in his striving to improve, is making him or herself vulnerable. He is no longer the authority on a pedestal that knows best and goes his own way, but becomes a partner of the patient and family that together with them strives for the best result.

Further research on ICU well being should include not only patients and relatives but also look at the effects on the ICU professionals themselves. Because the changing role is a good thing but may lead to people losing the solid ground they had for years. This may lead to stress and burnout. The change in paradigm toward family centered care is the way to go but we need to be aware of all effects, also the negative ones, in future studies.



Samenvatting

Bij intensive Care denkt men vaak dat het gaat om heroïek en apparaten. De essentie van intensive care geneeskunde is echter het maken van keuzes. Het gaat erom de beste zorg te bieden aan die patiënt op de juiste plek op het goede tijdstip. Om te bepalen welke behandeling aan welke patiënt aangeboden wordt is vaak een lastig dilemma. De vier basis principes van de bio-ethiek: autonomie, goed doen, niet schaden en rechtvaardigheid zijn daarin leidend. Omdat de meeste patiënten bij wie intensive care behandeling wordt overwogen te ziek zijn om adequaat te kunnen beslissen speelt naast bij de eerder genoemde vier principes ook het probleem van de indirecte beslissing door naasten. Familieleden, in de ruimste zin van het woord, betrekken bij de zorg in het algemeen en bij het nemen van beslissingen omtrent zorg in het bijzonder is een dagelijks terugkerende taak van de intensive care professional. Medisch technische problemen, ethische dilemma's en de zorg voor de patiënt en zijn of haar omgeving maakt het vak intensivist uitdagend maar geeft ook veel voldoening als het goed gedaan wordt. Om goede zorg te kunnen en mogen aanbieden aan patiënt en de naasten is een fantastische taak. Maar om die taak goed te kunnen uitvoeren moet de ICU professional op de hoogte zijn van de wensen en verlangens van die patiënt en zijn familie. Om de waarden, wensen en verwachtingen van patiënten en de familie goed in te kunnen schatten en zo zoveel mogelijk tegemoet te kunnen komen is mijn professionele uitdagende taak en uiteindelijk het onderwerp van dit proefschrift. **Hoofdstuk één**, de inleiding, verdiept bovengenoemde dilemma's en schetst de opbouw van het proefschrift.

In **hoofdstuk twee** worden redenen gegeven om naast zorg voor de patiënt ook aandacht te besteden aan zorg voor de familie, de zogenaamde “family-centered care “ (FCC). Er worden praktische adviezen beschreven om FCC vorm te geven. Familieleden onbeperkt de gelegenheid geven bij hun naasten aanwezig te kunnen zijn, het beschikbaar stellen van handvatten en hulpmiddelen aan de families om de gecompliceerde IC omgeving te kunnen snappen en communicatie met de professionals te verbeteren zijn voorbeelden. Verder wordt het advies om laagdrempelig externe expertise zoals ethici of consulenten palliatieve zorg te betrekken bij de zorg gegeven. Deze, door bewijs onderbouwde aanbevelingen, zijn ontleend aan de recent door de Amerikaanse Intensive care beroepsvereniging, Society of Critical Care Medicine (SCCM) gepubliceerde richtlijn.

Hoewel het overgrote deel van de op de intensive care behandelde patiënten levend wordt ontslagen, is er ook een deel waarbij de behandeling niet leidt tot herstel en die op de intensive care overlijdt. Om ook voor deze groep patiënten en hun naasten goede zorg, met name einde-leven-zorg te kunnen bieden is een integraal en belangrijk onderdeel van intensive care zorg.

In **hoofdstuk drie** wordt geprobeerd vast te stellen hoe familieleden, artsen en verpleegkundigen op de IC het stervensproces en de eind-leven zorg hebben beleefd. Deze prospectieve studie vond plaats in drie Nederlandse intensive care afdelingen (ICU) Een vertaalde versie van de Amerikaanse vragenlijst "The Quality of Dying and Death questionnaire (QODD) is als meetinstrument gebruikt waarbij er ook vragen over het proces van het komen tot beslissingen waren toegevoegd. Gerapporteerd worden medianen en interkwartiel spreiding. We hebben 100 opeenvolgende patiënten geïncludeerd. Gemiddeld verblijfsduur op de IC voor overlijden bedroeg 8 [3-16] dagen. APACHE-II score was 24 [19-31]. 89% van de familieleden heeft gereageerd. Families waren tevreden met overall QODD (score 8 [7-9]) en voelde zich gesteund door het ICU team (8[7-9]). Voorkomen van adequate pijnstilling werd door familieleden lager gescoord 8[5.75-8.25]) dan door artsen en verpleegkundigen (9[8-10]; p=0.024). Bijna altijd werd door artsen met familie over de wensen omtrent het levenseinde gesproken Maar familieleden beoordeelden deze gesprekken minder goed 7 [5.5-8.5] dan de artsen zelf 9 [6.5-10] (p=0.045). De meerderheid van de families (89%) voelde zich betrokken bij het nemen van beslissingen rond het levenseinde. Echter meer dan de helft van de familieleden (57%) gaf aan dat de arts de uiteindelijke beslissing had genomen na informatie te hebben ingewonnen bij hen, toch vindt een derde van de naasten 36.8% dat zij echt hebben geparticipeerd in het nemen van de beslissing levensverlengende behandeling te beperken. Familieleden beoordeelden de QODD vragenlijst als ingewikkeld 6[5-8] en diverse items als irrelevant. Er lijkt een noodzaak te bestaan om de QODD vragenlijst aan te passen voor lokaal gebruik.

In **hoofdstuk vier** hebben zijn de ervaringen met einde-leven-behandeling beschreven van Nederlandse (NL) patiënten en verpleegkundigen. Deze worden vergeleken met hun Amerikaanse (US) evenknieën. We hebben daarvoor de QODD vragenlijst gebruikt. Er werd gezocht naar overeenkomsten en verschillen om gebieden te identificeren waarop verbeteringen mogelijk zijn binnen de einde-leven-zorg. De QODD vragenlijst is gebruikt als een self-reported instrument. De gegevens warden door familieleden van patiënten die op de IC zijn overleden en de hen tijdens de laatste fase verzorgende verpleegkundigen te ondervragen. In Nederland in drie algemene ziekenhuizen en in de Verenigde Staten in twaalf ziekenhuizen die mee deden in een gerandomiseerd onderzoek naar einde-leven-zorg. De QODD bestaat uit 25 items en deze vragenlijst is gevalideerd in de USA. Nederlandse patiënten ware ouder dan de Amerikaanse (72 ±10.2 vs. 65 ±16.0, $p<0.0025$). De door familieleden gescoorde overall QODD score was hetzelfde in beide landen: NL 9 [8-10], US 8[5-10]. Twee items werden door US familieleden hoger gescoord dan door Nederlandse families: “tijd doorgebracht met de naasten” en “tijd alleen doorgebracht”. De door de verpleegkundigen gerapporteerde QODD scores verschilden meer: de single-item QODD overall score was significant hoger in NL (NL 9 [8-10] dan in de US 7 [5-8]; $p<0.0025$), terwijl de zogenaamde QODD totaal score, score per item opgeteld, gedeeld door het aantal beantwoorde items, juist hoger was in de US (NL 6.9 [5.5-7.6] vs US.7.1 [5.8-8.4]; $p=0.014$), dit laatste verschil was echter niet significant. Van de 22 items die door de verpleegkundigen werden ingevuld waren er tien significant verschillend tussen de beide landen. Acht werden hoger in de US gescoord en twee hoger door Nederlandse verpleegkundigen. Sommige verschillen lijken te berusten op een verschil in ernst van ziekte van de beoordeelde patiënten zoals "patiënt was in controle" en "was in staat zichzelf te voeden" . Maar de meeste verschillen lijken toch veroorzaakt door verschillen in organisatie, culturele verschillen en verwachtingen van de respondenten.

Zoals reeds eerder opgemerkt moet de QODD vragenlijst aangepast worden om hem lokaal toepasbaar te maken voor een Europese populatie. In **hoofdstuk vijf** worden de eerste stappen beschreven van de ontwikkeling en voorlopige validatie van een vragenlijst om de door familie beleefde kwaliteit van de zorg voor hun naaste op de intensive care en van de zorg voor de stervende IC patiënt. Dit artikel beschrijft een studie die plaats vond op twee Europese IC's. Gebaseerd op literatuur, kwalitatief onderzoek en de mening van experts werd de elders gevalideerde Amerikaanse vragenlijsten: "Family Satisfaction with the ICU" (FS-ICU) en "Quality of Dying and Death" (QODD) aangepast en aangevuld. Familieleden werd gevraagd van iedere vraag in deze aangepaste vragenlijst de begrijpelijkheid en de relevantie te beoordelen. Construct validatie omvatte ook een "test-retest" betrouwbaarheidsmeting. In totaal deden 110 familieleden mee. 87% van de aangezochte naasten hebben geparticipeerd. Van alle vragen werd mediaan 97% (94-99%) als relevant en mediaan 98% (97-100%) als begrijpelijk beoordeeld. Er was sprake van een plafond effect 41% (30-47%). Er waren mediaan 0% ontbrekende data (0-1%). Test-retest liet een gewogen kappa van 0.69 (0.53-0.83) zien. Validatie liet een significante correlatie zien tussen de overall scores en hoeksteen vragen. Deze uitkomsten zijn veelbelovend voor gebruik van de vragenlijst in onderzoek, maar voor routine klinisch gebruik moet eerst verdere validatie worden afgerond. Dit proces wordt in hoofdstuk zes beschreven.

Om kwaliteit van intensive care zorg te beoordelen kan gebruikt worden gemaakt van het perspectief van familieleden. In **hoofdstuk zes** wordt een Deens-Nederlandse studie beschreven met een aangepaste versie van de Amerikaanse "Family Satisfaction in the ICU" (FS-ICU) vragenlijst . Het doel van deze studie is om de beleefde kwaliteit van de intensive care zorg te onderzoeken in een groot cohort van Deense en Nederlandse familieleden en om de clinimetrische karakteristieken van het aangepaste instrument, de "euro-FS-ICU" te onderzoeken. Dit deel bestaat uit deel 1 en 2 van de "euroQ2" vragenlijst.

Data werden verzameld op 11 Deense en10 Nederlandse IC's familieleden van patiënten die langer dan 48 uur warden behandeld kwamen in aanmerking. Vragenlijsten werden per post naar de familie verstuurd drie weken na ontslag van de patiënt. In totaal deden 1077 familieleden van 920 patiënten mee aan dit deel van het onderzoek. 72% van de benaderde familieleden heeft daadwerkelijk de vragenlijst ingevuld en teruggestuurd. "Uitstekend" of " Zeer goed" als antwoordcatagorie varieerden tussen 58-96% per item. Items met de hoogste score waren "zorgzaamheid en hartelijkheid"," sfeer op de IC", "mogelijkheden om bij de patiënt te zijn" en "het gemak om informatie te verkrijgen". Items met een minder hoge score en dus ruimte voor verbetering waren: "behandeling van patiënts onrust", "emotionele steun voor de familie", "consistentie van informatie" en "betrokkenheid en steun bij besluitvorming".

Exploratoire factor analyse suggereerde vier onderliggende factoren. Maar bevestigende factor analyse leverde een multi-factor model doordat er tussen de metingen in de twee nationale datasets teveel variantie zit (measurement invariance) . Mogelijk is dit veroorzaakt doordat formatieve indicatoren als reflectieve indicatoren zijn geïnterpreteerd. Vragenlijsten zoals de euroFS-ICU hebben mogelijk baat bij extra reflectieve indicatoren waardoor de factor structuur duidelijker wordt.

De euroFS-ICU zoals beschreven in hoofdstuk zes beschrijft beleefde tevredenheid met intensive care zorg in het algemeen. Omdat zorg rond het levenseinde een belangrijk aspect is van intensive care zorg is daar een speciaal deel (deel3) van de euroQ2 vragenlijst aan gewijd. Dit deel bevat vragen over het besluitvormingstraject en over de zorg aan de familieleden zelf. Het doel van deze studie, beschreven in **hoofdstuk zeven,** is om de beleefde kwaliteit van einde-leven-zorg te onderzoeken in een cohort van of Deense en Nederlandse familieleden, daarnaast is het doel om de klinimetrische eigenschappen van de "euroQODD" te analyseren. Familieleden van patiënten die overladen op de IC, na daar voor tenminste 48 uur te zijn behandeld kregen, drie weken na dat overlijden, de euroQODD vragenlijst per post thuisgestuurd. In totaal deden elf Deense en tien Nederlandse intensive care afdelingen mee. 217 familieleden vulden ook het euroQODD deel van de euroQ2 vragenlijst in en retourneerde die naar de onderzoekers. Overall scores waren hoog, mediaan 9 in Nederland en 10 in Denemarken op een 0 tot 10 schaal ($p<0.001$). Deense ondervraagden rapporteerde vaker adequate pijnstilling voor hun naaste (95% vs 73%; $p<0.001$). Als er beslissingen werden genomen on een behandelbeperking in te stellen was het overgrote deel van de familieleden het daarmee eens (93%). De meeste familieleden (92%) gaven aan date r enige vorm van betrokkenheid van hen bij die beslissing was geweest, waarbij de helft (50%) vond dat ze de beslissing samen met de dokter hadden genomen. Ongeveer 18% van de familieleden zou een grotere betrokkenheid hebben willen hebben. Factor analyse van de euroQODD toonde twee constructen; "kwaliteit van einde-leven-zorg" en "kwaliteit van sterven en dood". Het construct "kwaliteit van sterven en dood" bevatte fysiek comfort, mentaal comfort en waardigheid.

De **conclusie** van dit proefschrift is dat de door familie beleefde kwaliteit van intensive care zorg in het algemeen en van einde-leven-zorg in het bijzonder op Deense en Nederlandse intensive care afdelingen goed is. Er zijn echter deelgebieden waarop verbetering noodzakelijk is. Met de ontwikkeling en validatie van de euroQ2 vragenlijst is een nuttig instrument aan de gereedschapskist van de Deense en Nederlandse intensive care professional toegevoegd. Het meetinstrument moet nog verder worden ontwikkeld en gevalideerd voordat het voor routinegebruik in andere Europese landen om de kwaliteit van intensive care zorg te kunnen meten kan worden aanbevolen. Studies hiervoor zijn reeds begonnen.

Curriculum Vitae

Rik Gerritsen was born on 15th May 1962 in Amsterdam. He went to primary school in Hoogeveen and Assen. He did his pre-university education (VWO) at the Christelijke Scholengemeenschap Assen from 1974-1980. From 1980-1987 he attended Medical School at the Rijksuniversiteit Groningen. His internships were at the University Medical Center Groningen. After graduation he was a house officer at Diaconessenhuis Meppel for two years and a Senior House officer A&E at Southport District General Hospital and Royal Liverpool University Hospital.

The first three years of his training in internal medicine he performed at the Medical Center Leeuwarden (Dr. M.P. Leemhuis). The second three years at Medisch Spectrum Twente in Enschede (Dr. J.G.M. Jordans). After completion of his physician training he did a two year fellowship in intensive care medicine at the University Medical Center St. Radboud, Nijmegen (Dr. F. Santman). He graduated among the first group of antegrade registered intensivists in the Netherlands. In 1998 he started as the first intensivist in Medical Center Leeuwarden.

Next to clinical tasks Rik is the chair of the medical staff of Medical Center Leeuwarden. Since 2016 he also chairs the section on ethics of the European Society of Intensive Care (ESICM) and is a member and past president of the ethics section of the Dutch Intensive Care (NVIC) Society.

Rik is married to Claudia Ligthart Schenk, together they have four children: Willemijn, Lidewij, Joost-Jelle and Pieter-Dirk.

Dankwoord

Natuurlijk moet Matty Koopmans als eerste genoemd. Zonder haar enorme inzet, advies en expertise was er voor mij helemaal geen onderzoek mogelijk geweest, laat staan een proefschrift gekomen. Lieve Matty, ik ben je heel dankbaar voor alles wat we samen en jij voor mij hebben gedaan. Ik hoop nog heel lang met je te mogen samenwerken en misschien ooit, jou te steunen om ook te promoveren.

Mijn hooggeleerde promotor, Jan Zijlstra. Dank voor jouw gepaste afstand, maar waar nodig steun, hulp en correctie in jouw eigen, door mij zeer gewaardeerde stijl. Je wist precies waar ik hulp en begeleiding nodig had en waar je, soms letterlijk, even achter uit kon leunen en mij mijn gang kon laten gaan. Ik voel het als een eer één van de promovendi te zijn die jij nog wilde begeleiden nadat je je klinische taken had beëindigd. Ook heel bijzonder en eervol vond ik het feit je beide zoons te hebben mogen begeleiden tijdens hun opleiding op de intensive care van het MCL.

Zeergeleerde co-promotor Peter Spronk, jij stond aan de wieg van mijn loopbaan als onderzoeker. Je schetste een opzet van dit proefschrift letterlijk op de achterkant van een bierviltje in een café in Nashville tijdens het SCCM congres. Aan ieder onderdeel van dit proefschrift, zowel de artikelen als ook de ander stukken, heb jij heel belangrijke bijgedragen geleverd en ze sterk verbeterd. Zowel wat betreft inhoud maar zeker ook qua stijl en taalgebruik.

Beste Hanne na onze ontmoeting tijdens het SCCM congres in Houston hebben we onze gezamenlijke interesse in tevredenheid van familieleden van IC patiënten vastgesteld en daar een gezamenlijk onderzoeksproject van gemaakt. Jouw inzet doorzettingsvermogen en kritische opstelling heeft mede geleid tot dit proefschrift en de “euroQ2”vragenlijst. Je was vasthoudend in je mening en ik heb veel gehad aan onze interacties directe bezoeken en telefonische overleggen. Hoewel je formeel niet tot de co-promotores behoort is jouw inbreng heel groot en van essentiële waarde geweest. Dank voor alles

Dear Hanne Irene Jensen since we met during SCCM congress in Houston in 2012 we shared the interest in ICU quality of care measurement by families. During the last six years we exchanged views, held meetings, discussed a lot face to face and by phone. This led to the euroQ2 project which resulted in this thesis. I thank you for your constructive criticism and rigorous methodologic support. Although you are not mentioned as co-promotor your input has been of great importantce. Thank you for all that

De leden van de promotiecommissie dank ik voor de beoordeling van dit proefschrift en de gelegenheid daarover met hen van gedachten te mogen wisselen.

Mijn directe collega's intensivisten Michael Kuiper en Christiaan Boerma. Door jullie is wetenschappelijk onderzoek een deel van de zorg op onze intensive care geworden. Jullie stimulerende invloed heeft gemaakt dat we staan waar we nu staan. Peter Kingma als vakgroep voorzitter heeft door zijn dwingende onderhandelingen de formatie van de afdeling zo op orde gekregen dat er naast directe zorg mogelijkheid voor ander belangrijke taken zijn. Hanneke Buter dank voor het verzinnen van de naam van de vragenlijst "euroQ2". Peter Egbers, Peter Koetsier, Nynke Bruins, Corine de Jager, Sjieuwke Derksen, Nadia Koek en Niels Koopmans vormen samen met de eerder genoemde een hechte vakgroep. Dat is het "geheim" van de goede resultaten van de IC van het MCL. Samen met het geweldige team verpleegkundigen leveren wij topzorg.

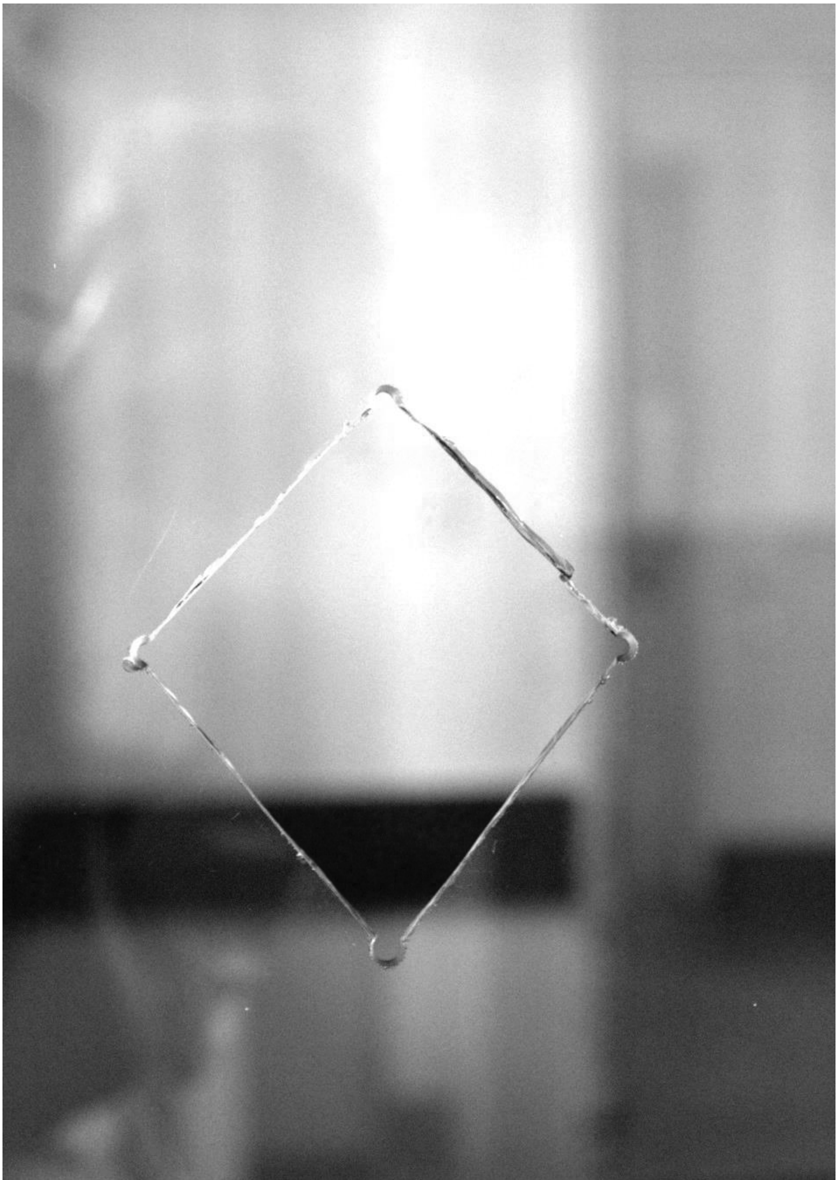
Ik bedank mijn mede Tanzania-gangers: Carien Scheltinga, Klaas Boersma, Els klop, Wybe Henstra en Ralph Lenior voor de geweldige tijd en energie die ik dankzij hen heb gekregen door onze bezoeken aan Kilimanjaro Christian Medical Center in Moshi Tanzania. En Ralph speciaal voor de mooie foto's waarvan één op de omslag van dit proefschrift prijkt.

Libbe Hoekstra van het MCL, dank ik voor zijn hulp bij het drukklaar maken van het proefschrift. Ik had geen idee hoeveel daar bij komt kijken. Linda Dost, Els Ploeg en Ingrid de Boer hebben mij enorm geholpen om de verzending van de proefschriften rond te krijgen. Naast hun werk dat het mij mogelijk maakt om effectief mee te kunnen besturen in het MCL.

Ik dank mijn ouders zonder wiens eigenwijsheid en vertrouwen maar ook opoffering ik helemaal niet was gaan studeren en mijn broertje Tom, het is goed om weer contact te hebben.

Natuurlijk dank ik mijn kinderen, niet zoals zo vaak omdat ze door het promoveren hun vader hebben gemist. Ik heb zo genoten van alles wat we hebben meegemaakt. Maar omdat ze echt de reden voor mijn bestaan zijn. Willemijn, mijn oudste en nu mijn paranimf. Je doet het zo goed. Lidewij mijn ondernemende dochter, wat ben ik trots op je. Joost-Jelle mijn opvolger in de geneeskunde en duikbuddy en Pieter-Dirk, grote tennisser en harde werker. Kus voor jullie.

Claudia, zonder jouw had ik geen gezin gehad. Had ik geen carrière kunnen maken en waren onze kinderen niet zo goed terecht gekomen. Al vindt je het promoveren maar onzin, door jou is alles mogelijk geworden.



This questionnaire is about experiences that you and your family member (the patient) had during his or her stay in the Intensive Care Unit (ICU). We are interested in your experiences because we want to improve the care received by patients and family members.

Some of these questions may be difficult to answer because you may not have had all these experiences. Other questions may be hard to answer because they remind you of a difficult emotional time. Please feel free to skip questions that you find too difficult to answer.

The questions that follow ask **YOU** about your family member's ICU admission. We understand that you might perceive that care varied in time and between caregivers but we are interested in **your overall assessment** of the quality of care we delivered. Your responses will be used to improve our ICU care.

When the term ICU staff is used, it concerns nurses, doctors, and other personnel from the ICU

If you want to elaborate on your answers or to add additional comments, this will be much appreciated and can be done in the comment boxes at the end of each part of the questionnaire.

As we still are in the process of developing the questionnaire, you are also very welcome to comment on whether there are questions which you do not find understandable and/or relevant or if you have other comments and general ideas in regard to the questionnaire. These comments can be written in connection with the individual question or in the comment boxes.

Please fill in the questionnaire and return it in the enclosed pre-paid envelope. If you do not wish to participate you can just return the questionnaire blank.

Thank you.

ABOUT YOU

In this section, we would like to ask a few questions about you

1. How old are you? ……………

2. What is your gender?

Male ☐
Female ☐

3. How are you related to your family member (the patient)?

I am his/her spouse or partner ☐
I am his/her child ☐
I am his/her sibling ☐
I am his/her parent ☐
I am another relative ☐
I am his/her friend ☐
Other (please specify) ______________________________

PART 1: SATISFACTION WITH CARE

In this section, we would like to ask some questions about your overall experience of the care provided to your family member (the patient) and to you

Please check one box that best reflects your views. If the question does not apply to your family member's stay, then check the "not applicable" box (N/A).

HOW DID WE TREAT YOUR FAMILY MEMBER (THE PATIENT)?

1. Concern and caring by ICU staff: The courtesy, respect and compassion your family member (the patient) was given

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

2. Symptom management: How well the ICU staff assessed and treated your family member's symptoms

2 a. Pain

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

2 b. Breathlessness

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

2 c. Agitation

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

HOW DID WE TREAT YOU?

3. Atmosphere of the ICU: How well the involved ICU staff made you feel that your presence was appreciated

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

4. Consideration of your needs: How well the involved ICU staff showed an interest in your needs

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

5. Emotional support: How well the involved ICU staff provided emotional support

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

7. Presence at the bedside. The possibilities to be present at the bedside

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

8. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here

PART 2: SATISFACTION WITH INFORMATION AND DECISION-MAKING AROUND CARE OF CRITICALLY ILL PATIENTS

In this section, we would like to ask some questions about the information you received and how you feel about your involvement in decision making related to your family member's health care.

INFORMATION NEEDS

1. Ease of getting information: Willingness of ICU staff to answer your questions

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐
N/A	☐

2. Understanding of information: How well ICU staff provided you with explanations that you understood

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐
N/A	☐

3. Honesty of information: Perceived honesty of information provided to you about your family member's condition

Excellent	☐
Very good	☐
Good	☐
Fair	☐
Poor	☐
N/A	☐

4. Completeness of Information:

4.a. How well ICU staff informed you about **what was happening** with your family member

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

4.b. How well ICU staff informed you about **why things were being done** to your family member

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

5. Consistency of Information: The consistency of information provided to you about your family member's condition (Did you get a similar story from the doctor, nurse, etc.)

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

6. Overall quality of information:

6a. The overall quality of information provided to you by **doctors**

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

6b. The overall quality of information provided to you by **nurses**

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

PROCESS OF DECISION-MAKING

The decisions doctors made in regard to tests, surgery, treatments etc.

7. Inclusion in the decision-making processes. How well the staff involved you in major decision-making processes

Excellent	☐	(go to question 8)
Very good	☐	(go to question 8)
Good	☐	(go to question 8)
Fair	☐	(go to question 7b)
Poor	☐	(go to question 7b)
N/A	☐	(go to question 10)

7a. If you found inclusion in the decision-making processes fair or poor, was it because:

You were involved too much? ☐
You were not involved enough? ☐
Other reasons (please specify) ☐
____
____
____

8. Support during the decision-making processes: How well ICU staff supported you when major decisions were made

Excellent ☐
Very good ☐
Good ☐
Fair ☐
Poor ☐
N/A ☐

9. When major decisions were made, did you have adequate time to have your concerns addressed and questions answered?

I had adequate time ☐
I could have used more time ☐
Don't know ☐
N/A ☐

OVERALL ASSESSMENT

10. Please rate the overall care your family member received from all doctors, nurses and other health care professionals during his or her ICU stay.
(Circle the number)

Worst care possible	0	1	2	3	4	5	6	7	8	9	10	Best care possible

(Only in version 1)

11. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here.

Thank you for taking the time to complete this survey
Please put it in the stamped, self-addressed envelope and mail it to us as soon as possible
Thank you again for your help

(When only part one and two are used)

PART 3: SATISFACTION WITH QUALITY OF CARE FOR DYING PATIENTS

In this section, we would like to ask some questions about your experiences of the quality of care provided to your family member <u>in the last days</u> of his/her life

1. How often did your family member appear to have his/her pain under control?

All the time ☐
Most of the time ☐
A good bit of the time ☐
Some of the time ☐
A little bit of the time ☐
None of the time ☐
Don't know ☐
N/A ☐

2. Did your family member receive help from a mechanical ventilator (respirator) to breathe?

Yes ☐
No (go to question 3) ☐
Don't know (go to question 3) ☐

2a. How often did your family member appear comfortable on the ventilator

All the time ☐
Most of the time ☐
A good bit of the time ☐
Some of the time ☐
A little bit of the time ☐
None of the time ☐
Don't know ☐

3. How often did your family member appear to keep his/her dignity?

All the time ☐
Most of the time ☐
A good bit of the time ☐
Some of the time ☐
A little bit of the time ☐
None of the time ☐
Don't know ☐

4. Do you think that your family member got the emotional support he/she needed?

Yes ☐
Partially ☐
No ☐
Don't know ☐

5. Do you think that your family member got the spiritual support he/she needed?

Yes ☐
Partially ☐
No ☐
Don't know ☐

6. Please rate the overall care your family member received from all doctors, nurses and other health care professionals during the last several days of his or her life while in the ICU. *(Circle the* *number)*

Worst care possible	0	1	2	3	4	5	6	7	8	9	10	Best care possible

7. Did your family member discuss his or her treatment preferences regarding end-of-life care (for example, resuscitation or intensive care) with a doctor (GP or hospital doctor) before admittance to the ICU?

Yes ☐
No ☐
Don't know ☐

8. Did your family member discuss his or her treatment preferences regarding end-of-life care with the ICU staff during the ICU stay?

Yes ☐
No ☐
Not able to ☐
Don't know ☐

9. Was the end-of-life–care according to the wishes of your family member?

Yes ☐
Partially ☐
No ☐
I did not know the wishes ☐

10. Did you feel your family member's life was prolonged unnecessarily?

Yes	☐
Partially	☐
No	☐
Don't know	☐

11. Did you feel you got the chance to say goodbye to your family member?

Yes	☐
Partially	☐
No	☐
Don't know	☐

12. If a decision was made to limit care, did you agree about what was decided?

Totally	☐
Mostly	☐
Partially	☐
Mostly not	☐
Not at all	☐
Don't know	☐
N/A	☐ (go to question 15)

13. Which part did you experience you had in connection with the decision to limit life sustaining treatment?

The patient made the decision	☐
The doctors made the decision without involving me (and/or my family)	☐
The doctors made the decision after discussing it with me (and/or my family)	☐
The decision was made jointly between the doctors and me (and/or my family)	☐
I (and/or my family) made the decision after being informed of the situation by the doctors	☐
I (and/or my family) made the decision alone	☐
Don't know	☐

In (Denmark) the legislation states that decisions to limit life sustaining treatment must be made by the patient or the doctors. Families have no legal right or duty to make decisions.

14. If you disregard the legislation, which part would you have wished to have in connection with the decision to limit life sustaining treatment?

That the doctors made the decision without involving me (and/or my family) ☐
That the doctors made the decision after discussing it with me (and/or my family) ☐
That the decision was made jointly between the doctors and me (and/or my family) ☐
That I (and/or my family) made the decision after being informed of the situation by the doctors ☐
That I (and/or my family) made the decision alone ☐
Don't know ☐

15. If you have comments to your responses or other experiences (good or bad) from the ICU we could learn from, please add them here

Thank you for taking the time to complete this survey
Please put it in the stamped, self-addressed envelope and mail it to us as soon as possible
Thank you again for your help

Back cover

Name and contact information at the top - V1 or V2

At the bottom
euroQ2. European Quality Questionnaire.
Questionnaire on family experiences of quality of care in the ICU

Vragenlijst naar de kwaliteit van zorg op de Intensive Care afdeling

Intensive Care

Deze vragenlijst gaat over de ervaringen van u en uw familielid (de patiënt) gedurende zijn of haar verblijf op de Intensive Care afdeling (IC). We zijn geïnteresseerd in uw ervaringen omdat we de zorg gegeven aan patiënten en familieleden willen verbeteren.

Sommige van deze vragen zijn misschien moeilijk te beantwoorden omdat u mogelijk niet al deze ervaringen heeft gehad. Andere vragen zijn moeilijk te beantwoorden omdat deze vragen u herinneren aan een moeilijke emotionele tijd. Voelt u zich vrij om vragen over te slaan die te moeilijk zijn om te beanwoorden.

De vragen die volgen gaan over wat **U** vindt van de gegeven zorg aan uw familielid op de IC. We begrijpen dat uw ervaring in de tijd en tussen verschillende zorgverleners kan variëren. We zijn geïnteresseerd in de gegeven kwaliteit van zorg in het **algemeen.** Uw reactie zal worden gebruikt om de zorg op onze IC te verbeteren.

Wanneer we spreken over IC personeel bedoelen we verpleegkundigen, artsen en andere medewerkers op de IC.

Mocht u aanvullingen hebben op de vragen of andere opmerkingen willen plaatsen, dan is hier ruimte voor aan het einde van elk onderdeel van deze vragenlijst.

Omdat deze vragenlijst nog in ontwikkeling is, wordt u ook uitgenodigd commentaar te leveren als u een vraag niet relevant en/of begrijpelijk vindt. Deze opmerkingen kunnen naast de vragen worden genoteerd of in de ruimte aan het einde van elk onderdeel.

U kunt meedoen door de vragenlijst in te vullen en terug te sturen in de bijgesloten antwoordenveloppe. Een postzegel is niet nodig. Indien u niet mee wilt doen, kan u de vragenlijst leeg terug sturen.

Wanneer u vragen heeft of problemen bij het beantwoorden van de vragen kunt u natuurlijk ook contact met ons opnemen. Wij zullen dan proberen u hierbij te helpen.
Matty Koopmans en R.Th.Gerritsen

matty.koopmans@znb.nl
058 2866738

Alvast hartelijk dank voor uw hulp.

Over Uzelf

In dit gedeelte willen wij graag een paar vragen stellen over u

1. Wat is uw leeftijd ....

2. Wat is uw geslacht?

Man	☐
Vrouw	☐

3. Wat is uw relatie met uw familielid (de patiënt)?

Ik ben zijn/haar echtgenoot of partner	☐
Ik ben zijn/haar kind	☐
Ik ben zijn/haar zus of broer	☐
Ik ben een ouder	☐
Ik ben een ander familielid	☐
Ik ben zijn/haar vriend/vriendin	☐

Anders, nl. ____________________________

DEEL 1: TEVREDENHEID OVER ZORG

In dit onderdeel willen wij u enkele vragen stellen over hoe u de zorg die aan uw familielid (de patiënt) en u werd geboden, in het algemeen hebt ervaren.

Kruis één hokje aan dat uw mening het beste weergeeft. Als de vraag niet van toepassing is op het verblijf van uw familielid op de IC, dan kruist u het hokje "niet van toepassing" (n.v.t.) aan.

HOE HEBBEN WIJ UW FAMILIELID (DE PATIËNT) BEHANDELD?

1. Zorgzaamheid en hartelijkheid van IC-personeel: de beleefdheid, het respect en het medeleven dat uw familielid (de patiënt) kreeg

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

2. Omgang met klachten: hoe goed het IC-personeel klachten van uw familielid beoordeelde en behandelde

2 a. pijn
uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

2 b. kortademigheid
uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

2 c. onrust
uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

HOE HEBBEN WIJ U BEHANDELD?

3. Sfeer op de IC: hoe goed het betrokken personeel u het gevoel gaf dat uw aanwezigheid op prijs werd gesteld

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

4. Aandacht voor uw behoeften: hoe goed het betrokken personeel belangstelling toonde voor uw behoeften

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

5. Emotionele ondersteuning: hoe goed het betrokken personeel emotionele ondersteuning bood

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

6. Aanwezigheid aan het bed: de mogelijkheid om aanwezig te zijn aan het bed

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

7. Wanneer u aanvullende opmerkingen heeft of andere ervaringen (goed of slecht) mbt de IC waar wij van kunnen leren, dan kunt u dit hieronder vermelden

DEEL 2: TEVREDENHEID OVER HET NEMEN VAN BESLISSINGEN ROND DE ZORG VOOR ERNSTIG ZIEKE PATIENTEN

In dit onderdeel willen wij u enkele vragen stellen over hoe u uw betrokkenheid heeft ervaren rond het nemen van beslissingen over de zorg aan uw familielid.

INFORMATIEBEHOEFTE

1. Beschikbaarheid van informatie: bereidheid van IC-personeel om uw vragen te beantwoorden

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

2. Begrijpen van informatie: hoe goed IC-personeel u uitleg gaf die begrijpelijk voor u was

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

3. Eerlijkheid van informatie: hoe eerlijk, in uw beleving, de informatie was die u kreeg over de toestand van uw familielid

uitstekend	☐
zeer goed	☐
goed	☐
redelijk	☐
slecht	☐
n.v.t.	☐

4. Volledigheid van informatie:

4a. hoe volledig het IC-personeel u informeerde over wat er met uw familielid **aan de hand was**

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

4.b. hoe goed het IC-personeel u informeerde over **waarom bepaalde handelingen werden gedaan** bij uw familielid

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

5. Consequentheid van informatie: de eenduidigheid van informatie die aan u werd gegeven over de toestand van uw familielid (Was het verhaal dat u kreeg van de arts, verpleegkundige, enz. hetzelfde?)

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

6. Kwaliteit van de gegeven informatie in het algemeen:

6a. Kwaliteit van de gegeven informatie door de **dokters**

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

6b. Kwaliteit van de gegeven informatie door **verpleegkundigen**

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

BESLUITVORMINGSPROCES

Beslissingen genomen door <u>artsen</u> met betrekking tot onderzoeken, operaties, behandeling etc.

7. Betrokkenheid bij de besluitvorming: hoe goed het personeel u betrok bij belangrijke besluiten

uitstekend	☐	(ga naar vraag 8)
zeer goed	☐	(ga naar vraag 8)
goed	☐	(ga naar vraag 8)
redelijk	☐	(ga naar vraag 7b)
slecht	☐	(ga naar vraag 7b)
n.v.t.	☐	(ga naar vraag 10)

7a. Wanneer u uw betrokkenheid bij de besluitvorming redelijk of slecht vond, was dat omdat:

U was teveel betrokken? ☐
U was te weinig betrokken? ☐
Andere redenen (licht toe) ☐

____
____

8. Steun tijdens de besluitvorming: hoe goed het IC-personeel u steun bood tijdens het nemen van belangrijke besluiten

uitstekend ☐
zeer goed ☐
goed ☐
redelijk ☐
slecht ☐
n.v.t. ☐

9. Was er bij belangrijke beslissingen voldoende tijd voor het aan de orde stellen van uw zorgen en het beantwoorden van uw vragen?

Ik had voldoende tijd ☐
Ik had meer tijd kunnen gebruiken ☐
Weet ik niet ☐
Niet van toepassing ☐

10. Wanneer u aanvullende opmerkingen heeft of andere ervaringen (goed of slecht) mbt de IC waar wij van kunnen leren, dan kunt u dit hieronder vermelden.

DEEL 3: TEVREDENHEID VAN FAMILIE OVER DE KWALITEIT VAN ZORG VOOR STERVENDE PATIËNTEN

In dit onderdeel willen wij u enkele vragen stellen over hoe u de zorg hebt ervaren die werd geboden aan uw familielid in de laatste dagen van zijn/haar leven.

1. Hoe vaak leek het dat uw familielid zijn / haar pijn onder controle had?

de hele tijd ☐
meestal ☐
vrij vaak ☐
soms ☐
heel af en toe ☐
nooit ☐
weet ik niet ☐
n.v.t. ☐

2. Heeft uw familielid aan een beademingsapparaat gelegen die voor hem/haar ademde?

ja ☐
nee(ga naar vraag 3) ☐
weet ik niet (ga naar vraag 3) ☐

2a. Hoe vaak leek uw familielid zich comfortabel te voelen aan het beademingsapparaat?

de hele tijd ☐
meestal ☐
vrij vaak ☐
soms ☐
heel af en toe ☐
nooit ☐
weet ik niet ☐

3. Hoe vaak leek uw familielid zijn/haar waardigheid te behouden?

de hele tijd ☐
meestal ☐
vrij vaak ☐
soms ☐
heel af en toe ☐
nooit ☐
weet ik niet ☐

4. Denkt u dat uw familielid de emotionele steun heeft gekregen die hij/zij nodig had?

ja ☐
gedeeltelijk ☐
nee ☐
weet ik niet ☐

5. Denkt u dat uw familielid de geestelijke steun heeft gekregen die hij/zij nodig had?

ja ☐
gedeeltelijk ☐
nee ☐
weet ik niet ☐

6. Geef een cijfer voor de zorg die uw familielid heeft gekregen van alle artsen, verpleegkundigen en andere zorgverleners tijdens zijn/haar laatste levensdagen op de IC. *(Omcirkel het cijfer)*

slechtste zorg die mogelijk is	0	1	2	3	4	5	6	7	8	9	10	beste zorg die mogelijk is

7. Heeft uw familielid zijn/haar behandelvoorkeuren voor zorg rond het levenseinde (bijv. reanimatie of intensieve zorg) besproken met een arts (huisarts of ziekenhuisarts) vóór opname op de IC?

ja ☐
nee ☐
weet ik niet ☐

8. Heeft uw familielid zijn/haar behandelvoorkeuren voor zorg rond het levenseinde besproken met het IC-personeel tijdens opname op de IC?

ja ☐
nee ☐
was niet in staat tot ☐
weet ik niet ☐

9. Was de zorg rond het levenseinde volgens de wensen van uw familielid?

ja ☐
gedeeltelijk ☐
nee ☐
weet ik niet ☐

10. Had u het gevoel dat het leven van uw familielid onnodig werd gerekt?

ja ☐
gedeeltelijk ☐
nee ☐
weet ik niet ☐

11. Hebt u het gevoel dat u de kans hebt gekregen om afscheid te nemen van uw familielid?

ja ☐
gedeeltelijk ☐
nee ☐
weet ik niet ☐

12. Was u het eens met de beslissingen die genomen zijn rond het levenseinde?

helemaal ☐
grotendeels ☐
deels wel, deels niet ☐
enigszins ☐
helemaal niet ☐
weet ik niet ☐
niet van toepassing ☐ (ga naar vraag 15)

13. Welke rol speelde U in uw beleving bij beslissingen rond het levenseinde

De patiënt nam de beslissing ☐
De dokter nam de beslissing zonder mij ☐
De dokter nam de beslissing na overleg met mij ☐
De beslissingen is samen, dokter en familie, genomen ☐
Ik heb de beslissing genomen na informatie van de dokter ☐
Ik heb de beslissing alleen genomen ☐
Ik weet het niet ☐

Volgens de Nederlandse wetgeving worden beslissingen rond het levenseinde genomen door de patiënt of de dokters. Families hebben geen wettelijke rechten of plichten om deze beslissingen te nemen

14. Als dit niet het geval was, welke rol zou u willen spelen bij beslissingen rond het levenseinde(los van wat wettelijk mogelijk is)

De dokter nam de beslissing zonder mij ☐
De dokter nam de beslissing na overleg met mij ☐
De beslissingen is samen, dokter en familie, genomen ☐
Ik heb de beslissing genomen na informatie van de dokter ☐
Ik heb de beslissing alleen genomen ☐
Ik weet het niet ☐

15. Wanneer u aanvullende opmerkingen heeft of andere ervaringen (goed of slecht) mbt de IC waar wij van kunnen leren, dan kunt u dit hieronder vermelden.

Hartelijk bedankt voor uw tijd om deze vragenlijst te beantwoorden.
U kunt de vragenlijst opsturen, een retour envelop is bijgesloten.
Nogmaals bedankt voor uw hulp.

Medisch Centrum Leeuwarden
Intensive Care
Henri Dunantweg 2
8902 BR Leeuwarden
058 2866738

matty.koopmans@znb.nl

euroQ2 European Quality Questionnaire
Europese vragenlijst naar de kwaliteit van zorg op de Intensive Care afdeling

Spørgeskema om pårørendes oplevelser af kvaliteten af intensiv pleje og behandling

(Navn på lokalt intensivt afsnit)

Dette spørgeskema handler om de oplevelser, som du og din pårørende (patienten) havde i forbindelse med indlæggelsen på intensivafsnittet. Vi er interesserede i dine oplevelser, fordi vi ønsker at forbedre den pleje og behandling, patienter og pårørende får.

Nogle af disse spørgsmål kan være svære at besvare, fordi du ikke har haft de oplevelser. Andre kan være svære at besvare, fordi de minder dig om en svær følelsesmæssig tid. Er der spørgsmål, der er for svære at besvare, er det helt i orden at springe dem over.

De følgende spørgsmål handler om **DIN** vurdering af din pårørendes indlæggelse i intensiv afsnit. Vi har forståelse for, at du kan have oplevet, at behandlingen og plejen varierede over tid og mellem forskellige personaler, men vi er interesserede i **din overordnede vurdering** af kvaliteten af den pleje og behandling, vi har givet. Dine svar vil blive brugt til at forbedre vores intensive pleje og behandling.

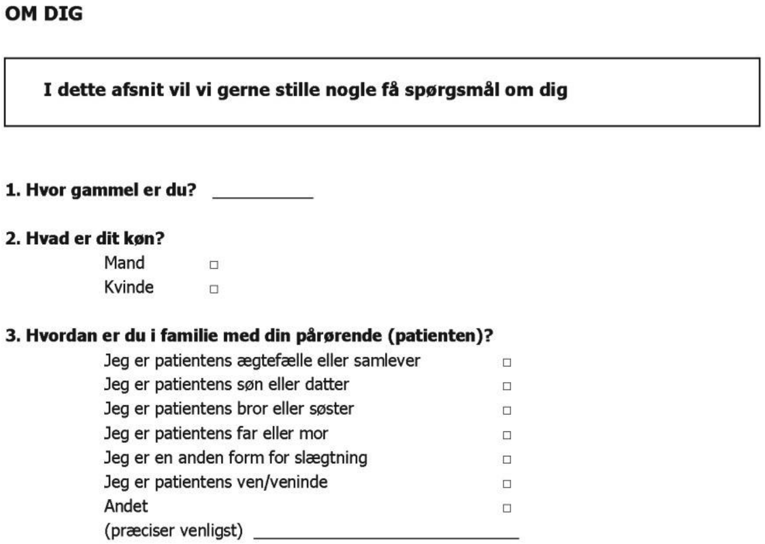
Når vendingen "intensivpersonalet" er anvendt, dækker det over sygeplejersker, læger og andet personale fra intensivafsnittet.

Hvis du ønsker at uddybe dine svar eller tilføje kommentarer, vil det blive meget værdsat, og det kan gøres i kommentarboksen i slutningen af hvert afsnit af spørgeskemaet.

Da vi stadig er i gang med at udvikle spørgeskemaet, må du også meget gerne skrive, hvis der er spørgsmål, som du ikke oplever som forståelige og/eller relevante, eller hvis du har andre kommentarer og ideer til spørgeskemaet generelt. Disse kommentarer kan skrives ved de enkelte spørgsmål eller i kommentarfelterne.

Udfyld venligst spørgeskemaet og returner det i den vedlagte, frankerede svarkuvert. Hvis du ikke ønsker at besvare spørgeskemaet, kan du bare returnere det blankt.

Endnu engang tak for din hjælp.



OM DIG

I dette afsnit vil vi gerne stille nogle få spørgsmål om dig

1. Hvor gammel er du? ___________

2. Hvad er dit køn?

Mand ☐
Kvinde ☐

3. Hvordan er du i familie med din pårørende (patienten)?

Jeg er patientens ægtefælle eller samlever ☐
Jeg er patientens søn eller datter ☐
Jeg er patientens bror eller søster ☐
Jeg er patientens far eller mor ☐
Jeg er en anden form for slægtning ☐
Jeg er patientens ven/veninde ☐
Andet ☐
(præciser venligst) ______________________________

AFSNIT 1. TILFREDSHED MED PLEJE OG BEHANDLING

I dette afsnit vil vi gerne stille dig nogle spørgsmål om din samlede oplevelse af den pleje og behandling, din pårørende (patienten) og du selv modtog

Vær venlig at sætte ét kryds i den rubrik, der bedst dækker dine synspunkter. Hvis spørgsmålet ikke er relevant for din pårørendes ophold i intensiv afsnit, sættes krydset i boksen "Ikke relevant"

HVORDAN BEHANDLEDE VI DIN PÅRØRENDE (PATIENTEN)?

1. Intensivpersonalets opmærksomhed og omsorg: Den høflighed, respekt og medfølelse, som personalet viste din pårørende

Fremragende ☐
Meget god ☐
God ☐
Nogenlunde ☐
Dårlig ☐
Ikke relevant ☐

2. Symptom behandling: Hvor godt intensivpersonalet vurderede og behandlede din pårørendes symptomer

2a. Smerter

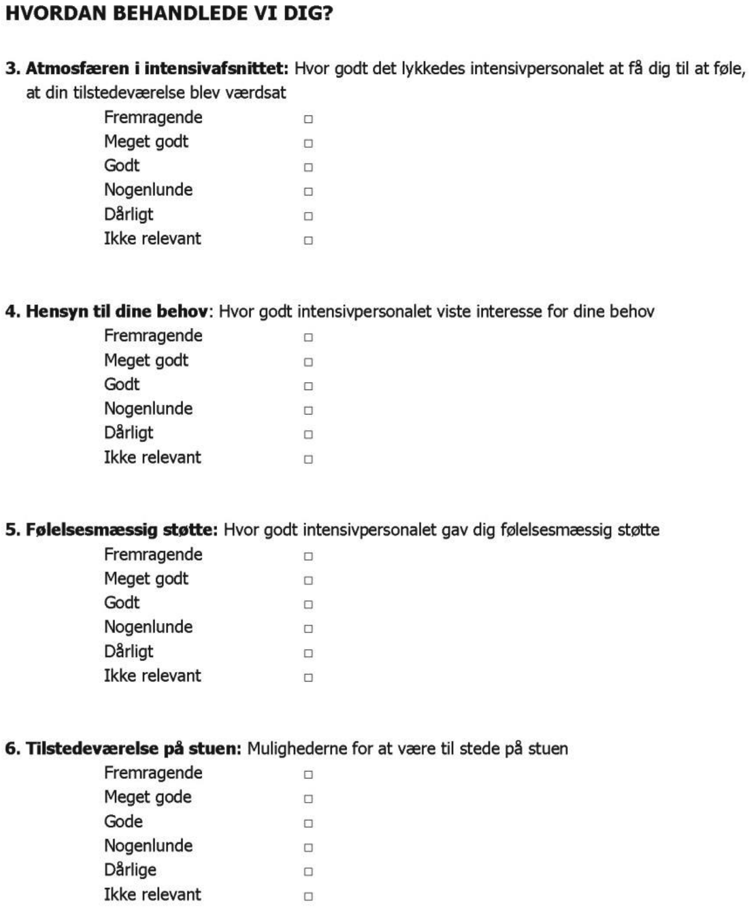
Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

2b. Åndenød

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

2c. Uro og sindsoprivelse

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐



HVORDAN BEHANDLEDE VI DIG?

3. Atmosfæren i intensivafsnittet: Hvor godt det lykkedes intensivpersonalet at få dig til at føle, at din tilstedeværelse blev værdsat

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

4. Hensyn til dine behov: Hvor godt intensivpersonalet viste interesse for dine behov

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

5. Følelsesmæssig støtte: Hvor godt intensivpersonalet gav dig følelsesmæssig støtte

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

6. Tilstedeværelse på stuen: Mulighederne for at være til stede på stuen

Fremragende ☐
Meget gode ☐
Gode ☐
Nogenlunde ☐
Dårlige ☐
Ikke relevant ☐

7. Hvis du har kommentarer til dine svar eller andre oplevelser (gode eller dårlige), som vi kan lære af, må du meget gerne tilføje dem her

AFSNIT 2: TILFREDSHED MED INFORMATION OG BESLUTNINGSTAGNING VEDRØRENDE PLEJE OG BEHANDLING AF KRITISK SYGE PATIENTER

I dette afsnit vil vi gerne stille dig nogle spørgsmål om, hvordan du har oplevet den information, du har modtaget, og om din inddragelse i beslutningsprocesser vedrørende din pårørendes behandling

BEHOV FOR INFORMATION

1. Tilgængelighed af information: Intensivpersonalets villighed til at svare på dine spørgsmål

Fremragende ☐
Meget god ☐
God ☐
Nogenlunde ☐
Dårlig ☐
Ikke relevant ☐

2. Forståelse af information: Hvor godt intensivpersonalet gav dig forklaringer, som du kunne forstå

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

3. Ærlig information Din oplevelse af ærligheden af den information, du fik om din pårørendes tilstand

Fremragende ☐
Meget god ☐
God ☐
Nogenlunde ☐
Dårlig ☐
Ikke relevant ☐

4. Fuldstændig information:

4.a. Hvor godt intensivpersonalet informerede dig om, **hvad der skete** med din pårørende

- Fremragende ☐
- Meget godt ☐
- Godt ☐
- Nogenlunde ☐
- Dårligt ☐
- Ikke relevant ☐

4b. Hvor godt intensivpersonalet informerede dig om, **hvorfor noget blev gjort** ved din pårørende

- Fremragende ☐
- Meget godt ☐
- Godt ☐
- Nogenlunde ☐
- Dårligt ☐
- Ikke relevant ☐

5. Overensstemmende information: Overensstemmelsen af den information, du fik om din pårørendes tilstand (fik du den samme forklaring fra læger, sygeplejersker etc.)

- Fremragende ☐
- Meget god ☐
- God ☐
- Nogenlunde ☐
- Dårlig ☐
- Ikke relevant ☐

6. Samlet kvalitet af information:

6a. Den samlede kvalitet af den information, du fik af **lægerne**

- Fremragende ☐
- Meget god ☐
- God ☐
- Nogenlunde ☐
- Dårlig ☐
- Ikke relevant ☐

6b. Den samlede kvalitet af den information, du fik af **sygeplejerskerne**

- Fremragende ☐
- Meget god ☐
- God ☐
- Nogenlunde ☐
- Dårlig ☐
- Ikke relevant ☐

BESLUTNINGSPROCESSER

De beslutninger <u>lægerne</u> tog omkring undersøgelser, operation, behandling etc.

7. Deltagelse i beslutningsprocesser: Hvor godt personalet involverede dig i væsentlige beslutningsprocesser

Fremragende ☐ (gå til spørgsmål 8)
Meget godt ☐ (gå til spørgsmål 8)
Godt ☐ (gå til spørgsmål 8)
Nogenlunde ☐ (gå til spørgsmål 7a)
Dårligt ☐ (gå til spørgsmål 7a)
Ikke relevant ☐ (gå til spørgsmål 10)

7a. Hvis du fandt involvering i beslutningsprocesser nogenlunde eller dårlig, var det så fordi

Du blev for meget involveret? ☐
Du ikke blev tilstrækkelig involveret? ☐
Andre grunde (præciser venligst) ☐

____

____

8. Støtte i forbindelse med beslutningsprocesser: Hvor godt intensivpersonalet støttede dig, når væsentlige beslutninger skulle tages

Fremragende ☐
Meget godt ☐
Godt ☐
Nogenlunde ☐
Dårligt ☐
Ikke relevant ☐

9. Havde du tilstrækkelig tid til at formulere dine bekymringer og få svar på dine spørgsmål, når væsentlige beslutninger skulle tages?

Jeg havde tid nok ☐
Jeg kunne have brugt mere tid ☐
Ved ikke ☐
Ikke relevant ☐

10. Hvis du har kommentarer til dine svar eller andre oplevelser (gode eller dårlige), som vi kan lære af, må du meget gerne tilføje dem her

AFSNIT 3. TILFREDSHED MED KVALITETEN AF PLEJE OG BEHANDLING AF DØENDE PATIENTER

I dette afsnit vil vi gerne stille dig nogle spørgsmål om dine oplevelser af kvaliteten af plejen og behandlingen af din pårørende i de sidste dage af hans/hendes liv.

1. Hvor ofte så det ud til, at din pårørendes smerter var velbehandlede?

Hele tiden ☐
Det meste af tiden ☐
En god del af tiden ☐
Noget af tiden ☐
Lidt af tiden ☐
På intet tidspunkt ☐
Ved ikke ☐
Ikke relevant ☐

2. Fik din pårørende hjælp af en respirator til at trække vejret?

Ja ☐
Nej ☐ (gå til spørgsmål 3)
Ved ikke ☐ (gå til spørgsmål 3)

2a. Hvor ofte så din pårørende ud til at være tilpas med at ligge i respirator?

Hele tiden ☐
Det meste af tiden ☐
En god del af tiden ☐
Noget af tiden ☐
Lidt af tiden ☐
På intet tidspunkt ☐
Ved ikke ☐

3. Hvor ofte så din pårørende ud til at bevare sin værdighed?

Hele tiden ☐
Det meste af tiden ☐
En god del af tiden ☐
Noget af tiden ☐
Lidt af tiden ☐
På intet tidspunkt ☐
Ved ikke ☐

4. Tror du, din pårørende fik den følelsesmæssige støtte, han/hun havde behov for?

Ja ☐
Delvist ☐
Nej ☐
Ved ikke ☐

5. Tror du, din pårørende fik den åndelige støtte, han/hun havde behov for?

Ja ☐
Delvist ☐
Nej ☐
Ved ikke ☐

6. Vær venlig at vurdere den samlede pleje og behandling, din pårørende fik af læger, sygeplejersker og andre sundhedspersoner i de sidste dage af sit liv i intensivafsnittet

(sæt ring om den relevante værdi)

Værst tænkelig pleje og behandling	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Bedst tænkelig pleje og behandling

7. Diskuterede din pårørende sine ønsker til behandling ved livets afslutning med en læge (praktiserende læge eller læge fra stamafdelingen) **før** indlæggelsen i intensiv afsnit (f.eks. genoplivning eller intensiv behandling)?

Ja ☐
Nej ☐
Ved ikke ☐

8. Diskuterede din pårørende sine ønsker til behandlingen ved livets afslutning med intensivpersonalet **under** indlæggelsen i intensivafsnittet?

Ja ☐
Nej ☐
Ikke i stand til ☐
Ved ikke ☐

9. Var behandlingen ved livets afslutning i overensstemmelse med din pårørendes ønsker?

Ja ☐
Delvist ☐
Nej ☐
Ved ikke ☐

10. Følte du, at din pårørendes liv blev unødvendigt forlænget?

Ja ☐
Delvist ☐
Nej ☐
Ved ikke ☐

11. Følte du, at du fik mulighed for at sige farvel til din pårørende?

Ja ☐
Delvist ☐
Nej ☐
Ved ikke ☐

12. Hvis der blev taget beslutning om at begrænse eller ophøre den livsforlængende behandling, var du da enig i beslutningen?

Meget enig ☐
Enig ☐
Hverken enig eller uenig ☐
Uenig ☐
Meget uenig ☐
Ved ikke ☐
Ikke relevant ☐ (gå til spørgsmål 15)

13. Hvilken rolle oplevede du, at du havde i forbindelse med beslutningen om at begrænse eller ophøre den livsforlængende behandling?

Patienten tog beslutningen ☐
Lægerne tog beslutningen uden at involvere mig (og/eller min familie) ☐
Lægerne tog beslutningen efter at have diskuteret det med mig (og/eller min familie) ☐
Beslutningen blev taget i fællesskab af lægerne og mig (og/eller min familie) ☐
Jeg (og/eller min familie) tog beslutningen efter at være blevet informeret af lægerne om situationen ☐
Jeg (og/eller min familie) tog beslutningen alene ☐
Ved ikke ☐

I Danmark siger lovgivningen, at beslutning om at begrænse eller ophøre livsforlængende behandling skal tages af patienten eller af det lægefaglige personale. Pårørende har ikke juridisk ret eller pligt til at tage beslutninger.

14. Hvis man ser bort fra lovgivningen, hvilken rolle vil du så ønske at have haft i forbindelse med beslutningen om at begrænse eller ophøre den livsforlængende behandling?

At lægerne tog beslutningen uden at involvere mig (og eller min familie) ☐
At lægerne tog beslutningen efter at have diskuteret det med mig (og/eller min familie) ☐
At beslutningen blev taget i fællesskab af lægerne og mig (og/eller min familie) ☐
At jeg (og/eller min familie) tog beslutningen efter at være blevet informeret af lægerne om situationen ☐
At jeg (og/eller min familie) tog beslutningen alene ☐
Ved ikke ☐

15. Hvis du har kommentarer til dine svar eller andre oplevelser (gode eller dårlige), som vi kan lære af, må du meget gerne tilføje dem her

Tak fordi du har taget dig tid til at udfylde dette spørgeskema

Læg venligst skemaet i den frankerede kuvert og send det til os så snart som muligt

Endnu engang tak for din hjælp

Forskningsmedarbejder
Hanne Irene Jensen
Anæstesiologisk Afdeling
Vejle Sygehus
Telefon: 2337 9545
Mail: hanne.irene.jensen@rsyd.dk

V2

euroQ2 European Quality Questionnaire

Europæisk spørgeskema om pårørendes oplevelser af kvaliteten af intensiv pleje og behandling