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Research article

Development and initial validation of the Swedish Family Satisfaction Intensive Care Questionnaire (SFS-ICQ)

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ABSTRACT

Objectives: Measuring patients satisfaction is an important part of continuous quality improvement in health care. In intensive care, family satisfaction is often used as a proxy for patient experience. At present, no suitable instrument to measure this has been fully validated in Sweden. The purpose of this study was to develop and validate a questionnaire intended to evaluate families' satisfaction of quality of care in Swedish intensive care units.

Methods: Based on literature and the modification of pertinent items in two existing North American questionnaires, a Swedish questionnaire was developed. Content validity was assessed by experts, and the cognitive method *Think Aloud* was used with twelve family members of intensive care patients in two different intensive care units. Data was analysed using qualitative content analysis.

Findings: Seven items in the questionnaire were identified as problematic, causing eight problems concerning questioning of content and 23 concerning misunderstanding. Six of these items were changed in order to be understood the way they were intended, and one item was removed.

Conclusion: A family satisfaction questionnaire applicable in Swedish intensive care units has been developed and validated for respondents' understanding of the questions being asked. However, further psychometric testing should be performed when more data are available.

Implications for clinical practice

- Measuring family satisfaction of care in intensive care units helps to highlight areas of care that are of high quality as well as ones that need improvement.
- Until now, a questionnaire appropriate for measuring family satisfaction in Swedish intensive care units has not been available.
- The first steps in validating a family satisfaction questionnaire for use in Swedish intensive care units has been conducted.

Introduction

Supporting patients to be actively involved in their own care and treatment can improve outcomes (Little et al., 2001; Sainio et al., 2001; Say et al., 2006). Patient satisfaction has been shown to increase when patients are involved in their own care pathway (Veilleux et al., 2018). The involvement may induce a sense of control of the situation (Carlsen and Aakvik, 2006). Measuring patient satisfaction is therefore considered to be an important part of continuous quality improvement work (Phillips et al., 2016). However, self-perceived ratings in critically ill patients may be difficult to obtain, since many patients are unconscious or sedated, which may limit their recall from the intensive care unit (ICU)-stay (Burry et al., 2015). To circumvent this problem, questionnaires for assessing patient satisfaction in ICUs have been directed towards patients' family. The opinion of patients' family members has served as proxy for patient-reported satisfaction (Stricker et al., 2011). Family members of ICU-patients often react with psychological distress because of the stressful situation they are in

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(Pochard et al., 2001, 2005; Trevick and Lord, 2017). The psychological distress seems to decrease if certain needs, such as information, emotional support and the opportunity for visitation are sufficiently provided by the ICU staff (Khalaila, 2014). Internationally, questionnaires assessing family satisfaction with the quality of care in ICU have been developed (van den Broek et al., 2015). None of these has been found to be applicable for a direct translation into Swedish settings due to differences in culture and health care systems. For example, there are legal issues that concern the distinctive laws that govern the role and use of surrogate decision-makers in the different countries concerned. Furthermore, there are translation issues that concern the distinctive languages used. For instance, the closest Swedish expression for an English expression often has a different range of meanings than its English counterpart.

Methods

Objectives

The purpose of this study was to develop and conduct initial validation of a questionnaire intended to evaluate families' satisfaction regarding quality of care in Swedish ICUs. The questionnaire was called SFS-ICQ (Swedish Family Satisfaction Intensive Care Questionnaire). The specific aims were: (1) to pre-test the first version of the questionnaire with clinical experts and a questionnaire-design expert, (2) to examine family members' understanding of the items in the second version of the questionnaire and (3) to produce a final version of the questionnaire, in light of the findings, for further psychometric evaluations.

Setting

Research was conducted in two ICUs in a regional tertiary-care university hospital in Sweden. One of the units was a 13-bed general ICU that receives patients from medical–surgical–trauma specialities. The other unit was a seven-bed thoracic ICU that admits patients in cardiogenic shock and after cardiac, lung and vascular surgery. Both units had a nurse-to-patient ratio of 1:1–2 and a 24 hour presence of a physician intensivist.

Ethical approval

This study did not involve sensitive personal information, biological samples, physical procedures or manipulation of subjects physically or psychologically. It was, therefore, exempt from the requirements for ethical approval, according to the Ethical Review Act, Central Ethical Review Board in Sweden (https://www.epn.se). The study was carried out in compliance with the Declaration of Helsinki and with permission granted by the Medical Directors at each of the intensive care units at Karolinska University Hospital, Stockholm, Sweden. All participants received written and verbal information and provided informed consent prior to their participation.

Participants

Using purposive sampling, prospective participants were included only if they were a family member to a surviving patient with an ICU length of stay of 48 hours or more, were at least 18 years old, could understand Swedish, had visited their family member at least once in the ICU and were willing to participate in the study. "Family members" was defined widely and included persons nearest to the patient such as parents, partners, siblings, adult children, friends or other people close to the patient. Only two family members per patient were allowed to participate.

Questionnaire development

In a recent systematic review (van den Broek et al., 2015), two questionnaires were identified as being of high quality for measuring family satisfaction with ICU care: Family Satisfaction in the ICU (FS-ICU 24) (Wall et al., 2007) and Critical Care Family Satisfaction Survey (CCFSS) (Wasser et al., 2001). These questionnaires were developed in the United States (US) and Canada, which made some of the items difficult to transfer directly into a Swedish setting, e.g., the items concerning family members as health care surrogates in regard to decision-making. However, in these questionnaires, 21 items were found to be suitable, with modifications, for evaluating family satisfaction with Swedish ICU care. Eleven items of these 21 were found in both FS-ICU 24 and CCFSS, five items were found only in the FS-ICU 24 and five only in the CCFSS (Table 1). Two additional items, found in the literature, were also included in the new questionnaire, since they were identified as important for assessing family satisfaction. They were "*the environment where information was given*" (Henrich et al., 2011; Schwarzkopf et al., 2013) and "*nurse's participation in information meetings for family members*" (Gay et al., 2009). A third item, "*family member's overall impression of the reception that they received from those who worked in the ICU*", was considered important in order to get information concerning the family members' overall perspective, rather than only specific aspects thereof.

Pre-test by experts

A critical review of the *first version* of the SFS-ICQ was performed by three ICU specialist nurses, working in ICU follow-up, with extensive experience of meeting family members in the ICU. Based on their recommendations, one question regarding from what profession the family members had received support was excluded and another question was divided into two, one assessing nurses' communication skills and the other physicians' communication skills. Thereafter, the modified version was sent to an expert in questionnaire-design, which led to a few minor linguistic and layout changes.

The second version

The *second version* of the SFS-ICQ included 24 scaled items (Table 1), which were organised into six main areas: environment/atmosphere (three items: question 1–3), treatment/care of the patient (six items: 4–7, 11, 12), participation in care (three items: 8, 9, 19), reception of family members (two items: 10, 21), information (eight items: 13–18, 20, 22) and overall satisfaction (two items: 23, 24). Each item was phrased as a statement to which the responder was supposed to rate how well each statement agreed with their opinion on a four point Likert scale ("Strongly agree", "Tend to agree", "Tend to disagree", "Strongly disagree" with a "N/A" option). Three open-ended questions were included in the questionnaire: "*Do you have any suggestions on how the care in the ICU could improve?*" (item 25) "*What were the most important things that you thought were good in the ICU?*" (item 26) and "*Do you have any other comments that you think might be useful to us who work in the ICU?*" (item 27) (Table 1). In addition, demographic data of the family members was collected regarding age, gender and relationship to the patient.

Table 1
Second version and final version of the Swedish Family Satisfaction Intensive Care Questionnaire (SFS-ICQ).

Items	
1.[a,b]	The environment in the intensive care room was *welcoming* [good]
2.[a,b]	The environment in the family waiting room was *suitable* [good]
3.	The environment [where the information was given] was *suitable for information meetings* [good]
4.[a]	My family member was treated respectfully by the staff in the ICU
5.[a,b]	When my family member appeared to be in pain, the staff handled it well
6.[a,b]	When my family member appeared to have breathing problems, the staff handled it well
7.[a,b]	When my family member appeared to experience anxiety, the staff handled it well
8.[b]	*The ICU staff gave me* [I was given] the opportunity to visit my family member as often as I desired
9.[b]	*The ICU staff gave me* [I was given] the opportunity to *actively* participate in the care* *of my family member* [to the extent that I desired]
10.[a]	I was treated well by the staff in the ICU
11.[a]	I had confidence in the doctors that worked in the ICU
12.[a]	I had confidence in the nurses that worked in the ICU
13.[a,b]	I received sufficient information from the doctors regarding my family member's care
14.[a,b]	I received sufficient information from the nurses regarding my family member's care
15.[a,b]	The information that I received from the doctors was easy to understand
16.[a,b]	The information that I received from the nurses was easy to understand
17.[a]	The information that I received from the doctors and the nurses was consistent
18.	[A nurse always participated in the information meetings that I received.]
19.[b]	I felt included in discussions concerning my family member's care
20.[b]	I received ongoing information regarding tests/examinations carried out in the ICU
21.[a,b]	I received the support that I needed during the time of care in the ICU
22.[b]	I was well prepared for the *transfer* [discharge] from the ICU
23.[a,b]	My overall impression of the care my family member received in the ICU is good
24.	My overall impression of how the ICU staff conducted themselves towards me is good
Open questions	
25.	Do you have any suggestions on how the care in the ICU could improve?
26.	What were the most important things that you thought were good in the ICU?
27.	Do you have any other comments that you think might be useful to us who work in the ICU?

Note: The *second version* of the questionnaire is all of the above words except for the italicised ones and the *final version* is all of the above words except for the bracketed ones; * = the Swedish word for "care" was changed in the final version to a word that denotes care that can be performed by non-professional health care providers; [a] = question adapted from SF-ICU 24; [b] = question adapted from CCFSS; ICU = intensive care unit.

Cognitive interviews

In order to test the intelligibility of the items for family members, the second version of the questionnaire was tested using cognitive interviews (Berntson et al., 2016; Collins, 2003; van Oort et al., 2011). The cognitive interview method *Think Aloud*, which was utilised in this study, is used for the purpose of revealing the informants' thought processes when performing a task, such as deciding on an answer while filling out a questionnaire (Collins, 2003). The thoughts expressed by the informants are then analyzed to assess whether or not the questions functioned properly for the purposes of the questionnaire.

Data collection

Family members who fulfilled the criteria for inclusion in the study were approached face-to-face after the decision was made for the patient to be discharged from the ICU to a general ward. Family members were informed about the study and asked if they were interested in participating. Interview times were arranged shortly after the patients were discharged from the ICU. The interviews were conducted by four nurses, one nurse per interview session. All four nurses were post-graduate students in a master program. During the time period of data collection in October 2013, none of the interviewers worked or trained clinically with the patients and their participating family members. Each interview took place individually in private rooms in each of the two ICUs, at which time written and verbal information was given, and informed consent was obtained. The participants received verbal instructions on how to use the method *Think Aloud*, practiced the method on a short pre-test-questionnaire and were given feedback on their performance before the cognitive interview started (van Oort et al., 2011). Thereafter, they completed the second version of the SFS-ICQ. If the participants were silent for more than 10 seconds, the interviewer reminded them to keep talking (van Oort et al., 2011). Otherwise the interviewer did not interrupt the process. All interviews were audio recorded and transcribed verbatim (French et al., 2007; Green, 1996; van Oort et al., 2011).

Data analysis

The type of analysis used in this study was an "inspect-and-repair" model focusing on improving survey questions and on reducing response error (Willis, 2015). The analysis consisted of four steps in sequence: (1) the transcription of raw data from audio recordings, (2) the production of text based summaries, (3) the interpretation of data and assignment of codes and (4) the presentation of results (Willis, 2015). Data analysis of transcripts was performed by the interviewers and two of the authors while data collection was in progress. Each participant was considered a case and their responses to each item were summarized and thereafter interpreted and assigned a code representing one of four categories inspired by French et al. (2007): (A) no significant problems identified, (B) rereading an item, (C) questioning an item's content and (D) misunderstanding an item. To achieve credibility of the findings, the interpretation was discussed between the members in the research team until consensus was reached (French et al., 2007; Green, 1996; van Oort et al., 2011). Once coding and categorisation was completed, an additional analysis was conducted of participants' responses in order to investigate whether or not an item was problematic. Frequency counts were tallied for each category and descriptive statistical summaries were produced.

Findings

Participants

Twelve family members participated in the study, six from the general ICU (five women and one man, age range 34–78 years) and six from the thoracic ICU (four women and two men, age range 41–78 years). The family members were spouses, partners, parents, adult children or siblings to patients. Of these two were family members to the same patient.

Cognitive interviews

Among the participants' responses, 53 were seen as in need of further examination in order to investigate whether the item was problematic or not. These response issues were grouped into one of three categories: four of them were a matter of a participant's *rereading an item* (category B), twelve of them were a matter of a participant's *questioning an item's content* in some way while understanding it (category C) and 37 of them were a matter of a participant's *misunderstanding an item* (category D). On further investigation, many of the response issues did not lead to seeing an item as problematic and, therefore, no changes in the questionnaire were required for those issues. For instance, all of the six response issues involving the open questions and all of the four response issues involving a respondent rereading an item were not ultimately seen as problematic (which was a total of eight issues, since two of the four rereading issues involved an open question). None of the reread response issues led to seeing an item as problematic, because it was noted that the participants had reread the items as a method of concentrating their thoughts on the items. Furthermore, one individual accounted for near half of the *misunderstanding* issues. The participant found it difficult to separate events taking place in the ICU from events in the emergency department and in the general ward. Consequently, the text in the cover letter to the questionnaire was rephrased and it was emphasised that the items only concerned experiences in the ICU.

Seven items were ultimately identified as problematic, causing 31 response issues. Eight of these response issues concerned participants questioning the content of an item and 23 of them concerned participants misunderstanding an item. The seven problematic items were discussed between the researchers and six of the items were changed and one item was removed. Table 1 presents the second version of the SFS-ICQ and the changes that were made in the final version of SFS-ICQ. Table 2 is an overview of the problems in the seven problematic items in the general ICU and thoracic ICU. In both units, items in the main areas environment/atmosphere (items 1, 2 and 3), participation in care (item 8 and 9) and information (item 18 and 22) caused the greatest problems. The following examples illustrate the problems in the seven items that occurred in both units presented under main areas.

Environment/atmosphere

All three items (1, 2 and 3) in this main area generated altogether eight problems, two participants in each unit questioned the content in the items and four participants from the general ICU misunderstood the items. One example of questioning the content was in item 1, intended to relate to the comfort and atmosphere in the patient room. The participant questioned what the term "good" referred to and for whom it was supposed to be good:

> "*The environment in the intensive care room was good. . . .Well then, I specifically think about "good", what is "good"? . . . I guess it was . . . What's the intention of the term "good"? It was great for my mother* (the patient)*, because she was constantly monitored, but for us, obviously it wasn't so good, actually even a bit scary. But I strongly agree, it was a great environment since it was a safe environment for my mother and that was most important for me*". (Participant 1, general ICU).

To clarify the intention of these items, the term "*good*" was changed to "*welcoming*", "*suitable*" and "*suitable for information meetings*", respectively for the three items (Table 1).

Participation in care

In this main area items 8 and 9 generated eleven problems. Two participants from the general ICU misunderstood item 8, which concerned availability to the patient. This item was intended to investigate whether the ICU staff gave the responder enough opportunity to be close to their family member in the ICU. However, one participant misunderstood the item to also involve other engagements, in this case the situation at home:

> "*I was given the opportunity to visit my family member as often as I desired. . . .I agree to some extent. I have a small baby at home, who I also need to take care of. So I couldn't visit as much as I wanted*". (Participant 6, general ICU)

To avoid such misunderstandings the item was rephrased to "*The ICU staff gave me the opportunity to visit as much as I desired.*" (Table 1).

Nine participants had problems with item 9, participation in care, where the term care was questioned or misunderstood. Two participants stated that they had neither the education nor the skills required to care for a critically ill person. For example:

> "*I was given the opportunity to participate in the care to the extent that I desired. . . .I don't really understand the question. I'm not supposed to participate in any care here. I have no education for that*". (Participant 5, thoracic ICU)

In Swedish, there are several words for care. In analysing the responses, it was recognised that there was a risk for interpreting the word we used for care meaning *care exclusively performed by professional health care providers*. Therefore, we changed the word we used for care in item 9 to one that is less likely to be associated with health care provided by professionals (Table 1).

Table 2
Types and frequency of problems in the second version of the SFS-ICQ. Problematic items as disclosed through *Think aloud* sessions in two separate intensive care units.

		Label			
		Questioned content or phrasing		Misunderstanding	
Items		General ICU	Thoracic ICU	General ICU	Thoracic ICU
1.	The atmosphere in the ICU room was good	**1**23456	123456	1234**5**6	123456
2.	The atmosphere in the waiting room was good	123456	12**34**56	1234**5**6	123456
3.	The environment where the information was given was good	**1**23456	123456	1**2**34**5**6	123456
8.	I was given the opportunity to visit my family member as often as I desired	123456	123456	1234**56**	123456
9.	I was given the opportunity to participate in the care to the extent that I desired	123456	**1**234**5**6	**1**23**45**6	1**234**5**6**
18.	A nurse always participated in the information meetings that I received	**1**23456	123456	1**2345**6	**1**2**3**4**56**
22.	I was well prepared for the discharge from the ICU	**1**23456	123456	1234**5**6	1234**5**6

Note: SFS-ICQ = Swedish Family Satisfaction Intensive Care Questionnaire; "123456" represent six individual respondents in each intensive care unit, bold numbers represent that the main label above the number is applied to the individual respondent.

Information

In this main area, items 18 and 22 generated 12 problems. Item 18, assessing whether nurses were present in family information meetings, was difficult for nine participants to understand. Several of these participants stated that they constantly received information and could not distinguish between meetings. One example from the thoracic ICU:

> "*A nurse always participated in the information meetings that I received… Hmm, yes, they have only, it has probably mostly been nurses… and otherwise doctors. Yes, I totally agree*". (Participant 3, thoracic ICU)

Another example from one participant from the general ICU:

> "*A nurse always participated in the information meetings that I received… Well, a nurse was not always there when I spoke to the doctor, when I talked to him, it was just him, there was no nurse, so I can say that I agree to a large extent because most of the times a nurse was there, …but when a doctor was there, a nurse was not*". (Participant 4, general ICU)

This item was not primarily focused on family satisfaction and was therefore excluded from the questionnaire (Table 1).

Regarding item 22 concerning being adequately prepared before being discharged, one participant questioned the content and two participants thought that discharge referred to discharge from the hospital and not from the ICU. For example:

> "*I was well prepared for the discharge … Well, it was a little bit chaotic. But, that was also because of me, since I didn't know that he was coming home so early*". (Participant 5, general ICU).

The item was clarified by replacing the word "*discharge*" with "*transfer*" from the ICU (Table 1).

Discussion

In most hospitals today, patient satisfaction assessment is included in quality improvement work. However, to obtain such information from ICU patients is difficult (Burry et al., 2015). Instead, family satisfaction is proposed as a proxy for such measures (Stricker et al., 2011). Several instruments for evaluating family satisfaction with ICU care have been developed (van den Broek et al., 2015), but none, to our knowledge, has been translated and adapted to Swedish settings. In this study, such a questionnaire has been developed and tested for content validity. The cognitive method *Think Aloud* was used to explore problems that responders encountered while completing the SFS-ICQ.

Family satisfaction is an important complement to other quality indicators for evaluating ICU care and treatment (de Vos et al., 2007; Flaatten, 2012; Schleyer and Curtis, 2013). However, the concept family satisfaction is poorly defined and has currently no gold standard. Since there are many factors that influence satisfaction with care, such as expectations of care, information provided, communication, hospital infrastructure and, not the least, patient and family related factors (Jongerden et al., 2013; Rothen et al., 2010) it is difficult to evaluate. Nevertheless, since ICU patients seldom can be asked about satisfaction with care (Burry et al., 2015), an option is to turn to their families (Stricker et al., 2011). By conducting cognitive interviews with participants selected from the population that is the target group, we captured the users' views (Berntson et al., 2016). Even though the items in the tested version of the SFS-ICQ were generated from two validated and well-used questionnaires (Wall et al., 2007; Wasser et al., 2001) and evaluated by experts, the cognitive interviews revealed several shortcomings in item phrasing and respondent understanding. This shows the importance of evaluating respondent understanding with representatives of the actual population the questionnaire is intended for (Berntson et al., 2016). Our results suggest that, after rephrasing, the questions seem logical and comprehensible for the purpose of evaluating families' satisfaction of the quality of care in the ICU. The validity of an instrument is essential for the quality of data that the evaluation renders (Berntson et al., 2016). Questionnaires that lack good psychometric values may not measure the construct they intend to assess, and the results may not be valid or useful for evaluating and developing clinical practice. The respondent understanding was tested in two different ICUs with significantly diverse patient profiles (i.e. mainly elective versus acute admissions). This may suggest transferability to ICUs with a diverse patient mix.

In developing country-specific instruments it is important to be attentive to how legal matters concerning health care differ from country to country. Such matters will have implications for how questionnaires should be formulated in an appropriate way for specific countries and also for how responses to the questionnaires ought to be interpreted. Furthermore, it is important to be attentive to matters of translation, since words have different ranges of meaning in different languages.

Limitations

The advantage of using the *Think Aloud* method is that the researcher gets insight in the cognitive processes during performance of a task in an authentic situation (Green, 1996); however, since some thoughts appear quickly and simultaneously, all thoughts may not be verbalised (Fonteyn et al., 1993). Some information can therefore remain unknown to the researcher. Some participants can also be less articulate and may find it difficult to verbalize their thoughts (Fonteyn et al., 1993). To minimise the effect of these limitations, all participants in our study completed a warm up task and received feedback on their performances before answering the SFS-ICQ. Participants were also reminded to keep talking if being silent for more than ten seconds (French et al., 2007; van Oort et al., 2011).

All interviews were made before revising the questions, which may be a limitation of the study. A mid-time analysis and revision or additional interviews might have ensured that the questions were comprehensible for the remaining responders (Humphrey et al., 2013).

Furthermore, family members' experiences from other care situations could influence their perceptions of care in the ICU. For instance, a bad experience in the general ward due to less attention from nurses (Cullinane and Plowright, 2013), might make the memories from the ICU with extensive vital sign surveillance seem as better care or vice versa. This may influence the responses given in answering the questionnaire. In this study, one participant had difficulties in separating experiences and events in the ICU from the emergency department and general ward. Memory may also be affected by the stressful situation the family member is in (de Quervain et al., 1998). Therefore, we recommend that the information letter clearly states that the items only refer to the ICU and that the questionnaire should be completed close in time to the ICU discharge.

Conclusion

Measuring family satisfaction of care in intensive care units helps to highlight areas of care that are of high quality as well as ones that need improvement. Evaluation of family satisfaction with ICU-care demands a valid and reliable tool. This study was a first step in validating the Swedish family satisfaction questionnaire (SFS-ICQ). A next step will be to assess construct validity, reliability, responsiveness and sensitivity of the questionnaire.

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Conflict of interest

The authors have no conflicts of interest to disclose.

Contributor's statement

Johan Thermaenius: Mr. Thermaenius conceptualized and designed the study, were responsible for the acquisition of data, carried out the analysis and the interpretation of data, drafted the initial article, revised and approved the final version of the article as submitted.

Anna Schandl: Dr. Schandl contributed considerably to the conception and design of the study, revised the article critically for important intellectual content, and approved the final version of the article as submitted.

Kerstin Prignitz Sluys: Dr. Sluys contributed substantially to the design, analysis and interpretation of data, critically reviewed and revised the article for important intellectual content, and approved the final version of the article as submitted.

Ethical statement

This study did not involve sensitive personal information, biological samples, physical procedures or manipulation of subjects physically or psychologically. It was, therefore, exempt from the requirements for ethical approval, according to the Ethical Review Act, Central Ethical Review Board in Sweden (https://www.epn.se). The study was carried out in compliance with the Declaration of Helsinki and with permission granted by the Medical Directors at each intensive care unit, Karolinska University Hospital, Stockholm, Sweden. All participants received written and verbal information and provided informed consent prior to their participation.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.iccn.2018.05.003.

References

Berntson, E., Bernhard-Oettel, C., Hellgren, J., Näswall, K., Sverke, M., 2016. Enkätmetodik. Natur & kultur, Stockholm.

Burry, L., Cook, D., Herridge, M., Devlin, J.W., Fergusson, D., Meade, M., et al., 2015. Recall of ICU stay in patients managed with a sedation protocol or a sedation protocol with daily interruption. Crit. Care Med. 43 (10), 2180–2190. https://doi.org/10.1097/CCM.0000000000001196.

Carlsen, B., Aakvik, A., 2006. Patient involvement in clinical decision making: the effect of GP attitude on patient satisfaction. Health Expect. 9 (2), 148–157. https://doi.org/10.1111/j.1369-7625.2006.00385.x.

Collins, D., 2003. Pretesting survey instruments: an overview of cognitive methods. Qual. Life Res. 12 (3), 229–238.

Cullinane, J.P., Plowright, C.I., 2013. Patients' and relatives' experiences of transfer from intensive care unit to wards. Nurs. Crit. Care 18 (6), 289–296. https://doi.org/10.1111/nicc.12047.

de Quervain, D.J., Roozendaal, B., McGaugh, J.L., 1998. Stress and glucocorticoids impair retrieval of long-term spatial memory. Nature 394 (6695), 787–790. https://doi.org/10.1038/29542.

de Vos, M., Graafmans, W., Keesman, E., Westert, G., van der Voort, P.H., 2007. Quality measurement at intensive care units: which indicators should we use? J. Crit. Care 22 (4), 267–274. https://doi.org/10.1016/j.jcrc.2007.01.002.

Flaatten, H., 2012. The present use of quality indicators in the intensive care unit. Acta Anaesthesiol. Scand. 56 (9), 1078–1083. https://doi.org/10.1111/j.1399-6576.2012.02656.x.

Fonteyn, M.E., Kuipers, B., Grobe, S.J., 1993. A description of Think Aloud Method and protocol analysis. Qual. Health Res. 3 (4), 430–441. https://doi.org/10.1177/104973239300300403.

French, D.P., Cooke, R., McLean, N., Williams, M., Sutton, S., 2007. What do people think about when they answer theory of planned behaviour questionnaires? A 'think aloud' study. J. Health Psychol. 12 (4), 672–687. https://doi.org/10.1177/1359105307078174.

Gay, E.B., Pronovost, P.J., Bassett, R.D., Nelson, J.E., 2009. The intensive care unit family meeting: making it happen. J. Crit. Care 24 (4). https://doi.org/10.1016/j.jcrc.2008.10.003. 629 e621–612.

Green, C.G.K., 1996. Protocol analysis: practical implementation. In: Richardson, J.T. E. (Ed.), Handbook of Qualitative Research Methods for Psychology and the Social Science. BPS Books, Leicester, pp. 55–74.

Henrich, N.J., Dodek, P., Heyland, D., Cook, D., Rocker, G., Kutsogiannis, D., et al., 2011. Qualitative analysis of an intensive care unit family satisfaction survey. Crit. Care Med. 39 (5), 1000–1005. https://doi.org/10.1097/CCM.0b013e31820a92fb.

Humphrey, L., Kulich, K., Deschaseaux, C., Blackburn, S., Maguire, L., Stromberg, A., 2013. The caregiver burden questionnaire for heart failure (CBQ-HF): face and content validity. Health Qual. Life Outcomes 11, 84. https://doi.org/10.1186/1477-7525-11-84.

Jongerden, I.P., Slooter, A.J., Peelen, L.M., Wessels, H., Ram, C.M., Kesecioglu, J., et al., 2013. Effect of intensive care environment on family and patient satisfaction: a before-after study. Intensive Care Med. 39 (9), 1626–1634. https://doi.org/10.1007/s00134-013-2966-0.

Khalaila, R., 2014. Meeting the needs of patients' families in intensive care units. Nurs. Stand. 28 (43), 37–44. https://doi.org/10.7748/ns.28.43.37.e8333.

Little, P., Everitt, H., Williamson, I., Warner, G., Moore, M., Gould, C., et al., 2001. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. BMJ 323 (7318), 908–911.

Phillips, N.M., Street, M., Haesler, E., 2016. A systematic review of reliable and valid tools for the measurement of patient participation in healthcare. BMJ Qual. Saf. 25 (2), 110–117. https://doi.org/10.1136/bmjqs-2015-004357.

Pochard, F., Azoulay, E., Chevret, S., Lemaire, F., Hubert, P., Canoui, P., et al., 2001. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. Crit. Care Med. 29 (10), 1893–1897.

Pochard, F., Darmon, M., Fassier, T., Bollaert, P.E., Cheval, C., Coloigner, M., et al., 2005. Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. J. Crit. Care 20 (1), 90–96.

Rothen, H.U., Stricker, K.H., Heyland, D.K., 2010. Family satisfaction with critical care: measurements and messages. Curr. Opin. Crit. Care 16 (6), 623–631. https://doi.org/10.1097/MCC.0b013e32833e9718.

Sainio, C., Lauri, S., Eriksson, E., 2001. Cancer patients' views and experiences of participation in care and decision making. Nurs. Ethics 8 (2), 97–113. https://doi.org/10.1177/096973300100800203.

Say, R., Murtagh, M., Thomson, R., 2006. Patients' preference for involvement in medical decision making: a narrative review. Patient Educ. Couns. 60 (2), 102–114. https://doi.org/10.1016/j.pec.2005.02.003.

Schleyer, A.M., Curtis, J.R., 2013. Family satisfaction in the ICU: why should ICU clinicians care? Intensive Care Med. 39 (6), 1143–1145. https://doi.org/10.1007/s00134-013-2939-3.

Schwarzkopf, D., Behrend, S., Skupin, H., Westermann, I., Riedemann, N.C., Pfeifer, R., et al., 2013. Family satisfaction in the intensive care unit: a quantitative and qualitative analysis. Intensive Care Med. 39 (6), 1071–1079. https://doi.org/10.1007/s00134-013-2862-7.

Stricker, K.H., Kimberger, O., Brunner, L., Rothen, H.U., 2011. Patient satisfaction with care in the intensive care unit: can we rely on proxies? Acta Anaesthesiol. Scand. 55 (2), 149–156. https://doi.org/10.1111/j.1399-6576.2010.02293.x.

Trevick, S.A., Lord, A.S., 2017. Post-traumatic stress disorder and complicated grief are common in caregivers of neuro-ICU patients. Neurocrit. Care 26 (3), 436–443. https://doi.org/10.1007/s12028-016-0372-5.

van den Broek, J.M., Brunsveld-Reinders, A.H., Zedlitz, A.M., Girbes, A.R., de Jonge, E., Arbous, M.S., 2015. Questionnaires on family satisfaction in the adult ICU: a systematic review including psychometric properties. Crit. Care Med. 43 (8), 1731–1744. https://doi.org/10.1097/CCM.0000000000000980.

van Oort, L., Schroder, C., French, D.P., 2011. What do people think about when they answer the Brief Illness Perception Questionnaire? A 'think-aloud' study. Br. J. Health Psychol. 16 (Pt. 2), 231–245. https://doi.org/10.1348/135910710X500819.

Veilleux, S., Noiseux, I., Lachapelle, N., Kohen, R., Vachon, L., Guay, B.W., et al., 2018. Patients' perception of their involvement in shared treatment decision making:

key factors in the treatment of inflammatory bowel disease. Patient Educ. Couns. 101 (2), 331–339. https://doi.org/10.1016/j.pec.2017.07.028.

Wall, R.J., Engelberg, R.A., Downey, L., Heyland, D.K., Curtis, J.R., 2007. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Crit. Care Med. 35 (1), 271–279. https://doi.org/10.1097/01.ccm.0000251122.15053.50.

Wasser, T., Pasquale, M.A., Matchett, S.C., Bryan, Y., Pasquale, M., 2001. Establishing reliability and validity of the critical care family satisfaction survey. Crit. Care Med. 29 (1), 192–196.

Willis, G.B., 2015. Analysis of the Cognitive Interview in Questionnaire Design. Oxford University Press, New York.