

**The Role of Several Factors on Stress and Anxiety in Loved Ones of Intensive Care Unit  
Patients**

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### Abstract

**Background.** When Intensive Care Unit (ICU) patients are admitted to the ICU, loved ones can become involved with the ICU and the ICU patient's process. Several studies show that having someone close to you on the ICU can lead to stress, which in turn can lead to physical health risks, such as strokes, and mental health risks, such as anxiety. Information on what influences stress and anxiety in loved ones of ICU patients is still scarce, but the factors 'satisfaction with shared decision-making', 'understandability of information' and 'friendliness of healthcare professionals' might be involved according to the literature.

**Aim.** The aim of this paper is to gather more information on the role of 'satisfaction with shared decision-making', 'understandability of information' and 'friendliness of healthcare professionals' on stress and anxiety in loved ones of ICU patients, in the hope to contribute to stress and anxiety prevention. Scores for anxiety were considered to be high when they scored equal to or above four, which in the questionnaire had the label 'regularly'. Scores for stress were considered to be high when they scored above or equal to three, which was labelled 'frequently'.

**Methods.** Participants ( $N = 4$ ) were gathered by a local hospital, and they were asked to fill in a questionnaire assessing the several factors possibly influencing stress and anxiety after the patient's ICU stay. Data were analysed via mean-computations and Kendall's Tau correlations.

**Results.** Data analysis showed that stress ( $M_{\text{stress}} = 1.545$ ) and anxiety ( $M_{\text{anxiety}} = 1.286$ ) neither had the anticipated high levels. In addition to that, Kendall's Tau Correlations showed that satisfaction with shared decision-making in relation to stress ( $\tau_b = 0.183, p = 0.781$ ) and anxiety ( $\tau_b = -0.816, p = 0.221$ ) should be rejected, whereas satisfaction with shared decision-making in relation to anxiety did show the expected negative correlation. Furthermore, understandability of information in relation to stress ( $\tau_b = 0.183, p = 0.781$ ) and anxiety ( $\tau_b = 0.000, p = 1.000$ ) was rejected due to positive findings with insignificant p-values. Lastly, for friendliness of healthcare professionals no results came out of SPSS due to zero variance.

**Discussion.** Levels of stress and anxiety were found to be quite low, with no significant relations to the three studied factors. In addition to that, whereas relations were expected to be negative, most of them were positive. Factors that might explain these findings include familiarization with the ICU, high education in relation to an older age, friendliness of healthcare professionals, seriousness of obtained information and pressure of shared decision-making.

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## Introduction

Many people, at some moment in their life, will have someone close to them being critically ill. In such cases, it might be that this loved one has to be admitted to the Intensive Care Unit (ICU). According to the Nationale Intensive Care Evaluatie (NICE) (2020), there were 68.936 admissions to the ICU in 2020 in the Netherlands. Many of these ICU patients will have someone that cares about them and might then be involved in their ICU process. During this process, loved ones are assumed to go through some negative emotions, such as stress and anxiety (Beesley et al., 2018). Whereas some research has been done on the topic of stress, anxiety, and which factors influence these feelings, information is scarce.

In order to properly investigate the topic of stress, anxiety and influencing factors in the ICU, one term had to be defined. According to the Cambridge Dictionary (n.d.), a loved one is “a person that you love, usually a member of your family” (p. 1). However, in this paper, the term loved ones will be defined a little different. Here, we define loved ones as “someone close to the ICU patient, for example a relative or spouse, who cares about and who loves the ICU patient and who is closely involved in their ICU process”.

## Stress and Anxiety

Stress and anxiety are emotions that can come up during difficult times, such as during the ICU admission. According to Trichopoulous et al., Kario (1983), McEwen and Pickering (2003), and to Wittstein et al. (2005, as cited in Garfin, Thompson, & Holman, 2018), experienced stress can lead to severe physical health risks, such as strokes or heart attacks. In addition to that, according to Norris et al. (1999) and McFarlane & Van Hooff (2009) (as cited in Garfin, et al., 2018), people who experience stress have an increased risk for developing several psychopathologies, for example anxiety (Chapman et al., 2004; Garfin & Silver, 2016, as cited in Garfin et al., 2018).

Research can confirm that loved ones of ICU patients suffer from stress while involved or having been involved with the ICU. Jamerson et al. (1996) found in their interview-study that relatives of ICU patients experience stress. Next to that, they often were uncertain and bewildered (Jamerson et al., 1996). In addition to that, a different study shows that 33% of relatives suffered from stress while having someone close to them on the ICU (Azoulay, Chaize & Kentish-Barnes, 2014)

Furthermore, research can confirm that loved ones of ICU patients can suffer from anxiety. The study of Köse et al. (2016) shows that 35.9% of participants who had a loved one on the ICU started to suffer from anxiety. Another study showed a percentage that was

considerably high; they showed that 73% of family members of ICU patients started to suffer from anxiety (Azoulay et al., 2004). Likewise, Pochard et al. (2001) found that 69.1% of family members experienced anxiety while having someone close to them in the ICU.

Whereas studies have been able to show that loved ones of ICU patients can experience stress and anxiety, more research on these two issues should be done to get a better view of the topic. Therefore, this paper will test whether loved ones of ICU patients do experience high levels of stress and anxiety while having someone close to them on the ICU. In this paper, a high level of stress will be high when feelings of stress are felt frequently, which Cambridge Dictionary defines as “happening often” (n.d., p.1). Levels of anxiety will be high when it happens regularly, which Cambridge Dictionary defines as “happening or doing something often” (n.d., p.1). Next to answering whether loved ones experience stress and anxiety, this study will look at which factors influence feelings of stress and anxiety. According to Azoulay et al. (2004) and White et al. (2007) (as cited in Komachi & Kamibeppu, 2015), loved ones oftentimes experience serious amounts of stress during the ICU admission as a result of having to make high-risk decisions for their loved ones.

### **Satisfaction with Shared Decision-Making**

Although patients can sometimes make decisions for themselves, this is not always the case. According to Cohen, McCue and Green (1993) and to Ferrand et al. (2001) (as cited in Heyland et al., 2003), patients on the ICU are often not able to make decisions for themselves due to the severity of their illness. In order for the patient to still get the care they would have wanted, a loved one can help in making patient-related decisions (Hanson et al, 1994.; Prendergast, Claessens & Luce, 1998; as cited in Heyland et al., 2003). This process of deciding as a loved one of the ICU patient together with a healthcare professional can be seen as shared decision-making, which this paper defines as “the collaboration between health care professionals and loved ones in order to come up with treatment for the ICU patient in question”.

Whereas mentioned earlier that loved ones can experience stress due to shared decision-making, this does not always have to be the case. One study showed that family members of ICU patients could be content when they are satisfied with the provided care for the patient, when they are satisfied with the information obtained and when they feel hospital personnel is supportive towards them (Heyland et al., 2003). Furthermore, best treatment will be able to be given when families are involved in shared decision-making in which their priorities and the ICU patient’s values are taken into account (Cai et al., 2015), which is the goal and thus could lead to greater satisfaction with shared decision-making.

Another study showed that family members of ICU patients feel better when they receive decent information (Azoulay et al., 2001, as cited in Azoulay et al., 2004). Satisfactory information can facilitate participation in shared decision-making, since loved ones then can make a decision based on the patient's wishes (Coulter, Entwistle, & Gilbert, 1999; Burchardi, 2001; Azoulay et al., 2003, as cited in Azoulay, 2004).

As some factors are known to influence the perception of satisfaction with shared decision-making, information on how shared decision-making influences stress and anxiety remains scarce. Therefore, one aim of this paper is to reveal this relation. As stated earlier, information should be adequate to happily participate in shared decision-making. Therefore, understandability of information is essential in shared decision-making.

### **Understandability of Information**

Whereas understandability of information is indispensable for loved ones on the ICU, loved ones do not always receive or feel the opportunity to receive information that is understandable. According to Davidoff (1997) (as cited in Bickmore, Pfeifer, & Paasche-Orlow, 2009), healthcare professionals only have limited time with every single patient, which might leave loved ones with not enough time to understand given information. These time restrictions might pressure patients and loved ones with the consequence being that they do not ask further (Davidoff, 1997, as cited in Bickmore, Pfeifer, & Paasche-Orlow, 2009). A study done by Bell et al. (2018) can confirm this; they found that 50% - 70% of loved ones of ICU patients do not speak up when receiving information they do not fully understand (Bell et al., 2018).

Understanding provided information can have positive effects on loved ones of ICU patients. According to McKiernan and McCarthy (2010), loved ones who receive information they understand are better able to manage the difficulties of having someone close to them being on the ICU. Furthermore, Lautrette (2007) showed in their study that anxiety was lower in the intervention group where loved ones were evoked to ask questions.

On the contrary, not understanding can have negative effects on loved ones. According to Boyle et al. (2005), not understanding information can lead to confusion, which in turn might lead to feelings of anxiety due to uncertainty (Carleton, 2012, as cited in Gu et al., 2020). However, information is scarce on how understandability of information and stress and anxiety are related, thus one more aim of this paper is to make this relation clear. As aforementioned, understandability of information can be influenced by healthcare professionals, and therefore behaviour of healthcare professionals should be further investigated.

### **Friendliness of Healthcare Professionals**

One more aspect that could influence stress and anxiety levels of loved ones of ICU patients is how kind healthcare professionals are towards loved ones. Relatives of ICU patients can become emotional while on the ICU, which Van Keer et al. (2015) showed in their study that healthcare workers found to be stressful. This resulted in healthcare professionals being distant towards loved ones (Van Keer et al., 2015). Loved ones, in turn, perceived this as unkind behaviour, which is a factor leading to conflict between loved ones and healthcare personnel (Van Keer et al., 2015).

However, kindness greatly benefits loved ones in the ICU. As mentioned by Shamay-Tsoory, Aharon-Peretz and Perry (2009) and Peterson and Bredow (2004), nursing empathy is the skill to feel what a patient is feeling, which includes being attuned to how a patient feels, what they need and how they should be communicated with (as cited in Moghaddasian, Dizaji, & Mahmoudi, 2013). Whereas this term applies to patients, loved ones could benefit from nursing empathy. According to Wong, Koch, and Rawson (2015), this kind of empathetic communication was key to the mental well-being of relatives (as cited in Kynoch, Ramis, & McArdle, 2021). Therefore, this can be seen as a friendly attitude of healthcare professionals towards loved ones and thus high in friendliness of healthcare professionals. As information on the relation between friendliness of healthcare professionals and stress and anxiety is scarce, this paper has as one of its goals to visualize this connection.

### **Research Question and Hypotheses**

The goal of this study is to explore the connection between anxiety, stress, friendliness of healthcare professionals, satisfaction with shared decision-making and understandability of information. The research question (RQ) that this research will try to answer is “What is the role of satisfaction with shared decision-making, understandability of obtained information and friendliness of healthcare professionals on stress and anxiety in loves ones of ICU patients?”.

The subsequent hypotheses are the following:

- H<sub>1</sub>: Self-reported stress and anxiety in loved ones of ICU patients are high in comparison to the average or low stress and anxiety loved ones of ICU patients could experience.
- H<sub>2</sub>: Self-reported stress and anxiety in loved ones of ICU patients is negatively associated with satisfaction with shared decision-making.
- H<sub>3</sub>: Self-reported stress and anxiety in loved ones of ICU patients is negatively associated with understandability of information.



- H<sub>4</sub>: Self-reported stress and anxiety in loved ones of ICU patients is negatively associated with friendliness of healthcare professionals.

## **Methods**

### **Design**

This study made use of a survey design, which took place from the end of May 2022 until the end of June 2022. This research was ethically approved by the local hospital the study took place and by the University of Twente. In addition to that, all participants filled in an informed consent form before filling in the questionnaire (Appendix A).

### **Participants**

In this study, loved ones of ICU patients took part by filling in a questionnaire. Inclusion criteria for this study were (1) that the participant should be a loved one of an ICU-patient that has been at least 48 hours on the ICU and (2) that the participant should own a mobile phone. Exclusion criteria for this study were (1) people who did not master the Dutch language and (2) people who were suffering from addictions or other severe psychopathologies. These participants were recruited by research nurses of a local hospital.

### **Materials**

In order to carry out this research, a questionnaire was needed that measured the different variables. This questionnaire consisted of self-made questions and of questions from pre-existing questionnaires (Appendix B); questions that were not relevant for this research were not added to the appendix (Appendix B). This bigger questionnaire was meant for two studies, which contained the concepts (1) 'demographics', (2) 'stress', (3) 'anxiety', (4) 'understandability of information', (5) 'satisfaction with shared decision-making', (6) 'friendliness of healthcare professionals', (7) 'conflict of role' and (8) 'information need'. For this study, only the first six concepts were used. The questionnaire had to be filled in through Qualtrics which was accessible via a laptop, computer or a mobile phone.

### ***Demographics***

The first part of the questionnaire was designed to get an overview of general aspects of the ICU patient's loved one. Questions that were asked were about the participants age, their gender,

their relation to the patient, and so on. One question was about the participant's level of education (Centraal Bureau voor de Statistiek, 2017). (Appendix B).

### *Stress*

The next measured variable was stress, in which seven items from the Perceived Stress Scale (PSS) were used (Cohen, Kamarck, & Mermelstein, 1983). The PSS measures how stressful certain events are perceived for different individuals (Cohen et al., 1983). Seven items were chosen that would best fit the ICU; these items were adapted and translated from English to Dutch (Cohen et al., 1983). One example item was “Gedurende de opnameperiode, hoe vaak had u het gevoel dat u alles onder controle had buiten de IC?” which would translate to, but would not be a literal translation of Cohen et al. (1983), to “During the admission period, how often did you have the feeling that you had everything under control outside of the ICU?” (Cohen et al., 1983, p. 394). The questionnaire had a coefficient alpha ranging from 0.84 to 0.86 depending on the sample and answer options would go from zero to four (Cohen et al., 1983), in this case one to five. For this factor in this study, Cronbach's alpha was not computed, due to one item having zero variance and a warning in SPSS stating that the determinant was close to zero. Furthermore, four self-made items were not analysed, since they were originally created to measure something else than this paper intended to measure. For the eventual stress score, the mean was computed. A score of above three or equal to three was considered a high score, since three had the label ‘frequent’. A high score meant that the participant suffered high levels of stress. A score of below three was considered low or average.

### *Anxiety*

Following stress, anxiety was measured. This variable was measured by using the Hospital Anxiety and Depression Scale (HADS), which measures anxiety and depression (Bokhorst, 2019). One example item was “Ik voel me de laatste tijd rusteloos.” (Pouwer, Snoek, & Van der Ploeg, 1997, as cited in Meetinstrument in de zorg, n.d., p. 2), which would translate to “I have been feeling restless lately”. The HADS has an internal consistency of between .76 and .88 (Van Ballegooijen et al., 2016). For this factor in this study, Cronbach's alpha was not computed, due to several items having zero variance and a warning in SPSS stating that the determinant was close to zero. Furthermore, four self-made items were not analysed, since they were originally created to measure something else than this paper intended to measure. The questions used ranged from score one to five, where the eventual anxiety score would be the mean of all anxiety questions. Since four had the label ‘regular’, all mean-scores above or equal

to four were considered high and all scores lower than four were considered average or low. A high score meant that the participant suffered high levels of anxiety.

### ***Understandability of Information***

Understandability of information was measured by four self-made items and one item from the questionnaire of Heyland and Tranmer (2001) which was translated to Dutch and rephrased so that it fit the style of the questionnaire. The self-made questions were made to see how well loved ones understood treatment options and how well they understood the illness of the loved one before and after receiving information. One example of a self-made question is “Hoe goed snapte u wat behandelingsopties zouden zijn na het contact met een zorgprofessional?”, which would translate to “How well did you understand what treatment options would be after contact with a healthcare professional?”. For this factor in this study, Cronbach’s alpha was not computed, due to a warning in SPSS stating that the determinant was close to zero. Answer possibilities were rated one to five, for which eventually a mean-score was computed. The higher the score, the better the participant understood the information.

### ***Satisfaction with Shared Decision-Making***

A second factor that might influence the dependent variables is ‘Satisfaction with Shared Decision-Making’, in which four items from Grover et al. (2011) were translated to Dutch and formulated to fit this questionnaire and research. These items measured whether participants felt like they were part of the decision-making process. One example item was “Hoe goed heeft de zorgprofessional geprobeerd te begrijpen hoe u in het proces van medische besluitvoering betrokken wilde worden?”, which would approximately translate, but is not a fully copied citation, to “How well did the healthcare professional try to understand how you wanted to be involved in shared decision-making?” (Grover et al., 2011, p.1). For this factor in this study, Cronbach’s alpha was not computed, due to a warning in SPSS stating that the determinant was close to zero. Answer possibilities ranged from one to five, in which a mean score was computed. The higher the score, the more the participant felt satisfied with shared decision-making.

### ***Friendliness of Healthcare Professionals***

The last variable measured to answer the research question is ‘Friendliness of Healthcare Professionals’, in which it became evident whether participants thought healthcare personnel were friendly towards them. This question was self-made and contained information on whether

participants thought healthcare professionals acted kindly towards them. This question was phrased the following: “Hoe vriendelijk vond u het zorgpersoneel?”, which would translate to “How friendly did you think hospital personnel were?”. Scores ranged from one to five, in which a higher score meant a more friendly attitude from healthcare professionals.

### **Procedure**

When patients were still admitted to the ICU, loved ones of ICU patients were contacted by healthcare personnel about the possibility to partake in this study one to two days before the patient would be discharged to the clinical wards. The participants were informed, after which they received the information sheet (Appendix C) and the informed consent form. The participant had the opportunity to ask hospital personnel questions about the study.

After participants signed the informed consent, they did not get the opportunity to fill in the questionnaire until after the patient was discharged from the ICU. Once the patient was discharged, the participant would receive a participation form which contained a QR-code and website link (Appendix D). This QR-code and website link led the participant to the Qualtrics Questionnaire, in which the participant was asked about ‘stress’, ‘anxiety’, ‘understandability of information’, ‘satisfaction with shared decision-making’ and about ‘friendliness of healthcare personnel’. The participant had 24 hours to fill in this questionnaire after the patient’s discharge. Participants were able to fill in the questionnaire at their preferred time and place.

After the Questionnaire was completed, participants got a message on Qualtrics that they finished the questionnaire. They were thanked for their participation and they were informed that this was the ending of their study participation.

### **Data analysis**

The data analysis was performed using SPSS 27. A general overview of participant information, such as gender and age, was made using descriptive statistics. For all demographic variables, frequencies (N) and percentages (%) were given. In addition to that, the mean and standard deviation were given for demographic variable ‘age’.

In order to answer the RQ and to be able to accept or reject the hypotheses, several statistical analyses were done. Firstly, the hypothesis was answered that only focused on one variable, which was  $H_1$  (stress and anxiety). For this hypothesis, the mean and standard deviation were calculated. In addition to that, for the three independent variables ‘friendliness of healthcare professionals’, ‘understandability of information’ and ‘satisfaction with shared

decision-making' the means, standard deviations, minimums and maximums of scores were given so that results could be interpreted more meaningfully.

For the other hypotheses, which predicted a negative correlation between stress, anxiety and satisfaction with shared decision making (H<sub>2</sub>), a negative correlation between stress, anxiety and understandability of information (H<sub>3</sub>), and a negative correlation between stress, anxiety and friendliness of healthcare professionals (H<sub>4</sub>), Kendall's Tau Correlation was applied. Kendall's Tau is a form of statistical analysis that is nonparametric and which shows the relationship between two variables (Laerd Statistics, n.d.). Kendall's tau needed to be used due to the data's nonparametric nature as a result of this study's small sample size (Corporate Finance Institute, 2022). Kendall's Tau was chosen for its accuracy with small sample sizes (Statistics Solutions, n.d.). Furthermore, Croux and Dehon (2010) show in their study that Kendall's Tau is preferred over Spearman's rho, since Kendall's Tau has a higher efficiency and is considered less affected by outliers, which is another reason for why this method was chosen.

In order to answer the hypotheses, the Kendall's Tau-b correlation ( $\tau_b$ ) and the  $p$ -value were considered (Laerd Statistics, n.d.). For  $\tau_b$  the strength and direction of a relation was given, so a positive number meant a positive correlation and a higher number meant a stronger correlation. In addition, the  $p$ -value was given, in which a value of  $\leq 0.05$  was considered significant (Statistics Solutions, n.d.).

## Results

### Participants

After completing data analysis, four participants were recruited of which none were excluded ( $M_{age} = 62.25$ ,  $SD_{age} = 13.401$ ; 75% female, 25% male). Ages ranged from 47 to 74, by which ages of participants were 47 (25%), 55 (25%), 73 (25%) and 74 (25%). As for days on the ICU, three loved ones had been on the IC for three days (75%) and one had been on the ICU for six days (25%). Lastly, two participants were a child of an ICU patient (50%) and two participants were a partner of an ICU patient (50%). For all the other demographics, such as 'level of education' and 'relation to patient', statistics can be found in Table 1.

**Table 1**

*Demographics.*

Variables with answer options	Frequencies (N)	Percentages (%)
-------------------------------	-----------------	-----------------

Gender	Man	1	25
	Woman	3	75
	Other	0	0
Level of education	Basisonderwijs	0	0
	Vmbo, mbo1, avo onderbouw	2	50
	Havo, VWO, MBO	0	0
	HBO, WO Bachelor	1	25
	WO, master, doctor	1	25
Ethnicity	Nederlands	3	100
First time on the IC	Yes	2	50
	No	2	50

*Note.* For the variable ‘ethnicity’ there are only 3 participants for the reason that one participant filled in an unfitting answer. In addition to that, all participants filled in their ethnicity slightly different, so answers have been adapted so that they would all fit the same category.

### **Scores on Understandability of Information, Satisfaction with Shared Decision-Making and Friendliness of Healthcare Professionals**

For the three independent variables ‘understandability of information’, ‘friendliness of healthcare professionals’ and ‘satisfaction with shared decision-making’, means, standard deviations, minimums of means and maximums of means can be found in table 2. In this table it can be seen that all mean-scores are very high and close to the maximum score. In addition to that, all independent variables have a very small standard deviation. This means that, overall, all participants felt satisfied with shared decision-making, understood information well and found healthcare professionals friendly.

#### **Table 2**

*Means, standard deviations, minimums of means and maximums of means for the independent variables.*

Independent variable	Mean (M)	Standard deviation (SD)	Minimum	Maximum
Understandability of Information	4.500	0.383	4.200	5.000
Friendliness of Healthcare Professionals	5.000	0.000	5.000	5.000
Satisfaction with shared decision-making	4.625	0.479	4.000	5.000

### Levels of Stress and Anxiety

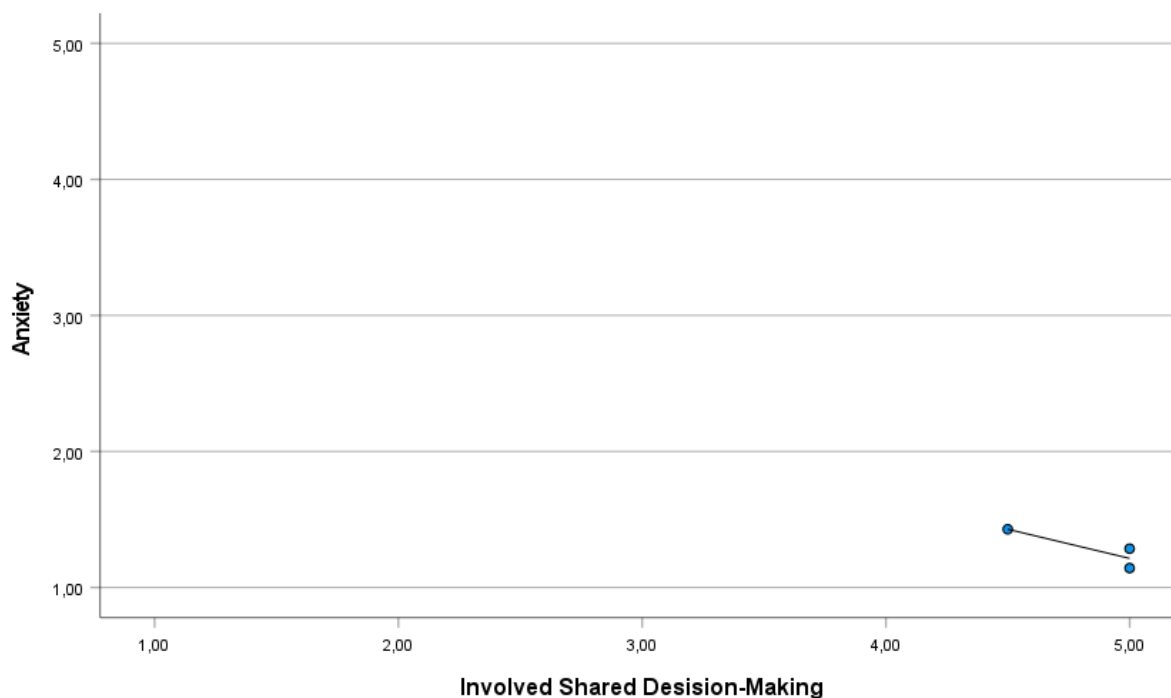
The first hypothesis that self-reported stress and anxiety in loved ones of ICU patients is high ( $M_{\text{stress}} \geq 3$ ;  $M_{\text{anxiety}} \geq 4$ ) was rejected for stress ( $M_{\text{stress}} = 1.545$ ,  $SD_{\text{stress}} = 0.472$ ) and for anxiety ( $M_{\text{anxiety}} = 1.286$ ,  $SD_{\text{anxiety}} = 0.143$ ). This means that levels of stress and anxiety were considered moderate to low, which entails that participants did not experience much anxiety or stress.

### Stress, Anxiety and Satisfaction Shared Decision-Making

The second hypothesis, which assumed a negative association between stress and satisfaction with shared decision-making, was rejected ( $\tau_b = 0.183$ ,  $p = 0.781$ ). In addition, this hypothesis assumed a negative association between anxiety and satisfaction with shared decision-making, which was rejected ( $\tau_b = -0.816$ ,  $p = 0.221$ ). As both  $p$ -values are above 0.05, correlations are not significant. However, whereas stress had a positive relation, anxiety did have the anticipated negative relation, which could still be an indication that satisfaction with shared decision-making could lead to less anxiety (Figure 1).

### Figure 1

*The relationship between anxiety and satisfaction with shared decision-making.*



*Note.* This relation was in line with H<sub>2</sub>, but was insignificant. As can be seen, the line continuously goes down, which could be an indication that perceived shared decision-making could decrease levels of anxiety.

### **Stress, Anxiety and Understandability of Information**

The third hypothesis, which assumed a negative association between stress and understandability of information, was rejected ( $\tau_b = 0.183$ ,  $p = 0.781$ ). In addition, this hypothesis assumed a negative association between anxiety and understandability of information, which was rejected ( $\tau_b = 0.000$ ,  $p = 1.000$ ). As can be seen, neither of the  $p$ -values showed a significant relation. Furthermore, neither Kendall's Tau values showed a negative relation, which would not indicate that understandability of information reduces stress or anxiety.

### **Stress, Anxiety and Friendliness of Healthcare Professionals**

Lastly, the fourth hypothesis, which assumed a negative association between stress, anxiety and a friendly attitude of healthcare professionals could not be accepted nor rejected. To start, the sample size was too small for Kendall's Tau to produce an outcome. Furthermore, there was no variation in scores, since all participants gave healthcare professionals the highest score of friendliness, which thus meant participants found healthcare professionals to be very friendly.



## Discussion

### Summary

The goal of this study was to explore the role of satisfaction with shared decision-making, understandability of obtained information and friendliness of healthcare professionals on stress and anxiety in loved ones of ICU patients. This study found that there were no high levels of anxiety and stress among the four participants and that there were no significant relations between the dependent variables of anxiety and stress and the independent variables of satisfaction with shared decision-making and understandability of information. In addition, mostly low positive correlations were found, with an exception between anxiety and satisfaction with shared decision-making. Furthermore, there was zero variation in friendliness of healthcare professionals, and therefore the fourth hypothesis could not be accepted nor rejected. Although these results do not yet allow for generalization to the broader population, it is interesting to further discuss the first indications in comparison to existing literature to make recommendations for the larger follow-up study on stress and anxiety among loved ones of ICU patients.

### Low Levels of Stress and Anxiety

One variable that might be able to explain the lower levels of anxiety and stress is the amount of times a participant has been on the ICU. According to Geoghegan et al. (2016), families who stay longer in the ICU might become familiarized with the environment and its staff. Whereas none of the participants stayed more than six days on the ICU, 50% of participants had been once before to the ICU environment. As shown by Ponzoni et al. (2017), 29.3% of ICU patients who need to be readmitted will return to the ICU within 72 hours. This shows the possible similarity between situations.

However, even if the previous ICU stay was longer than 72 hours ago, even if it was another hospital and even if it was another patient, some kind of familiarity might still have occurred. Someone who has already been to the ICU might have an idea about how things go on the ICU and how staff generally act, which could have taken some uncertainty away and with that also some stress and anxiety.

One more reason as to why levels of stress and anxiety were lower than anticipated might be due to the friendliness of healthcare professionals. According to Wong et al. (2015), when healthcare professionals act in a supportive and kind way, they might be able to reduce stress and anxiety in loved ones of ICU patients. As can be seen in the results, friendliness of healthcare professionals was always perceived with the highest score of friendliness. Therefore,

the attitude of healthcare professionals might have played a big role in how loved ones perceived the ICU environment and therefore these loved ones did not experience a lot of stress and anxiety.

One last reason as to why levels of anxiety were not as high as anticipated might be due to the level of education. A study done by Chartier and Coutu-Wakulczyk (1989) found that the higher the level of education after elementary school, the less anxiety families of loved ones of ICU patients experience. In addition to this, Bjelland et al. (2008) show that a higher education might prevent anxiety; they also showed that this effect becomes greater as age increases (Bjelland et al., 2008). As can be seen in the results, all participants had an education of above elementary school level, with two participants scoring at the higher end of the scale. Furthermore, all participants were already at an older age. These two factors could have contributed to the lower levels of anxiety.

### **Stress and Anxiety in Relation to Satisfaction with Shared Decision-Making and Understandability of Information**

Whereas this study predicted that understandable information would decrease stress and anxiety, the opposite turned out to be the case. One reason as to why understandable information could increase anxiety might be due to the severity of the obtained information. As found out by Engström and Söderberg (2004), information can sometimes be very disheartening. When receiving information that shows the severity of the ICU patient's illness, it might be very confrontational and thus stress and anxiety inducing. As can be seen in the results, participants in this study did understand the information. Thus, it might have been the case that the information received was not promising enough and thus did not improve levels of stress and anxiety.

Furthermore, this study predicted that satisfaction with shared decision-making would decrease levels of stress and anxiety, which eventually was not the case. As aforementioned, having to make high-risk decisions for loved ones could lead to stress. Whereas levels of anxiety and stress were not high, participants might still have felt some form of pressure while having to make decisions on behalf of the ICU patient. A study done by Lind (2019) found that loved ones feel responsible when participating in shared decision-making, which thus could lead to feeling pressure to make the right decision. According to Ashcraft and Kirk (2001), Beilock and Carr (2005), and Martens, Vealey and Burton (1995) (as cited in Byrne, Silasi-Mansat, & Worthy, 2015), pressure can occur in situations where a lot counts on the decision made, which in turn could lead to anxiety. Thus, having all factors present to be satisfied with shared

decision-making does not necessarily mean a decrease in stress and anxiety and thus might explain this study's findings.

### **Strengths and Limitations**

One strength of this study that should be mentioned is what this study still contributes to research. Not much research has been done on the topic of stress and anxiety of loved ones in the ICU and which factors influence these feelings. This study has shown some results that could still be useful for further research. Furthermore, a questionnaire has been created that can further be used in other studies. Thus, this study contributes to answering which factors influence stress and anxiety and could in turn help with stress and anxiety prevention of loved ones of ICU patients. However, this study also comes with some limitations.

One limitation is sample size. Only having four participants is too little to make any proper conclusions. According to Deziel (2018), a small sample size leaves more room for results that do not fit reality. Therefore, with a bigger sample size, the results of this study might have been completely different and ultimately fit reality better. Furthermore, no factor analysis or reliability testing was able to be performed. Whereas factor analysis could not be done in SPSS, Cronbach's alpha came with several warnings and deleted items due to zero variance. This might be due to sample size, as Birmingham City University (2017) found that sample size should be at least 30 for reliability testing.

Another limitation is time of data collection. What is meant is the moment the survey got filled in by participants. Whereas the ICU stay might have been very stressful and anxiety-inducing, the patient might have left the ICU with good news. This, in turn, can have big effects on how loved ones feel. They might feel more positive at the time of filling in the questionnaire in comparison to how they actually felt during the time on the ICU.

### **Recommendations for Future Research**

On the basis of aforementioned findings, several recommendations will be made. The first recommendation is that the sample size should be increased to properly reflect the population and thus improve validity and reliability. In addition to that, a more diverse sample size might have shown what would have happened to factors explaining current findings.

The second recommendation is to have an Experience Sampling Method study instead of a survey study. With Experience Sampling Method, participants have to fill in the questionnaire multiple times per day. This can give a more complete overview of the ICU stay, which in turn would improve validity and reliability.

The last recommendation is to integrate factors that this study has not done yet. One such factor might be the ICU environment itself. According to McCuskey Shepley (2006), positive distraction can help people within certain environments to focus their attention on more positive, healthy aspects instead of on the negative sides. As they mention, the three aspects ‘art’, ‘nature’ and ‘music’ can be of big influence to someone’s mental state, and thus have a big impact on how one experiences the ICU environment (McCuskey Shepley, 2006).

## Conclusion

This study shows that levels of stress and anxiety in loved ones of ICU patients is moderate to low. Furthermore, understandability of information and satisfaction with shared decision-making could show to increase stress. In addition to that, understandability of information might be able to show an increase in levels of anxiety, whereas perceived shared decision-making could show to decrease anxiety. Thus, satisfaction with shared decision-making might be an important factor in decreasing anxiety in loved ones of ICU patients and could therefore be used for anxiety prevention. However, due to this study’s small sample size, one should be cautious when drawing conclusions from this study. Therefore, more research should be done on the topic, keeping the recommendations of increasing the sample size, implementing ESM and implementing new factors in mind.

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## **Appendix**

### **Appendix A – Informed consent**

#### **Mate van ervaren stress gedurende de IC-opname van uw naaste**

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.



- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden op te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens voor de beantwoording van de onderzoeksvraag in dit onderzoek.
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn antwoorden kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor inzage door deze personen.
- Ik geef  **wel**  
 **geen**  
toestemming om mijn persoonsgegevens langer te bewaren en te gebruiken voor toekomstig onderzoek op het gebied van stress bij naasten van patiënten op de Intensive Care.
- Ik wil meedoen aan dit onderzoek.

Naam proefpersoon:

Handtekening:

Datum : \_\_ / \_\_ / \_\_

-----  
Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):

Handtekening:

Datum: \_\_ / \_\_ / \_\_

---

## Appendix B – Questionnaire

# Fluctuaties van stress bij naasten van IC-patiënten

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### Start of Block: Informatie

Introductie Beste deelnemer,

U heeft gekozen om deel te nemen aan het onderzoek. Onderstaand zult u eerst wat vragen vinden die gaan over u in het algemeen waarna u verschillende vragen zult tegenkomen die betrekking hebben op uw ervaringen en gevoelens tijdens uw tijd op de IC. U mag deze vragen invullen naar eigen mening en inzicht.

We willen nogmaals benadrukken dat terugtrekken aan dit onderzoek mogelijk is te allen tijde.

Mocht u na deze vragenlijst alsnog eventuele vragen hebben over het onderzoek, dan kunt u ons altijd bereiken via de contactgegevens op de informatiebrief die u heeft ontvangen van het zorgpersoneel.

Verder willen u alvast bedanken voor uw deelname aan dit onderzoek.

Met vriendelijke groet,

Het Onderzoeksteam

End of Block: Informatie

---

Start of Block: Demografische vragen

1 Wat is uw geslacht?

- Man (1)
  - Vrouw (2)
  - Anders (3)
- 

2 Wat is uw leeftijd?

---

---

3 Wat is uw hoogst afgeronde opleidingsniveau?

- Basisonderwijs (1)
  - Vmbo, mbo1, avo onderbouw (2)
  - Havo, VWO, MBO (3)
  - HBO, WO Bachelor (4)
  - WO, master, doctor (5)
- 

4 Wat is uw ethniciteit?

---

5 Wat is uw relatie tot de patiënt?

- Partner (1)
  - Ouder (2)
  - Kind (3)
  - Broer/zus (4)
  - Vriend(in) (5)
  - Kennis (6)
  - Anders (7)
-

6 Hoeveel dagen heeft uw naaste op de IC gelegen?

- 2 (4)
  - 3 (5)
  - 4 (6)
  - 5 (7)
  - 6 (8)
  - 7 (9)
  - 8 (10)
  - 9 (11)
  - 10+ (12)
- 

7 Was dit de eerste keer dat u in aanraking bent gekomen met de IC-afdeling?

- Ja (1)
- Nee (2)

**End of Block: Demografische vragen**

---

**Start of Block: Stress**

9 Onderstaande vragen gaan over de periode waarin uw naaste op de IC verbleef in relatie tot uw ervaren stress.

	Nooit (1)	Soms (2)	Regelmatig (3)	Vaak (4)	Erg vaak (5)
Gedurende de opnameperiode, hoe vaak bent u van streek geweest door iets wat onverwachts gebeurde buiten de IC? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gedurende de opnameperiode, hoe vaak heeft u zich nerveus en gestrest gevoeld over de situatie van uw naaste? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gedurende de opnameperiode, hoe vaak heeft u het volle vertrouwen gehad dat u kon omgaan met de situatie van uw naaste? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gedurende de opnameperiode, hoe vaak had u het gevoel dat u niet kon omgaan met alle dingen die u moest doen buiten de IC? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gedurende de opnameperiode, hoe vaak had u het gevoel dat u alles onder controle had buiten de IC? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Gedurende de opnameperiode, hoe vaak was u boos over zaken die buiten uw macht lagen zowel binnen en buiten de IC? (6)

Gedurende de opnameperiode, hoe vaak heeft u het gevoel gehad dat moeilijkheden buiten de IC zich zo hoog opstapelden dat u ze niet meer te boven kon komen? (7)

End of Block: Stress

---

Start of Block: Informatie



11 Onderstaande vragen gaan over de periode waarin uw naaste op de IC verbleef in relatie tot de begrijpbaarheid van informatie.

	Niet (1)	Een beetje (2)	Redelijk (3)	Erg (4)	Heel erg (5)
Hoe goed begreep u de informatie van het zorgteam? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed snapte u wat er met uw dierbare aan de hand was voor het contact met een zorgprofessional? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed snapte u wat behandelingsopties zouden zijn voor het contact met een zorgprofessional? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed snapte u wat er met uw dierbare aan de hand was na het contact met een zorgprofessional? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed snapte u wat behandelingsopties zouden zijn na het contact met een zorgprofessional? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Informatie

Start of Block: SDM

12 Onderstaande vragen gaan over de periode waarin uw naaste op de IC verbleef in relatie tot het gezamenlijke besluitvormingsproces.

	Niet (1)	Een beetje (2)	Redelijk (3)	Goed (4)	Erg goed (5)
Hoe goed heeft de zorgprofessional geprobeerd te begrijpen hoe u in het proces van medische besluitvoering betrokken wilde worden? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed heeft de zorgprofessional, na het besluit van wel of niet meehelpen in het besluitvormingsproces, met u gewerkt op de manier waarop u betrokken wilde worden tijdens het proces van besluitvorming over de zorg van de patiënt? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe goed heeft de zorgprofessional geprobeerd te begrijpen wat uw waarden en voorkeuren waren rondom de zorg van de patiënt? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hoe erg heeft u het gevoel gehad dat uw familie waarden en uw voorkeuren respectvol zijn gebruikt als leidraad voor de besluiten rondom de zorg van de patiënt? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: SDM

15 Onderstaande vragen gaan over de periode waarin uw naaste op de IC verbleef in relatie tot uw ervaren gevoelens van angst.

	Meestal (1)	Vaak (2)	Af en toe (3)	Soms (4)	Helemaal niet (5)
Ik voel me de laatste tijd gespannen. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik krijg de laatste tijd het angstige gevoel alsof er elk moment iets vreselijks zal gebeuren. (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik maak me de laatste tijd ongerust. (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik kan de laatste tijd rustig zitten en me ontspannen. (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik krijg de laatste tijd een soort benauwd, gespannen gevoel in mijn maag. (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik voel me de laatste tijd rusteloos. (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ik krijg de laatste tijd plotselinge gevoelens van angst of paniek. (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Angst

Start of Block: Attitude

16 Onderstaande vraag gaat over de periode waarin uw naaste op de IC verbleef in relatie tot de houding van de zorgprofessional.

	Niet (1)	Een beetje (2)	Redelijk (3)	Erg (4)	Heel erg (5)
Hoe vriendelijk vond u het zorgpersoneel? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Attitude

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Start of Block: Opmerkingen

17 Tot slot kunt u hier nog overige opmerkingen toevoegen over het onderzoek. Dit is optioneel, dus u kunt dit veld ook leeglaten.

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End of Block: Opmerkingen

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## Appendix C – Information sheet

### Proefpersoneninformatie voor deelname aan medisch-wetenschappelijk onderzoek

#### Mate van ervaren stress gedurende de IC-opname van uw naaste

## **Inleiding**

Geachte heer/mevrouw,

Wij vragen u om mee te doen aan een medisch-wetenschappelijk onderzoek. Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig. U ontvangt deze brief omdat we samen met de Universiteit Twente onderzoek doen naar hoe de naasten van onze IC-patiënten de afgelopen periode op de IC ervaren hebben. Omdat u de contactpersoon bent van een van onze patiënten, nodigen we u uit tot vrijwillige deelname aan dit onderzoek. Het onderzoek betreft een digitale vragenlijst, waarvoor u wordt uitgenodigd door de IC-nazorg verpleegkundige van XXX. Aan dit kleinschalige pilot onderzoek zullen naar verwachting 20 personen meedoen.

Dit onderzoek is beoordeeld door de lokale toetsingscommissie van XXX.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker uitleg als u vragen heeft. U kunt er ook over praten met uw partner, vrienden of familie. U kunt ook de onafhankelijk deskundige, die aan het eind van deze brief genoemd wordt, om aanvullende informatie vragen.

### **1. Doel van het onderzoek**

We willen door middel van onderzoek beter begrijpen wat een IC-opname doet met de naasten van patiënten. Factoren die we in dit onderzoek bestuderen zijn mogelijk ervaren stress, angstgevoelens en contactmomenten met zorgpersoneel. Ook is er ruimte om (anoniem) andere ervaringen met ons te delen via de vragenlijst in dit onderzoek. Zo beogen

we door beter te begrijpen hoe naasten van patiënten de IC-opname ervaren, de aandacht die we kunnen besteden in bijvoorbeeld de contactmomenten te verbeteren.

## **2. Wat meedoen inhoudt**

Als u deelneemt aan dit onderzoek wordt u gevraagd om eenmalig een digitale vragenlijst in te vullen over uw ervaringen als naaste van een patiënt op de IC. De brief met daarop een QR code die u kunt scannen met de camera van uw telefoon (wij leggen u in de betreffende brief uit hoe dit werkt) geeft u toegang tot de vragenlijst. Deze brief ontvangt u nadat uw naaste van de IC wordt ontslagen. Vervolgens kunt u deze vragenlijst invullen op iedere plek die u zelf wenst, het liefst zo spoedig mogelijk, maar binnen 24 uur na ontslag van de IC. De vragenlijst zal ongeveer 5 minuten in beslag nemen om deze in zijn totaliteit in te vullen. Nadat u deze vragenlijst heeft ingevuld is dit tevens ook het einde van het onderzoek.

## **3. Wat wordt er van u verwacht**

Om het onderzoek goed te laten verlopen is het belangrijk dat u zich aan de volgende afspraken houdt. De afspraken zijn dat u:

- de instructies van de onderzoeker volgt
- het aan de onderzoeker meldt als u ook nog aan een ander medisch-wetenschappelijk onderzoek meedoet/wil meedoen

## **4. Mogelijke voor- en nadelen**

Bij dit onderzoek zijn de risico's die u loopt bij deelname nagenoeg nihil. Het is wel belangrijk dat u de mogelijke voor- en nadelen goed afweegt voordat u besluit mee te doen. Het voordeel van uw deelname aan het onderzoek is dat u ons helpt om beter te begrijpen wat de naasten van onze patiënten doormaken tijdens een IC-opname. Zo proberen we onze zorg

continue te verbeteren. Een mogelijk nadeel van uw deelname aan dit onderzoek kan zijn dat u de vragen als enigszins confronterend ervaart. In dat geval kunt u er ten alle tijden voor kiezen om te stoppen met het invullen van de vragenlijst.

## **5. Als u niet wilt meedoen of wilt stoppen met het onderzoek**

U beslist zelf of u meedoet aan het onderzoek. Deze deelname is vrijwillig. Als u na het lezen van deze brief besluit om niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. Als naaste van de patiënt wordt u op de gebruikelijke manier behandeld.

Als u wel besluit om mee te doen, kunt u zich nog steeds ten alle tijden bedenken en toch stoppen, ook tijdens het invullen van de vragenlijst. Dan kunt u de geopende vragenlijst afsluiten. U hoeft niet te zeggen waarom u stopt. Ook hoeft u géén contact op te nemen met de onderzoekers. De gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek.

## **6. Einde van het onderzoek**

Uw deelname aan het onderzoek stopt als:

- u de vragenlijst heeft afgerond
- u zelf kiest om te stoppen
- de onderzoeker het beter voor u vindt om te stoppen
- de Raad van Bestuur, de overheid of de beoordelende medisch-ethische toetsingscommissie besluit om het onderzoek te stoppen

## **7. Gebruik en bewaren van uw gegevens**

Voor dit onderzoek worden uw persoonsgegevens verzameld, gebruikt en bewaard. Het gaat om gegevens zoals uw leeftijd, geslacht, relatie tot de patiënt en om gegevens over uw gezondheid. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen die in dit onderzoek worden gesteld te kunnen beantwoorden en de overkoepelende resultaten te kunnen publiceren. Wij vragen voor het gebruik van deze gegevens uw toestemming.

### **Vertrouwelijkheid van uw gegevens**

Om uw privacy te beschermen hoeft u nergens uw naam in te vullen. Zo bent u niet te herleiden in rapporten en publicaties over het onderzoek.

### **Toegang tot uw gegevens voor controle**

Sommige personen kunnen op de onderzoek locatie toegang krijgen tot uw antwoorden. Dit is nodig om te kunnen controleren of het onderzoek goed en betrouwbaar is uitgevoerd.

Personen die ter controle inzage krijgen in uw gegevens zijn: de uitvoerende onderzoekers, de hoofdonderzoekers en de onderzoekscoördinator (zie lijst contactgegevens). Wij vragen u voor deze inzage toestemming te geven.

### **Bewaartermijn gegevens**

Uw gegevens moeten 10 jaar worden bewaard bij de opdrachtgever (Universiteit Twente).

### **Bewaren en gebruiken van gegevens**

Uw gegevens kunnen na afloop van dit onderzoek ook nog van belang zijn voor ander wetenschappelijk onderzoek op het gebied van stress bij naasten van patiënten op de IC.

Daarvoor zullen uw gegevens 10 jaar worden bewaard. Indien u hier niet mee instemt, kunt u gewoon deelnemen aan het huidige onderzoek.



### **Intrekken toestemming**

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

### **Meer informatie over uw rechten bij verwerking van gegevens**

Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van Universiteit Twente ( <https://www.utwente.nl/nl/cyber-safety/privacy/avg/#privacy-by-design-en-privacy-by-default> en <https://www.utwente.nl/nl/cyber-safety/privacy/jouw-privacyrechten/#verzoek-indienen>) en de Autoriteit Persoonsgegevens raadplegen. Bij vragen over uw rechten kunt u contact opnemen met de verantwoordelijke voor de verwerking van de persoonsgegevens. Voor dit onderzoek is dat: *Thomas Vaessen, hoofdonderzoeker Universiteit Twente*.

Zie bijlage A voor contactgegevens.

Bij vragen of klachten over de verwerking van uw persoonsgegevens raden we u aan eerst contact op te nemen met de onderzoekslocatie. U kunt ook contact opnemen met de XXX van de instelling, zie bijlage A voor de contactgegevens, of de XXX.

### **8. Geen Vergoeding voor meedoen**

Voor deelname van dit onderzoek ontvangt u geen vergoeding. Echter zijn aan dit onderzoek voor deelname ook geen kosten verbonden.

### **9. Heeft u vragen of een klacht?**

Bij vragen kunt u contact opnemen met het onderzoeksteam.

Indien u klachten heeft over dit onderzoek, dan kunt u dit bespreken met het onderzoeksteam of de IC-nazorg verpleegkundige. Alle gegevens vindt u in **Bijlage A: Contactgegevens**.

## **10. Ondertekening toestemmingsformulier**

Wanneer u voldoende bedenktijd heeft gehad, wordt u gevraagd te beslissen over deelname aan dit onderzoek. Indien u toestemming geeft, zullen wij u vragen deze op de bijbehorende toestemmingsverklaring schriftelijk te bevestigen (Bijlage B). Door uw schriftelijke toestemming geeft u aan dat u de informatie heeft begrepen en instemt met deelname aan het onderzoek. Zowel uzelf als de onderzoeker ontvangen een getekende versie van deze toestemmingsverklaring.

Dank voor uw aandacht.

## **Appendix D – Participation Form**

### **Mate van ervaren stress gedurende de IC-opname van uw naaste**

Op dit deelnameformulier vindt u de toegang tot de digitale vragenlijst. U kunt deze op twee verschillende manieren openen:

- 1) Link naar de vragenlijst
- 2) QR Code

#### Optie 1: Deelnemen via onderstaande link naar de vragenlijst:

U kunt de volgende link overtypen in uw Internet browser op uw telefoon, computer of ipad/tablet: XXX

#### Optie 2: Deelnemen via onderstaande QR code naar de vragenlijst:

Met sommige smartphones en ipads/tablets kunt u een QR code scannen zoals de QR code hieronder.

Dat doet u door de volgende stappen te volgen:

- 1) Open de camera-app op uw smartphone;
- 2) Richt de camera van uw smartphone op de QR code;
- 3) Als uw smartphone QR codes kan scannen, dan zal er in het scherm een [ ] oplichten om de QR code en daarbij de link naar de vragenlijst tonen;
- 4) U kunt op deze link in het touchscreen van uw smartphone klikken;
- 5) De vragenlijst wordt geopend.