

The Influence of Perceived SDM on Stress in Surrogates of Intensive Care Patients

Brigit Beukeveld, s2199610

Department of Psychology, University of Twente

Bachelor Thesis

Thomas Vaessen & Jorinde Spook

July 18th, 2022

Abstract

Background: Surrogates often need to make treatment decisions for a cognitively impaired patient in the Intensive Care Unit (ICU). Many hospitals use shared decision-making (SDM) to make decision-making more comfortable and less stressful. Nevertheless, many surrogates still experience stress despite the use of SDM. However, little is known about which factors cause surrogates' stress during the SDM process. Possible factors could be conflict of role and provision of information.

Aim: This study examined the relationship between perceived SDM and self-reported stress by ICU patients' surrogates and the relationship between provision of information and conflict of role with perceived SDM.

Methods: A cross-sectional study was conducted involving a sample ($N=4$) of adult surrogates of ICU patients who were at least 48 hours exposed to the ICU department at a local hospital in the Netherlands. The variable stress was measured using the perceived stress scale. Provision of information, perceived SDM, and conflict of role were measured using questions from other existing or self-developed questionnaires. A Spearman's rank correlation matrix was created to explore the association of perceived SDM with stress, provision of information with perceived SDM, and conflict of role with perceived SDM.

Results: The Spearman's rank correlation coefficient of perceived SDM and stress was $-.32$, of conflict of role and perceived SDM $-.83$, and of provision of information and perceived SDM $.50$. These findings suggest that perceived SDM is negatively correlated with stress, that conflict of role is negatively correlated with perceived SDM, and that provision of information is positively correlated with perceived SDM.

Discussion: This study may indicate that increased perceived SDM due to higher information provision and lower conflict of role results in decreased stress. Therefore, it could be essential for clinicians to be aware of the preferred decision-making role of the surrogate in the SDM process at the beginning of admission of the patient to the ICU and to provide adequate, sufficient, and understandable information to the surrogate. In addition, decreased stress could lead to less "Post-Intensive Care Syndrome-Family" for surrogates of ICU patients. Further investigation into this topic, with more participants, is needed to state if the associations are significant and clarify the actual relationships and effects of the variables between themselves.

Fluctuations of Acute Stress in Surrogates of ICU Patients

The Intensive Care Unit (ICU) is a special hospital department where patients receive special care medicine. It can be a complex and stressful environment, not only for the patients but also for their relatives, called surrogates (Beesley et al., 2018). The surrogates have to deal with an acute admission, a long stay in the ICU, and uncertainty of the medical trajectory. Furthermore, since patients often show cognitive impairments that hinder them from making good decisions about important topics (e.g., treatment options), surrogates frequently have to make these decisions for their relatives (Azoulay et al., 2014). Therefore, clinicians and patients or their surrogates collaborate to make decisions about the treatment together. This process is called shared decision-making (SDM) (Kon et al., 2016). A study by Iverson et al. (2014) suggests that good communication between healthcare professionals and surrogates of critically ill patients, an essential part of SDM, manages stress. Nevertheless, research shows that 56.8% of surrogates still demonstrate stress symptoms within three to five days after admission of their relative to the ICU (Schmidt & Azoulay, 2012). However, little is known about which factors cause surrogates' stress during SDM.

Consequences of ICU

Previous literature shows several reasons for feelings of stress for the surrogates after their time in the ICU. For example, the role of the decision-maker for the cognitively impaired patient has shown to result in physical, cognitive, and psychological consequences, such as stress, dissociative amnesia, or emotional numbness (Hickman & Douglas, 2010). Moreover, during the admission period of their relative to the ICU, surrogates display symptoms of anxiety, depression, and post-traumatic stress disorder (PTSD) in the first few days after admission and in the period after discharge of their relative (Schmidt & Azoulay, 2012). These symptoms are defined as "Post-Intensive Care Syndrome-Family" (PICS-F) (Sottile et al., 2016). In addition, feelings of stress can eventually result in PICS-F (Beesley et al., 2018; Schmidt & Azoulay, 2012). Hence, it is essential to reduce stress for surrogates of ICU patients to prevent long-lasting negative psychological consequences or reduce symptoms of these consequences. This reduction of stress levels could possibly be reached with the use of SDM processes.

Shared Decision-Making

To make the decision-making task more comfortable, many hospitals use SDM processes. In this study, SDM is defined as the collaboration of the patients or their surrogates and clinicians to make decisions about the treatment together, taking into account the

preferences and values of the patient (Kon et al., 2016). The SDM process has three main aspects: information exchange, a period of deliberation, and the eventual treatment decision (Wubben et al., 2021). The goal of SDM is to make adequate decisions about the treatment. These decisions should be medically appropriate and in line with the patients' values and preferences (Kon et al., 2016). In order to have adequate communication between surrogates and clinicians during SDM, a meeting with the family as early as possible after admission of the patient to the ICU is essential. In addition, regular meetings with the family are necessary to include them in discussions about changes in the patient's clinical situation and the treatment progression (Grignoli et al., 2018).

In the environment of the ICU, SDM is used to manage stress levels for surrogates of the ICU patient. First, SDM is developed to pay close attention to communication with surrogates and their emotional needs to reduce stress levels (Rego et al., 2015). Simple acts of communication can already reduce psychological distress and uncertainty among family members of ICU patients. Such acts of communication can be family conferences or assigning advanced practice nurses as family liaisons (Hickman & Douglas, 2010). Furthermore, a study by Grignoli et al. (2018) showed that support offered by clinicians during decision-making is essential in detaining stress and negative feelings among surrogates of ICU patients. Although SDM is seen as the perfect approach for decision-making, reality showed that clinicians who felt very distressed used SDM (Vivian et al., 2019). Hence, using SDM processes is not only decreasing stress levels. In some cases, stress is still experienced despite using SDM processes. This could be due to factors influencing how SDM is perceived.

Provision of Information

One of those factors that could influence how SDM is perceived is provision of information. In this study, we define provision of information as the understandability, sufficiency, and adequacy of the information provided by healthcare professionals. This definition is based on the combination of definitions from the studies of Azoulay et al. (2004) and Rego et al. (2015). Literature showed that feelings of lack of information or not being informed adequately by clinicians caused psychological distress in surrogates of ICU patients (Rego et al., 2015). Furthermore, Azoulay et al. (2004) demonstrated two decades ago that 35% of family members did not understand the information they received from clinicians, causing acute stress. More recently, a study by Azoulay et al. (2014) stated that an obstacle to SDM was the understandability of the information provided by the healthcare professionals. At last, Xiao et al. (2022) demonstrated that higher scores on information acquisition ability were associated with higher perceived SDM by cancer patients. Thus, higher provision of

information could increase perceived SDM and decrease stress levels for surrogates of ICU patients.

Moreover, increasing provision of information may result in fewer damaging negative psychological consequences. For example, a study by Mesters et al. (2001) among cancer patients revealed that people with greater information need had higher levels of emotional distress such as anxiety and depression. Furthermore, Rego et al. (2015) demonstrated that surrogates who received sufficient and adequate information, especially those of very ill patients, were less likely to develop symptoms of post-ICU anxiety or PTSD caused by stress. All in all, increasing provision of information during SDM may decrease the chances of obtaining negative psychological consequences such as PICS-F.

Conflict of Role

Another factor influencing how surrogates of ICU patients could perceive SDM is conflict of role. In this study, conflict of role is defined as the discrepancy between the preferred decision-making role of surrogates in the SDM process and their actual decision-making role. The definition used in this study for conflict of role is based on a statement of the study by Schmidt and Azoulay (2012). This statement is used to define conflict of role because no existing definitions for conflict of role in a medical setting could be found in the literature.

Research shows that some surrogates prefer an active role in the decision-making (even for small decisions), whereas others prefer a passive role (even for essential decisions) (Kon et al., 2016). Therefore, when clinicians leave decisions to the surrogates without the expected support, this can increase psychological distress. Conversely, a study by Kon et al. (2016) found that when clinicians make decisions without involving the surrogate, this can enable psychological distress because of feelings of being unfairly excluded from decisions. Moreover, unwillingly sharing in decision making can be perceived as a burden and increase stress, even when SDM is adequately performed (Azoulay et al., 2014). Furthermore, a research of Schmidt and Azoulay (2012) showed that family members whose preferred role was not in line with their actual role were at higher risk of obtaining symptoms of PICS-F. At last, a research of Ismail and Midin (2021) showed that 60% of the patients with a preferred autonomous role, hence, patients with a conflict of role during SDM, experienced low SDM. Therefore, reducing conflict of role could possibly increase perceived SDM for surrogates of ICU patients and decrease stress levels.

The Current Study

In sum, this study can be used to reveal factors that influence how surrogates of ICU

patients perceive SDM and how perceived SDM affects their experienced levels of stress. The hypotheses of the current study are; 1) Perceived SDM is negatively associated with self-reported levels of stress in surrogates of ICU patients, 2) Self-reported conflict of role is negatively associated with perceived SDM in surrogates of ICU patients, and 3) Self-reported provision of information is positively associated with perceived SDM in surrogates of ICU patients.

Methods

Design

This study used a cross-sectional design with an online survey in Qualtrics. The study took place between May 2022 and June 2022. The BMS ethics committee of the University of Twente (ref. 220427) and the board of the local hospital in the Netherlands provided ethical approval.

Participants

Participants were recruited via the ICU department at a local hospital in the Netherlands. The inclusion criteria for the study were as follows: 1) older than 18 years, 2) surrogate of a patient at the ICU, and 3) a minimum exposure to the ICU setting of 48 hours. Exclusion criteria for the study were as follows: 1) having any form of an acute addiction or a severe psychiatric problem, and 2) being unable to communicate in Dutch. Before participating in this study, all participants needed to agree on their cooperation.

Procedure

One or two days before their relative was discharged from the ICU, the surrogate received information about the study, including an invitation to participate. The research nurses provided the information and invitation for the study during their morning visits to the surrogates. The information letter was combined with the informed consent form, which the participant could sign and return to the research nurses. After handing in the informed consent form, they received a participant form with a link and QR code that directed them to the online questionnaire. Participants were asked to complete this questionnaire within 24 hours after the discharge of their relative from the ICU. Answering the questionnaire could be done at a self-chosen time and location. Completion of the questionnaire took approximately ten minutes. After completing the survey, the participants were informed that this was the questionnaire's end and thanked for their participation.

Materials

Data for this study regarding surrogates' stress levels, perceived SDM, information

need, and conflict of role were obtained using the online survey in Qualtrics. In addition, the online survey consisted of demographic questions and questions based on the variables friendliness of healthcare professionals, anxiety, and understandability of information. These variables were used in the research thesis of a fellow bachelor's student.

Demographic Questions

Several demographic questions (see Appendix A) were asked to check the background of the participants in the study. These questions were about gender, age, relation to the patient, educational level, duration of stay in the ICU, and so on.

Stress

Self-reported stress was assessed using seven out of the ten items of the Perceived Stress Scale (PSS), measured on a 5-point Likert scale ranging from 0 (*never*) to 100 (*very often*) (Cohen et al., 1983). The scale items were translated into Dutch before usage for this questionnaire. Moreover, the content of the PSS items was changed to reflect the ICU setting (see Appendix B). The estimated internal consistency in this study was .73. After the deletion of item 2 and item 7, the internal consistency was .85, which is considered good (Peterson, 1994). Thus, this study deleted items 2 and 7 to increase the scale's reliability. The finale scale is based on the five items' mean score. A score of 100 would be the highest possible score, while a score of 0 would be the lowest possible score for the subscale.

Perceived SDM

Grover et al. (2011) developed a questionnaire to measure the family's perception of SDM in the ICU. The questionnaire consisted of four items on a 5-Point Likert scale ranging from 0 (*Poor*) to 100 (*Excellent*). The scale items were translated into Dutch before usage for this questionnaire (see Appendix C). The estimated internal consistency in this study was .83, which is considered good (Peterson, 1994). The final scale is based on the mean score of the four items. A mean score of 100 would be the highest possible score, while a score of 0 would be the lowest possible score.

Provision of Information

Self-reported provision of information was assessed using the subscale "Information needs" from the family satisfaction questionnaire (Heyland & Tranmer, 2001). The scale consists of six items on a 5-Point Likert scale ranging from 0 (Very Poor) to 100 (Excellent). The subscale items were translated into Dutch before usage for this questionnaire. Moreover, the items were reformed into complete sentences instead of single concepts, as Heyland and Tranmer (2001) had in their study, to make it more understandable for the participants (see Appendix D). The estimated internal consistency in this study was .80, which is considered

good (Peterson, 1994). The final scale is based on the mean score of the six items. A mean score of 100 would be the highest possible score, while a score of 0 would be the lowest possible score.

Conflict of Role

For conflict of role, no existing scientifically approved scale was available. Therefore, a Dutch self-report scale was developed for this study. The scale consisted of eight items on a 5 Point-Likert scale ranging from 0 (*Completely Disagree*) to 100 (*Totally Agree*) (see Appendix E). The estimated internal consistency in this study was .77. After deletion of item 8, “During interaction moments with the healthcare professional, I had the feeling that I would have preferred to have a different role regarding the participation around the care process, than the role I had at that time”, the internal consistency was .81, which is considered good (Peterson, 1994). Thus, this study deleted item 8 to increase the score's reliability. The final scale is based on the mean score of the remaining seven items. A mean score of 100 would be the highest possible score, while a score of 0 would be the lowest possible score.

Data Analysis

The data of this study were analyzed using SPSS. Descriptive statistics were used to calculate frequencies for categorical variables and mean and standard deviations for continuous variables. The demographic variables included in the descriptive statistics were as follows: age, gender, relationship to the patient, educational level, nationality, length of exposure to ICU setting, and first time at ICU. In addition, this study calculated the mean scores with standard deviations for perceived SDM, conflict of role, stress, and provision of information prior to the analysis. Furthermore, to test all three hypotheses, the association of perceived SDM with self-reported stress, the association of self-reported conflict of role with perceived SDM, and the association of self-reported provision of information with perceived SDM, this study inspected a non-parametric Spearman's rank correlation matrix to see what the associations of these variables were among themselves. Non-parametric tests are useful when data only consist of at least ordinal variables. Furthermore, prior to conducting the Spearman's rank correlation analysis, two assumptions had to be checked, these two assumptions were 1) the variables are at least ordinal, and 2) the scores of the variables must be monotonically related to each other. The second assumption was checked using scatterplots.

Results

Of the original five participants, one participant was removed from the data set due to missing items in the online survey. After deletion, four participants were used in the data

analysis. The mean age of these four participants was 62.30 years ($SD=13.40$). Of the participants, 75% were female ($N=3$), and 25% were male ($N=1$). All participants were of Dutch nationality ($N=4$). Looking at the relationship to the patient, 50% of the participants were spouses ($N=2$), and 50% were offspring ($N=2$) of the patient. Moreover, 50% of the participants had intermediate vocational education ($N=2$) as the highest completed educational level, 25% higher educational study ($N=1$), and 25% university ($N=1$). The mean length of ICU stay was 3.25 days ($SD=.50$). For 50% of the participants, this was their first time at the ICU ($N=2$), and for 50%, this was not their first time ($N=2$).

General Description of Constructs

The internal consistencies and descriptive statistics, including mean scores and standard deviations, for the variables are displayed in Table 1. The scores for the subscales range from 0 to 100. They are to be understood so that a score of 0 would mean no stress, conflict of role, perceived SDM, and provision of information, and that a score of 100 would mean high stress, conflict of role, perceived SDM, and provision of information.

Table 1

Descriptive Statistics of Variables (Perceived SDM, Conflict of Role, Provision of Information, and Stress) ($N=4$).

	No. items	Cronbach's Alpha	Mean	SD	Min	Max
Stress	5	.85	16.25	17.02	.00	40.00
Conflict of role	7	.81	4.46	6.67	.00	14.29
Perceived SDM	4	.83	87.50	10.21	75.00	100.00
Provision of information	6	.80	92.71	8.59	83.33	100.00

Note. 'SDM = shared decision-making'

Additional Analysis

Overall, there could be seen that all participants rated provision of information ($SD=8.59$) and conflict of role ($SD=6.67$) somewhat the same. Stress ($SD=17.02$) and perceived SDM ($SD=10.21$) differed more among participants. This may be explained due to the demographic variable first time at the ICU. Figure 1 indicates that self-reported stress was slightly higher when it was the first time at the ICU for the surrogate, and Figure 2 indicates

the perceived SDM was slightly higher when it was the first time at the ICU for the surrogate. Looking at scatterplots, there was no possible relationship between first-time exposure to the ICU and the variables conflict of role and provision of information.

Figure 1

Scatterplot Depicting The Relationship of The Variables (First Time at ICU and Self-Reported Stress) (N=4)

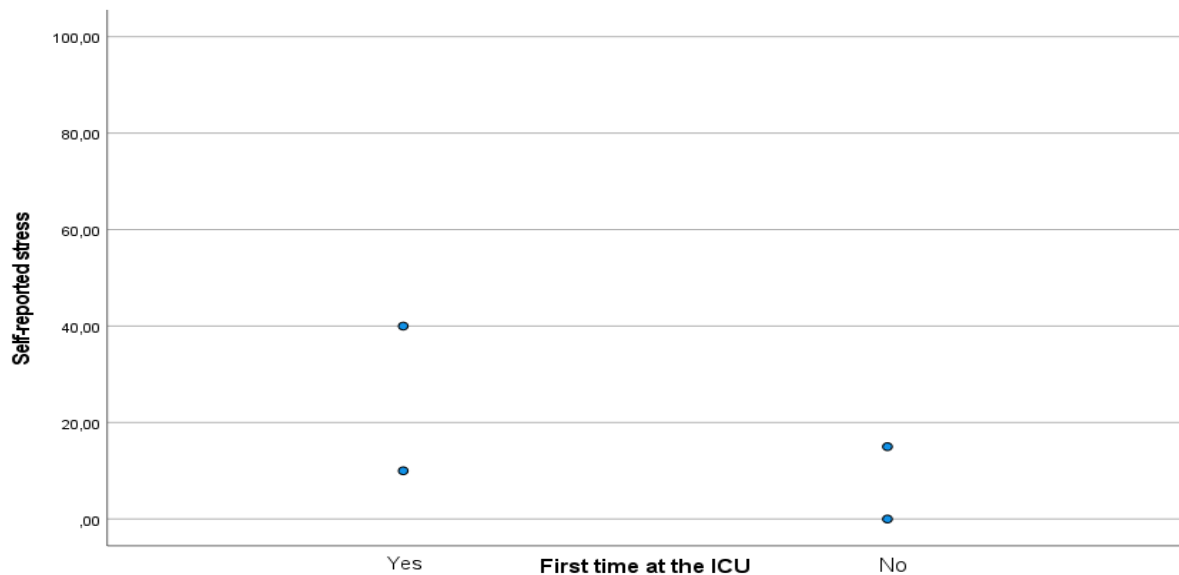
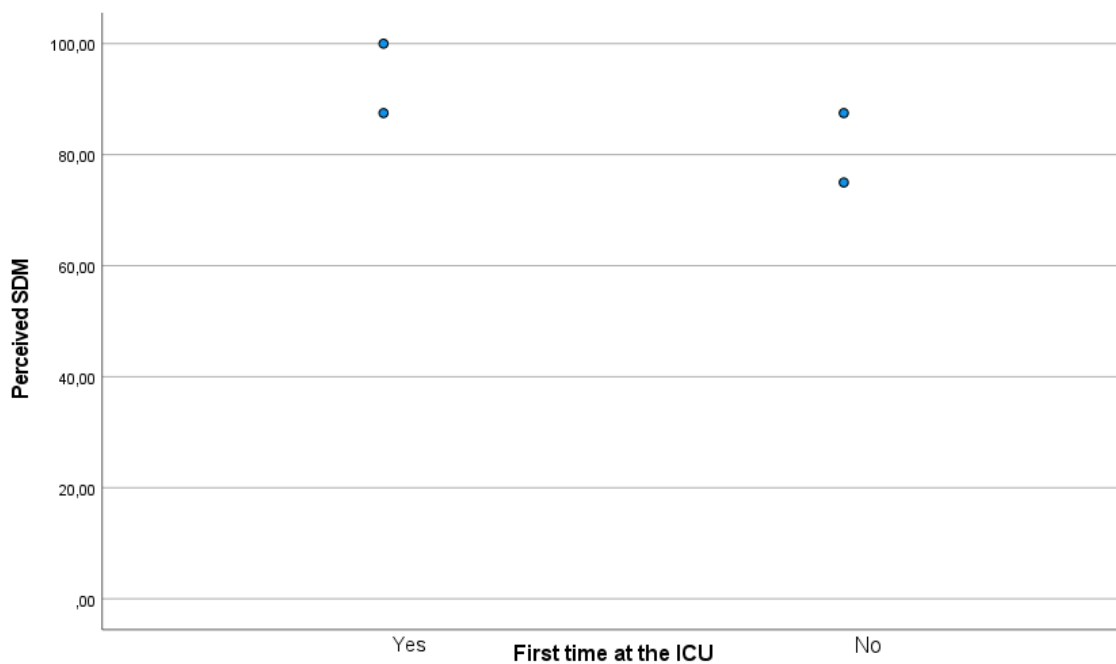


Figure 2

Scatterplot Depicting The Relationship of The Variables (First Time at ICU and Perceived SDM) (N=4)



Note. ‘SDM = shared decision-making’

Confirmatory Analysis

The two assumptions, at least ordinal variables, and monotonically related scores, were met for Spearman’s rank correlation analyses. Furthermore, Spearman’s rank correlation coefficients range from -1 to 1. A value of 0 means no relationship, a value of +1 indicates a perfect positive relationship, and a value of -1 indicates a perfect negative relationship. According to Spearman’s rank correlation analysis, stress and perceived SDM appeared to be negatively but non-significantly correlated, $r(2) = -.32, p = .342$. Thus, this suggested that perceived SDM would be higher if stress were lower. Moreover, the Spearman’s rank correlation matrix presented in Table 2 illustrates the relationships between the variables perceived SDM, conflict of role, and provision of information. Perceived SDM and conflict of role seemed negatively but non-significantly correlated, $r(2) = -.83, p = .083$, and provision of information and perceived SDM seemed positively but non-significantly correlated, $r(2) = .50, p = .250$. This suggested that provision of information would be higher, and conflict of role would be lower if perceived SDM were higher.

Table 2

Spearman’s Rank Correlation Matrix Including Variables (Perceived SDM, Provision of Information, and Conflict of Role).

	Perceived SDM	Provision of information	Conflict of role
Perceived SDM	-		
Provision of information	.50	-	
Conflict of role	-.83	.78	-

Note. ‘SDM = shared decision-making’

Discussion

This study aimed to examine the role of SDM on self-reported stress by surrogates of ICU patients and the associations of self-reported conflict of role and provision of information with perceived SDM. Although our small sample size limited the interpretability of our findings, correlation analyses suggested that there may be a negative association between perceived SDM and stress, which might mean that when perceived SDM is higher, stress levels would be lower. Furthermore, correlation analyses suggested that there may be a moderate, positive association between information provision and perceived SDM and a

strong, negative association between conflict of role and perceived SDM. This might mean that when perceived SDM is higher, information provision is higher and conflict of role is lower.

Perceived SDM

The association between SDM and stress may indicate that when people perceive a collaboration between the healthcare professional and the surrogate to make treatment decisions together, their stress levels are lower. Although these findings should be interpreted with caution due to the small sample size and cross-sectional nature of the data, they seem in accordance with the findings of other studies. For example, the results seem to support a previous study by Vivian et al. (2019), which examined the association between perceived SDM and perceived stress by clinicians. However, this study is different from the study of Vivian et al. because this study gives the unique perspective of the surrogate of the ICU patient instead of the clinician's perspective.

The outcome of this study seems in line with the first hypothesis. Therefore, these results could indicate that enhancing the cooperation between healthcare professionals and surrogates of ICU patients during decision-making, incorporating patient values and preferences, could decrease their stress levels. Eventually, a decrease in stress could result in less persistent negative psychological consequences, such as PICS-F (Beesley et al., 2018; Schmidt & Azoulay, 2012). This is because stress is responsible for causing structural degeneration in the brain and decreased functioning of the hippocampus and prefrontal cortex, which increases the probability of developing disorders like depression and anxiety (Khan, 2016). Moreover, several studies suggest that changes in brain dopamine function are related to stress-related psychopathologies, such as PTSD (Kambeitz et al., 2014). Thus, it seems that when stress levels are lower because surrogates perceive SDM, the functioning of their hippocampus and prefrontal cortex may not be inhibited, and their brain dopamine function may not be disturbed, reducing the chances of obtaining PICS-F symptoms.

Conflict of Role

The association between conflict of role and SDM may represent that when surrogates experience a higher discrepancy between the role they prefer in the decision-making process and their actual role, they perceive more SDM. Again, results should be interpreted cautiously due to the limited sample size. Nevertheless, the outcomes of this study corroborate the findings of previous studies. For example, the outcomes seem to align with the results of the study by Ismail and Midin (2021), which examined different preferred role types and their influence on perceived SDM by patients with cancer. The difference with this study is that it

examined the influence of conflict of role and perceived SDM for surrogates of ICU patients, whereas the study of Ismail and Midin focused on the patients themselves.

The outcome of this study seems in line with the second hypothesis. This finding implies that when clinicians are more aware of the preferred decision-making role of the surrogates in the SDM process at the beginning of the patient's admission, the whole SDM process could be adapted to this preferred role with tailored support strategies (Beesley et al., 2018). When clinicians use these support strategies to increase perceived SDM for the surrogates, their stress levels might decrease, and they might have fewer chances of obtaining PICS-F, as explained above.

Provision of Information

The association between perceived SDM and provision of information may indicate that when surrogates think the information provided by the healthcare professionals is insufficient, inadequate, or not understandable, they perceive less SDM. These findings are in line with the findings of other studies. The results of the study of Xiao et al. (2022), which examined the effect of health literacy on perceived SDM by cancer patients, seemed to support the results of this study. The difference between the study of Xiao et al. and this study is that it focused on ICU patients' surrogates while the study of Xiao et al. focused on the patients themselves. This study's outcomes seem to align with the third hypothesis. Therefore, these findings may indicate that when clinicians focus on providing sufficient, adequate, and understandable information, this could result in more perceived SDM. An increase in perceived SDM due to increased provision of information could lead to the same beneficial consequences as apply to conflict of role.

Limitations, Strengths, and Future Research

This study had several limitations. The most prominent limitation is the sample size used for the data analysis. The sample size of this study was relatively small (N=4), resulting in low statistical power. In addition, the small sample size caused that no regression and moderator analyses could be performed. Thus, no statements could be made about the true relationships and effects of the variables. For example, levels of stress could also have impacted how SDM is perceived, perceived SDM could have impacted provision of information and conflict of role or these variables could have impacted the relationship between perceived SDM and stress. Without a bigger sample, it is impossible to make statements about the causes and effects of the relationships. Hence, future research could benefit from a bigger sample to obtain more statistical power and clarify the actual relationships and effects of the variables between themselves.

Another limitation of the study was the design used to collect the data. This study used a cross-sectional survey design. In addition, the survey was conducted after the surrogate's relative was discharged from the ICU. Since time decreases the accessibility to memories and affects the retention of emotionally salient events (Mercer & Jones, 2019), this may have impacted the validity of surrogates' responses. Therefore, future studies could use an "experienced sampling method" (ESM) to improve the accuracy of the data collected. It is a structured self-report diary technique that assesses mood, symptoms, and so on as they occur in daily life (Myin-Germeys et al., 2018). Therefore, in ESM, a person receives one or more daily notifications to fill in a quick questionnaire. Hence, retrieving emotionally salient events is more adequate because less time has passed. This is likely to result in more valid and reliable results.

Furthermore, a strength of the study was the scale used to measure conflict of role. No original scientifically proved scale was available to measure conflict of role in a clinical setting. Therefore this study developed its own questionnaire for measuring conflict of role for surrogates of ICU patients. The internal consistency of this scale was .81, which is considered good. However, to improve the scale of this study for future research, it could be analysed further using factor analysis to see what the validity of the scale is and to improve the scale when necessary. This could not be done in this study because a factor analysis was not possible due to the small sample size.

At last, future research could benefit from analyzing the effect of the variable first time exposure to the ICU department on the variables perceived SDM and self-reported stress. This study noticed, looking at scatterplots, that there could be a relationship between the variable first time exposure to the ICU and the variables self-reported stress and perceived SDM. The scatterplots indicated that when surrogates are for the first time exposed to the ICU environment they might experience more stress and more perceived SDM. Thus, first time exposure to the ICU could possibly effect stress and perceived SDM or moderate the relationship between stress and perceived SDM. However, this should be examined in future research to see if the variables are truly effecting eachother.

Conclusion

All in all, the current study may indicate that perceived SDM is negatively related to stress among surrogates of ICU patients. Furthermore, it seems that conflict of role is negatively associated with perceived SDM and that provision of information is positively associated with perceived SDM. Thus, decreasing conflict of role and increasing provision of information could increase perceived SDM. An increase in perceived SDM will be likely to

decrease stress and result in less PICS-F symptoms for surrogates of ICU patients. Thus, this study highlights the potential importance for healthcare professionals to provide sufficient, adequate and understandable information to the surrogates of ICU patients and to adjust the decision-making process to the role preferences of the surrogate at the beginning of admission of their relative to the ICU. However, a bigger sample size is needed to draw conclusions about this research topic with more certainty and to clarify the actual relationships and effects of the variables between themselves. Moreover, conducting ESM research on this topic may increase the validity of the outcomes. At last, future research could benefit from further analyzing the scale for conflict of role and examining the relationship between first time exposure to the ICU and levels of stress and perceived SDM for surrogates of ICU patients.

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Appendix A
Demographic Questions

1. Wat is uw geslacht?
2. Wat is uw leeftijd?
3. Wat is uw hoogst afgeronde opleidingsniveau?
4. Wat is uw ethniciteit?
5. Wat is uw relatie tot de patiënt?
6. Hoeveel dagen heeft uw naaste op de IC gelegen?
7. Was dit de eerste keer dat u in aanraking bent gekomen met de IC-afdeling?

Appendix B

Items to Measure Self-Reported Stress

1. Tijdens uw tijd op de IC, hoe vaak bent u van streek geweest door iets wat onverwacht gebeurde?
2. Tijdens uw tijd op de IC, hoe vaak heeft u zich nerveus en gestrest gevoeld?
3. Tijdens uw tijd op de IC, hoe vaak heeft u het volle vertrouwen gehad dat u het vermogen had uw persoonlijke problemen te hanteren?
4. Tijdens uw tijd op de IC, hoe vaak had u het gevoel dat u niet kon omgaan met alle dingen die u moest doen.
5. Tijdens uw tijd op de IC, hoe vaak had u het gevoel dat u alles onder controle had?
6. Tijdens uw tijd op de IC, hoe vaak was u boos over zaken die buiten uw macht lagen?
7. Tijdens uw tijd op de IC, hoe vaak heeft u het gevoel gehad dat moeilijkheden zich zo hoog opstapelden dat u ze niet meer te boven kon komen?

Appendix C

Items to Measure Self-Reported Perceived SDM

1. Hoe goed heeft de zorgprofessional geprobeerd te begrijpen hoe u in het proces van medische besluitvoering betrokken wilde worden?
2. 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?
3. Hoe goed heeft de zorgprofessional geprobeerd te begrijpen wat uw waarden en voorkeuren waren rondom de zorg van de patiënt?
4. 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?

Appendix D**Items to Measure Provision of Information**

1. Het was gemakkelijk om aan informatie te komen over de status van de patiënt en het zorgproces.
2. Ik begreep de informatie die ik vanuit het zorgteam heb ontvangen.
3. De informatie die vanuit het zorgteam heb ontvangen was naar mijn idee waarheidsgetrouw.
4. De informatie die ik vanuit het zorgteam heb ontvangen was naar mijn idee compleet.
5. De informatie die ik vanuit het zorgteam heb ontvangen was naar mijn idee consequent (het zorgteam deed wat er werd verteld).
6. Ik ontving voldoende informatie vanuit het zorgteam over het zorgproces en de status van de patiënt.

Appendix E

Items to Measure Conflict of Role

1. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik onvoldoende inspraak had over het zorgproces.
2. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik teveel werd betrokken bij de besluitvoering rondom het zorgproces.
3. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik liever op een andere manier betrokken wilde zijn in het zorgproces, dan de manier waarop ik nu betrokken werd.
4. Tijdens interactie momenten met de zorgprofessional, had ik naar mijn idee precies voldoende inspraak in het zorgproces.
5. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik teveel inspraak had over het zorgproces.
6. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik onvoldoende werd betrokken bij de besluitvoering rondom het zorgproces.
7. Tijdens interactie momenten met de zorgprofessional, werd ik precies betrokken in het zorgproces op de manier zoals ik dit graag wilde.
8. Tijdens interactie momenten met de zorgprofessional, had ik het gevoel dat ik liever een andere rol had willen hebben betreft de inspraak rondom het zorgproces, dan de rol die ik op dat moment had.