

Bachelor Thesis

Positive Psychology and Technology
Behavioural, Management and Social Sciences

*Symptoms of depression in relatives of former Intensive Care Unit patients and the
association with perceived social support*

Joana Grahl

s2113996

Date: 25.06.2021

1st Supervisor: Dr. Jorinde Spook

2nd Supervisor: Dr. Stans Drossaert



Abstract

Background. Having a beloved person in the ICU can feel overwhelming for close family members and can cause psychological problems that can even persist after the hospital discharge. This study investigates the association between the support received by family and friends, as well as by the ICU staff and the level of depression in relatives of former ICU patients. There is already an extensive body of literature on the influence of social support on caregivers and older relatives of ICU patients, but this paper focuses on the younger generation of relatives and the support by the ICU staff.

Method. A convenience sample of 47 participants (68% female, M age = 22 ($SD = 2,53$, 83% German nationality) was included in the current study. An online survey was measuring the perceived social support by family and friends (MSPSS), the support received by the ICU staff and the level of depression (HADS). The associations between the variables were assessed by a linear regression analysis and a paired sample t-test was done to compare support by family and friends with the support by the ICU staff.

Results. The key findings of this study are that no significant association was found between the time since the hospital discharge and the level of depression ($\beta = .03$, $F(1, 45) = .03$, $p = .862$). Additionally, social support was found to be positively related to the level of depression, meaning that individuals who received a high amount of social support showed higher levels of depression ($\beta = .40$, $F(1, 45) = 8.6$, $p = .005$). No significant association was found between the support by the ICU staff and the levels of depression ($\beta = .13$, $F(1, 45) = .71$, $p = .404$). Furthermore, relatives of former ICU patients rate the perceived social support by family and friends ($M = 69.68$, $SD = 15.10$) significantly higher than the support received by the ICU staff [$(M = 47.15$, $SD = 12.89)$; $t(46) = 9.26$, $p < .001$].

Conclusion. These results demonstrate the need to conduct further studies investigating the effects of the admission of a relative into the ICU on the level of depression in young adults since the findings are contra-intuitive regarding the social support and the admission time, as well as regarding the association between the time since discharge and the level of depression.

Keywords: ICU admission, depression in adolescents, social support, support by ICU staff, social cognitive theory, relatives of ICU patients

Table of content

Introduction	4
Social Support	6
Social Cognitive Theory by Bandura	6
Methods	7
Study Design	7
Participants	8
Materials	8
Measures	9
Procedure	10
Data Analysis	10
Results	10
Drop-out Analysis	11
Correlations between main variables	11
Main findings	15
Discussion	18
General Discussion	19
Strengths & Limitations	21
Future Research Recommendations	21
Conclusion	
References	23
Appendix A	25
Appendix B	27
Appendix C	29

Introduction

When a close family member is admitted to the Intensive Care Unit (ICU) it can be very overwhelming for the relatives, especially during times of COVID-19 when visiting ones' family members is often not possible. Additionally, the atmosphere of the hospital, as well as the uncertainty about the condition of the relative and the treatment plan can easily unsettle family members. Relatives of ICU patients often show high levels of perceived stress, anxiety, depressive symptoms, posttraumatic stress symptoms, sleeping problems and general exhaustion, which can persist for months after the patient was admitted into the ICU (Bolosi et al., 2018). A previous study by Cameron et al. (2016) has found that 43% of the family members of ICU patients still had high levels of depressive symptoms one year after their relative had been released from the ICU. According to the DSM-5, the most common symptoms of depression are anhedonia, weight changes, depressed mood, insomnia, general exhaustion and feelings of guilt (Tolentino & Schmidt, 2018).

Studies showed that the family members of ICU patients are more at risk of developing depressive symptoms than the patients themselves and these symptoms are also present over a longer period of time in the relatives than in the patients (Fumis, Ranzani, Martins, & Schettino, 2015). Research already suggests that depression rates increased from 38% on the day of hospitalization to 58.3% on the 7th day among relatives of Intensive Care Unit Patients (Bolosi et al., 2018). This can be due to the high psychological stress, the unfamiliar environment and treatments as well as the general anxiety about losing their relatives. Especially difficult for family members of ICU patients is the uncertainty they have to deal with (Alsharari, 2019).

What is often expressed by family members of ICU patients is the wish to be updated more regularly about the condition of the family members and the need to be reassured and supported by the hospital staff, as well as by family members and friends (Alsharari, 2019). This uncertainty can be especially difficult for the relatives because it can increase their fear of losing their family member and if no appropriate social support is available this can cause stress and anxiety. The anxiety about the critical health condition of their family member can then have a substantial impact on the psychological well-being of the relatives themselves, which is an immense additional burden during this stressful time. Moreover, supporting the patient during this time or even making decisions that have a crucial impact on the patient's life, if the patient is not able to engage in the decision making themselves, can be a huge burden for the family members and can easily overwhelm them. Also, since patients often do not communicate with the relative about

their treatment wishes prior to the hospital admission, it can be very conflicting, when the relatives have to make difficult decisions for the patients (Davidson, 2009). Furthermore, having a loved one in the ICU puts the relatives in a vulnerable position, since they are unable to help the patient, besides emotionally supporting them. To mitigate the distress caused by the admission of a relative into an ICU, social support, either from friends or from the healthcare system might bring positive change to family members' mental health.

Social Support

Evidence exists on the importance of social support for an individual's mental health in general. Lakey and Cohen (2000) suggest simply knowing that there is the possibility to receive support from others can help individuals to have a more positive view on stressful events like the hospitalization of a close family member and it improves the ability to cope with the difficult and unknown situation. The research by Lakey and Cohen (2000) also shows that the quantity and nature of support someone receives influences their ability to cope with stressful life events. It can also influence the health condition of the family members of the patient (Lakey & Cohen, 2000). Moreover, people who have to deal with stressful situations that have a supportive social environment are, as Helgeson (2003) found "almost as well off as the person who is not experiencing the stressor" (p. 2). Also, according to this study, being emotionally supported by family members and friends can be as helpful as being supported by doctors and nurses, and can prevent the development of depressive symptoms in relatives of ICU patients. This demonstrates the importance of social support by family and friends, as well as by the ICU, which is supported by the Social Cognitive Theory by Bandura.

Social Cognitive Theory by Bandura

According to the Social Cognitive Theory by Bandura (1998), an individual's social surroundings, cognition and past behaviour need to be considered when thinking about the future behaviour of this person. According to Bandura, social support is needed to minimize the consequences of stressful life events on the overall well-being of a person and also to build up behaviour that is actively promoting the health of individuals. Social support can also "reduce vulnerability to stress, depression, and physical illness" (Bandura, 1998, p.5). This emphasizes the need to investigate the effects of social support and ICU support on young adults that have

had a relative admitted into the ICU. In the past, there has already been an extensive amount of research on this topic, which was focusing merely on the psychological wellbeing of the ICU patients themselves, on the spouse or the informal caregivers of these patients, who were mostly adults or elderly people. Therefore, this study is focusing on the close family members, which are defined as the parents, children, grandchildren, siblings, cousins, as well as the nephews and nieces of ICU patients.

This study

This study investigates the development of symptoms of depression in family members of patients that have been admitted into an ICU and tests the association between the perceived social support and the development of depression symptoms in relatives of ICU patients, as well as between the ICU support and the feelings of depression. Additionally, the study aimed at comparing the support received from family and friends to the support received by the ICU staff. This research focused on the psychological consequences of the admission of a close family member into an ICU on adolescents and young adults and this paper is aiming at testing the hypotheses that are presented below.

Hypothesis 1: Family members of former ICU patients that have been discharged from the hospital between 7 to 12 months ago, show significantly less depressive symptoms than relatives of patients that have been discharged from the hospital up to 6 months ago.

Hypothesis 2a: There is a negative association between the perceived level of support by family and friends and the level of depressive symptoms in relatives of former ICU patients.

Hypothesis 2b: There is a negative association between the perceived level of support by the ICU staff and the level of depressive symptoms in relatives of former ICU patients.

Hypothesis 3: Family members of former ICU patients rate the social support received by the ICU staff lower than the social support received by family members and friends.

Methods

Study Design

A cross-sectional survey study was carried out. The online questionnaire was conducted using several already existing psychological questionnaires, which aimed at assessing depression symptoms in relatives of former ICU patients as well as the perceived social support. Furthermore, data collection took place from March to May 2021. Prior to the start of the data collection, the topic of the research, as well as the procedure of the study, was approved by the Ethical Committee of the Behavioural, Management and Social Sciences at the University of Twente (210239). Also, participants were gathered by means of social media and through personal contacts of the researchers. Therefore, convenience sampling and snowballing sampling were used. Furthermore, participation was voluntary with the opportunity to withdraw at any time. Participants did not receive any compensation for filling out the questionnaire, apart from the possibility of gaining SONA system or Survey circle points. The data collection was conducted together with 5 other researchers, who have focused on different individual topics. These research papers investigated the aspects of stress symptoms, health-related quality of life, symptoms of anxiety, self-efficacy, flourishing of family members, the association between the hospital admission of a relative and sleeping patterns, as well as the aspect of emotional eating and avoidance coping.

Participants

In total, 129 individuals participated in this study, but only 47 participants could be included in the final data analysis (68% female, 28% male, 2 % non-binary/third gender, 2% did prefer not to state their gender). The final age range was from 18-29 years ($M = 22$, $SD = 2,53$). 83% of the participants were German, 5% Dutch and 12% Other. English proficiency was necessary in order to be included in the study and only healthy individuals were targeted who were not undergoing therapy for anxiety, depression or post-traumatic stress disorder, which was also explicitly stated in the Informed Consent Form.

Materials

This research was conducted using an online questionnaire through the software Qualtrics. The online survey comprised already existing questionnaires, as well as one questionnaire regarding the support received by the ICU staff that was created by the researchers. Since the study was conducted online, the only materials that were necessary to take part in this research were a smartphone, tablet or laptop and an internet connection to enter the online survey.

Measures

Since the research was conducted in collaboration with other researchers, the overall online study comprised 11 questionnaires regarding the physical and mental well-being of the relatives of former ICU patients. The Perceived stress scale, Hospital Anxiety and Depression Scale, Mental Health Continuum, Multidimensional Scale for Perceived Social Support, The SF-8, Social Self-Efficacy Scale, Dutch Eating Behaviour Questionnaire, Holland Sleep Disorder Questionnaire, Coping Inventory and the International Physical Activity Questionnaire were included in this study. Additionally, a scale regarding the social support received by the ICU staff was created, which is based on the structure of the Multidimensional Scale for Perceived Social Support and consists of similar questions. Only the questionnaires that are listed below are included in the data analysis aiming at answering the research questions of this paper.

Hospital Anxiety and Depression Scale. The Hospital Anxiety and Depression Scale by Zigmond and Snaith (1983) consists of two subscales, namely one scale measuring the level of anxiety and one scale measuring the level of depression (Appendix D). Both scales consist of seven items each using a four-point Likert scale. The HADS has a Cronbach's Alpha of .61 after deleting item 8, which indicates that it has a questionable internal consistency. Example items from the HADS are "I feel restless as I have to be on the move" and "I look forward with enjoyment to things".

Perceived Social Support. The Multidimensional scale of perceived social support by Zimet, Dahlem, Zimet and Fraley (1988) is a questionnaire comprising 12 items that rank on a 7-point Likert scale (Appendix C). The Likert scale is ranged from 1, which means "very strongly disagree" to 7, which states that the participants "very strongly agree". The questionnaire consists of three subscales, namely support by family, by friends and by a significant other and each

subscale comprises four items (Canty-Mitchell & Zimet, 2000). Example items of this scale are “I can count on my friends when things go wrong” and “there is a special person with whom I can share joys and sorrows” The MSPSS has an overall Cronbach’s Alpha score of .96 for, which indicates an excellent internal consistency. The Cronach’s Alphas for the subscales are .97 for support by significant others, .93 for family support and .96 for support by friends, which also means that the subscales have a high internal consistency.

Social Support by the Intensive Care Unit staff. The scale that was used to assess the level of social support received by the ICU staff consists of 12 items measured on a 7 item Likert scale ranging from 1 “strongly disagree” to 7 “strongly agree” (Appendix B). The scale has a relatively high internal consistency with a Cronbach’s Alpha of .817 but it is yet not validated across trials. Example items of the scale are “I always felt well informed about my relatives' condition” and “There were always doctors or nurses around when they were needed”. The scale has an Cronbach’s Alpha of .81, which indicates that it shows a high internal consistency. Furthermore, a factor analysis with varimax rotation was conducted for the questionnaire regarding the ICU support, to check for underlying factors and patterns between the items, because the scale is created based on other existing scales. Item 1 and 2 are the only items with an Initial Eigenvalue above 1, which indicates that there are 2 underlying factors. The proportions of variance accounted for by the different components are the Extraction Eigenvalues. Item 4 is the only item with a communality lower than 0.4, which indicates that this variable does not contribute much to the underlying factors.

Procedure

Before taking part in the study, the participants were asked to sign an online Informed Consent Form, which provided the research population with information about the general procedure of the study as well as with the contact information of the researchers (Appendix A). Also, participants were informed about the voluntary nature of the participation in the study and about the possibility of withdrawal from the survey at any time. Additionally, the participants were informed that completing the survey would take approximately 30 minutes and the used scales were explained. After the participants finished the questionnaire, a debriefing text informed them about the purpose of the individual parts of the survey in more detail.

Data Analysis

The data that was obtained from Qualtrics was analyzed using the statistical package for the social sciences (IBM SPSS 27) and the Significance was set for 5%.

At first, the mean scores, as well as the standard deviations, were calculated for all used questionnaires and the assumptions were tested before carrying out the analysis. Also, the four negatively framed items that were measuring the social support received by the ICU staff were recoded before they could be further analyzed. Furthermore, an independent sample t-test was conducted to compare the scores of the participants who have finished the study with the results of the participants who have not completed the questionnaire.

In order to test the first hypothesis, the Pearson's Correlation Coefficient was computed for the Continuous Variables and possible Covariates and a Linear Regression Analysis was carried out. Additionally, an independent sample t-test was conducted to compare the depression scores of the participants who had a relative in the ICU in the past 6 months with the participants who have a relative that was discharged from the hospital in the past 7-12 months.

To assess the first part of the second hypothesis, a Linear Regression Analysis was performed to analyze the association between social support and the development of depressive symptoms in individuals. In order to test the second part of this hypothesis, a Linear Regression Analysis was done to test the association between support by the ICU staff and the level of depression. Also, the Pearson's Correlation Coefficient was computed.

A Factor Analysis with varimax rotation was carried out for the questionnaire regarding the ICU support since the scale was created by the researchers and is not yet validated across trials. During a Reliability Analysis, it was also assessed if the reliability would improve if one of the items would be deleted from the questionnaire. A paired sample t-test was conducted to compare the level of support by family and friends with the level of support received by the ICU staff, which was possible since the questionnaire regarding the ICU support was created based on the items of the MSPSS and the scales consist of similar questions.

Results

Drop-out Analysis

In total, 129 participants filled out this study. 48 participants had to be deleted because they did not fill out the consent form or did not finish the demographic questions (see Table 2). Additionally, 24 participants could not be included in the final data analysis because they indicated that they had no relative in the ICU. Furthermore, 2 participants stated that the number of ICU stays of their relative was 0 times, who were also excluded from the data analysis. Moreover, 2 more participants had to be deleted because the hospital stay of their relative was more than 18 months ago, and 1 participant just answered every question with 0 or 1, which was also excluded. In the end, 5 more participants had to be deleted due to missing data on the questionnaire regarding the ICU support.

Table 1

Stripping of data (N=129)

Characteristics	N	%	M	SD
Gender	47			
Male	13	27,66		
Female	32	68,08		
Non-binary/third gender	1	2,13		
Prefer not to say	1	2,13		
Nationality				
Dutch	2	4,25		
German	39	82,98		
Other	6	12,76		
Age			22,383	2,532
Time since discharge (in months)			6,595	4,470
≤1	6	12,76		

2-3	13	27,66
4-6	4	8,51
7-12	22	46,81
13-18	2	4,25
<hr/>		
Relationship		
Own Child	2	4,25
Parent	10	21,28
Grandparent	19	40,42
Sibling	3	6,38
Aunt/Uncle	7	14,89
Cousin	4	8,51
Other	2	4,25
<hr/>		
Length of ICU stay (in days)		2,96
		1,12
Admission times		2,11
		4,384
<hr/>		

Total	47	100
-------	----	-----

Note. Final Dataset = 52 including 6 participants with missing items

An independent sample t-test was conducted to compare the depression scores of the group of participants who have finished the questionnaire with the participants who have not fully completed it. There were no significant differences found between complete responders and non-complete responders on any of the main outcome variables.

Description of the study group

Table 2

Descriptives of the Hospital Anxiety and Depression Scale, Multidimensional Scale of Perceived Social Support and the Questionnaire measuring perceived ICU support (N = 47)

	N	Minimum	Maximum	Mean	Std. Deviation
Social support	47	12 (12)	84 (84)	70,02	14,88
Significant other support	47	4 (4)	28 (28)	24,14	5,79
Family support	47	4 (4)	28 (28)	22,94	5,61
Friends support	47	4 (4)	28 (28)	22,94	5,64
ICU support	47	21(12)	71(84)	47,15	12,889
Depression	47	4 (0)	18(18)	11,11	2,807

In the following paragraph, the sample characteristics, as well as the Means and the Std. Deviations of the sample characteristics are presented. The mean score of the months that have passed since the hospital discharge is $M = 6.59$, $SD = 4.48$. The shortest recorded time since the hospital discharge is 0 months and the longest recorded time is 17 months. Most participants indicate that the relative who was admitted into the ICU was their grandparent. The mean ICU stay of the relative was $M = 2.96$, $SD = 1,12$. The mean score of the hospital admissions was $M =$

2.11, $SD = 4.38$ and the most recorded ICU admissions were 29 times. The results also show that in most cases a formal caregiver still provides care for the relative.

Correlations between the main variables

In table 3 below, the correlations between the main variables depression, social support and ICU support are presented. The Pearson's Correlation Coefficient was used to assess whether the time since the hospital discharge and the level of depression is correlated with each other. Time since discharge and depression have a Pearson's Correlation Coefficient of .02, which indicates that there is a very low positive correlation between the two items. The 2-tailed significance value is $p = .86$, which indicates that it is not significant. Pearson's Correlation Coefficient was also used to test the correlation between the perceived social support and the level of depression. Results of the Pearson's Correlation indicate that there is a medium positive correlation between the two variables and the model is significant ($t(46) = .401, p = .005$). Additionally, a significant positive correlation was found between ICU Support and Social Support ($t(46) = .298, p = .042$) and a significant negative correlation was found between Depression and Gender ($t(46) = -.302, p = .039$). Furthermore, a positive correlation was found between the length of the ICU stay and the Social Support ($t(46) = .330, p = .023$). This means that the length of ICU stay of the relative had a moderately positive influence on the perceived Social Support. Lastly, Depression and the Number of admissions into the ICU were found to have a positive correlation ($t(46) = .36, p = .016$).

SY Table 3
Correlation Matrix

		Time since discharge	Length of ICU stay	Admission times	Significant other support	Family support	Friends support	Depression	ICU support	Male	Female	Non-binary	Prefer not to say
Time since discharge	Pearson Correlation	1											
Length of ICU stay	Pearson Correlation	.18	1										
Admission times	Pearson Correlation	-.18	.21	1									
Significant other support	Pearson Correlation	.25	.28	.08	1								
Family support	Pearson Correlation	.10	.28	.11	.60**	1							
Friends support	Pearson Correlation	.22	.31*	.09	.59**	.75**	1						
Depression	Pearson Correlation	.02	.21	.36*	.17	.34*	.55**	1					
ICU support	Pearson Correlation	.06	.09	.07	.14	.44**	.20	.13	1				
Male	Pearson Correlation	-.30*	.11	.33*	-.23	-.05	-.06	.32	.08	1			
Female	Pearson Correlation	.36*	-.07	-.29	.22	.16	.16	-.29	-.04	-.90	1		
Nonbinary	Pearson Correlation	-.15	-.13	-.04	-.10	-.05	-.05	.10	.03	-.09	-.22	1	
Prefer not to say	Pearson Correlation	-.09	.01	-.04	.10	-.31*	-.28	-.17	-.16	-.09	-.22	-.02	1

*. Correlation is significant at the 0.05 level (2-tailed)

** . Correlation is significant at the 0.01 level (2-tailed)

Main findings

Association between the time since discharge and depression

Linear Regression Analysis showed no significant association between the time since hospital discharge and depression ($\beta = .026$, $F(1, 45) = .03$, $p = .862$) with an R^2 of .001, which was counter expectational. An independent samples t-test was carried out to compare the depression scores of the group of 23 participants who have a relative that has been discharged from the ICU in the past 6 months ($M = 11.22$, $SD = 2.34$) with the scores of the 24 participants who have a relative that has been discharged in the past 7-12 months ($M = 11.0$, $SD = 3.27$). No significant difference was found between these two groups $t(46) = -.26$, $p = .208$. Additionally, 40% of the participants scored above the cut-off score of 11 on the depression subscale of the HADS, which is considered as an abnormal score.

Association between social support and depression

Social support was a significant predictor of depression, ($\beta = .40$, $F(1, 45) = 8.6$, $p = .005$) with an R^2 of .161 but surprisingly, the direction of the association was opposite as expected: more support was associated with more depressive feelings.

Association between ICU support and depression

Counter-expectational, support by the ICU staff was not found to be a significant predictor of depression ($\beta = .13$, $F(1, 45) = .709$, $p = .404$) with an R^2 of .016.

Comparison of social support with the support by the ICU staff

During the paired samples t-test, a significant difference was found in the scores for support by family and friends ($M = 69.68$, $SD = 15.10$) and ICU support ($M = 47.15$, $SD = 12.89$); $t(46) = 9.26$, $p < .001$, meaning that the level of support by family and friends was rated significantly higher than the level of support by the ICU staff.

Discussion

Since the effects of hospital admission of relatives on young adults is not well represented in existing studies, our research adds quite some interesting results to the body of literature, especially on the support received by the ICU staff. In contrast to the common body of literature, no significant association was found between the time since the hospital discharge of the relative and the level of depression. Counter-exceptional was also that a positive association was found between the perceived social support and the level of depression in relatives, which indicates that a higher social support is related to a higher level of depression. Lastly, the perceived support by family and friends was rated significantly higher than the support received by the ICU staff.

General Discussion

The first hypothesis, which states that the participants who have a relative that has been discharged from hospital in the past 7-12 months show significantly lower levels of depression than individuals who have a relative that has been discharged in the past 6 months can not be accepted. Research by Cameron et al. (2016) also showed that 43% of the close relatives of ICU patients still showed increased levels of depression one year after the hospital discharge. These relatively high depression scores indicate that there might be some underlying factors like the severity of the illness of the relative that is accounting for the long-lasting effect on the psychological well-being of the individuals. One limitation that could explain that there is no big difference between the two groups in the t-tests is the fact that the two samples are not representative, as they are too small.

Surprisingly, the current research found a positive association rather than a negative between the perceived social support and the level of depression. In consideration of this, the first part of the second hypothesis needs to be rejected since a negative association between the two variables was expected to be found. Additionally, the results on the association of the ICU support on the level of depression indicate that the second part of the second hypothesis needs to be rejected. These results deviate from previous research, which indicate that social support can diminish the effects of the hospital admission of a relative on the health of the family members (Lakey & Cohen, 2000). A possible explanation for this result could be the uncommon age group

that was targeted for this study, young adults. Most studies on this topic use a research group that consists of the spouse or the caregiver of elderly people and there is still not a lot of research about the emotional burden on the younger generation. The high levels of depression in relatives who also receive a high level of social support might be explained by the reason that some patients are chronically ill and need to be cared for and supported over a long period of time. This is an extremely high burden for the caregiver/close relative and can result in many psychological problems (Bialon & Coke, 2012). This is also in line with the positive correlation between the number of hospital admissions and the level of depression. Therefore, one possible explanation for these results could be the high burden on the relatives, which puts them in an extremely vulnerable position, which can easily result in psychological problems. To have their own psychological problems additionally to the illness of their family member could explain why a higher level of social support is needed in comparison to relatives who have a relatively high psychological well-being and only need little support, in order to be able to cope with the stressful situation. Additionally, different ways of coping with the burden of having a family member in the ICU could also be an underlying factor that might influence the ability to accept social support by family members, as well as by the ICU staff.

The participants rate the perceived social support higher than the support received by the ICU staff, and therefore the third hypothesis can be accepted. This is consistent with the general body of literature regarding the family satisfaction with the ICU staff and the support received. This can also be explained by the study by Helgeson (2003), which states that emotional support by the social environment is as helpful as support by doctors and nurses in the prevention of depression in family members of ICU patients. Carlson and Spain (2015) found that families of ICU patients often indicate that they would appreciate better communication with the ICU staff and that the emotional support provided by the ICU staff is often inadequate from the perspective of the families. A study by MaloneBeach and Zarit (1995) also found that even though emotional support is commonly considered to be an important factor in the prevention of depression, emotional support and depression were not significantly related in their study. Research showed that the satisfaction of the relatives of ICU patients is closely connected to the communication with the ICU staff and the amount of shared decision making (Hinkle, Bosslet & Torke, 2015). Hence, further studies that examine the effect of shared decision making on the level of depression and on the satisfaction with the support received by the doctors and nurses are

needed. What is striking is that individuals who have not fully completed the questionnaire often stopped while filling out the ICU related questions. The mean scores of these participants on the support received by the ICU staff are also lower than the scores of the group who finished filling out the questionnaire.

Strengths & Limitations

One strength of this study is the focus on the support provided by the ICU staff, as most studies focus on the support received by the social environment and there are not many scales available that measure the perceived support by the ICU staff, which can serve as a starting point for further research. The small sample size and the only moderate reliability of the depression scale of the HADS can also be considered as limitations affecting the overall results of the study. Most participants scored relatively high on social support, but the standard deviation on this score, as well as on the ICU score is also very high, which could have influenced the results. Lastly, most individuals that have participated in the study have indicated that their relative has been released from the ICU in the past 7-12 months, which could also have had an impact on the results regarding the comparison of the different groups.

Future Research Recommendations

These findings can be seen as a starting point that needs more extensive research to fully understand the needs of the family members of ICU patients, especially regarding the support by the social environment and by the ICU staff. Based on the study findings that are presented above, more research is needed to gain a broader understanding of the emotional burden that lasts on the family members and how these can better be handled by the ICU staff and how the communication between the family members and the doctors and nurses can influence the psychological well-being of relatives. This is especially important since a large proportion of relatives of ICU patients show psychological problems, since 40% of the participants scored above the cut-off score, indicating an abnormal case. Additional research on psychological support that also involves the family of the ICU patients and continues even after the hospital discharge could offer some more insights into the individual needs of the social surrounding of ICU patients. Hence, interventions that aim to decrease the emotional burden on young relatives

who are not the main caregivers can be suggested to be implemented in the ICU, as well as a family centered care.

Conclusion

This research did not show the expected results regarding the association between the time since the ICU discharge and the level of depression in relatives of former ICU patients, as well as regarding the effect of social support on the level of depression. However, the perceived social support is an interesting factor that can in the development of depressive symptoms in young adults and these counter-exceptional results demonstrated the need to conduct further studies on this topic, as well as on the association between the time since the hospital discharge and the level of depression. This study also pointed out the importance of providing support not only for the patient but also for the family of the patients by the ICU staff. This support can be given with for example interventions, aiming at decreasing the emotional burdens of family members of ICU patients and the emotional burdens of the ICU staff.

References

- Alsharari, A. (2019). The needs of family members of patients admitted to the intensive care unit. *Patient Preference and Adherence, Volume 13*, 465-473. doi:10.2147/ppa.s197769
- Bandura, A. (1998). Health promotion from the perspective of social cognitive theory. *Psychology and health, 13*(4), 623-649.
- Bialon, L. N., & Coke, S. (2012). A study on caregiver burden: stressors, challenges, and possible solutions. *American Journal of Hospice and Palliative Medicine®*, 29(3), 210-218.
- Bolosi, M., Peritogiannis, V., Tzimas, P., Margaritis, A., Milios, K., & Rizos, D. V. (2018). Depressive and Anxiety Symptoms in Relatives of Intensive Care Unit Patients and the Perceived Need for Support. *Journal of neurosciences in rural practice, 9*(4), 522–528. https://doi.org/10.4103/jnrp.jnrp_112_18
- Cameron, J. I., Chu, L. M., Matte, A., Tomlinson, G., Chan, L., Thomas, C., Friedrich, J. O., . . . Margaret, S. (2016). One-Year Outcomes in Caregivers of Critically ILL Patients. *New England Journal of Medicine, 379*(19), 1831-1841. DOI: 10.1056/NEJMoa1511160
- Canty-Mitchell, J. & Zimet, G.D. (2000). Psychometric properties of the Multidimensional Scale of Perceived Social Support in urban adolescents. *American Journal of Community Psychology, 28*, 391-400.
- Caregivers and Families of Critically Ill Patients. (2016). *New England Journal of Medicine, 375*(10), 1000–1002. <https://doi.org/10.1056/nejmc1608225>
- Carlson, E. B., Spain, D. A., Muhtadie, L., McDade-Montez, L., & Macia, K. S. (2015). Care and caring in the intensive care unit: Family members' distress and perceptions about staff skills, communication, and emotional support. *Journal of critical care, 30*(3), 557–561.
- Davidson, J. E. (2009). Family-Centered Care: Meeting the Needs of Patients' Families and Helping Families Adapt to Critical Illness. *Critical Care Nurse, 29*(3), 28–34. <https://doi.org/10.4037/ccn2009611>
- Fumis, R. R. L., Ranzani, O. T., Martins, P. S., & Schettino, G. (2015). Emotional Disorders in Pairs of Patients and Their Family Members during and after ICU Stay. *Plos One, 10*(1), e0115332. DOI:10.1371/journal.pone.0115332

- Gough, K., & Hudson, P. (2009). Psychometric properties of the Hospital anxiety and Depression scale in family caregivers of palliative care patients. *Journal of Pain and Symptom Management, 37*(5), 797-806. doi:10.1016/j.jpainsymman.2008.04.012
- Helgeson, V. S. (2003). Social support and quality of life. *Quality of Life Research, 12*, 25-31. doi:10.1023/a:1023509117524
- Hinkle, L. J., Bosslet, G. T., & Torke, A. M. (2015). Factors associated with family satisfaction with end-of-life care in the ICU: a systematic review. *Chest, 147*(1), 82–93. <https://doi.org/10.1378/chest.14-1098>
- Lakey, B., & Cohen, S. (2000). Social support theory and measurement. *Social Support Measurement and Intervention, 29*-52. doi:10.1093/med:psych/9780195126709.003.0002
- MaloneBeach, E. E., & Zarit, S. H. (1995). Dimensions of social support and social conflict as predictors of caregiver depression. *International psychogeriatrics, 7*(1), 25–38. <https://doi.org/10.1017/s1041610295001827>
- Tolentino, J. C., & Schmidt, S. L. (2018). Dsm-5 criteria and depression severity: Implications for clinical practice. *Frontiers in Psychiatry, 9*. doi:10.3389/fpsy.2018.00450

Appendix A

Consent Form

Consent Form for Participation in a Study

University of Twente

Survey on Health: A comparison between young adults with relatives as former ICU patients

Description of the research and your participation

You are invited to participate in a research study conducted by Anita Suntharalingam, Luca Marie Schlieper, Lena Fitzian, Joana Grahl, Mirjam Kühne, and Leona Rudolph. This study is part of our bachelor theses that we are writing, under supervision of Jorinde Spook, PhD (Assistant Professor, Health Psychology & Technology at the University of Twente).

Please read the following instructions carefully, as it informs you about the purpose of the study, your task and the way we would like to use your information.

About this research:

As the admission of a patient to the Intensive Care Unit (ICU) also impacts the patients' family members, it is important to gain more thorough understanding of the wellbeing of these relatives. Especially young adults in the age category of 18-29 years old are underrepresented in the current body of research. Therefore, we aim to study different (mental and physical) health-related concepts in relation to an ICU-admission of a relative in the past 12 months (i.e., symptoms of anxiety, depressive feelings, quality of life, sleep disturbance, eating pattern, and stress), completed with questions about social support, flourishing, self-efficacy, and coping strategies. Filling in the questionnaire will take about 30 minutes.

Before we begin, some aspects of the research are explained and how we will handle the data.

There are no known risks associated to this survey research.

There are no known benefits to you that would result from your participation in this research.

We are targeting healthy individuals that are not undergoing any treatment for depression, anxiety or PTSD.

We are interested in your own personal experiences. This means that there are no right or wrong answers: you are the expert on this subject.

Each of the researchers will write a bachelor thesis report concerning their topic of research. These theses will be assessed by our first and second supervisor. Furthermore, we only report anonymous, analyzed data in our theses. The final (anonymous) dataset may be used by future students of the University of Twente to continue studying the topic.

Your participation in this research study is voluntary. You may choose not to participate, and you may withdraw your consent to participate at any time. You will not be penalized in any way should you decide not to participate or to withdraw from this study. You are allowed to withdraw the study at any time without stating any reason.

Study contact details for further information

If you have further questions, feel free to contact the researchers: Anita Suntharalingam (a.suntharalingam@student.utwente.nl), Luca Marie Schlieper (l.m.schlieper@student.utwente.nl), Lena Fitzian (l.fitzian@student.utwente.nl), Joana Grahl (j.grahl@student.utwente.nl), Mirjam Kühne (m.u.kuehne@student.utwente.nl), Leona Rudolph (l.rudolph@student.utwente.nl) or our supervisor: Jorinde Spook (j.e.spook@utwente.nl).

Contact Information for questions about your rights as a research participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences at the University of Twente by ethicscommittee-bms@utwente.nl (ethical number:210239)

Appendix B

Questionnaire on the social support received by the ICU staff

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
There were always doctors or nurses around when they were needed							
I felt emotionally supported by the ICU staff							
I always felt well informed about my relative's condition							
I did not receive the emotional support from the doctors and nurses that I needed							
I felt like the ICU staff could emotionally support me in a better way than my family and friends							
I did not feel like the ICU staff was interested in my psychological well-being							
I felt like the doctors and nurses were trying to include the family members during the whole treatment plan							

I did not feel like the ICU staff was including the family members of patients in the decision-making process

I was aware that I could receive support by the social workers in the ICU when needed

I felt like the doctors and nurses did not have enough time to carefully talk to the family members of their patients

I feel like the support received from the ICU staff helped me cope with this distressing situation

The ICU staff was able to comfort me during stressful situations

Appendix C

Multidimensional Scale of Perceived Social Support

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).