The association between flourishing and well-being, social support and social coping strategies of ICU patient's family members after hospital discharge

Bachelor Thesis

Luca Marie Schlieper

1st Supervisor: Dr. Jorinde Spook 2nd Supervisor: Dr. Stans Drossaert

July, 2021

B.Sc. Psychology

Department of Clinical Positive Psychology & Technology Faculty of Behavioral, Management and Social Sciences (BMS) University of Twente, Enschede, Netherlands

UNIVERSITY OF TWENTE.

Abstract

Background: An ICU hospitalization is a burdensome experience to not only the patient but also their relatives, resulting in long lasting psychological consequences and decreasing wellbeing. While young adulthood receives only little attention in research in this context, this study focuses on the age of 18-29 years. Further, the positive influence of social support on the wellbeing and the use of social coping strategies in stressful life situations has been emphasized in research. Therefore, it was expected that increased time after hospital discharge leads to increased well-being. Further, perceived social support was expected to have a positive influence on the well-being while social coping strategies moderated the association.

Method: A convenience sample of 129 participants was gathered. After exclusion, 46 participants were included in the final sample (28.3% male, 67.4% female; age in years: M = 22.36, SD=2.55). An online survey was administered using the MHC-SF, the MSPSS, and the Social Support Subscale of the CI. Afterwards, the associations were tested using linear regression models and a linear regression model with interaction effect.

Results: Time passed since discharge was not found to be significantly associated with wellbeing [$\beta = .063$, t(46) = .418, p = .678]. However, perceived social support showed a positive significant association with well-being [$\beta = .324$, t(46) = 2.335, p = .024] and the psychological well-being subscale [$\beta = .433$, t(46) = 3.183, p = .003]. Furthermore, social coping strategies were not found to be a moderating factor in the association of perceived social support and wellbeing [$\beta = -.252$, t(46) = -.831, p = .411].

Conclusion: The insignificant association between time and well-being can be explained through situational factors such as continuous care or death of the relative. Further, the positive significant association between perceived social support and well-being are in line with available literature. Finally, the insignificant moderation of social coping strategies may be explained through a mediation instead of a moderation.

Keywords: flourishing, well-being, social support, social coping strategies, young adults, ICU,

1. Introduction

On the 27th of January 2021, 651 patients in the Netherlands were stationed in the Intensive Care Unit due to Covid-19 and the daily admissions rose with 35 ICU admissions per day (Rijksoverheid, 2021). While this number only makes up 57% of the total ICU cases in the Netherlands, one can undoubtedly say that the ICU cases have been higher than normal. It is widely acknowledged, that the hospitalization into the ICU and critical illness is a burdensome experience to not only the patient but also their relatives as they are facing an unknown future, diagnostic uncertainty and possible fears of dying or losing a family member (Garrouste-Orgeas, Flahault, Fasse, Ruckly, Amdjar-Badidi, Argaud, & Timsit, 2017). The environment of the ICU has adverse physical, cognitive, functional, and especially psychological implications for both patients and family members (Beesley et. al, 2018). During the months following the ICU hospitalization, family members of ICU patients frequently experience psychological disorders such as anxiety, depression and Post Traumatic Stress Disorder (Beesley et. al, 2018). Additionally, the ICU admission of a relative impacts the well-being of ICU patient's family members for a longer term (Garrouste-Orgeas et. al, 2017). Yet our understanding on how human flourishing and well-being are affected in this post-admission time frame is rather limited.

1.1 Flourishing and well-being

According to the positive psychological perspective of the hedonic treadmill model, every life event which evokes a positive or negative emotional reaction temporarily affects the well-being of an individual (Diener, Lucas, & Scollon, 2009). Therefore, an ICU hospitalization, which can be conceptualized as a life event, negatively affects the well-being (if negative emotions are evoked).

1.1.1 The definitions of well-being. The concept of well-being is, opposed to the frequently held assumption, more than the absence of negative emotional states and psychological complaints. Further, the concept of well-being comprises two different facets

(Keyes, 2002). The first, hedonic well-being, includes emotional components such as happiness, life satisfaction and a balance between positive and negative affect (Keyes, 2002; Galper, Trivedi, Barlow, Dunn, & Kampert, 2006). The second, eudaimonic well-being, is composed of psychological components, such as purpose in life, personal growth and autonomy, and social components, such as meaning, positive relations, social acceptance and social integration (Schotanus-Dijkstra, Pieterse, Drossaert et al., 2015; Keyes, 1998).

Individuals who display high levels of both hedonic and eudaimonic well-being are conceptualized to be "flourishing" (Schotanus-Dijkstra, Pieterse, Drossaert et al., 2015). The concept of flourishing was introduced by Keyes (2002) to explain and understand how the highest level of well-being is constructed. The state of "flourishing" is regarded as the most favourable positive form of mental health and is described as a subjective estimate of the individual's perceptions and evaluations of their own life in concern of their emotional, social and psychological functioning (Keyes, 2002; Keyes 2010). Moreover, research showed that flourishers have excellent mental and physical health and find it easier to handle challenging life situations than non-flourishers (Schotanus-Dijkstra, Pieterse, Drossaert et al., 2015).

1.1.2 Flourishing after negative life events. When investigating the concept of flourishing in a context of a negative life event, research found that people higher in flourishing show a lower negative affect of negative life events (Prizmió-Larsen, Kaliterna-Lipovčan, Larsen, Brkljačić, & Brajša-Žganec, 2019). Therefore, the well-being of flourisher's is less influenced by negative life events, such as an ICU hospitalization of a relative. Another question that arises is to what extent flourishing exists in the months after hospital discharge as mental health issues are frequently found after such a negative life event. To this effect, available research on this topic indicated family caregivers still experienced problems such as anxiety, sleep problems, feelings of recurrent stress, negative feelings and were likely to develop depression even years after hospital discharge (Cameron, Herridge, Tansey, McAndrews, & Cheung, 2006; van Sleeuwen, van de Laar, Geense, van den Boogaard, & Zegers, 2020).

1.1.3 Target Groups in existing research. The majority of available research focuses on the target group of informal caregivers which mostly comprises a higher age. As an example, in the previously mentioned study of Im, Belle, Schulz, Mendelsohn, and Chelluri (2004), the mean age of the caregivers was 56.2 years where all of the caregivers were spouses. The demands of young adults and the difficulties they encounter, however, do not receive a lot of attention in research and a generalization of these findings to age groups in different life stages may not be valid (Bonnie, Stroud, & Breiner, 2014). According to Stroud, Walker, Davis, and Irwin (2015), young adulthood is a critical developmental period which is recommended to be researched separately. Therefore, the focus of this study is to investigate a target group which is not typically studied in this situational setting.

Furthermore, in addition to the aspect of flourishing, further factors capable of potentially having a soothing effect on the negative consequences of negative life events, such as social support, should be examined.

1.2 Social Support

In the past, the positive influence of social support on well-being has been frequently emphasized in research. For example, in the presence of stress, social support is shown to be an explaining factor for the measures of psychological well-being (Winefield, Winefield, & Tiggemann, 1992). Social support can be conceptualized as the supply of both psychological and material resources with the motivation of helping and supporting the recipients to cope with stress (Cohen, 2004). Social support can be displayed in three different forms: as network resources, social behaviors and appraisals of support (Demirtepe-Saygılı, & Bozo, 2011). According to Cohen and Willis (1985), social support is associated with well-being as it provides positive emotions, a sense of self-worth, and predictability in life. Moreover, social support can act as a buffer for stress by reinforcing self-esteem, self-efficacy, and problem-solving behaviors (Chu, Saucier, & Hafner, 2010). Psychological theories, such as the Social

Cognitive Theory of Bandura (1998), have acknowledged social support to having a decreasing effect on the vulnerability to stress, depression and physical illness.

Furthermore, research was able to demonstrate that social support is connected to higher subjective and psychological well-being whereas the lack of social support is associated with more distress, higher levels of problem behavior, and lower life satisfaction (Schotanus-Dijkstra, et al., 2015; Bal, Crombez, Van Oost, and Debourdeaudhuij, 2003). Specifically adolescents are found to be less satisfied with the social support they receive from their environment (Kafetsios, & Sideridis, 2006). Hence, it might be especially valuable to investigate to what extent the presence of social support is able to increase the well-being of young adults after a relative has been discharged from the ICU.

Furthermore, in addition to the aspect of social support, there are further factors capable of influencing well-being, such as coping strategies (Nakano, 1991).

1.3 Social Coping Strategies

A coping strategy can be conceptualized as an individual's continuous endeavours to handle specific external and/or internal demands that are appraised as exceeding the individual's resources and abilities (Lazarus, & Folkman, 1984). Therefore, social coping strategies following a stressful life event include an active part opposed to just perceiving social support. Hence, social support serves as a resource for social coping strategies (Cicognani, 2011). As an example, a social coping strategy includes social resources or social networks that individuals can make use of when they require advice, help, assistance, approval or protection in a stressful life event (Nakano, 1991). Therefore, social coping strategies can help individuals handle difficult and stressful life events (Malkoç, & Yalçın, 2015).

Nevertheless, according to Nakano (1991), perceiving social support to be available was shown to be a better predictor of well-being than when actual social support is given and used as a coping strategy. Furthermore, Kim, Jeong Yeob Han, Shaw, McTavish, and Gustafson (2010) noted that it has been suggested that the degree to which perceived social support is associated with increased well-being might depend on coping strategies. Further, research indicates that an interaction of social support and active coping styles is associated with less psychological distress (Griffin, Friend, Kaell, & Bennett, 2001). Therefore, it would be important to investigate whether an interaction of the two (perceived social support and social coping strategy) would serve as a greater benefit for the well-being of individuals in stressful life events. With this knowledge, greater help and assistance could be given to people in difficult life situations, such as ICU patient's family members.

1.4 Current Study

The current study aims at examining the association between perceived social support and the (positive) mental well-being of ICU patient's young adult family members and to what extent the presence of perceived social support can be a benefit to the well-being in the time after hospital discharge. Moreover, the application of social coping strategies is examined as a possible moderator in the association of perceived social support and well-being. Therefore, this study aims to answer the following hypotheses:

H1: After hospital discharge, the psychological, emotional, and social well-being of ICU patient's family members increases over time.

H2: Perceived social support is positively associated with the well-being of ICU patient's family members after hospital discharge.

H2a: Perceived social support is positively associated with the psychological well-being of ICU patient's family members after hospital discharge.
H2b: Perceived social support is positively associated with the emotional well-being of ICU patient's family members after hospital discharge.
H2c: Perceived social support is positively associated with the social well-being of ICU patient's family members after hospital discharge.

H3: Social coping strategies increase the association between perceived social support and well-being of ICU patient's family members in the first 18 months after hospital discharge.

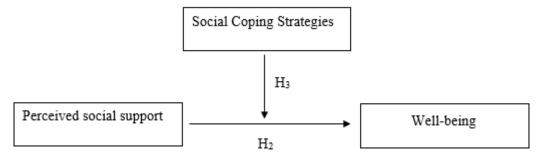


Figure 1. The moderating effect of social coping strategies in the association of perceived social support and well-being

2. Methods

2.1 Design

The current study yields a cross-sectional design, using convenience sampling strategies and the SONA system of the University of Twente to recruit participants. Quantitative data was gathered through a questionnaire in Qualtrics, and established together with 5 other bachelor students of the UT, as part of our bachelor thesis. The data collection took place over a period of one month in April 2021. The research was approved by the Ethics Committee of the University of Twente (ethical number 210239).

2.2 Participants

In total, 46 participants were included in the final sample (28.3% male, 67.4% female, 2.2% non-binary, 2.2% prefer not to say). Participants were 22.36 years old on average (SD=2.55), 82.9% of the participants were German, 4.3% were Dutch and 13% were of other nationalities. Most frequently, a grandparent (41.3%) or a parent (21.7%) were the relative admitted to the ICU. On average, 6.56 months have passed since the relative has been discharged from the ICU

(M=6.56, SD=4.51). Inclusion criteria included being at the age of 18-29 years old, speaking English and having a family member who was admitted to the ICU and released in the past 18 months. Further, exclusion criteria included not providing informed consent, having selected not having a relative who was admitted to the ICU or not having finished the questionnaire. Additionally, the participants were required to have an internet connection and as the whole study was conducted online. Table 1 displays all relevant sociodemographic characteristics of the sample.

Table 1

Characteristics	Ν	%	М	SD
Total Sample	46	100		
Gender				
Male	13	28.3		
Female	31	67.4		
Non-binary	1	2.2		
Prefer not to say	1	2.2		
Nationality				
German	38	82.6		
Dutch	2	4.3		
Other	6	13		
Age			22.36	2.55
Time since discharge			6.56	4.51
(in months)				
<1	6	13		
2-3	13	28.3		
4-6	4	8.7		

Sociodemographic characteristics of the sample

	7-12	21	45.6
	13-18	2	4.4
R	elationship		
	Own Child	2	4.3
	Parent	10	21.7
	Grandparent	19	41.3
	Sibling	3	6.5
	Aunt/Uncle	6	13
	Cousin	4	8.7
	Other	2	4.3

2.3 Materials

The online questionnaire was published over the platform Qualtrics and Survey Cycle. The online questionnaire was created and used by six bachelor students and composed of several already existing scales/questionnaires including the Perceived Stress Scale, the Hospital Anxiety Depression Scale, the Mental Health Continuum Short Form, the Multidimensional Scale for Perceived Social Support, the Social Support Received by the ICU Staff Scale, the SF-8, the Social Self-Efficacy Scale, the Dutch Eating Behavior Questionnaire, the Holland Sleep Disorder Questionnaire, the Coping Strategies Inventory and the International Physical Activity Questionnaire. However, for the purposes of the current study only the measures of the Mental Health Continuum Short Form, the Multidimensional Scale for Perceived Social Support and the Social Support Subscale of the Coping Strategies Inventory are included.

2.4 Measures

2.4.1 Mental Health Continuum Short Form (MHC-SF). The 14-item MHC-SF was used to assess the well-being of the participants and therefore as the screening tool for identifying if an individual was flourishing (Keyes, 2009). This was done by means of all three

dimensions of well-being (emotional, psychological, and social). Emotional well-being was measured through three questions, psychological well-being through five questions, and social well-being through six questions. Example questions were, '*In the past month, how often did you feel happy*?' (emotional well-being), '*In the past month, how often did you feel that our society is becoming a better place for people*?' (psychological well-being) and '*In the past month, how often did you feel confident to think or express your own ideas and opinions*?' (social well-being). Answer categories ranged from *Never (1)* to *Every Day (5)* (see Appendix A). The scores were calculated as mean scores, in which a higher score indicated a higher well-being and a higher likelihood of flourishing. The overall reliability of the MHC-SF was tested and indicated an excellent reliability with a Cronbach's alpha of .9. Additionally, the reliability of the subscales of psychological well-being ($\alpha = .84$) and emotional well-being ($\alpha = .87$) indicated good reliability, and social well-being ($\alpha = .7$) indicating acceptable reliability. Moreover, the results of the MHC-SF were tested for normality with a Shapiro Wilk Test and indicated a normal distribution (p = .344).

2.4.2 Multidimensional Scale for Perceived Social Support. The 12-item MSPSS was used to determine the perceived social support of the participants (Zimet, Dahlem, Zimet, & Farley, 1988). Example questions were "*I can talk about my problems with my friends*." Or "*I get emotional help & support I need from my family*". The participants had to indicate to what extent they agree with the presented statement on a scale from *Strongly disagree (1)* to *Strongly agree (7)* (see Appendix B). The reliability of MSPSS was tested and indicated excellent reliability with a Cronbach's alpha of 0.96. The normality of the data was tested with a Shapiro Wilk Test and indicated a unnormal distribution of the results of the MSPSS (p = .000).

2.4.3 Coping Strategies Inventory. The 72-item CSI was designed to asses coping thoughts and behaviors in response to explicit stressors and is made up of six subscales (Tobin, Holroyd, & Reynolds, 1984). For the purpose of this study, the subscale "social support" was used to assess the extent to which an individual seeks emotional support from people, one's

family, and one's friends as a coping strategy. Example questions were "*I found someone who was a great listener*." or "*I talked to someone about how I was feeling*". The subscale included 9 items with a 5-point Likert scale ranging from "*Not at all*" to "*Very much*" (see Appendix C). The Social Support subscale of the CSI was tested upon its reliability and showed a good reliability with a Cronbach's alpha of .80. A Shapiro Wilk test was conducted and confirmed a normal distribution of the data (p = .056).

2.5 Procedure

After the participants were recruited by the research team, the link to the online questionnaire was distributed to the participants. Furthermore, the participants who were recruited over the participant management software "Sona-System" and "Survey Cycle" were immediately redirected to the questionnaire online. Participants first filled out the informed consent (see Appendix D) form and answered questions concerning demographic data such as gender, age, nationality, time passed since ICU discharge and relationship to the patient (see Appendix E). Following, the 11 scales included in the questionnaire were filled out of which the MHC-SF was filled out third, the MSPSS fourth, and the Social Support Subscale of the CSI filled out second last. At the end of the online questionnaire, the participants were thanked for their participation.

2.6 Data Analysis

Following the data collection phase, the data from Qualtrics was imported to IBM SPSS Statistics 27 for statistical analysis. Firstly, the raw data set was prepared for further analysis. Further, the data was cleaned according to exclusion criteria. Moreover, the demographical values, such as age, gender, nationality, time passed since hospital discharge, relation to the patient, were examined and the frequency, means and standard deviations were computed.

To test the first hypothesis, the association between time passed since hospital discharge and well-being was examined. A positive association was expected, i.e. the more time passed after hospital discharge the greater the well-being. The association was tested through a univariate linear regression. Results between 0 and 0.3 are considered a weak association, results between 0.4 and 0.59 indicate moderate association and values above 0.6 are considered as a strong association (Cohen, 1988). Furthermore, the second hypothesis was tested. The association between psychological, emotional, social, and overall well-being (dependent variable) and perceived social support (independent variable) was tested through a univariate linear regression. A positive association was expected i.e., the greater the perceived social support the greater the well-being. Lastly, the third hypothesis was tested. It was expected, that social support coping strategies moderates the association between well-being and perceived social support. To test this hypothesis, a regression analysis with an interaction effect was conducted in order to assess the moderation of social support coping strategies (moderating variable) in the association between well-being (dependent variable) and perceived social support (independent variable) where a significant moderation would be found with a 95% confidence interval (Baron, & Kenny, 1986).

3. Results

3.1 Exploratory Analysis

3.1.1 Drop Out Analysis. After cleaning the data set of people who did not meet the inclusion criteria, a final sample of 46 participants was included in the data analysis resulting from a total of 129 participants. All participants included in the data analysis were family members of former ICU patients. Exclusion criteria were not giving informed consent, not finishing the demographics, not having a relative in the ICU, indicating no ICU stay, a longer stay than 18 months, suspicious responses, and outliers in the data. Table 2 shows the exclusion criteria and corresponding excluded cases.

Table 2Stripping of data (N=129)Reason of exclusion

Did not give consent/finish demographics	48
Indicated to not have a relative in the ICU	24
Number of stays 0	2
More than 18 months	2
Suspicious responses (only 0s and 1s)	1
Missing data	6

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

To determine, whether there is a significant difference of means of well-being measures between participants who finished the questionnaire and participants who didn't and to investigate whether a lower well-being measure could be a possible reason for not finishing the questionnaire, an independent sample t-test was done. The 43 participants who finished the questionnaire (M = 3.704, SD = .919) compared to the 7 participants who did not finish the questionnaire (M = 3.316, SD = .87) demonstrated no significant difference in well-being measures, t(48) = -1.043, p = .302. Therefore, the participants who did not finish the questionnaire but answered the corresponding questions relevant for this analysis were included into the data analysis.

3.2.1 Descriptive Statistics. The descriptives of the scales can be found in Table 3. The descriptives of the MHC-SF scale reveal that on average the participants show a relatively moderate well-being whereas the maximum number of scored points is close the achievable scale maximum. However, the low standard deviation indicates low variations in well-being scores. Moreover, this similarly applies to the psychological, emotional, and social well-being subscores where moderate well-being mean scores and low standard deviations can be seen. Furthermore, the results from PSS scale reveal that the majority of participants perceived a relatively high amount of social support. However, the relatively high standard deviation indicates rather high variations in the perceived social support. This can also be confirmed by the observation that the lowest and the highest possible scores were both obtained. Lastly, the

Social Coping Subscale of the CI showed a higher than moderate mean score indicating that the majority of participants applied social coping strategies. Anyhow, the higher standard deviation shows that the application of social coping strategies varied among participants.

Variable	Ν	Min	Max	Mean	SD
Well-being	46	1.71 (0)	5.50 (6)	3.68	.93
Psychological Well-being	46	1.67 (0)	6 (6)	3.99	1.04
Emotional Well-being	46	1 (0)	6 (6)	4.02	1.11
Social Well-being	46	1 (0)	4.6 (5)	3.10	.973
Perceived Social Support	46	12 (12)	84 (84)	69.91	15.18
Social Coping Strategies	46	9 (9)	42 (45)	29.93	6.81

Table 3

Descriptives of Well-being, Perceived Social Support, and Social Coping Strategy scores

3.1.3 Correlational Analysis. In Table 4, the correlations between variables and all potential covariates are displayed. The correlational analysis revealed that the main variable well-being shows a significant negative correlation with the patient being a sibling (r = -.392). This means that participants who's relative admitted to the ICU was their sibling showed lower well-being. Moreover, perceived social support showed a positive correlation with the duration time (r = .333) and a negative correlation with the patient being the child (r = -.311). Consequently, the variables of patient being a sibling, duration time, and patient being a child are included as covariates in the further analysis. Additionally, significant correlations were found between the main variables. Well-being was found to have a significant positive correlation with social coping strategies (r = .711). Finally, all other correlations found which were not related to the main variables were not included as covariates in the following analysis.

Correlati	ion Ma	trix betwe	een main vo	ariables ar	ıd all pote	ntial covar	riates			
Variables	Ν	1	2	3	4	5	6	7	8	9
1. Time passed	46	-								
2. Well-being	46	.02	-							
3. Perceived	46	.223	.362*	-						
Social Support										
4. Social Coping	46	.217	.241	.711**	-					
5. Stay Duration	46	.178	.165	.333*	.109	-				
6. Patient is child	46	.045	050	311*	172	277	-			
7. Patient is parent	46	.040	.055	.084	.091	167	112	-		
8. Patient is	46	.003	.258	.231	.172	.190	179	442**	-	
grandparent										
9. Patient is	46	.045	392**	051	245	-167	056	139	222	-
sibling										

Note. Pearson Correlation was calculated to examine the association between the variables. ** p < .01. * p < .05. N = 46.

3.2 Main Findings

Table 4

3.2.1 Association of time and well-being. Firstly, the association of time and psychological, emotional, social well-being, and total well-being was examined through an ANOVA. Results showed, that the time passed since hospital discharge was not a significant predictor of psychological well-being [$\beta = .063$, t(46) = .418, p = .678], emotional well-being [$\beta = -.017$, t(46) = -.114, p = .910], social well-being [$\beta = -.015$, t(46) = -.098, p = .923], and total well-being [$\beta = .020$, t(46) = .135, p = .894]. These insignificant associations indicate that, unlike expected, increasing time passed since hospital discharge is not associated with increased well-being. Despite the non-significant results, Figure 2 displays the association of time and total well-being.

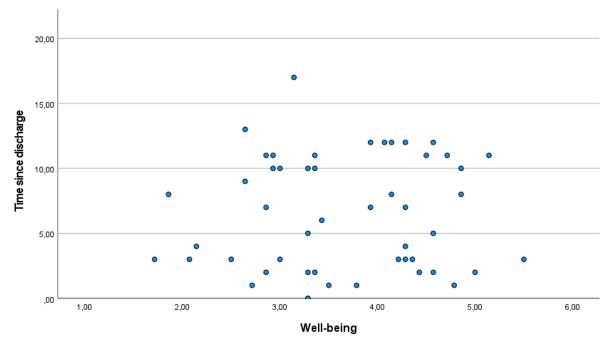


Figure 2. Association of time since discharge and total well-being.

3.2.2 Association of perceived social support and well-being. Secondly, the association of perceived social support and well-being was assessed by an ANOVA and revealed a weak significant positive association [$\beta = .324$, t(46) = 2.335, p = .024] as displayed in *Figure 2*. These results indicate that the greater the perceived social support, the higher the experienced well-being. Therefore, the second hypothesis can be confirmed. Additionally, the association between perceived social support and the well-being subscales of psychological, emotional, and social well-being were examined. The psychological well-being subscale indicated a weak positive significant association [$\beta = .433$, t(46) = 3.183, p = .003] whereas the emotional well-being subscale [$\beta = .243$, t(46) = 1.665, p = .103] and the social well-being subscale [$\beta = .247$, t(46) = 1.689, p = .098] indicated insignificant results. Hence, only the psychological well-being in specific is affected by perceived social support. Furthermore, the covariates were examined. The covariate of the relative in the ICU being a sibling was found to have a negative significant association with well-being [$\beta = .382$, t(46) = -2.923, p = .005], indicating that the well-being is decreased when the relative in the ICU is a sibling. Further, the

covariates duration in hospital [β = .116, t(46) = .838, p = .406] and relative in the ICU being a child [β = .063, t(46) = .459, p = .649] did not show a significant association with well-being. Overall, a total R-squared of .29 was found indicating a weak explained variance of well-being [F(4,41) = 4.184, p = .006, R^2 = .29, $R^2_{adjusted}$ = .221]. The outcomes of the analysis can be seen in Table 5.

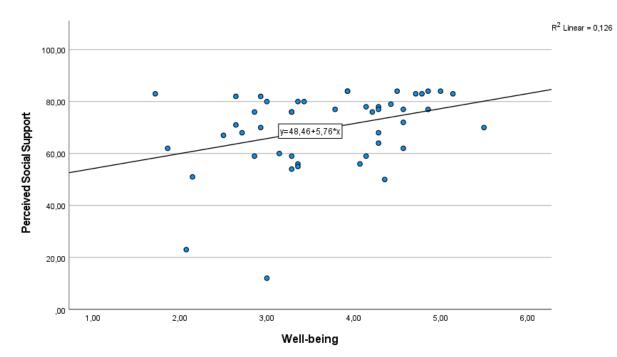


Figure 2. The association between perceived social support and well-being.

Table 5

Parameter Estimates of ANOVA between perceived social support and well-being

β	Std. Error	t	Sig.
2.064	.654	3.198	.003
.019	.009	2.165	.036
.119	.119	1.002	.322
.295	.640	.462	.647
-1.485	.503	-2.951	.005
	2.064 .019 .119 .295	2.064 .654 .019 .009 .119 .119 .295 .640	2.064 .654 3.198 .019 .009 2.165 .119 .119 1.002 .295 .640 .462

3.2.3 Moderation of social coping. Furthermore, the moderation of social coping in the relationship of perceived social support and well-being was assessed through an ANOVA with interaction effect. The outcomes of the moderation analysis showed that social coping was not a significant moderator [β = -.252, *t*(46) = -.831, *p* = .411] and, therefore, surprisingly does not strengthen the relationship of perceived social support and well-being.

4. Discussion

The current research showed that perceived social support was found to be a significant predictor of well-being whereas social coping strategies were not found to be a significant moderator. In addition, time since discharge was also not found to be a significant predictor of social, psychological, emotional, and total well-being.

4.1 Main Findings

First, the analysis indicated no significant association found between months passed since discharge and well-being. Unlike expected, this shows that the social, psychological, emotional, and total well-being does not increase over time after hospital discharge, therefore, the first hypothesis is rejected. One possible explanation for this non-significant association might be situational factors after hospital discharge. Quite frequently, ICU patients are still in need of care after hospital discharge. The data of the current study revealed that 39.1% of the participant's relatives in the ICU still required and received care from either the participant him/herself, the family or a formal caregiver. Therefore, the relatives might still worry about the health state of the patient or experience psychological burden due to care which affects the well-being.

Otis-Green and Juarez (2012) conducted a study on the impact of a cancer diagnosis and the implications this has on the social well-being of the family caregivers. According to them, the burden of caregiving, defined as the distress which caregivers experience as a result of providing care, is found to be contributing to poorer social well-being. Moreover, the study of Im, Belle, Schulz, Mendelsohn, and Chelluri (2004) investigated the caregiver burden, caregiver depressive symptomatology, and caregiver limitations in activities of patients 2 months after prolonged mechanical ventilation in an ICU. It was found that the risk of developing clinical depression among caregivers was 33.95%, indicating poor psychological well-being. As can be seen, the situational factor of continuous care after discharge may negatively affect the well-being and, therefore, inhibit the relatives to recover from the negative live event in the months after hospital discharge.

Furthermore, in the current study 34.8% of the participant's relatives in the ICU died during their ICU stay. The study of Liu, Forbat, and Anderson (2019), examined the impact of a major life event, such as the death of a close friend, on the physical, psychological and social well-being. It was found that the death of a close friend had significant adverse effects on the psychological well-being such as poorer mental health and social functioning occurring up to four years after the death. Therefore, one can conclude that possibly the death of the participant's relative might have also affected the inability to recover from the negative life event and the well-being to increase. In conclusion, situation factors such as the continuous care or death of the participant's hospitalized relative could possibly account for the non-significant association between time passed since discharge and well-being.

Second, the analysis revealed a weak significant positive association between perceived social support and well-being. This indicates that the presence of perceived social support is beneficial to the well-being of ICU patient's young aged family members, therefore, confirming the second hypothesis. This finding is in line with the available research on the association between perceived social support and well-being. As an example, Chu, Saucier, and Hafner (2010) showed perceived social support to have a positive influence on the well-being of children and adolescents. Furthermore, perceived social support was found to have a significant positive association only on the psychological well-being subscale. However, this finding is supported by the available research. For instance, the study of Winefield, Winefiled, and

Tiggemann (1992) indicated social support being an explaining factor for the measures of psychological well-being in the presence of stress. Moreover, the research of Schotanus-Dijkstra, et. Al (2015) demonstrated social support to be connected with higher subjective and psychological well-being. Yet, perceived social support was not found to be significantly associated with the emotional and social well-being subscale. This could be explained by how the MHC-SF scale defined and, therefore, measured these constructs. Social well-being as such was defined in terms of social contribution, social actualization, or social integration (Keyes, 2009). Further, emotional well-being was conceptualized in terms of life satisfaction, happiness in life, and balance between positive and negative affect (Keyes, 2002). Thus, the insignificant findings can be explained by the way of conceptualizing the well-being subscales which focus on facets of well-being other than the psychological/mental state.

Furthermore, it is noteworthy to add that the current study was able to highlight the association between perceived social support and well-being during a negative life event whereas the other mentioned studies examined this association in a regular life setting. Additionally, the flourishing model of Keyes (2002) does not cover which factors may influence flourishing in negative life situations. Therefore, the found association is able to extend the flourishing model by indicating that factors, such as perceived social support, are able to also enhance flourishing in negative life situations. Thus, it enhances the overall understanding of flourishing. As the current study was able to highlight the association being consistent in difficult as well as non-negative life situations, this association seems to be applicable to a wide array of situations.

Lastly, the analysis revealed no significant moderation of social coping strategies in the association of perceived social support and well-being, therefore, the third hypothesis is rejected. A possible explanation for the insignificant results is that a social coping strategy doesn't function as a moderator in the association of perceived social support and well-being but as a mediator. Therefore, social support and social coping strategies don't interact but social

coping strategies mediate the association between perceived social support and well-being. Furthermore, when paying closer attention to the differentiation between social support and social coping, it becomes apparent that social support serves as a necessary resource and basis to apply social coping strategies (Nakano, 1991). Hence, it is more likely that the presence of social support is needed so that social coping strategies can follow and be applied rather than an interaction of the two.

Kim, Yeob Han, Shaw, McTavish, and Gustafson (2010) noted that researchers have used different approaches in investigating the relationship between social support and social coping strategies. While some have studied an interaction effect, others have suggested that social coping strategies serve as a mediator. Because of a lack of consistency in explaining the relationship of social support, social coping strategies and well-being, the study of Kim, Yeob Han, Shaw, McTavish, and Gustafson (2010) aimed at clarifying the given association. This was done by adding social coping strategies as a moderator and a mediator in the association of perceived social support and well-being and examining which of the two is more suitable. Hence, it was found that the mediation model was more applicable than the moderation model. Consequently, the insignificant results of this study can be explained by the fact that social coping strategies function as a mediator in the association of perceived social support and wellbeing, not as a moderator.

4.2 Strengths and Limitations

One may first note multiple strengths that increase the importance of the current study. The current study investigated the well-being of ICU patient's young aged family members. As previously noted, the great majority of research focuses on different age groups (van Sleeuwen, van de Laar, Geense, van den Boogaard, & Zegers, 2020; Im, Belle, Schulz, Mendelsohn, & Chelluri, 2004) whereas the current study focused on young adults aged 18-29. As young adults face different life challenges than older adults the results of this study were able to broaden the research on well-being having added research with a new target group. Moreover, the current

study was able to add an innovative new perspective to the field as it applied a new more positive psychological perspective with flourishing in the ICU setting. Instead of investigating the factors that cause mental illness, the focus of this study was to examine how well-being in negative life situations can be enhanced. In addition, the current study combined the two fields of health psychology and positive clinical psychology as the topics of perceived social support and coping strategies complemented each other, hence, widening the scope of this study. Overall, the study was able to prove as a pioneer of new approaches, such as an unresearched target group, new perspectives, and multiple fields were applied.

Besides the strengths of this study, there are a number of limitations that must be considered. Due to the short amount of time given for the data collection and the very specific target group, only a very limited and normally insufficient number of participants were found for this study. While 129 participants were found for this study, only 46 could be included due to not fulfilling the inclusion criteria such as having a relative in the ICU or not finishing the questionnaire. Hence, with such a small number of participants one needs to be careful to draw inferences as it can't be said with certainty that the sample in the current study is an adequate representative for the general population. Furthermore, the current study was based on a crosssectional study design and the found associations must not be confused with causal effects. Therefore, one should be cautious of interpreting the causality given the cross-sectional data. Nevertheless, the given results can serve as a basis for future research in this field.

4.3 Future research

As a first suggestion for future research, one could take a closer look at the situational factors that might influence the well-being after hospital discharge. Unlike expected, the well-being did not increase over time after discharge which might be connected to further care after hospital discharge or even death in the ICU. Investigating further to what extent these and also other situational factors, such as care after hospitalization or severity of the medical condition, might influence the well-being after hospital discharge could be of great interest. Like this, one can

increase the knowledge on which factors influence the well-being of ICU patient's family members. Furthermore, a second suggestion could be examining the previously suggested mediation of social coping skills in the association of perceived social support and well-being. As the investigated moderation of social coping skills did not prove to be significant, discovering whether social coping skills function as a mediator can enhance the understanding of how well-being can best be positively influenced in negative life situations.

4.4 Practical implications and conclusion

The current research found a significant association between perceived social support and wellbeing and was able to widen the knowledge on which factors affect the well-being of ICU patient's family members after hospital discharge. Through this newly gained knowledge, one can develop and provide better care for ICU patient's family members after hospital discharge to support them in this difficult life situation. This could be in the form of interventions which aim at supporting the family members' well-being after hospital discharge or through informing the individuals how to deal with the difficult situation and enhance their well-being. Therefore, showing support and developing care interventions can then help to increase their well-being, recover more quickly and overall function better. In addition, this study was able to contribute to a growing body of research in the field of well-being. While many studies have investigated the cause of mental illness, the focus of this study was how well-being can be supported, especially in difficult and negative life situations. For this, the current study was able to stress a greater positive focus in times of negativity.

References

- Bal, S., Crombez, G., Van Oost, P., & Debourdeaudhuij, I. (2003). The role of social support in well-being and coping with self-reported stressful events in adolescents. *Child abuse* & neglect, 27(12), 1377-1395. Doi: https://doi.org/10.1016/j.chiabu.2003.06.002
- Bandura, A. (1998). Health promotion from the perspective of social cognitive theory.Psychologyandhealth,13(4),623-649.https://www.uky.edu/~eushe2/Bandura/Bandura1998PH.pdf
- Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. Journal of personality and social psychology, 51(6), 1173. doi:10.1037/0022-3514.51.6.1173
- Beesley, S. J., Hopkins, R. O., Holt-Lunstad, J., Wilson, E. L., Butler, J., Kuttler, K. G., ... & Hirshberg, E. L. (2018). Acute physiologic stress and subsequent anxiety among family members of ICU patients. *Critical care medicine*, 46(2), 229. doi: 10.1097/CCM.0000000002835
- Bonnie, R. J., Stroud, C. E., & Breiner, H. E. (2014). *Investing in the health and well-being of young adults*. National Academies Press.
- Cameron, J. I., Herridge, M. S., Tansey, C. M., McAndrews, M. P., & Cheung, A. M. (2006).
 Well-being in informal caregivers of survivors of acute respiratory distress syndrome. *Critical care medicine*, *34*(1), 81-86.
 doi: 10.1097/01.CCM.0000190428.71765.31
- Cicognani, E. (2011). Coping strategies with minor stressors in adolescence: Relationships with social support, self-efficacy, and psychological well-being. *Journal of Applied social psychology*, *41*(3), 559-578. Doi: https://doi.org/10.1111/j.1559-1816.2011.00726.x
- Chu, P. S., Saucier, D. A., & Hafner, E. (2010). Meta-Analysis of the Relationships Between Social Support and Well-Being in Children and Adolescents. *Journal of Social and Clinical Psychology*, 29(6), 624–645. doi:10.1521/jscp.2010.29.6.624
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357. Retrieved from: http://www.lchc.ucsd.edu/MCA/Mail/xmcamail.2012_11.dir/pdfYukILvXsL0.pdf
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2 ed.). Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, *59*, 676-684. Retrieved from: https://psycnet.apa.org/buy/2004-20395-002
- Demirtepe-Saygılı, D., & Bozo, Ö. (2011). Perceived social support as a moderator of the

relationship between caregiver well-being indicators and psychological symptoms. *Journal of Health Psychology*, *16*(7), 1091-1100. Doi: https://doi.org/10.1177/1359105311399486

- Diener, E., Lucas, R. E., & Scollon, C. N. (2009). Beyond the hedonic treadmill: Revising the adaptation theory of well-being. In *The science of well-being* (pp. 103-118). Springer, Dordrecht. Retrieved from: https://link.springer.com/chapter/10.1007/978-90-481-2350-6_5
- Garrouste-Orgeas, M., Flahault, C., Fasse, L., Ruckly, S., Amdjar-Badidi, N., Argaud, L., ... & Timsit, J. F. (2017). The ICU-Diary study: prospective, multicenter comparative study of the impact of an ICU diary on the wellbeing of patients and families in French ICUs. *Trials*, *18*(1), 1-11. Retrieved from: https://link.springer.com/article/10.1186/s13063-017-2283-y
- Griffin, K. W., Friend, R., Kaell, A. T., & Bennett, R. S. (2001). Distress and disease status among patients with rheumatoid arthritis: Roles of coping styles and perceived responses from support providers. Annals of Behavioral Medicine, 23(2), 133-138. Doi: https://doi.org/10.1207/S15324796ABM2302_8
- Im, K., Belle, S. H., Schulz, R., Mendelsohn, A. B. & Chelluri, L. (2004). Prevalence and
- Outcomes of Caregiving After Prolonged (<48 Hours) Mechanical Ventilation in the ICU*. Chest, 125(2), 597-606. Doi: https://doi.org/10.1378/chest.125.2.597
- Jezierska, N. (2014). Psychological reactions in family members of patients hospitalised in intensive care units. *Anaesthesiology intensive therapy*, 46(1), 42-45. Retrieved from: https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.919.5567&rep=rep1&type =pdf
- Kafetsios, K., & Sideridis, G. D. (2006). Attachment, social support and well-being in young and older adults. *Journal of health psychology*, *11*(6), 863-875. Doi: https://doi.org/10.1177/1359105306069084
- Keyes, C. L. M. (1998). Social well-being. Social psychology quarterly, 121-140. Doi: https://doi.org/10.2307/2787065
- Keyes, C. L. M. (2002). The Mental Health Continuum: From Languishing toFlourishing in Life. *Journal of Health and Social Behaviour*, 43(2), 207-222. retreived from:

https://www.jstor.org/stable/pdf/3090197.pdf?casa_token=5Dl93KN3E8IAAAAA:yF OWZu4BXc1tS0UmglZh__agGWwUxZpRRR9sHniycI2qELx7y3wdzM0JYgE8pWa KZ8tkoCNDyfXc2g29eQnvTCr2Uahz2FiGbNV0H0GSP9SdbMUG3ZE

- Keyes, C. L. M. (2009). Atlanta: Brief description of the mental health continuum short form (MHC-SF). Available: http://www.sociology.emory.edu/ckeyes/. [On–line, retrieved 24 March, 2021].
- Keyes, C. L. (2010). Flourishing. *the Corsini encyclopedia of psychology*, 1-1. Doi: https://doi.org/10.1002/9780470479216.corpsy0363
- Kim, J., Jeong Yeob Han, Shaw, B., McTavish, F., & Gustafson, D. (2010). The Roles of Social Support and Coping Strategies in Predicting Breast Cancer Patients' Emotional Wellbeing. *Journal of Health Psychology*, 15(4), 543–552. doi:10.1177/1359105309355338
- Lamers, S. M., Westerhof, G. J., Bohlmeijer, E. T., ten Klooster, P. M., & Keyes, C. L. (2011). Evaluating the psychometric properties of the mental health continuum-short form (MHC-SF). *Journal of clinical psychology*, 67(1), 99-110. Doi: https://doi.org/10.1002/jclp.20741
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York: Springer.
- Liu, W. M., Forbat, L., & Anderson, K. (2019). Death of a close friend: Short and long-term impacts on physical, psychological and social well-being. *PloS one, 14*(4), e0214838.
 Doi: https://doi.org/10.1371/journal.pone.0214838
- Malkoç, A., & Yalçın, İ. (2015). Relationships among resilience, social support, coping, and psychological well-being among university students. *Turkish Psychological Counseling and Guidance Journal*, 5(43). Retrieved from: http://turkpdrdergisi.com/index.php/pdr/article/view/4
- Nakano, K. (1991). The role of coping strategies on psychological and physical well-being. *Japanese Psychological Research*, 33(4), 160-167. Retrieved from: https://www.jstage.jst.go.jp/article/psycholres1954/33/4/33_4_160/_pdf
- Otis-Green, S., & Juarez, G. (2012). Enhancing the social well-being of family caregivers. *Seminars in oncology nursing*, 28(4), 246-255. Doi: https://doi.org/10.1016/j.soncn.2012.09.007
- Prizmić-Larsen, Z., Kaliterna-Lipovčan, L., Larsen, R., Brkljačić, T., & Brajša-Žganec, A. (2019). The role of flourishing in relationship between positive and negative life events and affective well-being. *Applied Research in Quality of Life*, 1-19. Retrieved from: https://link.springer.com/content/pdf/10.1007/s11482-019-09743-y.pdf
- Rijksoverheid (2021, February 28). Intensive Care Admissions by day. Retrieved from: https://coronadashboard.government.nl/landelijk/intensive-care-opnames
- Schotanus-Dijkstra, M., Pieterse, M. E., Drossaert, C. H. C., Westerjof, G. J., de Graaf, R., ten

Have, M., Walburg, J. A., & Bohlmeijer, E. T. (2015). What Factors are Associated with Flourishing? Results from a Large Representative National Sample. *Journal of Happiness Studies*, *17*, 1351-1370. Doi: https://doi.org/10.1007/s10902-015-9647-3

- Stroud, C., Walker, L. R., Davis, M., & Irwin Jr, C. E. (2015). Investing in the health and wellbeing of young adults. *Journal of Adolescent Health*, 56(2), 127-129. Doi: https://doi.org/10.1016/j.jadohealth.2014.11.012
- Tobin, D. L., Holroyd, K. A., & Reynolds, R. V. C. (1984). Coping strategies inventory. CSI Manual. Retrieved from: https://d1wqtxts1xzle7.cloudfront.net/50592066/Manual-Coping-Strategies-Inventory-9.pdf
- van Sleeuwen, D., van de Laar, F., Geense, W., van den Boogaard, M., & Zegers, M. (2020).
 Health problems among family caregivers of former intensive care unit (ICU) patients:
 an interview study. BJGP open, 4(4). Retrieved from: https://bjgpopen.org/content/bjgpoa/4/4/bjgpopen20X101061.full.pdf
- Winefield, H. R., Winefield, A. H., & Tiggemann, M. (1992). Social Support and Psychological Well-Being in Young Adults: The Multi-Dimensional Support Scale. *Journal of Personality Assessment*, 58(1), 198–210. doi:10.1207/s15327752jpa5801_17
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The multidimensional scale of perceived social support. Journal of personality assessment, 52(1), 30-41. Retrieved from: https://www.researchgate.net/profile/Gregory-Zimet/publication/240290845_The_Multidimensional_Scale_of_Perceived_Social_Su pport/links/54cf9e250cf298d65664ac8d/The-Multidimensional-Scale-of-Perceived-Social-Support.pdf

Appendix A

Mental Health Continuum - Short Form (MHC-SF)

Adult MHC-SF (ages 18 or older)

Please answer the following questions are about how you have been feeling during the past month. Place a check mark in the box that best represents how often you have experienced or felt the following:

During the past month, how often did you feel	NEVER	ONCE OR TWICE	ABOUT ONCE A WEEK	ABOUT 2 OR 3 TIMES A WEEK	ALMOST EVERY DAY	EVERY DAY
1. happy						
2. interested in life						
3. satisfied with life						
 that you had something important to contribute to society 						
 that you belonged to a community (like a social group, or your neighborhood) 						
SEE BELOW 6. that our society is a good place, or is becoming a better place, for all people						
7. that people are basically good						
8. that the way our society works makes sense to you						
9. that you liked most parts of your personality						
10. good at managing the responsibilities of your daily life						
 that you had warm and trusting relationships with others 						
12. that you had experiences that challenged you to grow and become a better person						
13. confident to think or express your own ideas and opinions						
14. that your life has a sense of direction or meaning to it						

Note: The original wording for item 6 was "that our society is becoming a better place for people like you." This item does not work in all cultural contexts. However, when validating the MHC-SF, test both versions of item 6 to see which one works best in your context.

Appendix B

Multidimensional Scale of Perceived Social Support (MSPSS)

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).

Appendix C

	Not at all	A little	Somewhat	Much	Very much
I accepted sympathy and understanding from someone.	0	0	0	0	0
I found somebody who was a good listener.	0	0	0	0	0
I talked to someone about how I was feeling.	0	0	0	0	0
I just spent more time with people I liked.	0	0	0	0	0
I talked to someone that I was very close to.	0	0	0	0	0
I let my friends help out.	0	0	0	\circ	0
I asked a friend or relative I respect for advice.	0	0	0	0	0
I spent some time with my friends.	0	0	0	0	0
I talked to someone who was in a similar situation.	0	0	0	0	0

Social Support Subscale of Coping Strategies Inventory (CSI)

Appendix D

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)

I have read and understood the conditions and terms. Hereby, I agree with them.

- O Yes, I agree.
- No, I do not agree.

Appendix E

Demographics

Gender

First, we would kindly ask you to answer a few questions concerning your demographics.

Gender

- 🔿 Male
- O Female
- Non-binary / third gender

Prefer not to say

Age

Nationality

- O Dutch
- O German

Other

Do you have a relative who was admitted to the ICU in the past 12 months?

YesNo

How many months have passed since your relative was discharged from the ICU?

What relationship do you have with the relative?

The relative is my...

🔿 Child

- Parent
- Grandparent
- Sibling
- Aunt/Uncle
- O Cousin
- Other

How long was the ICU stay of your relative? (in days)

< 2
2-7
8-14
15-31
> 31

How many times was your relative admitted to the ICU?

Is your relative still in need of receiving care from relatives/ former caregivers?

○ Yes, I/my family provides the care

O Yes, a formal caregiver provides the care

 \bigcirc My relative died in the ICU

O No