Stress Symptoms, Social Support and Health-Related Quality of Life in Young Adults Family Members of Former ICU Patients

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Abstract

Background: The admission of patients in the ICU is growing more than ever. Research has shown that family members of patients who have been in the ICU also experience a decrease in their health-related quality of life as the patients themselves. In this, stress constitutes one of the most influential psychological symptoms among adults. Yet, less is known about young adults', aged 18 to 29, health-related quality of life due to the increased stress. Furthermore, studies have shown that as time passes by, the health-related quality of life increases, although it still remains lower than before. Additionally, research has shown that young adults are less satisfied with their perceived social support. Therefore, this thesis aimed to investigate the association of perceived stress symptoms on the health-related quality of life of young adults of family members who had been discharged from the ICU in the past 18 months, while taking into account the perceived social support and the time the relative has been discharged from the ICU.

Method: A cross sectional self-report study design was employed with 49 young adults (M = 22.45, SD = 2.5 years, 69.4 % female). The stress symptoms, perceived social support, time after discharge of the relative and the health-related quality of life of the participants were measured.

Results: The mean score on the stress scale (M = 14.53, SD = 4.47) as well as on the health-related quality of life scale (M = 70.02, SD = 14.88) came out to be moderate. The mean score for the social support scale came out to be high (M = 70.02, SD = 4.37). The results demonstrated a positive association between stress and the HRQoL [$\beta = .31$, $t\,(47) = 2.72$, $p = .01$] for the target group. This relationship was not moderated by perceived social support or time after discharge.

Conclusion: The findings for young adults with a relative in the ICU have shown to be contradictory with the literature findings for older aged adults above the age of 30. Factors contributing to these results, as for example the age and relationship of the patient are discussed. Suggestions for future research to explore causal relationships are given.

Keywords: stress, health-related quality of life, social support, time after discharge, young adults, ICU

Stress Symptoms and Health-Related Quality of Life in Younger Aged Family Members of Former ICU Patients

The admission in the intensive care unit (ICU) is a demanding experience for patients and their involved family members (McAdam, Fontaine, White, Dracup, & Puntillo, 2012). Patients often need family care after hospital discharge. Thus, it is expected that family members, mainly the spouses and older aged children of the patient, change their daily routine, work life and step back from their own needs to be able to take care of the patient after admission (Alfheim et al., 2019; van Sleeuwen, van de Laar, Geense, van den Boogaard, & Zegers, 2020). Consequently, several mental health issues are commonly recognized among older aged family members such as high stress symptoms, depression, and anxiety due to the changed life conditions (Davidson, Jones, & Bienvenu, 2012; Lemiale et al., 2010; Petrinec & Martin, 2018).

Mental health issues do have an immense impact on the health-related quality of life of the family members (Hickman Jr & Douglas, 2010; Rawal, Yadav, & Kumar, 2017; Wintermann, Weidner, Strauß, Rosendahl, & Petrowski, 2016). Research has already shown that post-traumatic stress following ICU admission is negatively associated with the health-related quality of life of the spouse and older aged adults above 30 (Alfheim et al., 2019; van Sleeuwen et al., 2020). Yet, less is still unknown about other relatives of the patients as the young adults who are generally not considered as the primary caregivers. Investigations established that age can be a factor influencing the health-related quality of life as well as the perceived amount of stress (Alfheim et al., 2019; Kafetsios & Sideridis, 2006; Lemiale et al., 2010). This suggests that due to the ICU admission of a relative, young adults may experience higher stress symptoms and a lower health-related quality of life.

Next to age, perceived social support has also been shown to influence the perceived stress symptoms as well as the health-related quality of life among young adults. Among older aged adults the study from van Sleeuwen et al., (2020) has shown that a strong social network helped family members to cope with the changed conditions. Additionally, the research from Sandler and Barrera Jr (1980) have presented that only the satisfaction of the perceived social support serves as a stress-buffer, reducing the amount of perceived stress. However, the research from Kafetsios and Sideridis (2006) have also illustrated that younger aged adults are less satisfied with their perceived social support than older aged adults. This brings young adults more at risk for high perceived stress symptoms and a decreased level of health-related quality of life.

Thus, little is known about the association of stress symptoms after ICU admission on the health-related quality of life of younger adult family members between 18-29 years old specifically. Furthermore, studies have shown young adults are less satisfied with their perceived social support. Therefore, it is important to investigate the moderation of the perceived social support on the association between stress and the HRQoL among young adults. Also, depending on the time the patient has been discharged from the ICU, the association can be different, hence time needs to be considered as a moderating variable as well. Those results could indicate whether younger aged family members with a relative in the ICU need to be more recognized and supported. We do not know enough about them although research demonstrates that they can be more at risk of developing serious mental health symptoms affecting their health-related quality of life (Schmidt & Azoulay, 2012). This is a psychological concept which focuses on the health part of quality of life which can change during disease and its treatment (Chaboyer & Elliott, 2000; Lemiale et al., 2010).

Health-Related Quality of Life

The Health-related quality of life (HRQoL) displays the everyday functioning in life of an individual which can be changed due to a disease, in this case due to an illness of a relative (Lemiale et al., 2010; Wu, Cheng, Zou, Duan, & Campbell, 2021). As the concept focuses on the general functioning in life, the main dimensions within the concept are the psychological, physical and social satisfaction (Lemiale et al., 2010; Wu et al., 2021). More precisely, the psychological dimension describes the emotional state of an individual by focusing on the emotional stability and functioning due to psychological symptoms such as the stress level (Azoulay, Kentish-Barnes, & Pochard, 2008; Yiengprugsawan, Kelly, & Tawatsupa, 2014). The physical dimension is about the physical health and physical health problems (Azoulay et al., 2008). The social satisfaction dimension refers to the social well-being and functioning of an individual in social interactions (Azoulay et al., 2008). Thus, the quality of life depending on health is assessed with this concept.

Past research showed that an ICU admission diminished the HRQoL for patients and family members, whereby their mental health seemed to be affected the most (Hofhuis et al., 2008; Lemiale et al., 2010; Petrinec & Martin, 2018). Thus, the psychological symptoms family members experience could negatively influence their HRQoL. Interestingly, although the psychological HRQoL has increased after the patients have been discharged from the ICU, it stayed lower than before the admission (Hofhuis et al., 2008). However, this was not investigated for young adults specifically. Thus, it is important to investigate if this

association is still positive for this specific target group. It is also important to assess the time patients have been discharged from the ICU.

As already mentioned, investigations demonstrated that the psychological HRQoL is affected the most due to the ICU admission of a relative (Lemiale et al., 2010; Petrinec & Martin, 2018; Petrinec & Daly, 2016; Wintermann et al., 2016). A symptom influencing the psychological dimension of HRQoL can be the perceived stress symptoms.

Stress Symptoms

Stress has been reported to be the most prevalent and persistent symptom among family members, even after the discharge of the patient from the ICU (Alfheim et al., 2019; Azoulay et al., 2005; Petrinec, Mazanec, Burant, Hoffer, & Daly, 2015; Wintermann et al., 2016). The qualitative study of van Sleeuwen et al. (2020) among adults showed that family members reported high amounts of restlessness, reduced physical contact, impaired freedom and physical complaints themselves which all influence their perceived stress. Schmidt and Azoulay (2012) have underlined that among the family members 56.8% show significant symptoms of an acute stress disorder after the patient has been discharged. Furthermore, 33% of the family members have shown high levels of stress symptoms regarding post traumatic stress disorder 90 days after the ICU admission (Schmidt & Azoulay, 2012). Nevertheless, research is lacking in considering the age of the family members. Young adults for example may have a different relationship to the patient and with that a different role in the informal care than older adults.

Alfheim et al. (2019) have shown in their research that age is also an important factor influencing the perceived amount of stress and consequently the HRQoL. Studies have investigated that younger adults are more at risk in developing post-traumatic stress symptoms and developing serious mental health symptoms after the discharge of the patient (Alfheim et al., 2019; Kafetsios & Sideridis, 2006; Lemiale et al., 2010). Thus, it is important to investigate the association between stress and the HRQoL in younger aged adults. Furthermore, multiple studies have shown factors being influential on the perceived stress and on the perceived HRQoL. One notable factor is high perceived social support (Bland et al., 2012; van Sleeuwen et al., 2020).

Social Support

Early theories have already stressed the relation of sufficient social support and a strong social network and HRQoL of an individual (Achat et al., 1998; Bandura, 1998; Sandler & Barrera Jr, 1980). The social cognitive theory of Bandura (1998) emphasizes the importance of social support as a factor to decrease the effects of stress, depression and

physical dysfunction (Bandura, 1998). Furthermore, the research from Sandler and Barrera (1980) found out that social support matters specifically, if it is perceived as satisfying. Contrary, the amount of social support is less functional while coping with perceived stress (Sandler & Barrera Jr, 1980). This is defined as the stress-buffer for perceived stress (Cohen & Wills, 1985; Sandler & Barrera Jr, 1980). Thus, it could be assumed that the HRQoL could be more diminished due to the higher perceived dissatisfaction with social support of young adults.

Furthermore, the research from van Sleeuwen et al. (2020) has shown that high perceived social support is an important factor for relatives of ICU patients. The relatives who felt sufficient social support were consequently more satisfied with other factors as well (van Sleeuwen et al., 2020). Thus, social support can help to enhance health-promoting behaviour as well (Bandura, 1998). Interestingly, the research from Kafetsios and Sideridis (2006) has compared the perceived social support of younger and older adults. Their results show that family members who are younger are less satisfied with the social support and consequently experience a decreased level of well-being than older adults. Thus, it could be assumed that it is additionally more difficult for young adults to deal with the increased experience of stress symptoms after a relative has been admitted to the ICU.

This Study

It is noticeable that previous research has not directly targeted young adults with a relative in the ICU. This is important to investigate, as past studies have demonstrated that the experience of having a family member in the ICU could influence younger aged adults more intensively. Furthermore, factors such as the perceived social support have been shown to have a greater influence on young adults. Additionally, research has not yet focused on the relevance of time after the patient has been discharged from the ICU for young adults. Thus, the aim of this study is to investigate the association of stress symptoms with the HRQoL of family members aged 18-29 of ICU patients while considering their perceived social support. Furthermore, the association of time after discharge with the HRQoL for this specific target group will be investigated. The following hypotheses were derived from the current state of research:

1. **Hypothesis:** The time after the discharge of the relative from the ICU is positively associated with the HRQoL in family members between the ages of 18 to 29.
2. **Hypothesis**: Perceived stress symptoms following ICU discharge of a relative is negatively associated with the HRQOL in individuals between the ages of 18 to 29.

3. **Hypothesis:** Perceived social support moderates the association between perceived stress and HRQOL in individuals between the ages of 18 to 29.

Method

This study was part of a larger research with the title "Survey on Health: A comparison between young adults with relatives as former ICU patients", which was conducted cooperatively by six bachelor students. Even though the research topics on psychological symptoms after the discharge of a relative in the ICU were the same, every student had their own independent research focus. Thus, different symptoms were measured together in one survey. Next to measuring stress symptoms (as predictor variables), perceived support (as moderator variable), time after discharge (as predictor variable) and HRQoL (as outcome variable), the additional items included depression and anxiety symptoms, mental health, the social self-efficacy, the social support experienced from the ICU staff members, eating behaviour, sleep, coping styles in stressful situations and physical activity.

Study Design

This study had a cross-sectional survey design conducted in April 2021. The online survey was conducted in English with the online programme Qualtrics. Participants were either gathered through the SONA system at the University of Twente, through the researcher's private social media accounts (Facebook, Instagram) or they were asked privately by the researchers. Thus, the used sampling methods were convenient sampling and snowball sampling. The participation in this study was voluntarily. The procedure was approved by the Ethical Committee of Social and Behavioural Sciences from the University of Twente (ethical approval number: 210471).

Participants

The final sample consisted of 49 participants (M = 22.45, SD = 2.5 years, 69.4 % female). Out of 129 participants, 80 participants needed to be excluded (see drop-out analysis). In order to be eligible to participate in the study, inclusion criteria were (a) being aged between 18 and 29, (b) being fluent in English, (c) having a relative that was administered to the ICU in the past 18 months (d) finishing the survey. Table 1 shows the sample characterics of the participants.

Table 1

Sample Characteristics (N=49)

Characteristics	Frequency	Mean	SD	Minimum	Maximum
Age		22.45	2.50	18	29
Time since the release (in months)	49 (100%)	6.65	4.43	0	17
Gender	49 (100%)				
Female	34 (69.4%)				
Male	13 (26.5%)				
Non-binary/third gender	1 (2.0%)				
Prefer not to say	1 (2.0%)				
Nationality	49 (100%)				
Dutch	2 (4.1%)				
German	41 (83.7%)				
Other	6 (12.2%)				
Relationship with the patient	49 (100%)				
Own Child	2 (4.1%)				
Parent	11 (22.4%)				
Grandparent	19 (38.8%)				
Sibling	3 (6.1%)				
Aunt/ Uncle	7 (14.3%)				
Cousin	5 (10.2%)				
Other	2 (4.1%)				
Patient receiving care after discharge	49 (100%)				
Yes, provided by family	16 (32.7%)				
Yes, provided by a formal caregiver	2 (4.1%)				
The relative has passed away	19 (38.8%)				
No	12 (24.5%)				

Materials

The cooperatively conducted online survey consisted of eleven different questionnaires in total. For this thesis, three questionnaires were used. Namely, the used scales were the Perceived Stress Scale (PSS), the Multidimensional Scale for Perceived Social Support (MSPSS) and the Short Form-8 Health Survey (SF-8). Potential participants needed to be in charge of a notebook or a smartphone with an internet connection. Next to social media accounts, the platform Qualtrics was used as a source to give answers to the questionnaires, which is a platform to conduct online surveys. Furthermore, the SONA system at the University of Twente was used as a source to gather the participants. Additionally, IBM SPSS Statistics 26 was used to analyse the data.

Measures

Perceived Stress Scale (PSS). The self-report 10-item PSS instrument was used to measure the perceived stress in the last four weeks (Cohen, Kamarck, & Mermelstein, 1994; Lee, 2012). Participants had to rate the statements on a 5-point scale ranging from 0 to 4 (0= *Never* to 4= *Very Often).* An example of a statement is *"In the last month, how often have you been upset because of something that happens unexpectedly?".* In past research the PSS has shown a high internal consistency and reliability with $\alpha = .70$ (Lee, 2012). Similar to previous research, the reliability of the PSS in this thesis has shown to be high as well with $\alpha = .81$ (see Appendix A).

Multidimensional Scale for Perceived Social Support (MSPSS). The MSPSS Scale is a 12-item scale with a 3-factor model measuring the perceived social support of the participants in three dimensions: family (Item 3,4,8 and 11), friends (Item 6,7,9 and 12) and significant others (Item 1,2,5 and 10) (Zimet, Dahlem, Zimet, & Farley, 2010). The statements are rated on a 7-point likert scale (1= *very strongly disagree* to 7= *very strongly agree).* An example statement is *"There is a special person around when I am in need"*. The MSPSS showed a high internal reliability of $\alpha = .93$ in previous studies (Canty-Mitchell & Zimet, 2000). In this study the internal consistency has also appeared to be excellent with $\alpha = .96$ (see Appendix B).

Short Form-8 Health Survey (SF-8). The self-report 8-item SF-8 scale aims to measure the HRQoL with a 2-factor model, namely the psychological and physical health in the past month (Lang et al., 2018; Yiengprugsawan et al., 2014). Item 1 and 4 are ranked on a 6-point likert scale whereas item 2,3,5,6,7 and 8 are ranked on a 5-point likert scale (see Appendix C). Each item measured a different dimension on the psychological and physical model, namely the (a) ***Overall health*** (1 = *very poor* to 6 = *excellent*), (b) ***Physical***

functioning capacity (1= *could not do physical activities*, to 5= *not at all*), (c) ***Physical pain*** (1= *could not do daily work* to 5= *none at all*), (d) ***Bodily pain*** (1=*very severe to* 6= none), (e) ***Vitality*** (1= *none* to 5= *very much*), (f) ***Social functioning*** (1= *not do social activities* to 5= *not at all*), (g) ***Mental health or emotional problems*** (1= extremely to 5= *not at all*) and (h) ***Emotional dimension*** (1 = *could not do daily activities* to 5= *not at all*) (Yiengprugsawan et al., 2014). An example statement for the general health dimension is *"Overall, how would you rate your health during the past 4 weeks?"*. In past research the reliability was mostly high with α = .88 (Turner-Bowker, Bayliss, Ware, & Kosinski, 2003).). In this research however, the reliability came out to be low with α = .49. Thus, item 1 and item 5, asking about the overall health and vitality, were deleted. This resulted in a high reliability of α = .81 (see exploration of the data).

Procedure

Participants, who were gathered through convenience sampling through the researcher, were asked personally whether they could fill in the questionnaire. A short description about the survey and the link to the questionnaire were sent to them via social media platforms (Whatsapp, Email, Facebook, Instagram). The remaining participants were reached via the SONA system from the University of Twente where an extensive description of the research as well as the inclusion criteria were given, before the participants filled out the questionnaire. The gathered participants were asked to fill out the online questionnaire independently at their chosen time and place on the online platform Qualtrics. There was no time limit given for completing the questionnaire.

First, they had to agree on the informed consent form, where participants were informed about the study, the anonymised use of their data and that they are eligible to withdraw from the study at any time without giving a reason (see Appendix D). After that, the participants were asked to answer some demographic questions (see Appendix E). For this thesis, three different questionnaires followed, which were ordered by PSS (see Appendix A), MSPSS (see Appendix B) and the SF-8 (see Appendix C). The survey ended with a short debriefing about the research topic. Filling in the questionnaire took about 15 to 20 minutes.

Data analyses

Statistical analyses were carried out via IBM SPSS Statistics 26. Firstly, the data from Qualtrics were transformed into an SPSS file and adapted by detecting and removing incorrect and incomplete data from the dataset. Participants who did not fulfill the inclusion criteria were excluded as well. After that, the raw data was prepared for the following

analyses by recoding and relabeling the instruments for the scoring procedure, if needed. Afterwards, descriptive statistics were estimated to gather the demographics of the participants. The reliability of the used scales was calculated via Cronbach's alpha (Cohen, 1988).

For the analysis of the results categories with cut off scores were needed. For the PSS the scores between 0 and 13 were considered to be low, scores between 14 and 26 were considered to be moderate and scores between 27 and 40 were considered to be high in perceived stress (Cohen et al., 1994). For the MSPSS scores between 1 to 28 are considered as low support, scores of 29 to 56 as moderate support and scores of 57 to 84 are considered as high support. For the SF-8 scores from 1 to 14 are used to define low HRQoL, scores between 15 and 28 for moderate HRQoL and scores between 29 and 42 for high HRQoL.

Thirdly, inferential statistics were estimated. For this, factor analyses with varimax rotation were run first on the used scales, to explore underlying latent constructs. This helped to reveal constructs that may exist and to see how much is explained by the items measured. After that, the data were tested for normality using a Shapiro-Wilk test. Then, a Pearson correlation analysis with all relevant main and sub variables was run. With this, the first hypothesis, respectively the association of time after discharge with the HRQoL was tested. It was investigated whether the moderation is positive and significant. Correlations between 0 and 0.30 were considered as weak, correlations between 0.40 and 0.59 were considered as moderate and values above 0.6 were considered strong (Cohen, 1988).

For the second hypothesis, namely the association between perceived stress (independent variable) and HRQoL (dependent variable) a linear regression analysis was conducted. To test the third hypothesis, a multiple regression analysis with an interaction effect was run to assess the moderation of social support (moderator) in the association between perceived stress (independent variable) and HRQoL (dependent variable). Before conducting the regression analysis the independent and moderating variables were centralized in order to reduce multicollinearity. The analyses were all conducted applying a 95% confidence interval (Baron & Kenny, 1986).

Results

Drop-out analysis

In total 129 individuals participated in the study whereas 80 participants had to be excluded. Within the excluded participants 48 have either given their consent or their demographics but did not start with the questionnaires. 14 participants did not finish the survey, whereby three have stopped after the stress scale, three after the depression and

anxiety scale, three after the mental health scale and five after the social support scale. Fourteen participants did not have any relatives in the ICU. For three participants the time after discharge was more than 18 months ago. Finally, one participant was deleted, as the same answer was always given which was suspicious.

Due to the high drop-out rate it was also analyzed whether there was a significant difference in the mean-score of the stress scale and the HRQoL scale between the ones who have dropped-out and the ones who have finished the questionnaire. Though, no significant difference could be found concerning their stress level (t (46) = .43, p = .29) nor the HRQoL (t (46) = -.15, p = .95).

Exploration of the data

After recoding and relabeling the relevant scales and assessing their reliability, factor analyses were run. For the PSS the Kaiser-Meyer-Olkin measure of sampling adequacy was .80 and the Bartlett's test of sphericity was significant ($\chi 2$ (45) = 145.75, p < .001). Two initial Eigenvalues explain 41 % and 13 % of the variance, whereas the first factor explained the negatively stated items and the second factor was based on the positively stated items. Although a single factor solution was aimed at, the items of the second factor (item 4,5,7 and 8) had still been incorporated into further analysis due to content validity. The factor loadings for the two factors ranked from .89 to .78.

In the MSPSS the Kaiser-Meyer-Olkin measure of sampling adequacy was .86 and Bartlett's test of sphericity was significant ($\chi 2$ (66) = 744.94, p < .001). Thus, a factor analysis had been applied. The analysis has shown that two Eigenvalues were explaining 68% and 14% of the variance. The rotated matrix has displayed that the first factors were explaining family and friends and that the second factor is based on significant others (Zimet, Dahlem, Zimet, & Farley, 2010). No changes have been conducted. The factor loadings ranked from .69 to .93.

The SF-8 was feasible for a factor analysis as the Kaiser-Meyer-Olkin measure of sampling adequacy was .76 and Bartlett's test of sphericity was significant ($\chi 2$ (28) = 139.26, p < .001). The analysis has shown two factors explaining 47% and 15% of the variance, which resulted to be the two subscales, namely the PCS and MCS. However, item 1 and item 5, namely the dimension about the overall health and vitality, had no strong correlation with either of the 2 factors. This was expected, as studies have already shown the inconsistency of these two items with the two factors (Lang et al., 2018). Nevertheless, they were deleted for further analysis, resulting in a higher reliability with α = .81. The factors loading ranked from .90 to .65.

Lastly, the data was tested for normality. The Shapiro-Wilk test showed that the SF-8 ($W(49) = .96$, $p = .06$) and PSS ($W(49) = .98$, $p = .72$) were distributed normally. However, the MSPSS scale was not normally distributed ($W(49) = .80$, $p < .001$). Thus, a reflection and a log transformation was applied for the negatively skewed scale which led to a somewhat normal distribution with the Shapiro-Wilk test being marginally significant ($W(49) = .95$, $p = .04$). Thus, for further analysis parametric statistics were applied. Therefore, Pearson correlational analyses were conducted. In addition, the mean scores of male and female participants were tested via a t-test analysis due to the high majority of female participants. This has shown that the HRQoL of the female participants were higher than for the males ($t(45) = -2.31$, $p = .02$).

Descriptive Statistics

The descriptives of the scales can be found in Table 2. The PSS scale reveals that on average the participants show moderate symptoms of stress. More precisely, from 49 participants 32.7% were categorized in low perceived stress whereas 67.3% were considered moderate in their perceived stress. Thus, even the maximal amount of scored points is moderate. The low standard deviation as well as the item mean suggest low variations in the perceived stress.

The results from the MSPSS have shown that the majority of people are experiencing a high level of support. The subscale family and friends are similar in their mean score, whereas the support of a significant other is slightly higher.

The SF-8 reveals that the participants had on average a moderate HRQoL. The physical component and the mental component were also quite moderate in their mean scores. Nevertheless, the mental component is slightly higher on average. Thus the participants showed more satisfaction with their mental well-being than with their physical state.

Table 2

Descriptives of Perceived Stress Scale, Multidimensional Scale Perceived Social Support and Short Form-8 Health Survey (N=49)

	Minimum	Maximum	Mean	SD
Stress (PSS)	5 (0)	24 (40)	14.53	4.37
Multidimensional Scale Perceived Social Support (MSPSS)	12 (12)	84 (84)	70.02	14.88
Family Support	4 (4)	28 (28)	22.94	5.61
Friends Support	4 (4)	28 (28)	22.94	5.64
Significant other Support	4 (4)	28 (28)	24.14	5.79
Short-Form-8 Health Survey (SF-8)	14 (8)	32 (42)	21.55	3.99
Physical Health	6 (4)	16 (22)	10.18	2.11
Mental Health	6 (4)	17 (20)	11.37	2.60

Note. SD = standard deviation

Correlational analysis

In Table 3 the correlation matrix of the relevant main variable and sub-variable is visible. The Pearson correlational analysis has revealed that time after discharge is not correlated with the HRQoL (r (49) = -.04, p = .77). Thus the first hypothesis needs to be rejected. Furthermore, HRQoL and stress (r (49) = .57, p < .001) are positively correlated, which means that the higher the stress level of the participant the higher their HRQoL. Similarly applied to stress and the mental HRQoL (r (49) = .37, p = .01) and the physical HRQoL (r (49) = .62, p < .001). Moreover, neither HRQoL and social support (r (49) = -.01, p = .96) nor the mental HRQoL and social support (r (49) = -.10, p = .50) are correlated with each other. Interestingly, gender is positively correlated with HRQoL (r (49) = .38, p < .01) and its mental (r (49) = .36, p = .01) and physical dimension (r (49) = .30, p = .03) in particular. Males therefore reported a lower HRQoL than females.

Table 3

Correlation Matrix between the main and sub-variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.
1. Gender	1														
2. Age	.20	1													
3. Relationship	.00	.05	1												
4 Time	.15	.13	-.06	1											
5. Parent	.19	-.12	-.53**	.01	1										
6. Grandparent	-.30*	-.06	-.27	-.01	-.43**	1									
7. Own Child	.07	.13	-.34*	.04	-.11	-.16	1								
8. HRQoL	.38**	.20	.05	-.04	.12	-.17	-.06	1							
9. Mental_HRQoL	.36*	.24	.09	.07	.04	-.13	-.03	.86**	1						
10. Physical_HRQoL	.30*	.10	-.02	-.15	.16	-.16	-.06	.86**	.48**	1					
11. Stress	.14	-.03	.08	-.11	.08	-.16	-.02	.57**	.37**	.62**	1				
12. Support	.04	-.15	.20	-.23	-.04	-.23	-.00	-.01	-.10	.09	.06	1			
13. Family Support	-.15	.17	-.12	.10	.17	.22	-.24	.03	.14	-.10	-.01	-.78**	1		
14. Friends Support	-.10	.18	-.07	.21	.03	.22	-.25	-.09	.03	-.19	-.23	-.74**	.73**	1	
15. Significant other Support	.20	.18	.02	.26	.03	.14	-.29*	.14	.19	.05	.02	-.69**	.58**	.60**	1

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

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

Regression analysis

The association between stress and HRQoL (H2).

The results of the regression analyses are presented in Table 4. The linear regression analysis revealed that the association between perceived stress was significantly positively associated with the HRQoL in individuals between the ages of 18 to 29 [$\beta = .59$, $t\ (47) = 4.99$, $p = .01$]. Thus, the higher the perceived stress the higher the HRQoL. As a negative association was expected, H1 needs to be rejected.

The association between stress and the HRQoL with the moderator social support (H3).

The multiple regression analysis has revealed that perceived social support as the moderating variable has no significant influence on the association of perceived stress and HRQol on individuals aged 18 to 29 [$\beta = -.17$, $t\ (47) = -1.41$, $p = .17$]. Thus, the hypothesis needs to be rejected.

Table 4

Regression analysis results of Perceived Stress and Social Support on HRQoL

	Unstandardized Coefficients	Standard Coefficients		
Model	SE	β	t	Sig.
Constant	.09	-	26.83	.01
PSS	.03	.59	4.99	.01*
Moderation of MSPSS	.04	-.17	-1.41	.17

Note. SE= standard error; PSS= Perceived Stress Scale; MSPSS = Multidimensional Scale for Social Support; R-squared = .36; *Correlation is significant at the .01 level

Discussion

The aim of this study was to investigate the association between perceived stress and the HRQoL of relatives, aged between 18 and 29, from former ICU patients. Additionally, it was examined whether perceived social support moderated this relationship and if the time after the patient had been discharged from the ICU had a positive association. All three hypotheses needed to be rejected, although, contrary to the expectations, a positive association was found between perceived stress and HRQoL.

Main Findings

Contrary to the findings in this thesis, several reports have shown that post traumatic stress is negatively associated with the HRQoL of former ICU patients' family members above the age of 30 (Alfheim et al., 2019; van Sleeuwen et al., 2020; Hickman Jr & Douglas, 2010; Larzelere & Jones, 2008; Rawal, Yadav, & Kumar, 2017; Wintermann et al., 2016). Thus, it is interesting and somewhat surprising that this research has shown the opposite results in family members aged between 18 to 29 which is, that the perceived stress is positively related to the HRQoL. Some explanation can be given for these contra-intuitive findings.

First, high perceived stress was expected due to studies showing a higher dissatisfaction concerning the social support among young adults (Kafetsios & Sideridis, 2006). Nevertheless, the results of this study showed a moderate level of stress and HRQoL. This can be explained in regard to the age and current life position of the participants. The study from Welle and Graf (2011) has shown that self-control influences how individuals perceive and cope with stress and that self-control is moderately high among university students. Thus, this could indicate that at the moment of gathering the data, a manageable amount of stress was perceived, resulting in a moderate level of stress and HRQoL.

Furthermore, still being reminded of the special age group this study has focused on, the majority of participants had their grandparents in the ICU. Multiple studies have shown that the relationship to the patient matters in terms of the severity of the psychological symptoms (Alfheim et al., 2019; Wintermann et al., 2016). Therefore, it can be assumed that the differences in the closeness of the relationship between the young adults and the patient has influenced the contrary outcomes of this study. In previous studies, the relationship may have been more intense as it involved one's parents or spouse.

Next to the tightness of the relationship there are other factors influencing the results due to the greater age of the grandparents. Studies have shown for example, that the family members were more satisfied with their ICU experience, when the patients had passed away in the ICU compared to families with patients who have survived (Wall, Curtis, Cooke, & Engelberg, 2007). In their research the patients who have died in the ICU were also older and had a shorter stay inside the ICU (Wall et al., 2007). Thus, as a majority of the participants who had their grandparents in the ICU could have been more satisfied with the experience resulting in a better HRQoL and a moderate level of stress.

Noticeable in this study is also the high majority of female participants. The study of Izutsu, Tsutsumi, Asukai, Kurita, and Kawamura (2004) has shown that there are gender

differences regarding the relationship of a traumatic event and the alteration of the stress response. In general, they have shown that the stress response got worse due to a traumatic event and that participants were more prone to stress afterwards. However, there was no alteration in the stress response for the female participants. Additionally, the results have shown that the female participants had a higher HRQoL than the male participants. This is in line with the research from Kynoch, Chang, Coyer and McArdle (2019) as they have also demonstrated that the female participants in their studies were more satisfied with their needs being met, thus relating to a higher level of HRQoL. Hence, as the majority of this sample were female, it can be suspected that the participants dealt better with the stress and therefore, had a better HRQoL.

Nevertheless, concerning the contrary outcome for the perceived stress symptoms there are also differences from past research. This study was focussing on current perceived stress and not post-traumatic stress symptoms, which is more related to the event itself. As an example, in past studies it was common to use the Impact of Event Scale, where the questions have focused on the post traumatic stress symptoms related to the experience primarily. In this study however, the focus was on general perceived stress in the past four weeks (Anderson, Arnold, Angus, & Bryce, 2008; Alfheim et al., 2019; McAdam et al., 2012). Thus, the way stress was measured was different compared to past research as it was held more general. As the participants were not primarily reminded of the experience, the outcome could have been different compared to other studies.

It was initially expected that the participants show a high amount of perceived stress. An interesting finding in this study is therefore, that the sample was relatively moderate in perceived stress with a moderate standard deviation. Furthermore, the participants were very high in perceived social support. As the results have shown that there was no significant correlation between the high perceived social support and the moderate perceived stress, no association can be derived from it. Nonetheless, the high perceived social support could have influenced the perceived stress indirectly. As the participants were gathered over convenience sampling and the university, it can be assumed that most of them were university students. With this in mind, research by Bland et al. (2012) has found in their analysis of coping factors among students that high perceived social support functions as a protective factor for higher stress tolerance. This is also in line with the social cognitive theory from Bandura (1998), as it has been shown that social support is important for human health. Additionally, it could be assumed that the social support dealt as a stress buffer, as the participants showed high satisfaction of social support (Cohen & Wills, 1985; Sandler & Barrera Jr, 1980).

Lastly, it is worth noting that the thesis was conducted during the corona pandemic. For most of the german participants the lockdown restricted the social interaction and social gatherings to a minimal amount. Several researchers are already presenting the negative impact of the COVID-19 pandemic due to the current uncertainty on stress, anxiety and depression (Alzahrani et al., 2021; Nobari et al., 2021). Although the amount of stress has shown to be moderate in this sample, other psychological states such as anxiety and depression are unknown (Kynoch et al., 2019). Thus, there could be a probability that unknown psychological factors have influenced the moderate HRQoL. Moreover, most of the participants in this study were female. Studies have shown that in social isolations, such as in the current pandemic, a decrease in the mental and physical well-being is most prevalent for the female sex (Achat et al., 1998). Thus, it could be assumed that, as the sample were mostly female, the current pandemic has influenced the findings regarding HRQoL.

Strengths and Limitations

A strength of this study was the target group. This group consisted of relatives, aged 18 to 29, who had family members in the ICU in the past 18 month. As this thesis was also conducted cooperatively with 5 other students, convenience sampling was more successful. Furthermore, the thesis was written at the University of Twente which made it easier to assess students in the same age range. Nevertheless, it is worth mentioning that because a very specific sample was needed, the recruitment of the participants became more difficult at some point in time and resulted in a lower sample size than aimed for. Additionally, due to convenience sampling it is dominated by students mainly.

Furthermore, this study is one of the first ones studying the association between social support, stress and the HRQoL in younger aged individuals. Although past research has focused on the association between stress and the HRQoL, there has not been a study looking into the moderating association of social support and for this target group specifically as a lot has focused on the spouses of the patients (Van Sleeuwen et al., 2020).

This thesis, however, has some limitations in terms of the psychometric properties of the SF-8 scale. The reliability of the scale, measuring the HRQoL, was rather low at the beginning ($\alpha = .49$). Two items, namely item 1 and item 5 which were asking about the general health and the vitality of a person, were not correlating well with the two determined factors and had to be deleted. Thus, content validity is lacking in this research as each of the items were measuring different dimensions relevant for the whole concept of HRQoL and the included subscales. Furthermore, the SF-8 has already been the short form of the SF-36 and was used to keep the large survey as user friendly and short as possible. Thus, the concept of

HRQoL could not be measured representatively, meaning that this has prompted the unexpected results.

Furthermore, the concepts used in this thesis, namely stress, social support and HRQoL, were relatively complex concepts. Although validated questionnaires were used, the evaluation of these concepts via a self-report questionnaire is influenced by many subjective factors not accessible by the researcher. Thus, self-report scales can result to be less reliable because people are influenced by their present mood and skewed memories which can bias the results (Montag, Duke, & Markowetz, 2016). Next to the SF-8 scale, the World Health Organization Quality of Life Instrument and the SF-36 was also assessed. As this was a cooperatively made survey however, the shortest one was chosen with the best interest of the participants and to prevent drop-out rate. Nevertheless, one single question per dimension is not necessarily representative for the overall HRQoL.

Coming back to the cooperative study-design the questionnaire was rather long which has possibly been a disadvantage regarding the high dropout rate. Another limitation in this study is the gender distribution as the majority of participants were female. Several studies have shown significant gender differences in the perceived stress and HRQoL outcome due to a stressful life event in general (Achat et al., 1998; Izutsu et al., 2004). Thus, a representation of the whole population cannot be expected.

Next to that, this thesis was written during the COVID-19 pandemic. During this uncommon situation, many social contacts have been canceled to prevent the spread of COVID-19. This also has an effect on family meetings and visits in hospital facilities as in the ICU. The data was gathered in April 2021 and the pandemic has started in march 2020 which means that all the participants had their relatives in the ICU during the covid-19 pandemic. Another source of uncertainty due to the pandemic is the social support scale, as social life and physical social interaction is currently restricted. This uncommon social situation may have driven the participants to respond differently than in a non-pandemic situation where social interactions are not restricted.

Lastly, this study was conducted via a cross-sectional study design. Thus, it did not allow any causal relationship. Specifically with these contrary results, the reasons behind the positive association would have been useful to make reliable conclusions for this specific target group.

Future Research

The current study looked into the association of psychologically perceived stress on the overall HRQoL, while also focusing on the moderation of this association through

perceived social support and time. This was explored with a quantitative study design. However, there is also abundant room for further progress in determining the causal relationship of this unique, unexpected positive association between stress and the HRQoL as well as interesting stress results in this target group. Thus, to explore these findings even more, future research could focus on a mixed method design with a qualitative follow up. Thus, HRQoL, perceived stress and perceived social support can be assessed via self-report questionnaires. Additionally, the participants can be interviewed about their current perceived stress symptoms and their satisfaction with social support to gather causalisations between the association. This would also allow more reliable causal results between the ICU stay of the relative, the discharge, and the time afterwards.

Furthermore, for the scope of this study a cooperational survey was developed whereby a short survey was used to measure the HRQoL. As this survey showed some problems concerning the reliability, it could be of an advantage to use a more extensive questionnaire measuring the HRQoL as the SF-36 (Ware Jr, 2000). Hence, the different dimensions such as the psychological, social and physical dimensions can be assessed more extensively and with a higher reliability and content validity, thus a better representation of the concept can be expected.

Perceived social support came out to be very high among the sample although previous research found that young adults are less satisfied with their perceived support than older aged adults. Thus it would be interesting to investigate whether this is different with this specific target group and if the experience enhances the perceived social support.

It should be noted that the majority of this sample were female and University students. Thus, to get a better representation of the specific population it will be of an advantage to get a bigger sample with an equal number of male and female participants.

Another factor, which could have influenced this study is the fact that it was conducted during a pandemic situation with restricted possibilities for physical activities and social interactions. Thus, a repetitional study without the given circumstances due to the pandemic could show differentiated results.

Conclusion

The present study investigated the association of time after discharge and stress on the health-related quality of life including perceived social support as a moderating variable in young adults aged 18 to 29. In contrast to the expectations, the results demonstrated that perceived stress was positively associated with the HRQoL of young adults having a relative in the ICU in the past 18 month. Thus, according to the results, the higher the perceived stress

the higher the HRQoL. The time after the discharge on the other hand has shown no correlation with the HRQoL of the relative. Furthermore, perceived social support has not shown any significant moderating association. For future research it is advised to conduct a mixed method design with a short interview and a qualitative follow up.

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Appendix A

Perceived Stress Scale (PSS)

PERCEIVED STRESS SCALE

The questions in this scale ask you about your feelings and thoughts during the last month. **In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.**

Name _____ Date _____

Age _____ Gender (*Circle*): **M F** Other _____

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3. In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the last month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the last month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Appendix B

Multidimensional Scale of Perceived Social Support

	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
There is a special person who is around when I am in need (1)	o	o	o	o	o	o	o
There is a special person with whom I can share joys and sorrows (2)	o	o	o	o	o	o	o
My family really tries to help me (3)	o	o	o	o	o	o	o

I get the emotional help & support I need from my family (4)	o	o	o	o	o	o	o
I have a special person who is a real source of comfort to me (5)	o	o	o	o	o	o	o
My friends really try to help me (6)	o	o	o	o	o	o	o
I can count on my friends when things go wrong (7)	o	o	o	o	o	o	o
I can talk about my problems	o	o	o	o	o	o	o

with my family (8)							
I have friends with whom I can share my joys and sorrows (9)	o	o	o	o	o	o	o
There is a special person in my life who cares about my feelings (10)	o	o	o	o	o	o	o
My family is willing to help me make decisions (11)	o	o	o	o	o	o	o

I can talk about my problems with my friends (12)	o	o	o	o	o	o	o

Appendix C

Short Form-8 Health Survey (SF-8)

SF 8 Questionnaire

1. Overall, how would you rate your health during the past 4 weeks?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Very poor ☐

2. During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?

Not at all ☐ Very little ☐ Somewhat ☐ Quite a lot ☐ Could not do physical activities ☐

3. During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?

None at all ☐ A little bit ☐ Some ☐ Quite a lot ☐ Could not do daily work ☐

4. How much bodily pain have you had during the past 4 weeks?

None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very Severe ☐

5. During the past 4 weeks, how much energy did you have?

Very much ☐ Quite a lot ☐ Some ☐ A little ☐ None ☐

6. During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?

Not at all ☐ Very little ☐ Somewhat ☐ Quite a lot ☐ Could not do social activities ☐

7. During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?

Not at all ☐ Slightly ☐ Moderately ☐ Quite a lot ☐ Extremely ☐

8. During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?

Not at all ☐ Very little ☐ Somewhat ☐ Quite a lot ☐ Could not do daily activities ☐

Appendix D

Informed Consent Form

Consent Form for Participation in a Study
University of Twente

Survey on Mental 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 and Joana Grahl. 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) health-related concepts in relation to an ICU-admission of a relative in the past 12 months (i.e., symptoms of anxiety, depressive feelings, stress and quality of life), completed with questions about social support, flourishing and self-efficacy. Filling in the questionnaire will take about 10-15 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 treatmen**t 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) or 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

- I have read and understood the conditions and terms. Hereby, I agree with them.
    - Yes, I do agree.
    - No, I do not agree.

Appendix E

Demographic Questionnaire

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

Gender

- o Male
- o Female
- o Non-binary / third gender
- o Prefer not to say

Age

Nationality

- o Dutch
- o German
- o Other

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

- o Yes
- o No

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...

- o Child
- o Parent
- o Grandparent
- o Sibling
- o Aunt/Uncle
- o Cousin
- o Other