

**Physical, mental and cognitive functioning in daily life of former Dutch Intensive Care patients, who perceive a decline in quality of life, one year after ICU admission.**

A qualitative study

<b>Name</b>	M. de Graaf
<b>Student number</b>	5948606
<b>Version</b>	Concept Master thesis
<b>Date</b>	16-06-2020
<b>Programme</b>	Master Clinical Health Sciences, Nursing Science, Utrecht University
<b>Lecturer</b>	J.F.M. van Dijk, PhD.
<b>Internship</b>	Radboud UMC, Nijmegen
<b>Supervisor</b>	M. van den Boogaard, RN., PhD.
<b>Journal</b>	Intensive and Critical Care Nursing
<b>Reporting criteria</b>	COREQ
<b>Reference style</b>	Vancouver
<b>Word count</b>	3799 words
<b>Abstract</b>	291 words
<b>Samenvatting</b>	300 words

## **Abstract**

**Background** As a result of improving treatments in intensive care medicine, more patients survive severe illness. Long-term consequences of an Intensive Care (ICU) admission, referred to as Post Intensive Care Syndrome (PICS), can have serious impact on a patient's health and quality of life (QoL). Research into the experiences of Dutch ICU survivors with functioning in daily life, perceived health and QoL is scarce.

**Aim** To gain insight into the experienced quality of life and the physical, mental and cognitive functioning in daily life of former intensive care patients, who perceive a decline in quality of life, one year after ICU-admission.

**Method** Fifteen ICU survivors, who indicated a decline in the PCS and MCS of the SF-36 questionnaire were interviewed in a generic qualitative study. Semi-structured interviews were conducted face to face and by (video)call. The interview-guide was based on the PROMIS framework, exploring physical, mental (including cognitive-) and social health. QoL was added as a domain, because of its importance to ICU-patients.

**Results** Theoretical analysis was applied and identified 25 themes within the 4 PROMIS domains. Major issues were cognitive problems with impaired memory and concentration, physical limitations in mobility, decreased stamina, fatigue and changed priorities and relationships. Impairments had impact on the performance of work and hobbies. Aspects such as acceptance and being independent increased QoL. Most patients found their QoL sufficient.

**Conclusion** Most participants indicated impairments in one or more domains of physical, mental (cognitive-) and social health. Although Health Related QoL was decreased, most participants rated their QoL as sufficient.

**Recommendation** Having knowledge of the outcomes in health domains and QoL of ICU-patients is relevant for caregivers. It can help them to improve healthcare and policy decisions.

**Keywords** quality of life, experiences, PICS, critical care, PROMIS

## **Samenvatting**

**Achtergrond** Als gevolg van verbeterde behandelingen in de intensive care-geneeskunde overleven meer patiënten ernstige ziekten. De langetermijneffecten van een opname op de Intensive Care (ICU), ook wel Post-Intensive-Care-Syndroom genoemd, kunnen ernstige gevolgen hebben voor de gezondheid en kwaliteit van leven (QoL) van een patiënt.

Onderzoek naar de beleving van Nederlandse ICU patiënten over het functioneren in het dagelijks leven, hun ervaren gezondheid en kwaliteit van leven is schaars.

**Doel** Inzicht verwerven in de beleving van kwaliteit van leven en het fysieke, mentale en cognitieve functioneren in het dagelijks leven van voormalige ICU patiënten, die een jaar na opname op de ICU een achteruitgang van de kwaliteit van leven ervaren.

**Methode** Vijftien ex-ICU patiënten, die een afname in de PCS en MCS van de SF-36-vragenlijst aangaven, werden geïnterviewd in een generiek kwalitatief onderzoek. Semigestructureerde interviews werden face-to-face en per (beeld) telefoon afgenomen. De interviewgids was gebaseerd op het PROMIS-raamwerk en onderzocht de fysieke, mentale (inclusief cognitieve-) en sociale gezondheid. QoL is als domein toegevoegd vanwege het belang ervan voor ICU-patiënten.

**Resultaten** Theoretische analyse werd toegepast, 25 thema's werden gevonden binnen de 4 PROMIS-domeinen. Grote problemen waren cognitieve beperkingen met verminderd geheugen en concentratie, fysieke beperkingen in mobiliteit, verminderd uithoudingsvermogen, vermoeidheid en veranderde prioriteiten en relaties. Beperkingen hadden invloed op het uitvoeren van werk en hobby's. Aspecten als acceptatie en onafhankelijkheid verhoogden de QoL. De meeste patiënten vonden hun QoL voldoende.

**Conclusie** Veel deelnemers gaven aan beperkingen te hebben in een of meer van de fysieke, mentale of sociale gezondheidsdomeinen. Hoewel de gemeten QoL was verlaagd, beoordeelden de meeste patiënten hun QoL als voldoende.

**Aanbeveling** Kennis hebben van de uitkomsten in gezondheidsdomeinen en QoL van ICU-patiënten is relevant voor zorgverleners. Het kan hen helpen om beslissingen over gezondheidszorg en beleid te verbeteren.

**Sleutelwoorden** kwaliteit van leven, beleving, PICS, intensive care, PROMIS

## Introduction

As a result of improved knowledge and treatments, the number of patients surviving critical illness increases over the years<sup>1</sup>. More research has been done the last two decades on long-term consequences of surviving critical illness. It becomes increasingly clear how much impact severe illness, in combination with admission to an intensive care unit (ICU)<sup>2</sup>, has on physical, mental and cognitive functioning of patients. These consequences and their impact in daily life are referred to as Post-Intensive Care Syndrome (PICS). PICS<sup>3</sup> is defined as “new or worsening impairments in the physical, cognitive, and/or mental health of ICU survivors, arising and persisting after hospitalization for critical illness”. Impairment refers to the fact that deficits may improve slightly over time but in most cases remain permanent<sup>4</sup>. Frequent physical impairments are pain, fatigue, lung problems, loss of bodyweight<sup>5</sup>, problems in daily life activities<sup>2,6-8</sup> and mobility problems, often related to (ICU-acquired-) weakness<sup>9</sup>. Of former ventilated ICU-patients, 75% experiences functional decline in daily life activities and need caregiver support<sup>2,8,10</sup>. Mental health is threatened by post-traumatic stress disorder, anxiety and depression. This affects up to 50% of former ICU-patients<sup>9</sup>. Impairments of this order can persist for years. Cognitive impairment<sup>8</sup> including memory, planning, attention and executive function problems, occurs in approximately 30-80% cases<sup>9</sup>. Physical, mental and cognitive changes may also influence patient’s social-economic status and quality of life (QoL)<sup>9</sup>. Due to the high impact of PICS on patients’ health status, much previous research focused on problems patients experience after ICU-admission.

The past five years an average of 80,000<sup>11-12</sup> patients was admitted annually to Dutch ICUs. An estimated 20 to 50 percent of Dutch ICU survivors suffer from sequelae of PICS<sup>13</sup>. Knowledge about these impairments and Health Related Quality of Life (HRQoL) of Dutch survivors has been mainly generated by validated questionnaires<sup>14-18</sup>. Previous research<sup>14</sup> on 36,000 Dutch ICU-patients, showed that the HRQoL one year after ICU-admission, was lower up to 36 months after discharge, compared to the reference population.

However, little is known about how Dutch patients<sup>19</sup> experience health and QoL after ICU-admission. What challenges their functioning in daily life, how do they perceive their QoL? Their perceptions could strengthen and increase current knowledge in healthcare or nursing practice or demonstrate potential gaps. Above all, they provide a better picture of ICU survivors’ problems and needs and their appreciation of QoL.

## **Aim**

The aim of this study is to gain insight into the experienced quality of life and the physical, mental, and cognitive functioning in daily life of former ICU-patients, who perceive a decline in quality of life, one year after ICU-admission.

## **Method**

### **Study Design**

A generic qualitative study was conducted as part of the ongoing MONITOR-IC study<sup>20</sup>: a large cohort study, carried out in ICU's of six Dutch hospitals, tracking approximately 12,000 ICU-patients for five years on outcomes such as HRQoL, physical, mental and cognitive symptoms, and care and support needs. A generic qualitative design applies to investigate beliefs, opinions or experiences<sup>21</sup> and was therefore considered appropriate to explore participants perceived QoL and experienced health after critical illness and ICU treatment<sup>22</sup>.

### **Study population and domain**

The study domain concerned intensive care patients after surviving critical illness. Eligible participants were former ICU-patients, meeting the following inclusion criteria: participating in the MONITOR-IC study; age over 18 years; complete datasets of T0 (before ICU-admission), and T3 (one year after ICU-admission); a decline in the MCS and PCS score of the Short Form-36 (SF-36) survey one year after ICU-admission, compared to the pre-admission score; understanding and speaking Dutch and able to give written informed consent. Patients with whom conversation would be complicated or impossible, were excluded from participation.

### **Study sample**

Purposive sampling<sup>23</sup> was used to include patients who had been admitted to ICU between July 30 and December 30, 2018 and completed the T3 SF-36 up to five months before the start of the data extraction.

Self-reported HRQoL was determined by using the SF-36 questionnaire<sup>24-27</sup>. The scores of the SF-36 can be merged in two components: the Physical Component Score (PCS) and the Mental Component Score (MCS)<sup>28</sup>. The PCS gives an impression of patient's physical functioning, pain and general health. The MCS is an indication of patient's mental health, emotional role, vitality and social functioning. Patients who indicated the largest decline in PCS and MCS compared to pre-admission, with a score in the first three quartiles of the delta PCS (Q3<-3) and delta MCS (Q3<-2,62) were eligible.

## Data collection

To study experienced health and HRQoL, the Patient Reported Outcomes Measurement Information System (PROMIS)<sup>29-30</sup> was used to collect and analyse data. PROMIS is an internationally applied model to display research outcomes of importance to patients. It contains 3 domains: physical, mental (including cognitive functioning) and social health. With PROMIS it is possible to assess the impact of diseases on HRQoL and compare patient outcomes in research<sup>29-32</sup>.

Patient characteristics were retrieved by an experienced researcher (WG) from the database of the MONITOR-IC study.

Between February 14 and March 25, 2020, 15 interviews were conducted at a location of the patient's choice: the university hospital or the patient's residence. Due to the CoVid-19 outbreak, six interviews were conducted by video call or telephone (Table 1). To avoid influencing, interviews were performed without the presence of relatives. The interviews were conducted by a trained master student of the Master Nursing Science (MG), the first two interviews together with an experienced researcher (WG).

A semi-structured interview guide based on the PROMIS<sup>29</sup> domains, was developed by WG and MG. Topics<sup>31</sup> included physical, mental and social health, cognitive functioning, and QoL. The interview-guide was literature-based<sup>31</sup>, checked by two senior researchers (MZ and MvdB), and adjusted on outcomes of the first few interviews. All interviews were transcribed verbatim and pseudonymized before analysis.

## Data analysis

Theoretical Analysis<sup>21</sup>(ThA) was applied in a deductive way<sup>21-22,33-34</sup> to analyse the interviews. ThA uses pre-existing categories, based on literature, as a framework of research to answer the research question. The emerge of new themes and categories is possible during data analysis.

The described steps of ThA were followed as systematically as possible. Transcripts of the interviews were read to get familiar with the data. To support the analysing process, the domains of the PROMIS framework were applied as the base of the code tree. Quality of life was assigned as an additional domain because of its importance to ICU survivors<sup>25,28,35</sup>. All interviews were coded by assigning themes to the domains. The themes were refined by the allocation of subthemes, obtained from the data. To enhance the trustworthiness<sup>36</sup> of the study, three interviews were independently coded by two researchers (WG and MG). Overall, a large amount of consensus turned out: only a few codes needed discussion and recoding. The final themes were discussed in a similar way and assessed by a senior researcher (MZ). Also, a member check was performed. Due to time constraints, only three participants, who

expressed interest in the results, were invited to check a preliminary analysis of their interviews<sup>36</sup>. Before sending an invitation by email, the participants were checked for self-reported post-traumatic-stress-disorder symptoms (WG). They were asked to provide feedback on themes concerning QoL within the transcript of their interview (due to the amount of themes). This feedback was processed and corroborated researchers' interpretation of their story.

Software program Atlas.ti 8 Windows (ATLAS.ti Scientific Software Development GmbH, version 8,4, 2019)<sup>37</sup> supported the analysis of the interviews.

## **Procedures**

Participant information was sent by post along with the invitation for the interview study. Participants gave written informed consent by returning the signed answer form. They received a telephone-call to confirm their participation and to make an appointment for the interview. Additional information about participation was provided on request during this call.

Before starting an interview, again oral confirmation was asked from the participant. The executive researcher (MG) informed the participant about the study objective and emphasized the pseudonymity of participant data, the voluntariness of participation and answering questions, and the possibility to end the interview at any time.

## **Ethical issues**

This study was conducted according to the principles of the Declaration of Helsinki (version 2013)<sup>38</sup> and the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>39</sup>. The study is part of the MONITOR-IC study<sup>20</sup>, which has been approved by the research ethics committee of the Radboud University Medical Centre, CMO region Arnhem-Nijmegen (2016-2724), and is registered in the ClinicalTrials.gov database (NCT03246334).

## **Results**

### **Participants**

Of the 66 patients who reported a decline in their SF-36 PCS and MCS score, 42 eligible patients were invited for the interview study. The other participants reported a minimal decrease in MCS and PCS on the SF-36 (n=24) or had died (n=2). Fifteen patients (36%) gave written informed consent. Reasons for non-responding were not inquired.

The study sample included 13 men and 2 women, aged between 52 and 77 years.

Admission indications were medical (n=4, (26,7%)) or elective and emergency surgery (n=7, (47%), n=4, (26,7%)) (Table 1).

Interviews were audio recorded and lasted between 37 and 106 minutes, with a mean of 72 minutes.

[Table 1]

## **PROMIS**

Twenty-five themes (Table 2) were derived from the interviews and categorized within the determined four domains of the PROMIS framework. They reflected the current status of the participants.

[Table 2]

## **Physical health**

Most of the participants mentioned a decreased stamina in comparison to pre-ICU-admission and expected they would not reach their old level again. Activities like cycling, walking and going to the gym were undertaken to maintain this current level. Participants also mentioned physical limitations as a cause of not returning to the old level.

*“The stamina, I can't get that corrected, let me put it that way. I go to the gym to keep it from getting worse”. (Participant 2)*

Fatigue was a problem in performing work or tasks. To save energy, choices often had to be made in time use and (social) activities. Most participants slept well; some had a disturbed sleep pattern due to pain.

*“Now I always take a break at noon. Lie down for an hour and recover, and then I can take it on again” (Participant 14)*

*“I consciously deal with my energy. Now I have home care in the morning and stopped dressing myself, because I think these things are pointless actions. It does not bring you anything, it costs a lot of energy” (Participant 8).*

Although most participants were mobile; limitations in speed and duration of walking or cycling were mentioned. Some needed adapted transport such as a bicycle with an accessory or an adapted car. This gave them more autonomy by being less dependent on their partner. Due to mobility problems participants had to move or adapt their house.

*“From that time on I was able to cycle. The right leg made a small rotation and the other made a large rotation. I was no longer dependent on my wife because I cannot drive a car”. (Participant 11).*



Also, daily pain was mentioned. In two participants, the pain was due to concomitant diseases. Participants had to take this pain into account in their movements and activities. Pain involved wound pain, neuralgia and bone pain and affected sleep, breathing, QoL and mental health.

*"Pain sometimes makes you very grumpy, very vulnerable, especially if you are in more pain. If my wife throws a duvet over me, it already hurts. (Participant 11)*

Other physical problems were poor sight, skin problems, incontinence and joints' stiffness. These physical problems were due to comorbidities, ICU therapy, critical illness and side effects of medication.

### **Mental health**

Emotional changes ranged from emotional flattening to being more emotional, tears outbreaks, higher irritation level and petulant behavior. The participants perceived this as annoying.

*"Emotions...My entire palette of emotions has shifted anyway." (Participant 9).*

Causes of having frustration and stress were e.g. cognitive impairments in memory. Restrictions by physical impairments irritated participants.

*"You want more than just sitting at home, exercising, walking." (Participant 1)*

Anxiety over repetition of the life event was identified as a problem in two participants. One received professional help in dealing with this fear. A few participants reported they had been or felt depressed after ICU-admission. This was due to becoming more aware of what happened, additional circumstances or future prospects. Others called themselves gloomy for the same reasons. Some participants mentioned a decrease in taking initiatives.

*"Sometimes I thought, where should this go?" (Participant 6).*

Notable was a lack of empathy in resuscitated participants. They described this as "living in your own bubble". This improved by time, but one person stated he was still not interested in many things. The strong will to survive or to do ones best for the family, persevered participants to go on and achieve physical improvements. This willpower brought them to what they had accomplished.

*"I thought, damn, they can't get me under it. And I have always kept that image with me. Whatever will come, I'll get through it." (Participant 11).*

### *Cognitive functioning: memory, concentration, and information processing*

Nearly all the participants named deterioration in cognitive functioning. Having problems with short term memory (remembering names, word finding disorder), information processing and concentration were mentioned most frequent. This was experienced as a major problem; especially among the younger participants with a (former) working life. Elderly participants related memory problems also to advanced age: annoying, but manageable.

*“It is just that I don’t know it anymore, that I just can’t remember.” (Participant 10).*

Concentration disturbances such as getting lost in a conversation, had social consequences.

*“At some point I drop out in a conversation. And then I withdraw and let it happen.” (Participant 1).*

Carrying out practical matters, required more attention. Reduced load capacity affected the ability to work and learn and made it necessary to make choices in work and leisure.

Disturbed information processing affected the learning ability and the speed in (strategic) thinking and analyzing.

*“This brain damage turns off something I actually still need.” (Participant 8).*

### **Social health**

Most participants assigned a more important role to the partner after critical illness.

Participants indicated that they felt more respect and affection and were more aware of the role of the spouse. Spending more time together and feeling a closer bond was also often mentioned. Spouses had to get used to participants’ changed emotions and were more concerned about their health. Due to physical limitations of participants, some partners became caregiver or driver.

*“Now it becomes even more emphatic. You learn to appreciate it more, but also to express it more as appreciation. Because before, I was not the kind of person who often said this so consciously (Participant 6).*

Relationships were unchanged or enhanced by the impact of ICU-admission and critical illness. Children were concerned about the parent, but also participants were more concerned about the children, about picking up their own lives again.

Critical illness affected the functioning and awareness of the family relationship. The past with siblings became more important due to critical illness. In general, family was considered a support.

*“The relationship is also more intense and even deeper. It was good in itself but it has just been reinforced.” (Participant 1).*

Social life had changed for most participants. They appreciated social contacts more, but (mainly) due to fatigue had less contact than before. Also, concentration problems in conversations and spending more time with the spouse, resulted in less contact. Some participants experienced a barrier, caused by not wanting to be pitiful or a burden to others.

*“I don't like it, when I am seen as a psychiatric patient, so to speak.” (Participant 6)*

Most participants were retired. Those who worked, described a change in work activities and worked less hours or awaited partial disability as a result of cognitive and physical impairments (concentration, memory, fatigue). Work had less priority than before ICU-admission.

Sport was already mentioned as an important part of life, basically to maintain physical fitness. Fatigue and physical impairments were identified as main problems in picking up hobbies, such as running, cycling, playing tennis and doing odd jobs around the house. Most did not reach their former level. Some persons started volunteering jobs because it made them feel meaningful.

### **Quality of life**

Approximately a year after ICU-admission most participants experienced a reduced QoL compared to pre-admission, but still mentioned their QoL sufficient. Two participants experienced insufficient QoL, due to the loss of family (child, partner) and lack of future prospects. Also, comorbidities like epilepsy, COPD, diabetes and cancer affected QoL. A few participants rated their QoL as different, but unchanged. They felt more conscious of (little things in) life. Some others mentioned their QoL as “good, but not as it used to be”. Even a participant with a short life expectancy rated his QoL as good.

*“Now it's okay...there is an upward trend. I think some things will return back to normal, but it's not what I expected from my life and what it was like. Not yet.” (Participant 9)*

*“You try to optimize the quality of life within the given limitations. In concrete terms, you give meaning to things that you might otherwise find unimportant. By doing that, the quality of your life improves. If I feel that I am working on something meaningful, with a meaningful interpretation of my life, then the quality of my life will improve by leaps and bounds.” (Participant 13)*

Some participants resigned their current situation or stated to accept their life with limitations. Others were grateful that they were alive, that life was worth living. One participant considered his cognitive and physical situation unacceptable.

*“Those things just happen, and you just have to deal with it.” (Participant 7)*

*” I try to deal with it and no more than that. Acceptance is something you order from internet and is delivered at home. Then you can accept it. I did not ask for this.” (Participant 8)*

To deal with current life, coping strategies varied widely between denial, avoiding confrontations and facing the challenges. Some put their own situation into perspective. Confronting the surroundings with the “new me” helped one participant to take barriers and to continue. Some participants gave up hope on further recovery, while others were highly motivated to get the maximum out of the situation. One participant held on to his philosophy of life. Another patient stated that choosing someone to mirror yourself, helped to create perspective.

*“Man is a meaningful being, meaning is within me. So, no one else can fill that in for me. I am the person who gives meaning to my life.” (Participant 13)*

*“I've done everything for my family and loved ones, because anything you stop and where you stay passive or give up, the family gets sadder than I do. And I cannot allow that.” (Participant 8)*

Some participants perceived a changed self-image. Cognitive and physical limitations, being unable to act efficiently and effectively and wasting time in daily activities, made one participant consider himself a B-category human. Another felt a separation between body and mind and wondered who he was. Many participants lost confidence in their body, which took a while to regain. Other issues were not wanting to be pitiful, reduced self-confidence and overestimation.

After being critically ill, priorities changed for some participants. Work became far less important where the relationship with family and friends was given high priority. Also “doing nice things” was mentioned several times as another priority.

*“If I can influence it: only the nice things. And where I can't influence and I don't like it, then I quit.” (Participant 4)*

Having control and being independent was important for almost all participants. Examples of this were self-reliance in daily functioning, mobility, medication intake and rehabilitation schedules.

Limitations were a cause of loss in QoL. Participants were not able to pick up their former normal life due to stamina and age. Small examples were no more traveling with the caravan; doing less than before and being unable to exercise one's passion.

A few participants mentioned no longer having a goal in life, due to illness or circumstances. One participant dared not to set goals, because they always were too ambitious and not

meeting them felt as a failure. In line with this, participants had no major plans for the future. Some still enjoyed their work and wanted to retire in a few years. Most did not look far ahead. They indicated they were more concerned with the present because the future cannot be influenced. Nevertheless, many hoped to grow old, practice their hobbies and enjoy house and garden.

*“And we are going on a trip on Sunday. That is the future. And then we see every day what we are going to do tomorrow.” (Participant 1).*

## **Discussion**

This qualitative study describes experiences of ICU survivors regarding their health and QoL, approximately a year after ICU-admission. Important and recurrent issues in physical health were fatigue, stamina, pain and mobility problems. In mental health, cognitive problems in memory, concentration and information processing were predominant. In addition, many participants were more emotional, some reported stress or agitation, due to cognitive and physical impairments, or felt gloomy. In the social domain, relationships took on a different meaning for participants. Family played a major role and was considered an important support. The partner was more appreciated. A reduced social life was mainly the result of fatigue. Work was adjusted in hours and tasks, also due to physical and cognitive disability, and was less important than before. Most participants had adapted to their situation and accepted it, using different coping strategies. Being in control and mobile resulted in greater independence and higher QoL. Other influencing factors were comorbidities and family circumstances. Remarkable was that most participants named their QoL “different” or “slightly less”, but sufficient.

Findings of this study correspond with prior research. In a Danish study<sup>40</sup> participants rated physical aspects (reduced physical strength, fatigue, and limited walking distance), as their most important outcomes after ICU-admission. After a year, physical strength and activities had not restored to the old level<sup>41</sup>. Eakin<sup>31</sup> also described the importance of physical functioning for patients. Agard<sup>6</sup> et al. mentioned the striving for physical improvement for independence purposes (especially in the first year after admission), renewed feelings of connectedness with spouse and family. Pre-existing diseases were linked to a reduced QoL after ICU-admission<sup>42-45</sup>.

Participants in this study were selected on a decreased HRQoL. Studies<sup>46-47</sup> into (long-term) ICU outcomes concluded there was an association between low HRQoL and self-reported unacceptable outcome of ICU treatment. But ICU-patients with overall low HRQoL might

judge their outcome acceptable. This could explain the discrepancy between the SF-36-HRQoL and patients' appreciation of their QoL. Another explanation (and also a limitation of the study) might be the lead time between the completion of the SF-36 at T3 and the conducting of the interviews. Although it was kept as short as possible, the interviews were conducted until approximately 18 months after admission. Research exposed that physical, mental, and social health slowly improved up to two years after admission<sup>43,48</sup>. Therefore, the results of this study might not accurately reflect the measured (SF-36) HRQoL, one year after ICU-admission. As one patient noted: "If you had asked me six months ago, I would have given you a completely different answer." An explanation for the discrepancy between the SF-36-HRQoL and the experienced QoL, might be that the SF-36 may not cover all relevant domains for former ICU-patients. Lim<sup>49</sup> identified items of interest to ICU-patients, not covered in the SF-36 such as "Perception of, interpretation of, and responses to life", referring to the effects of patient's health status on perception. Lim suggested that the SF-36 does not fully cover the psychological /emotional status of patients and argued for a critical care specific instrument to measure HRQoL. And finally, outcomes on QoL in this study were purely subjective, a representation of how participants currently thought about their QoL. HRQoL (SF-36) measures a different construct, namely QoL related to disease, where other conditions that may affect QOL are not included<sup>50-52</sup>.

### *Strengths*

Qualitative research on quality of life after ICU-admission is scarce, especially in the Netherlands. This is presumably the first Dutch study on experiences in daily life functioning and QoL of former ICU-patients, approximately one year after ICU-admission. The use of the PROMIS framework made it possible to identify and compare patient centered outcomes.

### *Limitations*

All participants were included in the overarching study, the MONITOR -IC study. This might have caused bias in the results; patients who were in a worse or better condition, might not have responded. It may also be possible that the SF-36 at T0 (before ICU-admission) was completed by family, or later on by the patient, which may also lead to a distorted picture of the HRQoL. Due to Covid-19, six interviews had to be conducted by telephone or video calling. This made it more difficult to build rapport with the participants<sup>53</sup>, but it did not affect the input of the participants. Due to the heterogeneity of the sample and the extension of the themes, it was not possible to attain complete data saturation<sup>22,54-55</sup>. Probably the largest palette of health and QoL was described, but this could not be confirmed.

### *Recommendations*

This is presumably the first qualitative study in Dutch ICU-patients over a longer period after ICU-admission. Follow-up research on long-term experiences of ICU survivors is needed to confirm health and QoL outcomes of this study. The SF-36 may not be complete enough to measure the perceived QoL in former ICU-patients. Other factors besides the SF-36 domains influence this QoL. In accordance with Lim's advice<sup>49</sup>: a more specific tool for ICU-patients may be of added value. By educating caregivers about health issues and experiences of ICU survivors, more knowledge and understanding will be gained of the problems they meet and should also enable longer-term follow-up care after ICU-discharge.

### **Conclusion**

The aim of this study was to explore the experiences in physical, mental, cognitive and social functioning and QoL in former ICU-patients, who perceive a decline in HRQoL, one year after ICU-admission. All participants reported altered functioning or disorders in one or more of these health domains, with cognitive and physical impairments being the most impactful. Participants indicated a decline in HRQoL according to the SF-36, but most of them rated the experienced QoL as sufficient. A discrepancy exists between measured HRQoL and the (subjective) perceived QoL of patients, with QoL being influenced by many more elements, including acceptance, independency, family circumstances, comorbidities, age and major life events. It is important researchers are aware of this discrepancy. Having knowledge of the outcomes in health domains and QoL of ICU-patients is relevant for caregivers. It can help them to improve healthcare and policy decisions.

## References

- (1) Wunsch H, Guerra C, Barnato AE, Angus DC, Li G, Linde-Zwirble WT. Three-Year Outcomes for Medicare Beneficiaries Who Survive Intensive Care. *JAMA* 2010 Mar 3;;303(9):849-856.
- (2) Jutte JE, Erb CT, Jackson JC. Physical, Cognitive, and Psychological Disability Following Critical Illness: What Is the Risk? *Seminars in Respiratory and Critical Care Medicine* 2015 Dec;36(6):943-958.
- (3) Needham D, Davidson J, Cohen H, Hopkins R, Weinert C, Wunsch H, et al. Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Critical Care Medicine* 2012 Feb;40(2):502-509.
- (4) Jackson JC, PsyD, Mitchell N, Hopkins RO, PhD. Cognitive Functioning, Mental Health, and Quality of Life in ICU Survivors: An Overview. *Critical Care Clinics* 2009;25(3):615-628.
- (5) Kvåle R, Flaatten H. Outcome after intensive care. *Tidsskrift for den Norske laegeforening : tidsskrift for praktisk medicin, ny række* 2010 Jan 14,;130(1):44.
- (6) Ågård AS, Egerod I, Tønnesen E, Lomborg K. Struggling for independence: A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive & Critical Care Nursing* 2012 Apr;28(2):105-113.
- (7) Svenningsen H, Langhorn L, Ågård AS, Dreyer P. Post-ICU symptoms, consequences, and follow-up: an integrative review. *Nursing in Critical Care* 2017 Jul;22(4):212-220.
- (8) Desai SV, Law TJ, Needham DM. Long-term complications of critical care. *Critical Care Medicine* 2011 Feb;39(2):371-379.
- (9) Harvey M, Davidson J. Postintensive Care Syndrome: Right Care, Right Now...and Later. *Critical Care Medicine* 2016 Feb;44(2):381-385.
- (10) Bagshaw SM, Webb SAR, Delaney A, George C, Pilcher D, Hart GK, et al. Very old patients admitted to intensive care in Australia and New Zealand: a multi-centre cohort analysis. *Critical care (London, England)* 2009;13(2):R45.
- (11) Jaarboek 2018  
Het nut van de NICE-registratie. 2019; Available at: <https://www.stichting-nice.nl/doc/jaarboek-2018-web.pdf>. Accessed 25 oktober, 2019.
- (12) Basisgegevens IC units voor het jaar 2018. . Available at: <https://www.stichting-nice.nl/datainbeeld/public>. Accessed 25 oktober, 2019.
- (13) Kerckhoffs MC, Soliman IW, Wolters AE, Kok L, Van Der Schaaf M, Van Dijk D. Langetermijnuitskomsten van IC-behandeling. *Nederlands Tijdschrift voor Geneeskunde* 2016;160(5).
- (14) Soliman IW, BSc, de Lange, Dylan W., MD, PhD, Peelen LM, PhD, Cremer, Olaf L., MD, PhD, Slooter, Arjen J.C., MD, PhD, Pasma W, DVM, et al. Single-center large-cohort study into quality of life in Dutch intensive care unit subgroups, 1 year after admission, using EuroQoL EQ-6D-3L. *Journal of Critical Care* 2014;30(1):181-186.
- (15) van der Schaaf M, Beelen A, Dongelmans DA, Vroom MB, Nollet F. Functional status after intensive care: A challenge for rehabilitation professionals to improve outcome. *Journal of Rehabilitation Medicine* 2009 Apr;41(5):360-366.
- (16) Dettling-Ihnenfeldt DS, de Graaff AE, Beelen A, Nollet F, van der Schaaf M. Coping style and quality of life in Dutch intensive care unit survivors. *Rehabilitation psychology* 2016;61(2):165-172.
- (17) Wolters A, Slooter A, van der Kooi A, van Dijk D. Cognitive impairment after intensive care unit admission: a systematic review. *Intensive Care Med* 2013 Mar;39(3):376-386.
- (18) Boogaard, M. H. W. A. van den, Schoonhoven L, Evers AW, Hoeven, J. G. van der, Achterberg Tv, Pickkers P. Delirium in critically ill patients: Impact on long-term health-related quality of life and cognitive functioning. *Critical Care Medicine* 2012;40(1):112-118.



- (19) Hofhuis JGM, Spronk PE, van Stel HF, Schrijvers AJP, Rommes JH, Bakker J. Experiences of critically ill patients in the ICU. *Intensive & Critical Care Nursing* 2008;24(5):300-313.
- (20) Geense W, Zegers M, Vermeulen H, van den Boogaard M, van der Hoeven J. MONITOR-IC study, a mixed methods prospective multicentre controlled cohort study assessing 5-year outcomes of ICU survivors and related healthcare costs: a study protocol. *BMJ Open* 2017 Nov;7(11):e018006.
- (21) Percy WH, Kostere K, Kostere S. Generic qualitative research in psychology. *The Qualitative Report* 2015 Feb 1;20(2):76.
- (22) Boeije H. *Analysis in Qualitative Research*. London: SAGE; 2014.
- (23) Etikan I. Comparison of Convenience Sampling and Purposive Sampling. *American Journal of Theoretical and Applied Statistics* 2016;5(1):1.
- (24) An excerpt from the User's Manual for the SF-36v2 Health Survey, . 2nd ed.
- (25) Dowdy D, Eid M, Sedrakyan A, Mendez-Tellez P, Pronovost P, Herridge M, et al. Quality of life in adult survivors of critical illness: A systematic review of the literature. *Intensive Care Med* 2005 May;31(5):611-620.
- (26) Chrispin PS, Scotton H, Rogers J, Lloyd D, Ridley SA. Short Form 36 in the intensive care unit: assessment of acceptability, reliability and validity of the questionnaire. *Anaesthesia* 1997 Jan;52(1):15-23.
- (27) Aaronson NK, Muller M, Cohen P, Essink-Bot ML, Fekkes M, Sanderman R, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *Journal of Clinical Epidemiology* 1998 Nov;51(11):1055-1068.
- (28) Ferrand N, Zaouter C, Chastel B, Faye K, Fleureau C, Roze H, et al. Health related quality of life and predictive factors six months after intensive care unit discharge. *Anaesthesia Critical Care & Pain Medicine* 2019 Apr;38(2):137-141.
- (29) Rothrock NE, Hays RD, Spritzer K, Yount SE, Riley W, Cella D. Relative to the general US population, chronic diseases are associated with poorer health-related quality of life as measured by the Patient-Reported Outcomes Measurement Information System (PROMIS). *Journal of Clinical Epidemiology* 2010;63(11):1195-1204.
- (30) Intro to PROMIS. 2020; Available at: <https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis>. Accessed 9 juni, 2020
- (31) Eakin MN, Patel Y, Mendez-Tellez P, Dinglas VD, Needham DM, Turnbull AE. Patients' Outcomes After Acute Respiratory Failure: A Qualitative Study With the PROMIS Framework. *American journal of critical care : an official publication, American Association of Critical-Care Nurses* 2017 Nov;26(6):456-465.
- (32) Williamson PR, Altman DG, Blazeby JM, Clarke M, Devane D, Gargon E, et al. Developing core outcome sets for clinical trials: issues to consider. *Trials* 2012 Aug 6;13(1):132.
- (33) Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health* 2000 Aug;23(4):334-340.
- (34) Roberts K, Dowell A, Nie J. Attempting rigour and replicability in thematic analysis of qualitative research data; a case study of codebook development. *BMC medical research methodology* 2019 Mar 28;19(1):66.
- (35) Hashem MD, Nallagangula A, Nalamalapu S, Nunna K, Nausran U, Robinson KA, et al. Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge. *Critical care (London, England)* 2016 Oct 26;20(1):345.
- (36) Creswell JW PC. *Qualitative inquiry and research design*. 4th ed.: Sage; 2018.
- (37) Atlas.ti. Available at: <https://atlasti.com>. Accessed 26-04-, 2020.

- (38) World Medical Association. World Medical Association Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects. *Journal International de Bioéthique* 2004;15(1):124.
- (39) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007 Dec;19(6):349-357.
- (40) Nedergaard HK, Haberlandt T, Reichmann PD, Toft P, Jensen HI. Patients' opinions on outcomes following critical illness. *Acta Anaesthesiologica Scandinavica* 2018 Apr;62(4):531-539.
- (41) King J, O'Neill B, Ramsay P, Linden MA, Darweish Medniuk A, Outtrim J, et al. Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. *Critical care (London, England)* 2019 May 24;;23(1):187.
- (42) Orwelius L, Nordlund A, Nordlund P, Simonsson E, Bäckman C, Samuelsson A, et al. Pre-existing disease: the most important factor for health related quality of life long-term after critical illness: a prospective, longitudinal, multicentre trial. *Critical care (London, England)* 2010;14(2):R67.
- (43) Gerth AMJ, Hatch RA, Young JD, Watkinson PJ. Changes in health-related quality of life after discharge from an intensive care unit: a systematic review. *Anaesthesia* 2018 Oct 1;;74(1):100-108.
- (44) Winters B, Eberlein M, Leung J, Needham D, Pronovost P, Sevransky J. Long-term mortality and quality of life in sepsis: A systematic review. *Critical Care Medicine* 2010 May;38(5):1276-1283.
- (45) Winters B, Eberlein M, Leung J, Needham D, Pronovost P, Sevransky J. Long-term mortality and quality of life in sepsis: A systematic review. *Critical Care Medicine* 2010 May;38(5):1276-1283.
- (46) Kerckhoffs MC, Kosasi FFL, Soliman IW, Delden JJM, Cremer OL, Lange DW, et al. Determinants of self-reported unacceptable outcome of intensive care treatment 1 year after discharge. 2019 Jun 1,.
- (47) Cuthbertson BH, Elders A, Hall S, Taylor J, Maclennan G, Mackirdy F, et al. Mortality and quality of life in the five years after severe sepsis. *Critical Care* 2013 Apr 1;;17(2):R70.
- (48) Langerud AK, Rustøen T, Småstuen MC, Kongsgaard U, Stubhaug A. Health-related quality of life in intensive care survivors: Associations with social support, comorbidity, and pain interference. *PloS one* 2018;13(6):e0199656.
- (49) Lim WC, PhD, Black N, MD, Lamping D, PhD, Rowan K, PhD, Mays N, MA. Conceptualizing and measuring health-related quality of life in critical care. *Journal of Critical Care* 2015;31(1):183-193.
- (50) Cummins RA, Lau AL, Stokes M. HRQOL and subjective well-being: noncomplementary forms of outcome measurement. *Expert Review of Pharmacoeconomics & Outcomes Research* 2004 Aug 1;;4(4):413-420.
- (51) Chahraoui, Khadija, MD, PhD, Laurent, Alexandra, MD, PhD, Bioy, Antoine, MD, PhD, Quenot, Jean-Pierre, MD, PhD. Psychological experience of patients 3 months after a stay in the intensive care unit: A descriptive and qualitative study. *Journal of Critical Care* 2015;30(3):599-605.
- (52) Fok SK, Chair SY, Lopez V. Sense of coherence, coping and quality of life following a critical illness. *Journal of Advanced Nursing* 2005 Jan;49(2):173-181.
- (53) Sturges JE, Hanrahan KJ. Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note. *Qualitative Research* 2004 Apr;4(1):107-118.
- (54) Boddy CR. Sample size for qualitative research. *Qualitative Market Research: An International Journal* 2016 Sep 12;;19(4):426-432.
- (55) Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? *Field Methods* 2006 Feb;18(1):59-82.
- (56) Zimmerman J, Kramer A, McNair D, Malila F. Acute Physiology and Chronic Health Evaluation (APACHE) IV: Hospital mortality assessment for today's critically ill patients. *Critical Care Medicine* 2006 May;34(5):1297-1310.

Table 1

*Patient characteristics*

	<b>Gender</b>	<b>Age at admission</b>	<b>ICU-admission</b>	<b>Admission diagnosis</b>	<b>ICU LoS * days</b>	<b>Hospital LoS * days</b>	<b>APACHE IV score**</b>	<b>Interview</b>
1	M	66	Planned	Surgical	2	8	47	Face to face
2	M	61	Unplanned	Medical	10	20	114	Face to face
3	M	58	Planned	Surgical	1	8	39	Face to face
4	M	58	Planned	Surgical	2	8	53	Face to face
5	M	76	Unplanned	Surgical	1	11	58	Face to face
6	M	72	Planned	Surgical	1	6	60	Face to face
7	F	70	Planned	Surgical	1	12	55	Face to face
8	M	57	Unplanned	Surgical	54	61	110	Face to face
9	M	52	Unplanned	Medical	4	17	127	Face to face
10	F	69	Planned	Surgical	5	12	78	Telephone call
11	M	74	Unplanned	Surgical	3	59	73	Video call
12	M	68	Unplanned	Surgical	5	18	57	Video call
13	M	72	Unplanned	Medical	2	7	84	Telephone call
14	M	77	Unplanned	Medical	14	35	54	Telephone call
15	M	77	Planned	Surgical	4	9	77	Telephone call
	Male 13 (87%)	Median 69 years (52-77)	Planned 7 (47%)	Medical 4 (27%)	Median 3 (1-54) days	Median 12 (6-61) days	Median 60 (39-127)	Face to face 9 (60%)
	Female 2 (13%)	IQR 16	Unplanned 8 (53%)	Surgical 11 (73%)	IQR 4	IQR 12	IQR 30	Video call 2 (13%) Telephone call 4 (27%)

\*LoS: Length of Stay

\*\*APACHE IV score: indicating mortality probability<sup>56</sup>

Table 2

*Themes and subthemes*

<b>Domain</b>	<b>Themes</b>	<b>Subthemes</b>
Physical Health	Physical fitness	Stamina; limitations; moving as necessity
	Energy, fatigue, and sleep	Saving energy; conscious use of energy; afternoon nap; unaltered sleep; pain
	Mobility	Adjusted means of transport; limitations; (in-)dependence
	Pain	Effect of pain; wound pain; bone pain; neuralgia
	Additional physical problems	Poor sight; skin problems; joints' stiffness; incontinence; comorbidities
Mental Health	Emotions	Shifted emotion palette; less emotional; more emotional; irritated
	Stress and agitation	Frustration due to physical and cognitive impairments; impotence
	Anxiety	Fear of repetition
	Gloom, depression, initiatives	Beyond the depression; gloomy because of more awareness and future prospects; taking initiative is largely unchanged
	Empathy	Living in your own bubble
	Willpower	Do the best for the family; not wanting to be limited; make the best of the situation
	Cognitive functioning:	Memory: disrupted short-term memory; forgetting names and things; reading; age-related; Concentration: reduced load capacity; difficulty tracking conversations; better at practical matters than in thinking tasks Information processing: deteriorating information processing and learning ability
Social Health	Relations	Partner: more respect and affection; closer bond; changed partner role; spend more time together Children: more appreciation, gratitude and concern Family: more aware of (the meaning of) family; support, changed relations
	Social life	Changed social life; increased appreciation but fewer contacts; barrier
	Impact at work	Changed work activities; physical and cognitive limitations; less priority
	Outdoor activities	Sport to maintain physical fitness; less energy and physical limitations; volunteer work
Quality of life (QoL)	Acceptance	Much acceptance; resignation; unacceptable
	Coping	Radiating positivity; put your situation into perspective; devising solutions for limitations; adaption to situation; commitment and attitude influences environment and recovery; not wanting to talk about it
	Identity, self-image	Loss of confidence in body; reduced self-confidence; overestimation of own ability; a B-category human
	Priorities	Setting other priorities; work is less important; relations and doing fun things is more important; living in the moment
	Being in control	Having control; independence; being self-supporting
	Goals	Not having a goal anymore; not daring to set goals
	Limitations	Due to physical and cognitive functioning; loss of QoL
	Future prospects	To get old, enjoying small things of life; not being occupied with the future
	Appreciation of QoL	Appreciation of QoL; insufficient due to lack of future and loss of family; unchanged but different; less but sufficient; comorbidities