Critical Care Medicine
June 2025 • Volume 53 • Number 6 • Pages e1190–e1201

FEATURE ARTICLE

OPEN

Beyond Functional Outcomes: Exploring Quality of Life After Critical Illness—A Qualitative Study

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OBJECTIVES: After ICU admission, the quality of life (QoL) of ICU survivors is often significantly lower compared to their peers. However, recent studies showed that this impaired QoL cannot be fully explained by the physical, mental, and cognitive problems post-ICU, alluding to other determinants of QoL. Therefore, we aimed to explore ICU survivors' experienced QoL 1–2 years post-ICU, focusing on factors beyond functional outcomes.

DESIGN: Qualitative interview study.

SETTING: Seven hospitals in the Netherlands.

PATIENTS: ICU survivors aged greater than or equal to 16 years admitted to the ICU between July 2022 and January 2023.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: ICU patients were purposively sampled. Interviews were audiotaped, transcribed, and analyzed according to the principles of thematic content analysis. All interviews were coded independently by two researchers and participant recruitment was continued until no new themes were identified. Twenty-four semistructured interviews were performed between March and June 2024. The interviews resulted in 28 categories, from which seven main themes emerged regarding patients' experienced QoL: functional impairments (e.g., physical problems), participation (e.g., independence, work), support (e.g., informal care), environment (e.g., financial resources, personal circumstances), individual values (e.g., perspective on life, religion), comparison (e.g., expectations, reference), and coping (e.g., adaptation, acceptance). Patients described how these themes affected their QoL, both positively and negatively.

CONCLUSIONS: This study shows that perceived QoL after critical illness is impacted not only by patients' functional impairments but also by participation, support, environment, individual values, comparison, and coping. The themes identified in this study stress the importance of considering patients' individual and context factors to provide optimal post-ICU support.

KEYWORDS: critical care; critical care outcomes; prognosis; quality of life

Every year millions of patients are admitted to an ICU, of which the majority survives (1–4). However, in the months and years following ICU admission, the quality of life (QoL) of ICU survivors is lower than their peers (5–8). Postintensive care syndrome, including new or worsened symptoms and decreased function like muscle weakness and cognitive decline, has been assumed to contribute to this impaired QoL, whereas also increasing healthcare utilization and costs (9–11). However, studies indicate that many

DOI: 10.1097/CCM.0000000000006665

KEY POINTS

Question: To explore how ICU survivors experience their quality of life (QoL) 2 years post-ICU, focusing on factors beyond physical, mental, and cognitive functioning.

Findings: This qualitative study shows that perceived QoL after critical illness is impacted not only by patients' functional impairments but also by participation, support, environment, individual values, comparison, and coping.

Meaning: The themes identified in this study stress the importance of considering patients' individual and context factors to provide optimal post-ICU support.

patients already had a reduced QoL before ICU, suggesting that this impaired QoL might not only be attributable to critical illness (6, 12, 13).

This alludes to other factors influencing QoL, consistent with QoL frameworks, indicating that besides functioning, individual and environmental characteristics contribute to QoL (14, 15). The World Health Organization defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Thus, it is unsurprising that these frameworks present functional status as part of a bigger picture, also considering how patients bounce back from impairments, known as resilience, and how they adapt to a new standard (16).

The first studies have confirmed that post-ICU QoL encompasses more than functioning: patients' self-reported physical, mental, and cognitive functioning explain 56.5% of variance in QoL, meaning 43.5% is determined by other factors (17, 18). Consequently, patients reporting similar impairments can experience a different QoL. These discrepancies between functioning and subjective wellbeing, known as the "disability paradox", were observed in almost half of ICU survivors (18, 19). However, an explanation for these discrepancies is lacking, possibly because of these studies' quantitative nature. Although quantitative data help explore patient characteristics—such as younger age and higher education among those with a lower-than-expected QoL—they leave little room to explore other potential determinants of post-ICU QoL (18). In contrast, qualitative research provides insight into patients' subjective experiences.

Furthermore, QoL being not only dependent on functional outcomes poses a challenge for clinical decision-making. Identifying other factors contributing to QoL could help ICU clinicians provide personalized care and improve long-term QoL predictions.

Therefore, this qualitative study aimed to explore ICU survivors' experienced QoL 1–2 years post-ICU through individual interviews, focusing on factors beyond physical, mental, and cognitive functioning.

METHODS

Study Design

This qualitative interview study is a substudy of the MONITOR-IC: an ongoing prospective multicenter cohort of adult ICU survivors, further described in the study protocol (20). The study was approved on August 23, 2016, by the research ethics committee of the Radboud university medical center (2016–2724) and conducted in accordance with the declaration of Helsinki. This study is described according to the Consolidated Criteria for Reporting Qualitative Studies (**Supplement 1**, http://links.lww.com/CCM/H711).

Study Participants

For this substudy, patients were eligible if they had reported their QoL and physical, mental, and cognitive functioning 1-year post-ICU. Cardiac surgery patients were excluded because of their typically short ICU stay and good long-term outcomes (5, 12, 21). Participants were purposively sampled from the MONITOR-IC, recruiting a heterogeneous sample that represents the full diversity of the ICU population, to obtain as many perspectives as possible. Purposive sampling was done by L.P. and K.W. based on the variables in **Box 1**. Initially, patients with a discrepancy between their reported QoL, assessed using the EuroQoL Visual Analogue Scale (EQ-VAS, range 0–100), and calculated QoL, based on a linear model describing the average relationship between QoL and self-reported physical, mental, and cognitive functioning, were sampled (22). A discrepancy was defined as a minimally clinically significant difference (> 8 points) between the reported EQ-VAS and the calculated EQ-VAS, meaning the QoL was lower or higher than expected based on self-reported functioning

BOX 1.
Sampling Variables

Variable	Definition/Categories/Scale
Age	Years
Gender	Male Female
Ethnicity	Dutch Non-Dutch
Education level	Low Middle (secondary school graduate) High (postsecondary graduate)
Living situation	Alone With someone else
Admission diagnosis	Primary diagnosis registered by ICU physician
ICU length of stay	Days
Hospital length of stay	Days
Quality of life 1-yr post-ICU	EuroQol Visual Analogue Scale, range 0–100

(23, 24). Thus, patients had a positive discrepancy if they rated their QoL greater than 8 points higher than calculated, whereas patients who rated their QoL greater than 8 points lower than calculated had a negative discrepancy. Details of these discrepancies and methods were described in a previous study (18). After analyzing 16 interviews, we observed similar themes among patients with positive and negative discrepancies. Therefore, patients with no discrepancy were also interviewed to obtain a full picture of how patients experience QoL in relation to functional outcomes.

As the goal was to interview patients 1–2 years post-ICU, initial sampling was done in February 2024, selecting patients admitted to the ICU between July 2022 and January 2023, aiming to maximize diversity across sampling variables.

Data Collection

Patients were informed about the study by email and approached by telephone several days later. After obtaining informed consent, semistructured interviews were performed by four researchers trained in conducting interviews: a male physical therapist/master student biomedical sciences (K.W.), a female physician/PhD candidate (L.P.), and two female psychology students (M.B., N.S.). The first five interviews were conducted in various pairs. The interview location (at home, in the hospital, or online via Microsoft Teams) was based on participant's preference. No prior relationship was established between interviewers and participants. Interviews lasted between 43 and 90 minutes (median 66) and took place between March and June 2024. Proxies were present in seven of 24 interviews. Comments made by proxies were not considered in analysis, as the goal was to explore patients' experiences.

A semistructured interview guide (**Box 2**; and **Supplement 2**, http://links.lww.com/CCM/H711), was developed based on conceptual models of QoL and insights from previous studies (14, 15). Questions were refined using the expertise of a multidisciplinary team, including researchers with a background in nursing (M.vdB.), health sciences (M.Z.), medical psychology (J.C.), physical therapy (K.W.), and medicine (L.P., K.S.). The interview guide was updated based on participant feedback, including feedback on missing topics. Physical, mental, and cognitive problems were explored to gain an understanding of how and why these problems affect patients. Other questions regarded patients' general perception of QoL, daily life, and social life.

Data Analysis

Interviews were audiotaped and transcribed verbatim by a professional transcriptionist. After the first interview, data analysis started according to the principles of thematic content analysis. All interviews were coded independently by two researchers (L.P., K.W.) using ATLAS.ti software version 24.0.0. Open coding was used to allow for new themes to be identified. An initial codebook was developed, describing all created codes. Subsequently, codes were grouped into categories, which were then placed under main themes. Codes, categories, and themes were compared until consensus was reached. Any discrepancies were discussed during meetings with the interviewers (L.P., K.W., M.B., and N.S.), as well as with M.Z., M.vdB., and J.C. Participant recruitment continued until no new themes were identified and data saturation was achieved.

RESULTS

In total, 147 MONITOR-IC participants were eligible, of which 61 patients were approached by telephone for

BOX 2.
Overview Interview Guide

Topic	Example Questions
Quality of life (general)	If you had to give your life a score right now between 1 and 10, with 10 being excellent, what score would that be? 1) Can you explain this score? 2) What is it that prevents the score from being higher? 3) What makes the score so high?
Daily life	What does a good day look like? What does a bad day look like?
Physical functioning	Do you experience any physical problems? 1) How does this compare to before critical illness? 2) How does this affect you? 3) How do you deal with this? 4) What has helped you in this regard? And what has not?
Mental/cognitive functioning	How would you rate your mood on a scale from 1 to 10? What contributes to this score? 1) What feelings are you experiencing? 2) Are there things that you find difficult to cope with? How is your memory? How is your focus?
Social	What does your social life look like? 1) How does this compare to before critical illness? 2) How does your environment react to your changed health? How does this affect you? 3) How do you experience the support? What helps? And what does not help?

study participation using purposive sampling. Twenty-three patients could not be reached, one patient had died, and 12 patients did not wish to participate. Consequently, 25 interviews were scheduled, of which one was canceled due to other obligations.

Of the 24 participants, 66.7% ($n = 16$) were male, with participants' age ranging from 28 to 78 years old. QoL 1-year post-ICU ranged from 25 to 90 (EQ-VAS, range 0–100). Admission diagnoses varied, as did ICU length of stay, ranging from 12 hours to 123 days (**Table 1**; and **Supplement 3**, http://links.lww.com/CCM/H711). Data saturation was achieved after 21 interviews.

From the interviews, 117 individual codes were identified, which were grouped into 28 categories, from which seven themes emerged: functional impairments, participation, support, environment, individual values, comparison, and coping. Themes, categories, and relevant quotes are shown in **Table 2** and **Figure 1**.

Theme Functional Impairments

Physical, mental, and cognitive impairments impacted patients' QoL. When asked what a bad day looked like, one participant responded *Pain* (#2). Commonly described cognitive impairments were lack of focus and memory problems. Furthermore, the mental impact of an ICU admission was described, with some participants struggling to think and talk about their ICU admission:

I still struggle when I think back to [my ICU admission]. (#8)

Theme Participation

Interviewed former ICU patients described participation as an important part of QoL. Various forms were mentioned: independence, hobbies, work, social, and societal. Participants described enjoying their work and appreciated their employer giving them the option to stay involved, and not pressuring an early return to work. Similarly, participants who were not able to work anymore, described missing their job. Besides work, hobbies kept participants busy, these (new) hobbies being an important source of enjoyment.

I started drawing. It's fun to discover a different side of yourself, especially since in your working life you didn't have the time to do so. (#6)

Social involvement, including social contact and interaction, was valued by participants. Sometimes

TABLE 1.
Characteristics of Study Participants

No.	Gender	Age (yr)	Education Level	Admission Diagnosis	EuroQol Visual Analogue Scale (Range 0–100)	ICU Length of Stay[a] (d)	Hospital Length of Stay[a] (d)
1	Male	58	Middle	Pneumonia	40	7	123
2	Male	34	Middle	Surgery for abdominal trauma	80	1	9
3	Male	74	Low	Surgery for cranial neoplasm	70	1	4
4	Male	76	High	Primary seizures	86	4	8
5	Male	70	High	Carotid endarterectomy	80	1	2
6	Male	68	High	Thoracotomy	40	2	9
7	Male	64	High	Adrenalectomy	26	2	11
8	Male	64	High	Surgery for GI perforation	61	2	12
9	Male	64	Low	Intracranial hemorrhage	85	1	2
10	Female	55	Low	Laminectomy/spinal cord decompression	30	5	18
11	Female	63	Low	Congestive heart failure	52	12	24
12	Female	61	Middle	Pneumonia	25	1	6
13	Female	59	Low	Pulmonary embolus	90	2	4
14	Female	78	Middle	Acid-base electrolyte disturbance	90	4	8
15	Female	28	High	COVID-19	50	1	2
16	Male	65		Guillain-Barre syndrome	30	66[b]	85[b]
17	Male	72	Middle	Cardiovascular (nonsurgical)	92	10	25
18	Male	56	Low	Out of hospital cardiac arrest	70	5	16
19	Male	66	Middle	Intra/retroperitoneal hemorrhage	33	7	17
20	Female	75	Middle	Pneumonia, fungal	90	15	26
21	Male	44	High	Chest/abdomen trauma	86	1	4
22	Female	31	High	Surgery for localized soft-tissue infection	35	1[b]	17[b]
23	Male	70	High	Surgery for GI perforation	65	17	36
24	Male	44	High	Aneurysm, dissecting aortic	88	4	13

GI = gastrointestinal.

[a] Some patients were transferred from another ICU/hospital. As we do not have access to those medical records, the ICU length of stay here represents the length of stay in the participating hospital.

[b] These patients indicated during the interview that they were transferred to another ICU/hospital.

though, disability resulted in social isolation and loneliness. This reduced the sense of belonging and feeling that you are needed. Being able to contribute to society, through (volunteer) work, or otherwise making a positive impact, gave participants a fulfilling feeling.

Yes, just to mean something for your fellow citizen. (#13)

Theme Support

Being supported was described as crucial, ranging from social support to (in)formal care. Participants were grateful for the help and support of family and friends, and described how their proxies helped them stay positive by focusing more on the positives than on the negatives. They mentioned the importance of

TABLE 2.
Overview of Themes, Categories, and Relevant Quotes

Theme	Category	Illustrative Quote
Functional impairments	Physical impairments	*I have no strength, it's just...Of course, it has gotten a bit better, but from the 100% I was, maybe only 30-40% is left. (#10)*
	Mental impairments	*I have emotional spikes. Sometimes I'm triggered by things, and then I go from zero to a hundred in anger or sadness. (#10)*
	Cognitive impairments	*Before, you could handle it all. But now you just notice that it becomes too much. It's like your mind is overloaded, and you can't process it properly anymore. (#9)*
Participation	Independence	*I'm not allowed to drive anymore. I find that very painful. (#4)*
	Work	*Also regarding my work, I'm really positive about it, in the sense that I experienced very little pressure from them, to hurry, so to speak. (#15)*
	Hobbies	*Start doing fun things again. That helps too. Just going on vacation together. Days out, doing things. (#2)*
	Social	*I knew it could be very difficult to go back, to return, but the social connections were enough to stay "Wow, I still belong here" (#1)*
	Societal	*I don't think it is really about volunteer work, but the fact that you add something. And that is important. (#7)*
Support	Social	*I think the more positive people you have around you, the easier and better your recovery will go. (#9)*
	Informal care	*My husband has really done everything for me. Because I really couldn't even make my own sandwich. I was that weak. So he still does the things I can't. So yes, very important. (#10)*
	Formal care	*I participated in an outpatient program at a rehabilitation center. Yes, that has all helped a lot. In improving energy, in coping with what you can do in a day, how you can best schedule your day. (#15)*
Environment	Financial resources	*Having a secure financial situation of course makes life a little easier than if you are in financial trouble or your business is not going well. (#18)*
	Social network	*If I had been alone, you end up sitting on the couch much more. (#17)*
	Personal circumstances	*In my environment, people were passing away left and right, including my brother-in-law. He was like a big brother to me, so I've been struggling quite a bit with that. (#9)*
Individual values	Perspective on life	*The biggest part needs to come from yourself. How difficult that may be. (#17)*
	Autonomy	*Control is very important. I'm not a control freak, you know. But autonomy is essential. Without autonomy, you cannot be happy. (#5)*
	Resilience	*I've had a difficult childhood, but I've battled through that period. And I believed that made me stronger. (#6)*
	Religion	*Well, you have a whole Bible full, of course, and it also contains proverbs … about normal life. It also sometimes gives you a bit of a foothold. (#7)*
Comparison	Expectations	*At first I thought it was just about rebuilding my endurance. Of course, that had taken a hit. But I hadn't expected [the heart attack] to have such a big impact. (#24)*
	Reference	*You end up looking back at yourself. At where you are coming from. From zero, so to speak, to now. (#10)*

(*Continued*)

TABLE 2. (*Continued*)

Overview of Themes, Categories, and Relevant Quotes

Theme	Category	Illustrative Quote
Coping	Trust	*I just have the idea that…Yes, someday I will get back to those 8 hours [of work], for example. (#15)*
	Dealing with negative thoughts	*Look, if I sit in my corner all day and think about everything that has happened, how bad it is…You just dig yourself a hole. (#7)*
	Acceptance	*It's just a matter of acceptance. That's it. And…Yes, very slowly…But also really very slowly. I do realize that this might be it. (#10)*
	Avoidance	*Because then I think, if I run into all these people, they will all want to talk again, I really don't feel like it. (#15)*
	Social	*You just have to talk about your emotions. You have to share that with your loved ones. You shouldn't keep walking around with it. (#8)*
	Goal-oriented	*No, I don't give up. And the reason why I don't give up, the goal, my grandchildren have only one grandmother, two grandfathers. (#12)*
	Adaptation	*For example, I can't do two or three things at the same time anymore. I can't do that anymore. I have to either choose, or I must… (#10)*
	Response shift	*Well, not that I wouldn't have wanted to miss it or anything, but it has had a…Yes, actually a positive effect on me. (#15)*

being treated normally, although they felt frustrated when people around them had limited understanding of what they were going through.

No offense, but … They don't know what you're going through. I don't know what you're going through right now, you know? (#13)

For some participants, critical illness brought their families and/or friends closer together, whereas for others it caused friction within relationships.

Has my relationship taken a hit? Yes, I think it has. (#12)

Family, friends, and neighbors played a large role in providing informal care. Participants described help with daily activities as important. The formal care, including returning to the ICU and medical guidance post-ICU, was appreciated by participants. Some described positive effects of ICU diaries, helping them understand what had happened during their ICU stay.

Theme Environment

Besides support, patients' environment was mentioned to impact QoL, including financial resources, social network, and personal circumstances. Participants mentioned the costs of impairments: necessary adjustments are expensive, and being able to cover these costs was considered crucial. Furthermore, financial security was generally described as relevant in regard to QoL, as the absence of security could cause worry and stress.

Social surroundings, like the positive impact of family, were also described as relevant. Having a partner to do stuff with and/or having family and friends nearby was considered important.

I always take someone with me, because I really don't like doing stuff alone. That's a downside of myself, that I find it very difficult to do fun things alone. (#14)

Other life events were commonly mentioned as influencing QoL. Despite critical illness, participants' lives went on, many enduring other major changes, both before and after critical illness.

Theme Individual Values

Participants also described personal values impacting QoL, with perspectives on life varying: some believe that there is always something wrong, whereas others see life as an adventure, or believe you determine your own happiness. In contrast, some participants described appreciation of others as an important contributor to QoL. The importance of putting things into perspective and not wasting energy on negative people or thoughts was outlined. Some even described conditions for QoL.

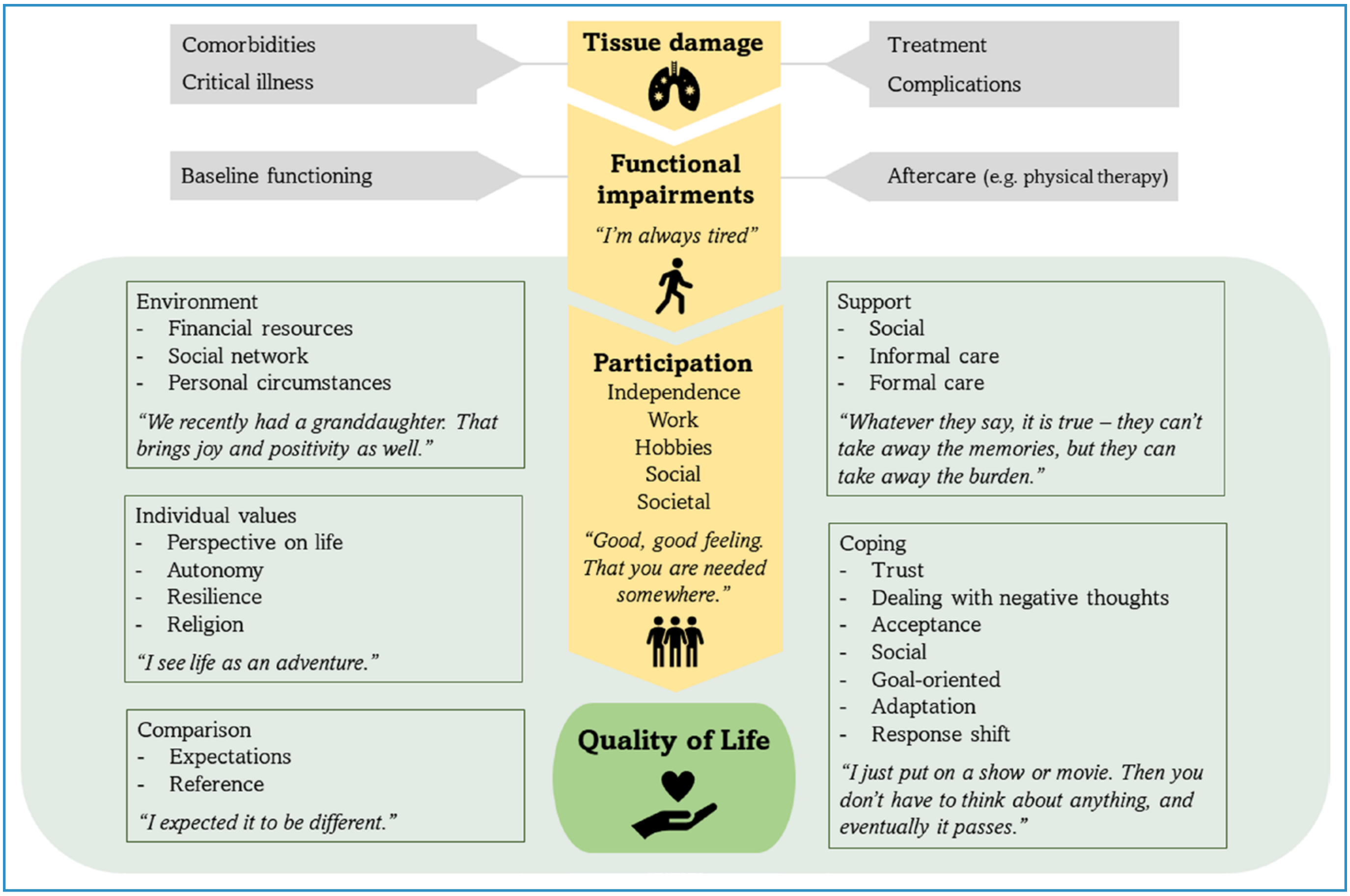

Figure 1. Visualization of the identified themes and categories of factors influencing quality of life.

I thought, if that also isn't possible anymore, then I don't want it anymore. (#8)

Other values mentioned were autonomy, resilience, and religion. Being self-reliant and in control was particularly valued. Being told what you can and cannot do, was experienced as burdensome, including having to take pills. When asked what would improve QoL, one participant said: *No medication. (#2)*

Participants discussed the importance of a positive outlook on life, and how personal traits helped them stay resilient. The impact of previous life events and how participants drew strength from these were also described, whereas for others strength was found in their religion.

Theme Comparison

What and who ICU survivors compared themselves with was also described as influencing QoL. Patients described comparisons between their current situation and their expectations, and comparisons with a reference state, being an earlier situation or their peers.

Participants' views on expectations differed. Although some had hope for improvement, others were careful with hope because of the possibility of disappointment. This disappointment was described when recovery was harder than expected. However, being well informed about their post-ICU trajectories, gave participants a secure feeling.

On the one hand [knowing what disease you have], you worry. But on the other hand, it brings peace, because you know exactly what's going to happen. (#22)

Participants also compared themselves to others and to their earlier selves, many times to put their disabilities into perspective.

There are plenty of people my age who are a lot more disabled than I am. I should not complain. (#20)

Theme Coping

Coping was discussed in different forms: trust, dealing with negative thoughts, acceptance, avoidance, social coping, goal-oriented, adaptation, and response shift.

Some participants felt vulnerable, their limitations resulting in fear. However, (expected) progress motivated them and increased the trust in their body. Trusting clinicians also provided a sense of calmness. Furthermore, many participants trusted that all would turn out okay. Some described keeping negative thoughts out, knowing that worrying is futile. Other participants mentioned lying awake at night worrying about possible scenarios regarding their health or future.

So that fear dominates my life. Like I said, you know…I could just collapse here and suddenly have a stroke. I could get so out of breath that I have another pulmonary embolism. You know, it's so unpredictable. (#13)

Some participants struggled to accept the consequences of their critical illness. They found their impairments confronting, sometimes wondering *why me?…*Sometimes, acceptance took time, while others described acceptance as a natural process, of letting go of what you cannot change.

What has passed has passed, there is nothing else I can do about it. (#16)

Some ICU survivors tried to ignore their emotions, sometimes not wanting to face the consequences of their critical illness. Many instead sought distractions. Although some avoided discussing their disease, others found talking about their illness helpful. Some participants tried to protect their family and friends by withholding information, whereas others experienced social pressure to be grateful for surviving.

I hear people telling me, like, you are enjoying life right now, right? You have been given a second chance, you are enjoying it now, right? Yes, but yes… (#13)

Most participants wanted to do everything in their power to get better and found solace in having a goal to focus on. Focusing on the future and possible improvements helped participants deal with the current situation. Participants adapted, seeking solutions to perform daily activities despite functional impairments. Sometimes this called for prioritization. Some also described developing a healthier lifestyle after critical illness.

What do you do? You flip that switch, then you start eating differently, drinking differently, you deal with your problems differently. (#13)

Gratitude for surviving critical illness was described by most participants. Being aware of their own mortality provided participants with a different perspective on life, valuing life differently and changing their priorities.

That colors your life, makes it more serious, but also makes that some things…are not important. (#7)

DISCUSSION

In this study, we explored the experienced QoL of ICU survivors using in-depth interviews, focusing on factors beyond physical, mental, and cognitive functioning. Several factors contributing to patients' experienced QoL were described: the main themes being functional impairments, participation, support, environment, personal values, comparison, and coping.

These findings align with previous research, indicating that functional outcomes can only partially explain variability in QoL after critical illness (17, 18). The reduced QoL of ICU survivors might reflect patients' pre-ICU health status and comorbidities, rather than being a consequence of critical illness (12, 13, 25–28). This study identified multiple factors (e.g., perspective on life, personal circumstances) unrelated to critical illness, thereby providing an explanation for discrepancies between patients' functional outcomes and QoL. Although functional impairments remain an important contributor to QoL, illustrated by strong correlations in previous studies, their impact varies (17, 18).

The identified themes, however, are not routinely assessed, and more difficult to measure than clinical factors like admission diagnosis. Still, the first studies investigating these nondisease-related factors have found coping style, realistic expectations, and resilience to be associated with QoL (16, 29–35). Furthermore, strong social support could contribute to higher resilience and acceptance (34, 36, 37). Incorporating these factors into standardized instruments could facilitate routine assessment, providing a broader perspective on patients' QoL.

Understanding what other factors determine patients' QoL could improve ICU decision-making, as expected long-term QoL is often taken into account despite uncertainty (38–41). By gaining a better grasp on what contributes to patients' QoL, these factors can be integrated into discussions with patients and family, leading to more informed and personalized decisions.

Furthermore, improving our understanding of long-term QoL could help manage patients' expectations, potentially improving patients' QoL, as QoL can be seen as the gap between expectations and experience (42, 43). Current interventions to improve long-term outcomes often focus on physical functioning, but their effectiveness has been limited (44, 45). Identifying factors unrelated to physical function, as done in this qualitative study, could help tailor (post-)ICU care to patients' individual needs. For instance, clinicians could discuss expected long-term physical, mental, and cognitive impairments to help ICU survivors and families prepare for recovery. Providing information on recovery in an early stage can normalize the problems patients may encounter post-ICU. Predischarge guidance on rehabilitation, coping strategies, and necessary resources can help families anticipate difficulties. Integrating socials workers and psychologists into ICU teams and post-ICU clinics could facilitate early recognition of personal and contextual factors that warrant attention, providing additional support when needed. Peer support programs may also provide emotional support through shared experiences. Nonetheless, if QoL can be improved by interventions incorporating nondisease-related factors, such as coping style or expectations, has yet to be seen, as studies examining such interventions are still limited (46–48).

Patients' values might not be easily altered by interventions and likely remain relatively stable over time. This stability could explain why discrepancies between patients' QoL and self-reported functioning are quite consistent at different timepoints post-ICU (18). Personality traits, often mentioned by patients themselves, may contribute here. When asked why participants cope a certain way, they described traits they were born with, or how they were raised as a child. This is supported by previous literature, demonstrating an association between personal characteristics and QoL (49).

By conducting exploratory interviews, we were able to identify which themes contribute to former ICU patients' experienced QoL in a real-world context, moving beyond theoretical QoL frameworks. However, this study has limitations. First, interviews were performed by young, healthy interviewers, possibly affecting patients' responses, especially regarding sensitive subjects. Furthermore, a proxy was sometimes present, possibly leading to socially desirable answers. However, considering participants openly discussed effects on marriage and the mental burdens they experienced, we believe this bias was minimal. Second, selection bias possibly occurred, with certain patient groups being more willing to discuss their long-term outcomes than others. However, because of high willingness to participate and purposive sampling, we obtained a heterogeneous sample regarding both sociodemographic and disease characteristics. Still, these views might not reflect those of a population with a more diverse cultural background, as we only included participants who spoke the Dutch language. Furthermore, because of universal healthcare coverage in the Netherlands, financial concerns were likely underrepresented. Third, we did not examine how the identified themes relate to each other. Future studies are needed to refine conceptual models of QoL.

CONCLUSIONS

This study shows that perceived QoL after critical illness is impacted not only by patients' functional impairments but also by participation, support, environment, individual values, comparison, and coping. The themes identified in this study stress the importance of considering patients' individual and context factors to provide optimal post-ICU support.

ACKNOWLEDGMENTS

We thank the participants for their contribution. Furthermore, they thank Marieke Bakhuizen and Nadine Sigmans for contributing to the interviews, and Mireille Blom for her support in communication with patients and organizing the interviews.

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Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's website (http://journals.lww.com/ccmjournal).

Authors Porter, Simons, van den Boogaard, Custers, and Zegers designed the study. Porter and Wijntjes contributed substantially to the acquisition of data. Porter drafted the article. All other authors provided critical revisions and approved the final version of the article.

This work was funded, in part, by Radboud university medical center and Jeroen Bosch Hospital.

Dr. Porter received support for article research from Radboud university medical center and Jeroen Bosch Hospital. The remaining authors have disclosed that they do not have any potential conflicts of interest.

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Informed consent was obtained from all individual participants included in this study.

Trial Registration: The Monitoring cOnsequeNces of InTensive care fOR Intensive Care patients (MONITOR-IC) study was registered at ClinicalTrials.gov: NCT03246334.

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