

## RESEARCH ARTICLE

# Intensive care-treated COVID-19 patients' perception of their illness and remaining symptoms

Ewa Wallin<sup>1</sup>  | Michael Hultström<sup>1,2</sup>  | Miklos Lipcsey<sup>1,3</sup>  | Robert Frithiof<sup>1</sup> | Sten Rubertsson<sup>1</sup> | Ing-Marie Larsson<sup>1</sup>

<sup>1</sup>Department of Surgical Sciences, Anesthesia and Intensive Care Medicine, Uppsala University, Uppsala, Sweden

<sup>2</sup>Department of Medical Cell Biology, Integrative Physiology, Uppsala University, Uppsala, Sweden

<sup>3</sup>Department of Surgical Sciences, Hedenstierna laboratory, CIRRS, Anesthesiology and Intensive Care Medicine, Uppsala University, Uppsala, Sweden

#### Correspondence

Ewa Wallin, Department of Surgical Sciences, Anesthesia and Intensive Care Medicine, Uppsala University, Uppsala, Sweden.

Email: ewa.wallin@surgsci.uu.se

#### Funding information

Svenska Läkaresällskapet, Grant/Award Number: SLS-938101; Vetenskapsrådet, Grant/Award Number: 2014-02569 and 2014-07606; Knut och Alice Wallenbergs Stiftelse, Grant/Award Number: KAW 2020.0182

## Abstract

**Background:** The remaining symptoms in patients with coronavirus disease 2019 (COVID-19) treated in intensive care unit are limited described. Therefore, we assessed patient's perception of their COVID-19 disease, stay in intensive care, and remaining symptoms three to six months after intensive care.

**Methods:** Prospective cohort study was performed in one intensive care unit of a university hospital in Sweden during the first wave. A questionnaire with open-ended questions and closed-ended questions was used. Data were analyzed using qualitative and quantitative content analysis and descriptive statistics.

**Results:** Out of 123 patients treated for COVID-19, 64 answered the questionnaire 3–6 months after discharge from intensive care. Memories from illness and hospital stay revealed in three categories; awareness of the illness, losing anchor to reality and being cared for in a dynamic environment. Information was perceived as spare by 48% and they wanted the information to be more personal. The diary was perceived as personal and was received by 33% patients. The relationship with family was affected among 39% and 13% of the patients indicated that they had not resumed their daily life. A large amount, 84%, indicated that they had remaining symptoms from COVID-19. The dominated symptoms were impaired strength and energy both physically and mentally.

**Conclusion:** Patients reported a variety of physical and mental symptoms, and revealed memories from the ICU, and specific awareness of other patients' health. It illustrates the need for screening patients for remaining symptoms after COVID-19 disease and ICU care and may affect resuming patients' daily life.

## KEYWORDS

critical care, information, long COVID-19, memories, outcome, patient reported measures, remaining symptoms

This study was performed at the Department of Surgical Sciences, section for Anaesthesiology & Intensive Care, Uppsala University, Sweden.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2021 The Authors. Acta Anaesthesiologica Scandinavica published by John Wiley & Sons Ltd on behalf of Acta Anaesthesiologica Scandinavica Foundation

### Editorial comment

Post-intensive care syndrome is common among ICU survivors. During the COVID-19 pandemic, this has also gained much public interest. To systematically report of this, and to analyze the effects of critical illness after discharge, is an important approach to try to improve care for ICU COVID-19 patients as well as for non-COVID-19 ICU patients.

## 1 | BACKGROUND

Post-intensive care syndrome (PICS) affects many survivors of intensive care and is characterized by persisting long-term consequences, encompassing both physical, psychological, and cognitive impairment.<sup>1-4</sup> With the large number of ICU patients treated at intensive care units (ICUs) during the coronavirus disease 2019 (COVID-19) pandemic, this is likely to become a major long-term burden for patients and health care systems.<sup>5,6</sup> COVID-19 patients may be at high risk of PICS because they often spent a long time in intensive care and many receive extended mechanical ventilation, sedation combined with muscle relaxants, and prone positioning, all of which are known risk factors.<sup>7,8</sup> Suffering from PICS affects independence, and return to daily life after severe illness, which results in an increased burden on both at-home caregivers and the health care system.<sup>1-4</sup> Physical impairment, including reduced physical capacity and mobility, is common.<sup>1,9</sup> Common psychological consequences are anxiety, depression, and post-traumatic stress symptoms.<sup>1,2</sup> Fatigue occurs in as many as 50% of patients after intensive care.<sup>10,11</sup> Cognitive impairment, such as reduced memory, executive function, attention, processing speed, or visuospatial ability, occurs in 30%–80% of patients.<sup>1-3,12</sup> Recovery after PICS is individual and dependent on several factors, including age, length of ICU stay, and comorbidity; residual symptoms can persist for up to 8 years.<sup>2,3</sup> The situation of patients hospitalized with COVID-19 shows similarities to PICS at two to six months' follow-up.<sup>13,14</sup> There is a need to investigate if these remaining symptoms are also present in patients who have required intensive care for COVID-19 and to address their experiences.

The aim of the present investigation was to describe how patients from the first wave perceived their COVID-19, their stay at an ICU, and remaining symptoms three to six months after intensive care.

## 2 | METHOD

### 2.1 | Design

Prospective, descriptive study with a quantitative and qualitative approach.

### 2.2 | Ethical approval

The study was approved by the Swedish Ethical Review Authority (EPM-2020-02697) and was performed in accordance with the declaration of Helsinki. Patients were included after giving informed consent. The study was registered *à priori* (ClinicalTrials ID: NCT04474249).

### 2.3 | Participants (and setting)

The study was performed at a general ICU at a university hospital in Sweden, at the time treating only COVID-19 patients. Patients were eligible to participate in this follow-up study if they had previously been included in an ongoing research regarding the acute effects of COVID-19 (ClinicalTrials ID NCT04316884). During the period March 13–July 14 2020, i.e., first wave of COVID-19, a total of 123 patients were admitted for COVID-19 and included in the ongoing research. Between three to six months after discharge from the ICU, the patients were contacted and asked to participate in this follow-up study. Out of them ( $n = 123$ ), three were excluded as they had not had COVID-19, 32 had died, 23 declined to participate or were lost to follow-up, and one did not return the questionnaire. This resulted in 64 patients being analyzed in this follow-up study. Data from patients were coded and anonymized.

### 2.4 | Data collection

Patients were contacted by telephone and sent a questionnaire with structured questions concerning their perception of the hospital stay and their recovery after the COVID-19 infection.

The questionnaire consisted of 13 questions and was constructed with five open-ended questions and eight closed-ended questions. The closed-ended questions were answered by yes/no and it was possible to write free-text comments. The questions focused on four areas: 1. Memories of illness and hospital stay. 2. Information about their illness. 3. Contact with relatives. 4. Daily living after the hospital stay and remaining symptoms (Table 1). The questionnaire was developed by the first and last author. Demographic and clinical data included age, sex, comorbidities, and clinical data from the ICU stay and follow-up.

### 2.5 | Organization

In Sweden, the ICU specialty is multidisciplinary, and the team caring for critically ill patients consists of specialist nurses, nurse assistants, specialist physicians, and physiotherapists. The treatment of COVID-19 patients was based on international and national recommendations and guidelines were continuously updated during the first wave. To meet an increased number of patients during the first wave of COVID-19, the specialist nurse-to-patient ratio and specialist physicians-to-patient ratio decreased, also temporary ICU beds

TABLE 1 Questionnaire and responses to yes/no questions

		Yes	No	Not answered
Area	(1) Memories of illness and hospital stay			
Q1	What are your strongest memories from the ICU?			1 (2%)
Q2	What are your strongest memories from your time at the general ward?			1 (2%)
Area	(2) Information about their illness			
Q3	What information have you received about your time at the ICU?			2 (3%)
Q4	What information have you received about the course of your illness?			6 (9%)
Q5	Have you received a diary from the time when you were at the ICU?	21 (33%)	43 (67%)	0 (0%)
Area	(3) Contact with relatives			
Q6	Did you receive any visits from your relatives during your time at the ICU?	4 (6%)	60 (94%)	0 (0%)
Q7	Did you receive any visits from your relatives during your time at the general ward?	10 (16%)	54 (84%)	0 (0%)
Q8	Could you communicate with your relatives during your time in intensive care?	36 (56%)	28 (44%)	0 (0%)
Q9	Could you communicate with your relatives during your time at the general ward?	57 (89%)	6 (9%)	1 (2%)
Area	(4) Daily life after hospital stay and remaining symptoms			
Q10	Have relationships within your family changed following your illness?	25 (39%)	37 (58%)	2 (3%)
Q11	Have you resumed your activities of daily life, such as household chores like shopping on your own, cooking, doing laundry, gardening, driving, etc.?	49 (77%)	13 (20%)	2 (3%)
Q12	Are there any problems related to your COVID-19 illness?	54 (84%)	8 (13%)	2 (3%)
Q13	Is there anything else that you want to inform us about?	27 (42%)	8 (12%)	29 (45%)

Abbreviation: ICU, intensive care unit.

Data are presented as n (% of the whole cohort,  $N = 64$ ).

were opened. Professions from other areas, mainly anesthesia, were introduced to work in the ICU, who received a brief introduction to inpatient care in the ICU. Routines regarding visits and the possibility for relatives to be in touch with the ICU changed, as well as practices regarding diary and follow-up visits. At our hospital, one ICU unit was responsible for and admitted all COVID-19 patients. The current ICU included eight beds before the pandemic, and to meet the increased number of patients, temporary ICU beds were opened. During the peak of the first wave, 23 ICU beds were dedicated for COVID-19 patients (see also Table A1). The criteria for admittance to ICU during the first wave were based on the concept of potential benefit and did not differ compared to usual criteria for ICU care in Sweden.<sup>15</sup>

## 2.6 | Data analysis

Data from the open-ended questions Q1 and Q2, regarding memories of the illness and hospital stay, were analyzed using

manifest content analysis, with an inductive approach that included open coding, creating categories, and abstraction.<sup>16,17</sup> The answers consisted of a few words up to eight sentences and were read and re-read to get an overall sense of the material. NVivo software (Release 1.3.1, 2020, QSR International, Melbourne, Australia) was used to organize the data and derive codes. Thereafter, the codes were grouped into categories. The analysis was conducted by two authors (EW and IML) and discussed during the process.

Data from the open-ended questions Q3, Q4 and Q13, and free-text comments Q5–Q12 were analyzed using quantitative content analysis.<sup>17</sup> Excel (Microsoft Corp., Seattle, WA, USA) was used to organize the data.

The closed-ended questions, Q5–Q12, were processed using Excel and presented using descriptive statistics (frequencies and percentages). Demographic and clinical characteristics data are also presented using descriptive statistics (frequencies and percentages, median and interquartile range (IQR)).

TABLE 2 Demographic and clinical characteristics and follow-up data on the patients (N = 64)

<b>Demographics</b>	
Age	58 (51–69)
Sex (female)	17 (27%)
BMI at admission	30 (27–34)
<b>Comorbidities</b>	
Lung disease	17 (27%)
Hypertension	30 (47%)
Heart failure	0
Ischemic heart disease	3 (5%)
Vascular disease	6 (9%)
Malignancy	3 (5%)
Diabetes mellitus	12 (19%)
Neurological disease	2 (3%)
Psychiatric disease	3 (5%)
<b>ICU characteristics</b>	
SAPS3	51 (46–56)
Length of ICU stay (days)	13 (5–16)
Invasive ventilation	36 (56%)
Mild ARDS	3 (5%)
Moderate ARDS	28 (44%)
Severe ARDS	26 (41%)
Vasopressor	33 (52%)
Renal replacement therapy	8 (13%)
Delirium	7 (11%)
Critical illness weakness	7 (11%)
Length of hospital stay (days)	32 (13–38)
<b>Follow-up</b>	
Time to follow-up (days)	122 (113–128)
BMI at follow-up	30 (27–33)
Tertiary education ( $\geq 12$ years schooling)	36 (56%)
<b>Marital status</b>	
Living together	50 (78%)
Living alone	13 (20%)
Missing data	1 (2%)
<b>Place of residence before illness</b>	
Home	63 (98%)
Hospital, surgical ward	1 (2%)
<b>Place of residence at follow-up</b>	
Home	61 (95%)
Convalescent home	2 (3%)
Nursing home	1 (2%)
<b>Occupational status before illness</b>	
Working full-time	41 (64%)
Working part-time	4 (6%)

TABLE 2 (Continued)

Unemployed	0
Retired	16 (25%)
On sick leave	3 (5%)
<b>Occupational status at follow-up</b>	
Working full-time	21 (33%)
Working part-time	7 (11%)
Unemployed	1 (2%)
Retired	19 (30%)
On sick leave	16 (25%)

Abbreviations: ARDS, Acute respiratory distress syndrome; BMI, Body mass index; ICU, Intensive care unit; SAPS3, Simplified acute physiology score-3.

Data are presented as number (percentage) or median with interquartile range (IQR).

### 3 | RESULTS

Sixty-four patients treated for COVID-19 during the first wave were included. Demographic and clinical characteristics and follow-up data for the patients are presented in Table 2.

#### 3.1 | Memories from illness and hospital stay (Q1 and Q2)

The qualitative analysis generated three categories: *Awareness of the illness, a feeling of lost connection to reality, and being cared for in a dynamic environment.*

Patients expressed *awareness of their illness.* Their perception of the illness became tangible when they experienced impaired health and understood that they required hospital care. Common expressions were feelings of fear, uncertainty, powerlessness, and anxiety, as well as fear of dying. The most frightening experiences were being in need of invasive ventilation and being anesthetized.

The patients' memories of their ICU stay involved physical conditions, such as breathlessness, thirst, hunger, pain, and being unable to move or talk. A common memory was sleep disturbance and some had felt vulnerable. They also had memories of their recovery, such as when the ventilator was disconnected and when they were first able to sit on the edge of the bed. Later important memories were when supplemental oxygen could be removed and when they were able to set goals in their achieved recovery.

*A feeling of lost connection to reality* was described in the form of fragmented memories when patients moved between a dream state and reality, with many days blending into one. Many patients had had dreams that they could describe in detail afterward. Some of the dreams were enjoyable; others were strange or like déjà vu. Patients described having frequent nightmares, even after the ICU stay. Hallucinations were described as frightening and realistic experiences.

*Being cared for in a dynamic environment* encompassed memories from both the ICU and the general ward. Memories from the ICU involved their first arrival, with all the staff wearing protective equipment. Many patients described sounds and warning signals from equipment, and a lack of daylight. A common and persistent type of memory was awareness of other patients coughing, having anxiety, and dying. Positive memories of carers and supporting staff included them providing a sense of security and appearing competent. Prominent memories from the general ward included feelings of being isolated and trapped in their room and feelings of abandonment and that the staff avoided entering the room. Time stood still and they longed to go home. Being able to eat and take a shower was a positive memory and was described as giving a sense of slow recovery.

Example quotations from the different categories are presented in Table 3.

### 3.2 | Information about their illness and hospital stay (Q3 to Q5)

The patients experienced a lack of information about their ICU stay and illness (48%,  $n = 31$  (Q3) and 44%,  $n = 28$  (Q4), respectively), and some patients could not remember any information that they received during or about their intensive care and illness. The patients who remembered getting information had received this from their family, the ICU diary, online access to their patient journal, and from staff, usually physicians. This information was focused on the ventilator treatment and the severity of the illness. Later, information on test results and examinations was given on daily basis. Twenty-one (33%) patients, with an ICU stay of 3–45 days ((median 19 (IQR 10–24))), received an ICU diary kept by staff during the stay, while those who did not receive a diary had an ICU stay of 2–30 days (median 9

(IQR 4–12)) (Q5). The diary was appreciated, and patients felt gratitude toward the staff for taking the time to keep a diary for them. Patients described that the diary helped them to understand their stay in ICU, and how seriously ill they had been. They also felt that the diary provided information they would otherwise have lacked, and it gave them an opportunity to reflect on their illness.

### 3.3 | Contact with relatives (Q6 to Q9)

Patients expressed understanding and respect for the visiting restrictions in the hospital during the pandemic. Still, visits from relatives had occurred during the ICU stay in some cases and were usually preceded by a precarious health status with risk of patient death, leading to relatives being contacted. At the general ward, a few patients were visited by relatives dressed in protective equipment, with outdoor visits being more common. Some felt sad about not being able to meet relatives during the hospital stay, but others said that they would not have had the strength for visits. It was possible to be in contact with relatives, usually by telephone. During the time in the ICU, staff conveyed greetings between patients and relatives.

### 3.4 | Daily living after the hospital stay and remaining symptoms (Q10 to Q13)

Relationships with relatives had changed for the better in some ways, meaning that the relationships had been strengthened. However, the patients also said that their relatives were anxious and overprotective and had opinions on their health. Some patients felt that they had become more selfish and withdrawn and had difficulties speaking about their illness. Furthermore, they were aware that

Category	Examples of quotation
Awareness of the illness	<p>Extreme death anxiety</p> <p>Afraid of ending up on a respirator</p> <p>Effort and the perceptual sensations that it meant to try to sit on the edge of the bed</p> <p>Was physically incapable of moving on my own, even very basic movements</p>
A feeling of lost connection to reality	<p>I thought I knew what was going on, but in retrospect everything has blended into one</p> <p>The hallucinations were so severe that I was sure they were had happened in real life</p> <p>A nasty memory was that I woke up and thought I had been abducted and did not understand where I was</p> <p>That I had caused an accident which had led to worries that they died</p>
Being cared in a dynamic environment	<p>Other patients' coughing and anxiety. Not pleasant to see someone [another patient] being ferried out, dead.</p> <p>The happiness of the staff when I woke up after having been on anesthesia for several weeks</p> <p>Isolated, the staff rationed their visits to the room</p>

TABLE 3 Examples of quotations from categories in the area *Memories of illness and hospital stay*, questions Q1 and Q2

**TABLE 4** Total number of remaining symptoms reported by the patients ( $N = 64$ ) (Q12 and Q13) and numbers of remaining symptoms among the patients presented as  $n$  (% of the cohort)

Total number of remaining symptoms reported	$n = 181$
Physical	$n = 104$
Breathlessness	$n = 28$
Reduced lung function (other)	$n = 2$
Reduced physical strength	$n = 25$
Reduced physical capacity	$n = 6$
Balance difficulties	$n = 4$
Pain	$n = 8$
Hair loss	$n = 5$
Lost sense of taste and/or smell	$n = 3$
Cough, irritation in the throat	$n = 4$
Headache	$n = 2$
Other	$n = 17$
Psychological	$n = 6$
Nightmares	$n = 1$
Lethargy/Listlessness	$n = 2$
Stress	$n = 2$
Depressed	$n = 1$
Cognitive	$n = 30$
Memory difficulties	$n = 15$
Concentration difficulties	$n = 12$
Difficulties finding words	$n = 3$
Fatigue	$n = 34$
Tiredness	$n = 12$
Mental fatigue	$n = 18$
Sleep disturbances	$n = 4$
Affected daily life	$n = 7$
Remaining symptoms	$n = 62$
None	8 (13%)
1 or 2	21 (34%)
3 to 5	24 (39%)
>5	9 (14%)

their illness had affected relationships, for instance through misunderstandings and their own insight into the hardships that their illness had entailed for their relatives. Patients with young children felt that their children had missed them a lot. Some described personality changes in their children, such as less independence.

Remaining symptoms (Q12 and Q13) (Table 1) were experienced by 84% ( $n = 54$ ) of the patients. The number of remaining symptoms described by patients ranged between one and ten (Table 4). No differences in remaining symptoms were found with age, sex, length of ICU stay, invasive ventilation, or simplified acute physiology score-3 (SAPS3). Most of the patients, 76% ( $n = 49$ ), felt that they had been able to resume daily life (Q11) (Table 1). Answers to the last open-ended question about any additional thoughts they want to share (Q13) (Table 1) concerned thoughts about the future,

gratitude toward health care staff, and shortcomings that they had experienced during their hospital stay. Some additional remaining symptoms were mentioned—these are presented in Table 4.

## 4 | DISCUSSION

The main result was that 84% stated that they had remaining symptoms such as fatigue and physical, psychological, or cognitive impairment at follow-up. Dependent on invasive ventilation and being anesthetized were common experiences. Awareness of their own health as well as other patients' health or death were described as strong memories; nightmares and hallucinations were also common memories from the ICU.

Patients described memories of both real and surreal episodes and these memories were highly present in their consciousness after discharge from ICU. This is in line with previous studies describing the memories of ICU patients.<sup>18–20</sup> Several patients mentioned awareness of other patients' health, including perceiving that a patient died in a nearby bed. This was a frightening and uncomfortable experience. To our knowledge, there is limited knowledge about patients' experiences and descriptions of other patients' health. The increased number of ICU patients during the first wave of COVID-19 required an increase in ICU capacity and resulted in temporary ICUs. These environments were not planned for ICU patients, which meant the rooms had high numbers of beds and a low ICU nurse-to-patient ratio. The temporary environments with decreased possibilities to maintain patient integrity may be one reason for clear memories of other patients in the ICU. Another reason may be that several patients in the present study ( $n=28$ , 44%) had not been sedated and could therefore be more observant of their environment, despite severe hypoxia. The enormous media attention during the first wave about the pandemic and intensive care may also be a reason for patients' increased awareness of their illness and ICU stay in the present study.

Among the patients in this study, 84% stated that they had remaining symptoms such as fatigue or physical, psychological, and cognitive impairment. The patients' descriptions of remaining symptoms can be compared with recently published data on COVID-19 patients.<sup>13,21</sup> The proportion of patients with remaining symptoms in our study was slightly higher than in previous studies. One reason for this might be that our study reported data from intensive care patients and their burden of symptoms may be higher than that of patients who have not needed intensive care. The results from our study, together with prior studies on Covid-19 patients<sup>13,21</sup> illustrate similarities to previous studies on non-COVID-19 patients regarding symptoms of PICS, as physical, psychological, and cognitive impairment.<sup>1–4</sup>

The dominating symptoms, based on patients' descriptions of their experiences, in the present study were impaired strength and energy, both physically and mentally. Eight patients (13%) stated that they had no remaining symptoms, which is in line with previously presented data.<sup>22,23</sup> Comparing our results with other studies should be done with caution, as the present study was based on patients'

descriptions of their experiences, not used validated instruments. However, our results may highlight COVID-19 infection as a risk factor for developing PICS.

Despite remaining symptoms, 62% (n=28) of those who were employed before their ICU stay had returned to work at follow-up. Other recently published data from an ICU cohort reported that 47%–84% had returned to work.<sup>22,24</sup> A younger COVID-19 population could imply more patients are in work before illness and thus lead to more patients being on sick leave. This calls for further studies.

Many patients perceived that the information they received regarding their own illness was sparse and mainly of a medical nature. Patients expressed a desire to receive more information regarding them as a person. Given the increase in ICU capacity and the many temporary ICUs with high numbers of beds and low ICU nurse-to-patient ratios, it can be assumed that writing a diary was not a priority. However, 33% of the studied patients had received a diary. Patients who received an ICU diary kept by the staff expressed gratitude about this. The diary was perceived as written for them personally and gave them an opportunity to read about their ICU stay after discharge. It can be interpreted as the value of diaries may be enhanced by these special conditions during the pandemic. The relatives could not add comments in the diary, and there were limited opportunities for the patients to discuss ICU memories with their relatives after discharge from ICU, as they did not share this specific background and the visit restrictions in the hospital. The significance of a diary for ICU patients has been described previously.<sup>25–27</sup> Our findings suggested that patients appreciated the personal information that a diary can provide and that the writing could be developed further to be more personal. Based on patients' descriptions of the benefits of an intensive care diary, the use of an intensive care diary should be highlighted and seen as a complement to the medical information patients receive during their hospital stay. However, the significance of the diary during the pandemic should be further explored in future studies. Visits from relatives were also a part of being seen as a person during hospitalization and illness.<sup>28,29</sup> Visiting restrictions during the pandemic made visits impossible or very limited and reduced the opportunity for patients to share their experiences with relatives and get help to remember afterward.

Patients were asked to answer a self-reporting questionnaire constructed by the first and the last author with experiences of ICU follow-up and qualitative methods. To our knowledge, there are no validated intensive care-specific follow-up instruments containing questions in this area at the time of this study. Predominant studies that have requested patients' experiences from intensive care are, have mainly been interview studies. The self-reporting questionnaire used in this study was based and inspired by previous studies that had interviewed and requested patients' experiences from intensive care.

#### 4.1 | Strengths and limitations

The strengths of this study included the comprehensive descriptions given by former ICU patients treated for COVID-19,

gathered using a questionnaire and person-centered approach. The questionnaire included both closed- and open-ended questions, which gave patients the opportunity to describe their experiences, thus strengthening the study's credibility. We also acknowledge some limitations to our study. The results do not include any objective measures of functional outcome giving additional information. However, patients' own descriptions add aspects that can be difficult to catch in objective measures which is valuable information. The questionnaire was in Swedish and developed for this study and has not been validated, but a majority of the questions were answered by the patients, indicating that they understood the questions. This strengthens the study's credibility but the result should be interpreted with caution as patients may have been affected by external factors affecting their response. Further, there is no opportunity to ask follow-up questions to clarify a patient's answers when using a questionnaire instead of interviews. However, this was compensated by including a larger number of patients. Lastly, the study was performed with patients from one hospital and thus reflected only the perceptions of patients treated there, and there was a loss to follow-up, but the response rate of 73% is fairly high in an ICU survivor population.

## 5 | CONCLUSION

This study revealed patients' memories from the ICU, including nightmares, hallucinations, and specific awareness of other patients' health. Patients' descriptions and perceptions of their COVID-19, ICU stay, and later health status showed that a majority reported a variety of remaining symptoms, including both physical and mental impact, three to six months post-ICU discharge. A quarter of the patients were still on sick leave and patients' workability had decreased.

### ACKNOWLEDGMENTS

The authors would like to thank the participants for sharing their experiences for this study, and research nurses for help with project and data organization. The study was funded by the SciLifeLab/Knut and Alice Wallenberg national COVID-19 research program (M.H.: KAW 2020.0182, KAW2020.0241), the Swedish Heart-Lung Foundation (M.H.: 20210089, 20190639, 20190637), the Swedish Research Council (R.F.: 2014-02569, 2014-07606).

### CONFLICTS OF INTEREST

The authors have no conflict of interest.

### AUTHOR CONTRIBUTIONS

All authors contributed to the study design. The analysis process and the first draft of the manuscript were conducted by Wallin E and Larsson I-M. All authors contributed to the manuscript and approved the final manuscript.

## ORCID

Ewa Wallin  <https://orcid.org/0000-0003-2492-8666>

Michael Hultström  <https://orcid.org/0000-0003-4675-1099>

Miklos Lipcsey  <https://orcid.org/0000-0002-1976-4129>

## REFERENCES

1. Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. *Crit Care Med.* 2012;40(2):502-509. doi:10.1097/CCM.0b013e318232da75
2. Harvey MA, Davidson JE. Postintensive care syndrome: right care, right now and later. *Crit Care Med.* 2016;44(2):381-385. doi:10.1097/CCM.0000000000001531
3. Marra A, Pandharipande PP, Girard TD, et al. Co-occurrence of post-intensive care syndrome problems among 406 survivors of critical illness. *Crit Care Med.* 2018;46(9):1393-1401. doi:10.1097/CCM.0000000000003218
4. Elliott D, Davidson JE, Harvey MA, et al. Exploring the scope of post-intensive care syndrome therapy and care. *Crit Care Med.* 2014;42(12):2518-2526. doi:10.1097/ccm.0000000000000525
5. Biehl M, Sese D. Post-intensive care syndrome and COVID-19 – Implications post pandemic. *Cleve Clin J Med.* 2020. doi:10.3949/ccjm.87a.ccc055
6. Stam HJ, Stucki G, Bickenbach J. Covid-19 and post intensive care syndrome: a call for action. *J Rehabil Med.* 2020. doi:10.2340/16501977-2677
7. Grasselli G, Greco M, Zanella A, et al. Risk factors associated with mortality among patients with COVID-19 in intensive care units in Lombardy, Italy. *JAMA Intern Med.* 2020;180(10):1345. doi:10.1001/jamainternmed.2020.3539
8. Stralin K, Wahlstrom E, Walther S, et al. Decline in mortality among hospitalised covid-19 patients in Sweden a nationwide observational study. *medRxiv.* 2020.
9. Kress JP, Hall JB. ICU-acquired weakness and recovery from critical illness. *N Engl J Med.* 2014;370(17):1626-1635. doi:10.1056/nejma1209390
10. Spadaro S, Capuzzo M, Valpiani G, et al. Fatigue in intensive care survivors one year after discharge. *Health Qual Life Outcomes.* 2016. doi:10.1186/s12955-016-0554-z
11. Wintermann GB, Rosendahl J, Weidner K, Strauß B, Hinz A, Petrowski K. Self-reported fatigue following intensive care of chronically critically ill patients: a prospective cohort study. *J Intensive Care.* 2018. doi:10.1186/s40560-018-0295-7
12. Pandharipande PP, Girard TD, Jackson JC, et al. Long-term cognitive impairment after critical illness. *N Engl J Med.* 2013;369(14):1306-1316. doi:10.1056/nejmoa1301372
13. Pilotto A, Cristillo V, Piccinelli SC, et al. COVID-19 severity impacts on long-term neurological manifestation after hospitalisation. *medRxiv.* 2021.
14. Carfi A, Bernabei R, Landi F. Persistent symptoms in patients after acute COVID-19. *JAMA.* 2020;324(6):603. doi:10.1001/jama.2020.12603
15. SFAI/SIS. *Riktlinjer för svensk intensivvård.* 2015. [https://sfai.se/wp-content/uploads/2015/02/Riktlinjer-Svensk-Intensivvård\\_rev-2015.pdf](https://sfai.se/wp-content/uploads/2015/02/Riktlinjer-Svensk-Intensivvård_rev-2015.pdf). Accessed 210819.
16. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* 2008;62(1):107-115. doi:10.1111/j.1365-2648.2007.04569.x
17. Krippendorff K. *Content analysis: an introduction to its methodology.* SAGE; 2019.
18. Olsen KD, Nester M, Hansen BS. Evaluating the past to improve the future – a qualitative study of ICU patients' experiences. *Intensive Crit Care Nurs.* 2017;43:61-67. doi:10.1016/j.iccn.2017.06.008
19. Roberts B, Chaboyer W. Patients' dreams and unreal experiences following intensive care unit admission. *Nurs Crit Care.* 2004;9(4):173-180. doi:10.1111/j.1362-1017.2004.00066.x
20. Wade DM, Brewin CR, Howell DCJ, White E, Mythen MG, Weinman JA. Intrusive memories of hallucinations and delusions in traumatized intensive care patients: an interview study. *Br J Health Psychol.* 2015;20(3):613-631. doi:10.1111/bjhp.12109
21. Huang C, Huang L, Wang Y, et al. 6-month consequences of COVID-19 in patients discharged from hospital: a cohort study. *Lancet.* 2021;397(10270):220-232. doi:10.1016/S0140-6736(20)32656-8
22. Kawakami D, Fujitani S, Morimoto T, et al. Prevalence of post-intensive care syndrome among Japanese intensive care unit patients: a prospective, multicenter, observational J-PICS study. *Crit Care.* 2021;25:69.
23. Taboada M, Moreno E, Cariñena A, et al. Quality of life, functional status, and persistent symptoms after intensive care of COVID-19 patients. *Br J Anaesth.* 2021;126(3):e110-e113. doi:10.1016/j.bja.2020.12.007
24. McCue C, Cowan R, Quasim T, Puxty K, McPeake J. Long term outcomes of critically ill COVID-19 pneumonia patients: early learning. *Intensive Care Med.* 2021;47(2):240-241. doi:10.1007/s00134-020-06313-x
25. Strandberg S, Vesterlund L, Engström Å. The contents of a patient diary and its significance for persons cared for in an ICU: a qualitative study. *Intensive Crit Care Nurs.* 2018;45:31-36. doi:10.1016/j.iccn.2017.12.004
26. Barreto BB, Luz M, Rios MNDO, Lopes AA, Gusmao-Flores D. The impact of intensive care unit diaries on patients' and relatives' outcomes: a systematic review and meta-analysis. *Crit Care.* 2019. doi:10.1186/s13054-019-2678-0
27. Åkerman E, Langius-Eklöf A. The impact of follow-up visits and diaries on patient outcome after discharge from intensive care: a descriptive and explorative study. *Intensive Crit Care Nurs.* 2018;49:14-20. doi:10.1016/j.iccn.2018.09.002
28. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med.* 2017;45(1):103-128. doi:10.1097/CCM.0000000000002169
29. Nassar AP, Besen BAMP, Robinson CC, Falavigna M, Teixeira C, Rosa RG. Flexible versus restrictive visiting policies in ICUs: a systematic review and meta-analysis. *Crit Care Med.* 2018;46(7):1175-1180. doi:10.1097/CCM.0000000000003155

## SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

**How to cite this article:** Wallin E, Hultström M, Lipcsey M, Frithiof R, Rubertsson S, Larsson I-M. Intensive care-treated COVID-19 patients' perception of their illness and remaining symptoms. *Acta Anaesthesiol Scand.* 2022;66:240-247. doi:[10.1111/aas.13992](https://doi.org/10.1111/aas.13992)