Netherlands Journal of Critical Care
Submitted February 2019; Accepted June 2019

ORIGINAL ARTICLE

Post-ICU care after a long intensive care admission: a Dutch inventory study

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Keywords - **PICS, post-ICU care, post intensive care syndrome**

Abstract

Background: The growing awareness of the long-term consequences of critical care led to various post intensive care unit (ICU) interventions for patients after their ICU admission. The aim of this study was to describe which post-ICU interventions are applied by Dutch ICUs.

Methods: A survey was conducted among all non-paediatric ICUs in the Netherlands. The person most familiar with the local post-ICU care process, the ICU representative, was asked to complete the questionnaire. The survey consisted of 41 questions regarding ICU characteristics, awareness of post-ICU syndrome (PICS), and forms of early in-hospital and late post-discharge post-ICU care. Data were collected from February until April 2018.

Results: The response rate was 97% (77 out of 79). All ICU representatives were aware of PICS. The most common interventions were in-hospital follow-up by ICU clinicians and the use of ICU diaries. Except for one ICU, all applied late post-ICU care. This varied from official outpatient post-ICU clinics (52%) to a post-ICU care app (12%). When asked, most respondents thought that PICS should primarily be recognised and treated by the general practitioner.

Conclusion: Dutch ICUs provide a large variation of post-ICU care. Evidence of effectiveness is scarce and guidelines are not available. Randomised controlled trials and guidelines which include the involvement of general practitioners are needed to improve post-ICU care in the Netherlands.

Introduction

After discharge from the ICU, patients often suffer new or worsening physical,[1-8] cognitive[9,10] and mental health[1,6,7,11,12] impairments.

The combination of these symptoms is known as post intensive care syndrome (PICS).[13] Social consequences of PICS are the inability to resume employment and reduced social participation.[1,6,14,15] PICS can persist for many years and also affect family members or informal caregivers (PICS-F).[4,13,16-19] Some risk factors for developing PICS are immobility, pre-existing impairments, age, sedation, duration of mechanical ventilation, delirium and sepsis. In the last two decades several post-ICU interventions have been studied, showing conflicting results regarding effectiveness and cost-efficacy.[5,20,21] Three systematic reviews show only small, if any, improvements in psychological outcomes for different types of post-ICU care, while all state that the amount of evidence is too limited for firm conclusions.[5,20,22] Only the use of prospective diaries mitigates unfavourable mental health outcomes as depression or anxiety after ICU discharge.[5,20,22,23] In 2012, Van der Schaaf et al. conducted a survey among 82 Dutch ICUs to describe the post-ICU care provided in the Netherlands. They recommended the implementation of outpatient post-ICU clinics.[24] Today, the growing awareness of PICS and the lack of solid evidence-based medicine-guided treatment and guidelines has led to a wide diversity of applied post-ICU care.

In this study, we aimed to describe how post-ICU care is organised by Dutch adult ICUs in well-organised First World countries five years after Van der Schaaf's survey, to assess awareness of PICS and to clarify which healthcare provider should recognise and guide the treatment of PICS after hospital discharge, according to ICU caregivers.

Methods

Subjects

All adult ICUs (n=79) in the Netherlands were invited to participate in the survey regarding post-ICU care. A list of all adult ICUs was obtained through the Netherlands Society of Intensive Care (NVIC). The person most familiar with the local post-ICU care process was contacted by telephone. Participants could be ICU physicians, ICU nurses or ICU managers. The survey could be answered immediately by telephone. Otherwise,

a follow-up call was arranged. If this was not feasible, the online version of the survey was sent by email. A reminder by telephone or email was issued after two and four weeks. The study was registered at the Local Institutional Review Board of the Catharina Hospital, Eindhoven, the Netherlands. As a result of the non-interventional character of the study, the institutional review board approved this study, without the need for informed consent (W18.029)

The survey

The survey consisted of 41 questions, which were clustered in five categories: ICU characteristics; early, in-hospital, post-ICU care; late, post-discharge, post-ICU care; experiences with different types of post-ICU care; and the awareness of PICS. Although all questions were primarily closed-ended, open ad lib comments were always recorded. The questionnaire was based on expert opinions and surveys in previous published studies. [5,20, 24,25] The questionnaire is added in *appendix 1*:
https://njcc.nl/file/19-26-hendriks-appendix1-link-website-pdf
The methodological quality of the questionnaire survey was reviewed by an independent medical epidemiologist.
The survey was entered in the online platform 'Survey Monkey' to collect the answers. To prevent grammatical or technical problems and misinterpretations, the survey was pilot-tested and verified by two physicians and two nurses of the Intensive Care Department at the Catharina Hospital, Eindhoven.

Data collection

Data were collected from 20 February 2018 to 13 April 2018. The survey started with the collection of ICU characteristics. The requested characteristics were the number of ICU beds, and type of ICU, differentiating academic hospitals from teaching hospitals and general ICUs from cardiothoracic, neurosurgical or trauma ICUs.
Early (in-hospital) post-ICU care was defined as follow-up by the ICU team during the period after discharge to the general ward and before hospital discharge. A handover from the ICU to the nursing ward was not considered as early post-ICU care.
Late (post-discharge) post-ICU care includes all ICU-initiated interventions that could help the patient after hospital discharge. Participating ICUs were asked if they provided one or more forms of post-ICU care as reported in the literature, such as outpatient post-ICU clinics, telephone consultations, multidisciplinary rehabilitation programs, ICU diaries and ICU visits.[5,20,25] Post-ICU interventions not included in the survey could be mentioned by the participants and were then added as free text if the survey was entered by telephone or recorded in the open fields of the online survey. In addition, the persons answering the survey were asked about the design of their post-ICU care, their experiences and the potential limitations that ICUs experienced in providing post-ICU care.
ICU representatives were asked to describe the meaning of PICS in order to gain insight into the awareness of PICS and the presumed local prevalence of PICS.
In addition, responders were asked which healthcare providers should be responsible for the recognition of PICS and for guidance regarding the treatment of long-term consequences of critical care after hospital discharge. Finally, responders were asked to share their opinions regarding the effects of post-ICU interventions.

Statistical analysis

Data analysis primarily consisted of descriptive statistics, and outcomes were mainly described in percentages or proportions. The Chi-squared test was used to quantify significant differences between ICU characteristics and applied post-ICU care, or Fisher's exact test when appropriate. To this end, the ICUs were clustered in three groups based on their sizes: less than 10 beds, 10 to 20 beds, and more than 20 beds. A p-value $p \leq 0.05$ was chosen for statistical significance. Data were converted with SPSS statistics version 24. Microsoft Excel version 16.1 was used for graphics.

Results

The overall response rate of the survey was 97% (77 out of 79). Fifty-nine ICUs (77%) answered the survey questions by telephone. The semi-structured interviews by telephone were done by one researcher. *Table 1* shows the main characteristics of the participating ICUs.

Table 1. Characteristics of participating ICUs (n=77)

ICU size	N (%)
<10 beds	30 (39)
10-20 beds	33 (43)
>20 beds	14 (18)
ICU type	
General	49 (64)
General + Trauma	4 (5)
General + Cardiothoracic surgery	4 (5)
General + Neurosurgery	2 (3)
General + Trauma + Cardiothoracic surgery	2 (3)
General + Trauma + Neurosurgery	7 (9)
General + Trauma + Cardiothoracic surgery + Neurosurgery	9 (12)
Hospital type	
Academic	7 (9)
Peripheral	70 (91)
Post-ICU care	
None	1 (1)
Only early post-ICU care	2 (2)
Only late post-ICU care	31 (40)
Both early and late post-ICU care	43 (56)

Post-ICU care characteristics in general

Post-ICU care was provided by 99% (n=76) of the participating ICUs. The majority of the ICUs offered post-ICU care based on the criterion length of stay, which was mostly between 48 and 72 hours of ICU admission. Other criteria where the duration of mechanical ventilation, a clinical assessment or a combination of the three mentioned criteria. The majority of the ICUs (70%) organised their local post-ICU care based on local guidelines, protocols or checklists. Family members were involved in different forms of post-ICU care in 70% of the ICUs that offered post-ICU care. *Table 2* shows the main characteristics of post-ICU follow-up care.

Table 2. Characteristics of post-ICU care in general (n=76)

Inclusion criteria for receiving post-ICU care	N (%)
Length of stay on ICU	28 (37)
Duration of mechanical ventilation	6 (8)
Clinical assessment/expectation of problems arising	5 (7)
Combination of the three criteria above	29 (38)
Length of stay on ICU + clinical assessment	13 (17)
Length of stay on ICU + length of mechanical ventilation	9 (12)
Length of stay on ICU + length of mechanical ventilation + clinical assessment	5 (7)
Length of mechanical ventilation + clinical assessment	2 (3)
All patients	4 (5)
On request	3 (4)
Unknown	1 (1)
Involving family members	
No	23 (30)
Only in early post-ICU care	3 (4)
Only in late post-ICU care	29 (38)
Both in early and late post-ICU care	21 (28)
Using guidelines/protocols/checklists	
No	23 (30)
Only for early post-ICU care	9 (12)
Only for late post-ICU care	25 (33)
Both for early and late post-ICU care	19 (25)

Early and late post-ICU care

Figure 1 shows the prevalence of each applied post-ICU intervention. Of all these ICUs, 77% paid special attention to PICS (n=57).

Early post-ICU care: After ICU discharge, 95% (n=73) of the ICUs had representatives visiting patients that they believed needed follow-up. Almost all follow-up visits were done by ICU nurses (n=72 of 73), while intensivists participated in the follow-up visits in four hospitals (5%). The main limitations for providing early post-ICU care were lack of staff, lack of time and lack of evidence for the effectiveness of post-ICU care.

Late post-ICU care: Seventy-four ICUs (96%) provided some form of late post-ICU care.

ICU revisiting and diaries

Almost all ICUs (n=73, 95%) provide the opportunity to revisit the ICU after ICU discharge. During ICU admission, the majority of ICUs provide ICU diaries (n=67 (87%)), which are mostly written by the patients or by their family during the patients' ICU stay (n=54 (81%)). Thirty of these ICUs also evaluate if patients used their diary.

Outpatient clinics and telephone consultations.

An official outpatient post-ICU clinic was reported to be available in 52% (n=40) of the ICUs, while 27% (n=21) offered face-to-face post-ICU consultations. In 46% (n=28) of the ICUs that offer consultations, a first post-ICU consultation is planned between three to six months after discharge from the hospital. Most of the consultations were conducted both by an intensivist and an ICU nurse (n=34 (56%)), while 41% (n=25) are provided only by an ICU nurse. In 11 of the 40 outpatient post-ICU clinics, consultations were provided by other medical disciplines, such as rehabilitation doctors (n=4), psychologists (n=5) and physiotherapists (n=9).

Post-ICU telephone consultations were provided by 33 ICUs (43%) and were mainly conducted by ICU nurses (91%). Of these ICUs, 25 mainly use these consultation calls to invite patients for their face-to-face consultations, unless a patient is unable to come to the hospital, in which case the telephone call is used for a real post-ICU consultation.

Other forms of late post-ICU care

A total of 95% of the ICUs also provided another form of post-ICU care, such as handing out leaflets (n=48 (62%)), referring to websites (n=39 (51%)), organising peer-group meetings (n=11 (14%)), or multidisciplinary rehabilitation programs with a rehabilitation physician (n=9 (12%)). A post-ICU care app was implemented in three ICUs (4%), while six ICUs are currently developing a post-ICU care app. Most of the ICUs (n=56 (73%)) provide the opportunity to contact the ICU by telephone or email after discharge. Of the 74 ICUs that offer late post-ICU care, 67 ((91%)) inform the general practitioner about the admission by letter (n=66) or telephone (n=1). Half of these ICUs inform the general practitioner about the outcome of their post-ICU care (n=12 (16%)) or about how to recognise and treat long-term ICU symptoms or PICS (n=25 (34%)).

Experiences with post-ICU care

Most of the ICU representatives (n=64 (83%)) believed that the post-ICU interventions they used were effective for preventing or treating post-ICU symptoms. Ten ICU representatives had no clear opinions about the effectiveness of their interventions, while two believed that their post-ICU interventions are not effective for preventing or treating post-ICU symptoms.

Five ICUs experienced no limitations for providing post-ICU care. The most common limitations were lack of financial means (n=55 (74%)), time (n=55 (74%)) and medical staff members (n=46 (62%)). The lack of guidelines (n=27 (36%)) and scientific evidence on effectiveness (n=26 (35%)) was less often reported

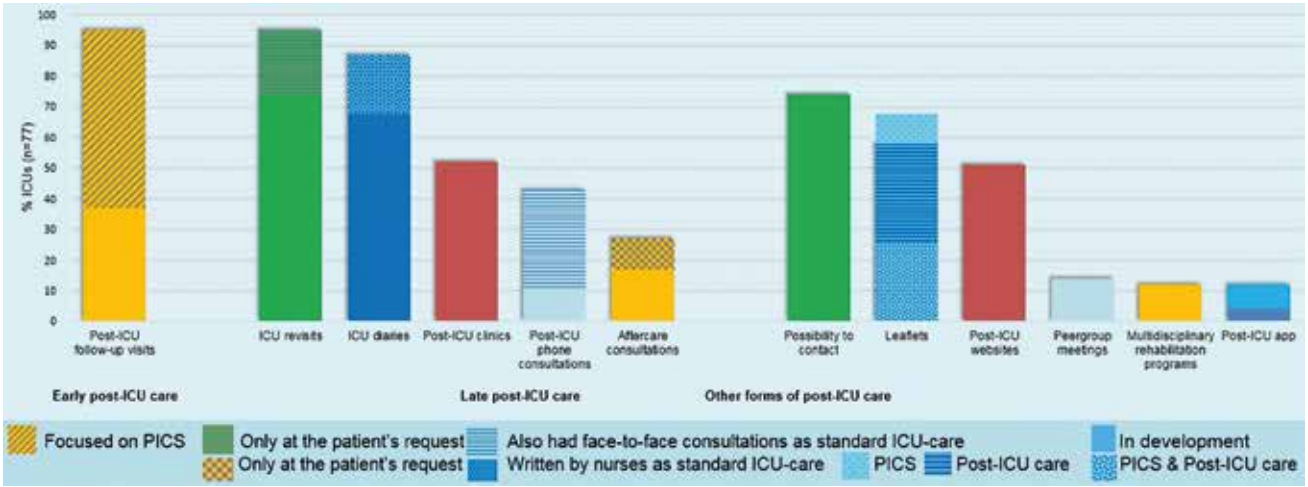

Figure 1. Percentage of Dutch ICUs providing different forms of ICU aftercare

as a limitation. The majority of the ICUs (n=66 (86%)) would like to provide more post-ICU care if there were no limitations.

PICS

All representatives were aware of the term PICS. When asked to define PICS, only 36% (n=28) described all three domains (physical, cognitive and psychological). Almost a quarter of the ICU representatives (n=18 (23%)) did not know what the prevalence of PICS was within their ICUs. A majority of the respondents replied that the general practitioner should have a central role in recognising and treating post ICU symptoms *(figure 2).*

Discussion

In the Netherlands, post-ICU care is diverse with no clearly structured approach or guideline. This inventory study with a response rate of 97% improves our insight into which post-ICU interventions are provided in the Netherlands. Except for one, all responding ICUs provide post-ICU care. More than half provide early in-hospital post-ICU care, while 96% provide late post-ICU care after hospital discharge. The most commonly provided types of post-ICU care were in-hospital follow-up by ICU clinicians and ICU diaries. There were no significant differences between the characteristics of ICUs that did or did not provide any of the different forms of post-ICU care. All participants were aware of PICS, although fewer were familiar with the formal definition of the syndrome. The majority of the respondents believe that the recognition (47%) and treatment (54%) of PICS is mainly a task of the local physician. Their considerations and the best method to manage this are interesting topics to explore further. Compared with the study by Van der Schaaf et al. in 2012, our findings indicate that the provision of post-ICU care has increased in the Netherlands.[24] In 2012, follow-up care was provided by 40% of the responding ICUs (n=23), which varied from follow-up on the general ward to post-ICU clinics, consultations at the request of patients, patient information days and organised peer-group meetings. None of the hospitals provided follow-up consultations by telephone, while nowadays post-ICU telephone consultations are provided by almost half of the ICUs.[24]

Similar studies in Denmark (2016; 100% response rate) and Norway (2014; 59% response rate) reported similarly high prevalences of post-ICU care, with 84% in Denmark and 69% in Norway.[25,26] This high prevalence might be explained by an increased awareness due to the publication of a national recommendation for the use of patient diaries.[27] In line with the present study, the most common post-ICU interventions in these Scandinavian studies were post hospital discharge patient revisits and the use of ICU diaries. The use of ICU diaries differs between countries. In most countries, nurses were the main authors of these diaries, while in Dutch ICUs, the main authors are the patients or their families.[26,28,29]

In contrast to our finding that 52% of the included Dutch hospitals have post-ICU clinics, the prevalence in the United Kingdom was 30% in 2006 and in Denmark it was 13% in 2016.[24,25,30] The presence of these outpatient post-ICU clinics in the Netherlands has more than doubled since 2012, when Van der Schaaf et al. reported a prevalence of 25%. This increase might be explained by the recommendations by Van der Schaaf et al. in 2012 because of increased awareness and the willingness to help people after experiencing a serious life event. However, considering the available evidence, this widespread use of outpatient post-ICU clinics is remarkable since randomised controlled trials (RCTs) reporting reductions of PICS symptoms remain scarce and show conflicting results. Only a few RCTs on post-ICU clinics have been published, and the methodological quality varied.[1,22] In contrast, a systematic review and meta-analysis reported that post-ICU clinics did not improve quality of life, symptoms of depression and anxiety, or physical and cognitive outcomes. The only effect shown was the reduction of symptoms of post-

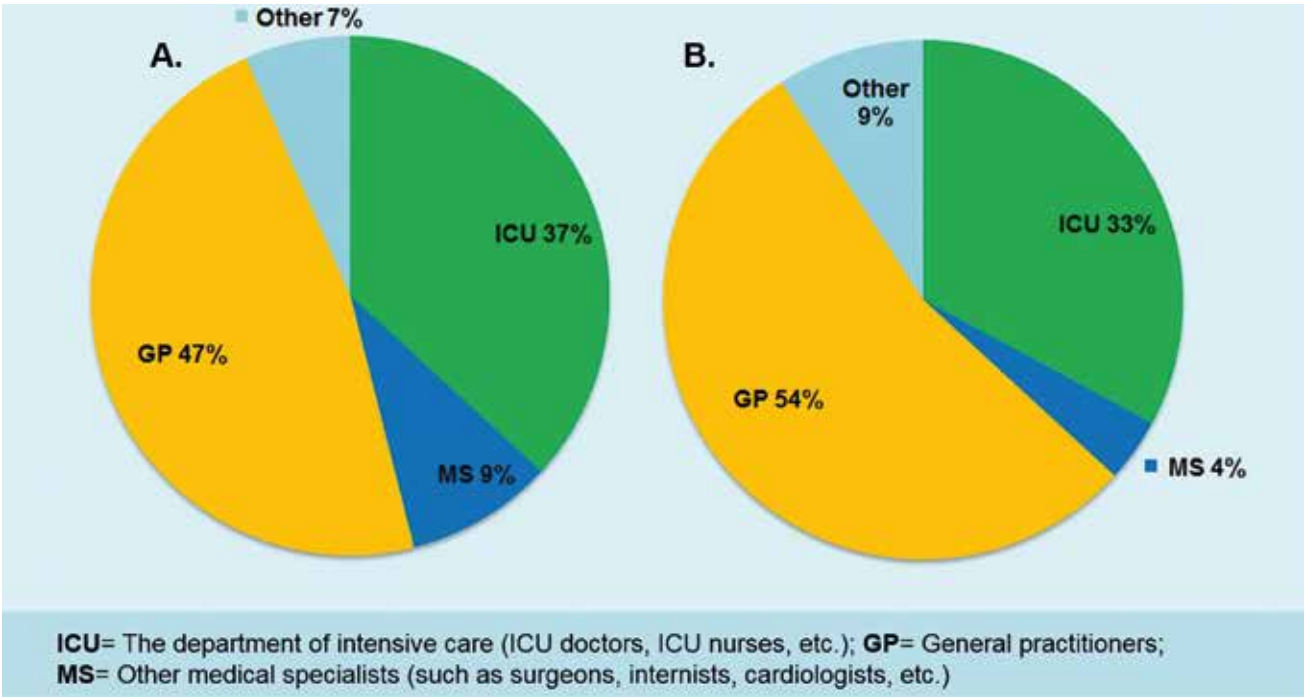

Figure 2. Percentage of ICU representatives who believe that this medical institution or individual should be most responsible for (A) recognising PICS and (B) guiding PICS

traumatic stress disorder.[22] This outcome could be a result of reframing the ICU experience because of unintentional use of cognitive behavioural therapy.[1,20,22,23] Moreover, Hernandez et al. (the PRaCTICaL trial; 2014) demonstrated that post-ICU follow-up clinics are not cost-effective.[21]

Other post-ICU interventions, such as post-discharge ICU revisiting, peer-group meetings and the use of post-ICU care apps, have not been sufficiently investigated to consider them useful as modalities to prevent or treat PICS.[31] Limitations of our study are the general limitations of a survey. First of all, the results of the survey depend on the participating persons' knowledge of post-ICU interventions. To overcome this limitation, participants were chosen who were the most familiar with the local post-ICU care process. Secondly, it is important to keep in mind that respondents could feel obligated to respond in socially desirable ways, especially when the survey was answered by telephone. In addition, all interviews by telephone were done by one researcher. Hence, the results may have been influenced by interviewer bias.

The large application and diversity of post-ICU interventions is probably the result of the desire to help patients after a serious life event while a structured guideline for this post-ICU care is absent,[2,3] resulting in a great variety of post-ICU interventions. However, it remains hard to provide recommendations for establishing a guideline since evidence of post-ICU care is scarce, inconsistent and of varying methodological quality.

The majority of the ICU representatives suggest the need for recognising and guiding patients with long-term consequences of critical care by the general practitioner or local physician. The extent of impairment in PICS spans several domains, therefore the treatment of ICU survivors with these impairments needs expertise from a wide array of clinical teams. Therefore, the communication to, and the involvement and education of the general practitioner or other medical specialists, for whom ICU patients are not part of their daily practice, should be investigated. In patients at high risk for developing PICS, we recommend sending a standard letter from the ICU to the general practitioner. This letter should include regional agreements about the organisation of post-ICU care, so patients could be referred easily to physiotherapists, psychologists or occupational therapists if necessary.

In the end, careful evaluation of applied interventions and proper research with RCTs focussing on these post-ICU interventions, prevention of PICS during ICU admission, and involvement of local caregivers seem to be most warranted now. However, it will be difficult to perform these RCTs due to the heterogeneity of the ICU population and diversity in available interventions and widespread definitions of outcome measures. To achieve that, a clear international or national consensus will be indispensable for formulating standardised outcome measurements for different domains of PICS. And although some studies already suggest that clinical interventions might lower incidences of PICS,[32] a clear consensus will definitely help to better evaluate whether PICS is indeed preventable during the ICU admission.

Conclusion

Dutch ICUs provide a large variety of post-ICU care. The majority of ICU representatives believed the interventions they used had positive effects on treating or preventing post-ICU symptoms. However, the evidence of effectiveness is scarce and conflicting. Structured evidence-based guidelines, randomised controlled trials, and a focus on prevention and involvement of general practitioners are needed to harmonise and improve post-ICU care in the Netherlands.

Disclosures

All authors declare no conflict of interest. No funding or financial support was received.

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