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RESEARCH ARTICLE

Outcomes of prolonged intensive care and rehabilitation at a specialized multidisciplinary center in Sweden

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Abstract

Background: Specialized clinics may improve the outcome for patients with prolonged intensive care stays. Admission may depend on diagnosis, need of respiratory support and more. We report the results from a Swedish specialized center with a multidisciplinary team approach to continued intensive care and simultaneous rehabilitation regardless of patients' primary diagnosis or ventilator need.

Methods: All patients admitted and discharged from 2015 to 2018 were included. Demographics, diagnoses, ventilatory support requirement, discharge destination and survival were retrieved from the center´s quality registry.

Results: A total of 181 patients, mean age 61 ± 16 years, 64% men, were analyzed. A neurological diagnosis was the cause for hospitalization in 46% of patients. Of the 55 patients admitted to the center for weaning from mechanical ventilation, 89% were successfully weaned within a median of 25 (interquartile range (IQR) 16–45) days. Decannulation was intended in 117 patients of which 90% were successful within a median of 25 (IQR 13–43) days. Readmission to intensive care was 4%. Most patients were discharged to their home or to rehabilitation clinics with a lower level of care. In-clinic mortality was 3%. Survival beyond 1 and 2 years after discharge was 79% and 70%, respectively.

Conclusion: Patients with prolonged intensive care and complex medical needs treated at a specialized center in Sweden had weaning and decannulation rates comparable to or better than previously reported. Mortality was low, and most patients were discharged home or for further rehabilitation. This was achieved with a multidisciplinary team approach to continued intensive care and simultaneous rehabilitation.

KEYWORDS
chronic critical illness, decannulation, multidisciplinary team, persistent critical illness, post-intensive care rehabilitation, prolonged intensive care, prolonged mechanical ventilation, weaning from mechanical ventilation

Editorial Comment

This report concerns a multidisciplinary, specialized rehabilitation unit managing long-term ventilator-dependent patients. The unit is not localized within an acute care hospital. The results from this cohort show promising results.

1 | INTRODUCTION

With the advancements in intensive care medicine, more patients survive the acute phase of critical illness. As a result, the number of patients that require prolonged intensive care treatment is growing. In the general intensive care unit (ICU) population, between five and ten percent of patients fall into this category,[1-4] the fraction likely higher in the elderly, after sepsis, surgery or traumatic injury.[5,6] As these patients commonly need a considerably longer ICU stay than average, it is estimated that more than one-third of ICU beds are utilized for this patient group.[3,4] Not only is a vast amount of resources required to treat these patients, it is also increasingly recognized that traditional intensive care commonly cannot provide the continuity, rehabilitation and supportive therapy these patients require.[7,8] Acknowledging these needs, specialized clinics have been developed in several countries to improve patient outcomes while simultaneously reducing the burden on traditional intensive care. Reports from such clinics are important, as this is a field under development and reasons for variations in the outcome should be analyzed.

Historically, patients requiring prolonged intensive care had a poor prognosis, particularly if mechanical ventilation was required.[1,7,9] More recent studies from specialized clinics challenge this notion and indicate better outcomes.[10-13] Importantly, patient selection, content and quality of care provided, organization of society and health care, local traditions, population size and health status, and several other factors vary significantly between regions and should be considered when outcomes are compared. To our knowledge, this is the first report from a specialized clinic in the Nordic countries. The Remeo Clinic was started in 2013 in Stockholm, Sweden, and has since established a multidisciplinary approach to continued intensive care combined with simultaneous individualized rehabilitation. In this report, we provide an analysis of 181 patients admitted between 2015 and 2018.

2 | MATERIALS AND METHODS

This study was based on data from 2015 to 2018 reported routinely to a quality registry database at the Remeo Clinic in Stockholm, Sweden. Data for the descriptive study was retrieved from the database retrospectively. Patients with prolonged ICU stays and patients who had been discharged from an ICU after a prolonged stay and had a high risk of return were accepted to the center. Invasively mechanically ventilated patients with a tracheostomy tube were accepted, while endotracheally intubated patients were not. Further criteria rendering patients not eligible for admission to the center are presented in Table 1. Prolonged intensive care patients no longer in need of mechanical ventilation were accepted if adequate treatment and rehabilitation could not be provided elsewhere. Continued intensive care with simultaneous rehabilitation adjusted to each patient's need and ability was provided through multidisciplinary teams consisting of physicians, nurses, physiotherapists, occupational therapists, speech and language pathologists, dieticians, social workers, engineers, and other specialists and health care professionals when needed. The majority of the patients were referred to the center from the university hospitals in the Stockholm region, however, patients from other parts of Sweden were also accepted. The Remeo clinic in Stockholm was at the time of the study owned by AGA Gas AB (Lidingö, Sweden), a part of The Linde Group (Munich, Germany). In January 2015, the center had six beds and then gradually expanded to eleven beds by the end of 2018. The study was approved by the Regional Ethical Review Board in Stockholm (Dnr 2019-04466).

TABLE 1 Admission exclusion criteria.

Endotracheal intubation
Severe circulatory instability requiring continuous intravenous therapy
Continuous renal replacement therapy
Need of continuous intravenous sedation
Active drains
End-of-life care[a]

Note: Patients who, after evaluation by the Remeo team, were found too unstable for safe transfer to the center remined in their respective ICUs for later transfer.

[a]Patients were not accepted for end-of-life care on admittance. However, patients deteriorating while at the center, and eventually entering a palliative stage of care, were allowed to stay.

All patients with an admittance date on or after January 1, 2015, and a discharge date before or on December 31, 2018, were included in the study. Patients not admitted from acute care hospitals were excluded. The primary outcome measures were defined as in-clinic mortality and one-year survival after discharge. For patients with invasive mechanical ventilation and patients with a tracheostomy, additional primary outcome measures were weaning from mechanical ventilation and decannulation. Secondary outcome measures were two-year survival after discharge for all patients. For invasively ventilated or tracheostomized patients, additional secondary outcome measures were time to weaning from mechanical ventilation and time to decannulation. Discharge destination was considered an exploratory outcome measure for all patients.

Invasive mechanical ventilation was defined as all ventilator modes and settings providing controlled ventilation or supported spontaneous breathing via a tracheostomy. Patients were considered weaned from invasive mechanical ventilation the first day they no longer needed ventilatory support via the tracheostomy unless mechanical ventilation was resumed before discharge. Patients with an intermittent need of invasive mechanical ventilation during the day were considered not successfully weaned. Decannulated patients receiving non-invasive ventilatory support via mask part of the day were considered successfully weaned, while patients with a tracheal cannula using non-invasive ventilatory support as

habituation before decannulation were not. Non-invasive ventilatory modes provided either airway pressure varying through the breathing cycle (BilevelPAP) or continuous positive airway pressure (CPAP). Decannulation was defined as successful if the patient was discharged without a tracheal cannula. If more than one attempt at decannulation was made, time to decannulation was defined as the time from admittance to the center until the final decannulation before discharge.

2.1 | Statistics

For categorical data, we used the Pearson Chi-Square test. Non-parametric analysis was used for data that were assessed as skewed. Mann–Whitney U test and Kruskal-–Wallis ANOVA test were used for comparison of continuous data between groups. Mortality analysis was performed using Cox regression analysis. All statistical analysis was performed using SPSS Statistics Version 27 (IBM Corp). p-values < 0.05 were considered statistically significant. Continuous data are shown as mean ± standard deviation (SD) or median and interquartile range (IQR) as appropriate.

3 | RESULTS

A total of 183 patients were admitted to and discharged from the center between 1 January 2015 and 31 December 2018. All 183 patients were included in the study, however, two patients were excluded as they were community service patients not admitted from acute care hospitals rendering 181 patients for analysis. Patient characteristics are reported in Table 2.

The median length of stay (LOS) in an acute care hospital before transfer to the center was 45 (IQR 31-77) days. The absolute majority of patients, 177 (98%) spent more than 10 days in an acute care hospital before transfer.

Eighty-three (46%) of the included patients had neurological primary diagnoses, making this the most common in the studied group (Table 2). Of these, 71 related to central, and 12 to peripheral neurological diseases. Of the 71 patients with central neurological disease, 32 suffered from traumatic injuries, with the majority being traumatic brain injuries. Another seven patients had non-neurological traumatic injuries as their recorded main diagnosis. Of the 24 patients with infection main hospital admission diagnoses, 14 had sepsis and ten had pneumonia combined with severe underlying

TABLE 2 Patient characteristics.

Age	Overall age for study population—mean (SD)	61 (±16)
Sex	Male—n (%)	117 (65)
	Female—n (%)	64 (35)
Main diagnosis on acute care hospital admission	Neurological diagnoses[a]—n (%)	83 (46)
	-Traumatic neurological diagnosis—n	32
	- Infectious neurological diagnosis—n	7
	Thoracic and vascular[b]—n (%)	33 (18)
	Infection (excluding neurological infections)[c]—n (%)	24 (13)
	Cancer surgery (excluding neurological surgery)—n (%)	17 (9)
	Trauma (excluding neurological trauma)—n (%)	7 (4)
	Respiratory failure—n (%)	4 (2)
	Other[d]—n (%)	13 (7)
Surgery as reason for acute care hospital admission	Elective procedures—n (%)	42 (23)
	Acute procedures—n (%)	56 (31)
Referred from	Intensive care unit—n (%)	148 (82)
	Step-down or High depency unit—n (%)	29 (16)
	Regular ward—n (%)	4 (2)

[a]Neurological main diagnoses included mainly traumatic injuries, viral and bacterial infections, cerebrovascular incidents, tumors, Guillain-Barré syndrome and polyneuropathies.

[b]Thoracic and vascular main diagnoses included mainly aortic aneurysms, cardiac arrests and endocarditis.

[c]Infection main diagnoses included primarily sepsis.

[d]Other included patients in whom one main diagnosis could not be determined from the dataset.

diseases. Another seven patients had infections in the nervous system, here reported as neurological main diagnoses.

3.1 | Weaning from mechanical ventilation and decannulation

Sixty-two patients (34%) were dependent on invasive mechanical ventilation on admittance. Seven of them were planned for lifelong invasive mechanical ventilatory support and were therefore not subjected to weaning attempts. Reasons for this were high cervical spinal cord injury and progressive neurological disease without the possibility to recover. Of the 55 patients who underwent weaning attempts, 49 (89%) were successfully weaned (Table 3). The median time to successful weaning from mechanical ventilation was 25 (IQR 14-39) days after transfer to the center. Forty-five (92%) of the successfully weaned patients were free from invasive mechanical ventilation within 90 days from transfer to the center. The remaining four patients' weaning times ranged from 114 to 126 days. Of the 20 patients who underwent weaning attempts and had a neurological main diagnosis, 16 were successfully weaned. All six patients with peripheral neurological disease and 10 of 14 patients with central neurological main diagnoses who underwent weaning attempts were eventually weaned, with median weaning times of 36 (IQR 19-81) and 27 (IQR 15-50) days, respectively. Statistical analysis of weaning success from mechanical ventilation and diagnoses was not performed due to the small number of patients in some of the groups. Patients who could not be weaned from mechanical ventilation were in most cases transferred home with ventilator care and community provided personal care assistants.

The use of non-invasive ventilatory support is reported in Table 3. No patient was treated continuously with non-invasive BilevelPAP or CPAP at the time of discharge from the center. Rather, these forms of respiratory support were used nocturnally and, if needed, during bedrest daytime.

One hundred and thirty-one patients (72%) were tracheostomized before admittance to the center. Fourteen of these had a previous decision not to pursue decannulation attempts due to a projected lifelong need of an artificial airway. Seven of these patients were permanently dependent on invasive mechanical ventilatory support and the remaining seven had permanently compromised upper airways.

Of the 117 patients in whom decannulation was an intended goal, 105 (90%) had the tracheal cannula successfully removed (Table 3). The median time to decannulation was 24 (IQR 13-43) days. The median time to decannulation for patients dependent on mechanical ventilation on admittance to the center was 36 (IQR 22-58) days while patients who were no longer mechanically ventilated on admittance had a median time to decannulation of 19 (IQR 8-27) days. In 99 (94%) of the successfully decannulated patients, the tracheal cannula was removed within 90 days from arrival at the center. Six patients had longer decannulation times, ranging from 103 to 121 days. Sixty-seven of the patients subjected to decannulation attempts had a neurological main diagnosis and 59 of them were eventually decannulated with a median time to successful decannulation of 22 (IQR 12-41) days. Seven of the eight patients with a peripheral neurological main diagnosis and 52 of the 59 patients with a central neurological main diagnosis were decannulated with median times to decannulation of 36 (IQR 21-72) and 22 (IQR 9-36) days, respectively. Successful decannulation did not differ significantly between main diagnoses nor did time to decannulation ($p = 0.2$).

3.2 | Length of stay and discharge destination

The median LOS at the center was 47 (IQR 28-75) days. Patients with a tracheostomy on admittance had a longer LOS compared to patients with no tracheostomy, 53 (IQR 34-84) vs. 37 (22–52) days ($p = 0.03$). Three patients had a LOS of more than one year. The reasons for these prolonged stays were mainly unrelated to medical need but rather pertaining to administrative difficulties concerning discharge planning. There was no significant association between the median length of stay and the primary diagnosis ($p = 0.5$).

Of the 181 included patients, 168 (93%) recovered to be discharged to a lower level of care (Figure 1). Most patients improved to be accepted for further rehabilitation at clinics dedicated to specific diagnoses (51 patients, 29%) or could return straight to their

TABLE 3 Respiratory outcomes.

Invasive ventilation	Patients in whom weaning from mechanical ventilation was attempted—*n*	55
	Patients successfully weaned—*n* (%)	49 (89)
	Days to weaning—median (IQR)	25 (14–39)
Tracheostomy	Decannulation an intended goal—*n*	117
	Patients successfully decannulated—*n* (%)	105 (90)
	Days to decannulation—median (IQR)	24 (13–43)
Non-invasive ventilation support	BilevelPAP or CPAP during stay at the center—*n* (%)	50 (28)
	Of which had BilevelPAP or CPAP at home prior to hospital admission—*n*	13
	BilevelPAP continued after discharge—*n*	25
	CPAP continued after discharge—*n*	11

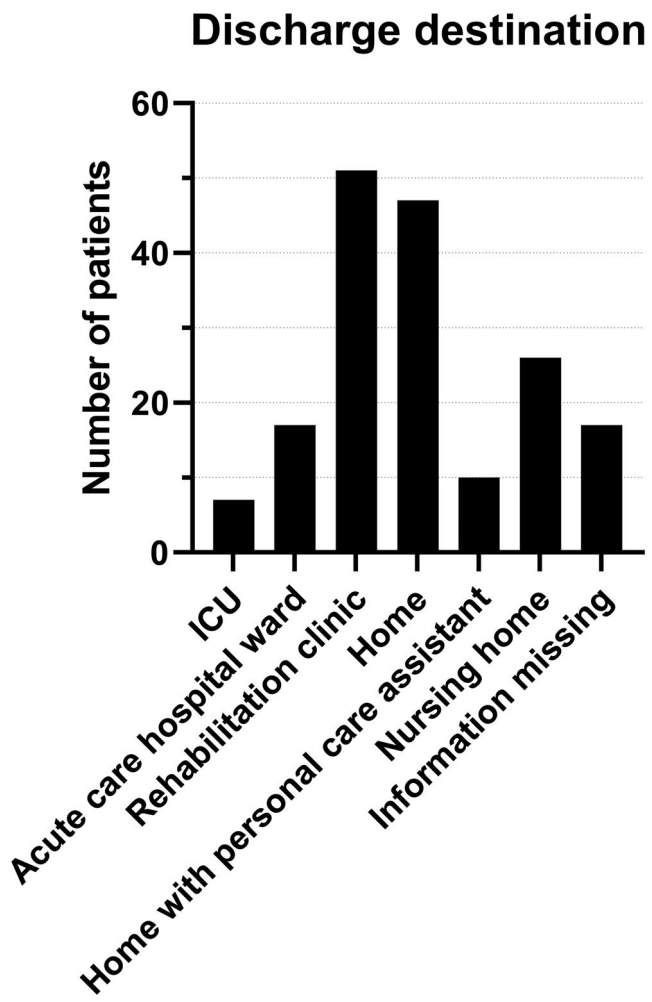

FIGURE 1 Discharge destinations for the 175 surviving patients. Seven patients (4%) needed readmission to intensive care units and did not return to the center. Seventeen patients (10%) were discharged to acute care hospital wards. Fifty-one patients (29%) recovered to be accepted for further rehabilitation at clinics specialized on specific diagnoses and with a lower level of care. Forty-seven patients (27%) could return straight to their home from the center and another 10 patients (6%) could return to their home with the help of personal care assistants. Twenty-six patients (15%) were discharged to nursing homes. Specific discharge destinations for patients sent to their local hospital outside the Stockholm region were not recorded and information was therefore missing for 17 patients (10%).

home (47 patients, 27%). Another 10 patients (6%) were discharged to their home with the help of personal care assistants. Seventeen patients (10%) were discharged to regular wards at acute care hospitals for further treatment and planning. Seven patients (4%) suffered acute worsening of their conditions and were transferred to intensive care units and did not subsequently receive further care at the center. Twenty-six patients (15%) were discharged to nursing homes. Seventeen patients (10%) were sent to their local hospital outside the Stockholm region for further rehabilitation and home planning. Data for the exact discharge destination for these patients were therefore missing. Seven patients (4%) needed transfer to an acute care hospital sometime during their stay at the center but could then return to continue their care and rehabilitation.

3.3 | Mortality

Six patients died at the center rendering an in-clinic mortality of 3%. A Kaplan–Meier plot of 2-year survival from the time of discharge from the center for the remaining 175 patients is shown in Figure 2. Seventeen patients died during the first 30 days after discharge. Three of these were among the seven sent to ICU due to acute deterioration. Another 19 patients died during the following 11 months, and an additional 16 in the second year after discharge, rendering a 1- and 2-year survival after discharge of 79% and 70%, respectively. There was no significant association between 1- or 2-year mortality and the main diagnosis on hospital admission ($p = 0.1$ and $p = 0.4$, respectively).

4 | DISCUSSION

In this study performed at a Swedish specialized rehabilitation center for patients with a prolonged need of intensive care, we found success rates for weaning from mechanical ventilation and decannulation comparable to or better than previously reported from similar clinics.[9-13] The majority of patients were discharged to a lower level of care, mostly for further specialized rehabilitation or directly to their home, while mortality at the center and during the two years follow-up after discharge was lower than reported by others.[5,10,11,13-16] However, all comparisons of our results to patient outcomes in other clinics are hazardous due to potential differences in patient characteristics. There are to our knowledge no previous reports from specialized clinics in the Nordic countries. This is important, as regional as well as national differences in population size and density, organization of society and health care, and local tradition may affect the possibilities of providing high-quality care and outcomes.

The present results were achieved with a multidisciplinary team approach to individualized advanced medical treatment and simultaneous rehabilitation. This has been found to be characteristic for successful clinics with a similar focus.[8] Though the multidisciplinary team was comprised of experienced healthcare professionals, staff was trained on site to achieve specific necessary skills in complicated weaning from mechanical ventilation and decannulation. This may have contributed to favorable patient outcomes; however, patient characteristics likely also had an impact. Respiratory failure as primary hospital admission diagnosis occurred in only 2% of the included patients and weaning attempts were continued for a relatively long time which may have contributed to the high success rate of weaning from mechanical ventilation. The data set did not provide information on the ventilator mode or setting on admission nor on when weaning was first attempted in the ICU. However, the documented time of 25 days from transfer to the center until successfully

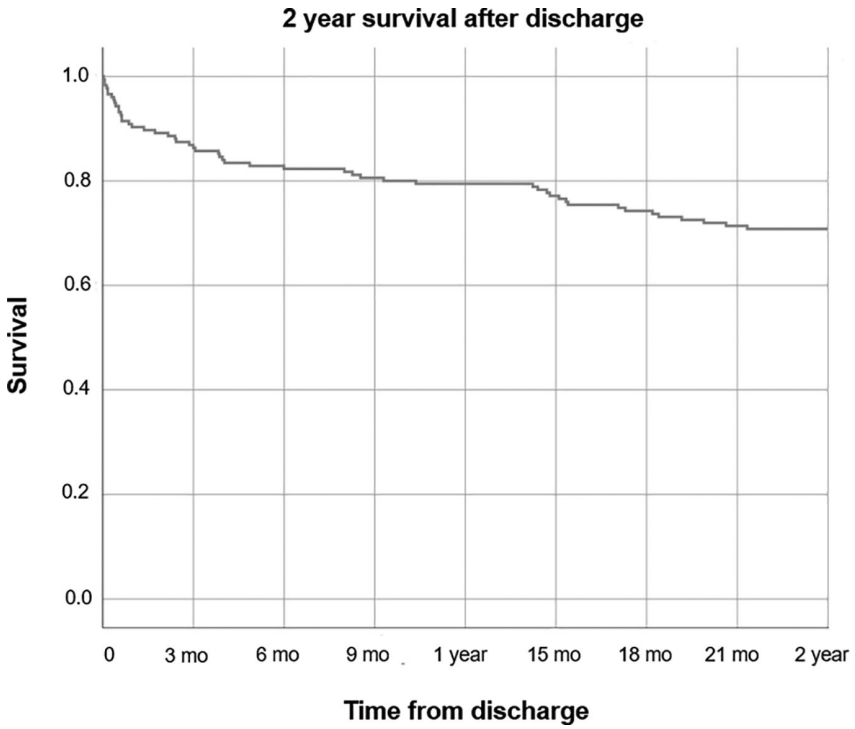

FIGURE 2 Kaplan–Meier plot of 2-year survival after discharge. One hundred seventy-five patients survived do discharge. Of these, 17 died within the first 30 days after discharge, another 19 during the following 11 months and 16 during the second year after discharge, rendering a 1- and 2-year survival of 79% and 70%, respectively.

weaned was still longer than reported by others[11,15,17] and 8% of the successfully weaned patients had weaning times between 114 and 126 days. Pursuing weaning attempts extendedly may increase the number of patients eventually rendered ventilator free and even longer weaning times have been reported by other groups.[17] However, weaning efforts may be stressful for patients and their families and prolonging hospital stay blocks resources that could be used for other patients. Our data set did not provide information on when the decision to abandon weaning attempts was made for the six patients that failed weaning, thus, we cannot report how long weaning efforts may have been pursued in vain. Continuous non-invasive BilevelPAP or CPAP was not used as an alternative for patients who failed their weaning attempts, but rather for support during sleep at night and during daytime bedrest if necessary. Occasionally mask ventilation was introduced during the weaning process before decannulation and continued beyond if necessary. In addition, CPAP was used after decannulation to alleviate obstructive sleep apnea when appropriate.

Measuring disease burden is a difficult task and there are currently no scoring systems developed for this patient group.[3] Accordingly, relating reported rates for successful weaning from mechanical ventilation, decannulation and mortality to disease burden is at present not possible. However, Sweden has, compared to many other countries, relatively few intensive care beds, approximately 5 per 100 000 inhabitants, and ICU stays average 2.7 days according to the Swedish Intensive Care Registry. This implies that patients are sent from ICUs quite early and that few patients have long ICU stays as a precautionary measure. The syndrome of persistent multiorgan failure preventing patients from a successful discharge from the ICU within a few weeks has been termed "chronic critical illness" with several partly overlapping definitions.[1,2,6,7] While this may be a long-lasting disease state, "chronic" should not be interpreted as without the possibility of improvement, as shown in this study and by others.[13] A transition from the acute phase of critical illness to the still critical, but frequently less fluctuating state of multiorgan dysfunction termed "persistent critical illness", usually occurs between seven and ten days from ICU admission.[3,4] Within this timeframe, the reason for continued intensive care has commonly shifted from the primary admission diagnosis to one or more conditions acquired during ICU treatment.[18-20] This illustrates the complexity of diagnoses and the susceptibility to complications that is typical for patients in the ICU and may explain why main diagnoses did not correlate to any of the outcome variables measured in the present study.

As continued demand for mechanical ventilation is a widely recognized reason for prolonged ICU stays, specialized weaning units limiting admittance to patients dependent on mechanical ventilatory support, have been developed.[10,12,21] However, a recent study found that one-third of patients in intensive care beyond ten days have other reasons than mechanical ventilation for their prolonged stay.[20] In line with this, 66% of patients included in our study were not dependent on mechanical ventilation when admitted to the center and 28% did not have a tracheal cannula. There are also clinics collaborating with specialized ICUs, thus admitting primarily patients with certain diagnoses.[11] These approaches may be efficient in areas where the numbers of such patients are high, allowing a reasonable size of the units. However, the demographics of Sweden and other less densely populated areas such as the Nordic countries, may prohibit strict admission criteria. A prolonged need of intensive care may follow after a multitude of diagnoses, and most patients with persistent or chronic critical illness suffer from disease states in several organ systems simultaneously[1-3,6,7] and thus have very complex medical needs regardless of ventilator dependence. By admitting patients

with long ICU stays and complex medical requirements, irrespective of ventilator dependence and hospital admission diagnosis, the multidisciplinary intensive care and rehabilitation team approach at the center resulted in success rates for weaning and decannulation comparable to pure weaning units. In addition, patients who were excluded from other rehabilitation clinics because of too advanced medical requirements, benefitted equally from the multidisciplinary treatment and rehabilitation.

The study was performed at a stand-alone center, not co-localized with an acute care hospital. The center's location offers some advantages such as access to beautiful gardens for continued intensive care also outdoors and proximity to nature, which may be difficult to find at most acute care hospitals. In addition, the center is relatively small, facilitating flexibility and close communications. However, there are several drawbacks with not being in direct connection to a hospital. Patients may need transfer for more advanced radiological examinations, surgery and specific treatments, transfers that may pose a risk for the patient and consume resources. In addition, some patients' transfer to the center may have been delayed by the distance to acute care. Moreover, while it can be argued that co-localization with a hospital may increase efficiency, close organizational proximity may cause hospital acute care to take priority, obscuring the focus on this specific patient group.

Survival rates among patients included in this study was high, 97% of all included patients survived to discharge. The one- and two-year survival after discharge of 79% and 70% may be regarded as high as these patients are frequently considered to have a much worse prognosis.[1,16] Similar to other reports, the first 30 days after discharge was the time period with the highest mortality.[22] Our data did not allow to determine if support after discharge was insufficient, why this needs further investigation in future studies.

4.1 | Strengths and limitations of the study

The presented data set provides unique information as this patient group has not been systematically followed up previously in Sweden. The center offers a controlled setting with highly skilled multidisciplinary staff focused on weaning from mechanical ventilation, decannulation and rehabilitation, contributing to the validity of the results. The data recorded in the quality registry was regularly checked for accuracy and likely to be correct. However, available information was limited as data were collected for quality surveillance purposes and only retrospectively retrieved from the registry for the study. Information on where the patients were treated at the time of referral was available, however, as some patients were not transferred immediately due to a lack of beds at the center, patients may have been moved for example from the ICU to a regular ward or vice versa before being transferred to the center. Moreover, though the median time in acute care before admittance to the center was 45 days, we had no information on mechanical ventilation time before admittance. The time with mechanical ventilation may influence weaning success rate,[17] however, this has also been challenged.[23] Furthermore, co-morbidities and pre-illness functional status may affect outcome[23] of which we had no data. A more thorough characterization of included patients and delivered treatment, also comprising follow up data after discharge, would have facilitated interpretation of results, and will be attempted in future studies.

4.2 | Conclusion

This study of patients with prolonged intensive care and complex medical needs treated at a specialized center in Sweden show weaning and decannulation rates comparable to the most successful specialized clinics worldwide. Mortality was low, and the vast majority of patients were discharged home or for further rehabilitation at a lower level of care. This was achieved with a multidisciplinary team approach to continued intensive care and individualized simultaneous rehabilitation.

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CONFLICTS OF INTEREST

All authors are employed by Remeo AB, the current owner of the Remeo Clinic.

AUTHOR CONTRIBUTION

ES and AIHC conceived the study. ES planned and directed the project. ML, JEP, JU, AIHC and ES collected and analyzed data. ML and JEP verified collected data. ES and ML drafted the manuscript. All authors edited the manuscript.

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