Beyond survival: Functionality and health-related quality of life among a cohort of ICU survivors 6 months after hospital discharge – a single-centre study in the Eastern Cape Province of South Africa

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Background. New or worsened impairments in physical, cognitive and/or psychological health may persist after critical care discharge and impact negatively on survivors' health-related quality of life (HRQOL), functionality and life roles.
Objective. To describe functionality, changes in life roles and HRQOL among an Eastern Cape single-centre cohort of ICU survivors, 6 months after hospital discharge.
Methods. The study was conducted in a multidisciplinary tertiary ICU in the Eastern Cape and enrolled critically ill patients who required organ support and had an ICU stay for at least 48 hours. Patients were assessed at 6 weeks and 6 months post hospital discharge. The Lawton's Instrumental Activities of Daily Living (IADL) score and employment/educational status were determined. The Rand Short Form-36 HRQOL questionnaire's physical and mental component scores (PCS and MCS) were used to determine quality of life at baseline and study visits.
Results. A total of 107 patients with a median age of 42, half of whom had COVID-19, completed the 6-month follow-up. At the 6-month follow-up, 17.5% of previously non-frail patients were still unable to complete at least two IADLs, and 24.3% one IADL. Overall, 34% had not returned to their life roles of home making, studying or remunerative work due to ill-health. At 6 months, 58.9% and 62.6% had significantly lower mean PCS and MCS scores, respectively. Overall, 62.6 % of survivors had either a significantly lower PCS and/or MCS at 6 months.
Conclusion. This relatively young cohort of ICU survivors, with minimal previous comorbidities, demonstrated a high incidence of significantly lower HRQOL scores at the 6-month follow-up, affecting 6 out of every 10 patients. The proportion of patients who were unable to complete all IADLs at follow-up, explains the reported changes in relation to life roles, including remunerative employment. These findings have implications for the introduction or reengineering of rehabilitation resources and ICU follow-up services.

Keywords. critical care; intensive care unit; ICU; health-related quality of life; activities of daily living; functionality; return to work; post-ICU syndrome.

South Afr J Crit Care 2025:41(2):e2940. https://doi.org/10.7196/SAJCC.2025.v412940

Contribution of the study
This study adds to the limited body of evidence on post-ICU outcomes in South Africa by documenting high rates of impaired functionality, reduced HRQOL, and disrupted life roles at 6 months after hospital discharge. These findings support the need for context-appropriate ICU follow-up and rehabilitation strategies.

Improved survival rates through therapeutic advances have resulted in an increase in critical care survivors.[1-3] However, survivors often undergo unexpected life changes after discharge due to illness related/acquired deficits in one or more health-related domains.[4] Psychological and physical impairment post intensive care (ICU) impacts on functionality, life roles, social reintegration and, ultimately, may lead to a reduction in health-related quality of life (HRQOL), causing it to be inferior to that of age- and sex-matched counterparts.[4-10] Among ICU survivors, the ability to live independently, return to work and experience a reasonable HRQOL, are essential considerations.

There is a distinct paucity of studies pertaining to the follow-up and wellbeing of ICU survivors from low- and middle-income countries.[11]

The present study aimed to investigate the functionality, return to life roles and trajectory of the HRQOL among ICU survivors in the Eastern Cape Province in the months following hospital discharge.

Methods

This single-centre, prospective observational cohort study screened and enrolled critically ill patients either at ICU discharge or shortly thereafter in the ward. The current study constituted a component of a broader study that investigated the physical, mental, and cognitive after-effects in ICU survivors at 6 weeks and 6 months after hospital discharge. Inclusion criteria were: age ≥18 years and the requirement of ≥48 hours admission to ICU either for respiratory support (invasive or non-invasive mechanical ventilation; or high-flow humidified nasal oxygen (HFNO)); or shock requiring vasopressor support; or management for any other organ failure. Patients were ineligible for inclusion if any of the following factors were present: they were prisoners; had a life expectancy gauged to be less than 6 months; resided more than 300 km from the enrolling centre; were unable to be interviewed in English or isiXhosa; had active or recent psychosis; were admitted for self-harm or with central neurological pathology; or had preexisting cognitive impairment (as determined by the Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE).[12] Patients were also excluded from the final data analysis if they did not survive until the 6-month follow-up or did not complete the 6-month study assessment.

Data collected at enrolment included demographic and clinical information. Premorbid clinical frailty was determined using the Clinical Frailty Scale score (CFS) and a score of 5 or more defined clinical frailty.[13] The patients' retrospective, pre-morbid HRQOL was determined by completing the RAND-corporation Short Form-36 HRQOL questionnaire, hereafter referred to as the SF-36.[14] The SF-36 comprise eight scale scores namely, physical functioning (PF), bodily pain (BP), role limitations due to physical health problems (RP), role limitations due to personal or emotional problems (RE), general mental health (MH), social functioning (SF), energy/fatigue or vitality (VIT), and general health perceptions (GH). These are aggregated to calculate two sub scores, namely, the physical component summary score (PCS) and the mental component summary score (MCS). [14] No South African (SA) population norms exist for the SF-36. A 5-point score change is considered a minimal clinically important difference (MCID),[15] and has been used for research related to ICU survivors.[16] A poor HRQOL outcome in the current study was defined as a negative change of 5 or more points from baseline. All questionnaires were clinician administered. If patients preferred to be interviewed in isiXhosa, or when the clinician observed discrepancies using the English SF-36 version, an isiXhosa-speaking ICU physician conducted the interview using a certified isiXhosa translation.

Patients were followed up at 6 weeks and 6 months post hospital discharge. At these visits the SF-36 questionnaire was repeated and information collected encompassed the return to previous life roles including employment, studying and home making, as well as reasons for being newly unemployed. The patients' level of functioning was determined by completion of the Lawton Instrumental Activities of Daily Living score (IADL) which is sensitive to early cognitive decline and subtle dysfunction.[17] A fully functional person scores a maximum of eight points. A change in two or more IADL dependencies is considered significant and ensures that the measured dysfunction is meaningful to patients and caregivers.[18,19]

Continuous data were tested for normality using the Kolmogorov-Smirnov test. Normally distributed data are reported as mean and standard deviation (SD) and skewed data as median and interquartile range (IQR). Binary data are presented as numbers and percentages. The *t*-tests for dependant and independent samples, Mann-Whitney *U*-test, Wilcoxon signed-rank test with continuity correction were used to compare continuous data. For comparison of binary variables, the Chi-square and Fischer's exact tests were used as appropriate. Bivariate analysis compared variables between patients with good and poor HRQOL at 6 months. In all cases, the level of significance was at 5%.

Informed consent was sought from patients or, alternatively, their surrogate decision-makers at ICU discharge or shortly thereafter in the ward, depending on when it was most feasible. Where a surrogate decision-maker provided the initial assent, consent was obtained from the patient when they regained the capacity to consent. Permission for the study was obtained from the Nelson Mandela University's Research Ethics Committee (Human) (ref. no. H20-HEA-PSY-001).

Results

Enrolment and data collection commenced on the 1st of August 2020, just after the peak of the first local COVID-19 pandemic wave and ended on the 31st of May 2022. There was a 3-week hiatus in the enrolment during December 2020, owing to the investigators contracting COVID-19. The study period also included the second and third waves of the pandemic. The process of screening and inclusion is set out in Fig. 1. While some patients died post enrolment (*n*=13; 8.7%), attrition was mostly due to non-attendance of the follow-up visits (*n*=29; 19.3%).

A comparison of the main characteristics (sex, age, diagnostic category, work status, severity of disease, frailty and co-morbidities and length of ICU stay) between the study group and those lost to follow-up, did not show any significant differences (Supplementary Table S1; http://coding.samedical.org/file/2375). A total of 107 patients completed the 6-month follow-up visit and were included in the final analysis. The demographic and clinical characteristics of the cohort are presented in Table 1. The cohort reported a low preadmission CFS (Fig. 2).

All patients received organ support which included invasive ventilation (implying endotracheal intubation), non-invasive mask ventilation, HFNO, haemodynamic support (vasopressor infusion), and/or dialysis. Eleven patients (10.3%) required triple organ support, 20 (18.7%) required double organ support and 76 (71.0%) required single organ support. Fifty-five (51.4%) received non-invasive respiratory support (HFNO and/or non-invasive mask ventilation). Nineteen (17.8%) patients were ventilated beyond a week. Twenty-two of the ventilated patients required additional non-invasive ventilation or HFNO for a median (IQR) of 2 (1 - 4) days.

A comparison between those with and without an admission diagnosis of COVID-19, is included in Table 1. COVID-19 ICU survivors demonstrated significantly lower ICU severity scores, as indicated by the SAPS 3 and SOFA scores. Non-COVID-19 patients received more vasopressor treatment and demonstrated more ICU-acquired delirium, ICU-acquired weakness, acute kidney injury and dialysis. As expected, COVID-19 patients had a higher incidence of ARDS with lower PF ratios. COVID-19 ICU survivors received more non-invasive ventilatory support for longer, whereas those without COVID-19, were more likely to have been intubated and ventilated.

Prior to admission 103 of 107 patients were considered non-frail, as measured by the Clinical Frailty Scale score. The 4 frail patients were all pensioners. Of the previously non-frail patients, 36 (34.9 %) had an IADL score of ≤6 out of 8 at the 6-week visit. At the 6-month

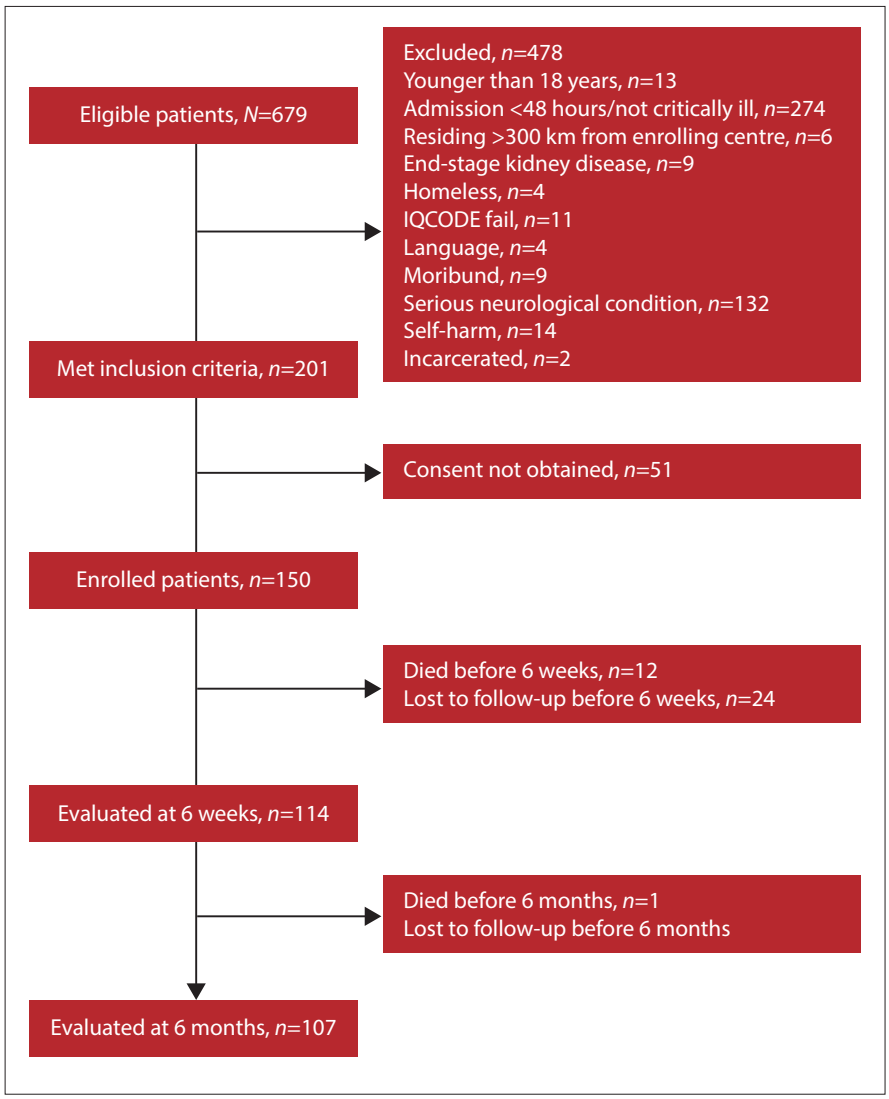

Fig. 1. Patient screening and enrolment process.

follow-up, 18 (17.5%) of previously non-frail patients were still unable to complete at least two IADLs, while 26 (24.3%) had at least one IADL deficiency. The four patients with pre-existing frailty were significantly impaired at both visits with low IADL values, with scores ranging between 1-5.

Seven patients had a lower IADL score at 6 months compared with the 6-week visit. On further analysis all except one of these patients had either worsening or new mental health symptoms which were associated with low HRQOL scores (Supplementary Table S2; http://coding.samedical.org/file/2375). Previously non-frail COVID-19 patients had a higher mean (SD) IADL score at 6 weeks compared with non-COVID-19 patients (7.2 (1.6) v. 5.9 (2.1); p=0.002), while there was no significant difference between these two groups at 6 months (7.6 (1.1) v. 7.1 (1.6); p= 0 .278).

The employment and life roles at baseline and 6 months are depicted in Fig. 3. The cohort included 8 pensioners and 3 students. None of the patients who were students had returned to their studies at 6 weeks after hospital discharge, and by 6 months, one still had not returned. There were 10 homemakers in the cohort, and at both follow-up visits, 4 (40%) of them were unable to fulfil this role. Prior to admission, 69 patients (64.5%) were engaged in remunerative employment. At the 6-week and 6-month study visits 39 (56.5 %) and 23 (33.3%), respectively, of the previously working patients were newly unemployed. Overall, 34% of patients had not returned to their previous remunerative work, studying or home making by 6 months. The study coincided with the COVID-19 pandemic and the impact of COVID-19 on employment was considered. The study period overlapped with the highest unemployment rates recorded to date in SA (30 - 35%).[20] However, only 3 of the newly unemployed patients indicated that the negative change in their employment status was the result of redundancy. Therefore, 20 (29%) of previously employed survivors were unemployed at 6 months due to ill health. Of the patients who had returned to work by 6 months, 19 (27.9%) took longer than 6 weeks to do so. Only three of the newly unemployed patients were receiving a disability grant 6 months after discharge. Those with a non-COVID-19 admission diagnosis were more likely to be newly unemployed at 6 months than those with a COVID-19-related admission. The unemployment rate was 18.2 % among patients admitted with COVID-19, 33% among those with other medical diagnoses, 44% among those with a surgical admission diagnosis and 35.3% among patients admitted for trauma.

The impact of the patients' physical health on HRQOL was measured by the SF-36 physical component summary score (PCS). The cohort's median (IQR) SF-36 PCS score at baseline (pre-morbid) was 59.2 (53.4 - 60.8). There was a significant improvement in the median (IQR) PCS score from 6 weeks (41.2 (33.0 - 48.4)) to 6 months (48.4 (40.3 - 55.7)), however, both scores were significantly lower compared with the baseline score (Fig. 4A).

The impact of the patients' mental health on the HRQOL was measured by the SF-36 mental component summary score (MCS). The median (IQR) SF-36 MCS score at baseline was 56.3 (51.1 - 61.2). At the 6-week and 6-month visits, the median (IQR) MCS scores were 47.5 (38.4 - 53.5) and 49.7 (41.3 - 56.8), respectively, and these were significantly lower than the baseline measurement (Fig. 4B).

At 6 months, 63 (58.9%) of the survivors had a significantly lower mean PCS, as defined by a negative score change of 5 or more (hereafter referred to as the 'poor' group), while 53 (49.5%) had a poor mean MCS at the same study visit. Overall, 67 (62.6 %) of survivors had either a low PCS and/or a low MCS at 6 months. There was considerable overlap between patients with a poor PCS and MCS: 47 patients (43.9%) of the survivors had lower scores for both. Table 2 compares the PCS and MCS scores of poor and good outcome groups.

A poor 6-month PCS was associated with an admission diagnosis of trauma (86.4% of those admitted with a diagnosis of trauma had a poor outcome, compared with 53.1% of those with medical emergencies and 47.6% of those with surgical emergencies (p=0.012). A higher median (IQR) Charlson Comorbid Index (CCI) was also associated with poor PCS (p=0.044). However, due to the overall low values for the CCI and distribution of the

Table 1. Demographic and clinical characteristics of the cohort

	All (*N*=107), *n* (%)*	COVID-19 admissions (*n*=50), *n* (%)*	Non-COVID-19 admissions (*n*=57), *n* (%)*	*p*-value
Female sex	58 (54.2)	33 (66)	25 (43.9)	0.022†
Age (years), median (IQR)	42 (33 - 51)	44.5 (36 - 51)	38 (31 - 57)	0.478
Years of education, median (IQR)	11 (10 - 12)	11.5 (10 - 15)	11 (9 - 12)	0.119
Clinical Frailty Scale score, median (IQR)	2 (2 - 2)	2 (2 - 2)	2 (2 - 3)	0.447
Charlson Comorbidity Index, median (IQR)	0	0	0	0.610
Diabetes mellitus	22 (20.6)	12 (24.0)	10 (17.5)	0.409
Hypertension	37 (34.6)	19 (38.0)	18 (31.6)	0.486
SAPS-3 score, median (IQR)	48 (43 - 55)	46 (42 - 49)	53 (47 - 62)	<0.001†
Highest SOFA score, median (IQR)	4 (4 - 9)	4 (4 - 4)	8 (5 - 11)	<0.001†
Hospital days, median (IQR)	23 (13 - 35)	21 (14.3 - 33.5)	24 (12 - 38.5)	0.928
ICU days, median (IQR)	7 (5 - 14)	8 (6 - 0)	6 (5 - 17)	0.787
ARDS	74 (69.2)	50 (100.0)	24 (42.1)	<0.001†
PF ratio mmHg, median (IQR)	121 (82 - 233)	83 (65 - 101)	225 (148 - 329)	<0.001†
Invasive ventilation	47 (43.9)	9 (18.0)	38 (66.7)	<0.001†
Invasive ventilation (days), median (IQR) (*n*=47)	7 (3 - 17)	7 (5 - 26)	6 (2 - 15)	0.337
NIV or HFNO therapy	55 (51.4)	41 (82.0)	14 (24.6)	< .001†
NIV or HFNO therapy (days), median (IQR) (*n*=55)	5 (3 - 7)	6 (4 - 7)	3 (3 - 4)	0.004†
Sepsis‡ (including COVID-19)	86 (80.4)	50 (100.0)	37 (64.9)	<0.001†
Septic shock, *n* (%)	24 (22.4)	2 (4.0)	22 (38.6)	<0.001†
ICU-acquired infections, *n* (%)	35 (32.7)	8 (16.0)	27 (47.4)	0.006†
ICU delirium, *n* (%)	29 (27.1)	5 (10.0)	24 (42.1)	<0.001†
Any degree of ICU acquired weakness, *n* (%)	35 (32.7)	8 (16.0)	27 (47.4)	0.006†
AKI, *n* (%)	58 (54.2)	12 (24.0)	46 (80.7)	<0.001†
Dialysis	18 (16.8)	0	18 (31.6)	<0.001†
Vasopressor treatment	31 (29.0)	2 (4.0)	29 (50.9)	<0.001†

IQR = interquartile range; SAPS = Simplified Acute Physiology Score; SOFA = Sequential Organ Failure Score; ICU = intensive care unit; ARDS = acute respiratory distress syndrome; PF ratio = arterial oxygen/fraction of inspired oxygen; NIV = non-invasive ventilation; HFNO = high-flow humidified nasal oxygen therapy; AKI = acute kidney injury.
*Unless otherwise specified.
†$p<0.05$.
‡Including COVID-19.

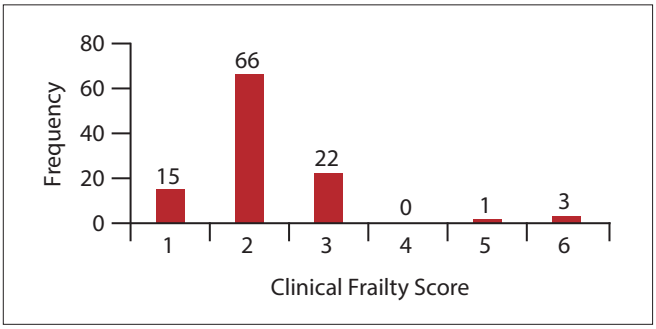

Fig. 2. Distribution of pre-ICU Clinical Frailty Scale scores.

data, the median (IQR) scores of both outcome groups were 0 (0 - 1) for poor v. 0 (0 - 0) for good.

Associations with a poor 6-month MCS included female sex (66% in the poor group v. 42.6% in the good outcome group; $p = 0.015$) and being unemployed at baseline (79% in the poor group v.13.2%; $p<0.001$). There was no association between a lower MCS and a prior history of mental health problems.

No significant associations were found between a poor 6-month PCS or MCS and other demographic variables, including years of education, comorbidities, admission diagnosis of COVID-19, severity of disease, length of stay, more benzodiazepine exposure, other ICU complications, or employment change on follow-up (Supplement Tables S3 and S4; http://coding.samedical.org/file/2375). Only sixteen patients (15%) had attended outpatient physiotherapy by the 6-week follow-up visit, and none had received occupational therapy.

Using a minimal clinical difference of 5 or more points, 12 patients reported a significantly better PCS at 6 months compared with their baseline, while the same was reported by 15 patients in terms of their MCS comparison. The baseline v.6-month SF-36 domain scores for the poor PCS and MCS groups are depicted in Figs 5A and 5B.

Discussion

At 6 months after hospital discharge ICU survivors reported a significantly lower physical and mental HRQOL compared with the period prior to their ICU admission. Nearly 6 out of every 10 patients had a lower physical HRQOL score, and 5 out of every 10 patients had a lower mental HRQOL score. Considering the ICU survivors' young age, non-frail status at baseline, and minimal pre-existing comorbidity, the number of ICU survivors who reported impaired activities of daily living, a negative change in employment status, and/or reduced HRQOL at follow-up, is notable. This research sheds light on the challenges that ICU survivors face in SA, where often young and previously healthy individuals may face difficulties in daily activities like taking care of themselves or working.

Among previously non-frail ICU survivors, 35% reported two or more IADL dependencies at 6 weeks after hospital discharge, and by 6 months this was still the case for 17.5% of them. In general, the reported incidence of new IADL dependencies among ICU survivors varies widely depending on the time of evaluation, the age of patients, diagnostic categories included, and pre-existing frailty, making comparison challenging.[4] Although the incidence of IADL deficiencies in this current study is somewhat lower than that reported during

the first year after ICU admission in two landmark studies (20 - 26%),[21,22] the mean age in these studies was much higher (~60 years), and frail patients were not excluded in their analysis. Given the local findings, it is not unexcepted that 34% of patients did not return to home making, studying or remunerative work, which often requires more complicated tasks than managing IADLs, e.g. problem solving, critical and logical thinking and emotional intelligence.

The finding that some of the patient's IADL scores worsened after the 6-week visit, was unexpected. All these patients experienced new or worsening mental health symptoms with corresponding low HRQOL scores. For some ICU survivors, the initial positive emotions related to survivorship may subsequently be overshadowed by the realisation that full recovery is either unattainable or is a slow process with no guarantee of full recovery. Also, patients may experience delayed onset of symptoms of PTSD, anxiety and depression.[23-25] Healthcare workers following up ICU survivors should therefore be alerted that patients may experience worsening in their functionality for months after hospital discharge and that this may be due to new mental health symptoms.

Poor mental or physical health, rather than redundancy, was by far the most common reason reported by patients for being newly unemployed at the 6-month follow-up. This links to the finding that the most affected domains of the SF-36 were those of role limitations due to physical health and emotional problems (Figs 5A and 5B). These two domains are indicative of problems with work or other daily activities due to physical health and emotional problems. The rate of new unemployment due to ill health at 6 months (29.0%), was comparable to that reported in some higher resourced countries (29- 33%),[26,27] but lower than the 36 - 45% reported in pooled rates at 6 months in two scoping reviews on unemployment post ICU discharge.[28,29] However, these publications from higher-income countries, reported overall unemployment rates, as opposed to unemployment due to ill health.

When compared with their baseline scores, 62.7% of ICU survivors reported a significantly lower HRQOL 6 months after hospital discharge. While some patients' HRQOL had recovered by 6 months, the physical and mental health of other patients continued to have a substantial impact on their quality of life, affecting around 60% and 50% of patients, respectively. In addition, around 44% reported that their HRQOL were affected by both mental and physical health aspects at 6-months follow-up. The trajectory of the good and poor outcome groups' SF-36 scores showed a decline in physical and mental scores from baseline to the 6-week's visit. While the good-outcome group's 6-month scores improved to values comparable with premorbid scores, the poor outcome group's scores remained low at 6 months.

Three studies reported the HRQOL of ICU survivors in the public sector in SA, and they all utilised the SF-36 as measuring tool. A 1-year follow-up study among 46 trauma critical care survivors, reported a poor HRQOL in all domains.[30] It was not stated which population norms were used for comparison. In a 6-month follow-up study of HRQOL in 42 ICU survivors of penetrating chest trauma, the subset of patients who were ventilated for more than 5 days experienced significantly lower PCS and MCS scores at one, three and 6 months after discharge, compared with their own baseline scores.[31] Those subjects who had greater morbidity and prolonged MV (>5 days), suffered from a reduced HRQOL for up to 6 months after discharge. A study conducted in the same Eastern Cape ICU as the current research, found that patients who were ventilated for seven or more days, had a significantly lower HRQOL at 6 and 12 months compared with pre-admission values.[32]

In the absence of SA population norms, it is interesting to note that the retrospective baseline PCS and MCS scores are consistent with the baseline scores reported previously in two SA follow-up studies, one from the same ICU, and one from Johannesburg.[31,32] The overall HRQOL scores 6 months after discharge were of a similar range as described among ICU survivors in Europe.[33] Furthermore, the trajectory of recovery is in keeping with findings in a systematic review which reported initial improvements over the first year following ICU discharge;[34] however it is sobering to note that many patients in the poor outcome group had minimal or no significant improvement.

In high income countries, the pre-ICU HRQOL of ICU survivors has been shown to be an independent predictor of post ICU HRQOL.[35,36] From the findings in the current study, the poor outcome groups' low 6-months median PCS and MCS scores were not supported by pre-existing poor HRQOL scores. This is likely explained by the cohort's low pre- admission comorbidity and frailty scores. The differences in the baseline PCS and MCS scores between the poor and good outcome groups in this study, where the poor group reported a slightly better baseline HRQOL compared with the good outcome group, is less than the minimal clinical important difference score of five. The poor outcome groups' baseline scores may have been influenced by recall bias, leading to their retrospective baseline score being somewhat inflated and limiting its accuracy. However, comparing patients with their own baseline as opposed to population norms, remains informative about the trajectory of an individual's recovery, since their baseline values may have been either lower or higher than the norm.[9]

There were few significant associations with a low HRQOL at 6 months, and these included a diagnosis of trauma, more pre-existing comorbidities, female sex and being unemployed pre-ICU admission. Although a review and metanalysis found that certain illness-related factors like ARDS, prolonged ventilation and sepsis were associated with impairments in HRQOL,[6] this was not confirmed in our or other recent studies.[35-37] Trauma had been found to be a risk factor for a poor HRQOL in ICU survivors

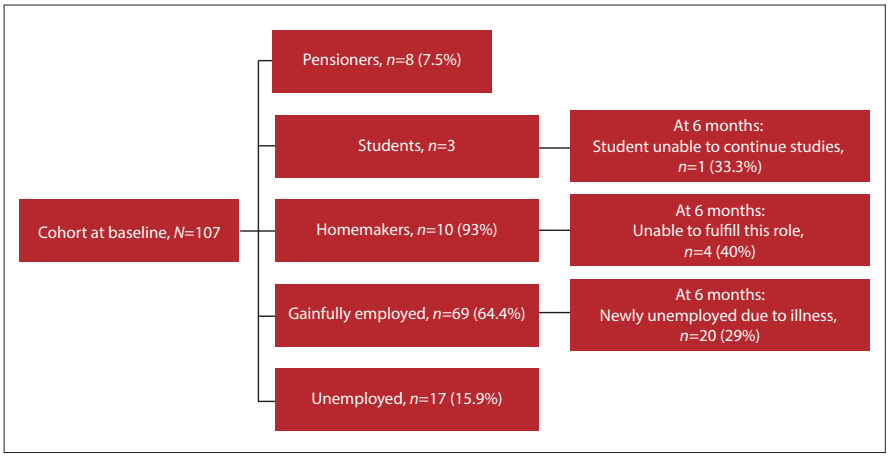

Fig. 3. Employment and life roles at 6 months after hospital discharge.

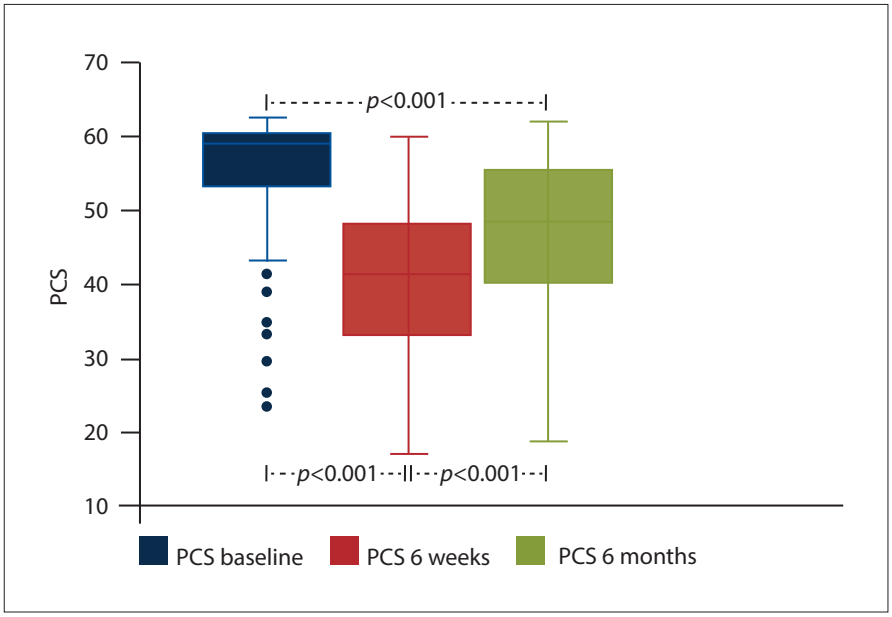

Fig. 4A. SF-36 PCS score at baseline, 6 weeks and 6 months. (PCS = Physical Component Summary score.)

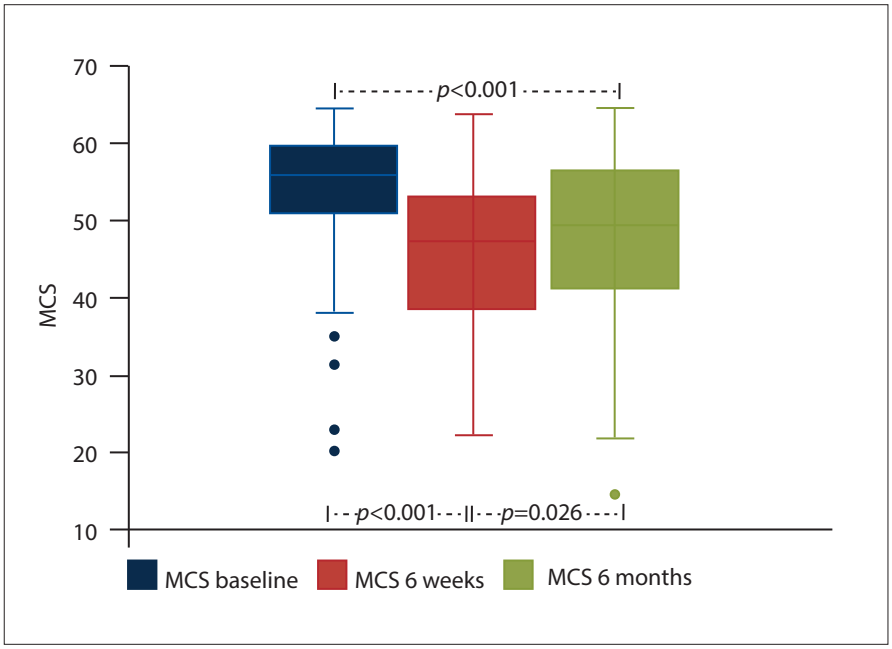

Fig. 4B. SF-36 MCS score at baseline, 6 weeks and 6 months. (MCS = Mental Component Summary score.)

both locally[32] and internationally[6,35,37] and these findings underscore the societal burden of trauma in SA. The finding that females in this study had a poorer mental-health quality of life after discharge, is different from the findings of a review on the HRQOL in ICU survivors.[6] However, the association in the current study is keeping with the findings from the same cohort that females were more at risk for significant psychological symptoms.[25] Symptoms of depression, anxiety and PTSD are known to be associated with a lower HRQOL across post-ICU studies.[38-40] The findings show that COVID-19 patients were not more likely to be newly unemployed, nor have a poorer HRQOL when compared with other ICU survivors. Although this is in keeping with the findings of recent research comparing the outcomes between COVID-19 and non-COVID-19 ICU survivors,[41] it may also be because of survival bias. There was a high mortality (70 - 80%) observed in SA COVID-19 patients who required intubation and mechanical ventilation[42-45] and the process of very strict triaging during the pandemic waves may also have introduced bias.

A small number of patients reported a better HRQOL at 6 months compared with their baseline. This may be explained by pre-existing medical problems that were addressed during hospitalisation. Another possibility is recall-bias or response shift, which is governed by a general sense of wellbeing among those who had not only survived ICU but had largely recovered. When completing the SF-36 questionnaire for determining the retrospective baseline, it is important to remind the patient before every question that it refers to the period prior to the onset of the acute condition that had brought them to ICU. The wording of several SF-36 questions starts with 'over

Table 2. Comparison between outcome groups' SF-36 PCS and MCS (*N*=107)

Variable	Time frame	Poor-outcome group	Good-outcome group	*p*-value*
	Baseline	*n*=63 (58.9%)	*n*=44 (41.1%)	
		59.5 (55.9 - 61.0)	57.0 (43.9 - 60.1)	
PCS score, median (IQR)	6 weeks	38.5 (30.2 - 43.1)	48.0 (40.5 - 54.3)	<0.001
	6 months	42.4 (36.2 - 48.5)	56.5 (51.5 - 59.0)	<0.001
	p-value†	<0.001	0.458	
		n=53 (49.5%)	*n*=54 (50.5%)	
	Baseline	57.7 (52.3 - 61.3)	55.0 (46.1 - 59.8)	
MCS score, median (IQR)	6 weeks	41.9 (35.0 - 51.3)	49.8 (44.0 - 57.0)	<0.001
	6 months	44.3 (36.3 - 49.0)	56.6 (50.7 - 60.4)	<0.001
	p-value†	<0.001	0.045	

SF36 = Short Form 36; MCS = Mental Component Summary score; PCS = Physical Component Summary score; IQR = interquartile range.
*Poor- v. good-outcome group.
†Baseline v. 6 months

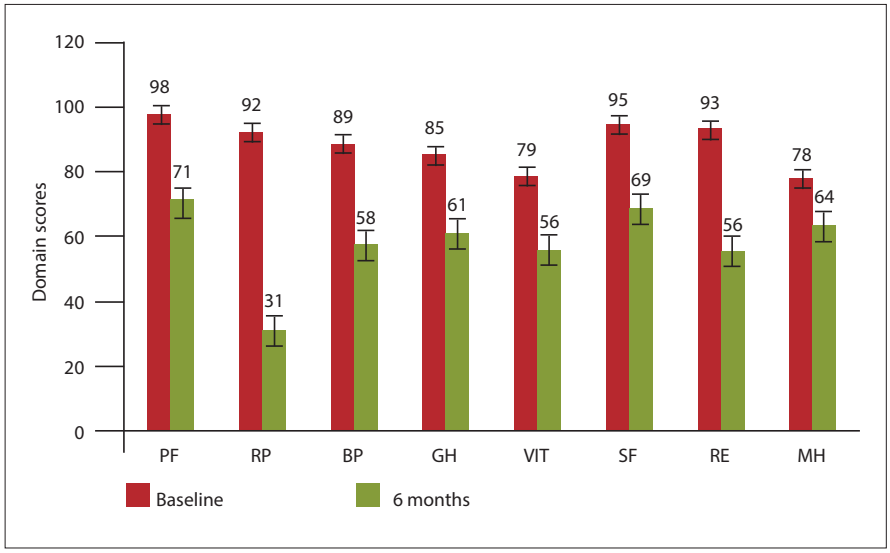

Fig. 5A. SF-36 domain scores for poor-outcome PCS group. (MCS = Mental Component Summary score; PF = physical functioning; RP = role limitations due to physical health; BP = bodily pain; GH = general health perception; VIT = vitality; SF = social functioning; RE = role limitations due to emotional problems; MH = mental health.)

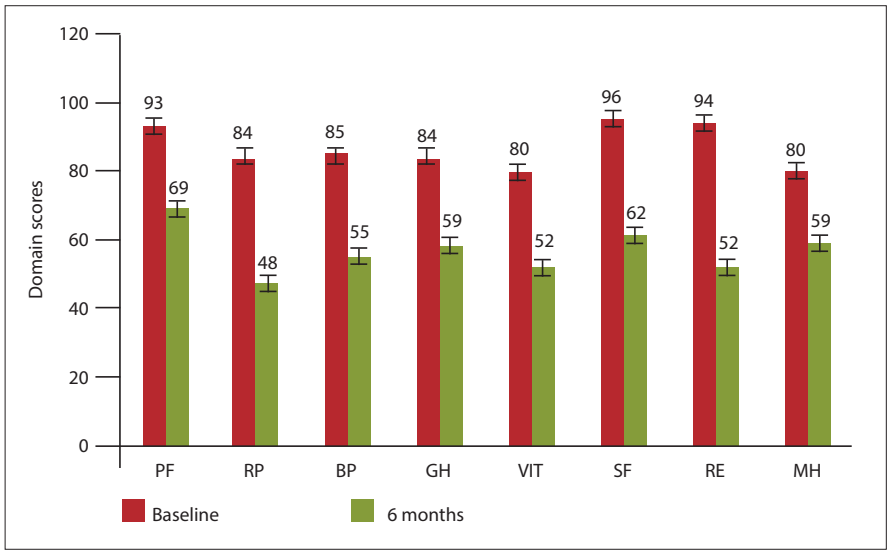

Fig. 5B. SF-36 domain scores for poor-outcome MCS group. (PCS = Physical Component Summary score; PF = physical functioning; RP = role limitations due to physical health; BP = bodily pain; GH = general health perception; VIT = vitality; SF = social functioning; RE = role limitations due to emotional problems; MH = mental health.

the last four weeks', which can easily be misinterpreted, limiting the accuracy of the retrospective baseline assessment. The baseline SF-36 needed to be repeated with some patients in the current study where it was noticed that scores did not reflect the patients' reported pre-admission health.

Lastly, the lowest SF-36 domain scores for both the calculation of PCS and MCS scores were that of role limitations due to physical health (Figs 6 and 7). This may be a clue that many patients experience mental health problems because of their physical impairment. Inadequate rehabilitation and psychosocial follow-up of patients may lead to poor outcomes in terms of the HRQOL.[8] It is therefore alarming that only sixteen (15.0%) patients had attended outpatient physiotherapy in the weeks after hospital discharge, and none had received occupational therapy. A finding of a poor HRQOL should prompt further investigation and action, e.g. appropriate referral to rehabilitation services including physiotherapy, occupational therapy, mental health services and speech therapy.[8]

Study limitations

Limitations of the present study include the unique clinical characteristics of COVID-19 disease and circumstances around the pandemic. As discussed earlier, this may limit the generalisability of the findings in the post-pandemic ICU setting. There was a paucity of trauma admissions and other 'usual' medical and surgical admissions in the cohort. Despite these limitations, this study shows that it is possible to follow state sector ICU survivors up over time with a good retention rate.

A poor HRQOL is often an unexpected outcome for ICU survivors, their family, their employers and even health professionals. When asked about their expectations, surrogate decision-makers of incapacitated patients, and the physicians of these same patients, had discordant views of expected outcomes, but the outcomes are ultimately worse than what either physicians or surrogates expected.[46] Creating awareness of these possible outcomes for ICU survivors among healthcare workers and the public, may lead to creating appropriate care pathways and social support for patients and families.

Conclusion

Previously well-functioning ICU survivors demonstrated a high incidence of significantly lower HRQOL scores at the 6-month follow-up. The proportion of patients who were unable to complete all IADLs at follow-up, explain the changes in life roles, including remunerative employment. Although there was an overall improvement in the functionality, employment status and HRQOL of ICU survivors over the 6-month study period, the findings tell the story of an arduous journey back to their previous activities and level of functioning, and for many it may extend beyond the follow-up period. These findings have implications for the introduction or re-engineering of rehabilitation resources and ICU follow-up services in SA.

Declaration. This research formed part of EvdM's PhD at Nelson Mandela University, SA.

Acknowledgements. We gratefully acknowledge funding from Kidney Infectious Diseases and Critical Care Non-profit Company (KICC).

Author contributions. The research concept was EvdM's original idea with input from the three supervisors, LS, GS and FP. They also contributed to the study planning and the write-up, while statistical analysis was performed by GS. NvV was instrumental in all the practical aspects of the investigation, including performing of the administration of the questionnaires, data collection and validation. She also reviewed

and edited the final article. MM and TF assisted with administration of the questionnaires and editing of the final article.

Funding. We gratefully acknowledge funding from Kidney Infectious Diseases and Critical Care Non-profit Company (KICC).

Conflicts of interest. None.

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Received 10 December 2024. Accepted 22 May 2025.