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Research Article

The impact of critical illness on patients' physical function and recovery: An explanatory mixed-methods analysis



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ABSTRACT

Keywords: Critical illness Patient Discharge Perception Post-intensive care syndrome (PICS) Rehabilitation Social Networking

Objectives: To determine how the perception of physical function 6-months following critical illness compares to objectively measured function, and to identify key concerns for patients during recovery from critical illness. *Research methodology and design:* A nested convergent parallel mixed methods study assessed physical function during a home visit 6-months following critical illness, with semi-structured interviews conducted at the same time. *Setting:* Participants were recruited from two hospitals at one healthcare network in Melbourne, Australia from

Setting: Participants were recruited from two hospitals at one healthcare network in Melbourne, Australia from September 2017 to October 2018 with follow-up data completed in April 2019.

Main Outcome Measures: Physical function was assessed through four objective outcomes: the functional independence measure, six-minute walk test, functional reach test, and grip strength. Semi structured interviews focused on participants function, memories of the intensive care and hospital stay, assistance required on discharge, ongoing limitations, and the recovery process.

Findings: Although many participants (12/20, 60%) stated they had recovered from their critical illness, 14 (70%) had function below expected population norms. Decreased function on returning home was commonly reported, although eleven participants were described as independent and safe for discharge from hospital-based staff. The importance of family and social networks to facilitate discharge was highlighted, however participants often described wanting more support and issues accessing services. The effect of critical illness on the financial wellbeing of the family network was confirmed, with difficulties accessing financial support identified.

Conclusion: Survivors of critical illness perceived a better functional state than measured, but many report new limitations 6-months after critical illness. Family and friends play a crucial role in facilitating transition home and providing financial support.

Implications for clinical practice: Implementation of specific discharge liaison personnel to provide education, support and assist the transition from hospital-based care to home, particularly in those without stable social supports, may improve the recovery process for survivors of critical illness.

Introduction

Although early intensive care unit (ICU) research was primarily

directed at improving mortality, the ongoing effect of critical illness on survivors physical, social, emotional, and cognitive well-being is now a focus for clinicians (McPeake et al., 2021). Frequently gathered under

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the term "post-intensive care syndrome" (PICS), these sequalae are gaining increased representation in the literature, not only due to their impact on outcomes, but the chronicity of their effect (King et al., 2019). Despite an increase in qualitative research in ICU survivors (Hashem et al., 2016; King et al., 2019) much of the impact of PICS is still measured through quantitative means. As qualitative research aims to identify participants' experiences, perceptions, and attitudes (Tenny et al., 2022), this information can provide key understandings into the complex nature of PICS, as well problems ICU survivors face following hospital discharge, a time known to be the most difficult for both ICU survivors and their families (Maddox et al., 2001). Although critical care survivors have been shown to place a high focus on physical recovery following discharge (Walker et al., 2015), little is known about their perception of function. As perceived health is understood to be one of the strongest determinants of subjective well-being (Turnbull et al., 2022), but the perception of function has been shown to vary from objectively measured functional performance in other cohorts (Aujla et al., 2019; Southard et al., 2021; Winters-Stone et al., 2019), our primary aim was to determine how the perception of physical function 6months from an ICU admission compares to objectively measured function relative to population age and sex matched norms. Our secondary objective was to identify key concerns for ICU survivors during the recovery from critical illness through qualitative analysis.

Methods

Study design

This nested study utilised a convergent-parallel mixed methods design by collecting quantitative and qualitative data simultaneously but analysing them separately to then compare results and draw conclusions (George, 2023). This allowed for discussion of convergence or divergence between the objectively measured physical function (obtained through the four performance-based outcomes) and the subjectively explored physical function (obtained through semi-structured interviews) (Creswell and Plano Clark, 2018). This study followed the "Good Reporting of a Mixed Methods Study (GRAMMS)" reporting guidelines (O'Cathain et al., 2008; Table S1, e-component).

Setting

Participants were recruited from two ICUs within the same healthcare network in Victoria, Australia that participated in a previous cohort study (Paton et al., 2023a). Recruitment occurred from September 4th, 2017, till October 16th, 2018, with the 6-month follow-up home visits completed by April 18th, 2019.

Ethical approval

Ethical approval was received from Monash Health Human Research Ethics Committee (Reference: HREC/17/MonH/298) for this registered study (NCT03413189), with participants providing written informed consent for participation. Participants were advised they could withdraw at any stage.

Participants

Monash Health patients that received mechanical ventilation for longer than 24 h and survived to hospital discharge were eligible for inclusion. Patients were excluded if they were aged less than 18 years, had a proven or suspected acute brain process likely to impact consciousness or cognition (e.g., traumatic brain injury, stroke, hypoxic brain injury, subarachnoid haemorrhage), did not speak English, or if they lived more than 90 km from the main recruitment site.

Recruitment occurred via an opt-out approach where eligible participants were posted research information and then contacted via telephone to seek consent to participate.

Data collection methods

Demographic and hospital-based data (age, gender, admission diagnosis, duration of mechanical ventilation, and length of stay in ICU and hospital) were obtained from hospital information systems. Illness severity was measured using the Acute Physiology and Chronic Health Evaluation (APACHE) III score. Information relating to participants' function at hospital discharge, discharge destination and follow-up services provided were obtained through hospital information systems.

Quantitative and qualitative data was collected at the participant's home by the primary researcher (MP) 6-months from ICU admission. Safety screening was completed prior to the home visit to ensure researcher safety, with the researcher trained in participant management and ensured participant comfort throughout the visit (refer to the distressed participant protocol, e-component).

Physical function was measured in person during the home visit using four performance-based outcome measures - the functional independence measure [FIM], 6-minute walk distance [6MWD], functional reach test [FRT] and grip strength. These outcomes were completed by a trained and accredited (where required) assessor (MP) as per the recommended guidelines (outlined in the e-component).

The semi-structured interview was designed by the research team based on pre-existing literature (Allum et al., 2018; Corner et al., 2019) and piloted with healthcare professionals and previous ICU patients (accessed via the patient liaison service at Monash Health) (refer to ecomponent). Interviews focused on the participants' functional level before and after the ICU admission, memories of the ICU and hospital stay, the assistance they required on return home and during their recovery, any ongoing limitations, and the recovery process in general. Questions were open-ended in design to reduce leading bias but allow participants to appropriately reflect on their experiences. Partial prompts were pre-determined to ensure some standardisation of the content obtained.

At the discretion of the participant, relatives or carers were invited to be present during the interview to facilitate recall and to provide their experiences.

All interviews were conducted and audio-recorded (following verbal consent from all parties) by the lead researcher (MP).

For reflexivity, the first author (MP) is an Advanced Critical Care Physiotherapist from the recruiting sites who had completed training in qualitative research methods. Although MP had some involvement in the care of the recruited patients during their ICU admission, she was not the sole care provider and was not remembered by any participants on follow-up. No other authors were involved with data collection, with CM (a physiotherapist at a separate healthcare network) and DB (a research fellow specialising in qualitative studies) assisting MP in transcript analysis and code development.

Data analysis

Quantitative data

Each participant's physical function (measured through the performance-based outcomes) was individually referenced to their published age and sex matched population norms (Casanova et al., 2011; Functional reach predictive values; Halliday et al., 2020; Massy-Westropp et al., 2011; Quach et al., 2019; Yorke et al., 2015) and described as either within or outside the normal range. When a participants' measured function was outside the expected range for their age and sex, the number of standard deviations (SD) from the anticipated value was reported to quantify the variance. When normal values were presented as median [Interquartile range(IQR)], these were converted to mean(SD) as per the method described by Wan et al (2014), and 95% confidence intervals converted to SD as per the process outlined in the Cochrane handbook (Higgins and Deeks, 2022).

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Qualitative data

Interviews were de-identified and transcribed verbatim using QSR International's NVivo software (released in March 2020). Transcripts were correlated against the interview audio recordings by two researchers (MP, CM) to ensure accuracy and completeness.

The method outlined by Corbin and Strauss (2008) was employed to analyse the interviews. Open coding was used initially to conceptualise, compare, and categorise the data until inductive thematic saturation occurred (20 interviews; Saunders et al., 2018). Two authors (MP and CM) then read transcripts independently to identify axial and selective codes which were reviewed and refined with the whole research team to ensure robustness and validity. Interviews were then further reviewed to ensure alignment of all pertinent content with the defined codes.

Four (20 %) interviews were double coded to ensure alliance of coding between researchers.

Findings

There were 325 eligible patients of whom 40 (12.3%) consented to the PREDICTABLE study, with thematic saturation achieved after 20 participant interviews (Fig. 1). These 20 participants had a median [IQR] age of 64.5 [52.5–70.5] years, with just over half being male (n = 11, 55%), and were admitted to ICU with mostly cardiac issues (n = 8, 40%). Baseline characteristics, demographic data and hospital outcomes are reported in Table 1.

Median [IQR] interview length was 23 min and 58 s [16:47 – 38:17] and interviews were conducted within a mean (SD) of 5.7 (\pm 8.3) days of the 6-month ICU admission date. Seven participants had a family member present during the interview. The distressed participant protocol did not need to be implemented throughout the study.

Physical function

The comparison of the performance-based outcomes in relation to age and sex matched population norms, with the corresponding quote from participants regarding their perception of recovery is shown in Table 2.

Measured function compared to expected

Only six of the 20 participants measured physical function (30%)

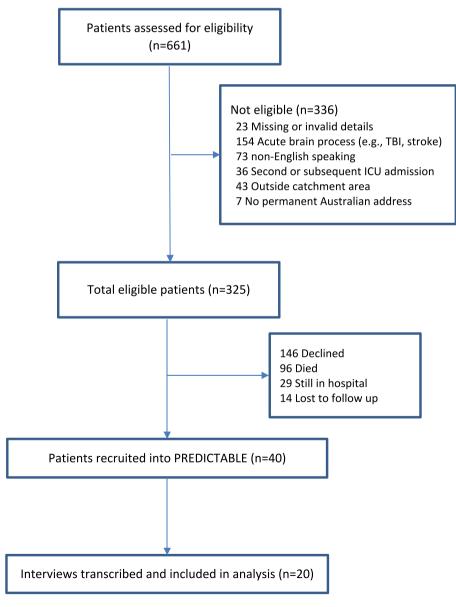


Fig. 1. Flow of patients in the study.

Table 1

Participant demographic and hospital data.

Variable	Participants ($n = 20$)
Age, median [IQR]	64.5 [52.5–70.5]
Male, n (%)	11 (55)
ICU LOS, days, median [IQR]	3.3 [2.8-4.3]
Hospital LOS, days, median [IQR]	13.9 [7.9–15.9]
MV duration, hours, median [IQR]	38 [31–69]
APACHE III, mean \pm SD	62.5 [45.8–73.3]
Primary Diagnosis on admission, n (%)	
Cardiac	8 (40 %)
Surgical	4 (20 %)
Respiratory	3 (15 %)
Neurological	3 (15 %)
Sepsis	2 (10 %)
Discharge destination, n (%)	
Home	15 (75 %)
In-patient rehabilitation	5 (25 %)

APACHE Acute Physiology and Chronic Health Evaluation score; ICU intensive care unit; IQR interquartile range; LOS length of stay; MV mechanical ventilation; n number; SD standard deviation

equalled their age and sex matched population norms across all four performance-based outcomes. The cohort performed the best in the functional reach test (FRT) with only four from the 19 that completed the assessment (21%) below their predicted value, and 32% (6/19) achieving above the expected range. The 6-minute walk distance (6MWD) showed the largest variance from normal values with one participant 5 SDs below their age and sex matched population norm, but just over half the cohort (11 of 20 participants, 55%) achieving the anticipated result. The group performed the worst in grip strength with only nine of the 20 participants (45%) within their age and sex matched population norm. Eight of the 20 participants (40%) were classified as having modified independence as per the Functional Independence Measure (FIM), with the other 12 achieving complete independence, the expected outcome for community dwelling adults. Although pre-morbid function was not able to be measured, patient reported outcomes taken retrospectively at 3-motnhs and again at 6-months (as part of the PRE-DICT study; Higgins et al., 2021) showed minimal change (see Table S2,

e-component).

Perception of function compared to objectively measured

When asked if they had recovered from their illness, 12 of the 20 participants (60%) stated that they had, with many having quite an optimistic attitude (Table 2). Despite this, six of these 12 (50%) were below their age and sex matched population norms across one or more performance-based outcome. Grip strength was the most common outcome effected with five of the 12 (42%) below their predicted value. Three of the 12 participants (25%) were identified as having modified independence via the FIM (a level lower than expected for community dwelling adults) with two of the 12 participants (17%) below their anticipated 6MWD. All bar one participant who perceived that they had recovered from their illness either met or exceeded their expected FRT value.

Functional limitations

Despite many participants reporting that they had recovered from their critical illness, when prompted 85% (17/20) described new limitations. Fatigue, being breathless or slower than they were before their admission was commonly reported, as seen in Table 3 and by the following quotes:

"I've slowed down a lot and any physical work is a limitation in itself." (Participant 7, 73 years, female)

"Like, if I do a little bit of cleaning and got out of breath and I've got to stop. I used to do a lot of gardening. Now, I can't do that. [I] can't lift things." (Participant 9, 68 years, male).

Physical limitations were the most described constraints, and participants tended to focus on activities that they couldn't continue following their illness such as sports or hobbies (Table 3).

Concerns during the recovery process

Function following discharge home from hospital-based care

The immediate period following discharge from hospital was described as a major concern by 17 of the 20 (85%) participants, despite

Comparison of measured performance-based outcomes to normal population (age and sex matched) with participants perception of recovery.

Participant	Age	Sex	6MWD (m)	FIM	FRT (cm)	Grip (kg)	Have you recovered?	
1	61	F	520	126	47.5	25.17	"Uh, yes. I don't feel that, you know, really very ill. I can do everything every single day, whenever I want"	
2	75	М	340#	119*	28*	26.33*	"I feel a lot better in myself, and I'm much better than I was"	
3	60	М	628.5	126	43.25	34.5*	"Yeah, I feel like I've recovered. I'm generally good. I'm doing a little bit more now"	
4	65	F	365#	123	36	16*	"Oh, no, no. I know I've come a long way, well over halfway compared to what I was [but I have] slowed down a little bit"	
5	59	М	535	119*	31.25*	24 [#]	"They're times that I get, I'm a little shocked, but I feel like I'm progressing"	
6	73	F	532	117*	_	18.5*	"I think I'm doing OK"	
7	69	М	450*	119*	40.5	25.67	"Oh, absolutely. I've, I've slowed down and physical work is a limitation in itself, but generally there's nothing I can't do"	
8	70	F	597.5	124	46	22.33	"Yes. You don't know whether it's an age-related thing, but you do get more aches and pains"	
9	68	Μ	455*	119*	31*	18*	"No, not really, there's a lot of things I can't do"	
10	45	F	490.5*	126	33.5	25.5	"I'm improving slowly, but I haven't completely recovered"	
11	64	М	370 [#]	116*	36	31.33*	"I still reckon that I'm still, on the way, on the way to getting there, but as they said, it's going to be a slow process"	
12	73	М	553	124	35	28.33*	"Yes, yes, definitely"	
13	69	М	539.5	125	41.25	33.5	"Oh, well, yeah, I feel have"	
14	72	F	284 [§]	117*	40.5	17.83	"Um, well, I think I've got a bit to go"	
15	36	F	560	125	45	28.67	"Үер"	
16	22	Μ	640	125	54.5	$30.67^{\#}$	"From where I was? Yeah"	
17	72	F	610	125	48.75	19.67	"Yes"	
18	51	Μ	631	126	43.5	44.33	"Yeah. I feel like I recovered pretty much the day I walked out of the hospital"	
19	25	М	325.5 [¶]	118*	42	13.67 [§]	"Physically, I feel alright, but everything's a lot harder to do, but I can do some things I'm used to, so in that consideration, physically, it's getting better"	
20	53	F	360#	124	24.5*	20.67*	"I'm recovering still"	

Key: * 2 SD below normal; # 3 SD below normal; § 4 SD below normal; ¶ 5 SD below normal; *italic* above predicted. 6MWD six-minute walk distance; FRT Functional Reach Test; SD standard deviation.

Table 3

Content from participants in relation to each identified theme.

Physical Function							
New limitations	"You don't know whether it's an age-related thing or since [the illness], but I'm slower and you get more aches and pains." (Participant 8)	"I find I get terrible, terribly exhausted just, you know, doing the housework." (Participant 4)	"I'm doing everything, but I'm doing a lot of things slower. Slower, not as strenuous. And that's how it is. So it's always got to do this, just take my time. And even just getting up, all of a sudden, I've got to slow everything down. That's how it is. Yeah." (Participant 19)				
Focus on physical restrictions	"I would play a lot of sport, I would play soccer, I would play hockey. I haven't been able. I haven't even been able to run so far since all this" (Participant 5)	"Well, I can't dance like I used to anyway. I still have aches and pains, but when I moved (previously), I had more, you know, I loosened up. But now it's like it gets heavier. Yeah, it's heavy. And I have tried, and I want to try, but yeah, there's various limitations." (Participant 4)	"I feel a lot better in myself, at the moment but I'm not. I don't feel as though I could do things that I used to be able to do, like get up and you know, just walk here or go there or go fishing. Things where I've got to use any strain, no, I'm not as, anywhere, nowhere near that at the moment." (Participant 2)				
Function and sup	port on discharge from hospital-based care	(martine)					
Issues on discharge home	"I just was very tired, really tired" (Participant 8)	"Well, I think, maybe they let me come home a week too soon. But I found it terribly hard to get under the shower. You know, and G had to help me under the shower, and put my undies on, you know, just leaning down was so hard" (Participant 4)	"I've come in the door and then got on the bed And then when I get up in the morning, I couldn't get up. This is for the first, oh, three or four days. M had to come around and get me up. I just had no strength in the core here. And then after say four or five days, I was doing it by myself. But it took that few days that I needed help" (Participant 17)				
Importance of family and friends	"When I first came back, I was relied very heavily on [wife] to doing everything. She probably still does everything for me to be quite honest" (Participant 2)	"It was mostly self-manageable besides the dressing stuff, but I had my parents around me all the time. So yeah, I was I was able. But yeah, other people may not" (Participant 19)	"But no, it's very good, and I wouldn't have got any better support from the council people. You know, I've got [husband]. I'm very lucky to come home to somebody. Yeah. A lot of people go home, and they don't have support like that at home. It makes a big difference. That's why I've got through this" (Participant 17)				
Accessing services	"After I left hospital, I don't know who to ring. But they don't give a phone number, so you can't contact anyone" (Participant 9)	"I don't know what other things I could have asked for anyway for when I did come home" (Participant 14)	"I could not get any help because I didn't have the assessment [] Then I rang to get that assessment, and they said at least four months waiting time. That's what I have, I've been waiting months, for months. I said, what is the point?" (Participant 6)				
Financial impact							
Financial issues	"I can't travel because of finances. Chemist bills and medicines keep piling up" (Participant 3)	"Yeah, finances have been having a little bit of an issue for us. We, we are, as I say, though depending totally on [wife's] salary now. I'm not getting a lot of finances in, and the bills keep coming in" (Participant 5)	"I mean it's like between seeing a psychologist every week that's about a hundred thirty, a hundred and fifty dollars a week. I do get rebated 80 bucks, but you know, out of expenses, travel into all appointments and feeding myself in-between, it's difficult. Like it leaves you with not much, but sometimes I'm lucky in a way that when it happened, I was saving for a house. I do have a bit of money saved" (Participant 19)				
Accessing financial support	"I was linked in with Centrelink, but I remember when this happened, in the first month, they were hassling me 'oh when are you coming in for your JobSeeker appointment?' and everything. It was just too hard" (Participant 19)	"So then they told me, you apply to Centrelink and they will give you some money, and they gave me a certificate. I filled in the form, but Centrelink is never easy. We went to Centrelink here, the girls were very helpful there, but they told us, you can't apply for permanent disability. We want you to apply for Newstart and sickness allowance. But then you know you'd be filling out forms for the rest of your life." (Participant 5)	"The paperwork is very daunting, and when you're not in that space, and I just, you know, ok, I'll do some other time, and then a few more weeks have gone past and then months have gone past and we've just only recently you know, completed it, cause it keeps on and on and on, like it's not just one page of forms, there's different sections. The paperwork is daunting" (wife of Participant 5)				

five of the 17 (29%) attending in-patient rehabilitation following their acute stay, and 11 of the 17 (65%) being deemed independent and safe for discharge by allied health staff in the acute hospital. Most participants reported fatigue and an inability to complete basics tasks, such as showering, when they first got home (Table 3).

"When I first got home from the hospital, I could not even make a cup of tea, I was so weak." (Participant 6, 73 years, female).

Support on discharge home from hospital-based care

When reviewing the transition from hospital-based care to home, nine of the 20 participants felt they received enough support despite all reporting decreased function on discharge. Assistance from family and friends was pivotal, as demonstrated by the quotes in Table 3 and the following:

"No, no [my family] helped me a lot. She's been, she's been a rock for me". (Participant 5, 59 years, male).

"My husband and my daughter were absolutely fantastic. They did all the stuff, and it was just great." (Participant 20, 53 years, female).

Of the other eleven participants stating they wanted more help on returning home, six did receive services (most commonly physiotherapy or cleaning and shopping assistance). A delay in the implementation of services, not knowing what was available or who they were meant to contact was commonly reported (Table 3). The utilisation of social workers to facilitate discharge home and coordinate support services (a common occurrence in acute Australian hospitals) only transpired in 20% of our cohort, with no interaction leading to community referrals either due to participants declining, being ineligible or continuing to inpatient rehabilitation.

Interesting, of the 12 participants stating they did not receive any services on discharge, five of these either did receive support (as documented in medical records) or were referred but then did not attend. Concerningly, four of the 20 participants (20%) had documentation from acute allied health staff identifying the need for services on discharge, however there was no further correspondence or confirmation from that service in the medical records. This could indicate staff

not completing the referral, or referrals being lost in the system. Unfortunately, two of these participants also described struggles on discharge and wanting more assistance during their interviews.

Financial impacts of recovering from critical illness

Financial issues were commonly reported following critical illness with none of the six participants working prior to ICU admission able to return to work at the time of review, relaying on partners salaries or savings. Many participants also reported an augmented cost of living following discharge due to an increase in medications, or the requirement to access more medical services to manage their health (Table 3).

Although the Australian government has an organisation (Centrelink) to assess and provide payments for people in need (e.g., unemployed, pensioners, or those temporarily or permanently disabled), many participants were either ineligible (due to partner income or assets) or found it too difficult to access, as highlighted by the quotes in Table 3.

Discussion

Key/novel findings of this study

This study provides novel data that despite critical care survivors having an optimistic view of their functional level, they remained below predicted age and sex matched population norms with many reporting new physical limitations 6-months from ICU admission. Decreased function and the inability to complete basic tasks following discharge from hospital-based care was frequent, despite many being reported as independent from hospital-based staff, possibly indicating variability in patient to staff expectations of function following a hospital stay. Assistance during the transition home was a main concern with the importance of family and friends to facilitate discharge highlighted. Participants expressed wanting more assistance than provided or inabilities accessing services, however we identified gaps in recall or acceptance of supports, with few receiving assistance from disciplines often used to facilitate this transition (i.e., social workers). The effect of critical illness on the financial well-being of the family network was confirmed, with an inability in accessing financial support identified, despite none of the cohort in paid work prior to their illness able to return at our review.

Comparison to other studies

As with many other studies utilising critical care survivors (Fan et al., 2014; Haines et al., 2018b), most of our cohort were identified as having decreased physical function compared to population aged and sex matched norms. However, our participants did not tend to identify their decreased capacity, with the majority stating they had recovered from their illness. Although other studies in critical care survivors have shown variance in perceived vs actual health (Turnball et al., 2022; Detsky et al., 2018), this is different to survivors of stroke, cancer and following joint replacement surgeries where patients have been found to report a worse function than that measured (Aujla et al., 2019; Southard et al., 2021; Winters-Stone et al., 2019). One hypothesis may be that ICU survivors have a more optimistic view of their health state following their critical illness, a phenomenon termed response shift (Oort, et al., 2009).

The importance of exercise capacity in the perception of recovery for survivors of critical illness was highlighted with fitness, or lack thereof, (measured through the 6MWD) the outcome most closely linked with perception of recovery. Only two participants that reported they had recovered were below the normal range for the 6MWD, with just one participant that felt that they had not recovered achieving a normal 6MWD. This aligns with previous research identifying that physical and functional sequela are major concerns for ICU survivors (Hashem et al., 2016).

Our cohort performed the worst in grip strength, which supports the fact that it has been reported as a stand-alone measurement to identify adults at poor risk of health (Bohannon, 2019), with critical care survivors known to access more healthcare resources (Morgan, 2021; Szakmany et al., 2019). Grip strength has also been found to have a high agreement with ICU acquired weakness (Bragança et al., 2019), a known factor associated with persistent deficiencies in functional ability, quality of life, prolonged recovery, and decreased survival (Hermans and Van deb Berfhe, 2015; Sidiras et al., 2019). Not only this, but decreased grip strength has also been shown to be a useful indicator of functional limitations (Wang et al., 2019), like those described by our cohort.

The importance for social support in the transition from hospital to home for critical care survivors has been highlighted previously (King et al., 2019) with decreased social supports identified as an independent predictor of moderate or severe disability 6-months from ICU admission (Hodgson et al., 2017). The fact that 60% (12/20) of our cohort stated they had enough support on discharge, even with 75% (9/12) reporting decreased function, and 67% (6/9) of those not receiving any formal services, highlights the importance of assistance from family and friends.

The inability for support services to meet the needs of critical care survivors is not a new concept. Laura Allum and team interviewed 12 critical care survivors and found that current support services did not have the sufficient flexibility to cater for the complex and individual needs of this population (Allum et al., 2018). Although this paper was completed in the UK, as Australia has a very similar healthcare network and follow-up process, it may be applicable to the issues identified by our cohort. While the recruitment centre did not offer a specific ICU follow-up service, benefits from such programs have been described (Haines et al., 2018a; Prinjha et al., 2009). Not only have they been shown to help identify and coordinate management of any long-term complications from the critical care admission (Morgan, 2021), but they can offer emotional and psychological benefits for both patients and families with the ability to talk about ICU experiences in a peer setting (Teixeira and Rosa, 2018). This would also prevent patients becoming"lost" after hospital discharge and provide a point of contact with healthcare services, a key issue identified by our cohort and one that has been reported previously for critical care survivors (Rousseau et al., 2021).

The financial impact of critical illness for patients and families beyond the initial hospital stay has been previously described (Griffiths et al., 2013; Khandelwal et al., 2020; King et al., 2019; Sevin et al., 2021). Our group were no different with the six participants who were working before admission not able to return to their previous role / capacity at the 6-month timepoint. This was confounded by many survivors requiring ongoing support from partners, often limiting their spouse's ability to maintain full-time employment. The lack of financial support available for patients and families, or difficulties in completing the necessary paperwork to obtain that support was often reported as a source of stress, as identified in other publications (Griffiths et al., 2013; Khandelwal et al, 2018; Sevin et al., 2021).

Application to clinical practice

Due to the focus on physical limitations identified in our cohort, providing supervised exercise programs for critical care survivors may be beneficial, with previous trials showing they can lead to increased motivation, energy levels, sense of achievement, social interaction, and confidence (Walker et al., 2015).

Improving the transition home from hospital-based care for ICU survivors should be a priority for healthcare networks. The mismatched perception between healthcare workers and patients on their abilities to manage tasks on discharge, or the possible variance in the importance placed on recovery milestones prior to going home should be investigated further. While evidence surrounding specific ICU follow-up clinics is limited and variable, often due to patient adherence, the increased use of telehealth following the pandemic may improve attendance and benefits for this cohort (Rousseau et al., 2021). Implementation of discharge coordinators or specific multi-disciplinary teams to streamline the discharge process has been shown to decrease inefficiencies and hospital length of stay, while increasing the likeliness of successful transition home (Houghton et al., 1996; Ibrahim et al., 2022; Logsdon and Little, 2020), and may be beneficial for this complex cohort. Finally, as the perception of recovery may not be the same as measured function, either formally assessing function, incorporating participants perceptions, or utilising appropriate patient reported outcomes that have been shown to correlate with measured function, such as the WHODAS 2.0 (Paton et al., 2023a), need to be considered when researching function with this cohort.

Future directions

Improving the physical function for survivors of critical illness has been a hot topic for the last decade. There are many studies currently investigating the effect of interventions to improve outcomes for this cohort, with early mobilisation in ICU showing improvements in outcomes including physical function, mechanical ventilation duration and length of stay (Paton et al., 2021; Waldauf et al., 2020; Wang et al., 2022). However recent publications have identified an increased probability of adverse events and mortality with its implementation (Paton et al., 2023b; TEAM Study Investigators and the ANZICS Clinical Trials Group et al., 2022), therefore identifying how to provide exercise interventions in a safe and effective manner for this cohort is a continued focus for many clinicians.

Providing an understanding of function prior to the ICU admission (preferably measured but even retrospectively reported by the participant) in future research would provide greater insights into the change in physical capacity that occurs following critical illness.

Streamlining the discharge process and improving access to assistance (financial, emotional, and physical) following critical illness should be a focus for all, with aims to improve the transition home and decrease anxiety during this difficult period.

Continuing to identify specific concerns patients and families have following an ICU stay is paramount to ensure that services meet their complex and diverse requirements.

Limitations

Although thematic saturation was obtained, and previous research has identified little new information is obtained as sample sizes reach 20 interviews (Saunders et al., 2018), as this study is a nested cohort describing only half the recruited participants, there may be variances not fully identified, especially when analysing the quantitative information. As our research was completed at only one healthcare network prior to the COVID pandemic with regulation of selection criteria for feasibility (i.e., limited participants from rural areas, from non-English speaking backgrounds or with neurological processes), our results may not be generalisable. Although our recruitment rate is comparable to other studies in ICU survivors (Grap and Munro, 2003), and exceeded the reported recruitment rate for health research in the UK (3.5 participants recruited per month vs 0.92 [IQR 0.43-2.79] reported by Walters et al., 2017), this study is subject to self-selection bias with results that may not be representative of all ICU survivors. The small sample size and inconsistent presence of caregivers during the interviews who often prompted answers increasing recollection and experiences mean our results are more hypothesis generating. Lastly, interviewing participants at only one time-point means we were not able to identify trajectory of recovery or perceptions over time.

Conclusion

Survivors of critical illness tended to have an optimistic perception of their function with many describing a better state than measured, but many still report limitations, particularly physical, 6-months from their admission. Family and friends play a crucial role in facilitating transition from hospital to home, with many reporting difficulties on discharge. Gaining access to financial and social supports required was difficult, with many participants unable to navigate current systems. Implementation of specific discharge liaison personnel, particularly in those without stable social supports, may improve the outcomes of critical care survivors.

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Clinical Trial registration number

NCT03413189.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2023.103583.

References

- Allum, L., Connolly, B., McKeown, E., 2018. Meeting the needs of critical care patients after discharge home: a qualitative exploratory study of patient perspectives. Nurs Crit Care. 23 (6), 316–323.
- Aujla, N., Walker, M., Vedhara, K., Sprigg, N., 2019. The relationship between patients' illness beliefs and recovery after stroke. Psychol Health Med. 24 (5), 551–558.
- Bohannon, R.W., 2019. Grip Strength: An Indispensable Biomarker For Older Adults. Clin Interv Aging. 14, 1681–1691.
- Bragança, R.D., Ravetti, C.G., Barreto, L., Ataíde, T.B.L.S., Carneiro, R.M., Teixeira, A.L., Nobre, V., 2019. Use of handgrip dynamometry for diagnosis and prognosis assessment of intensive care unit acquired weakness: A prospective study. Heart Lung. 48 (6), 532–537.
- Casanova, C., Celli, B.R., Barria, P., Casas, A., Cote, C., de Torres, J.P., Jardim, J., Lopez, M.V., Marin, J.M., Montes de Oca, M., Pinto-Plata, V., Aguirre-Jaime, A., Six Minute Walk Distance Project (ALAT), 2011. The 6-min walk distance in healthy subjects: reference standards from seven countries. Eur Respir J. 37 (1), 150–156.
- Corbin, J., Strauss, A., 2008. Basics of qualitative research (3rd ed.): Techniques and procedures for developing grounded theory. Sage Publications, Inc., Thousand Oaks, CA.
- Corner, E.J., Murray, E.J., Brett, S.J., 2019. Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. BMJ Open. 9 (2), e026348.
- Creswell, J.W., Plano Clark, V.I., 2018. Designing and Conducting Mixed Methods Research, third edition. Sage, Thousand Oaks, CA.
- Detsky, M.E., Kohn, R., Delman, A.M., Buehler, A.E., Kent, S.A., Ciuffetelli, I.V., Mikkelsen, M.E., Turnbull, A.E., Harhay, M.O., 2018. Patients' perceptions and ICU clinicians predictions of quality of life following critical illness. J Crit Care. 48, 352–356.
- Fan, E., Dowdy, D.W., Colantuoni, E., Mendez-Tellez, P.A., Sevransky, J.E., Shanholtz, C., Himmelfarb, C.R., Desai, S.V., Ciesla, N., Herridge, M.S., Pronovost, P.J., Needham, D.M., 2014. Physical complications in acute lung injury survivors: a twovear longitudinal prospective study. Crit Care Med. 42 (4), 849–859.
- Functional reach predictive values. http://www.hhvna.com/Functional_Reach_Test.pdf. (accessed 01.05.2022).
- George, T., 2023. Mixed Methods Research | Definition, Guide & Examples. Scribbr. [Available from: https://www.scribbr.com/methodology/mixed-methods-research/].
- Grap, M.J., Munro, C.L., 2003. Subject recruitment in critical care nursing research: a complex task in a complex environment. Heart Lung, 32 (3), 162–168.

Griffiths, J., Hatch, R.A., Bishop, J., Morgan, K., Jenkinson, C., Cuthbertson, B.H., Brett, S.J., 2013. An exploration of social and economic outcome and associated health-related quality of life after critical illness in general intensive care unit survivors: a 12-month follow-up study. Crit Care. 17 (3), R100.

- Haines, K.J., Berney, S., Warrillow, S., Denehy, L., 2018a. Long-term recovery following critical illness in an Australian cohort. J Intensive Care. 6, 8.
- Haines, K.J., Beesley, S.J., Hopkins, R.O., McPeake, J., Quasim, T., Ritchie, K., Iwashyna, T.J., 2018b. Peer Support in Critical Care: A Systematic Review. Crit Care Med. 46 (9), 1522–11153.
- Halliday, S.J., Wang, L., Yu, C., Vickers, B.P., Newman, J.H., Fremont, R.D., Huerta, L.E., Brittain, E.L., Hemnes, A.R., 2020. Six-minute walk distance in healthy young adults. Respir Med. 165, 105933.
- Hashem, M.D., Nallagangula, A., Nalamalapu, S., Nunna, K., Nausran, U., Robinson, K.A., Dinglas, V.D., Needham, D.M., Eakin, M.N., 2016. Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge. Crit Care. 20 (1), 345.
- Hermans, G., Van den Berghe, G., 2015. Clinical review: intensive care unit acquired weakness. Crit Care. 19 (1), 274.
- Higgins, J.P.Y., Deeks, J.J., 2022. Chapter 6: Choosing effect measures and computing estimates of effect. In: Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., Welch, V.A. (Eds.), Cochrane Handbook for Systematic Reviews of Interventions version 6.3 (updated February 2022). Cochrane [Available from: www.training.cochrane.org/handbook].
- Higgins, A.M., Neto, A.S., Bailey, M., Barrett, J., Bellomo, R., Cooper, D.J., Gabbe, B.J., Linke, N., Myles, P.S., Paton, M., Philpot, S., Shulman, M., Young, M., Hodgson, C.L., PREDICT Study Investigators, 2021. Predictors of death and new disability after critical illness: a multicentre prospective cohort study. Intensive Care Med. 47 (7), 772–781.
- Hodgson, C.L., Udy, A.A., Bailey, M., Barrett, J., Bellomo, R., Bucknall, T., Gabbe, B.J., Higgins, A.M., Iwashyna, T.J., Hunt-Smith, J., Murray, L.J., Myles, P.S., Ponsford, J., Pilcher, D., Walker, C., Young, M., Cooper, D.J., 2017. The impact of disability in survivors of critical illness. Intensive Care Med. 43 (7), 992–1001.
- Houghton, A., Bowling, A., Clarke, K.D., Hopkins, A.P., Jones, I., 1996. Does a dedicated discharge coordinator improve the quality of hospital discharge? BMJ Quality & Safety. 5, 89–96.
- Ibrahim, H., Harhara, T., Athar, S., Nair, S.C., Kamour, A.M., 2022. Multi-Disciplinary Discharge Coordination Team to Overcome Discharge Barriers and Address the Risk of Delayed Discharges. Risk Manag Healthc Policy. 15, 141–149.
- Khandelwal, N., Engelberg, R.A., Hough, C.L., Cox, C.E., Curtis, J.R., 2020. The Patient and Family Member Experience of Financial Stress Related to Critical Illness. J Palliat Med. 23 (7), 972–976.
- King, J., O'Neill, B., Ramsay, P., Linden, M.A., Darweish Medniuk, A., Outtrim, J., Blackwood, B., 2019. Identifying patients' support needs following critical illness: a scoping review of the qualitative literature. Crit Care. 23 (1), 187.
- Logsdon, K.D., Little, J.M., 2020. Evaluation of Discharge Coordinators and Their Effect on Discharge Efficiency and Preparedness. J Pediatr Health Care. 34 (5), 435–441.
- Maddox, M., Dunn, S.V., Pretty, L.E., 2001. Psychosocial recovery following ICU: experiences and influences upon discharge to the community. Intensive Crit Care Nurs. 17 (1), 6–15.
- Massy-Westropp, N.M., Gill, T.K., Taylor, A.W., Bohannon, R.W., Hill, C.L., 2011. Hand Grip Strength: age and gender stratified normative data in a population-based study. BMC Res Notes. 4, 127.
- McPeake, J., Sevin, C.M., Mikkelsen, M.E., 2021. Functional outcomes following critical illness: epidemiology, current management strategies and the future priorities. Curr Opin Crit Care. 27 (5), 506–512.
- Morgan, A., 2021. Long-term outcomes from critical care. Surgery (oxf). 39 (1), 53–57. O'Cathain, A., Murphy, E., Nicholl, J., 2008. The quality of mixed methods studies in health services research. J Health Serv Res Policy. 13, 92–98.
- Oort, F.J., Visser, M.R., Sprangers, M.A., 2009. Formal definitions of measurement bias and explanation bias clarify measurement and conceptual perspectives on response shift. J Clin Epidemiol. 62 (11), 1126–1137.
- Paton, M., Lane, R., Paul, E., Cuthburtson, G.A., Hodgson, C.L., 2021. Mobilization During Critical Illness: A Higher Level of Mobilization Improves Health Status at 6 Months, a Secondary Analysis of a Prospective Cohort Study. Crit Care Med. 49 (9), e860e869.
- Paton, M., Lane, R., Paul, E., Linke, N., Shehabi, Y., Hodgson, C.L., 2023a. Correlation of patient-reported outcome measures to performance-based function in critical care survivors: PREDICTABLE. Aust Crit Care. 36 (4), 485–491.
- Paton, M., Chan, S., Tipping, C.J., Stratton, A., Serpa Neto, A., Lane, R., Youn, G.P.J., Romero, L., Broadley, T., Hodgson, C.L., 2023b. The effect of mobilization at 6 months after critical illness — meta-analysis. NEJME. 2 (2). Epub ahead of print.
- Prinjha, S., Field, K., Rowan, K., 2009. What patients think about ICU follow-up services: a qualitative study. Crit Care. 13 (2), R46.

- Quach, N.T., Ehsanian, R., Dirlikov, B., Sechrist, S., Mohole, J., McKenna, S., Isaac, L., Duong, T.T., 2019. Burden of Care Implications and Association of Intracranial Hypertension With Extremely Severe Post-traumatic Amnesia After Traumatic Brain Injury: A 5-Year Retrospective Longitudinal Study. Front Neurol. 10, 34.
- Rousseau, A.F., Prescott, H.C., Brett, S.J., Weiss, B., Azoulay, E., Creteur, J., Latronico, N., Hough, C.L., Weber-Carstens, S., Vincent, J.L., Preiser, J.C., 2021. Long-term outcomes after critical illness: recent insights. Crit Care. 25 (1), 108.
- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., Jinks, C., 2018. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 52 (4), 1893–1907.
- Sevin, C.M., Boehm, L.M., Hibbert, E., Bastin, A.J., Jackson, J.C., Meyer, J., Quasim, T., Bakhru, R.N., Montgomery-Yates, A., Slack, A., Still, M., Netzer, G., Mikkelsen, M.E., Iwashyna, T.J., Haines, K.J., McPeake, J., 2021. Optimizing critical illness recovery: perspectives and solutions from the caregivers of ICU survivors. Crit Care Explor. 3 (5), e0420.
- Sidiras, G., Patsaki, I., Karatzanos, E., Dakoutrou, M., Kouvarakos, A., Mitsiou, G., Routsi, C., Stranjalis, G., Nanas, S., Gerovasili, V., 2019. Long term follow-up of quality of life and functional ability in patients with ICU acquired Weakness - A post hoc analysis. J Crit Care. 53, 223–230.
- Southard, E.J., Ode, G., Simon, P., Christmas, K.N., Pamic, D., Collin, P., Mighell, M.A., Frankle, M.A., 2021. Comparing patient-reported outcome measures and physical examination for internal rotation in patients undergoing reverse shoulder arthroplasty: does surgery alter patients' perception of function? J. Shoulder Elbow Surg. 30 (75), S100–S108.
- Szakmany, T., Walters, A.M., Pugh, R., Battle, C., Berridge, D.M., Lyons, R.A., 2019. Risk factors for 1-year mortality and hospital utilization patterns in critical care survivors: a retrospective, observational, population-based data linkage Study. Crit Care Med. 47 (1), 15–22.
- TEAM Study Investigators and the ANZICS Clinical Trials Group, Hodgson, C.L., Bailey, M., Bellomo, R., Brickell, K., Broadley, T., Buhr, H., Gabbe, B.J., Gould, D.W., Harrold, M., Higgins, A.M., Hurford, S., Iwashyna, T.J., Serpa Neto, A., Nichol, A.D., Presneill, J.J., Schaller, S.J., Sivasuthan, J., Tipping, C.J., Webb, S., Young, P.J., 2022. Early Active Mobilization during Mechanical Ventilation in the ICU. N Engl J Med. 387 (19), 1747–1758.
- Teixeira, C., Rosa, R.G., 2018. Post-intensive care outpatient clinic: is it feasible and effective? A literature review. Rev Bras Ter Intensiva. 30 (1), 98–111.
- Tenny, S., Brannan, G.D., Brannan, J.M., 2022. Qualitative Study. In: StatPearls [Internet]. Treasure Island (FL), StatPearls Publishing. [Available from: https:// www.ncbi.nlm.nih.gov/books/NBK470395/].
- Turnbull, A.E., Ji, H., Dinglas, V.D., Wu, A.W., Mendez-Tellez, P.A., Himmelfarb, C.D., Shanholtz, C.B., Hosey, M.M., Hopkins, R.O., Needham, D.M., 2022. Understanding patients' perceived health after critical illness: analysis of two prospective, Longitudinal Studies of ARDS Survivors. Chest 161 (2), 407–417.
- Waldauf, P., Jiroutková, K., Krajčová, A., Puthucheary, Z., Duška, F., 2020. Effects of rehabilitation interventions on clinical outcomes in critically ill patients: systematic review and meta-analysis of randomized controlled trials. Crit Care Med. 48 (7), 1055–1065.
- Walker, W., Wrigh, T.J., Danjoux, G., Howell, S.J., Martin, D., Bonner, S., 2015. Project Post Intensive Care eXercise (PIX): A qualitative exploration of intensive care unit survivors' perceptions of quality of life post-discharge and experience of exercise rehabilitation. J Intensive Care Soc. 16 (1), 37–44.
- Walters, S.J., Dos Anjos, B., Henriques-Cadby, I., Bortolami, O., Flight, L., Hind, D., Jacques, R.M., Knox, C., Nadin, B., Rothwell, J., Surtees, M., Julious, S.A., 2017. Recruitment and retention of participants in randomised controlled trials: a review of trials funded and published by the United Kingdom Health Technology Assessment Programme. BMJ Open. 7 (3), e015276.
- Wan, X., Wang, W., Liu, J., Tong, T., 2014. Estimating the sample mean and standard deviation from the sample size, median, range and/or interquartile range. BMC Med Res Methodol. 14, 135.
- Wang, Y.T., Lang, J.K., Haines, K.J., Skinner, E.H., Haines, T.P., 2022. Physical Rehabilitation in the ICU: A Systematic Review and Meta-Analysis. Crit Care Med. 50 (3), 375–388.
- Wang, T., Wu, Y., Li, W., Li, S., Sun, Y., Li, S., Zhang, D., Tan, Q., 2019. Weak Grip Strength and Cognition Predict Functional Limitation in Older Europeans. J Am Geriatr Soc. 67 (1), 93–99.
- Winters-Stone, K.M., Medysky, M.E., Savin, M.A., 2019. Patient-reported and objectively measured physical function in older breast cancer survivors and cancer-free controls. J Geriatr Oncol. 10 (2), 311–316.
- Yorke, A.M., Curtis, A.B., Shoemaker, M., Vangsnes, E., 2015. Grip strength values stratified by age, gender, and chronic disease status in adults aged 50 years and older. J Geriatr Phys Ther. 38 (3), 115–121.