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Patients' experiences and perspectives of post-hospital follow-up care to improve physical recovery for intensive care survivors: A systematic review of qualitative research

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ABSTRACT

Background: Intensive care units deliver care to a heterogeneous group of patients with pre-existing co-morbid disease. Focus has shifted to improving health related quality of life with more patients surviving beyond hospital discharge. Randomised controlled trials evaluating follow-up interventions, to improve physical recovery, have not demonstrated a health-related quality of life benefit. Qualitative research may provide the context to understand the experiences of intensive care survivors during follow-up care addressing physical limitations.

Objective: To synthesise qualitative studies and explore Intensive Care survivors' experiences and perspectives of physical symptoms in the context of follow-up care.

Setting(s): A systematic search of electronic databases (MEDLINE, Cumulative Index of Nursing and Allied Health Literature, Web of Science, Applied Social Sciences Index and Abstracts, Ovid Nursing and Ovid Emcare) was conducted to identify peer-reviewed primary qualitative studies. No date parameters were applied. Inclusion/exclusion criteria guided the screening process.

Participants: The data from eligible primary research studies was extracted into NVivo (v12).

Methods: Critical appraisal was completed using the Joanna Briggs Critical Appraisal Tool. Thematic analysis, guided by Braun and Clarke (2022), informed the data synthesis.

Results: From 2457 studies, ten relevant studies were included. Two main themes were identified:

1. Recovery as uncertain; which outlines the uncertainty experienced by intensive care unit survivors during recovery. This theme pertained to system-level factors (role of healthcare professional and information provision) which provides the context for delivering follow-up care. 2. Self-determination of recovery; outlines individual characteristics in determining recovery which is conceptualised by patient-level factors (motivation, support network and perception of health).

Conclusions: For intensive care survivors, the recovery trajectory is uncertain with a gap in information provision during the acute phase following hospital discharge. Patients' self-determination of recovery is an important consideration to ensure follow-up care addresses the needs of individual patients. The impact of pre-existing co-morbid disease and subgroups of patients deriving benefit from follow-up care remains uncertain.

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Tweetable abstract: Patients' experiences of post-hospital follow-up care to improve physical recovery for intensive care survivors: A Systematic Review of Qualitative Research

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Contribution of the paper statements

What is already known?

- More patients are surviving critical illness and the focus has shifted to improving long-term outcomes.
- Pre-existing co-morbid disease is prevalent amongst intensive care patients and is a known risk factor for reduced health-related quality of life in the convalescence period following critical illness.
- Follow-up interventions addressing physical limitations have not demonstrated a clinical benefit on long-term outcomes such as health-related quality of life and physical functioning.

What this paper adds?

- For healthcare professionals caring for intensive care survivors, understanding patients' perception of recovery, with regards to baseline health, should be incorporated into assessment and management to assist with goal planning.
- Future research is required to understand the long-term recovery experience of specific groups of intensive care survivors, particularly those with pre-existing co-morbid disease, so that follow-up care can be tailored to individual needs.
- To mitigate feelings of uncertainty future service design should make provisions to address the gap in informational needs between hospital discharge and receipt of follow-up care, with consideration of individuals stage in recovery and tailor the format and content of information to the needs of both intensive care survivors and family caregivers.

1. Introduction and background

Patients with complex and advanced health conditions, previously deemed “too sick” to tolerate invasive intensive care treatments are surviving beyond hospital discharge (Akinosoglou et al., 2023). Advances in research, technology, and therapeutics have led to a reduction in mortality, with research and clinical care shifting attention to the long-term implications of intensive care admission. Health-related quality of life of intensive care survivors is now at the forefront of outcome measurement (Feemster et al., 2015; Turnbull et al., 2016).

Two out of five critically ill patients suffer from at least a single pre-existing co-morbidity (Simpson et al., 2021). Pre-existing co-morbid disease is a risk factor for reduced health-related quality of life, protracted recovery, repeated hospital readmission, and increased long-term mortality rates (McPeake et al., 2021; Orwelius et al., 2010). Concurrently, with an increasing prevalence of co-morbid disease, patients suffer from persisting symptoms and chronic ill-health, termed ‘Post-Intensive Care Syndrome’ (Haas & Wunsch, 2016). Post-intensive care syndrome is defined as “new or worsening impairments in physical, cognitive, or mental health status arising after critical illness and persisting beyond acute hospitalisation” (pg, 505) (Needham et al., 2012). The physical impairments associated with Post-Intensive Care Syndrome have been reported to last for months or years following hospital discharge (Needham et al., 2012). Addressing the long-term consequences manifesting as Post-Intensive Care Syndrome has been widely reported as a priority for critical illness survivors and their relatives, with physical functioning an important outcome measurement (Auriemma et al., 2022).

Globally, follow-up services, such as physical rehabilitation programmes have attempted to address the burden of physical impairments associated with Post-Intensive Care Syndrome. Yet, a systematic review and meta-analyses found no improvement in health-related quality of life scores or mortality rate when physical rehabilitation programmes were compared to those receiving standard care (Taito et al., 2019). This has been attributed to the heterogeneity of the intensive care population. With growing recognition that sub-groups of intensive care survivors may benefit from follow-up care, a “one size fits all” approach is inappropriate (Griffith et al., 2018). Pre-existing co-morbid disease may influence intensive care survivors’ response to rehabilitation. A recent analysis of pooled data from four randomised controlled trials of physical therapy interventions, found intensive care survivors with two or more co-morbidities, exposed to the intervention reported significantly higher health related quality of life scores (Jones et al., 2023).

Additionally, the positivist nature of randomised controlled trials may not be amenable to providing insight into potential benefits of physical rehabilitation (Corry et al., 2019). A systematic review, synthesising qualitative research on patient important outcomes beyond hospital discharge highlighted a variance between patient perspective of recovery and standardised quantitative measurement tools (Hashem et al., 2016). Further, coupled with a paucity of gold standard and rigorously validated Health Related Quality of Life measurement tools, quantitative evaluation may not be sufficiently sensitive to reflect the nuances and experiences associated with critical illness recovery (Lau et al., 2021). Qualitative research can link processes and outcomes within specific settings and cultures to help understand this variance, add depth and understanding (CRD, 2008). This can bring in the patient’s experience of physical recovery and inform future research and practice within intensive care follow-up services. Therefore, the aim of this study is to synthesise qualitative studies and explore intensive care survivors’ experiences and perceptions of physical symptoms in the context of follow-up care. Specifically, the research questions include 1. How do intensive care survivors perceive physical recovery in the context of pre-existing co-morbid disease? 2. What are intensive care survivors experiences of follow-up care aimed at physical recovery? 3. How do intensive care survivors perceive any barriers or facilitators influencing physical recovery?

2. Design

This systematic review and qualitative evidence synthesis is reported in accordance with the 'Enhanced Transparency in Reporting for Qualitative Evidence Synthesis' statement (Cooper et al., 2018; Tong et al., 2012). The study protocol was registered with PROSPERO (no. CRD42022355711).

2.1. Eligibility criteria

Studies of interest included intensive care survivors (≥ 18 years old) discharged to their home environment and reporting perspectives of follow-up care addressing physical recovery. Studies recruiting both patients and caregivers were included but only the voice of the patient was captured within these dyads. The review included peer reviewed primary research studies reporting qualitative findings. Mixed methods studies were included provided the qualitative data addressed the research question. Studies primarily focusing on interventions delivered within the intensive care unit or ward setting, or that related to specialist intensive care units were excluded. No language or year limiters were applied. Detailed inclusion criteria are outlined in Box 1.

2.2. Data sources/search strategy

Following consultation with an expert subject librarian, a pre-planned comprehensive search strategy was employed to identify all relevant studies published within bibliographic databases (MEDLINE, Cumulative Index of Nursing and Allied Health Literature, Web of Science, Ovid Emcare, Ovid Nursing Database and Applied Social Sciences Index and Abstracts) (Flemming & Noyes, 2021; Tong et al., 2012). Key concepts included 'critical care', 'physical recovery intervention' and 'patient perspective'. Keywords and phrases, tailored to each database were identified, including synonyms and abbreviations, through brainstorming, reviewing published research articles and searching Major Subject Headings (Aromataris & Pearson, 2014). The key terms and search strategy is detailed in supplementary file (S1).

2.3. Screening

All initial articles were exported into EndNote (v20.5) (Clarivate Analytics, Philadelphia, USA) for de-duplication and screening of titles and abstracts (Bramer et al., 2017). Full-text articles meeting the inclusion criteria were retrieved, screened, and retained for the review. The screening process eliminated studies that failed to fulfil the inclusion criteria. All decisions were independently checked by a second reviewer (SM).

2.4. Data extraction

A customised data extraction form was designed to capture contextual and methodological data. The results, findings or discussion section of the study articles were extracted, provided it addressed the review question (Noyes et al., 2019). Line-by-line coding was completed using NVivo (v12). This process occurred in an iterative manner as data familiarisation took place.

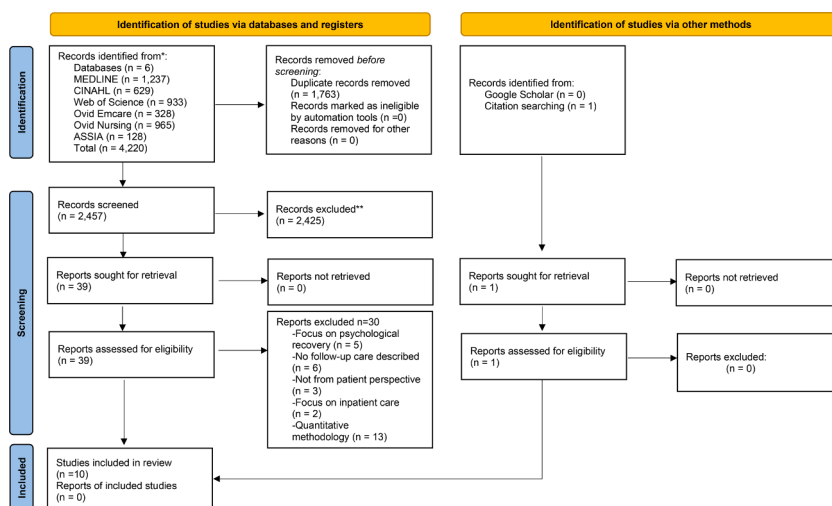


Fig. 1. Preferred reporting items for meta-analyses and systematic reviews (PRISMA).

Table 1
Study characteristics.

Author/Year/ Country	Study design and methods	Study aims and results	Participants (including number and age)	Sex	Timing of follow-up care	Primary admission diagnosis + Nature of admission	Evidence of pre-existing co- morbidity disease	Follow-up care
Pattison et al. (2007), United Kingdom	Mixed methods: Semi-structured questionnaires and in-depth qualitative interviews using a grounded theory approach (Glaser & Strauss, 1967)	<i>Aim:</i> To establish patients' experience after discharge from critical care and to evaluate implementation of a follow-up service <i>Results:</i> The themes identified include 1) rehabilitation from critical care 2) physiological issues and needs 3) memories: real and unreal 4) uncertainty 5) fear and empathy. Following discharge from hospital, issues were related to longer term needs. Recovery was made easier through the follow-up clinic	Intensive care survivors >48hours in critical care <i>n</i> = 22 open text questionnaires <i>n</i> = 14 participants interviewed and provided qualitative data <i>n</i> = 37 interviews in total carried out Age not reported	Not reported	Semi-structured questionnaire at 6 and 12 months Interviews to correspond with first surgical follow-up appointment (approximately six weeks post hospital discharge and at six months)	Surgical cancer patients (>18 years old) undergoing major cancer surgery for sarcoma and upper gastro-intestinal Elective	Not reported	-Ward follow-up on day one and five -Nurse-led follow-up appointment following discharge
Allum et al. (2018), United Kingdom	Qualitative exploratory study using thematic analysis (Braun & Clarke, 2006) Semi-structured telephone interviews	<i>Aim:</i> To describe former critical care patients' perspective on the support needed to optimise recovery <i>Results:</i> Four themes outlining support were identified including 1) effective management of transfer anxiety 2) tailored information provision 3) timely access to services 4) a supportive social network. Critical illness survivors should be equipped with information about ongoing health issues and recovery with holistic care at home. Follow-up facilitated these needs but should be flexible to be useful to ICU survivors.	ICU survivors 48 h stay in ICU within the last ten years (<i>n</i> = 12) Age range 25–75	Female (<i>n</i> = 7) Male (<i>n</i> = 5)	Range of six months to nine years (mean 4.9 years) following critical care discharge	Cardiac Arrest Trauma, Sepsis, Pancreatitis, Gastrointestinal Infection, Acute Respiratory Distress Syndrome, Sepsis with Acute Respiratory Distress Syndrome and Pneumonia with Acute Respiratory Distress Syndrome (<i>n</i> = 1) Sepsis (<i>n</i> = 6) Emergency	Not reported	Ad hoc: -General Practitioner follow-up -Follow-up clinics -Physical rehabilitation
Hanifa et al. (2018), Denmark	Focused ethnography (observations of follow-up consultation and interviews 2 to 4 weeks later)	<i>Aim:</i> 1) To describe former intensive care patients' experiences of the consultation, specifically regarding content and setting 2) To explore the benefits of the consultation regarding individual patients' symptoms of Post Intensive	Intensive care survivors (<i>n</i> = 10) Age 32–84	Female (<i>n</i> = 7) Male (<i>n</i> = 3)	Invited at 2 months	Common intensive care unit diagnosis (no further details given) Nature of admission not reported	Not reported	Follow-up consultation

(continued on next page)

Table 1 (continued)

Author/Year/ Country	Study design and methods	Study aims and results	Participants (including number and age)	Sex	Timing of follow-up care	Primary admission diagnosis + Nature of admission	Evidence of pre-existing co- morbidity disease	Follow-up care
Maddox et al. (2001), Australia	Qualitative Analysis using constant comparison Semi-structured interviews	<p>Care Syndrome <i>Results:</i> The content and setting of the consultation were of utmost importance. Involving relatives in follow-up care was essential as they were an important part of the patient's rehabilitation.</p> <p><i>Aim:</i> 1) To explore participants perception of the recovery period on the community on discharge home following ICU admission 2) To identify factors influencing participants' perceptions of the recovery period 3) To determine participants' perceptions of the role of community services and the factors influencing their use of these services during the recovery period</p> <p><i>Results:</i> Recovery is characterised by the patients' focus on physical recovery. The major theme 'moving on' describes participants incorporation of normalising life, returning to usual routines, and leaving behind the ICU experience. Factors influencing the recovery period included individual attitudes, prior experiences, the ICU experience and support of family and friends. Attention is given to the physical needs and care. Despite awareness of community support, patients were generally reluctant to avail themselves of any of these services.</p>	Intensive care survivors discharged from hospital to community ($n = 5$) Significant others ($n = 4$) Age 42–76 years (mean 59.6)	Both genders represented (exact number unclear)	6–15 weeks following discharge home	Post-operative support and acute medical illness Nature of admission not reported	Not reported	Community services: General Practitioner, hospital at home, district nursing service, domiciliary care, volunteer services, hospital social work, city council, hospital health promotion unit and critical care unit (staff available to talk to post-discharge)
Olsen et al. (2017), Norway	Qualitative explorative study Semi-structured	<p><i>Aim:</i> To investigate how adult patients experience intensive care and their recovery period and the</p>	Intensive care survivors Mechanical Ventilation for >48	Female ($n = 10$) Male ($n = 19$)	Three months after discharge from hospital	Admission diagnosis or nature of admission not reported	Not reported	Information pamphlet (given to patient whilst on the ward): Telephone interview at (continued on next page)

Table 1 (continued)

Author/Year/ Country	Study design and methods	Study aims and results	Participants (including number and age)	Sex	Timing of follow-up care	Primary admission diagnosis + Nature of admission	Evidence of pre-existing co- morbid disease	Follow-up care
	telephone interviews	usefulness of an information pamphlets <i>Results</i> : Two main themes were identified: 1) “Being on an unreal, strange journey” 2) “Balancing between who I was and who I am”. Continuity of care and the nurse’s ability to see and value individual differences is crucial. The information pamphlet helped intensive care survivors understand that their recovery was normal. Both ICU patients and their families must be included when information material and rehabilitation programs are designed and evaluated.	h and living at home with no nursing healthcare services (n = 29) Age 20–80					three months -Pamphlet evaluated -Information pamphlet outlined various physical conditions patients will go through after Intensive care
Prinjha et al. (2009), United Kingdom	Qualitative interviews with thematic analysis	<i>Aim</i> : To explore patients’ perceptions and experiences of follow-up services <i>Results</i> : Patients valued ICU follow-up services as they had made an important contribution to their physical recovery in terms of continuity of care, receiving information and gaining expert reassurance. Continuity of care involved having tests and being monitored referrals to other specialists and ICU follow-up appointments soon after hospital discharge.	Intensive care survivors (n = 34) Age 23–76	Female (n = 14) Male (n = 20)	Not reported	Various cancers, heart conditions, pneumonia, pancreatitis, head injury, bowel perforation, accidents, aneurysm and surgical complications Emergency	Not reported	All participants invited to follow-up clinic as outpatient
Lee et al. (2009), Canada	In-depth interviews and framework methodology	<i>Aim</i> : To explore the support needs of Acute Respiratory Distress Syndrome survivors during recovery <i>Results</i> : Information needs focused on the events surrounding the acute illness, while physical needs revolved around physical therapy. When patients were preparing for hospital discharge, they expressed a	Intensive care survivors (n = 25) Mean age 48.3	Female (n = 11) Male (n = 14)	Three months post ICU discharge, every six months for five years	Acute respiratory distress syndrome Emergency	Not reported	Clinical follow-up interviews -provide information on the long-term sequelae of critical illness and outpatient physiotherapy

(continued on next page)

Table 1 (continued)

Author/Year/ Country	Study design and methods	Study aims and results	Participants (including number and age)	Sex	Timing of follow-up care	Primary admission diagnosis + Nature of admission	Evidence of pre-existing co- morbidity disease	Follow-up care
		desire for specific information about the recovery and rehabilitation process, including outpatient physiotherapy and long-term sequelae of the illness. In the community, survivors' sought guidance on home care and secondary prevention.						
Czerwonka et al. (2015), Canada	Framework methodology In-depth, semi-structured interviews	<i>Aim:</i> To explore survivors' and caregivers' needs from critical illness through to return to independent living <i>Results:</i> One overriding theme: survivors do not experience continuity of medical care during recovery after critical illness with three subthemes, 1) Information needs changes across the recovery continuum 2) Fear and worry exist when families do not know what to expect 3) Survivors' transition from dependence to independence	Intensive care survivors mechanically ventilated for a minimum of 7 days ($n = 5$) Age: $n = 4 > 50$ years old (age of 5th participant not reported)	Female ($n = 2$) Male ($n = 3$)	Various timepoints up to 24 months	Medical and surgical intensive care patients (specific conditions not reported) Emergency and elective	Not reported	Outpatient rehabilitation and homecare services- further details not reported
Ferguson et al. (2019), United Kingdom	Qualitative interviews (telephone and in-person) Thematic content analysis (Burnard's description)	<i>Aim:</i> To explore patients' perceptions of engaging in an ICU follow-up exercise program <i>Results:</i> Patients provided insight into the physical and mental sequelae experiences following critical illness. There was a strong sense of patients' need for the exercise program and its importance for their recovery. Key facilitators included supervision. Tailoring of the exercises to personal needs. Barriers included existing physical limitations, poor mental health and a lack of motivation.	ICU survivors ($n = 21$) Age: Mean (Standard deviation) 53 (13)	Female ($n = 11$) Male ($n = 10$)	13 to 18 weeks following the end of the intervention	Respiratory ($n = 13$) Cardiovascular ($n = 3$) Neurological ($n = 2$) Gastrointestinal ($n = 2$) Trauma ($n = 1$) Not reported	Not reported	6 to 11 week personalised and supervised exercise programme

(continued on next page)

Table 1 (continued)

Author/Year/ Country	Study design and methods	Study aims and results	Participants (including number and age)	Sex	Timing of follow-up care	Primary admission diagnosis + Nature of admission	Evidence of pre-existing co- morbid disease	Follow-up care
Walker et al. (2015), United Kingdom	Thematic analysis (Braun & Clarke, 2006) Focus groups ($n = 4$)	<i>Aim:</i> To gain an in-depth insight into patients' perceptions of their quality of life after hospital discharge and their experiences of aftercare services <i>Results:</i> The themes identified included 1) social isolation 2) abandonment 3) reduced physical activity 4) vulnerability. The exercise program promoted motivation to engage and improved energy levels and supports an improvement in physical health.	ICU survivors Min. 3 days mechanical ventilation Mean age 42.6	Female ($n = 5$) Male ($n = 11$)	8 weeks from hospital discharge Timing of focus group unknown	Trauma and sepsis Emergency	Acute Physiology and chronic health evaluation II = 16.0 Intervention participants	Eight-week supervised exercise programme (in- hospital setting) versus usual care

2.5. Quality appraisal

The Joanna Briggs Institute critical appraisal tool was used to assess the methodological quality of the studies (Lockwood et al., 2015). Concurrently to data extraction, quality appraisal was carried out by one researcher (NR). Thirty percent of the eligible studies were independently quality appraised by a second researcher (SM). Discrepancies were minor and related to the level of reflexivity reported by the author. Methodological rigour was not an indicator for study eligibility, instead, it was recognised that omission of studies with lower methodological rigour may exclude insightful and novel findings (Dixon-Woods et al., 2005). The aim of this quality appraisal was to highlight the overall contribution of studies to the findings (supplementary file 2).

2.6. Data synthesis/analysis

One researcher (NR) completed the thematic synthesis guided by Braun and Clarke's six phase analytic process (Braun & Clarke, 2022). A second researcher (SM) was consulted for reflexive discussion and to sense-check theme development. An inductive approach was taken to theme development. During stage one, all studies were read in full and initial thoughts and ideas jotted down (stage one, familiarising). At stage two (coding), data was assigned codes, through 'open coding'. Codes were a combination of semantic, latent, or double coding. Theme development during stages three to five was completed as described by Braun and Clarke (2022). Once the final themes were clearly demarcated, the sixth phase involved writing the qualitative synthesis.

3. Results

From 4221 records initially identified, 2457 titles and abstracts were screened, with 39 retrieved for full text review. Ten studies fulfilled inclusion criteria, one of which was identified through reference list searching (Page et al., 2021) (Fig. 1 Preferred Reporting Items for Systematic Reviews and Meta-Analysis diagram). Overall, studies were of good methodological quality however, the theoretical underpinning was omitted in all ten studies. The influence of the researcher on the research was omitted in six studies with the other four studies determined to be unclear in their reporting.

3.1. Characteristics of included studies

Studies ($n = 10$) were predominantly conducted in the United Kingdom ($n = 5$), with Canada ($n = 2$), Denmark ($n = 1$), Norway ($n = 1$) and Australia ($n = 1$) also represented. The studies were conducted between the years 2001 and 2019. Data was collected from 169 intensive care survivors, through semi-structured interviews ($n = 8$), focus groups ($n = 1$) and a combination of observations and in-depth interviews ($n = 1$). The qualitative data from one mixed methods study was clearly defined and extracted for inclusion. A myriad of interventions were implemented to support follow-up (Table 1 Study Characteristics). Notably, demographic data, in all ten studies, did not report pre-existing co-morbid disease of the intensive care survivors.

3.2. Synthesis of findings

From ten studies, two overarching themes were identified: 'Recovery as uncertain' and 'Self-determination of recovery' to explain intensive care survivors' experiences and perceptions of physical recovery and follow-up care. 'Recovery as uncertain', encompasses three subthemes: 'preference of information delivery', 'presence of healthcare professional' and 'search for guidance'. These subthemes pertain to system-level factors, including information provision and the role of healthcare professionals, providing the context for delivering follow-up care and supporting the transition from hospital to home, and in turn influences physical recovery experiences. This overarching theme outlines the uncertainty experienced by intensive care survivors with regards to physical recovery. Theme two, 'Self-determination of recovery', is further divided into three subthemes; 'baseline health', 'changed self' and 'family support' and is conceptualised from the interpretation of intensive care survivors' individual characteristics to determine recovery. This theme outlines patient level factors including, motivation, perception of health and support network, individual to each patient, which either promotes or inhibits physical recovery. The presence of barriers and facilitators are outlined within both major themes and influence physical recovery (Box 2). Participant quotes illustrating the findings are represented in Table 2 ('Illustrative participant quotes').

3.3. Theme one: recovery as uncertain

3.3.1. Information delivery preference

All ten studies offered insight into the challenges of information provision to support physical recovery. The content, format and timing of information denotes effective information delivery. Information content ranged from specific individualised information, such as information about intensive care admission diagnosis, to a general overview of what to expect during recovery (Allum et al., 2018; Ferguson et al., 2019; Hanifa et al., 2018; Lee et al., 2009; Olsen et al., 2017; Prinjha et al., 2009). In isolation, general information was not deemed suffice for participants or caregivers to progress physical recovery (Allum et al., 2018; Lee et al., 2009; Prinjha et al., 2009; Walker et al., 2015). The studies outlined specific information important to intensive care survivors including; duration of recovery, potential repercussions, management of medical conditions, post-intensive care syndrome symptoms, pace of physical activity, progress, and additional community services (Allum et al., 2018; Czerwonka et al., 2015; Lee et al., 2009; Pattison et al., 2007; Prinjha et al., 2009). Three studies recognised the value of information to gauge physical progress (Czerwonka et al., 2015;

Table 2
Illustrative participant quotes.

Subthemes	Illustrative quotes
Preference of information delivery	<p>"The pamphlet was our 'user manual' after the ICU [intensive care unit] stay; to answer questions such as: What is happening in my body? Why have I lost my appetite?" (page 65) (Olsen et al., 2017)</p> <p>"It feels safe with the information; I can read it in black and white, and the written information can be read and re-read." (page 65) (Olsen et al., 2017)</p> <p>"I, of course, wasn't at work, still at home recovering...So you spend far too much time chewing the cud feeling frustrated that you'd like to kind of do something about it. And that's why it was a good thing that they had follow-up. But the follow up came far too long after. It needs to be a lot sooner" (page 5) (Prinjha et al., 2009)</p> <p>"...it felt like they just wanted a bed and had to throw me out...I just felt like...sort of abandoned really..." (page 41) (Walker et al., 2015)</p>
Search for guidance	<p>"to find that the GP[General Practitioner] doesn't know really much about what you've gone through it's a bit...worrying" (page 318) (Allum et al., 2017)</p> <p>"But when I approached my GP [General Practitioner] after, he was very dismissive and I think it was genuinely through not enough knowledge" (page 980) (Ferguson et al., 2019)</p> <p>"...my physiotherapists at the [rehabilitation centre] did research and found three physios for me, in the [home town] area, but that was pretty much all they did, they didn't give me any kind of information...like I couldn't drive, cause I couldn't walk...[husband] had to find a program for someone to come and pick me up and take me to physio...would be insane...I would say they did very, very, bare bones" (page 6) (Lee et al., 2009)</p> <p>"as the patient...you're still not with it...trying to come to terms with what has happened is quite a big task, let alone thinking about...how am I gonna cope? You need to almost be handed these things on a plate". (page 319) (Allum et al., 2017)</p> <p>"...we were kept in the dark...just to get put back into your home. No guidance for your family as to how to take care of you". (page 41) (Walker et al., 2015)</p> <p>"[I'd like to know] what to expect [...] Cause right now I'm having numbness at the tip of my fingers, tips of my toes, sometimes I feel more tired so easily now [...] even ten hours sleep is not good enough [...] I have no clue [if that's normal] I'm not a doctor but I would like to know if I'm doing the right thing or if I'm just going to make it worse" (page 245) (Czerwonka et al., 2015)</p>
Healthcare professional presence	<p>"To have [the physiotherapist] explaining everything to me and making sure that, I knew then I could trust her that if she was pushing me that wee bit further...I felt safe with her doing that, whereas if I had gone on my own and went on a treadmill, I wouldn't have stuck it." (page 981) (Ferguson et al., 2019)</p> <p>"...one to one...just focusing on you" (page 41) (Walker et al., 2015)</p> <p>"I think [I] probably [would have liked to receive more contact] with the health care system, because you're not quite sure as to how your recovery period is going" (page 245) (Czerwonka et al., 2015)</p>
Baseline Health	<p>"I thought it was nice to know it could be linked to having been in a coma. Here at the rehabilitation centre, they said it could be because of my type 2 diabetes" (page 89) (Hanifa et al., 2018)</p>
Changed-self	<p>"I have a good life. I have some physical problems, but I am optimistic after all" (page 64) (Olsen et al., 2017)</p> <p>"one of those blokes that..don't like to trouble people. You know..if I think I can do it, I'd rather do it myself than trouble anyone else" (page 10) (Maddox et al., 2001)</p> <p>"...but it turned out that I was normal. It's not just me that's special because I can't drink coffee anymore or eat green jelly beans or whatever. And...I lose my hair. Other people do as well..." (page 89) (Hanifa et al., 2018)</p>
Family support	<p>"I didn't understand...I thought she could be kind to me. She wasn't kind anymore. She saved my life, got me out of the hospital, brought me home, and then was mad and angry...maybe it was too much in retrospect to ask of my wife...my wife became my primary caregiver and that probably really ticked her off...she was mad at me...I was mad at her" (page 7) (Lee et al., 2009)</p> <p>"It's kind of hard right now because I think everything is on my mom. She's got to clean for me, she's got to do the food for me, I can't really depend on my father anymore [because he is in the hospital], now it's basically my mom. What choice does she have?" (page 245) (Czerwonka et al., 2015)</p>

Box 1

Inclusion/exclusion criteria.

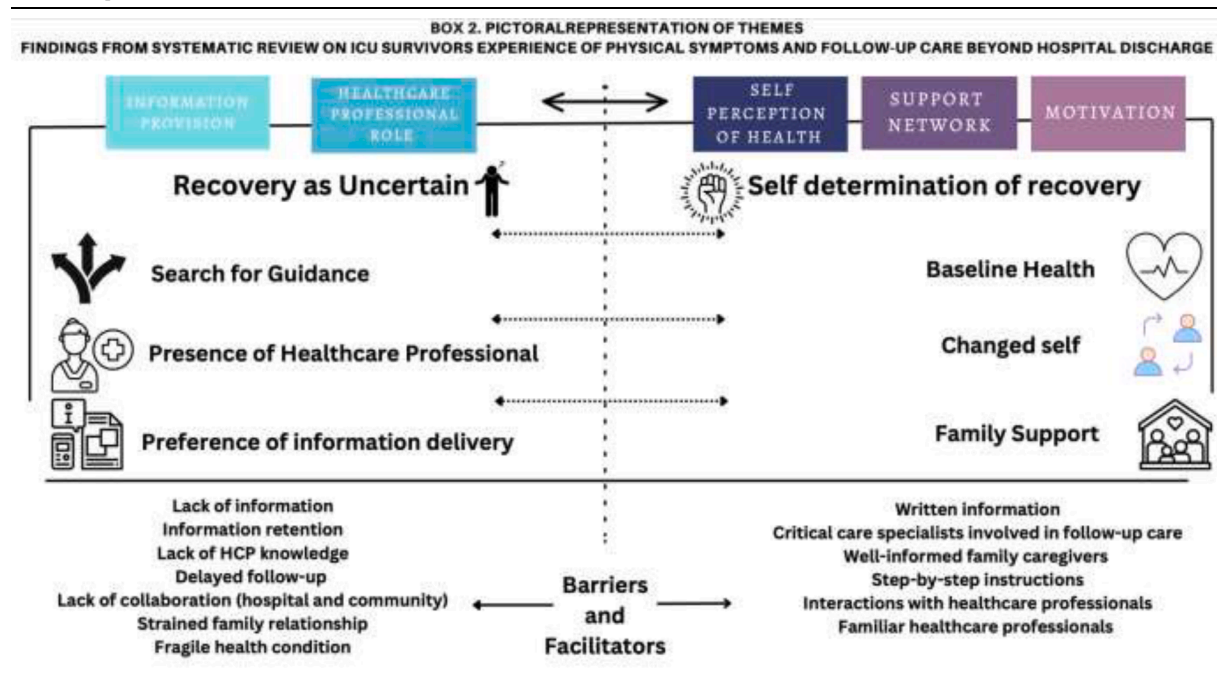
Inclusion	Exclusion
-Intensive Care Survivors (>18 years old)	-Studies that sought the perspective of healthcare professionals or family caregivers
-Studies addressing perceptions of follow-up care aimed at physical recovery	-Studies addressing perceptions of follow-up care solely implemented in intensive care and/or ward setting
-Patients discharged from hospital to home	-Follow-up care aimed at psychological recovery
-Primary research studies	-Patients discharged to long-term care facility (for example nursing home)
	-Studies focusing on specialist intensive care units
	-Literature reviews, conference abstracts and descriptive articles

Lee et al., 2009; Walker et al., 2015). Two studies identified information in the form of physical assessments, such as pulmonary function tests, was beneficial in providing reassurance of physical progress (Czerwonka et al., 2015; Lee et al., 2009).

Finding a balance of what constitutes enough information versus too much information was challenging. Studies recognised a need for extensive information, although participants ability to retain information was a barrier to effective communication (Allum et al., 2018; Lee et al., 2009; Olsen et al., 2017). Verbal information provided at hospital discharge was forgotten when the participants condition was fragile (Allum et al., 2018; Olsen et al., 2017). Written information, in the form of pamphlets, exercise manual and links

Box 2

Pictorial representation of themes.



to online information, was beneficial and patients could later refer to this information, describing it as their “user-manual” (Ferguson et al., 2019; Lee et al., 2009; Olsen et al., 2017; Pattison et al., 2007).

The timing of follow-up care to support physical recovery was important. Physical recovery interventions, are an information rich source, provide individually targeted explanations, and can act as a platform to ask questions (Allum et al., 2018; Lee et al., 2009; Olsen et al., 2017; Prinjha et al., 2009). Four studies, described information provision at follow-up as occurring too late, and highlighted the need for information delivery in the acute period shortly after hospital discharge (Allum et al., 2018; Czerwonka et al., 2015; Hanifa et al., 2018; Prinjha et al., 2009). Hanifa et al. (2018) described a preference for information on physical recovery prior to follow-up occurring at several months. Two studies suggested an interim telephone call or email to address this information gap (Allum et al., 2018; Prinjha et al., 2009). Hospital discharge was not a viable time to deliver the information required to support physical recovery due to poor staffing levels and rushed discharge process, preventing the opportunity for participants and family to ask questions (Allum et al., 2018; Czerwonka et al., 2015; Prinjha et al., 2009; Walker et al., 2015).

3.3.2. Search for guidance

Difficulty accessing information and follow-up services to support physical recovery was reported in four studies as a barrier to recovery (Allum et al., 2018; Czerwonka et al., 2015; Lee et al., 2009; Walker et al., 2015). Intensive care survivors recognised that relatives were often the first point of contact for information, yet they did not have the required information or knowledge (Czerwonka et al., 2015; Hanifa et al., 2018; Olsen et al., 2017). Intensive care survivors identified guidance on adapting the home environment, taking care of their relatives’ physical needs and available community services as important content of information for their relatives (Allum et al., 2018; Lee et al., 2009; Walker et al., 2015).

Two studies confirmed that healthcare professionals are well positioned to co-ordinate the delivery of information and signpost further information, such as, support groups and websites (Ferguson et al., 2019; Lee et al., 2009). Although five studies reported that healthcare professionals, predominantly primary care practitioners, did not have the required knowledge or information on physical recovery (Allum et al., 2018; Ferguson et al., 2019; Hanifa et al., 2018; Lee et al., 2009; Olsen et al., 2017). When healthcare professionals were ill-informed in critical illness symptomatology, its subsequent recovery trajectory, and the individuals experience, participants experienced a feeling of dismissal (Ferguson et al., 2019). Three studies confirmed that information and follow-up care should be delivered by critical care specialists (Allum et al., 2018; Ferguson et al., 2019; Hanifa et al., 2018). Two studies reported General Practitioner’s as a point of contact for participants who were physically well recovered (Maddox et al., 2001; Prinjha et al., 2009). Another study reported that participants who were recovering well, consulted medical notes and internet as a source of information but did not find an adequate explanation of their symptoms (Hanifa et al., 2018).

3.3.3. Presence of healthcare professionals

Interactions with healthcare professionals were a facilitator to positive follow-up care and physical recovery. Intensive care survivors highly value one-to-one attention and rapport building (Ferguson et al., 2019). Studies described follow-up interactions as

needing to occur in a timely manner (Allum et al., 2018; Ferguson et al., 2019; Prinjha et al., 2009). Three studies reported ongoing exposure to healthcare professionals as beneficial to physical recovery (Ferguson et al., 2019; Prinjha et al., 2009; Walker et al., 2015). This was particularly important for those struggling physically but for those well recovered one follow-up appointment was suffice (Prinjha et al., 2009). Others expressed they only wanted follow-up care when necessary (Maddox et al., 2001). Three studies reported that participants had to “fight” for contact with healthcare professionals and attributed a delayed follow-up to healthcare professionals being too busy (Allum et al., 2018; Prinjha et al., 2009; Walker et al., 2015). There was evidence of a lack of collaboration between hospital and community services (Maddox et al., 2001; Walker et al., 2015). Participants in three studies sourced their own follow-up care (Allum et al., 2018; Prinjha et al., 2009; Walker et al., 2015).

Receiving support from a familiar healthcare professional was important to participants. When participants were reviewed by healthcare professionals who were unfamiliar, they reported having to repeatedly provide explanations of their critical care treatments, experience and physical recovery progress, resulting in healthcare professionals being unprepared to carry out assigned care (Allum et al., 2018; Prinjha et al., 2009; Walker et al., 2015). Findings from two studies, suggested a nominated healthcare professional should oversee recovery and act as point of contact for ongoing support (Czerwonka et al., 2015; Prinjha et al., 2009).

Those with ongoing exposure to healthcare professionals felt more motivated to engage in physical recovery interventions, had increased satisfaction, perceived having received more care and were more compliant with physical rehabilitation programmes (Allum et al., 2018; Ferguson et al., 2019; Prinjha et al., 2009; Walker et al., 2015). Czerwonka et al. (2015) reported satisfaction with information received when attending follow-up care for co-existing conditions, which may reflect ongoing exposure to healthcare professionals. Studies highlighted participants placed high value on the face-to-face interaction during follow-up, wanting healthcare professionals to witness the gravity of their condition (Allum et al., 2018; Pattison et al., 2007; Prinjha et al., 2009). A positive experience of follow-up was reported when healthcare professionals had personal skills that built engagement, rapport, and empathy (Ferguson et al., 2019; Prinjha et al., 2009; Walker et al., 2015).

Seven studies reported findings relating to the supportive role relatives play in physical recovery (Allum et al., 2018; Czerwonka et al., 2015; Hanifa et al., 2018; Lee et al., 2009; Maddox et al., 2001; Olsen et al., 2017; Prinjha et al., 2009). This support complemented or compensated for the input provided by healthcare professionals. Two studies suggested participants relied on relatives to attend follow-up (Hanifa et al., 2018; Prinjha et al., 2009). In addition to providing transport and acting as a source of information, relatives commenced practical tasks, such as, providing personal care and taking over chores and household responsibilities (Allum et al., 2018; Czerwonka et al., 2015; Hanifa et al., 2018). Participants in three studies highlighted that relatives have a dual positioning, requiring support to adequately carry out their new role as caregiver and support for their own well-being (Allum et al., 2018; Czerwonka et al., 2015; Lee et al., 2009).

3.4. Theme two: self-determination of recovery

3.4.1. Baseline health

Across the studies, evidence of pre-existing co-morbid disease was poorly reported. The participants in Pattison et al. (2007) study underwent surgery for cancer diagnosis. Seven studies provided evidence that participants health status prior to critical illness determined how participants perceived their physical recovery progress (Czerwonka et al., 2015; Ferguson et al., 2019; Hanifa et al., 2018; Lee et al., 2009; Maddox et al., 2001; Olsen et al., 2017; Walker et al., 2015). Expectations of recovery was benchmarked in terms of chronic ill health (Czerwonka et al., 2015; Olsen et al., 2017). One study identified that older participants expressed a different perspective on what constitutes physical recovery, tolerating lower functional status and compensating with optimism (Hanifa et al., 2018). Two other studies reported the same finding for participants with chronic ill health who expressed gratitude for surviving and accepted that their physical health would not be better than before their intensive care admission (Maddox et al., 2001; Olsen et al., 2017). Pattison et al. (2007) study reflected this sentiment. Another study identified pre-existing limitations, such as back pain and mobility issues, to be a barrier to physical rehabilitation (Ferguson et al., 2019). The tailoring of physical rehabilitation to individual needs presented as a facilitator to participation in exercise program (Ferguson et al., 2019). In three studies, a return to baseline health signified physical recovery goals, defined by resuming usual activities (Czerwonka et al., 2015; Lee et al., 2009; Walker et al., 2015). This view was taken when participants were well prior to ICU admission. One study highlighted, that assessment of pre-existing conditions should be a priority in follow-up care (Ferguson et al., 2019).

3.4.2. Changed self

Changed self represented the new physical limitations participants found themselves to suffer from and how drawing on their intrinsic characteristics allowed adaptation to their new identity. Four studies outlined that returning home from hospital was viewed positively (Hanifa et al., 2018; Lee et al., 2009; Olsen et al., 2017; Pattison et al., 2007). Other studies identified transitioning home brought on negative feelings of self-image (Hanifa et al., 2018; Olsen et al., 2017; Pattison et al., 2007). Studies reported feelings of stigmatisation, which was characterised by physical symptoms such as, weight loss, using a walking stick, scars, and muscle wastage. Other less visible changes including pain, fatigue, inability to climb stairs and general poor health, were difficult for patients to accept (Hanifa et al., 2018; Olsen et al., 2017; Pattison et al., 2007). Studies described various strategies to cope and adapt to these physical limitations, such as using a humorous approach to accept new health status (Maddox et al., 2001). Four studies reported altering daily activities such as, pacing themselves and taking one day at a time (Lee et al., 2009; Maddox et al., 2001; Olsen et al., 2017; Pattison et al., 2007). Other studies discussed the importance of having a positive outlook in their approach to physical recovery (Maddox et al., 2001; Olsen et al., 2017; Pattison et al., 2007).

Six studies recognised gaining feedback from healthcare professionals that physical symptoms they experienced are “normal” and

facilitated the adjustment to changed self (Allum et al., 2018; Czerwonka et al., 2015; Hanifa et al., 2018; Olsen et al., 2017; Pattison et al., 2007; Prinjha et al., 2009). Benchmarking symptoms against other intensive care survivors, through information provision, provides reassurance and is a vital function of follow-up care (Allum et al., 2018; Czerwonka et al., 2015; Hanifa et al., 2018; Olsen et al., 2017; Pattison et al., 2007; Prinjha et al., 2009).

Studies demonstrated intensive care survivors have a desire to recover through taking ownership of physical recovery, such as, researching own symptoms and searching for available support (Allum et al., 2018; Czerwonka et al., 2015). This patient-led approach to recovery was criticised when participants were too unwell to take a proactive stance (Allum et al., 2018; Pattison et al., 2007). This suggests the interplay between patient-level factors (motivation) and system-level factors (information provision and role of healthcare professionals) is important to complement one another. When patients are motivated to recover, this is not always possible, meaning healthcare professionals need to provide mechanisms to support physical recovery. Further, Olsen et al. (2017) found the information pamphlet helped survivors to cope by explaining physical symptoms. Another study recognised the value of support at follow-up care to facilitate participants to move on (Pattison et al., 2007). There was evidence that adaptation and coping strategies were required long-term with some survivors not returning to pre-illness physical status between six months to two years (Czerwonka et al., 2015).

3.4.3. Family support

Intensive care survivors described a self-determination to recover which is influenced by the acceptance of support from family. When participants discussed accepting help from relatives this was described differently by individuals (Czerwonka et al., 2015; Lee et al., 2009). One study reported determination to recover independently, however support received from family was viewed positively (Maddox et al., 2001). Two other studies viewed themselves as burdensome when relying on relatives support with evidence this was a motivator to recover (Czerwonka et al., 2015; Walker et al., 2015). Walker et al. (2015) reported a benefit of exercise rehabilitation in providing the intensive care survivor with self-reliance in physical recovery. Another study highlighted that intensive care survivors are happy to be cared for by relatives (Lee et al., 2009).

In two studies, intensive care survivors provided evidence of feelings of frustration leading to tension with their relative (Czerwonka et al., 2015; Lee et al., 2009). This tension was linked to a mismatch in expectations between intensive care survivor and their relative (Czerwonka et al., 2015; Lee et al., 2009). Conversely, intensive care survivors in two studies reported that the critical illness experience strengthened their relationship and reported valuing their relative more than before (Maddox et al., 2001; Olsen et al., 2017). One study identified that intensive care survivors recognise the protective role of family caregivers whereby their relatives are reluctant to relinquish caregiving duties, delaying a return to independence and contributing to the strained relationships (Czerwonka et al., 2015).

Previous caregiving experience influenced the caring dynamic. In two studies, intensive care survivors with a history of chronic ill health, recognised that this led to relatives being more prepared to take on a caregiving role (Czerwonka et al., 2015; Maddox et al., 2001). When intensive care survivors had previously been well, they recognised a prominent change for their relative due to the new caregiving role (Maddox et al., 2001).

4. Discussion

To our knowledge, this is the first systematic review to present a Qualitative Evidence Synthesis to understand the perspectives of intensive care survivor's follow-up care in the context of physical symptoms. Uncertainty is experienced throughout recovery and is triggered by delayed information provision. Intensive care recovery is encompassed by extensive informational needs, healthcare professionals who are unfamiliar with the intensive care recovery trajectory and a need for prominent healthcare professional support. The intensive care survivor's perception of recovery is situated by their self-determination to recover, further influenced by their baseline health, "new" changed self and family support. Overall, there is an interplay between identified system level factors (information provision and healthcare professional roles) and patient level factors (motivation, perception of health and family support). When effective system factors are in place, patient factors are supported to enable recovery.

A notable finding of this review includes the heterogeneity of the population included in the primary studies and the ad-hoc nature of follow-up care. Participants included had a broad range of ages, were admitted under elective and emergency pathways with various admission diagnosis making comparisons and identifying subgroups of patients who derive benefit difficult. Follow-up care was poorly described and varied, ranging from consultations (telephone calls) to interventional (physical rehabilitation programmes). Reflecting this, Connolly (2015) conducted a survey in the United Kingdom that found significant variability in follow-up interventions indicating there is no "gold standard" to benchmark services against. This makes evaluating their impact problematic. Additionally, the heterogeneity of the intensive care population adds further complexity. It is unknown which group of patients benefit most and from which interventions (Connolly et al., 2021). Lasiter et al. (2016) suggest follow-up interventions need to be individualised to meet the range of patient specific conditions amongst the intensive care population.

Equally, this review did not demonstrate how follow-up care addresses and manages pre-existing co-morbid disease due to scant reporting of the primary studies. Yet, an interesting finding was that intensive care survivors may frame expectations of recovery in terms of baseline health status. This indicates intensive care survivors do not experience critical illness in isolation and baseline health is an important factor in perception of recovery. The impact pre-existing co-morbid disease has on the intensive care recovery trajectory is poorly understood and addressing post-intensive care syndrome symptoms has been the focus of follow-up care and research (Kean et al., 2021; McPeake et al., 2021). Contemporary evidence confirms that the presence of co-morbidities and increased hospital resources prior to intensive care is linked to increased healthcare use post-intensive care (Jouan et al., 2019; Lone et al., 2016; Prescott

et al., 2019). This may indicate that the limitations associated with critical illness (post-intensive care syndrome) are not experienced in isolation and baseline health has a significant part to play. This may also reflect the finding that intensive care survivors identified a need for ongoing exposure to healthcare professionals. Further research is warranted to understand whether persisting symptoms are caused by critical illness and its associated treatments (post-intensive care syndrome), if it is a manifestation of worsening co-morbidities or a combination of both (Jouan et al., 2019; Lone et al., 2016; Sjöberg et al., 2020). It is important to gain an understanding of how intensive care survivors perceive their recovery and determine any pre-existing limitations. This will facilitate goal planning, management of expectations and provide follow-up care accordingly.

Another finding of this review was a gap in information provision between hospital discharge and attendance at follow-up care. The extensive informational needs expressed through participant accounts have been recognised throughout intensive care rehabilitation research (King et al., 2019; Ramsay et al., 2016). The National Institute for Clinical Excellence Guidelines (CG83) (2017) stipulate information should be distributed to intensive care survivors and relatives prior to discharge from intensive care. In contrast, this systematic review highlighted challenges to information retention, recognising that the hospital is not always a viable time to deliver information. Fardanesh et al. (2021) also identified information retention as a challenge in this group of patients, advocating for the distribution of written and online informational resources. Awareness of available information sources needs to be communicated to all healthcare professionals involved in the care of intensive care survivors with future services designed to bridge this gap. Enhanced information provision promotes patient engagement, ensure patients and relatives are more informed and helps dispel the feeling of uncertainty.

This review outlined that general practitioners have a role in caring for intensive care survivors and acknowledged a gap in their knowledge, suggesting an educational opportunity. Nonetheless, general practitioners infrequent exposure to intensive care survivors may mean education is less effective (Kiernan, 2017). Discharge summaries outlining events in intensive care and required follow-up care are a viable and simple solution to bridge the information gap and document the ongoing care needs for individual patients (Bench et al., 2016; Daruwalla et al., 2012; Jones, 2014). Discharge summaries promote shared decision making whereby patients feel more informed approaching recovery (Bench et al., 2013). Consistent with the suggestion that critical care specialists should deliver follow-up care, this is now commonplace and provides a continuum of critical care expertise beyond the acute setting (Meyer et al., 2018).

Although this systematic review sought the perspective of intensive care survivors, relatives are intertwined with the patient's recovery process. This has been corroborated in previous research (Kang, 2023). The detrimental impact of intensive care admission is recognised with up to 30 % of relatives reporting new physical and psychological symptoms affecting their own health (Davidson et al., 2012; Rawal et al., 2017). Reflecting the significance of this, the definition of Post-Intensive Care Syndrome was expanded in 2012, now termed post-intensive care syndrome-family (PICS-F) (Davidson et al., 2012). Furthermore, the intrinsic characteristics of relatives are important for healthcare professionals to consider and address. In Coronary Artery Bypass Graft patients, Ruiz et al. (2006) linked lower pre-surgical optimism in relatives to increased levels of caregiving burden. Another study by Ågård et al. (2015) described relatives as optimistic, and although challenging, relatives gained a sense of reward and strengthening of their relationship. Healthcare professionals need to understand the perceptions and motivations of relatives, in addition to striving to identify possible physical and psychological symptoms associated with their new caregiving role. Follow-up care is an opportune time to ensure these supportive mechanisms are in place. In agreement with this review, the National Institute Clinical Excellence (2017) recommends information provision extends to family members.

Importantly, this review did not address the additional support needs of intensive care survivors without supportive family. Evidence suggests that patients who live alone have more physical limitations and are more likely to suffer a protracted recovery (van Delft-Schreurs et al., 2017). Therefore, identifying those who do not have relatives, to provide support or those who are unable to do so, should be at the forefront of healthcare professionals assessment of ongoing needs and follow-up care. Additional support should be provided where needed.

4.1. Limitations

This systematic review has several limitations. Firstly, the researcher's reflexivity was omitted from the primary studies nearly universally, and consequently, may have implications for introducing bias into the analysis. Secondly, the published transcripts of the included studies did not provide "thick descriptions" of the interventions carried out. This has implications for transferability. Thirdly, data was collected at various timepoints, in different locations and in some instances family members were present, thus, this may have influenced responses. Fourth, descriptions of participants baseline characteristics were varied, this has implications for contextualising the studies included. Lastly, whilst all the studies included data on physical recovery experiences, this was not always the primary aim of the study. It is recognised that there is an interplay between mental and physical health and patients do not experience psychological or physical sequelae in isolation. This subsequently may have influenced the responses provided.

5. Conclusion

For intensive care survivors, the recovery trajectory is uncertain with a gap in information provision during the acute phase following hospital discharge. To alleviate uncertainty and improve experience of physical recovery, future service design should target this gap. Patient level factors are important considerations in how intensive care survivors experience follow up care aimed at improving physical health. Healthcare professionals should strive to understand individuals' self-determination of recovery to ensure follow-up care addresses individuals physical needs. The impact of pre-existing co-morbid disease and subgroups of patients deriving

benefit from follow-up care remains uncertain and should be the focus of future research.

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Nicola M.A. Rea: Writing – original draft, Project administration, Investigation, Methodology, Formal analysis, Conceptualization. **Lis Neubeck:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Kalliopi Kydonaki:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Sheona McHale:** Writing – review & editing, Validation, Supervision, Methodology, Investigation, Formal analysis.

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.

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Supplementary materials

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