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Post-ICU Care: A Qualitative Analysis of Patient Priorities and Implications for Redesign

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Abstract

Rationale: While survival during critical illness is improving, little evidence exists to guide post-intensive care unit (ICU) care. Understanding patients' needs and priorities is fundamental to improving care quality.

Objective: To describe the evolution of patients' priorities for recovery across the spectrum of post-ICU care.

Methods: This was a secondary analysis of 39 semi-structured interviews conducted from 2005-2006, in participants' homes 19 days to 11 years after hospital discharge post-critical illness. Adult critical illness survivors (n=39) ≥ 20 years old from multiple ICUs across the United Kingdom were purposively selected to maximize diversity with respect to time since diagnosis, disease severity, gender, age, ethnicity, socio-economic group/status, region. age, ICU admitting diagnoses, and length of stay. We used the method of qualitative description to characterize patients' priorities for recovery and their evolution within and between individual patients, across three post-ICU periods: ICU transition to wards, early period (approximately the first 2 months) after discharge home, and late period (>2 months) after discharge home.

Results: The analysis revealed 12 core patient priorities during recovery: feeling safe, being comfortable, engaging in mobility, participating in self-care, asserting personhood, connecting with people, ensuring family well-being, going home, restoring psychological health, restoring physical health, resuming previous roles and routines, and seeking new life experiences. In general, priorities evolved from those pertaining to basic survival during the stay on wards to being broader and more aspirational by the late post-discharge period.

Conclusions: Understanding patients' priorities for post-ICU care is critical for developing stakeholder-driven clinical guidelines. Engaging other stakeholders (e.g., family members, healthcare providers, institutionalized and frail older adults) to inform the development of clinical guidelines for post-ICU care, together with the barriers and facilitators faced in achieving patient- and family-centered care, is an important next step.

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Introduction

During the past several decades, critical illness survivorship has steadily increased, a success story that has uncovered systemic problems with post-intensive care unit (ICU) care delivery (1–5). Post-ICU healthcare utilization is high and costly, with 6-month rehospitalization rates exceeding 35% (6, 7), and outcomes are poor, with long-term functional impairments and reduced health-related quality of life in over 50% of survivors (8, 9). Finally, patients' post-ICU experiences are fraught with challenges, for which they and their family caregivers receive little or no preparation or support.

One key barrier to addressing these problems is the lack of evidence-based, patient-centered guidelines that equip interdisciplinary care teams to develop and execute care plans meeting patients' medical, social, and rehabilitation needs after critical illness. Developing such guidelines will require understanding patients' priorities during recovery. Previous studies of critical illness survivors' experiences focused on the impact of long-term physical and psychological impairments on day-to-day life and sense of self (10–13), or evaluated healthcare delivery on the wards, in ICU recovery clinics, or in usual care (14–19). None have identified patients' priorities through the entire course of post-ICU care.

Accordingly, we sought to characterize patients' priorities during post-ICU care and how they evolved over time.

Materials and Methods

We conducted a secondary analysis of data from a national archive of qualitative interviews on health and illness held at the University of Oxford (www.healthtalk.org) (20). (See Supplemental Digital Content for methodologic details.) The parent study used maximum variation sampling (21) across clinical and demographic variables to achieve a sample of 39 community-dwelling, adult patients ≥ 20 years old who had previously received care in multiple ICUs across the United Kingdom.

A senior qualitative researcher (SP) interviewed participants at home between 2005-2006. She initially asked participants to describe their experiences in and after the ICU to generate an oral history focused on participant's priorities and concerns (22, 23). She then used an interview guide to probe topics identified through prior interviews, literature review, and communication with the Healthtalk advisory panel. The 1-2 hour interviews were video- or audio-recorded per participant preference and professionally transcribed.

Qualitative Analysis

We used the method of qualitative description (24, 25), which is an ideal analytic tool for comprehensively describing patients' health-related concerns in a clinically relevant way (26, 27). Two coders with training in critical care medicine (LS) and occupational therapy (JW) coded transcripts line by line to identify similar phrases, patterns, themes, and sequences related to patients' priorities, and then examined similarities and differences among them (26). We checked emerging codes with other clinicians for clinical relevance. We then independently coded all transcripts, meeting after every five transcripts to resolve differences by consensus and discuss new themes and patterns (28). We did not identify any new themes after the nineteenth transcript (29). We used Atlas.ti 8.2 (Berlin, Germany) for qualitative data management, and after initial coding, Crabtree and Miller's template method (30) to add codes for distinct recovery time periods: transition to the wards, early period after discharge home, and late period after discharge home.

Given the structure of the original interviews in which all participants were asked to describe their entire post-ICU course, data analysis was able to explore themes throughout the episode of care. Specifically, all 39 participants reported on both their time on the wards and early post-discharge. Additionally, 36 participants, whose interviews occurred more than two months after hospital discharge, provided insights into the late post-discharge analysis. Thus, we were able to explore patterns of care preference evolution within and across individuals. Due to the small number (n=4) that were discharged to a rehabilitation facility, we did not explicitly explore the data for this care context.

Strategies of Rigor

Throughout the parent study, an expert advisory panel of patient representatives, researchers and ICU clinicians advised investigators (31). The study involved prolonged engagement with diverse perspectives to inform data collection and analysis (a form of triangulation) (29). Participants reviewed and corrected interview transcripts to ensure accuracy (known as member checking) (29). Interviewing continued until thematic saturation occurred (32, 33). Codes were not mutually exclusive, thereby reducing the chance of losing important ideas (34).

Results

Maximum variation sampling produced a diverse group of participants (Table 1), including 34 emergency and five elective admissions. Participants' ages ranged from 23 to 76. Interviews occurred weeks to years after hospital discharge.

Patients' Priorities and Evolution over Time

We identified 12 priorities that distinctly evolved across the spectrum of post-ICU care (Supplemental Digital Content). Although they are inter-related and frequently co-occur, we present them roughly in the order that patients tend to first experience them after transfer out of the ICU.

Feeling safe

Patients wanted to know they were being cared for, able to communicate their needs, and have their needs addressed:

> "I was very scared because I couldn't do anything to get anybody's attention. And [the call bell] was no good to me because I, my hands weren't strong enough to press it…So I felt really scared. It was like being kind of bound and gagged." (35-year-old woman who survived sepsis)

On the wards, prioritizing feeling safe reflected a basic sense of vulnerability and dependence. After discharge, it related to the risk of relapse and how prepared a patient was for discharge. Several found a sense of safety in having a plan for addressing setbacks (e.g. emergency call bells, on-call home care). Others felt unsafe because they were unprepared to manage new disabilities at home, or lacked a plan for condition-specific complications (e.g., one had a chaotic emergency department visit because his tracheostomy tube fell out and he did not know what to do).

Being comfortable

A few patients expressed a desire to avoid ongoing or disabling pain on the wards:

> "So, this chest drain…every time I breathed in was, you know, rubbing on my, between the two ribs and…I was a bit too stoic and I put up with it for about two days and then…a doctor came and I burst into tears, which I'd never ever done before." (43-year-old woman who survived nephrectomy)

None described comfort as a priority after discharge.

Engaging in mobility

Patients prioritized being able to transfer, sit, stand, walk, take the stairs, and build strength and stamina:

> "And [the physiotherapists] were absolutely amazed because I had a [walker], and I said 'Right I will have this Zimmer frame on one condition: I am not taking this [walker] out of this hospital. I am going to get walking properly or else I shall be here forever, and I am determined that I shall walk.'" (66-year-old man who survived acute respiratory distress syndrome)

Focusing on basic mobility was typical on the wards. Early after discharge, patients mostly discussed enhancing mobility as a means of facilitating other priorities (e.g., acquiring the strength and stamina to resume normal roles and routines).

Participating in self-care

Performing self-care activities like toileting, eating, dressing, bathing, grooming, cooking, cleaning, using transportation, and sleeping was important to patients:

> "[W]hat I needed to achieve to be able to come out was to be able to stand up and walk to the toilet by myself. That became the kind of, the benchmark." (35-year-old woman who survived sepsis)

On the wards, participating in self-care was of primary importance and revolved around activities of daily living. Early after discharge, focus shifted to instrumental activities of daily living. Late after discharge, it became aspirational, seeking to build capacity for other goals like travel and going back to work.

Resuming normal roles and routines

Patients aimed to manage a daily routine, engage in leisure activities, fulfill their normal roles in their relationships with friends and family, and go back to work:

> "I started beginning to roam around a bit. I mean obviously I couldn't do what I would say normally do, as far as do it yourself jobs and house husbandry and stuff like that…"

> Wife: ”… And then you suddenly made up your mind you were going to start playing bowls again…He said, ‘Right I’ll go but I won’t play.’ So then he came but he couldn’t resist it.” (72-year-old man who survived heart failure)

On the wards, resuming normal roles and routines focused on leisure activities like watching television and reading. Early after discharge, patients began to focus on re-establishing daily routines and functioning within their families, and by late after discharge they wanted a broader sense of being “back to normal.”

Connecting with people

Patients consistently wanted human connections. Some expressed this need by socializing with anyone available (e.g., other patients, clinical staff), whereas others carefully managed time with family and friends:

> “I wanted very, very close friends. I would almost say friend and family, that was it. Not many [because I got too tired.]” (63-year-old man who survived immune thrombocytopenic purpura)

On the wards, patients described connecting with people in terms of the need for human contact. They rarely discussed it early after discharge. However, late after discharge, they prioritized strengthening the relationships that had grown during the experience of critical illness.

Asserting personhood

Patients expressed a need for agency and dignity, feeling respected, setting boundaries, and being empowered to play a role in their recovery:

> “[On the wards] I felt myself going downhill - the depression started. Because I wasn't getting that, well they can't get individual with everybody…But I think there's a lot of things that they can keep a watch on, if someone's distressed, you know? And then you

> didn't get your night drink, which upset me…I'm lying there waiting for my night drink…I felt that I'd been deprived of everything.” (76-year-old woman who survived pancreatitis)

Asserting personhood was mostly a priority on the wards and late after discharge. On the wards, it involved pushing back against depersonalizing systems issues (e.g., hospital gowns, poorly coordinated care, unresponsiveness to their needs, exclusion from medical decision-making) and policies or attitudes that limited mobility or self-care. Late after discharge, this priority involved the healthcare system and personal relationships. Many called out providers who were late to appointments, cancelled follow-up appointments if they did not perceive clear benefits, and advocated for patient-centered care. Some set new boundaries with people who did not support them in the ways they needed (e.g., those who had not visited while they were in the hospital).

Ensuring family well-being

Many patients recognized how critical illness impacted their families and wanted to ensure that family members were okay:

> “[I]t’s only me and my son and I couldn’t afford to …so we’re here [at my brother’s]. He was looked after by my mum and my dad and my brother, and my sisters and everybody sort of looked after him.” (38-year-old woman who survived a Crohn’s exacerbation)

The concern related to the emotional and physical toll of caregiving, as well as the ways families suffered when patients could not fulfill their normal roles. This priority was not common enough to describe temporal trends.

Going home

This desire to go home was nearly universal on the wards:

“My main concern was just to get better and to get out.” (45-year-old man who survived sepsis)

Early after discharge, a small number were living with relatives or brief stays in rehabilitation facilities and still maintained the goal of going home. All were home by the late discharge period.

Restoring physical health

Patients prioritized achieving and maintaining physical health. They protected themselves from sick contacts, monitored how they felt, took medications, followed medical advice, and advocated for themselves:

> "[A]ll the time I was in there really, I had to have aims. I aimed to get off the ventilator by [my wife's] birthday…and I did it a couple days beforehand. I then aimed to be off, have the tracheostomy out by then, end of January, which I did, by a couple of days again." (60-year-old man who survived Guillan-Barre Syndrome)

On the wards, patients tracked their progress by their liberation from medical supports like suctioning, medical devices like tracheostomies, and proximity to discharge. Early after discharge they tracked it by how frequently they accessed home health and other post-discharge services and the extent to which ongoing healthcare needs interfered with resuming their normal roles and routines. Late after discharge, several noted backsliding on attempted lifestyle modifications.

Restoring psychological health

Many patients worked hard restoring their psychological health, including managing ongoing depression, anxiety, and panic attacks. They sought information and professional help to process what had happened to them, studied their ICU diaries, started personal diaries, and talked things through with family and friends:

> "[Y]ou noticed all these other things then, like the lack of concentration and the nightmares and, you know, not being able to be in a room that's full of people…And once I'd told [the counselor] about things like that, she'd say…'From talking to other patients, this is what

> they've experienced'…And that kind of reassures you a bit." (41 year-old woman who survived post-partum sepsis)

On the wards, patients' desire to restore psychological health was often nascent amidst their emotional distress related to critical illness, hallucinations, and the experiences of hospital life. A few discussed the catharsis of crying or talking with their families early after discharge. However, the greatest urgency to restore psychological health came late after discharge, when some experienced panic in public settings (e.g., pubs and shopping centers) and many took a more active approach to seeking help.

Seeking new experiences

Patients sought a variety of new experiences during recovery from critical illness. Some found meaning by working to transform ICU care or to develop support programs for survivors. Others did something symbolic of moving on: redecorating the house, traveling, or even having a child. Many committed to making every second count by refocusing on family, training in a new career, or living more intentionally or spontaneously:

> "I've just applied for a job, actually I've got an interview tomorrow, for going into homecare, albeit only part-time at the moment. But I, that's what I want to do, I want to put something back into the community." (45-year-old man who survived sepsis)

Only one patient, a mental health professional, discussed seeking new experiences while still on the wards; he was already reforming systems of post-ICU care. The patients who sought new experiences early after discharge were in transitions (e.g., retirement, trying to have a baby) or had pre-existing plans before they became critically ill. For the remainder, seeking new experiences seemed to be a marker of advanced recovery.

Discussion

In this qualitative analysis, we identified 12 core patient priorities during critical illness recovery and described their evolution over time, from basic survival priorities on the wards (e.g., feeling safe and being comfortable) to active physical recovery early after discharge (e.g., enhancing mobility and self-care) to more holistic and aspirational priorities late after discharge (e.g., resuming normal roles and routines). These results should inform patient-centered guidelines and post-ICU healthcare delivery systems.

Many of the patient priorities address previously reported sources of suffering, providing new insight into what patients perceive to be important during recovery, e.g., prioritizing mobility, self-care, and normal roles and routines, feeling safe, going home and asserting personhood (10–14, 17, 35–37). However, two patient priorities, *connecting with people* and *seeking new experiences*, appear to be novel. This may reflect both the diversity of the sample and the timing of the interviews, many of which were conducted several years after critical illness, enabling patients to report on the full trajectory of recovery and to address goals rather than deficits only.

One unique aspect of this study was the ability to examine how patients' priorities evolved over time, up to several years after critical illness (from based survival priorities on the wards to aspirational priorities in the late post-discharge period), an evolution that recalls Maslow's hierarchy of needs (Figure) (38). Although Maslow's hierarchy has previously been suggested as a theoretical framework to inform holistic patient care within ICUs (47, 48), this study represents its first application to framing post-ICU care continuity, assessment, and interventions.

Patients' priorities may inform post-ICU healthcare delivery first by their relevance to patient-centered clinical guidelines and outcome measures (35, 49, 50), and second by the types and timing of healthcare services offered to patients recovering from critical illness

(Tables 2 – 4; see Supplemental Digital Content for expanded versions of these Tables detailing their relationships to the priorities). Thus, patients need services to address mobility and self-care on the wards and early after discharge (12, 15, 17, 18, 49), and services to address psychological health later (probably > 3 months after discharge) (12, 15, 18, 19). In general, care processes should be redesigned to foster human connections while balancing safety and autonomy/personhood (3, 14); one promising means of doing so is to engage patients and families as partners in care (44, 51–53). Finally, eliciting patients' priorities may also be useful in assessing where they are in the trajectory of functional recovery and anticipating their needs. Thus, resuming normal roles and routines is characteristic of the active recovery phase, indicating screening for physical, occupational or psychological therapy needs; alternatively, seeking new experiences may signal the transition to an advanced stage of recovery and functional independence.

This study has several potential limitations. First, secondary analyses of qualitative data typically raise concerns about whether the data can adequately address the study question, the secondary analyst is missing key insights into the data, or the data are out-of-date (20). In our case, the parent study's purpose aligned closely with ours; the original researcher is a co-author on the article; and no new post-ICU interventions have been widely adopted in the past decade to significantly change survivors' experience (54–57). Second, recall bias is more likely the later the interviews occurred, which would particularly reduce the accuracy of patients' descriptions of how their priorities evolved over time. Although their accounts are detailed and often corroborated in multiple interviews, future studies should consider serial interviews to mitigate this concern. Furthermore, interviewing patients in the late post-discharge period provided novel insights about how patients' priorities evolve over time. Third, study participants did not articulate specific priorities for cognitive recovery or end-of life-care, perhaps because they did not recognize the high risk for these outcomes (58–60). Both deserve further study and integration into the framework. Fourth, different healthcare systems have vastly different organization of post-ICU care delivery. The priorities identified by these post-ICU survivors fit with Maslow's hierarchy supporting the generalizability of the results across the course of ICU recovery, but they will require confirmation outside the United Kingdom, as well as specification for sites of care not in included in the study, such as nursing facilities.

Conclusions

The 12 core priorities of critical illness survivors identified in this study should inform stakeholder-driven clinical guidelines and quality measures for post-ICU care (now, in their infancy [41]). Future research should extend these findings among other stakeholders (e.g., family members, healthcare providers, institutionalized and frail older adults) and determine barriers and facilitators to patient-centered post-ICU care.

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Table 1. Participant characteristics

Characteristic	**Critical Illness Survivors (N=39)**
Age, Mean (SD)	52.6 (13.4)
Age groups, N (%)	
20-29 years old	1 (2.6%)
30-39 years old	6 (15.4%)
40-49 years old	10 (25.6%)
50-59 years old	8 (20.5%)
60-69 years old	9 (23.1%)
70-79 years old	5 (12.8%)
Female gender, N (%)	13 (33%)
White race, N (%)	36 (92%)
Marital status, N (%)	
Single	6 (15.4%)
Married or partnered	29 (74.3%)
Divorced or separated	4 (10.3%)
Reason for ICU admission	
Infectious (sepsis, pneumonia)	14 (35.9%)
Hematology-Oncology (cancer, sickle cell)	5 (12.8%)
Cardiac (transplant, heart failure)	4 (10.3%)
Pulmonary (ARDS, asthma, COPD)	3 (7.7%)
Neurologic (aneurysms, Guillan-Barre)	3 (7.7%)
Trauma	3 (7.7%)

Pregnancy-related	2 (5.1%)
Other (rheumatologic)	5 (12.8%)
ICU length of stay (Range 2 days – 8 weeks, 1 missing)	
≤ 2 days	4 (10.3%)
2 – 5 days	3 (7.7%)
5 – 14 days	11 (28.2%)
> 14 days	20 (51.3%)
Ward length of stay (Range 2 days – 5 months, 2 missing)	
≤ 2 days	1 (2.6%)
2 – 5 days	5 (12.8%)
5 – 14 days	16 (41.0%)
> 14 days	15 (38.5%)
Time from discharge to interview (Range 19 days – 11 years)	
≤ 2 months (did not contribute to late post-discharge analysis)	3 (7.7%)
2 – 12 months (contributed to analysis of all 3 time periods)	24 (61.5%)
> 12 months (contributed to analysis of all 3 time periods)	12 (30.8%)

ARDS – acute respiratory distress syndrome; COPD – chronic obstructive pulmonary disease

Table 2. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities on the wards. Some of the included elements anticipate priorities that patients describe as occurring later (e.g., screen for psychological function on the wards) because early identification and treatment may support more rapid recovery in multiple domains (e.g., poor motivation from unrecognized depression may reduce participation in rehabilitation).

Domain	Potential Interventions
Structures of care	
Personnel	• Rehabilitation specialists • Family support personnel • Peer navigators (1) • Spiritual care providers
Equipment & facilities	• Mobility & self-care equipment • Quiet spaces for rest/decompression • Community spaces for socialization • Recreation equipment (e.g., crafts, puzzles)
Processes of care	
Screening	Change from baseline/ICU admission related to: • Nutrition & hydration • Pain & discomfort • Physical function • Psychosocial function • Caregiver wellbeing
Communication	Anticipatory guidance • Transition to the wards • Transition home • Advance care planning

	Values elicitation & short- and long-term goal setting • **Focus up the hierarchy (e.g. love & belonging, self-esteem, & self-actualization)** • **Unpack what is meaningful about "going home"** • **Introduce the idea of setting goals around seeking new experiences** (2, 3)
Culture Change, Care Planning & Treatment	Culture change & care planning • Staff training to recognize & respond to unmet priorities • Enhanced opportunities for choice, autonomy, & self-efficacy • Identify & prescribe services, equipment, & medications required for a successful community discharge • Identify personnel responsible for follow-up Treatment • Rehabilitation • **Patient & family education & training in rehabilitation & care** (6, 7) • Psychiatric medication & peer support
Patient-centered outcomes	
Physical function	Strength, endurance, & self-care
Psychosocial function	Symptoms related to mood & sleep **Frequency & types of social contact**
Caregiver wellbeing	Mood & stress **Preparation for home caregiving**
Global health & function	Successful community discharge (10) Quality of life

Table 3. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the early post-discharge period.

Domain	Potential Interventions
Structures of care	
Personnel	• Rehabilitation specialists • Home health personnel • Mental health professionals • Healthcare providers trained in ICU recovery • Peer navigators • Spiritual care providers
Equipment & facilities	• Mobility & self-care equipment • Exercise equipment & facilities • Meal support services
Processes of care	
Screening	Trajectory of & resource use related to: • Physical function • Psychosocial function • Caregiver wellbeing
Communication	Check in about progress & new issues Follow-up about values & goals: • Determine which goals have been achieved • **Facilitate new goal-setting** (4, 5) • **Assess need for additional resources to achieve goals**
Culture Change, Care Planning & Treatment	Culture change & care planning • Continuity/communication between hospital, ICU follow-up, and primary care teams • Follow-up on care plan items • Add newly identified priorities to the care plan

	Treatment - Rehabilitation - **Family engagement & support** (8) - Psychiatric medication, peer support, &/or counseling
Patient-centered outcomes	
Physical function	Improved strength, endurance Independence in self-care
Psychosocial function	Improved mood & sleep **Motivation to participate in rehabilitation & other activities** (3)
Caregiver wellbeing	Mood & stress **Role function as a caregiver**
Global health & function	Reduced healthcare utilization Quality of life

Table 4. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the late post-discharge period.

Domain	Potential Interventions
Structures of care	
Personnel	- Mental health professionals - Healthcare providers trained in ICU recovery - Primary care providers - Peer navigators &/or support groups - Spiritual care providers
Equipment & facilities	- Vocational rehabilitation - Exercise equipment & facilities
Processes of care	
Screening	Outstanding recovery goals & resource needs related to: - Physical function - Psychosocial function - Caregiver wellbeing
Communication	Check in about progress & new issues **Set maintenance goals for health and function** **Set aspirational goals for wellness/whole health**
Culture Change, Care Planning & Treatment	Culture change & care planning - **Formal discharge/handoff process from post-ICU team to primary care team including all active elements of the care plan** Treatment - Rehabilitation **Family engagement & support** - Psychiatric medication, peer support, &/or counseling

Patient-centered outcomes	
Physical function	Maintenance of strength, endurance, & self-care **Achievement of patient's goals related to physical function**
Psychosocial function	Return to baseline mood & sleep **Resumption of family roles** (9) **Participation in broader social life** (9)
Caregiver wellbeing	Mood & stress Resumption of normal family and professional roles
Global health & function	Reduced healthcare utilization Quality of life **Success in seeking new experiences** (3)

Figure. Patient Priorities on the Wards, Early Home, and Late Home Organized Using Maslow's Hierarchy. The pyramid on the left depicts Maslow's hierarchy. The expansion on the right demonstrates the related codes at each time point (wards, early home, and late home).

REFERENCES

1. Whittington JW, Nolan K, Lewis N, et al.: Pursuing the triple aim: The first 7 years. *Milbank Q* 2015; 93:263–300

2. Berwick DM, Nolan TW, Whittington J: The triple aim: Care, health, and cost. *Health Aff* 2008; 27:759–769

3. Stelfox HT, Lane D, Boyd JM, et al.: A scoping review of patient discharge from intensive care: Opportunities and tools to improve care. *Chest* 2015; 147:317–327

4. Needham DM, Davidson J, Cohen H, et al.: Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Crit Care Med* 2012; 40:502–509

5. Elliott D, Davidson JE, Harvey MA, et al.: Exploring the scope of post–intensive care syndrome therapy and care: Engagement of non-critical care providers and survivors in a second stakeholders meeting. *Crit Care Med* 2014; 42:2518–2526

6. Prescott HC, Langa KM, Liu V, et al.: Increased 1-year healthcare use in survivors of severe sepsis. *Am J Respir Crit Care Med* 2014; 190:62–69

7. Hua M, Gong MN, Brady J, et al.: Early and late unplanned rehospitalizations for survivors of critical illness. *Crit Care Med* 2015; 43:430–438

8. Hill AD, Fowler RA, Pinto R, et al.: Long-term outcomes and healthcare utilization following critical illness - a population-based study. *Crit Care* 2016; 20:1–10

9. Dowdy DW, Eid MP, Sedrakyan A, et al.: Quality of life in adult survivors of critical illness: A systematic review of the literature. *Intensive Care Med* 2005; 31:611–620

10. Cox CE, Docherty SL, Brandon DH, et al.: Surviving critical illness: Acute respiratory

distress syndrome as experienced by patients and their caregivers. *Crit Care Med* 2009; 37:2702–2708

11. Kang J, Jeong YJ: Embracing the new vulnerable self: A grounded theory approach on critical care survivors ' post-intensive care syndrome. *Intensive Crit Care Nurs* 2018; 49:44–50

12. Ågård AS, Egerod I, Tønnesen E, et al.: Struggling for independence : A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive Crit Care Nurs* 2012; 28:105–113

13. Maddox M, Dunn S V, Pretty LE: Psychosocial recovery following ICU: Experiences and influences upon discharge to the community. *Intensive Crit Care Nurs* 2001; 17:6–15

14. Field K, Prinjha S, Rowan K: “One patient amongst many”: A qualitative analysis of intensive care unit patients’ experiences of transferring to the general ward. *Crit Care* 2008; 12:1–9

15. Hanifa AB, Glaeemose AO, Laursen BS: Picking up the pieces : Qualitative evaluation of follow-up consultations post intensive care admission. *Intensive Crit Care Nurs* 2018; 48:85–91

16. Ewens BA, Hendricks JM, Sundin D: Surviving ICU: Stories of recovery. *J Adv Nurs* 2018; 74:1554–1563

17. Czerwonka AI, Herridge MS, Chan L, et al.: Changing support needs of survivors of complex critical illness and their family caregivers across the care continuum : A qualitative pilot study of Towards RECOVER. *J Crit Care* 2015; 30:242–249

18. Deacon KS: Re-building life after ICU : A qualitative study of the patients ' perspective. *Intensive Crit Care Nurs* 2012; 28:114–122

19. Engstrom A, Andersson S, Soderberg S: Re-visiting the ICU experiences of follow-up visits to an ICU after discharge: A qualitative study. *Intensive Crit Care Nurs* 2008; 24:233–241

20. Ziebland S, Hunt K: Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *J Heal Serv Res Policy* 2014; 19:177–182

21. Coyne IT: Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs* 1997; 26:623–630

22. Sandelowski M: Telling stories: Narrative approaches in qualitative research. *J Nurs Scholarsh* 2007; 23:161–6

23. Mishler EG: Research Interviewing: Context and Narrative. Cambridge, MA: Harvard University Press; 1991.

24. Sandelowski M: Whatever happened to qualitative description? *Res Nurs Health* 2000; 23:334–340

25. Sandelowski M: What's in a name? Qualitative description revisited. *Res Nurs Health* 2010; 33:77–84

26. Sullivan-Bolyai S, Bova C, Harper D: Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nurs Outlook* 2005; 53:127–133

27. Neergaard MA, Olesen F, Andersen RS, et al.: Qualitative description-the poor cousin of health research? *BMC Med Res Methodol* 2009; 9:1–5

28. Scharer K: What parents of mentally ill children need and want from mental health

professionals. *Issues Ment Health Nurs* 2009; 23:617–640

29. Morse JM: Critical analysis of strategies for determining rigor in qualitative inquiry. *Qual Health Res* 2015; 25:1212–1222

30. Doing Qualitative Research. 2nd ed. Thousand Oaks, California: Sage Publications, Inc; 1999.

31. HealthTalk Advisory Panel Membership [Internet]. [cited 2019 Jan 2] Available from: http://www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-patients-experiences/credits

32. Marshall MN: Sampling for qualitative research. *Fam Pract* 1996; 13:522–525

33. Pope C, Ziebland S, Mays N, et al.: Analysing qualitative data. 2017; 320:114–116

34. Bern-Klug M: Calling the question of “possible dying” among nursing home residents: Triggers, barriers, and facilitators. *J Soc Work End Life Palliat Care* 2008; 2:61–85

35. König C, Matt B, Kortgen A, et al.: What matters most to sepsis survivors: A qualitative analysis to identify specific health-related quality of life domains. *Qual Life Res* 2018; 28:637–647

36. Leland NE, Gozalo P, Christian TJ, et al.: An Examination of the First 30 Days After Patients are Discharged to the Community From Hip Fracture. *Med Care* 2015; 53:879–887

37. RTI International: Technical Expert Panel Summary Report: Development of a Discharge to Community Quality Measure for Skilled Nursing Facilities (SNFs), Inpatient Rehabilitation Facilities (IRFs), Long-Term Care Hospitals (LTCHs), and Home Health Agencies (HHAs). 2016.

38. Zalenski RJ, Raspa R: Maslow's Hierarchy of Needs: A framework for achieving human potential in hospice. *J Palliat Med* 2006; 9:1120–1127

39. Mikkelsen ME, Jackson JC, Hopkins RO, et al.: Peer Support as a Novel Strategy to Mitigate Post-Intensive Care Syndrome. *AACN Adv Crit Care* 2016; 27

40. Marin RS, Bierdrzycki RC, Firinciogullari S: Reliability and validity of the Apathy Evaluation Scale. *Psychiatry Res* 1991; 38:143–162

41. Skidmore ER, Whyte EM, Butters MA, et al.: Strategy training during inpatient rehabilitation may prevent apathy symptoms after acute stroke. *P M R* 2015; 7:562–570

42. Skidmore ER: Activity interventions for cognitive problems. *Pediatr Blood Cancer* 2014; 61:1743–1746

43. Naylor MD, Hirschman KB, Toles MP, et al.: Adaptations of the evidence-based Transitional Care Model in the U.S. *Soc Sci Med* 2018; 213:28–36

44. Haines KJ: Engaging Families in Rehabilitation of People Who Are Critically Ill: An Underutilized Resource. [Miscellaneous Article]. 2018; 98:737–744

45. Rodakowski J, Skidmore ER, Rogers JC, et al.: Role of Social Support in Predicting Caregiver Burden. *Arch Phys Med Rehabil* 2012; 93:2229–2236

46. World Health Organisation: International Classification of Functioning, Disability and Health. Geneva: World Health Organization; 2001.

47. Karnatovskaia L V., Gajic O, Bienvenu OJ, et al.: A holistic approach to the critically ill and Maslow's hierarchy. *J Crit Care* 2015; 30:210–211

48. Jackson JC, Santoro MJ, Ely TM, et al.: Improving patient care through the prism of psychology: Application of Maslow's hierarchy to sedation, delirium, and early mobility in

the intensive care unit. *J Crit Care* 2014; 29:438–444

49. Major ME, Kwakman R, Kho ME, et al.: Surviving critical illness: What is next? An expert consensus statement on physical rehabilitation after hospital discharge. *Crit Care* 2016; 20:1–10

50. National Institute for Health and Care Excellence: Rehabilitation after critical illness in adults: Clinical guidelines [Internet]. 2009; [cited 2019 Feb 4] Available from: https://www.nice.org.uk/guidance/qs158

51. Van De Graaff M, Beesley SJ, Butler J, et al.: Partners in Healing: Postsurgical outcomes after family involvement in nursing care. *Chest* 2018; 153:572–74

52. Haines KJ, Kelly P, Fitzgerald P, et al.: The untapped potential of patient and family engagement in the organization of critical care. *Crit Care Med* 2017; 45:899–906

53. Major ME, van Ness F, Ramaekers S, et al.: Survivors of Critical Illness and Their Relatives: A Qualitative Study on Hospital Discharge Experience. *Ann Am Thorac Soc* 2019;

54. Jensen JF, Thomsen T, Overgaard D, et al.: Impact of follow-up consultations for ICU survivors on post-ICU syndrome: A systematic review and meta-analysis. *Intensive Care Med* 2015; 41:763–775

55. Mehlhorn J, Freytag A, Schmidt K, et al.: Rehabilitation interventions for postintensive care syndrome: A systematic review. *Crit Care Med* 2014; 42:1263–71

56. Calvo-Ayala E, Khan BA, Farber MO, et al.: Interventions to improve the physical function of ICU survivors: A systematic review. *Chest* 2013; 144:1469–1480

57. Schmidt K, Worrack S, Von Korff M, et al.: Effect of a primary care management

intervention on mental health–related quality of life among survivors of sepsis. *JAMA* 2016; 315:2703–2711

58. Pandharipande PP, Girard TD, Jackson JC, et al.: Long-term cognitive impairment after critical illness. *N Engl J Med* 2013; 369:1306–1316

59. Ferrante LE, Pisani MA, Murphy TE, et al.: Functional trajectories among older persons before and after critical illness. *JAMA Intern Med* 2015; 175:523–529

60. Brummel NE, Balas MC, Morandi A, et al.: Understanding and reducing disability in older adults following critical illness. *Crit Care Med* 2015; 43:1265–1275

Post-ICU Care: A Qualitative Analysis of Patient Priorities and Implications for Redesign

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Abstract

Rationale: While survival during critical illness is improving, little evidence exists to guide post-intensive care unit (ICU) care. Understanding patients' needs and priorities is fundamental to improving care quality.

Objective: To describe the evolution of patients' priorities for recovery across the spectrum of post-ICU care.

Methods: This was a secondary analysis of 39 semi-structured interviews conducted from 2005-2006, in participants' homes 19 days to 11 years after hospital discharge post-critical illness. Adult critical illness survivors (n=39) ≥ 20 years old from multiple ICUs across the United Kingdom were purposively selected to maximize diversity with respect to time since diagnosis, disease severity, gender, age, ethnicity, socio-economic group/status, region. age, ICU admitting diagnoses, and length of stay. We used the method of qualitative description to characterize patients' priorities for recovery and their evolution within and between individual patients, across three post-ICU periods: ICU transition to wards, early period (approximately the first 2 months) after discharge home, and late period (>2 months) after discharge home.

Results: The analysis revealed 12 core patient priorities during recovery: feeling safe, being comfortable, engaging in mobility, participating in self-care, asserting personhood, connecting with people, ensuring family well-being, going home, restoring psychological health, restoring physical health, resuming previous roles and routines, and seeking new life experiences. In general, priorities evolved from those pertaining to basic survival during the stay on wards to being broader and more aspirational by the late post-discharge period.

Conclusions: Understanding patients' priorities for post-ICU care is critical for developing stakeholder-driven clinical guidelines. Engaging other stakeholders (e.g., family members,

healthcare providers, institutionalized and frail older adults) to inform the development of clinical guidelines for post-ICU care, together with the barriers and facilitators faced in achieving patient- and family-centered care, is an important next step.

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Introduction

During the past several decades, critical illness survivorship has steadily increased, a success story that has uncovered systemic problems with post-intensive care unit (ICU) care delivery (1–5). Post-ICU healthcare utilization is high and costly, with 6-month rehospitalization rates exceeding 35% (6, 7), and outcomes are poor, with long-term functional impairments and reduced health-related quality of life in over 50% of survivors (8, 9). Finally, patients' post-ICU experiences are fraught with challenges, for which they and their family caregivers receive little or no preparation or support.

One key barrier to addressing these problems is the lack of evidence-based, patient-centered guidelines that equip interdisciplinary care teams to develop and execute care plans meeting patients' medical, social, and rehabilitation needs after critical illness. Developing such guidelines will require understanding patients' priorities during recovery. Previous studies of critical illness survivors' experiences focused on the impact of long-term physical and psychological impairments on day-to-day life and sense of self (10–13), or evaluated healthcare delivery on the wards, in ICU recovery clinics, or in usual care (14–19). None have identified patients' priorities through the entire course of post-ICU care.

Accordingly, we sought to characterize patients' priorities during post-ICU care and how they evolved over time.

Materials and Methods

We conducted a secondary analysis of data from a national archive of qualitative interviews on health and illness held at the University of Oxford (www.healthtalk.org) (20). (See Supplemental Digital Content for methodologic details.) The parent study used maximum variation sampling (21) across clinical and demographic variables to achieve a sample of 39 community-dwelling, adult patients ≥ 20 years old who had previously received care in multiple ICUs across the United Kingdom.

A senior qualitative researcher (SP) interviewed participants at home between 2005-2006. She initially asked participants to describe their experiences in and after the ICU to generate an oral history focused on participant's priorities and concerns (22, 23). She then used an interview guide to probe topics identified through prior interviews, literature review, and communication with the Healthtalk advisory panel. The 1-2 hour interviews were video- or audio-recorded per participant preference and professionally transcribed.

Qualitative Analysis

We used the method of qualitative description (24, 25), which is an ideal analytic tool for comprehensively describing patients' health-related concerns in a clinically relevant way (26, 27). Two coders with training in critical care medicine (LS) and occupational therapy (JW) coded transcripts line by line to identify similar phrases, patterns, themes, and sequences related to patients' priorities, and then examined similarities and differences among them (26). We checked emerging codes with other clinicians for clinical relevance. We then independently coded all transcripts, meeting after every five transcripts to resolve differences by consensus and discuss new themes and patterns (28). We did not identify any new themes after the nineteenth transcript (29). We used Atlas.ti 8.2 (Berlin, Germany) for qualitative data management, and after initial coding, Crabtree and Miller's template method (30) to add codes for distinct recovery time periods: transition to the wards, early period after discharge home, and late period after discharge home.

Given the structure of the original interviews in which all participants were asked to describe their entire post-ICU course, data analysis was able to explore themes throughout the episode of care. Specifically, all 39 participants reported on both their time on the wards and early post-discharge. Additionally, 36 participants, whose interviews occurred more than two months after hospital discharge, provided insights into the late post-discharge analysis. Thus, we were able to explore patterns of care preference evolution within and across individuals. Due to the small number (n=4) that were discharged to a rehabilitation facility, we did not explicitly explore the data for this care context.

Strategies of Rigor

Throughout the parent study, an expert advisory panel of patient representatives, researchers and ICU clinicians advised investigators (31). The study involved prolonged engagement with diverse perspectives to inform data collection and analysis (a form of triangulation) (29). Participants reviewed and corrected interview transcripts to ensure accuracy (known as member checking) (29). Interviewing continued until thematic saturation occurred (32, 33). Codes were not mutually exclusive, thereby reducing the chance of losing important ideas (34).

Results

Maximum variation sampling produced a diverse group of participants (Table 1), including 34 emergency and five elective admissions. Participants' ages ranged from 23 to 76. Interviews occurred weeks to years after hospital discharge.

Patients' Priorities and Evolution over Time

We identified 12 priorities that distinctly evolved across the spectrum of post-ICU care (Supplemental Digital Content). Although they are inter-related and frequently co-occur, we present them roughly in the order that patients tend to first experience them after transfer out of the ICU.

Feeling safe

Patients wanted to know they were being cared for, able to communicate their needs, and have their needs addressed:

> “I was very scared because I couldn’t do anything to get anybody’s attention. And [the call bell] was no good to me because I, my hands weren’t strong enough to press it…So I felt really scared. It was like being kind of bound and gagged.“ (35-year-old woman who survived sepsis)

On the wards, prioritizing feeling safe reflected a basic sense of vulnerability and dependence. After discharge, it related to the risk of relapse and how prepared a patient was for discharge. Several found a sense of safety in having a plan for addressing setbacks (e.g. emergency call bells, on-call home care). Others felt unsafe because they were unprepared to manage new disabilities at home, or lacked a plan for condition-specific complications (e.g., one had a chaotic emergency department visit because his tracheostomy tube fell out and he did not know what to do).

Being comfortable

A few patients expressed a desire to avoid ongoing or disabling pain on the wards:

> “So, this chest drain…every time I breathed in was, you know, rubbing on my, between the two ribs and…I was a bit too stoic and I put up with it for about two days and then…a doctor came and I burst into tears, which I’d never ever done before.” (43-year-old woman who survived nephrectomy)

None described comfort as a priority after discharge.

Engaging in mobility

Patients prioritized being able to transfer, sit, stand, walk, take the stairs, and build strength and stamina:

> "And [the physiotherapists] were absolutely amazed because I had a [walker], and I said 'Right I will have this Zimmer frame on one condition: I am not taking this [walker] out of this hospital. I am going to get walking properly or else I shall be here forever, and I am determined that I shall walk.'" (66-year-old man who survived acute respiratory distress syndrome)

Focusing on basic mobility was typical on the wards. Early after discharge, patients mostly discussed enhancing mobility as a means of facilitating other priorities (e.g., acquiring the strength and stamina to resume normal roles and routines).

Participating in self-care

Performing self-care activities like toileting, eating, dressing, bathing, grooming, cooking, cleaning, using transportation, and sleeping was important to patients:

> "[W]hat I needed to achieve to be able to come out was to be able to stand up and walk to the toilet by myself. That became the kind of, the benchmark." (35-year-old woman who survived sepsis)

On the wards, participating in self-care was of primary importance and revolved around activities of daily living. Early after discharge, focus shifted to instrumental activities of daily living. Late after discharge, it became aspirational, seeking to build capacity for other goals like travel and going back to work.

Resuming normal roles and routines

Patients aimed to manage a daily routine, engage in leisure activities, fulfill their normal roles in their relationships with friends and family, and go back to work:

> "I started beginning to roam around a bit. I mean obviously I couldn't do what I would say normally do, as far as do it yourself jobs and house husbandry and stuff like that…"
>
> Wife: "… And then you suddenly made up your mind you were going to start playing bowls again…He said, 'Right I'll go but I won't play.' So then he came but he couldn't resist it." (72-year-old man who survived heart failure)

On the wards, resuming normal roles and routines focused on leisure activities like watching television and reading. Early after discharge, patients began to focus on re-establishing daily routines and functioning within their families, and by late after discharge they wanted a broader sense of being "back to normal."

Connecting with people

Patients consistently wanted human connections. Some expressed this need by socializing with anyone available (e.g., other patients, clinical staff), whereas others carefully managed time with family and friends:

> "I wanted very, very close friends. I would almost say friend and family, that was it. Not many [because I got too tired.]" (63-year-old man who survived immune thrombocytopenic purpura)

On the wards, patients described connecting with people in terms of the need for human contact. They rarely discussed it early after discharge. However, late after discharge, they prioritized strengthening the relationships that had grown during the experience of critical illness.

Asserting personhood

Patients expressed a need for agency and dignity, feeling respected, setting boundaries, and being empowered to play a role in their recovery:

> "[On the wards] I felt myself going downhill - the depression started. Because I wasn't getting that, well they can't get individual with everybody…But I think there's a lot of things that they can keep a watch on, if someone's distressed, you know? And then you didn't get your night drink, which upset me…I'm lying there waiting for my night drink…I felt that I'd been deprived of everything." (76-year-old woman who survived pancreatitis)

Asserting personhood was mostly a priority on the wards and late after discharge. On the wards, it involved pushing back against depersonalizing systems issues (e.g., hospital gowns, poorly coordinated care, unresponsiveness to their needs, exclusion from medical decision-making) and policies or attitudes that limited mobility or self-care. Late after discharge, this priority involved the healthcare system and personal relationships. Many called out providers who were late to appointments, cancelled follow-up appointments if they did not perceive clear benefits, and advocated for patient-centered care. Some set new boundaries with people who did not support them in the ways they needed (e.g., those who had not visited while they were in the hospital).

Ensuring family well-being

Many patients recognized how critical illness impacted their families and wanted to ensure that family members were okay:

> "[I]t's only me and my son and I couldn't afford to …so we're here [at my brother's]. He was looked after by my mum and my dad and my brother, and my sisters and everybody sort of looked after him." (38-year-old woman who survived a Crohn's exacerbation)

The concern related to the emotional and physical toll of caregiving, as well as the ways families suffered when patients could not fulfill their normal roles. This priority was not common enough to describe temporal trends.

Going home

This desire to go home was nearly universal on the wards:

> "My main concern was just to get better and to get out." (45-year-old man who survived sepsis)

Early after discharge, a small number were living with relatives or brief stays in rehabilitation facilities and still maintained the goal of going home. All were home by the late discharge period.

Restoring physical health

Patients prioritized achieving and maintaining physical health. They protected themselves from sick contacts, monitored how they felt, took medications, followed medical advice, and advocated for themselves:

> "[A]ll the time I was in there really, I had to have aims. I aimed to get off the ventilator by [my wife's] birthday…and I did it a couple days beforehand. I then aimed to be off, have the tracheostomy out by then, end of January, which I did, by a couple of days again." (60-year-old man who survived Guillan-Barre Syndrome)

On the wards, patients tracked their progress by their liberation from medical supports like suctioning, medical devices like tracheostomies, and proximity to discharge. Early after discharge they tracked it by how frequently they accessed home health and other post-discharge services and the extent to which ongoing healthcare needs interfered with resuming their normal roles and routines. Late after discharge, several noted backsliding on attempted lifestyle modifications.

Restoring psychological health

Many patients worked hard restoring their psychological health, including managing ongoing depression, anxiety, and panic attacks. They sought information and professional help to process what had happened to them, studied their ICU diaries, started personal diaries, and talked things through with family and friends:

> "[Y]ou noticed all these other things then, like the lack of concentration and the nightmares and, you know, not being able to be in a room that's full of people…And once I'd told [the counselor] about things like that, she'd say…'From talking to other patients, this is what they've experienced'…And that kind of reassures you a bit." (41 year-old woman who survived post-partum sepsis)

On the wards, patients' desire to restore psychological health was often nascent amidst their emotional distress related to critical illness, hallucinations, and the experiences of hospital life. A few discussed the catharsis of crying or talking with their families early after discharge. However, the greatest urgency to restore psychological health came late after discharge, when some experienced panic in public settings (e.g., pubs and shopping centers) and many took a more active approach to seeking help.

Seeking new experiences

Patients sought a variety of new experiences during recovery from critical illness. Some found meaning by working to transform ICU care or to develop support programs for survivors. Others did something symbolic of moving on: redecorating the house, traveling, or even having a child. Many committed to making every second count by refocusing on family, training in a new career, or living more intentionally or spontaneously:

> "I've just applied for a job, actually I've got an interview tomorrow, for going into homecare, albeit only part-time at the moment. But I, that's what I want to do, I want to put something back into the community." (45-year-old man who survived sepsis)

Only one patient, a mental health professional, discussed seeking new experiences while still on the wards; he was already reforming systems of post-ICU care. The patients who sought new experiences early after discharge were in transitions (e.g., retirement, trying to have a baby) or had pre-existing plans before they became critically ill. For the remainder, seeking new experiences seemed to be a marker of advanced recovery.

Discussion

In this qualitative analysis, we identified 12 core patient priorities during critical illness recovery and described their evolution over time, from basic survival priorities on the wards (e.g., feeling safe and being comfortable) to active physical recovery early after discharge (e.g., enhancing mobility and self-care) to more holistic and aspirational priorities late after discharge (e.g., resuming normal roles and routines). These results should inform patient-centered guidelines and post-ICU healthcare delivery systems.

Many of the patient priorities address previously reported sources of suffering, providing new insight into what patients perceive to be important during recovery, e.g., prioritizing mobility, self-care, and normal roles and routines, feeling safe, going home and asserting personhood (10–14, 17, 35–37). However, two patient priorities, *connecting with people* and *seeking new experiences*, appear to be novel. This may reflect both the diversity of the sample and the timing of the interviews, many of which were conducted several years after critical illness, enabling patients to report on the full trajectory of recovery and to address goals rather than deficits only.

One unique aspect of this study was the ability to examine how patients' priorities evolved over time, up to several years after critical illness (from based survival priorities on the wards to aspirational priorities in the late post-discharge period), an evolution that recalls Maslow's hierarchy of needs (Figure) (38). Although Maslow's hierarchy has previously been suggested as a theoretical framework to inform holistic patient care within ICUs (47, 48), this study represents its first application to framing post-ICU care continuity, assessment, and interventions.

Patients' priorities may inform post-ICU healthcare delivery first by their relevance to patient-centered clinical guidelines and outcome measures (35, 49, 50), and second ~~to~~ by the types and timing of healthcare services offered to patients recovering from critical illness (Tables 2 – 4; see Supplemental Digital Content for expanded versions of these Tables detailing their relationships to the priorities). Thus, patients need services to address mobility and self-care on the wards and early after discharge (12, 15, 17, 18, 49), and services to address psychological health later (probably > 3 months after discharge) (12, 15, 18, 19). In general, care processes should be redesigned to foster human connections while balancing safety and autonomy/personhood (3, 14); one promising means of doing so is to engage patients and families as partners in care (44, 51–53). Finally, eliciting patients' priorities may also be useful in assessing where they are in the trajectory of functional recovery and anticipating their needs. Thus, resuming normal roles and routines is characteristic of the active recovery phase, indicating screening for physical, occupational or psychological therapy needs; alternatively, seeking new experiences may signal the transition to an advanced stage of recovery and functional independence.

This study has several potential limitations. First, secondary analyses of qualitative data typically raise concerns about whether the data can adequately address the study question, the secondary analyst is missing key insights into the data, or the data are out-of-date (20). In our case, the parent study's purpose aligned closely with ours; the original researcher is a co-author on the article; and no new post-ICU interventions have been widely adopted in the past decade to significantly change survivors' experience (54–57). Second, recall bias is more likely the later the interviews occurred, which would particularly reduce the accuracy of patients' descriptions of how their priorities evolved over time. Although their accounts are detailed and often corroborated in multiple interviews, future studies should consider serial interviews to mitigate this concern. Furthermore, interviewing patients in the late post-discharge period provided novel insights about how patients' priorities evolve over time. Third, study participants did not articulate specific priorities for cognitive recovery or end-of life-care, perhaps because they did not recognize the high risk for these outcomes (58–60). Both deserve further study and integration into the framework. Fourth, different healthcare systems have vastly different organization of post-ICU care delivery. The priorities identified by these post-ICU survivors fit with Maslow's hierarchy supporting the generalizability of the results across the course of ICU recovery, but they will require confirmation outside the United Kingdom, as well as specification for sites of care not in included in the study, such as nursing facilities.

Conclusions

The 12 core priorities of critical illness survivors identified in this study should inform stakeholder-driven clinical guidelines and quality measures for post-ICU care (now, in their infancy [41]). Future research should extend these findings among other stakeholders (e.g., family members, healthcare providers, institutionalized and frail older adults) and determine barriers and facilitators to patient-centered post-ICU care.

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872 **Table 1. Participant characteristics**

Characteristic	**Critical Illness Survivors (N=39)**
Age, Mean (SD)	52.6 (13.4)
Age groups, N (%)	
20-29 years old	1 (2.6%)
30-39 years old	6 (15.4%)
40-49 years old	10 (25.6%)
50-59 years old	8 (20.5%)
60-69 years old	9 (23.1%)
70-79 years old	5 (12.8%)
Female gender, N (%)	13 (33%)
White race, N (%)	36 (92%)
Marital status, N (%)	
Single	6 (15.4%)
Married or partnered	29 (74.3%)
Divorced or separated	4 (10.3%)
Reason for ICU admission	
Infectious (sepsis, pneumonia)	14 (35.9%)
Hematology-Oncology (cancer, sickle cell)	5 (12.8%)
Cardiac (transplant, heart failure)	4 (10.3%)
Pulmonary (ARDS, asthma, COPD)	3 (7.7%)
Neurologic (aneurysms, Guillan-Barre)	3 (7.7%)

Trauma	3 (7.7%)
Pregnancy-related	2 (5.1%)
Other (rheumatologic)	5 (12.8%)
ICU length of stay (Range 2 days – 8 weeks, 1 missing)	
≤ 2 days	4 (10.3%)
2 – 5 days	3 (7.7%)
5 – 14 days	11 (28.2%)
> 14 days	20 (51.3%)
Ward length of stay (Range 2 days – 5 months, 2 missing)	
≤ 2 days	1 (2.6%)
2 – 5 days	5 (12.8%)
5 – 14 days	16 (41.0%)
> 14 days	15 (38.5%)
Time from discharge to interview (Range 19 days – 11 years)	
≤ 2 months (did not contribute to late post-discharge	3 (7.7%)
analysis)	24 (61.5%)
2 – 12 months (contributed to analysis of all 3 time periods)	12 (30.8%)
> 12 months (contributed to analysis of all 3 time periods)	

ARDS – acute respiratory distress syndrome; COPD – chronic obstructive pulmonary disease

Table 2. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities on the wards. Some of the included elements anticipate priorities that patients describe as occurring later (e.g., screen for psychological function on the wards) because early identification and treatment may support more rapid recovery in multiple domains (e.g., poor motivation from unrecognized depression may reduce participation in rehabilitation).

Domain	Potential Interventions
Structures of care	
Personnel	• Rehabilitation specialists • Family support personnel • Peer navigators (1) • Spiritual care providers
Equipment & facilities	• Mobility & self-care equipment • Quiet spaces for rest/decompression • Community spaces for socialization • Recreation equipment (e.g., crafts, puzzles)
Processes of care	
Screening	Change from baseline/ICU admission related to: • Nutrition & hydration • Pain & discomfort • Physical function • Psychosocial function • Caregiver wellbeing
Communication	Anticipatory guidance • Transition to the wards • Transition home • Advance care planning

	Values elicitation & short- and long-term goal setting • **Focus up the hierarchy (e.g. love & belonging, self-esteem, & self-actualization)** • **Unpack what is meaningful about "going home"** • **Introduce the idea of setting goals around seeking new experiences** (2, 3)
Culture Change, Care Planning & Treatment	Culture change & care planning • Staff training to recognize & respond to unmet priorities • Enhanced opportunities for choice, autonomy, & self-efficacy • Identify & prescribe services, equipment, & medications required for a successful community discharge • Identify personnel responsible for follow-up Treatment • Rehabilitation • **Patient & family education & training in rehabilitation & care** (6, 7) • Psychiatric medication & peer support
Patient-centered outcomes	
Physical function	Strength, endurance, & self-care
Psychosocial function	Symptoms related to mood & sleep **Frequency & types of social contact**
Caregiver wellbeing	Mood & stress **Preparation for home caregiving**
Global health & function	Successful community discharge (10) Quality of life

Table 3. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the early post-discharge period.

Domain	Potential Interventions
Structures of care	
Personnel	• Rehabilitation specialists • Home health personnel • Mental health professionals • Healthcare providers trained in ICU recovery • Peer navigators • Spiritual care providers
Equipment & facilities	• Mobility & self-care equipment • Exercise equipment & facilities • Meal support services
Processes of care	
Screening	Trajectory of & resource use related to: • Physical function • Psychosocial function • Caregiver wellbeing
Communication	Check in about progress & new issues Follow-up about values & goals: • Determine which goals have been achieved • **Facilitate new goal-setting** (4, 5) • **Assess need for additional resources to achieve goals**
Culture Change, Care Planning & Treatment	Culture change & care planning • Continuity/communication between hospital, ICU follow-up, and primary care teams • Follow-up on care plan items

	• Add newly identified priorities to the care plan Treatment • Rehabilitation • **Family engagement & support** (8) • Psychiatric medication, peer support, &/or counseling
Patient-centered outcomes	
Physical function	Improved strength, endurance Independence in self-care
Psychosocial function	Improved mood & sleep **Motivation to participate in rehabilitation & other activities** (3)
Caregiver wellbeing	Mood & stress **Role function as a caregiver**
Global health & function	Reduced healthcare utilization Quality of life

Table 4. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the late post-discharge period.

Domain	Potential Interventions
Structures of care	
Personnel	• Mental health professionals • Healthcare providers trained in ICU recovery • Primary care providers • Peer navigators &/or support groups • Spiritual care providers
Equipment & facilities	• Vocational rehabilitation • Exercise equipment & facilities
Processes of care	
Screening	Outstanding recovery goals & resource needs related to: • Physical function • Psychosocial function • Caregiver wellbeing
Communication	Check in about progress & new issues **Set maintenance goals for health and function** **Set aspirational goals for wellness/whole health**
Culture Change, Care Planning & Treatment	Culture change & care planning • **Formal discharge/handoff process from post-ICU team to primary care team including all active elements of the care plan** Treatment • Rehabilitation **Family engagement & support** • Psychiatric medication, peer support, &/or counseling

Patient-centered outcomes	
Physical function	Maintenance of strength, endurance, & self-care **Achievement of patient’s goals related to physical function**
Psychosocial function	Return to baseline mood & sleep **Resumption of family roles** (9) **Participation in broader social life** (9)
Caregiver wellbeing	Mood & stress Resumption of normal family and professional roles
Global health & function	Reduced healthcare utilization Quality of life **Success in seeking new experiences** (3)

Figure. Patient Priorities on the Wards, Early Home, and Late Home Organized Using Maslow's Hierarchy. The pyramid on the left depicts Maslow's hierarchy. The expansion on the right demonstrates the related codes at each time point (wards, early home, and late home).

REFERENCES

1. Whittington JW, Nolan K, Lewis N, et al.: Pursuing the triple aim: The first 7 years. *Milbank Q* 2015; 93:263–300

2. Berwick DM, Nolan TW, Whittington J: The triple aim: Care, health, and cost. *Health Aff* 2008; 27:759–769

3. Stelfox HT, Lane D, Boyd JM, et al.: A scoping review of patient discharge from intensive care: Opportunities and tools to improve care. *Chest* 2015; 147:317–327

4. Needham DM, Davidson J, Cohen H, et al.: Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Crit Care Med* 2012; 40:502–509

5. Elliott D, Davidson JE, Harvey MA, et al.: Exploring the scope of post–intensive care syndrome therapy and care: Engagement of non-critical care providers and survivors in a second stakeholders meeting. *Crit Care Med* 2014; 42:2518–2526

6. Prescott HC, Langa KM, Liu V, et al.: Increased 1-year healthcare use in survivors of severe sepsis. *Am J Respir Crit Care Med* 2014; 190:62–69

7. Hua M, Gong MN, Brady J, et al.: Early and late unplanned rehospitalizations for survivors of critical illness. *Crit Care Med* 2015; 43:430–438

8. Hill AD, Fowler RA, Pinto R, et al.: Long-term outcomes and healthcare utilization following critical illness - a population-based study. *Crit Care* 2016; 20:1–10

9. Dowdy DW, Eid MP, Sedrakyan A, et al.: Quality of life in adult survivors of critical illness: A systematic review of the literature. *Intensive Care Med* 2005; 31:611–620

10. Cox CE, Docherty SL, Brandon DH, et al.: Surviving critical illness: Acute respiratory

distress syndrome as experienced by patients and their caregivers. *Crit Care Med* 2009; 37:2702–2708

11. Kang J, Jeong YJ: Embracing the new vulnerable self: A grounded theory approach on critical care survivors ’ post-intensive care syndrome. *Intensive Crit Care Nurs* 2018; 49:44–50

12. Ågård AS, Egerod I, Tønnesen E, et al.: Struggling for independence : A grounded theory study on convalescence of ICU survivors 12 months post ICU discharge. *Intensive Crit Care Nurs* 2012; 28:105–113

13. Maddox M, Dunn S V, Pretty LE: Psychosocial recovery following ICU: Experiences and influences upon discharge to the community. *Intensive Crit Care Nurs* 2001; 17:6–15

14. Field K, Prinjha S, Rowan K: “One patient amongst many”: A qualitative analysis of intensive care unit patients’ experiences of transferring to the general ward. *Crit Care* 2008; 12:1–9

15. Hanifa AB, Glaeemose AO, Laursen BS: Picking up the pieces : Qualitative evaluation of follow-up consultations post intensive care admission. *Intensive Crit Care Nurs* 2018; 48:85–91

16. Ewens BA, Hendricks JM, Sundin D: Surviving ICU: Stories of recovery. *J Adv Nurs* 2018; 74:1554–1563

17. Czerwonka AI, Herridge MS, Chan L, et al.: Changing support needs of survivors of complex critical illness and their family caregivers across the care continuum : A qualitative pilot study of Towards RECOVER. *J Crit Care* 2015; 30:242–249

18. Deacon KS: Re-building life after ICU : A qualitative study of the patients ’ perspective. *Intensive Crit Care Nurs* 2012; 28:114–122

19. Engstrom A, Andersson S, Soderberg S: Re-visiting the ICU experiences of follow-up visits to an ICU after discharge: A qualitative study. *Intensive Crit Care Nurs* 2008; 24:233–241

20. Ziebland S, Hunt K: Using secondary analysis of qualitative data of patient experiences of health care to inform health services research and policy. *J Heal Serv Res Policy* 2014; 19:177–182

21. Coyne IT: Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *J Adv Nurs* 1997; 26:623–630

22. Sandelowski M: Telling stories: Narrative approaches in qualitative research. *J Nurs Scholarsh* 2007; 23:161–6

23. Mishler EG: Research Interviewing: Context and Narrative. Cambridge, MA: Harvard University Press; 1991.

24. Sandelowski M: Whatever happened to qualitative description? *Res Nurs Health* 2000; 23:334–340

25. Sandelowski M: What's in a name? Qualitative description revisited. *Res Nurs Health* 2010; 33:77–84

26. Sullivan-Bolyai S, Bova C, Harper D: Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nurs Outlook* 2005; 53:127–133

27. Neergaard MA, Olesen F, Andersen RS, et al.: Qualitative description-the poor cousin of health research? *BMC Med Res Methodol* 2009; 9:1–5

28. Scharer K: What parents of mentally ill children need and want from mental health

professionals. *Issues Ment Health Nurs* 2009; 23:617–640

29. Morse JM: Critical analysis of strategies for determining rigor in qualitative inquiry. *Qual Health Res* 2015; 25:1212–1222

30. Doing Qualitative Research. 2nd ed. Thousand Oaks, California: Sage Publications, Inc; 1999.

31. HealthTalk Advisory Panel Membership [Internet]. [cited 2019 Jan 2] Available from: http://www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-patients-experiences/credits

32. Marshall MN: Sampling for qualitative research. *Fam Pract* 1996; 13:522–525

33. Pope C, Ziebland S, Mays N, et al.: Analysing qualitative data. 2017; 320:114–116

34. Bern-Klug M: Calling the question of “possible dying” among nursing home residents: Triggers, barriers, and facilitators. *J Soc Work End Life Palliat Care* 2008; 2:61–85

35. König C, Matt B, Kortgen A, et al.: What matters most to sepsis survivors: A qualitative analysis to identify specific health-related quality of life domains. *Qual Life Res* 2018; 28:637–647

36. Leland NE, Gozalo P, Christian TJ, et al.: An Examination of the First 30 Days After Patients are Discharged to the Community From Hip Fracture. *Med Care* 2015; 53:879–887

37. RTI International: Technical Expert Panel Summary Report: Development of a Discharge to Community Quality Measure for Skilled Nursing Facilities (SNFs), Inpatient Rehabilitation Facilities (IRFs), Long-Term Care Hospitals (LTCHs), and Home Health Agencies (HHAs). 2016.

38. Zalenski RJ, Raspa R: Maslow's Hierarchy of Needs: A framework for achieving human potential in hospice. *J Palliat Med* 2006; 9:1120–1127

39. Mikkelsen ME, Jackson JC, Hopkins RO, et al.: Peer Support as a Novel Strategy to Mitigate Post-Intensive Care Syndrome. *AACN Adv Crit Care* 2016; 27

40. Marin RS, Bierdrzycki RC, Firinciogullari S: Reliability and validity of the Apathy Evaluation Scale. *Psychiatry Res* 1991; 38:143–162

41. Skidmore ER, Whyte EM, Butters MA, et al.: Strategy training during inpatient rehabilitation may prevent apathy symptoms after acute stroke. *P M R* 2015; 7:562–570

42. Skidmore ER: Activity interventions for cognitive problems. *Pediatr Blood Cancer* 2014; 61:1743–1746

43. Naylor MD, Hirschman KB, Toles MP, et al.: Adaptations of the evidence-based Transitional Care Model in the U.S. *Soc Sci Med* 2018; 213:28–36

44. Haines KJ: Engaging Families in Rehabilitation of People Who Are Critically Ill: An Underutilized Resource. [Miscellaneous Article]. 2018; 98:737–744

45. Rodakowski J, Skidmore ER, Rogers JC, et al.: Role of Social Support in Predicting Caregiver Burden. *Arch Phys Med Rehabil* 2012; 93:2229–2236

46. World Health Organisation: International Classification of Functioning, Disability and Health. Geneva: World Health Organization; 2001.

47. Karnatovskaia L V., Gajic O, Bienvenu OJ, et al.: A holistic approach to the critically ill and Maslow's hierarchy. *J Crit Care* 2015; 30:210–211

48. Jackson JC, Santoro MJ, Ely TM, et al.: Improving patient care through the prism of psychology: Application of Maslow's hierarchy to sedation, delirium, and early mobility in

the intensive care unit. *J Crit Care* 2014; 29:438–444

49. Major ME, Kwakman R, Kho ME, et al.: Surviving critical illness: What is next? An expert consensus statement on physical rehabilitation after hospital discharge. *Crit Care* 2016; 20:1–10

50. National Institute for Health and Care Excellence: Rehabilitation after critical illness in adults: Clinical guidelines [Internet]. 2009; [cited 2019 Feb 4] Available from: https://www.nice.org.uk/guidance/qs158

51. Van De Graaff M, Beesley SJ, Butler J, et al.: Partners in Healing: Postsurgical outcomes after family involvement in nursing care. *Chest* 2018; 153:572–74

52. Haines KJ, Kelly P, Fitzgerald P, et al.: The untapped potential of patient and family engagement in the organization of critical care. *Crit Care Med* 2017; 45:899–906

53. Major ME, van Ness F, Ramaekers S, et al.: Survivors of Critical Illness and Their Relatives: A Qualitative Study on Hospital Discharge Experience. *Ann Am Thorac Soc* 2019;

54. Jensen JF, Thomsen T, Overgaard D, et al.: Impact of follow-up consultations for ICU survivors on post-ICU syndrome: A systematic review and meta-analysis. *Intensive Care Med* 2015; 41:763–775

55. Mehlhorn J, Freytag A, Schmidt K, et al.: Rehabilitation interventions for postintensive care syndrome: A systematic review. *Crit Care Med* 2014; 42:1263–71

56. Calvo-Ayala E, Khan BA, Farber MO, et al.: Interventions to improve the physical function of ICU survivors: A systematic review. *Chest* 2013; 144:1469–1480

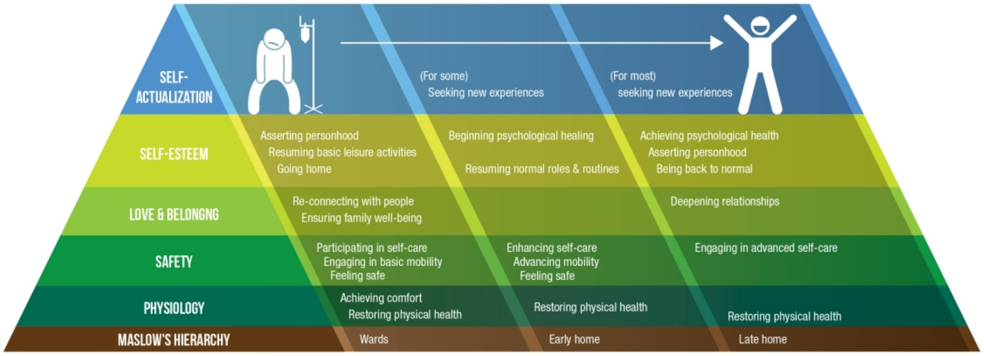
57. Schmidt K, Worrack S, Von Korff M, et al.: Effect of a primary care management

intervention on mental health–related quality of life among survivors of sepsis. *JAMA* 2016; 315:2703–2711

58. Pandharipande PP, Girard TD, Jackson JC, et al.: Long-term cognitive impairment after critical illness. *N Engl J Med* 2013; 369:1306–1316

59. Ferrante LE, Pisani MA, Murphy TE, et al.: Functional trajectories among older persons before and after critical illness. *JAMA Intern Med* 2015; 175:523–529

60. Brummel NE, Balas MC, Morandi A, et al.: Understanding and reducing disability in older adults following critical illness. *Crit Care Med* 2015; 43:1265–1275



Patient Priorities on the Wards, Early Home, and Late Home Organized Using Maslow's Hierarchy. The pyramid on the left depicts Maslow's hierarchy. The expansion on the right demonstrates the related codes at each time point (wards, early home, and late home).

229x87mm (300 x 300 DPI)

Supplemental Digital Content

Methods

Study data come from a national archive of qualitative interviews on health and illness held at the University of Oxford (16). The Eastern Medical Research Ethics Committee (03/5/016), Berkshire Research Ethics Committee (09/H0505/66), and University of Pittsburgh Internal Review Board (PRO17060235) granted ethics approval. An expert advisory panel of patient representatives, researchers and ICU clinicians advised throughout primary data collection, including on recruitment and sampling (1). Participants completed informed consent and copyrighted their interviews to the University of Oxford for use in secondary analysis. The University of Oxford and the University of Pittsburgh completed a data sharing contract to enable the analysis.

Description of the parent study

In 2005-6, a senior qualitative researcher (SP) recruited critical illness survivors to participate in interviews about their critical illness experiences for the Healthtalk website (www.healthtalk.org), an award-winning resource that publishes academic research findings to a general audience (17). Recruitment occurred through a range of sources including general practitioners, specialist nurses, hospital clinics, national and local support groups, media advertising, word of mouth, and snowballing. Eligible patients were adults ≥ 20 years old who had previously received care in an ICU in the United Kingdom. To describe a wide range of experiences (18), recruitment involved maximum variation sampling across types of experience (e.g. time since diagnosis and degree of disease severity/progression) and demographic variables (e.g. gender, age, ethnicity, socio-economic group, region). After reviewing information packets provided at recruitment sites, those who volunteered to participate contacted SP to schedule an interview.

SP interviewed participating critical illness survivors in their own homes about their experiences in and after critical illness, including its overall impact on them, their families, work and social lives. She initially asked participants to share their experiences, and allowed them to speak as long as they wished without prompting in order to generate an oral history focused on participant's priorities and concerns (19,20). Then, she used an interview guide to probe the importance of various topics identified through prior interviews, literature review, and communication with the HealthTalk advisory panel. Interviewing continued until thematic saturation occurred, i.e., no new experiences or themes emerged related to the primary analysis (2, 3).

Although the parent study consisted of 40 interviews, we excluded an interview with the parent of a deceased child because it could not provide insight in to adult ICU survivors' priorities during ICU recovery. Thus, this analysis represents data from 39 interviews.

Results

Table 1. Patients' Priorities During Post-ICU Recovery

Priority	N (%) participants reporting this priority	Exemplar
Feeling safe		So it was quite difficult and my relatives saw this and they knew that I'd gone from being in Intensive Care with my own nurse to suddenly being, alone really. And, you know, they were worried what would happen if I went off in the night, what would happen if nobody could, you know, I couldn't contact anybody so they were worrying about all those kinds of things. And it was quite daunting even for me even though I knew that that would happen, it was still quite daunting and, you know, frightening. And even if you did buzz the nurses, they were obviously busy. They couldn't come as quickly as they could on the Intensive Care Unit, you'd have to wait, which wasn't anybody's fault. But it would have been better if I could have done a bit more for myself. - 41-year-old woman who survived post-partum sepsis, ICU length of stay (LOS) 11 days, ward LOS 14 days

Being comfortable		That was part of, in the High Dependency they said to me, "We're gonna get you out the bed". Oh what a nightmare that was, 'cause they lifted like that. They used like a winch and they'd put me in the chair but because I hadn't been in that position for that long, after about twenty minutes every bit of me was hurting. I'd move from one buttock and try and lean on the other one, I'd say to the nurse, "Will you just put me back on the bed". And she kept on saying, "In a minute, in a minute, can you just wait?" [Laughs] I was thinking Oh, I was nearly in tears. And I said to her, "Can you get me back on the bed? I am really hurting". And she said, "Oh you won't be able to cope when you go on the general ward, this is the soft option here". And I thought, God if I could get up, I'd kill you. - 40-year-old woman who survived sepsis, ICU LOS 22 day, ward stay 18 days
Engaging in mobility		Well, yeah, as I've been here [home] a couple of weeks now, when I first got home I were walking with my Zimmer because they sent me home with a Zimmer. But then I thought, "Oh, bugger this, I don't need it." [Laughs] You know, just walk around furniture and things, because we've got a toilet in there. I'd say to my mum, "Just grab me vac" because it's heavy. And it were just like slowly, you know, doing it myself and like one night my mum took, I said to my mum, "Oh I want to go upstairs. I want to sleep in my bed." And I did the stairs and now the physio comes in, we do stairs and I can do stairs in two seconds. You know, I can.

		- 23-year-old woman who survived an ulcerative colitis exacerbation, ICU LOS 21 days, wards LOS 4 weeks
Participating in self-care		He had to, you had to do all the cooking, all the cleaning and sometimes I felt guilty because [partner] was having to serve my meals because I couldn't do it and then I'd get quite frustrated. I'd get quite frustrated and I'd get quite angry and you were confused as to why I was angry and then I had to be honest and say well I feel guilty and then you'd get a bit upset and say but why are you feeling guilty, I've got you home? And like you said to me even if I was stuck in a chair on a ventilator for the rest of my life, he was glad to have me home. But I didn't like being dependent on [my partner] to the degree that I was. And little things that like, oh and stupid things could potentially become a big issue where you know I wanted bobbles for my hair and I couldn't get to the shop or, and we had to be honest didn't we and I'd say you know. But sometimes you don't, you didn't want to ask but you'd had to ask because you were dependent. - 40-year-old woman who survived sepsis, ICU LOS 22 day, ward stay 18 days
Connecting with people		[On the wards] there was someone to talk to all the time, you know. When you're in Intensive Care sometimes you were sort of, you were on monitors, you had machines monitoring your condition, you know, but very often there wasn't anybody there and it could be very lonely, you know, it could be very lonely stuck in there.

		- 67-year-old man who survived heart transplant and sepsis, ICU LOS 8 weeks, wards LOS 3 weeks
Resuming normal roles and routines		I just want things to return to how our life was before…I've worked full time since I was sixteen so, like I do a professional job so I wanna be back in the workplace. I wrote to my colleagues in work and I just said like, I'm missing the team, I miss you…I was writing to my friend...And I said, and dare I say it, I actually miss work. And I know she would have laughed when she read it, and I miss work, I miss the workplace, I mean I don't miss all the moaning gits that go with it but I miss, I do miss getting up of a morning and going to work. And I mean I used to be like firing on all cylinders. I'd have the children's clothes ready, the shoes were polished and ready where I could find them. So everything was like, from the minute we got up it was like, go, go until I've got him to work and then I sat down. And then coming home and I just want things really to get back to how they were, and I just feel like the days just tick by and like da, da, da, just [laughs]. - 40-year-old woman who survived sepsis, ICU LOS 22 day, ward stay 18 days
Ensuring family well-being		What happened to make me come [to my brother's house] was, the day, I said to you, when I went back to work and I was ill and I came home I was, my temperature just shot up. But since I got home, and I was just collapsed and threw up and it's only me and my son and I couldn't afford to, just him and he's big, he's 13 but he's still young…so we're here. He was looked after by my mum and my dad and my brother, and my sisters and everybody sort of looked after him. It was

		hard on him and I think I had to allow him to have a normal life so he used to just, you know, go and see his friends and whatever. - 38-year-old woman who survived a Crohn's exacerbation, ICU LOS 1 month, ward LOS several months
Asserting personhood		It was just, I cried a lot. I cried more tears than you can imagine, with frustration, powerlessness, pain, you know not being able to see my daughter and just…I mean what the doctors can't tell you is how long you're going to be in. I mean now I can tell you that I was in for eight weeks and at this stage this happened and at this stage this happened. But at the time you don't know whether it's going to be eight weeks or ten weeks or twelve weeks. So every day it's just kind of more of the same. You don't feel as if you're making huge steps although you are slowly and just. As I got better I got more aware of just how ill I was perversely. So, you know I had to be put to sleep at night. The nurses had to put me in a position so that I could sleep because I couldn't move to put myself in a position and then I'd get achy in it. And so not being able to sleep. To have a bed bath I had to be manipulated, you know I had to be turned one way and turned another way and [um] all of that. You know, stuff which is just, just not great for your self esteem, I mean not. I mean self esteem is the last thing on your mind when you're that sick but it's just, it's just very, very unpleasant to kind of be in such a kind of weakened state. - 35-year-old woman who survived sepsis, ICU LOS 3 weeks, ward LOS 7 days

Going home		Yeah. I was walking. All the tubes went, so I was walking. Walking about, you know, it got to the stage because I'd been in hospital so long I was asking them, you know, "What do I need to do now? How long am I going to be here? How long do I have to be on the feed?" And they, you know, just, once my potassium level got evened out and everything was okay, I started to get a bit agitated. I wanted to go home. I was getting fed up because I have a son. I hadn't, I couldn't see my son. I said I want to go home. I want to see my son, you know all of this. They let me go home and basically the hospital let me pretty much go home every day and just come back to sleep because the surgeon realised that since I started to go home, I started to get a lot better. So he said, "All right then you can go home." They even used to like give the mediation I had to take because if you're going home, then fair enough. - 38-year-old woman who survived a Crohn's exacerbation, ICU LOS 1 month, ward LOS several months
Restoring physical health		Now the asthma nurse came to see me in connection with making an asthma plan that was specifically for me. And before I left I was given various new prescriptions to take and I was given a revised version of the peak flow meter which, oddly enough I must admit, I haven't taken for the last month or so. I'm given a target that I'm supposed to achieve, of 570. I was regularly achieving around 400, but if it flows below 300 I must take the blue inhaler every 4 to 6 hours. If it goes below 250 go back on the steroids. Now these steroids have been very difficult to get out of

		the GP. But the hospital have given me a stock of them because it's part of the asthma plan. And if it goes below 200 go straight to A and E, before an attack comes on. So, yes, I was given the information as to what causes asthma and what happens. Apparently the immune system detects something it doesn't like, and to protect you it starts to close the airways. And so, yes, on that round, yes. - 60-year-old man who survived an asthma exacerbation, ICU LOS 3 days, ward LOS 10 days
Restoring psychological health		I think my one area of, criticism overstates it but it's the one area that I didn't get any help. And I think I really could have done with some [psychological] help. And all, you know, even something like this to, you know, I did search on the Internet and you know, try and find something that would kind of give me a steer into, you know, has anybody else have the memories that I had. And I was never able to find anything. I mean I went out and privately found a counsellor to talk to and I had sort of six or so sessions with him. And I hadn't really had counselling before and I kind of went into it very much with the attitude that I'd kind of almost like, I'd be able to heal myself. So I'd be able to go and talk to him and talk it all through and talk it all out and then it would be over and I'd be able to kind of put it away in a box and forget about it. But you know, I realise that that's not actually the way that you can deal with these things and that actually, you know, that it was a major, major trauma. And that's not going to go away. - 35-year-old woman who survived sepsis, ICU LOS 3 weeks, ward LOS 7 days

Seeking new experiences		Yeah I'm much more, "let's just do it!" Things that are like, I mean me and my husband are just the worst combination. We're a pair of, "Oo shall we do that?". "Oh I don't know, let's think about it for three years". We're just like hopeless, but now I'm just like, "Let's just do it". I mean even like, over buying the computer, I mean we must have talked about it for about ten years. And like now, "Let's just get it, will you stop". We're in the shops, like he's going, "What about this feature?" And I just go, "Just buy it, just buy it". And he's like, and even like going on holidays, I'd just come out of hospital, got a magazine, booked a holiday, paid for it, and he was just like [sighs]. He said, "Well I'd love to go to New York". I said, "Right, go to New York in November". And he's just like, Oh God whereas I just think do it and even like to a certain extent spoiling the children, 'cause like they say, "Oh". Something's on the telly, "I want this". Or, "Can we go there?" And I just think, yep, let's just have it, spend it, go there, do that. I have more time for them as well. - 40-year-old woman who survived sepsis, ICU LOS 22 day, ward stay 18 days

Expanded Table 2. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities on the wards. Some of the included elements anticipate priorities that patients describe as occurring later (e.g., screen for psychological function on the wards) because early identification and treatment may support more rapid recovery in multiple domains (e.g., poor motivation from unrecognized depression may reduce participation in rehabilitation). The parentheses to the right of each item indicate which codes the item is intended to address, as follows:

a – Restoring physical health

b – Being comfortable

c – Feeling safe

d – Engaging in mobility

e – Participating in self-care

f – Ensuring family well-being

g – Connecting with people

h – Going home

i - Resuming normal roles and routines

j – Asserting personhood

k – Restoring psychological health

l – Seeking new experiences

Items novel to the ICU are bolded. References are not exhaustive but contextualize the recommendations.

Domain	Potential Interventions	
Structures of care		
Personnel	• Rehabilitation specialists (a, d, e, h) • Family support personnel (f) • Peer navigators (c, g, j, k)(1) • Spiritual care providers (g, j, k)	
Equipment & facilities	• Mobility & self-care equipment (c, d, e, h) • Quiet spaces for rest/decompression (j, k) • Community spaces for socialization (g, j, k) • Recreation equipment (e.g., crafts, puzzles) (e, i)	
Processes of care		Processes
Screening	Change from baseline/ICU admission related to: • Nutrition & hydration (a) • Pain & discomfort (b, k) • Physical function (a, d, e, g, h, j) • Psychosocial function (g, I, j, k) • Caregiver wellbeing (f)	
Communication	Anticipatory guidance • Transition to the wards (c, d, e, h, I, j) • Transition home (c, d, e, h, I, j) • Advance care planning (f, j) Values elicitation & short- and long-term goal setting • **Focus up the hierarchy (e.g. love & belonging, self-esteem, & self-actualization)** (g, I, j, k, l) • **Unpack what is meaningful about "going home"** (h) • **Introduce the idea of setting goals around seeking new experiences** (l)(2, 3)	
Culture Change, Care Planning & Treatment	Culture change & care planning • Staff training to recognize & respond to unmet priorities (a – l) • Enhanced opportunities for choice, autonomy, & self-efficacy (c, j) • Identify & prescribe services, equipment, & medications required for a successful community discharge (a, c, d, e, h) • Identify personnel responsible for follow-up (a, d, e, f, g, I, k, l) Treatment • Rehabilitation (d, e, h, I, k) • **Patient & family education & training in rehabilitation & care** (a, c, d, e, f, h, I, j, k)(6, 7) • Psychiatric medication & peer support (d, e, f, g, I, k)	
Patient-centered outcomes		Patient-ce
Physical function	Strength, endurance, & self-care (d, e, h, i)	
Psychosocial function	Symptoms related to mood & sleep (a, k) **Frequency & types of social contact** (g, i)	
Caregiver wellbeing	Mood & stress (f) **Preparation for home caregiving** (a, d, e, f, I, k)	
Global health & function	Successful community discharge (h) (10) Quality of life (a – l)	

Table 3. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the early post-discharge period. The parentheses to the right of each item indicate which codes the item is intended to address, as follows:

a – Restoring physical health

b – Being comfortable

c – Feeling safe

d – Engaging in mobility

e – Participating in self-care

f – Ensuring family well-being

g – Connecting with people

h – Going home

i - Resuming normal roles and routines

j – Asserting personhood

k – Restoring psychological health

l – Seeking new experiences

Items novel to the ICU are bolded. References are not exhaustive but contextualize the recommendations.

Domain	Potential Interventions
Structures of care	
Personnel	• Rehabilitation specialists (a ,d, e, i) • Home health personnel (a, d) • Mental health professionals (g, j, k) • Healthcare providers trained in ICU recovery (a) • Peer navigators (c, g, j, k)

	• Spiritual care providers (g, j, k)	
Equipment & facilities	• Mobility & self-care equipment (c, d, e, h) • Exercise equipment & facilities (a, d, i) • Meal support services (a, f) •	
Processes of care		Processes
Screening	Trajectory of & resource use related to: • Physical function (a, d, e, g, j) • Psychosocial function (g, I, j, k) • Caregiver wellbeing (f)	
Communication	Check in about progress & new issues (a, c, d, e, f, g, I, j, k) Follow-up about values & goals: • Determine which goals have been achieved (g, I, j, k, l) • **Facilitate new goal-setting** (a, d, e, f, g, I, j, k, l)(4, 5) • **Assess need for additional resources to achieve goals** (a, d, e, f, g, I, j, k, l)	
Culture Change, Care Planning & Treatment	Culture change & care planning • Continuity/communication between hospital, ICU follow-up, and primary care teams (a, d, e, f, g, I, k, l) • Follow-up on care plan items (a, d, e, f, g, I, k, l) • Add newly identified priorities to the care plan (a – l) Treatment • Rehabilitation (d, e, I, k) • **Family engagement & support** (a, c, d, e, f, I, j, k)(8) • Psychiatric medication, peer support, &/or counseling (d, e, f, g, I, k)	
Patient-centered outcomes		Patient-ce
Physical function	Improved strength, endurance (d, i) Independence in self-care (e, i)	
Psychosocial function	Improved mood & sleep (a, k) **Motivation to participate in rehabilitation & other activities** (d, e, I, k)(3)	
Caregiver wellbeing	Mood & stress (f) **Role function as a caregiver** (a, d, e, f, I, k)	
Global health & function	Reduced healthcare utilization (a, h) Quality of life (a – l)	

Table 4. Hypothetical structures, processes, and outcomes of care to incorporate into patient-centered design of post-ICU care to address the priorities during the late post-discharge period. The parentheses to the right of each item indicate which codes the item is intended to address, as follows:

a – Restoring physical health

b – Being comfortable

c – Feeling safe

d – Engaging in mobility

e – Participating in self-care

f – Ensuring family well-being

g – Connecting with people

h – Going home

i - Resuming normal roles and routines

j – Asserting personhood

k – Restoring psychological health

l – Seeking new experiences

Items novel to the ICU are bolded. References are not exhaustive but contextualize the recommendations.

Domain	Potential Interventions
Structures of care	
Personnel	• Mental health professionals (l, j, k) • Healthcare providers trained in ICU recovery (a) • Primary care providers (a) • Peer navigators &/or support groups (c, g, j, k) • Spiritual care providers (g, j, k)

Equipment & facilities	• Vocational rehabilitation (j, l) • Exercise equipment & facilities (a, d)
Processes of care	
Screening	Outstanding recovery goals & resource needs related to: • Physical function (a, d, e, g, j) • Psychosocial function (g, l, j, k) • Caregiver wellbeing (f)
Communication	Check in about progress & new issues (a, c, d, e, f, g, l, j, k) **Set maintenance goals for health and function** (a, d, e, f, g, l, j, k, l) **Set aspirational goals for wellness/whole health** (a, d, e, f, g, l, j, k, l)
Culture Change, Care Planning & Treatment	Culture change & care planning • **Formal discharge/handoff process from post-ICU team to primary care team including all active elements of the care plan** (a, d, e, f, g, l, k, l) Treatment • Rehabilitation (d, e, l, k) • **Family engagement & support** (a, c, d, e, f, l, j, k) • Psychiatric medication, peer support, &/or counseling (d, e, f, g, l, k)
Patient-centered outcomes	
Physical function	Maintenance of strength, endurance, & self-care (d, e, h, i) **Achievement of patient's goals related to physical function** (a, d, l)
Psychosocial function	Return to baseline mood & sleep (a, k) **Resumption of family roles** (i)(9) **Participation in broader social life** (g, i)(9)
Caregiver wellbeing	Mood & stress (f) Resumption of normal family and professional roles (f, l,)
Global health & function	Reduced healthcare utilization (a, h) Quality of life (a – l) **Success in seeking new experiences** (l)(3)

References

1. HealthTalk Advisory Panel Membership [Internet]. [cited 2019 Jan 2] Available from: http://www.healthtalk.org/peoples-experiences/intensive-care/intensive-care-patients-experiences/credits

2. Marshall MN: Sampling for qualitative research. *Fam Pract* 1996; 13:522–525

3. Pope C, Ziebland S, Mays N, et al.: Analysing qualitative data. 2017; 320:114–116