



# BMJ Open Barriers and facilitators to resuming meaningful daily activities among critical illness survivors in the UK: a qualitative content analysis

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## ABSTRACT

**Objective** To identify critical illness survivors' perceived barriers and facilitators to resuming performance of meaningful activities when transitioning from hospital to home.

**Design** Secondary content analysis of semistructured interviews about patients' experiences of intensive care (primary analysis disseminated on the patient-facing website [www.healthtalk.org](http://www.healthtalk.org)). Two coders characterised patient-perceived barriers and facilitators to resuming meaningful activities. To facilitate clinical application, we mapped the codes onto the Person-Task-Environment model of performance, a patient-centred rehabilitation model that characterises complex interactions among the person, task and environment when performing activities.

**Setting** United Kingdom, 2005–2006.

**Participants** 39 adult critical illness survivors, sampled for variation among demographics and illness experiences.

**Results** *Person-related barriers* included negative mood or affect, perceived setbacks; weakness or limited endurance; pain or discomfort; inadequate nutrition or hydration; poor concentration/confusion; disordered sleep/hallucinations/nightmares; mistrust of people or information; and altered appearance. *Task-related barriers* included miscommunication and managing conflicting priorities. *Environment-related barriers* included non-supportive health services and policies; challenging social attitudes; incompatible patient–family coping (emotional trauma and physical disability); equipment problems; overstimulation; understimulation; and environmental inaccessibility. *Person-related facilitators* included motivation or attitude; experiencing progress; and religion or spirituality. *Task-related facilitators* included communication. *Environment-related facilitators* included support from family, friends or healthcare providers; supportive health services and policies; equipment; community resources; medications; and accessible housing. Barriers decreased and facilitators increased over time. Six barrier–facilitator domains dominated based on frequency and emphasis across all performance goals: mood/motivation, setbacks/progress, fatigability/strength; miscommunication; lack/community support; lack/health services and policies.

**Conclusions** Critical illness survivors described a comprehensive inventory of 18 barriers and 11 facilitators

## Strengths and limitations of this study

- We conducted a pragmatic, cost-effective secondary content analysis that: (1) verified previously recognised barriers and facilitators to meaningful activity after critical illness; (2) provided a comprehensive inventory of them; and (3) applied the Person-Task-Environment model of performance, a common conceptual model in rehabilitation interventions, to the postintensive care unit context.
- Results suggest novel opportunities for intervention, especially enhancement of system-level (environmental) facilitators.
- Two qualitative methodologists including one from the original study collaborated on the analysis to ensure rigour, and four authors with clinical and research expertise in critical illness survivorship collaborated to ensure significance and relevance to current practice.
- Although long-lasting functional impairment remains a major problem for critical illness survivors, data were originally collected in 2005–2006.

that align with the Person-Task-Environment model of performance. Six dominant barrier–facilitator domains seem strong targets for impactful interventions. These results verify previous knowledge and offer novel opportunities for optimising patient-centred care and reducing disability after critical illness.

## INTRODUCTION

Over half of critical illness survivors experience functional impairments now termed the postintensive care syndrome (PICS).<sup>1</sup> Unfortunately, rehabilitation interventions to remediate specific functional impairments in PICS have achieved little success.<sup>2–4</sup> Thus, PICS care strategies have begun emphasising compensation and adaption to optimise performance of everyday activities, which is a top priority for patients.<sup>5</sup>



Because performance of everyday activities is associated with independence, quality of life, mortality, healthcare utilisation and costs,<sup>6–10</sup> interventions that enhance performance of everyday activities could substantially improve healthcare quality and outcomes.<sup>11</sup> To be effective, interventions must address barriers and facilitators to performance. Although research has extensively characterised many important factors related to ongoing disability (eg, weakness, changes in mood and cognition and unavailability of family support),<sup>12</sup> there is no comprehensive inventory of barriers and facilitators to activity performance of daily activities. Such an inventory could yield undercharacterised but modifiable barriers and facilitators related to environmental adaptations or goal activity modifications that could become targets for high-impact interventions. Thus, we used Sandelowski's method of qualitative description<sup>13</sup> to conduct a secondary content analysis of interviews with critical illness survivors, to characterise barriers and facilitators to resuming meaningful activities on the wards and after discharge from a critical illness hospitalisation.

## METHODS

### Description of the parent study

The parent study's overarching objective was to explore and understand critical illness survivors' experiences of intensive care and disseminate the findings on a patient-facing website ([www.healthtalk.org](http://www.healthtalk.org))<sup>14 15</sup> (online supplemental material 1). Briefly, in 2005–2006, the parent study team recruited UK residents  $\geq 20$  years old who had previously received intensive care unit (ICU) care for any reason. Sampling attempted to capture a broad range of survivor perspectives by maximising variation among demographic characteristics and illness experiences.<sup>16</sup>

A senior qualitative researcher (SP) conducted one-time semistructured interviews in participants' homes; families were sometimes present, and all participants provided informed consent. Interviews had two stages: (1) in-depth narratives about participants' experiences from critical illness onset<sup>17 18</sup>; (2) question-and-response using an interview guide informed by prior interviews, literature review and an expert advisory panel (online supplemental material 2). They were audio-recorded or video-recorded per participant choice and professionally transcribed and deidentified. Participants reviewed and corrected transcripts for accuracy (ie, member checking).<sup>19</sup> Interviews continued until no new themes emerged related to the primary analysis (ie, thematic saturation).<sup>19</sup>

### Description of the current study

Despite the data's age, we reasoned that they remained relevant for the current study because of the parent study's high quality and the lack of significant changes in typical post-ICU pathways of care since their collection (few survivors attend dedicated post-ICU clinics). Of 40 original interviews, we excluded one with the parent of a deceased child, retaining the 39 that provided insight

about barriers and facilitators to achieving performance goals after critical illness.

Coders with backgrounds in critical care medicine and geriatrics (LS) and occupational therapy (JSW) conducted a qualitative content analysis using the method of qualitative description<sup>13 20</sup> to identify barriers and facilitators, respectively defined as factors that made it harder and easier to achieve performance goals. To facilitate clinical application, codes reflect related concepts from the International Classification of Function (the WHO's taxonomy for function, disability and health<sup>21</sup>), when appropriate. We compared and contrasted codes to clarify underlying concepts<sup>22</sup> and reviewed them with other clinicians to ensure clinical relevance (a form of triangulation).<sup>19</sup> (The time elapsed since data collection precluded checking with participants.) We independently coded all transcripts, meeting after coding every five to resolve differences by consensus and discuss new patterns.<sup>23</sup> To avoid missing important ideas, codes were not mutually exclusive.<sup>24</sup> We required all coded statements to include at least one goal captured in the concurrent analysis (online supplemental e-Table 1).<sup>5</sup> This study reached thematic saturation by the 14th transcript.<sup>19</sup>

To augment this data-driven, inductive analysis, we created two a priori subcodes for timing (wards and home) using Crabtree and Miller's template method.<sup>25</sup> They signify a broad shift in tasks and environment across the transition home. Every coded barrier or facilitator received one of these two subcodes, enabling analysis of changes over time. We used Atlas.ti V.8.2 (Berlin, Germany) for qualitative data management.

Examination of the barrier and facilitator codes suggested fit with the Person-Task-Environment model of performance (hereafter PTE model), a theoretical framework for the performance of everyday activities commonly used in occupational therapy.<sup>26 27</sup> It posits that *performance*—doing a purposeful or personally meaningful activity—emerges from complex interactions between person, task and environment (online supplemental e-Figure 1). Characteristics of the *person* include personality and physical, cognitive and emotional regulation abilities. *Task* is the activity the person wants to do. *Environment* is the physical, social and attitudinal context. The PTE model suggests how changing the person, task and environment might impact achievement of performance goals on the hospital wards and at home after surviving critical illness. The research team reasoned that: (1) conceptually, the PTE model made sense because all coded data addressed at least one performance goal<sup>5</sup>; (2) practically, if the codes fit the PTE model, it would support their validity and clinical application; and (3) prospectively, the PTE model could expose gaps in findings for future study. In this additional analysis, all the barrier and facilitator codes are easily mapped to the PTE model.<sup>28 29</sup>

We quantised the codes by counting the total number of participants reporting each barrier or facilitator, dividing by 39 to calculate frequencies.<sup>30</sup> Because all barriers or

facilitators received timing subcodes indicating whether the participant experienced them on the wards or at home, we were able to use Atlas.ti's co-occurrence function to report changing patterns across the transition from hospital to home both qualitatively and quantitatively. We prepared the manuscript using the SRQR reporting guidelines.<sup>31</sup>

### Patient and public involvement

The Healthtalk expert advisory panel, comprising patient representatives, researchers and ICU clinicians,<sup>32</sup> oversaw conduct of the parent study, including recruitment, sampling and interview guide development. Patient participants were recruited through health professionals and national charities. The current study sought additional analysis of patients' experiences.

## RESULTS

Table 1 shows broad ranges of participant age (23–76 years), employment (1 student, 2 unemployed, 12 retired, 24 assorted vocations), ICU admitting diagnosis (all types) and time since hospital discharge (weeks to years).

Figure 1 summarises the 18 barriers and 11 facilitators using the PTE model, across the transition from wards to home. Tables 2 and 3 and online supplemental e-Table 2 provide frequencies and exemplars, with the a priori timing subcodes (wards or home) noted in parentheses.

### Person-related barriers

*Negative mood or affect.* Patients described fear, anxiety, panic, apathy, depression and frustration. On the wards, these feelings concerned the illness, care environment and disability. At home, negative feelings concerned inability to manage 'normal' tasks or to process the trauma of critical illness. Sometimes, feelings kept patients from attempting activities altogether, although they more commonly blunted patients' efforts.

*Perceived setbacks or stagnation.* All patients assessed their recovery trajectory. On the wards, patients described setbacks based on clinical status: prolongation of hospital stay, mobility or self-care disability. At home, setbacks or stagnation related to slow resumption of desired activities. They caused anxiety and frustration.

*Weakness or limited endurance.* Initially, most discussed feeling unsafe and dependent on hospital staff; later, they expressed impatience at inability to keep up with normal activities. Fatigability was tied to perceived stagnation and thereby frustration.

*Pain or discomfort.* Symptoms impacted mood, sleep, and mobility. Most discussed delays in symptom recognition and treatment, with providers frequently failing to listen or express empathy about them. Patients attempted stoicism, and many experienced trade-offs between enduring symptoms or medication side effects. Symptoms typically diminished over time.

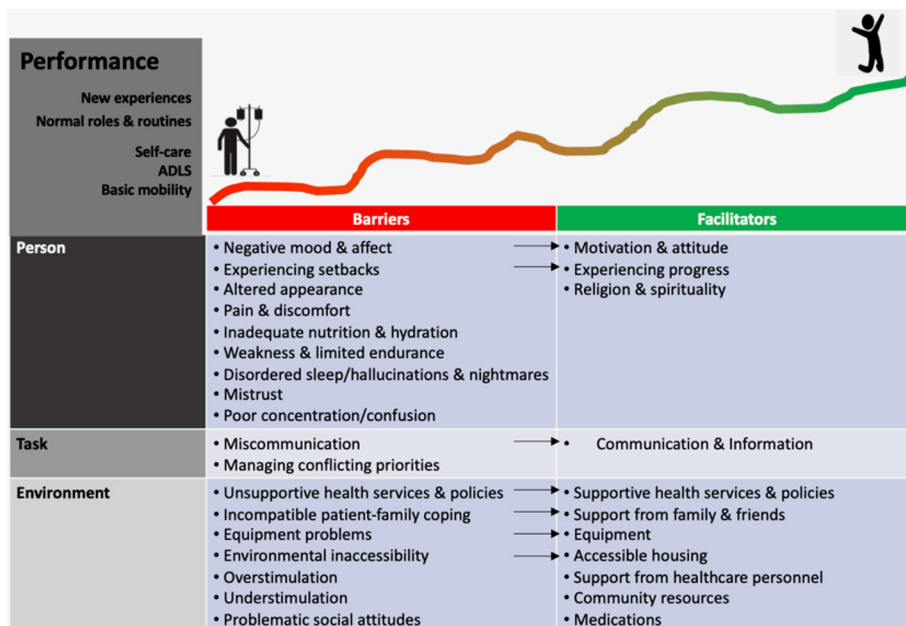
**Table 1** Participant characteristics

Characteristic	n=39
Age, mean (SD)	52.6 (13.4)
Female gender, n (%)	13 (33)
White race, n(%)	36 (92)
Marital status, n (%)	
Single	6 (15.4)
Partnered	29 (74.3)
Divorced or separated	4 (10.3)
Employment status at the time of the interview, n (%)	
Student	1 (2.6)
Employed*	24 (61.5)
Retired	12 (30.8)
Unemployed	2 (5.1)
Reason for ICU admission, n (%)	
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)
Neurological (aneurysms, Guillan-Barre)	3 (7.7)
Trauma	3 (7.7)
Pregnancy related	2 (5.1)
Other (rheumatological)	5 (12.8)
ICU length of stay, range	2 days–7 months (median 18.5 days)
Ward length of stay, range	2 days–5 months (median 14 days)
Time from critical illness to interview, range	2.5 weeks to - 11 years (median 9 months)

\*The sample's socioeconomic diversity was further reflected in participants' vocations at the time of the interview, including: gardener, bus driver, mechanic, maintenance worker, steel shutter fitter, teacher, care assistant, nurse (2), physician's assistant, social worker (2), housing officer, bank officer, finance officer, finance director, sales director, secretary, manager, television producer, researcher, utilisation manager and civil servant. One self-employed person did not note the nature of their work. ARDS, acute respiratory distress syndrome; COPD, chronic obstructive pulmonary disease.

*Inadequate nutrition or hydration.* Patients noted weight loss, digestive problems, altered taste and reduced appetite. Initially, they worried about eating enough to heal. At home, some regained their appetites and then struggled with weight management.

*Poor concentration or confusion.* People described inattentiveness, impulsivity, confusion and slowed thinking. Some attributed these symptoms to medications. On the wards, symptoms contributed to inactivity. At home, patients and families were unprepared for cognitive changes and experienced high stress while developing adaptive strategies (eg, reducing multitasking, making lists and transferring financial responsibility to prevent impulse buying).



**Figure 1** Barriers and facilitators to post-ICU recovery and discharge home using the Person-Task-Environment model of performance. ADLS, activities of daily living; ICU, intensive care unit.

*Disordered sleep, hallucinations or nightmares.* These often occurred in a complex tangle. Although more prominent on the wards, they were still troubling after discharge.

*Mistrust.* Some mistrusted information, some mistrusted people. On the wards, mistrust occurred with unmet informational or care needs. Once home, mistrust related to poor rapport with clinicians.

*Altered appearance.* Alterations in physical appearance (eg, swelling, wounds, scarring and weight loss) contributed to patients' pervasive sense of being unwell, disabled, alien or shy of social situations. This was most pronounced during hospitalisation and tended to dissipate across the transition home as the alteration became less pronounced or the patient adapted.

### Task-related barriers

*Miscommunication.* Miscommunication was multifaceted, comprising inability to obtain desired information, getting wrong or conflicting information, feeling unheard and lacking needed anticipatory guidance. Initially, miscommunication was evident in a patient's or family's sense that immediate needs were unmet or clinical information was unclear. Later, it was about not knowing what to expect or how to gauge progress.

*Managing conflicting priorities.* Conflicting priorities were complex and idiosyncratic, occurring at the intersection between following medical recommendations, wanting to feel normal and supporting family. On the wards, conflict centred around asking staff for help versus trying themselves. At home, it was limiting activity to protect their health versus approximating normal or keeping the status quo versus trying something new.

### Environment-related barriers

*Non-supportive health services or policies.* Problems were heterogeneous. On the wards, they concerned gaps in staffing, limited visitation policies, restrictive mobility policies and poor management of environmental stimuli. At home, they included failure to identify needs before discharge and lack of access to equipment, personal care, rehabilitation, mental health and ICU follow-up care.

*Challenging social attitudes.* Patients sometimes perceived a disconnect between the hardship of their experiences and the lack of compassion or understanding shown by others. When ward staff dictated that they must do for themselves, they felt infantilised and unsupported. After discharge, they felt self-conscious about disability, misunderstood by friends and family who underrecognised the lasting effects of critical illness or hurried by employers urging return to work without assessing their readiness.

*Incompatible patient-family coping.* Family visits interfered with rehabilitation or sleep. Some family members distanced themselves to deal with the emotional trauma of critical illness; others struggled to provide physical support; others were overprotective. Most patients and families did not communicate about these issues. On the wards, patients rarely discouraged visitors. At home, most accepted differences in family coping.

*Equipment problems.* Sometimes equipment discontinuation (eg, oxygen and tracheostomy) was so abrupt that patients felt unsafe. Equipment was uncomfortable, malfunctioned or interfered with activities. Sometimes patients lacked equipment or training to manage it. All these heterogeneous problems occurred on the wards; lack of equipment, inadequate training or equipment malfunction predominated at home.

**Table 2** Exemplars of survivors' perceived barriers to ICU recovery

PTE domain	Barrier	N (%) of 39 participants reporting barrier	N (%) of 39 participants reporting barrier on the wards	N (%) of 39 participants reporting barrier at home	Exemplar
Person	Negative mood or affect	32 (82.1)	21 (53.8)	27 (69.2)	(Interviewer): How have you been spending your days? (Participant): Frustrated I think really. Frustrated because I can't do anything. (71-year-old man who survived sepsis (home))
	Experiencing setbacks or stagnation	39 (100)	35 (89.8)	33 (84.6)	'I used to be like firing on all cylinders... (now) I feel like the days just tick by... I wanna go back to work, but then sometimes I worry that I won't be able to pick up the pieces and do the job again. And I'm scared to go back in case it's too soon'. (40-year-old woman after sepsis (home))
	Weakness or limited endurance	38 (97.4)	31 (79.5)	37 (94.9)	'I couldn't even walk, I couldn't get up and sit in the chair by myself. I could feed myself by that point, but I couldn't get to the toilet, I couldn't stand up. I couldn't get to the sink. If my glass was on a trolley at the bottom of the bed I wouldn't have been able to reach that'. (41-year-old woman who survived sepsis (wards))
	Pain or discomfort	26 (66.7)	22 (56.4)	15 (38.7)	'This (pain) is vastly different, you get backache, even shoulder ache and I put this down to some of the ways you have to lay to try and get some sleep in hospital'. (71-year-old man who survived abdominal aneurysm repair (wards))
	Inadequate nutrition or hydration	19 (48.7)	16 (41.0)	10 (25.6)	'I didn't have a problem maintaining my weight before... I do tend to slightly go over my fighting weight. I got to about ten nine, ten eleven and I try to maintain that because it's very difficult for me now to lose weight. So easy to put weight on but very difficult for me to lose it. It's not that I eat a lot during the day but for some reason I seem to put the weight on. I think if I was to count the calories or do it like the weight watchers do, point system, I would be well under what my weight value and what my point value would be but I think it's because I'm not as active as I was. I am not burning off the calories that one counteracts the other'. (58-year-old man who survived trauma (home))
	Poor concentration or confusion	21 (53.8%)	17 (43.6%)	13 (33.3%)	'I had a marvellous memory before the accident. I could do things without writing them down. I could remember two or 3 weeks in advance for work mainly. Work is the biggest structure of my life and I found that very difficult to come to terms with, that I had to write things down just to remember one thing, very, very difficult especially as I used to be a workaholic. Again very, very difficult when your body was letting you down. And what with the head injury and the body injury, I just needed to get my mind working and my body structure back to as it was'. (59-year-old man who survived trauma (home))
	Disordered sleep, hallucinations or nightmares	18 (46.2)	14 (35.9)	14 (35.9)	'(T)hat lasted 3 weeks, before I got a proper, what I call a settled night's sleep, where I slept through without waking up, without waking up because of a dream, because of a nightmare. And I really wasn't used to waking up because of nightmares... But they were so vivid, that on top of this hallucination, which was wearing off and had virtually gone, had been replaced by this dreadful nightmare'. (55-year-old woman who survived sepsis (home))
	Mistrust	19 (48.7)	17 (43.6)	8 (20.5)	'My GP has struck me off his list... (H)e did that because I told him I was going to leave so he did it first, so he wouldn't get into any trouble. We didn't get on. It was all right, on a GP level, he was fine. But once I was seriously ill, he just didn't keep on top of it. He didn't read all the things that were sent from... he never read them. And I'd go there and he hadn't a clue'. (50-year-old man who survived heart failure (home))
	Altered appearance	17 (43.6)	13 (33.3)	6 (23.1)	'(I) first I was covering (my tracheostomy scar) to protect them because I didn't want people to be embarrassed'. (46-year-old man after sepsis (home))

Continued

Table 2 Continued

PTE domain	Barrier	N (%) of 39 participants reporting barrier	N (%) of 39 participants reporting barrier on the wards	N (%) of 39 participants reporting barrier at home	Exemplar
Task	Miscommunication	37 (94.8)	32 (82.1)	27 (69.2)	'I had to get transport to come home and... I didn't realise that they'd phone through to say that I was coming home. So I was worried that... my visitors would be going one way and I'd be going the other and I'd arrive home and nobody would be there to let me in. That was a bit of a panic stations for a minute. The nurse didn't know they'd been informed either'. (60-year-old man who survived pneumonia (wards))
	Managing conflicting priorities	20 (51.2)	13 (33.3)	15 (38.5)	'(My) GP was very supportive in saying, "You know you're not well enough to go back to work until you're well enough to kind of manage at home. You know you're not getting well enough to go back to work and not be able to look after your daughter." So he was really supportive in kind of prioritising that first. And then by the time Christmas came... I probably would have been strong enough to go back to work and work was very supportive about saying... you can come back a day a week and we'll build it up from there but there was a redundancy offer on the table. And I actually decided that I needed spend... a good chunk of time being well with (with my daughter) rather than being ill with her. So I didn't go back'. (35-year-old woman who survived sepsis (home))
Environment	Non-supportive health services or policies	38 (97.4)	38 (97.4)	26 (66.7)	'I was fast in the bed, I had rails, I wasn't allowed to get out without support or help... and they then put fasteners on the bottom of the bed as well so I couldn't get out of the sides and I couldn't get out at the bottom'. (60-year-old man who survived ARDS (wards))
	Challenging social attitudes	22 (56.4)	18 (46.2)	11 (28.2)	'There were a number of instances where my wife had to assist me in clearing myself up, for want of a better term...it was a case of "Let's move him, get him out of here." And that's a shock to your system'. (Describing perceived staff attitudes toward care delivery).
	Incompatible family coping	18 (46.2)	8 (20.5)	13 (33.3)	(47-year-old man who survived pneumonia (wards))
	Equipment problems	26 (66.7)	22 (56.4)	13 (33.3)	'Yes, I had emotional moments. On my own, not in front of (my partner) because I knew it would upset her'. (45-year-old man who survived sepsis (home))
	Overstimulation	23 (59.0)	20 (51.3)	12 (30.8)	'My doctor wasn't notified I was home, the district nurse wasn't notified I was home. I came home, dressing on my toe and obviously still with my neck, so no one changed the dressings'. (44-year-old woman who survived pneumonia (home))
	Understimulation	20 (51.3)	16 (41.0)	7 (17.9)	'One night we decided that we'd just go for a pub tea somewhere...And as it started to fill up.... I just had to come home, but we didn't end up with our meal, just had to get out'. (41-year-old woman who survived sepsis (home)).
Environmental inaccessibility	14 (35.9)	5 (12.8)	11 (28.2)	'I'm back (at work) now, well except that they got me back in doing nothing really'. (46-year-old man who survived sepsis (home)) 'Eventually they decided to move me to a side ward... I didn't like them to shut the door because...should I get a coughing fit or something like that I felt, I can't communicate. They have these bells and things but I think they'd rather not use them because some patients probably use them too much'. (60-year-old man who survived pneumonia (wards)).	

Each quotation indicates when the participant experienced the barrier in parentheses (wards or home). ICU, intensive care unit; PTE, Person-Task-Environment model of performance.

**Table 3** Exemplars of survivors' perceived facilitators to ICU recovery

PTE domain	Facilitator	N (%) of 39 participants reporting facilitator	N (%) of 39 participants reporting facilitator on the wards	N (%) of 39 participants reporting facilitator at home	Exemplar
<b>Person</b>	Motivation or attitude	39 (100)	31 (79.5)	39 (100)	'I managed to get up the stairs, and then just every day I just forced myself to go up the stairs and come down. I mean I still like come down the wall ...And every day I'm like, just tried really to walk a bit further, do a little bit more, and just build up on things all the time'. (40-year-old woman who survived sepsis (home))
	Experiencing progress	38 (97.4)	30 (76.9)	38 (97.4)	'I've been home, the wound healed, went back to work'. (44-year-old man who survived pneumonia (home))
	Religion or spirituality	12 (30.8)	4 (10.3)	4 (25.6)	'It's made me a much more sensitive person, much more appreciative, made me much more aware of the low-level importance of material goods, much more aware of the importance of being at peace with your inner self. Now whatever label you stick on that doesn't matter. Whether you're talking about faith, spirituality, just an inner calmness, whatever label, it is important that you spend time getting to know yourself rather better.' (68-year-old man who survived pancreatitis (home))
<b>Task</b>	Communication	38 (97.4)	35 (89.7)	35 (89.7)	'[My diary] sort of made me aware, and also friends who'd come to see me, who'd written little messages in that were, you know, very poignant I think. And it just made me see what it was like for other people, which I don't think I'd considered. You've very self-centered when you're in hospital. Because everything revolves around you and the nurses are all, "Are you okay? How are you?" Your visitors come and ask how you are and they don't talk about themselves. And so you tend to think there's only you that's affected. And it made me see that this had affected everyone'. (47-year-old woman who survived ARDS (wards))
<b>Environment</b>	Support from family or friends	39 (100)	34 (87.2)	38 (97.4)	'You know my family couldn't do everything for myself so I had to have things like my husband's work mate's wife would come in and bathe my son for me. You know, that would help tremendously. I had my husband's friend's wife cook for the family'. (35-year-old woman who survived placenta accreta (home))
	Support from healthcare personnel	39 (100)	38 (97.4)	38 (97.4)	'When I came out I was sort of referred to physios and occupational health people who had to come out and sort my bath/shower stools out and things like that'. (35-year-old woman who survived pneumonia (home))
	Supportive health services or policies	32 (82.1)	19 (48.7)	29 (79.4)	'I started to get a bit agitated. I wanted to go home. I was getting fed up because I have a son... I couldn't see my son... basically hospital let me pretty much go home every day and just come back to sleep because the surgeon realized that since I started to go home, I started to get a lot better'. (38-year-old woman who survived a Crohn's flare (wards))
	Equipment	34 (87.2)	28 (72.0)	23 (59.0)	'I would like to have made some progress by October. By progress it means that if I could, instead of having a wheelchair all the time, if I could go in and out of a car, you, know, even if I can't drive, I'd like to get back into an ordinary car again, so I don't have to sit in a wheelchair in the back of everything. I don't wanna look like the Pope, we call it the Popemobile'. (60-year-old man who survived Guillain Barre (home))
	Community resources	24 (61.5)	3 (7.7)	24 (61.5)	'I've got my taxi card if I want to go a bit further afield. I did the bus today but I won't be doing that very often. I usually get a taxi, and it's door to door. And if I do go too town, my daughter-in-law comes with me We get on a train'. (76-year-old man who survived pancreatitis (home))
	Medications*	22 (56.4)	16 (41.0)	17 (43.6)	'I'm diabetic and I have to inject four times a day, but considering what the worst outcome could have been, having diabetes, it doesn't bother me whatsoever. I know there's long term complications but you know, just to, even if I have an extra say twenty years that I wouldn't have had before, I'm not going to worry about it at all'. (37-year-old man who survived pancreatitis (home))
	Accessible housing	9 (23.1)	3 (7.7)	7 (17.9)	'My husband helped me upstairs at night and brought me downstairs in the morning. But I stayed downstairs all day. We do have a downstairs toilet so I managed to be able to be downstairs'. (47-year-old woman who survived sepsis (home))

Each quotation indicates when the participant experienced the facilitator in parentheses (wards or home).

\*Medications were not limited to new or critical-illness related medications but included any that patients perceived to facilitate achieving their goals. ICU, intensive care unit; PTE, Person-Task-Environment Model of Performance.

*Overstimulation.* Tethers, noise, light, visitors and activity on the wards caused irritation and sleep disruption. After discharge, violent television was irritating, and patients felt overwhelmed in crowded public spaces or even at home with family.

*Understimulation.* Alongside overstimulation, patients experienced profound boredom and isolation. The physical hospital setting and social barriers to talking with other patients contributed to understimulation on the wards. At home, it was due to inadequate adaptations to support mobility or insufficiently challenging goals.

*Environmental inaccessibility.* Some hospital rooms made it harder for nurses or visitors to meet patients' needs. At home, challenges related to navigating stairs and transportation.

### Person-related facilitators

*Motivation or attitude.* Being positive and working hard were critical. Many specifically mentioned deciding that they *would* get better. After doing so, they strove towards their goals and did not let others hold them back. Motivation increased over time, buoyed by other facilitators.

*Experiencing progress.* All patients monitored progress. On the wards, it was clinical: liberation from equipment, performance of self-care. At home, it was proximity to 'normal'. Noting progress boosted morale.

*Religion or spirituality.* Personal faith or spirituality helped some feel supported or make meaning of their experience, both on the wards and at home.

### Task-related facilitators

*Communication.* Several types of communication helped. Clinicians provided diagnostic information, status updates, teaching and anticipatory guidance by which patients set expectations and gauged progress. ICU diaries and families provided details about what had happened. Clinicians, support groups and families helped patients process their experiences, set goals and work to achieve them.

### Environment-related facilitators

*Support from family or friends.* Initially, family and friends provided food, advocacy, and social and emotional support. After discharge, they assisted with self-care, emotional support and motivation to participate.

*Support from healthcare personnel.* Support on the wards came from dietitians, physical and occupational therapists, nurses and physicians. At home, it came from home health, ICU follow-up care, general practitioners and mental health providers. Patients appreciated both professional expertise and humanism.

*Supportive health services or policies.* On the wards, patients noticed safe infection control and staffing policies, and supportive mobility, family engagement and discharge planning policies. After discharge, key policies included access to ICU follow-up, mental health and occupational rehabilitation services, and policies promoting adequate recovery time and phased return to work.

*Equipment.* On the wards, equipment facilitated healing (eg, catheters) or rehabilitation (eg, walkers). At home, less equipment related directly to healing (eg, stoma bags, dressings) and more supported adaptations (eg, bedside commodes). Patients needed equipment less over time.

*Community resources.* Participants frequently discussed resources like gyms, group therapy, networks of critical illness survivors and public transportation. On the wards, access aided discharge planning. At home, it facilitated goal attainment.

*Medications.* Patients discussed how medications treated symptoms or restored physical health across the recovery trajectory.

*Accessible housing.* Accessible housing—especially a main-floor bathroom—facilitated safe discharge planning and a staged approach to increasing mobility at home.

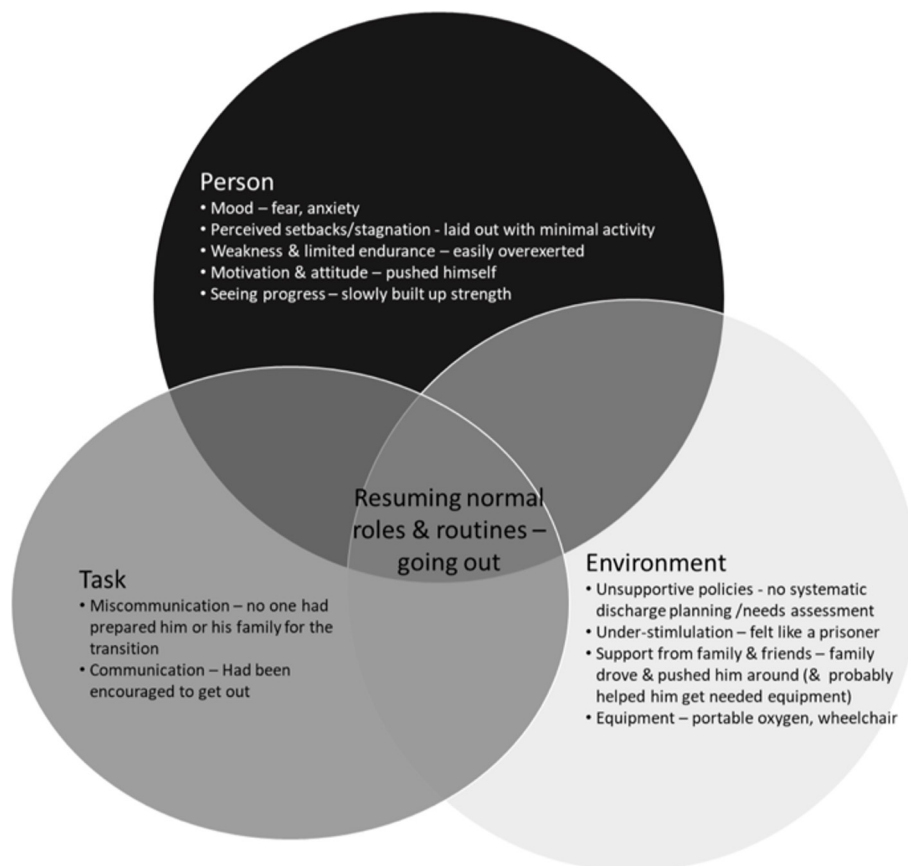
### Patterns and evolution over time

All barriers and facilitators occurred on the wards and at home. Most performance goals had multiple barriers, multiple facilitators or both (figure 2). Barriers were more frequent initially and decreased over time, whereas facilitators were less frequent initially and increased over time (table 2). Six barrier-facilitator domains dominated based on frequency and emphasis across all performance goals: mood/motivation, setbacks/progress, fatigability/strength; mis/communication; lack/community support; lack/health services and policies.

## DISCUSSION

In this qualitative content analysis of semistructured interviews, critical illness survivors reported that critical illness is life changing, and survivors need help leveraging resources across transitions to optimise life after critical illness. Three key contributions of the study are: (1) verification of previously recognised barriers and facilitators to performing desired activities across the post-ICU trajectory; (2) a comprehensive inventory of them; and (3) application of the PTE model to the post-ICU context. Together, these contributions have three important implications for intervention studies. First, they offer an alternative to 'bottom up' remediation-focused rehabilitation focused on drill and practice exercises (eg, sit-to-stand, squats, list memorisation and sequence completion). In particular, the PTE model promotes 'top down' adaptive rehabilitation strategies focused on the performance of problematic activities (eg, preparing a meal, managing medications) that address specific physical and cognitive deficits while enhancing independent, safe execution of activities via practice.<sup>33</sup> It also points to new potential mechanisms of recovery that expand beyond 'fixing the person' to focus on matching persons' abilities to 'meaningful tasks' and 'environment'. Second, areas of overlap in the PTE model suggest novel mechanisms by which barriers and facilitators may moderate one another. For example, perceived progress tends to impact productivity, engagement and well-being.<sup>34</sup> It may explain why





**Figure 2** The Person-Task-Environment model of performance at home soon after critical illness discharge. A 44-year-old man who survived pneumonia said, ‘When I came home it was several weeks, a long time before I had a bath. To start with I couldn’t go nowhere. I felt like a prisoner. And then I managed to have a portable gas cylinder that I could take out with me. They said it would be good to get out. And we managed to borrow a wheelchair. And I did, the first time out was frightening, and we didn’t go very far. I felt that everybody was looking at me, which they weren’t, but I did feel everybody was looking at me. And we’d go out in the car, take the wheelchair with us, and I’d be pushed around. I slowly started building up my strength, but I found if I’d done too much then I’d have a day where I was laid out, short of breath’. Although there are performance goals about self-care in this quotation, we illustrate only the barriers and facilitators related to resuming normal roles and routines (specifically, going out).

expectation management and validating progress are key components of ICU recovery programmes.<sup>35 36</sup> Third and perhaps most importantly, PICS interventions have largely focused on reducing patient-level *barriers*,<sup>2-4</sup> but this study’s results suggest novel and potentially high-impact strategies to enhance patient-level and system-level *facilitators* (online supplemental eTable 3 provides hypothetical examples).

At the patient level, we can enhance motivation, mood and agency through interventions like problem-solving therapy<sup>37 38</sup>; help patients perceive progress using active goal setting and goal attainment exercises<sup>39</sup>; and offer opportunities for spiritual practice.<sup>36</sup> Proactive communication strategies may provide anticipatory guidance related to patients’ goals<sup>35</sup>; teach patients and families compensatory methods like pacing, energy conservation and activity scheduling<sup>40 41</sup>; and emphasise listening to address challenges. Our findings suggest that families should be included in all aspects of care, from care planning, to mobility and self-care, to emotional support.<sup>42 43</sup> Telehealth may improve family availability.<sup>44 45</sup>

Intervening at the system level could have the greatest impact because it determines the structures, processes and culture of care. Patient, family and provider perspectives can all inform strategies.<sup>12 17 18 35 36 42 44 46 47</sup>

The observed differences on the wards and at home suggest that transitions involve shifting barriers and facilitators, so actively planning for and managing them could have an outsized impact on the rate and degree of successful adaptation. Because real-life transitions are rarely smooth,<sup>48</sup> teams should promote patient and family engagement<sup>49</sup> to ensure patient-and-family centred goals of care and identify needs for training, assistive devices, medication reconciliation and communication with providers. Doing so will require person-centred care policies that permit teams the time, flexibility and resources to match patients’ and families’ needs over prolonged or multiple transition periods. Developing and implementing such policies will necessitate strong partnerships between patients, families and healthcare providers on the one hand, and health



systems administrators and policymakers on the other hand in order to optimise the impact on care delivery and outcomes.<sup>48</sup>

Limitations of this study warrant comment. Despite its novel results, primary data collection did not focus on barriers and facilitators. Patients may be particularly apt to underdescribe task-related barriers and facilitators when not specifically probed. Future studies should address this potential gap. The data's age may limit generalisability. Indeed, ICU-based interventions have improved critical illness survival rates in the 16 years since these data were collected, and improved visiting policies in some parts of the UK may have enhanced environmental facilitators related to social support during critical illness hospitalizations prior to COVID-19. However, the PTE model should generalise beyond individual barriers and facilitators, providing flexibility to address a broad range of PICS-related performance limitations that remain unsolved problems.<sup>2-4 35 44 50 51</sup> All participants resided in the UK; barriers and facilitators may differ across countries and health systems. Nevertheless, our international research team found that mismatches between our expectations and the data revealed patterns we would not otherwise have perceived. Although a strength of the study is that many participants survived long enough to reflect on the evolution of survivorship, their recollections may suffer from recall bias, recency bias and conflation with factors unrelated to post-ICU care. However, the evolution of performance goals over time reported in longitudinal qualitative studies aligns well with our data.<sup>52-54</sup> Finally, all participants achieved sufficient function to live at home and give lengthy interviews. The most functionally impaired critical illness survivors—including the dying—likely face particular barriers and facilitators that deserve special attention.

## CONCLUSIONS

This study identified 29 barriers and facilitators to achieving performance goals that easily integrate with the PTE Model. Their pervasiveness suggests novel opportunities to redesign post-ICU care at both patient-level and system-level to optimise patient-centred care and reduce disability after critical illness.

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