

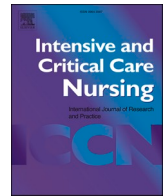
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Research Article

Using experience-based co-design to prioritise areas for improvement for patients recovering from critical illness

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ABSTRACT

Objectives: Critical illness recovery is a journey; from intensive care unit to hospital ward to home. However, evidence is limited on how best to enable recovery from critical illness. This study aimed to prioritise areas for improvement in care and services for patients recovering from critical illness.

Research design: This study used experience-based co-design. Service users and providers worked in partnership to identify and prioritise service improvements for patients who had survived an episode of critical illness.

Method: Qualitative interviews were carried out with patients (n = 10) who had experienced critical illness, and staff (n = 9) who had experienced caring for patients in the intensive care unit. Key patient touchpoints were identified and used to produce a film, reflecting the critical illness journey. A patient feedback event incorporated an emotional mapping exercise, to identify key points during the recovery journey. A joint patient/family (n = 10) and staff (n = 10) event was held to view the film and identify priorities for improvements.

Findings: Emotional mapping highlighted areas where services were not synchronised with patients' needs. Four patient-focussed priorities for service improvement emerged 1. Improving the critical care experience, 2. Addressing patients' emotional and psychological needs, 3. Positioning patients at the centre of services and 4. Building a supportive framework for recovery.

Conclusion: Evidence-based co-design was used successfully in this study to identify priorities for improvements for patients recovering from critical illness. This approach positions patients at the centre of service improvements and realigns care delivery around what matters most to patients. Person-centred care provision underpins all identified priorities.

Implications for clinical practice: Intensive care unit staff should get to know patients and their families by talking more to patients and families about their care and engaging in more non-medical conversations. Emotional and psychological support should be provided to aid rehabilitation and recovery from critical illness in the intensive care unit, on general wards, and in the community. Information and services should be available when patients need them, rather than at fixed time points or settings. Recovery services should focus on enabling and building the self-efficacy of patients to empower them to be in control of their recovery journey.

Introduction

The critical illness recovery experience can be perceived as a journey, often involving a stay in an intensive care unit (ICU) where close monitoring is required, followed by step-down to a hospital ward, and then discharge home. Improved survival rates for patients following critical illness has created the need to recognise and improve the experiences of survivors (Palakshappa and Christie, 2016) and explore

ways to promote recovery and mitigate associated health and social care usage and costs (Geense et al., 2019). Although not all patients experience issues following critical illness, many are affected by one or more significant impairments (Brück et al., 2018). The range of physical, mental and cognitive consequences following critical illness, and admission to ICU, is collectively known as Post Intensive Care Syndrome (PICS) (Harvey and Davidson, 2016). Twenty-five to 55% of critically ill patients admitted to ICU experience one or more symptoms of PICS,

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which may persist for months or years (Ohtake et al., 2018). A study involving 293 patients who had been in ICU for longer than 48 h found that 73% reported moderate or severe pain at 12 months and 44% remained significantly anxious or depressed (Griffiths et al., 2013). Survivors of critical illness often experience delayed return to work; those returning to work often experience job loss, occupation change or worse employment status (Kamdar et al., 2020).

The Intensive Care Society (ICS) and the Faculty of Intensive Care Medicine (FICCM) in the United Kingdom (UK) have published guidelines endorsing rehabilitation and follow-up as an approach to recovery from critical illness (GPICS, 2019). However, a systematic review and meta-analysis of interventions developed to deliver physical exercise rehabilitation following ICU discharge did not find any benefits in improved functional exercise capacity, quality of life, or reduced mortality (Taito et al., 2019). ICU follow-up encompasses strategies set up to support the physical, psychological and cognitive health needs of ICU survivors (Schofield-Robinson et al., 2018), although a Cochrane systematic review of ICU follow up strategies, including five studies and 1707 participants, found little or no measurable benefit in reduced mortality or PICS (Schofield-Robinson et al., 2018). However, patients perceive that follow-up services can improve continuity of care and mitigate physical and psychological symptoms related to ICU recovery (McPeake et al., 2020). Hence, it is not clear how best to address patients' needs during the critical illness journey. Enabling patients, carers and health care professionals to work together to understand how to address these needs may be a useful step forward.

Experience-based co-design (EBCD) in healthcare is a user-centred, participatory design approach to develop patient-centred healthcare services (Farr, 2017), which can improve relationships between healthcare users and providers, thereby increasing engagement and satisfaction with service (Palumbo, 2016). The EBCD method combines a user centred orientation (experience-based) and collaborative change process (co-design) (Bate and Robert, 2006). EBCD methodology has been used for service improvement in a wide range of local settings (Green et al., 2020) such as elderly care (Wolstenholme et al., 2010; Wright et al., 2018), paediatrics (Gustavsson et al., 2016; van Deventer et al., 2016), obstetrics (Kenyon et al., 2016), neonates (Gustavsson and Andersson, 2019), mental health (Cooper et al., 2016; Cranwell et al., 2016; Springham and Robert, 2015), cancer (Tsianakas et al., 2012; Weston et al., 2018) and palliative care (Borgstrom and Barclay, 2019). EBCD places patient experiences at the centre of service improvement and allows patients and health care professionals to work together to design services that are responsive to the needs of both services users and providers.

Evidence is limited on how best to enable recovery from critical illness. By exploring patient and hospital staff experiences to understand what works well, and not so well, within a service (Robert, 2013), this study aimed to prioritise areas for improvement in care and services for patients recovering from critical illness. Specifically, it intended to explore patient, family and hospital staff experiences, and use these experiences as a foundation for discussion and collaboration in order to determine priorities for service improvement.

Methods

This study was based upon the principles and methods of Experience-based co-design. This process leads to the identification of areas of care provision that need to be changed and provides a framework through which improvement activities can be undertaken (Bate and Robert, 2006; Bate and Robert, 2007; Robert, 2013). The full EBCD process involves eight stages including observations of clinical areas, interviews with service users and providers, developing a trigger film based on experiences, service user and provider feedback events, and joint service user and provider events (Point of Care Foundation, 2022). The EBCD approach is flexible but the most fundamental elements to retain are the service user experience data, and a joint service user-provider meeting/

workshop (Green et al., 2020).

This study included three main phases (see Fig. 1). Phase 1 involved capturing the experiences of both patients and hospital staff by carrying out individual qualitative interviews; narrative patient interviews were video recorded. Phase 2 involved analysis of interview data to capture patient touchpoints, creating a film to reflect patients' experiences, and organising a patient feedback event. Phase 3 involved a joint patient, family/friends and staff event to view the film and engage in group discussion. Identifying the main areas where improvements were needed was the intended outcome of Phase 3.

Research questions

This study aimed to identify and prioritise service improvements for patients who had survived an episode of critical illness.

Setting

The study took place in a large teaching hospital in the North West of England, with a 24 bedded ICU. The ICU was in a basement area and lacked natural light. The hospital had a follow-up clinic for critical care patients, offered to patients who had spent more than four days in ICU. An ICU outreach team provided early follow-up to patients for 24 to 48 h after transfer from ICU to ward areas, assessing physiological status and monitoring for indications of deterioration. A critical care in-reach service was available by formal referral to provide psychological care to patients on the ICU and hospital wards, provided by a psychologist. A nurse-led ICU support group, held every 6–8 weeks, was also available at the study site.

Participants

Participants included patients who had experienced ICU, their family/friends, and hospital staff involved in the care of ICU patients. Patients aged over 18 years, with full mental capacity, and able to speak English were eligible. Allowing for a low response rate, an approach to 80 patients was estimated to yield a convenience sample of 10 patients. This was considered sufficient to capture variation in personal characteristics and a range of recovery experiences whilst being small enough to maintain engagement in the different stages and activities of the EBCD process. Patients were screened from the Intensive Care National Audit and Research Centre (ICNARC) database of hospital admissions and discharges. Patients were approached by letters of invitation to the first 10 surviving patients discharged from ICU in January and July for the previous four years, to allow for seasonal differences in admission characteristics and to capture patients with both shorter and longer-term recovery processes. Fifteen patients replied, 14 initially agreed to participate and a total of 10 eligible patients were recruited to participate in the EBCD process. All 10 were interviewed for Phase 1 (interview phase), but only 7 of the 10 patients were available to participate in Phases 2 (patient feedback event) and 3 (joint patient, family and staff event). Patients were invited to bring along a family member or friend to Phases 2 and 3, and two family members and a friend ($n = 3$) attended.

A convenience sample of 16 hospital staff were recruited using posters within clinical areas and information provided by a research nurse at staff handovers. Nine of the 16 staff participated in phase 1 (interviews) and ten of the 16 staff participated in phase 3 (joint patient, family and staff event) of which three staff had also participated in the interviews. Staff were considered eligible if they had experience of caring for patients who had spent time in ICU. Overall, there was an almost equal balance of staff and patients in each stage of the study, as recommended in the EBCD approach, to enable an adequate mix for smaller group activities and encourage patient confidence in sharing their experiences with staff (Bate and Robert, 2006).

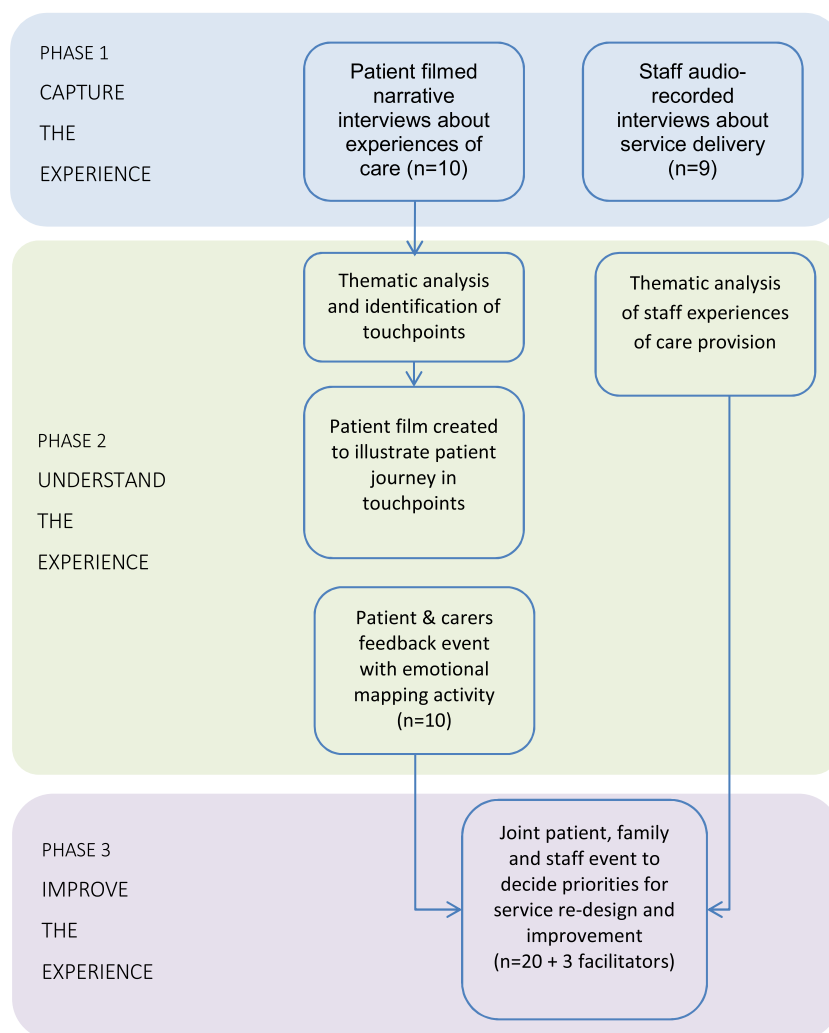


Fig. 1. Study design.

Ethical approval

This study was approved by the UK's National Research Ethics Service (REC reference: 15/NW/0791, IRAS Project ID: 181961). Each individual (patient, family/friend, hospital staff) gave informed signed consent to participate in the study. Written consent was also taken from patients to use selected clips from their filmed interviews to create the patient experience film. None of the authors had cared for any of the patients involved in the study in a health care professional capacity.

Data collection

PHASE 1: Capture the experience

All interviews with patients and staff were recorded and transcribed. Patient interviews were video-recorded, and staff interviews were audio-recorded. Interviews took place at the study location or in the patients' homes, according to participant preference. It was recognised that patients might become upset when discussing their critical care experiences; they were advised that they could pause or stop the interviews should they become distressed, and an appointment with the critical care psychologist could be arranged for anyone who wanted further support. An appointment was made for one participant to deal with ongoing issues.

Interview schedules were developed to act as flexible guides which enabled patients and staff to have control over what they chose to share. The schedule for the filmed narrative interviews with patients was

developed to capture patient touchpoints, which were moments that shaped patients' personal experiences of the service, using minimal prompting (Bate and Robert, 2006). Patient participants were given the opportunity to speak freely and at length about poignant moments during critical illness and recovery. A conversational approach was used, giving up control of the interview to follow the patient where the conversation led, being emotionally attentive and engaged, and reciprocating in the conversation. (Riessman, 2008). Additional questions followed, which focussed on patients' perceptions of how their recoveries were progressing, high and low points they experienced, important stages of recovery and what was helpful or could be improved. The full interview guide for the patient interviews is shown in Twamley 2020 (Appendix 4).

The focus of the staff interviews was to describe the service they delivered, to share their experiences of caring for ICU patients, and how they perceived the service was experienced by patients. Staff understanding of the whole recovery process of critically ill patients was explored. The interview schedule for staff was flexible to give staff the opportunity to discuss topics they felt were pertinent to the care of patients who had experienced critical illness.

PHASE 2. Understand the experience

A 30-minute patient experience film was produced based on the findings from patient interviews and the capture of patient touchpoints. The film illustrated the key stages of the patient journey and provided a deeper understanding of the emotional and practical impacts of each touchpoint. Phase 2 also involved a patient feedback event, which was

held with patients, family members and friends to verify the touchpoints and allow patients to bond as a group in a non-threatening environment. An emotional mapping exercise was included. Each touchpoint was displayed along a wall and an emotional map was created as patients shared key words associated with each touchpoint, recording these on post-it notes placed next to each touchpoint. This process of emotional mapping added context to experiences and helped to identify the high and low points during the recovery journey.

PHASE 3: Improve the experience

A joint patient, family and staff event was held to view and discuss the patient film. Small mixed groups summarised their discussions and shared these summaries with the larger group. Finally, a whole group discussion, stimulated by the emotional map displayed on the wall, focussed on identifying the main areas where improvements were needed. The whole group discussion was audio-recorded.

Data analysis

All Phase 1 interviews were transcribed and uploaded onto Atlas-ti software to organise the data. Analysis involved a thematic approach described by Ziebland and McPherson (2006) in their analysis of filmed interviews of patients for the healthtalkonline project (Ziebland and McPherson, 2006). This approach is a rigorous method for analysis of both text-based and film data whilst embracing aspects of narrative analysis such as grouping some larger sections of text as units of analysis to preserve the essence of the story. The process, which involved immersion in the data through reading and rereading, identification of broad categories through coding, and then into meaningful themes through axial coding, was undertaken by JT, with regular in-depth discussion and contributions throughout the process from RM and KB. The aim of the analysis was to identify important touchpoints for patients in their recovery process and staff perceptions of the services they provided and how well they met the needs of patients.

In Phase 2, 15 h of videos were synthesised to make a 30-minute patient experience film. This was an iterative process in which JT read the interview transcripts for clear and concise explanations of the touchpoints identified in the interview analysis and marked the video recordings at key facial expressions and gestures that provided emotive illustrations of these key touchpoints. Rigour was addressed by

following research guidance for visual analysis (Point of Care Foundation, 2022; Ziebland and McPherson, 2006) and regular input from RM and KB to minimise bias and ensure the film captured both positive experiences and areas for development, to give a balanced overview of the recovery journey. The framework used to structure the film followed the usual patient trajectory of admission to the ICU, transfer to the ward setting, and long-term recovery following hospital discharge.

Phase 3 analysis involved a progressive process which began with listing all the information summed up on post it notes during group sessions. Similar points were clustered together and categorised into the key topics that were discussed. The audio-recording was transcribed and further enabled identification of priorities for service improvement.

Findings

Findings are structured according to the three phases of the research process (Fig. 1). Table 1 provides characteristics of the study samples in all three phases. Detailed findings on the patient and hospital staff interviews can be found elsewhere (Twamley, 2020); in this paper we summarise the main interview findings to allow emphasis on the co-design aspects of the study.

PHASE 1: Capture the experience

Four key themes emerged from patient interviews: 'surviving,' 'towards independence,' 'reconstructing reality' and 'reshaping identity.' Illustrative quotations for each of the four themes are presented in Table 2. In the early stages of the critical illness journey the patient focus was on surviving ICU, a setting in which many patients described dehumanising experiences and aspects of care which impacted on their individuality, their agency and, for many, their grasp on reality. Patients recounted experiences relating to impersonal care, their own lack of involvement in, or understanding of the care they received, and the inability to influence events or decisions which were being made about their care. Many patients recalled the frustration and lack of control associated with being unable to speak. Unnatural lighting, noise and unfamiliar and unpleasant routines, and restrictive visiting policies further distanced patients from normality and compounded their loneliness. All the patients had episodes of altered consciousness and/or ICU related delirium which left them disoriented and unaware of what was happening around them, lessening their autonomy and further

Table 1
Characteristics of the study samples.

Patients			Hospital Staff			Family/Friends		
Phase 1 (interviews)	(n = 10)	n	(n = 9)		n	n/a	n	
Sex	Male	6	Nursing	ICU follow-up clinic nurse	2			
	Female	4		ICU outreach nurse	2			
Age range (years)		34–69		ICU discharge co-ordinator	1			
Type of admission	Emergency surgical	4		ICU nurse consultant	1			
	Elective surgical	3	Medical	ICU consultant	2			
	Emergency medical	2	Allied Health	Psychologist	1			
	Major trauma	1						
Phase 2 (patient feedback event)	(n = 7)			n/a			(n = 3)	
Sex	Male	5				Relationship	Friend	1
	Female	2					Son	1
Age range (years)		34–69					Wife	1
Type of admission	Elective surgical	3						
	Emergency surgical	2						
	Emergency medical	1						
	Major trauma	1						
Phase 3 (joint patient, family and staff event)	(n = 7)	n		(n = 10)	n		(n = 3)	n
Sex	Male	5	Nursing	ICU follow-up clinic nurse	2	Relationship	Friend	1
	Female	2		ICU nurse consultant	2		Son	1
Age range (years)		34–69		ICU discharge co-ordinator	1		Wife	1
Type of admission	Elective surgical	3		ICU nurse	1			
	Emergency surgical	2		ICU outreach nurse	1			
	Emergency medical	1	Medical	ICU consultant	1			
	Major trauma	1	Allied Health	ICU Physiotherapist	1			
			Admin	ICU support group liaison ward clerk	1			

Table 2
Phase 1 themes from patient interviews.

Theme	Illustrative quotation
Surviving	"I thought they were getting ready to take me...to experiment on me and they were going to kill me...and I didn't tell anyone, and that was a horrible feeling ...I thought I was going to die." (P04). "...if I could think what hell was like, that was getting close to it because I didn't understand why I was there. And I didn't understand what was going on." (P07). "...you might very often see up to twelve, thirteen people gathered around your bed and you could hear them talking about you but nobody's talking to you." (P01). "...we all realised at that particular time in our life we had no control of what was going to happen, none whatsoever." (P05).
Towards independence	"...I've always been a strong person but I just couldn't do anything I was so weak...it felt awful because I've always been independent..." (P04). "The first target was the clinic and I'd walk backwards and forwards to there. Then round a small block..... I felt pretty confident that I'd be able to make these targets...It came to a stage where suddenly I felt, well, I'm getting better all the time." (P02). "I had been having some very bad dreams...all I can remember they were vivid and they were very scary, very scary. I do remember one night, I don't think I slept more than about ten minutes, because I was frightened to go back to sleep." (P05).
Reconstructing reality	"...it all gets mixed up into a, "What's real? What's not real?" and again, less at the time but more afterwards, as you talk to people you can start joining the dots up." (P10). "...when it's in your head people can't see it and I think if they hear what you are talking about it might give them the impression that you're not a full shilling (of unsound mind)." (P06).
Reshaping identity	"I'd lost my place in life...I lost my position of being the one that helped to being the one that needed help." (P07). "I got back in my home which is a comfort zone but I suddenly felt so vulnerable it was frightening...I missed the bubble of the ward and the routine, and there was always someone to check that you are okay." (P05). "So you have the pressure of your friends, you have the pressure of what you think your boss is thinking, if your staff see you, but at the same time, I needed to go back [to work] because I needed something to – in some ways occupy my time but also make me have to get up." (P10).

increasing their dependence on healthcare staff.

As the journey continued, patients moved towards independence. Early recovery efforts focused on reducing their dependency on others and regaining the ability to perform self-care needs. Recovery efforts were impeded by sleep disruption associated with both physical restrictions due to their condition and treatments, and psychological responses to their ICU experiences. Anxiety, panic attacks, nightmares, and intrusive thoughts could continue for months and years. Patients were apprehensive about transitions to different environments, which were associated with less support and surveillance. Patients felt vulnerable leaving the security of the hospital and became dependant on considerable support from families and community healthcare workers for weeks and months following discharge. Some patients described feeling pressure to return to work. They perceived that their families, friends and employers expected them to resume work and further absence threatened their job security.

Four key themes emerged from hospital staff interviews: 'planning for change,' 'needs and expectations,' 'continuity' and 'information provision.' Illustrative quotations for each of the four themes are presented in Table 3. Staff tried to plan in advance for change, concerned that transitions between settings would compromise patient safety and progress. Involving patients and families in the process was perceived as enabling patients to regain some control over their circumstances and feel empowered to ask for the help they needed. Providing continuity of

Table 3
Phase 1 themes from hospital staff interviews.

Theme	Illustrative quotation
Planning for change	"It's just making them feel that they're not just a parcel that's just being moved around and things are being done to them, but that they're actually a part of it..." (S01, Outreach Nurse)
Continuity	"...we seem to assume that they know what happens after intensive care...certain specialties don't come down and review patients in intensive care so they don't see them when they're sick, and then they're supposed to be looking after them afterwards." (S07, Consultant in Intensive Care Medicine)
Needs and expectations	"...people express really unrealistic expectations about recovery, they'll express significant distress about the fact they're not back to normal yet." (S06, Psychologist). "And that acknowledgment that things are common...and that kind of description of what's normal stops you feeling abnormal." (S07, Consultant in Intensive Care Medicine).
Information provision	"...discharge is a moment in time of a continuum, and so the information that patients or relatives' need change over time, and that trajectory will change with individual patients." (S07, Consultant in Intensive Care Medicine).

care for patients during recovery was challenging. Care was perceived as fragmented and no individual member of staff co-ordinated care for patients throughout their recovery. Staff in different healthcare settings worked in isolation and their expertise was based upon their own specialties. Staff were concerned that patients' needs were not always met, and recognised ways in which services could be better, but lacked the time and resources to implement improvements. Staff reported that patients had different preferences in relation to the amount of information they wanted and acknowledged that patients' information needs changed over time. Providing generic information leaflets was seen as unlikely to address the concerns of individual patients and relatives and staff recommended talking and listening to patients as the best way to identify individual information needs.

PHASE 2: Understand the experience

The key touchpoints described by patients were representative of different stages in the critical illness journey (Fig. 2). The touchpoints were interwoven with the healthcare settings patients encountered; ICU, ward-based care, and community care.

Seven patients attended the patient feedback event; two family members and a friend were also present. The participants discussed the touch points and the emotional mapping exercise allowed patients to write their thoughts and feelings on post-it notes placed next to each touchpoint (Fig. 3).

The touchpoints related to ICU evoked strong, and often negative, key words and emotions. Patients valued the expert and professional care they received but had felt helpless, out of control, isolated and detached from the staff around them. Conversely, touchpoints related to care on hospital wards received positive comments. Patients had felt well cared for and valued building relationships with staff and talking to other patients on the ward. Patients also appreciated becoming more involved in their own care and were uplifted by the setting and achieving goals to become stronger, more mobile and more independent.

Hospital discharge was highlighted as being poorly coordinated, despite planning from healthcare professionals and social workers. Patients perceived that they had not been involved in the process which left them feeling vulnerable, frustrated and let down, and uncertain about what to expect when discharged home.

PHASE 3: Improve the experience

The patient experience film was viewed by patients, family/friends and hospital staff and had a strong emotional impact. The film triggered collaborative discussions about how to address the more distressing patient experiences. Bringing patients and staff together to discuss the film challenged staff assumptions about the service they were providing.

"As nurses, we do our best to look after people, but the film shows that this

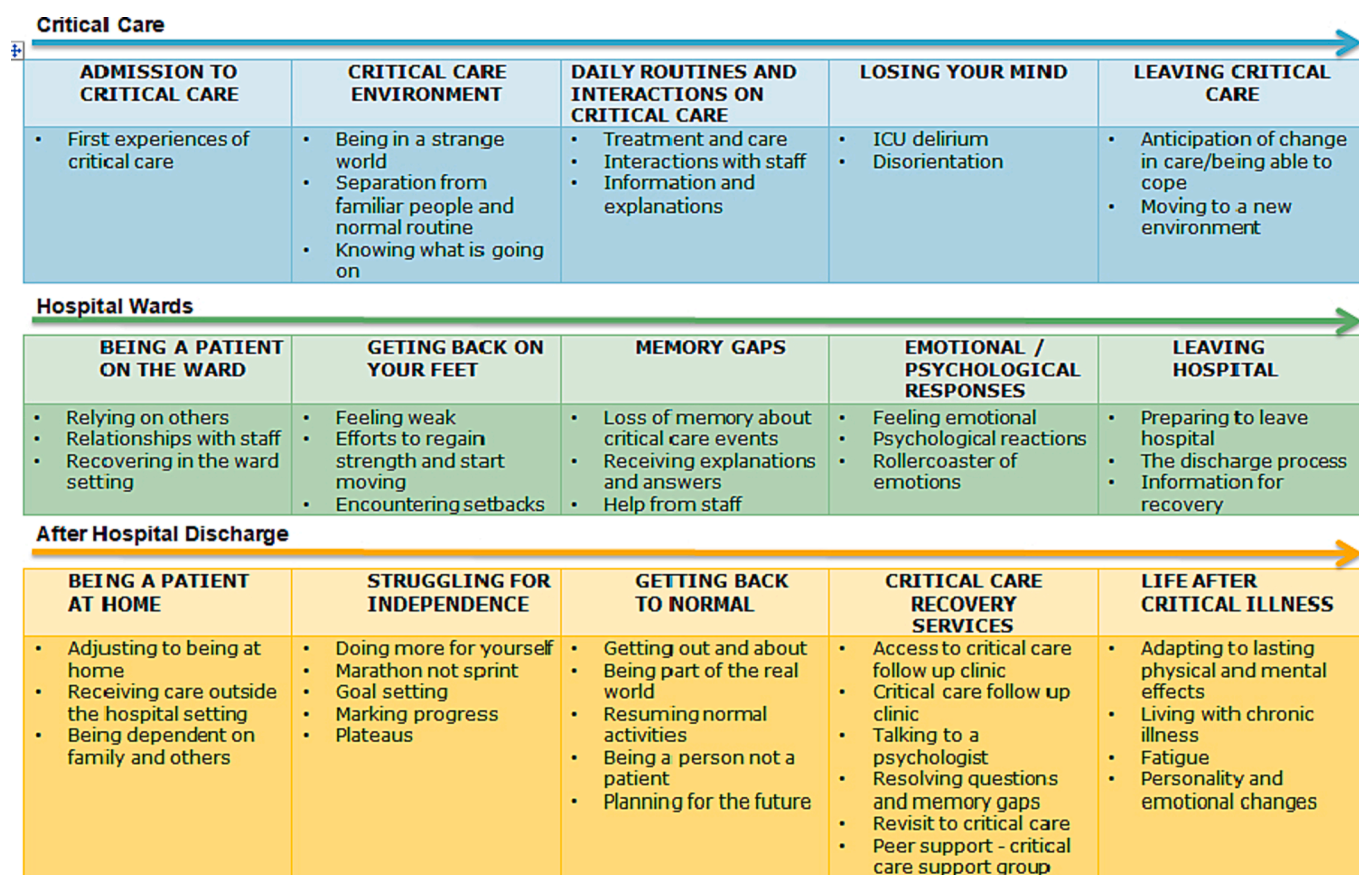


Fig. 2. Patient touchpoints.

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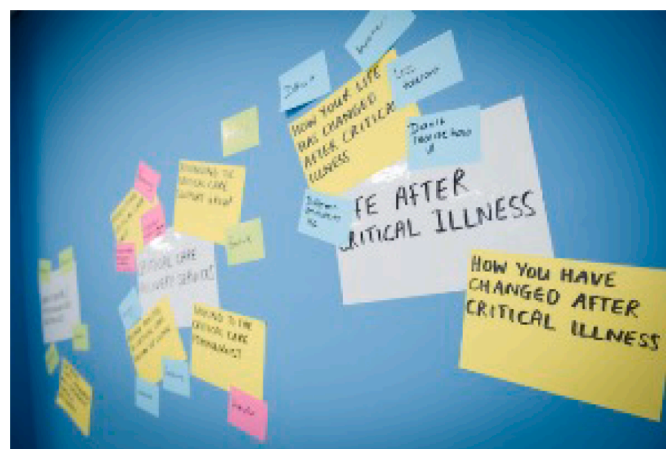
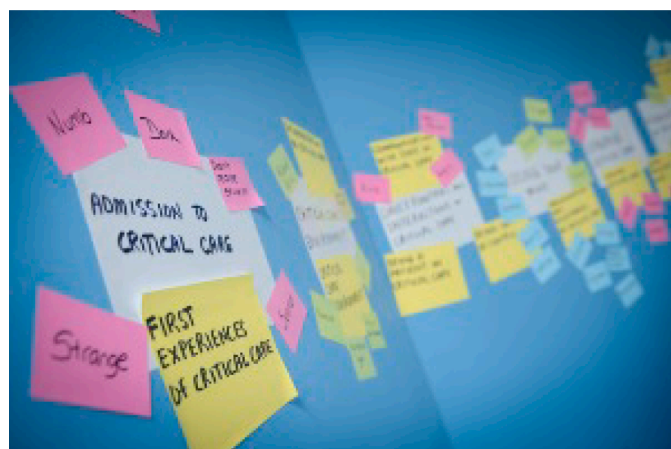


Fig. 3. Sections of the emotional mapping process.

is not always good enough because some people are still struggling with their experiences." (ICU nurse consultant).

Much of what was discussed further highlighted and repeated the views expressed in patient and staff interviews (Phase 1), the patient identified touchpoints (Phase 2) and the patient experience event (Phase 2). However, the collaborative process stimulated further discussions around the major concerns and priorities for patients and culminated in the identification of four patient-focussed priorities for service improvement; 1. Improving the ICU experience, 2. Addressing patients' emotional and psychological needs, 3. Positioning patients at the centre of services and 4. Building a supportive framework for recovery

(Table 4).

Discussion

This study achieved its aim of establishing priorities for service improvements for patients recovering from critical illness, using an EBCD approach. Service users and providers were able to openly discuss their experiences and make important recommendations for change. Individual interviews with patients and staff were essential in providing a foundation of understanding of the experiences of both service users and service providers. Although findings from patient interviews did not

Table 4
Priorities for service improvement.

1. Improving the ICU experience Staff should spend more time talking to patients, getting to know them Patients wanted non-medical conversations, but staff were perceived as too busy and focused on physical tasks Patients wanted to be better informed about the multiple interventions and procedures they received Patients felt isolated and detached from the people and the activity surrounding them Staff said they did provide explanations and information, except in emergency situations where interventions needed to be delivered immediately. Some patients had a limited capacity to absorb and comprehend information while in ICU; information needed repeating
2. Addressing patients' emotional and psychological needs Staff should discharge patients in the best physical and mental condition to avoid the need for psychological help at a later date Patients experienced long term ongoing psychological symptoms such as hallucinations, nightmares and flashbacks, and sleep disturbances which also delayed their recovery. Outside of ICU there was a lack of knowledge about the psychological reactions that were related to a patient's critical illness Staff proposed that ICU staff should offer a welfare visit to the patient and family once the patient had been on a hospital ward for a few days Family members provided the most significant emotional care as community staff not considered knowledgeable Family members wanted more resources and information to help them support the patient, including contact details for support services
3. Positioning patients at the centre of services Long-term recovery services were needed to manage ongoing problems; responsive to needs with patient input paramount Services needed to meet specialised needs during recovery from critical illness The ICU outreach team typically only provided follow-up of patients transferred from ICU in the first 24 h and had a physiological focus An ICU rehabilitation physiotherapist could provide more specialised and prolonged care for patients during their ward-based stay. Patients needed more choice about the care they received in the community; there was variability in the quality of care provided Ongoing limitations left patients unable to work and assume their pre-illness roles and activities
4. Building a supportive framework for recovery Patients wanted continuity of care, and access to information and resources to ensure continual progress towards recovery goals Transitions (to ward and home) were a positive sign of progress but evoked stress and apprehension; new staff and unfamiliar routines Patients felt uninvolved in the planning process for transfer to the ward and wanted to be involved in the decision-making process Leaving hospital was a further sign of progress but tempered with uncertainty about coping in a different environment. Several patients felt that hospital discharge was poorly coordinated Patients saw a different General Practitioner (GP) each visit and GP's not familiar with complexity of patient problems Patients and families spent a lot of time searching Internet for information

differ from other studies describing patient experiences in ICU (Hashem et al., 2016; Kean et al., 2021), individual interviews have been recommended to enhance participants commitment to the EBCD process and stimulate their further involvement in the co-design stages of studies (Green et al., 2020). This was evident in our study as most patient participants and staff were willing to continue their involvement in the study through all three phases. Bringing patients and their families/friends together prior to the joint patient-staff event was valuable in encouraging patients to feel confident about expressing their views. The joint event enabled a more equal power relationship than was usual in the care relationship (Green et al., 2020) and thereby ensured that clear priorities for improvement could be identified.

Although the focus of this study was on experiences over the whole critical illness journey, patients' experiences of ICU were at the forefront of their recollections. Improving the ICU experience was clearly a priority for patients and their family members. As indicated in the findings, patients in this study found aspects of the environment and their care to

be dehumanising and patients needed to recover their autonomy, self-esteem and self-confidence in order to be able to navigate the recovery journey and embrace the challenges of self-directed care. Treating the person rather than treating the condition presents the foundation from which to cultivate humanised care and mitigate emotional harm. Dehumanising behaviours and practices need to be acknowledged and addressed. This study was conducted prior to the COVID pandemic but dehumanising and ethical care has recently been acknowledged as an issue for COVID-19 patients who have been treated in ICU (Robert et al., 2020). Post registration curricula on ICU courses should better prepare staff to address dehumanising aspects of care. Delivering more humane care requires that patients' experiences are recognised and considered as important issues for targeted management within ICU (Sokol-Hessner et al., 2015) and not just viewed as inevitable consequences of critical illness and being in the ICU environment. This study adds to the wider debate by proposing that dehumanising care strips patients of their self-efficacy and is a further set-back to recovery (Brown et al., 2018; Wilson et al., 2019). Person-centred care should become a benchmark of practice for critical care services moving forward, to enable patients to embark on the recovery journey from the best position possible. Practical recommendations include talking more to patients and families about their care and also engaging in more non-medical conversations; getting to know patients and their families. Engaging patients (and their family members) in decisions about care and treatment, especially when planning transitions to different areas, would benefit patients, even if information had to be given repeatedly.

Addressing patients' emotional and psychological needs requires health care professionals to move beyond focussing solely on the physiological aspects of illness and to recognise the holistic needs of those who have experienced critical illness. In this study, patients' common emotional reactions were normal responses to a severe illness, whereas their more specific psychological symptoms stemmed from their ICU stay. Emotional and psychological issues were often not addressed either in hospital or community settings. This is an important issue to address during the early stages of recovery as patients' unmet needs can escalate over time (King et al., 2019) and psychological problems are linked to early hospital readmission for former ICU patients (Donaghy et al., 2018). Family members and ICU staff may also need psychological support (Wade and Howell, 2016). Although levels of post-traumatic stress disorder, anxiety and depression are highly variable in family members of critically ill patients, they are vulnerable to poor psychological outcomes (Johnson et al., 2019). ICU health psychology is a growing discipline (Wade and Howell, 2016) but there are too few psychologists available to meet the needs of all critical illness survivors (Critical Care Network – National Nurse Leads, 2016).

Psychological support should be provided to aid rehabilitation and recovery from critical illness in ICU, on general wards, and in the community but it is not clear to what extent psychological assessment and support is carried out, particularly in ICU (Wade & Howell, 2016). COVID-19 patients may need even more psychological support than 'normal' ICU patients, experiencing survivor guilt and post-traumatic stress syndrome (Thornton, 2020). This will also impact on community care; General Practitioners did not often consult with post ICU patients, but Covid-19 has drastically altered that experience (Thornton, 2020).

Patients had felt pressure to return to work. Delayed return to work and forced unemployment are common manifestations following critical illness; one-third of survivors do not return to work up to 60 months after critical illness (Kamdar et al., 2020). Potential risk factors for delayed return to work include pre-existing comorbidities and mental health impairments (Kamdar et al., 2020). Therefore, rehabilitation programmes need to focus attention on early discussions with patients about their expectations for return to work as well as open dialogue between patients and their employers about adaptations that may be needed in the workplace to support patients who have suffered ICU events.

The third priority was to position patients at the centre of services. Patient-centred care is not a new idea, but a key principle of person-centred care involves offering coordinated care and services (The Health Foundation, 2016). In this study there was a lack of effective communication between each service and a lack of overall coordination by a dedicated member of staff. Although the diversity of staff in this study reflects the intention to place key resources at critical time points (e.g. transfer to ward, discharge to home), patients still perceived a lack of continuity and coordination of care, which created additional challenges and obstacles for patients. Misalignment of services, due to lack of feedback and evaluation, resulted in delivery based on staff knowledge, perceptions and experience and resource-centred design. Perhaps a more useful approach would be to ensure information travelled with the patient, with services provided when patients needed them, rather than at fixed time points or settings. The COVID-19 pandemic has shown that support can be delivered in more innovative ways rather than the traditional outpatient clinic (Olver et al., 2020).

Building a supportive framework for recovery following critical illness would involve helping individuals return to 'normality', with a quality of life that they would find acceptable rather than being centred on treating a patient's physical and psychological conditions. Recovery services should focus on enabling and building the self-efficacy of patients to empower them to be in control of their recovery journey. The National Cancer Survivorship Initiative in England promoted a cultural shift away from the focus on acute illness to recovery, health, wellbeing and return to work (Jefford et al., 2013). As part of the recovery service, the initiative recommended supported self-management and tailored support during recovery, together with measurement of important patient reported outcomes measures (PROMS). Adopting similar approach for patients recovering from critical illness could support patients in rebuilding their autonomy and self-efficacy by enabling patients to select the care and services they choose that are appropriate to their individual needs.

In agreement with current evidence around PICS (Brück et al., 2018, Ohtake et al., 2018, Griffiths et al., 2013; Kamdar et al., 2020) the patients in this study were affected by a wide range of long-term physical, psychological, cognitive and work-related changes following critical illness. The study revealed that current service provision was out of alignment with patients' wide-ranging and varied needs during recovery. This concurs with evidence which found physical rehabilitation interventions and ICU follow up clinics did not have any measurable impact on PCIS (Taito et al., 2019, Schofield-Robinson et al., 2018). The advantage of the EBCD method used in this study was to identify patient derived priorities in order to design patient-centred services which meet the needs that patients report as important. As such this approach challenges conventional models and priorities for follow up by enabling services to be shaped by patients, based on their own experiences rather than clinicians' assumptions of patients' needs. A key recommendation from this study is that improving patient experiences of health services requires a person-centred approach to care, which recognises that each patient is different; individualised care should be centred around patients' needs rather than the needs of the service. Person-centred care provision underpins all four priorities for service improvement identified in the co-design process of this EBCD study.

Limitations

This study had a number of limitations. The study was conducted at one study site and findings reflect a local, rather than regional or national, perspective. The study had a small patient sample and a relatively low response rate, which may reflect the difficulties recruiting a 'hard to reach' and vulnerable population, with time consuming data collection methods. We were not intending to reach data saturation, and this may have been a limitation in that new insights could still have been forthcoming. Limiting recruitment to an English speaking and neurologically intact sample means the findings may not be generalizable to the wider

ICU population. The patients who responded to the invitation to participate may not be representative of the wider population of patients recovering from critical illness. The patients in this study all experienced issues during recovery, and their experiences may not be representative of those patients with fewer or different problems following critical illness. Finally, due to the constraints of completing this research as part of a PhD thesis, the EBCD methodology was adapted and did not proceed to the phase of re-designing services based on patients' priorities. Following completion of thesis and easing of the impact of Covid-19 on ICU services, a number of developments are underway to implement recommendations based on the findings of this study, which will be described in future papers.

Conclusion

The EBCD approach was used successfully in this study to identify priorities for improvements for patients recovering from critical illness. Participants identified four priorities to improve patients experiences when recovering from critical illness; the need to improve the ICU experience, better understanding of patients experiences to enable them to care for patients' emotional and psychological needs, position patients at the centre of services, and build a supportive framework for recovery. The provision of person-centred individualised care underpinned all identified priorities. This study provided valuable insight into recovery from critical illness as a journey, and the emotional touchpoints that characterised that journey for patients. Emotional mapping revealed how patients interacted with services throughout their journey and highlighted areas where services were not synchronised with patients' needs. EBCD positions patients at the centre of service improvements and realigns care delivery around what matters most to patients.

Author contribution

All authors contributed to the conceptualisation of the study. JT was responsible for data acquisition, with assistance from RM. Formal analysis, interpretation of the data and drafting of the manuscript was carried out by all authors. All authors have approved the final manuscript.

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Declaration of Competing Interest

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

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