



## King's Research Portal

DOI:

[10.1016/j.iccn.2023.103535](https://doi.org/10.1016/j.iccn.2023.103535)

*Document Version*

Peer reviewed version

[Link to publication record in King's Research Portal](#)

*Citation for published version (APA):*

Allum, L., Terblanche, E., Pattison, N., Connolly, B., & Rose, L. (2023). Clinician views on key actionable processes of care for prolonged stay intensive care patients and families: descriptive qualitative study. *Intensive and Critical Care Nursing*, 80(103535). Advance online publication. <https://doi.org/10.1016/j.iccn.2023.103535>

### **Citing this paper**

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

### **General rights**

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

### **Take down policy**

If you believe that this document breaches copyright please contact [librarypure@kcl.ac.uk](mailto:librarypure@kcl.ac.uk) providing details, and we will remove access to the work immediately and investigate your claim.

# Clinician views on actionable processes of care for prolonged stay intensive care patients and families.

## Abstract

**Objectives:** To explore clinician perspectives on key actionable processes of care that may improve outcomes and experience of patients experiencing a prolonged (over 7 days) intensive care unit stay, and their family members.

**Research methodology:** A descriptive qualitative interview study in the United Kingdom. We conducted online semi-structured interviews using video conferencing software (October 2020-August 2022). We used purposive sampling ensuring participation from a broad range of professions representing the interprofessional team in the United Kingdom. We used Framework Analysis methods to group actionable processes into the six themes of person-centred care. Analyses were informed by our previous scoping review and previous interviews with former patients and family members.

**Findings:** We interviewed 24 staff participants and identified 36 actionable processes of care under six themes of person-centred care. Processes relating to communication (both establishing an effective communication method for the patient and staff communication with the patient and family), continuity of staff and care plans, and personalising the environment and routines, and allowing flexible family visiting were most frequently articulated. These processes were perceived as having a multifaceted impact on patient and family wellbeing, for example family visiting helping patient and family emotional wellbeing and staff communication with family; and establishing an effective communication method for patients reduced their anxiety, enhanced their involvement in their care and allowed staff to include them in ward rounds more efficiently.

**Conclusion:** We identified 36 actionable processes of care from interviews with intensive care staff, with an emphasis on enhancing patient autonomy through optimising communication and involvement in decision-making, participation of family, and continuity of staff and care plans.

**Implications for clinical practice:** These 36 actionable processes of care will contribute to future development of quality improvement tools, which will be used to standardise the care of prolonged-stay intensive care patients and their families.

KEYWORDS patient care planning, chronic critical illness, critical care, artificial respiration, quality improvement

## INTRODUCTION

Less than one third of patients admitted to an intensive care unit (ICU) will remain for over seven days (Shaw et al., 2020), with an average ICU length of stay of 5.2 days in the UK (NHS Digital, 2022). Yet these patients account for up to 72% of ICU bed days and significant financial costs both in hospital and in the community (Cederwall et al., 2021; Rose et al., 2019). Advances in critical care medicine and technology have improved ICU survival rates (Ely, 2017). However up to 34% of ICU patients experience a transition from acute critical illness to persistent or chronic critical illness (Shaw et al., 2020).

Patients experiencing a prolonged ICU stay (defined as over seven days in ICU) with persistent or chronic critical illness have a different constellation of needs to their acutely ill counterparts (Rose et al., 2019). They are more likely to require complex ventilator weaning and experience delirium, ICU-acquired weakness, peripheral neuropathy, malnutrition, and psychological distress (Marchioni et al., 2015; Minton et al., 2019; Nelson et al., 2004). Family members are more likely to experience psychological and financial difficulties compared to family members of short stay ICU patients (Hickman & Douglas, 2010; Minton et al., 2019). Understanding what high-quality patient- and family-focused care consists of for these patients, as well as developing tools to support implementation of this care, may optimise the management of these patients and improving their experience.

Quality improvement (QI) tools designed for use in the ICU can standardise care, improve safety, and prevent healthcare-acquired infections (Leigh et al., 2019, 2020; Sauro et al., 2019). However our previous scoping review (Allum et al., 2022) found few QI tools designed specifically for the needs of prolonged ICU stay patients. These patients are often awake and able to participate in decisions about their care, are generally weaning from mechanical ventilation, and can participate in rehabilitation. Alternatively, some patients may not be showing signs of recovery and improvement, and instead may be transitioning towards end-of-life care. Furthermore, a significant proportion of patients experience psychological distress being more aware of their surroundings (Johnson et al., 2019; White et al., 2018).

The lack of patient- and family-centred QI tools bespoke to this patient population may contribute to missed or delayed opportunities to improve outcomes and patient-and family-experience. Recent studies suggest that there may be practices such as use of protocols and promotion of cohesive interprofessional practice that differentiate high and low-performing hospitals and contribute to

rates of prolonged critical illness (Hermans et al., 2019; Rak et al., 2020; Viglianti et al., 2020). To inform development of bespoke QI tools, actionable processes of care (interventions that can be influenced by ICU clinicians) must be identified that are specific and important to prolonged ICU stay patients and their families. In this paper, we use the active voice for clarity and accessibility (British Medical Journal 2023, APA Style Blog 2016).

### Aim

To identify, from a clinician perspective, actionable processes of care that may improve outcomes and experience of prolonged ICU stay patients and their family members. This study informs a wider research programme aiming to develop QI tools to enhance the experience of prolonged stay patients and their families, and builds on our understanding of important actionable processes of care as identified by former prolonged ICU stay patients and their families (Rose et al., 2022).

### Design and setting.

We conducted a qualitative semi-structured interview study in the UK between 2020 and 2022. This was part of a larger study, with previous interviews with former patients and their families described elsewhere (Rose et al., 2022).

### Ethical Approval

Approval for this interview study was sought in May 2019, as part of the wider project from London - South East Research Ethics Committee IRAS project ID: 225003. This is considered low-risk research, as staff are not considered to be vulnerable participants and the passive recruitment strategies used reduce the risk of participants feeling coerced to take part.

### Participants

We used a purposive sampling strategy (Campbell et al., 2020; Palinkas et al., 2015) to achieve variation in clinician profession. Participants with more than one year of ICU experience and registered with an appropriate professional body were included. We recruited 24 participants working in hospitals across England, Wales and Scotland using professional society and personal Twitter accounts, direct recruitment approaches to clinicians at our research site (Guy's & St Thomas' NHS Foundation Trust, London, UK), and snowballing methods (Parker et al., 2019). We continued to recruit participants until sufficient information power (Malterud et al., 2016) was attained. This was determined by the narrow focus of our study, the richness and amount of data from the interviews, and because our approach and analysis are informed by previous interviews with patients and families, and an evidence review.

### Data collection

Following informed consent, one researcher (LA) conducted one-on-one online semi-structured interviews using video conferencing software video interviews using MS Teams lasting up to 60 mins using a semi-structured interview guide developed iteratively by the study team (See Data S1). Interviews were digitally audio or video recorded (either over the telephone or using MS Teams) and transcribed verbatim by a professional transcription company (2020-2021), and by autotranscription (checked by the interviewer) via MS Teams in 2022. The interviews took place between October 2020-August 2022 and were interrupted during UK winter 2020 due to the COVID-19 pandemic and leave taken by the PhD student conducting the interviews.

### Data analysis and rigor

We used a framework approach as described by Pope (2000) as our analyses were informed by the findings of our previous review (Rose et al., 2019) and interviews with former ICU patients or family members (Rose et al., 2022). To identify actionable processes of care, and to generate the overarching framework, we followed the following steps (1) familiarisation; (2) identifying a thematic framework; (3) indexing, (4) charting and mapping; and (5) interpretation (Pope, 2000). Two researchers (X; Z) independently coded all interviews to ensure rigor and consistency, enhancing credibility and dependability (Sandelowski, 1998). For reflexivity, the first author is an experienced critical care physiotherapist with her own opinions on optimal management of long-stay ICU patients. To reduce any bias, two independent researchers analysed the data separately to establish rigour. We used the following six dimensions of person-centred care (Gerteis et al., 1993; Institute of Medicine (US) Committee on Quality of Health Care in America, 2001) to categorise the identified actionable processes of care:

- respect for patients' values, preferences, and expressed needs;
- coordination and integration of care;
- clear, high-quality information and education for the patient and family;
- physical comfort;
- emotional support—relieving fear and anxiety; and
- involvement of family and friends.

## Findings

We interviewed 24 clinicians including seven nurses, five intensivists, five physiotherapists, two occupational therapists, two pharmacists, two speech and language therapists, and one dietitian. Most (18/24) were of white British ethnicity; 14/24 had been practising for over 10 years (Table 1). Participants were recruited from England, Wales and Scotland, with 4/20 participants recruited from Guy's and St. Thomas' NHS Foundation Trust.

**Table 1. Participant Characteristics**

|                                |                                     |    |
|--------------------------------|-------------------------------------|----|
| <b>Profession</b>              |                                     |    |
|                                | Nurse                               | 7  |
|                                | Intensivist                         | 5  |
|                                | Physiotherapist (PT)                | 5  |
|                                | Occupational therapist (OT)         | 2  |
|                                | Pharmacist                          | 2  |
|                                | Speech and Language therapist (SLT) | 2  |
|                                | Dietitian                           | 1  |
|                                |                                     |    |
| <b>Years of working in ICU</b> |                                     |    |
|                                | 1-3 years <sup>1</sup>              | 3  |
|                                | 3-5 years <sup>2</sup>              | 4  |
|                                | 5-10 years <sup>3</sup>             | 2  |
|                                | 10 years + <sup>4</sup>             | 15 |
|                                |                                     |    |
| <b>Sex</b>                     |                                     |    |
|                                | F                                   | 19 |
|                                | M                                   | 5  |
|                                |                                     |    |
| <b>Working Pattern</b>         |                                     |    |
|                                | Full-time                           | 17 |
|                                | Part-time                           | 4  |
|                                | Not disclosed                       | 3  |

<sup>1</sup> = OT, dietitian, nurse. <sup>2</sup> = 2 nurses, 1 OT and 1 PT. <sup>3</sup> = intensivist, nurse. <sup>4</sup> = 4 PTs, 2 pharmacist, 3 nurses, 4 intensivists, 2 SLT.

We identified 36 actionable processes of care grouped under the six dimensions of person-centred care (Table 2). Participants emphasised the importance of active person-centred care in all processes, for example by encouraging patient and family participation in development of a rehabilitation plan, and developing individualised solutions to improve sleep.

Theme 1: Respect for patients' values, preferences, and expressed needs  
(Table 2, Section 1 - Six actionable processes of care)

Participants highlighted that prolonged ICU stay patients are frequently awake and aware rather than sedated, meaning that they are able to actively experience their ICU stay and are frequently able to participate in decisions about their care. Establishing an effective communication method (Table 2, 1b) allowed patients to express their needs and participate in decision-making, but was often not implemented in a timely manner, resulting in delays understanding their preferences as the following quote outlines:

*'[patient was using] a Passy Muir Valve and it wasn't till later he said "oh I hate them visiting at ten", like whoops they've been visiting you at ten for weeks...'*

*Clinician 14, Nurse*

Most participants said that understanding what matters to the patient allows them to meaningfully engage to improve mood and motivation (1c, d). However, whilst a range of ways in which patients' autonomy could be enhanced were described (Table 2, 1f), these actions were reported as exceptions to usual care, often occurring as responses to low mood or lack of progress with rehabilitation. As one nurse described,

*'there's no hard and fast "oh we'll put these communication tools in place"... it's... just up to whoever's on that day, whoever takes the initiative to think "oh I'm going to make up a board with easy phrases they can point at".'*

*Clinician 1, Nurse*

## Theme 2: Coordination and integration of care

### *(Table 2, Section 2 - Twelve actionable processes of care)*

All participants viewed care continuity and establishment of a unified care plan as challenging. Prolonged ICU stay patients tend to receive care/treatment from many clinicians due to their length of stay, and also because they require input from a range of professions including occupational therapy, speech and language therapy, and psychology. This creates opportunities for communication breakdown and inconsistent messaging. In particular, poor continuity manifested in disjointed ventilator weaning attempts (Table 2, 2a, d) c

*'there seemed to be no continuity in the weaning plan so we'd push her weaning too hard and she'd end up back on full ventilation and we'd say 'look... we've got to take this slowly...'*



*and then another consultant would come on and say 'right she should be on trache mask all day'... and you'd go 'no this isn't going to work' and nobody would listen to us and she'd be back [on full ventilation]'*

*Clinician 5, Physiotherapist*

A common strategy to establish continuity was using small teams for prolonged ICU stay patients, ensuring relationship and trust building, for example:

*'you had in total 4-5 nurses, but they were looking after her constantly. I think that that played a big role. Because she was getting used to the faces, so she was trusting you more as well. And then she was feeling more secure in the sense. 'OK, Oh Nurse X is here. I'm gonna feel nice now.'*

*Clinician 23, Nurse*

Most participants highlighted the need for longer-term planning, with shared weaning goals and shared plans for the day clearly documented (such as on a whiteboard in the patient's bedspace). This enabled staff to organise time and staffing for various activities and to ensure all parties had a shared understanding of the direction of care. Only five participants stated they had regular multidisciplinary meetings specifically to discuss progress against goals and care plans for prolonged ICU stay patients (Table 2, 2g), which they described as very important for communication and continuity of care. However, none of these meetings involved the patient or their family (Table 2, 2k).

### Theme 3 Clear, high-quality information and education for the patient and family (Table 2, Section 3 - Three actionable processes of care)

Some participants described a shift in informational needs as patients moved from an acutely unwell stage and often sedated, to being awake and able to communicate given the correct aids. Whilst it was universally seen as important to provide patients with information about their care, the time required for effective communication served as a barrier to inclusion in ICU rounds or care planning discussions (Table 2, 3a). One intensivist articulated this as:

*'you should take considerable time, considerable effort to communicate with this group to try and walk them through what's going on, where they're at... at least on a daily basis to try*

*and essentially inform them of what's going on, the decisions that are being made for them, around them, that they should be part of'*

Clinician 16, Intensivist

This shift in informational needs also occurs for family members. Most participants indicated that family would initially receive daily updates as a patient stabilises and serve as the spokesperson and decision-maker for their unconscious relative. As a patient becomes more stable, families receive fewer regular updates reflecting a more slowly changing clinical picture (Table 2, 3b). Some participants identified that family may receive even fewer updates once a patient is awake and less in need of their advocacy. However, the rationale for this reduction in the frequency of information provision may not be clearly articulated by clinicians, leaving relatives feeling an information gap with consequent anxiety and sometimes discordance, as described below:

*'We almost need to say well this is going to be a long admission we will update you once a week... unless you tell them they get more upset and anxious and frightened because they think things aren't being told to them'*

Clinician 14, Nurse

This change in informational needs necessitated shared discussions where all parties could express their needs and understanding (Table 2, 3c).

#### Theme 4 Physical comfort

*(Table 2, Section 4 - 7 actionable processes of care)*

All participants spoke of the fundamentals of care such as washing/bathing and toothbrushing as humanising activities, demonstrating respect and helping patients regain a sense of self and improving mood (Table 2, 4b,e, f). These activities also gave time for a care provider to engage with a patient, as an occupational therapist outlined:

*'Prioritizing things that would make you feel normal like... oral care or sips of water... Even brushing their hair... are so important to make you feel clean and nice. I know when as an OT when I get patients in the shower for the first time. Oh my God, they come out and they're like wow, you know, I feel so good again'.*

Clinician 21, Occupational Therapist

Symptom management such as pain and thirst also impacted on a patient's participation in rehabilitative activities (Table 2, 4a). Fifteen participants highlighted the need to ensure restful sleep via pharmacological and non-pharmacological methods, including rationalising the frequency at which observations were carried out (Table 2, 4g). One nurse said:

*'it's about what does this patient need right now and if it's sleep then don't do the obs. You can...you have visibility, they're safe'*

*Clinician 12, Nurse*

Theme 5 Emotional support—relieving fear and anxiety

*(Table 2, Section 5 - 6 actionable processes of care)*

The emotional needs of patients were addressed in a variety of ways; and support to communicate is vital in understanding these emotional needs. Effective management of anxiety and low mood (Table 2, 5c) also made rehabilitation and weaning attempts more successful as the quote below describes:

*'I think what went really well was the way that we... managed her wean in the context of her anxiety and the psychological support she needed in order to make that happen... how we developed that trust and that bond with her so that she trusted us as a team, she worked with us.'*

*Clinician 20, Speech and Language Therapist*

Nineteen participants spoke of the impact of delirium on their patients' emotional health and that of their families. They described delirium reduction strategies, both pharmacological and non-pharmacological, including meaningful occupation (such as practising self-care or playing games) in the day and adequate sleep at night (Table 2, 5a, b, e).

Most of the discussions of emotional support referred to informal support, however nine participants also recognised the need for formalised psychology services for patients during their prolonged stay. Some participants highlighted the lack of formal psychology or counselling available for family members (Table 2, 5f). Informal support included providing regular updates to alleviate anxiety, and signposting to sources of support such as the charity ICUSteps or to Citizens Advice UK for those in financial difficulty. All participants stated that they felt provision of support overall to family members was inadequate, highlighted by one nurse as:

*'I struggle to signpost them... I have opened this can of worms... and I don't know what to*

*do... I'm out of my depth now... I'm scrambling round... to see if they've got some support... '*

*Clinician 9, Nurse*

## Theme 6: Involvement of family and friends

*(Table 2, Section 6 - 2 actionable processes of care)*

All participants described family presence as a normalising experience for patients, improving mood and providing reassurance for both patient and family. Family involvement in care tasks (Table 2, 6b) provided the family with a role and feeling of usefulness, as exemplified by one dietitian:

*'quite often family members will say can I bring food in? Or I didn't realise I could bring food in... it's like therapy for the family members as well as the patient because they're quite often there then helping them eat or setting them up.'*

*Clinician 7, Dietitian*

Family presence during rehabilitation provided motivation for patients and a more holistic picture of their recovery. The value of regular visits from family and friends was emphasised, especially after in-person visiting restrictions imposed during the COVID-19 pandemic. Most participants perceived more flexible visiting should be encouraged to allow families to visit outside working hours (Table 2, 6a). However, this view was not universal, with five participants in a mix of professions describing difficulties completing care and rehabilitation tasks with family present, and the impact on nursing staff when the relationship with the family is difficult, , for example:

*'it can also be a challenge for the, you know, the staff as well... it's trying to strike that balance of them having a lot of access to see their relative and then having questions answered by the [multidisciplinary team], but then also the doctors and nurses having time to do their tasks... as well.'*

*Clinician 19, Pharmacist*

Some staff also felt that open visiting times were a barrier to families going home to rest and care for themselves. Some participants felt that families should be encouraged to be present during ward rounds to encourage more open information sharing and communication, although this was not common practice in UK ICUs. One intensivist said:

*'I know this isn't the view of everyone that we should have very open visiting hours on ICU, we should have family present for ward rounds and I think all of this would just create a*

*culture of openness, a culture of communication and I think would...would improve a patient's experience on ICU.'*

*Clinician 16, Intensivist*

### Non-actionable processes of care

Three processes of care were frequently mentioned but not directly actionable as part of patient care, namely:

- Providing support for staff, such as education for less experienced staff or debriefing for challenging cases
- Increasing staffing levels of nursing staff and therapists
- A designated area within the ICU or in another location in the hospital for long ICU stay patients.

Although participants expressed an interest in caring for prolonged ICU stay patients, many also noted that this could be demanding both physically and emotionally. Physical demands included the need for supporting rehabilitation activities and trips off the unit. Emotional demands arose from caring for patients with an uncertain prognosis, when relationships with family are challenging, or when the patient needed substantial reassurance. Some participants worked in teams in which they could request a temporary break from caring for a prolonged ICU stay patient; some had access to debriefing or counselling services. Participants frequently expressed that the education they had received to work in ICU did not include this patient group, leading to the perception that they did not have the correct skill set. This perception was amplified by staffing levels, with prolonged ICU stay patients often managed with a 1:2 nurse-to-patient ratio despite having larger rehabilitative and emotional support needs. Some participants expressed the view that prolonged ICU stay patients would be better cared for in separate lower acuity units, where the staffing model could be adapted, for example, to employ rehabilitation assistants.

### Discussion

Through interviews with 24 clinicians representative of the ICU interprofessional team, we identified 36 actionable processes of care considered important for the management of prolonged stay ICU patients. These actionable processes were similar to those identified previously by patients and families (Rose et al., 2022) although we identified a further twelve. These additional processes included medicine reconciliation and prevention of complications such as deep vein thromboses.

Encouragingly, clinicians identified all actionable processes previously identified in our patient and family interviews, suggesting alignment of the importance of actionable care processes for a respectful and humanising experience.

Clinicians strongly advocated for actionable care processes which helped patients to express their needs and preferences. Establishing effective communication methods for patients was described as essential in providing respectful care and establishing patient autonomy. Barriers to effective and consistent communication practices are multifactorial (Istanboulian et al., 2020;) and include the need for training amongst staff and burnout preventing the emotional engagement needed. These difficulties establishing communication and therefore patient preferences may partly explain our finding that many humanising activities such as hair washes, trips off the ICU (for example to go outside or sit in a hospital café), and patient involvement in goal setting were described as happening only if there was time, on a quiet shift, or with a particular clinician; i.e. they were not standardised practice, a finding that is supported by our previous work (Rose et al., 2022).

The need to coordinate care across professions and shifts was clearly identified, and attempts to do so used a variety of methods. These included the use of ventilator weaning protocols or plans, setting of rehabilitation goals with measurement of attainment, and interprofessional progress meetings. These methods were discussed in terms of ensuring continuity, providing structure, and enhancing communication across all stakeholders. However, no participant identified availability or use of a tool to coordinate overall care planning. Rather tools were used for single aspects of care such as weaning. This finding was reflected in our previous scoping review (Allum et al., 2022) that identified no bespoke QI tools for prolonged ICU stay patients. This is despite evidence on the value of QI tools in improving safety, reducing error, and improving outcomes of care (Pronovost et al., 2001; Reader et al., 2011; Weled et al., 2015). Furthermore, a lack of organisational or care factors might contribute to higher rates of persistent critical illness and associated morbidity and mortality (Hermans et al., 2019; Viglianti et al., 2020).

Only two participants indicated regular interprofessional meetings were held to discuss care for long-stay patients. However these occurred without the inclusion of patients or family. This is despite participants identifying the need for regular, structured communication about care plans and prognosis with the patient and family. Key barriers to their inclusion were failing to provide communication aids for patients, delirium preventing patient involvement, and staff time constraints – findings reflected in other studies (Ruggiero, 2018; Teno et al., 2000). This failure of involvement

contributes to family members feeling they cannot meaningfully contribute to decision-making (Nelson et al., 2007), caregiver burden (Dale et al., 2020), divergence in expectations of care (White et al., 2016) and conflict between staff and the patient and family (Higginson et al., 2016).

Participants spoke of the need to ensure physical comfort in all its forms due to how these impacted other aspects of care. Effective pain management enhanced participation in rehabilitation and occupation activities. Attention to adequate sleep helped with psychological wellbeing. Participants also described these fundamentals of care as opportunities to demonstrate respect for a patient's personhood, providing dignified care and focused time to establish a rapport. This is in keeping with findings of other studies that describe the challenges of establishing caring practice in a highly technological, fast-paced environment (Stayt et al., 2015). In our previous work (Rose et al., 2022) we identified that patients and family often experience these care activities as powerful acts of individual kindness serving as potential turning points when they feel more 'normal' and more in control of their ICU journey.

Our study participants identified that the emotional and psychological wellbeing of patients was targeted through direct approaches, such as via referrals for psychological services and employing delirium-reduction strategies. Emotional wellbeing was also felt to be a benefit of other actionable processes of care, including ensuring patients are informed about their care to reduce anxiety (Cutler et al., 2013; Nin Vaeza et al., 2020) and establishing a communication method to ensure patients can articulate their needs (Khalaila et al., 2011).

We found a strong emphasis on the importance of family presence and involvement, with descriptions of how this helped to provide holistic care, even though this was not consistently demonstrated in practice. Minton et al (2019) describe family members' experiences of a prolonged ICU stay as being plagued by 'relentless uncertainty' which can be alleviated by effective communication, plans for communication, and signposting to sources of support and emotional support (Hickman et al., 2012; Hickman & Douglas, 2010). Family involvement in care tasks can help to improve communication and help family to feel useful and respected (Mitchell & Chaboyer, 2010) and to aid patient recovery.

#### Limitations

Limitations of our study include the potential for selection bias. Most participants described themselves as having a specific interest in prolonged ICU stay patients which may not be reflective of

the wider ICU community, and reflect a particular empathy for this patient group. We conducted interviews during the COVID-19 pandemic which is likely to have influenced time and psychological reserve to participate. The study was conducted in the UK only and so the findings may not be representative of other regions, although findings are very similar to those we previously identified in a Canadian context (Rose et al., 2022).

## Conclusion

We identified 36 actionable processes of care important to UK ICU clinicians for improving outcomes and experiences of prolonged ICU stay patients and their family. No participant identified using a quality improvement tool that coordinated overall care for this patient population and few reported involvement of patients and families in interprofessional meetings focused on care planning. More commonly, fragmented and disjointed treatment plans and communication between ICU interprofessional team members were described. With further work we will use these findings to inform the development of a quality improvement tool specific to this patient group with the aim of standardising care to improve outcomes and experience.



**Table 2 Actionable processes of care identified in clinician interviews**

| Patient-centred Care Dimension                                   | Actionable Process of Care  | Examples  |
|--|---|---|
| 1. Respect for patient's values, preferences and expressed needs | a) Include the patient (when able) and family in the development of the weaning plan*   |   |
|  | b) Provide aids to enable patients to communicate (including a method to access help) (referral to speech specialist if required)                   | This may include referral to Speech and Language Therapy  |
|  | c) Enable access to activities (radio, tv, iPad) and personal possessions (including clothes) to prevent boredom, loneliness, and restore normality | Might include a referral to occupational therapy. This might include wearing clothes, using a radio/TV/laptop/books, or a trip off the ICU.                                   |
|  | d) Provide activities to promote cognitive stimulation based on patient preferences   | This might include referral to occupational therapy   |
|  | e) Ensure access to outside space where possible  |   |
|  | f) Preparing patient for more independence where possible   | Might include referral to occupational therapy. Including de-escalation of observations, encouragement, and assistance to perform self-care, eating, drinking, and ambulation |
| 2. Coordination and integration of care                          | a) Use a structured tool (i.e. weaning protocol or individualized weaning plan) to plan and guide weaning, developed by the ICU team*               | Individualised weaning plan/protocol developed by interprofessional team and as able patient and family   |
|  | b) Assess and treat respiratory muscle weakness*  | This might include inspiratory muscle training or influencing the weaning plan  |
|  | c) Assess readiness to deflate the tracheostomy cuff, downsize or decannulate the tracheostomy as part of the weaning process*                      | This may include referral to Speech and Language Therapy  |
|  | d) Assess and track ventilator weaning progress*  | Including documentation of weaning attempts and progress  |

|   |   |   |
|---|---|---|
|   | e) Assess & treat non-respiratory muscle wasting*   |   |
|   | f) Regular physical rehabilitation (including early mobilisation) with setting of and assessment of progress on weekly rehabilitation goals   | Including documentation and regular review of rehabilitation goals  |
|   | g) Conduct interprofessional team meetings to discuss patient and family-centred care plan*   | With patient and family where possible, reviewing progress on goals of care/weaning/rehabilitation/patient's views  |
|   | h) Appropriate and timely referral to palliative care*  |   |
|   | i) De-escalate (including a change to oral instead of IV drugs) or stop ICU pharmacotherapy and restart previous comorbidity pharmacotherapy* | For example, restarting drugs for chronic conditions that were stopped in ICU                                       |
|   | j) Ensure adequate nutritional support  |   |
|   | k) Enable continuity of care using shared interprofessional goals agreed with family and patient where possible                               | Might include a small team of nursing staff/AHPs, use of a whiteboard, named Consultant/care navigator              |
|   | l) Appropriate and timely discharge planning (discuss and arrange safe transitions in care location)  | Discuss and arrange safe transitions in the care location including preparing the patient and family for transition |
| 3. Clear, high-quality information and education for patient and family | a) Involve the patient in bedside rounds, and goals of care discussions as early as able  |   |
|   | b) Provide regular <u>proactive</u> family meetings to set goals, devise a care plan, and share information                                   | Including a social worker, signposting to financial advice (e.g. Citizens' Advice Bureau)                           |
|   | c) Family presence or participation in rounds and planning meetings   |   |
| 4. Physical comfort   | a) Assess and manage symptoms (i.e., pain, breathlessness, tiredness, thirst)   |   |

|  |   |   |
|--|---|---|
|  | b) Assess swallowing function and establish a safe return to normal drinking and eating (may require referral to speech and language therapy) | This may include referral to Speech and Language Therapy  |
|  | c) Assess, prevent/treat complications associated with prolonged bed rest/ICU stay (i.e., pressure ulcers, constipation, DVTs)*               |   |
|  | d) Assess/prevent ocular disorders arising from incomplete eyelid closure*  |   |
|  | e) Provide fundamental hygiene and elimination care   | Regular and timely washes and toileting   |
|  | f) Provide regular oral care including toothbrushing  |   |
|  | g) Limit physiologic monitoring and routine bloodwork   | Reduce observations as able to allow rest and preparation for ward-level care                     |
| 5. Emotional support -relieving fear and anxiety | a) Review the ongoing need for drugs used for sedation and decrease their use as able*  |   |
|  | b) Identify and use patient preferences for strategies to promote sleep   | Including reducing night time disturbance, ear plugs/eye mask/dimmed lights                       |
|  | c) Assess and treat psychological issues including anxiety, depression, and acute stress (with referral to psychiatry if required)            | This may include a referral to Psychology and/or Psychiatry                                       |
|  | d) Provide access to social support such as a social worker or signposting to advice agencies (patient and family)                            | Such as citizen's advice, debt advice charities   |
|  | e) Minimize practices such as night time light/noise that promote delirium  | Including physical restraint, use of opioids, or might include a referral to occupational therapy |

|                                      |   |  |
|--------------------------------------|---|--|
|                                      | f) Patient diary to aid communication with and provide psychological support for patient and family | This might include encouraging the family to make entries in a diary |
| 6. Involvement of family and friends | a) Minimising visiting restrictions   |  |
|                                      | b) Family participation in care and occupation tasks  | Such as washes, shaving, mealtimes, playing games, reading           |

\* Items identified by clinicians but not by patients or family members in a previous interview dataset.

#### Processes not actionable at the bedside

|   |   |
|---|---|
| Provide support for staff               | Specific training in the care of long-stay patients, psychological support/debriefing options for complex or challenging cases, ability to ask to take a break (i.e. spending shifts with other patients) if on a small team of staff caring for a long-stay patient. |
| Increased staffing levels               | To allow more personalised time with a patient e.g. for reading, trips off the unit, more rehabilitation time   |
| Specialised area for long-stay patients | With more rehabilitative focus and staffing, away from acute/emergency pressures of ICU   |

## References

- Allum, L., Apps, C., Pattison, N., Connolly, B., & Rose, L. (2022). Informing the standardising of care for prolonged stay patients in the intensive care unit: A scoping review of quality improvement tools. *Intensive and Critical Care Nursing*, 73, 103302. <https://doi.org/10.1016/j.iccn.2022.103302>
- American Psychological Association. (2020). *Style and Grammar Guidelines*. Accessed August 10<sup>th</sup> at <https://apastyle.apa.org/style-grammar-guidelines/grammar>
- British Medical Journal. (2023). *House Style: General writing style*. Accessed August 10<sup>th</sup> at <https://www.bmj.com/about-bmj/resources-authors/house-style>
- Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: Complex or simple? Research case examples. *Journal of Research in Nursing*, 25(8), 652–661. <https://doi.org/10.1177/1744987120927206>
- Cederwall, C.-J., Naredi, S., Olausson, S., Rose, L., & Ringdal, M. (2021). Prevalence and Intensive Care Bed Use in Subjects on Prolonged Mechanical Ventilation in Swedish ICUs. *Respiratory Care*, 66(2), 300–306. <https://doi.org/10.4187/respcare.08117>
- Dale, C. M., Carbone, S., Istanboulian, L., Fraser, I., Cameron, J. I., Herridge, M. S., & Rose, L. (2020). Support needs and health-related quality of life of family caregivers of patients requiring prolonged mechanical ventilation and admission to a specialised weaning centre: A qualitative longitudinal interview study. *Intensive and Critical Care Nursing*, 58, 102808. <https://doi.org/10.1016/j.iccn.2020.102808>
- Ely EW. (2017). The ABCDEF Bundle: Science and Philosophy of How ICU Liberation Serves Patients and Families. *Critical Care Medicine*, (2):321-330. doi: 10.1097/CCM.0000000000002175.
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (1993). *Medicine and health from the patient's perspective. Through the Patient's Eyes*. San Francisco, Calif: Jossey/Bass Inc.
- Hermans, G., Van Aerde, N., Meersseman, P., Van Mechelen, H., Debaveye, Y., Wilmer, A., Gunst, J., Casaer, M. P., Dubois, J., Wouters, P., Gosselink, R., & Van den Berghe, G. (2019). Five-year mortality and morbidity impact of prolonged versus brief ICU stay: A propensity score matched cohort study. *Thorax*, 74(11), 1037–1045. <https://doi.org/10.1136/thoraxjnl-2018-213020>
- Hickman, R. L., Daly, B. J., Douglas, S. L., & Burant, C. J. (2012). Evaluating the Critical Care Family Satisfaction Survey for Chronic Critical Illness. *Western Journal of Nursing Research*, 34(3), 377–395. <https://doi.org/10.1177/0193945911402522>
- Hickman, R. L., Jr, & Douglas, S. L. (2010). Impact of Chronic Critical Illness on the Psychological Outcomes of Family Members. *AACN Advanced Critical Care*, 21(1), 80–91. <https://doi.org/10.4037/15597768-2010-1010>
- Higginson, I. J., Rumble, C., Shipman, C., Koffman, J., Sleeman, K. E., Morgan, M., Hopkins, P., Noble, J., Bernal, W., Leonard, S., Dampier, O., Prentice, W., Burman, R., & Costantini, M. (2016). The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories. *BMC Anesthesiology*, 16(1), 11. <https://doi.org/10.1186/s12871-016-0177-2>
- Institute of Medicine (US) Committee on Quality of Health Care in America. (2001). *Crossing the Quality Chasm: [Data set]*. Washington (DC): National Academies Press (US). <https://doi.org/10.1037/e317382004-001>
- Istanboulian, L., Rose, L., Gorospe, F., Yunusova, Y., & Dale, C. M. (2020). Barriers to and facilitators for the use of augmentative and alternative communication and voice restorative strategies for adults with an advanced airway in the intensive care unit: A scoping review. *Journal of Critical Care*, 57, 168–176. <https://doi.org/10.1016/j.jcrc.2020.02.015>
- Johnson, C. C., Suchyta, M. R., Darowski, E. S., Collar, E. M., Kiehl, A. L., Van, J., Jackson, J. C., & Hopkins, R. O. (2019). Psychological Sequelae in Family Caregivers of Critically Ill Intensive Care Unit Patients. A Systematic Review. *Annals of the American Thoracic Society*, 16(7), 894–909. <https://doi.org/10.1513/AnnalsATS.201808-540SR>
- Khalaila, R., Zbidat, W., Anwar, K., Bayya, A., Linton, D. M., & Svirni, S. (2011). Communication difficulties and psychoemotional distress in patients receiving mechanical ventilation. *American*

*Journal of Critical Care: An Official Publication, American Association of Critical-Care Nurses*, 20(6), 470–479. <https://doi.org/10.4037/ajcc2011989>

Leigh, J. P., Brundin-Mather, R., Zjadewicz, K., Soo, A., & Stelfox, H. T. (2020). Improving transitions in care from intensive care units: Development and pilot testing of an electronic communication tool for healthcare providers. *Journal of Critical Care*, 56, 265–272.

Leigh, J. P., Petersen, J., de Grood, C., Whalen-Browne, L., Niven, D., & Stelfox, H. T. (2019). Mapping structure, process and outcomes in the removal of low-value care practices in Canadian intensive care units: Protocol for a mixed-methods exploratory study. *British Medical Journal Open*, 9(12), e033333.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>

Marchioni, A., Fantini, R., Antenora, F., Clini, E., & Fabbri, L. (2015). Chronic critical illness: The price of survival. *European Journal of Clinical Investigation*, 45(12), 1341–1349. <https://doi.org/10.1111/eci.12547>

Minton, C., Batten, L., & Huntington, A. (2019). A multicase study of prolonged critical illness in the intensive care unit: Families' experiences. *Intensive and Critical Care Nursing*, 50, 21–27. <https://doi.org/10.1016/j.iccn.2018.08.010>

Mitchell, M. L., & Chaboyer, W. (2010). Family Centred Care—A way to connect patients, families and nurses in critical care: A qualitative study using telephone interviews. *Intensive and Critical Care Nursing*, 26(3), 154–160. <https://doi.org/10.1016/j.iccn.2010.03.003>

Nelson, J. E., Meier, D. E., Litke, A., Natale, D. A., Siegel, R. E., & Morrison, R. S. (2004). The symptom burden of chronic critical illness. *Critical Care Medicine*, 32(7), 1527–1534. <https://doi.org/10.1097/01.CCM.0000129485.08835.5A>

Nelson, J. E., Mercado, A. F., Camhi, S. L., Tandon, N., Wallenstein, S., August, G. I., & Morrison, R. S. (2007). Communication About Chronic Critical Illness. *Archives of Internal Medicine*, 167(22), 2509–2515. <https://doi.org/10.1001/archinte.167.22.2509>

NHS Digital. (2022, September 22). *Summary Report—ACC. NDRS*. <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-admitted-patient-care-activity/2021-22/summary-reports---acc>

Nin Vaeza, N., Martin Delgado, M. C., & Heras La Calle, G. (2020). Humanizing Intensive Care: Toward a Human-Centered Care ICU Model. *Critical Care Medicine*, 48(3), 385–390. <https://doi.org/10.1097/CCM.0000000000004191>

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health*, 42(5), 533–544. <https://doi.org/10.1007/s10488-013-0528-y>

Parker, C., Scott, S., & Geddes, A. (2019). Snowball Sampling. *SAGE Research Methods Foundations*. <http://methods.sagepub.com/foundations/snowball-sampling>

Pope, C. (2000). Qualitative research in health care: Analysing qualitative data. *British Medical Journal*, 320(7227), 114–116. <https://doi.org/10.1136/bmj.320.7227.114>

Pronovost, P. J., Miller, M. R., Dorman, T., Berenholtz, S. M., & Rubin, H. (2001). Developing and implementing measures of quality of care in the intensive care unit. In *Current Opinion in Critical Care* 7,(4), pp. 297–303.

Rak, K. J., Ashcraft, L. E., Kuza, C. C., Fleck, J. C., DePaoli, L. C., Angus, D. C., Barnato, A. E., Castle, N. G., Hershey, T. B., & Kahn, J. M. (2020). Effective Care Practices in Patients Receiving Prolonged Mechanical Ventilation. An Ethnographic Study. *American Journal of Respiratory and Critical Care Medicine*, 201(7), 823–831. <https://doi.org/10.1164/rccm.201910-2006OC>

Reader, T. W., Flin, R., Mearns, K., & Cuthbertson, B. H. (2011). Team situation awareness and the anticipation of patient progress during ICU rounds. In *BMJ Quality & Safety* (Ovid Technologies; Vol. 20, Issue 12, pp. 1035–1042).

Rose, L., Allum, L. J., Istanboulian, L., & Dale, C. (2022). Actionable processes of care important to patients and family who experienced a prolonged intensive care unit stay: Qualitative interview study. *Journal of Advanced Nursing*, 78(4), 1089–1099. <https://doi.org/10.1111/jan.15083>

Rose, L., Istanboulian, L., X, L., Burry, L., Dale, C., Hart, N., Kydonaki, K., Ramsay, P., Pattison, N., Connolly, B., on behalf of the PatiEnt Reported Family Oriented performance Measures (PERFORM) Investigators. (2019). Patient and Family Centered Actionable Processes of Care and Performance Measures for Persistent and Chronic Critical Illness: A Systematic Review. *Critical Care Explorations*, 1(4), e0005. <https://doi.org/10.1097/CCE.0000000000000005>

Rose, L., Istanboulian, L., Amaral, A. C. K.-B., Burry, L., Cox, C. E., Cuthbertson, B. H., Iwashyna, T. J., Dale, C. M., & Fraser, I. (2022). Co-designed and consensus based development of a quality improvement checklist of patient and family-centered actionable processes of care for adults with persistent critical illness. *Journal of Critical Care*, 72, 154153. <https://doi.org/10.1016/j.jcrc.2022.154153>

Ruggiero, R. M. (2018). Chronic Critical Illness: The Limbo Between Life and Death. *The American Journal of the Medical Sciences*, 355(3), 286–292. <https://doi.org/10.1016/j.amjms.2017.07.001>

Sandelowski, M. (1998). Writing a good read: Strategies for re-presenting qualitative data. *Research in Nursing & Health*, 21(4), 375–382. [https://doi.org/10.1002/\(SICI\)1098-240X\(199808\)21:4<375::AID-NUR9>3.0.CO;2-C](https://doi.org/10.1002/(SICI)1098-240X(199808)21:4<375::AID-NUR9>3.0.CO;2-C)

Sauro, K. M., Brundin-Mather, R., Leigh, J. P., Niven, D. J., Kushner, B., Soo, A., Cook, D. J., Straus, S., Doig, C. J., & Bagshaw, S. (2019). Improving the adoption of optimal venous thromboembolism prophylaxis in critically ill patients: A process evaluation of a complex quality improvement initiative. *Journal of Critical Care*, 50, 111–117.

Shaw, M., Viglianti, E. M., McPeake, J., Bagshaw, S. M., Pilcher, D., Bellomo, R., Iwashyna, T. J., & Quasim, T. (2020). Timing of Onset, Burden, and Postdischarge Mortality of Persistent Critical Illness in Scotland, 2005–2014: A Retrospective, Population-Based, Observational Study. *Critical Care Explorations*, 2(4), e0102. <https://doi.org/10.1097/CCE.0000000000000102>

Stayt, L. C., Seers, K., & Tutton, E. (2015). Patients' experiences of technology and care in adult intensive care. *Journal of Advanced Nursing*, 71(9), 2051–2061. <https://doi.org/10.1111/jan.12664>

Teno, J. M., Fisher, E., Hamel, M. B., Wu, A. W., Murphy, D. J., Wenger, N. S., Lynn, J., & Harrell Jr., F. E. (2000). Decision-Making and Outcomes of Prolonged ICU Stays in Seriously Ill Patients. *Journal of the American Geriatrics Society*, 48(S1), S70–S74. <https://doi.org/10.1111/j.1532-5415.2000.tb03144.x>

Viglianti, E. M., Bagshaw, S. M., Bellomo, R., McPeake, J., Wang, X. Q., Seelye, S., & Iwashyna, T. J. (2020). Hospital-level variation in the development of persistent critical illness. *Intensive Care Medicine*, 46(8), 1567–1575.

Weled, B. J., Adzhigirey, L. A., Hodgman, T. M., Brilli, R. J., Spevetz, A., Kline, A. M., Montgomery, V. L., Puri, N., Tisherman, S. A., Vespa, P. M., Pronovost, P. J., Rainey, T. G., Patterson, A. J., Wheeler, D. S., & Task Force on Models for Critical Care. (2015). Critical Care Delivery: The Importance of Process of Care and ICU Structure to Improved Outcomes: An Update From the American College of Critical Care Medicine Task Force on Models of Critical Care. *Critical Care Medicine* 43(7), pp. 1520–1525.

White, D. B., Angus, D. C., Shields, A., Pidro, C., Paner, C., Buddadhumaruk, P., Chang, C. H., Kahn, J. M., Kowinsky, A., Martin, S., & Arnold, R. M. (2018). A stepped wedge randomized controlled trial of a pragmatic, nurse-led intervention to support surrogate decision makers in ICUs. *American Journal of Respiratory and Critical Care Medicine*. Conference: American Thoracic Society International Conference, ATS (Ovid Technologies; Vol. 197, Issue MeetingAbstracts).

White, D. B., Ernecoff, N., Buddadhumaruk, P., Hong, S., Weissfeld, L., Curtis, J. R., Luce, J. M., & Lo, B. (2016). Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients. *JAMA*, 315(19), 2086–2094. <https://doi.org/10.1001/jama.2016.5351>