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A Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery after Critical Illness.

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Title: A Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery after Critical Illness.

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1
2
3 **Competing interests:** No competing interests to declare.
4
5

6 **Authors contribution to the study:** EJC, SJB and EJM were involved in the methodological
7
8 design, data analysis and writing and reviewing the manuscript. EJC did all of the interviews
9
10 and data collection.
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12

13
14 **Patient and Public Involvement:** There was PPI involvement for the development of the
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16 interview topic guide.
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20 **Word count: 4,021**
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Abstract

Rationale: Early rehabilitation of the critically ill patient is recognized best practice, however further work is needed to explore the patients' experience of rehabilitation qualitatively; a better understanding may facilitate implementation, and elucidate the journey of survivorship.

Objectives: To explore patient experience of early mobilisation and rehabilitation from critical illness.

Design: Exploratory grounded theory study using semi-structured interviews.

Setting: Participants were recruited from the adult medical/surgical ICU of a 430 bedded London teaching hospital. Interviews took place in the hospital or at the participants' home or work.

Participants: A purposive sample of adult critical care survivors.

Analysis: Data analysis followed a four stage constant comparison technique: open coding, axial coding, selective coding, and theory development, with the aim of reaching thematic saturation. Peer debriefing and triangulation through a patient support group were carried out to ensure credibility.

Main results: Fifteen people were interviewed (with four relatives in attendance).

Participants recounted a rehabilitation period characterized by episodic memory loss, hallucinations, weakness, and fatigue, which created a desire for paternalism, and made early rehabilitation difficult to recall, and arduous.

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2
3 The central theory that emerged from this study was recalibration of the self. This is
4
5 driven by a lost sense of self, with loss of autonomy and competence; dehumanized
6
7 elements of care may contribute to this. Participants described a fractured life narrative
8
9 due to episodic memory loss, which meant that patients were shocked on awakening by
10
11 the discrepancy between their physical form and cognitive representation of
12
13 themselves; and an upturned vision of their future, impeding rehabilitation goal setting.
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17
18 **Conclusions:** Recovery from critical illness is a complex process of emotional trauma;
19
20 and exploration of, and then adaptation to a new body as autonomy recovers. This can
21
22 impede early therapy goal setting. Rehabilitation plays a key role in recalibrating and
23
24 reconstructing a desirable future.
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54 **Key words:** critical care, rehabilitation, patient experience, recovery, physical therapy.
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56 **Abstract word count:** 299
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Strengths and Limitations of this study

1. This was an exploratory qualitative grounded theory study using semi structured interviews with survivors of critical illness to explore their experience of early mobilisation and rehabilitation after critical illness; the approach adopted, and the data generated provided an extremely rich source of individual experience with many consistent features.
2. A constant comparison technique of data analysis was used, and enrolment continued with the aim of thematic saturation.
3. Triangulation and peer debriefing were completed to ensure credibility of the study findings that clearly resonated with an independent group of critical illness survivors.
4. The patients were all recruited from one centre, which may limit transferability of findings. Qualitative studies of this kind innately have a small sample size; however the richness of the data produced allows deep exploration of meaning and theory development and thematic saturation was also reached.
5. The variation in time to interview may also be considered a limitation of this study, in view of impaired recall for longer gaps, however there was no notable difference in the richness of memories and insight provided by those interviewed at different time points; this also added an understanding of the process of recovery over time.

Introduction:

The sequelae of critical illness are well documented; for some, rapid muscle wasting ensues^{1,2}, which can lead to weakness and functional decline³; coupled with the cognitive consequences of delirium⁴, the result can be a prolonged period of weaning from mechanical ventilation, disability, reduced endurance, anxiety and depression⁵⁻⁹. To combat this, early mobilisation, minimising sedation and spontaneous breathing should be instigated early, with research demonstrating safety and likely efficacy¹⁰⁻¹³. Furthermore, on-going rehabilitation following discharge from critical care, and attendance at ICU follow up clinics are also advocated; although research showing direct benefit of these interventions is limited¹⁴⁻¹⁵.

Although implementation of early mobilisation protocols and post-ICU rehabilitation is inconsistent^{14,16-17}, early adopters of these strategies are striving for them to become the norm^{12,13,18}. In such centres, it is not uncommon for patients to receive active out of bed rehabilitation whilst receiving full mechanical ventilation, renal replacement therapy, and inotropic support¹⁸. Due to the severity of weakness that can be associated with prolonged critical illness, these rehabilitation sessions are often delivered by two or more therapists/nurses, and can require technical equipment and intimate handling. It is perhaps unsurprising that pain, fatigue, weakness, anxiety, fear, lack of motivation and patient confidence have been reported as barriers and reasons for cessation of early rehabilitation^{19, 20}.

Sottile and colleagues (2015)²¹ completed a survey of patient experience of early mobilisation in ICU; they concluded that patients recognized its importance, however found it difficult, tiring and uncomfortable.

1
2
3 In spite of current enthusiasm, there remains a clinical rationale for exploring the
4
5 experience of recovery from critical illness, focusing on physical rehabilitation during and
6
7 after a stay on ICU from the perspective of survivors in an in-depth manner. Thus this
8
9 paper reports the first study specifically to investigate early mobilisation from the
10
11 patient viewpoint.
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16 **Aim:** To explore the patient experience of recovery from critical illness, with emphasis
17
18 on their experience of early mobilisation and rehabilitation; and to develop a theoretical
19
20 model grounded in these data.
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22

23
24 **Methods:**

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26
27 **Qualitative approach and research paradigm:** Constructivist grounded theory study²²
28
29 using semi-structured interviews with a purposive sample of adult ICU survivors.
30
31 Constructivism contends that individuals' views are directly influenced by their
32
33 experiences; and it is these individual experiences and views that shape their
34
35 perspective of reality. Constructivists believe that individuals have different realities that
36
37 will be influenced by context; this is a 'relativist' ontological stance²².
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43 **Setting:** Participants were recruited from the adult medical/surgical ICU of a 430 bedded
44
45 London teaching hospital between November 2015 and September 2016.
46
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48
49 **Participants and sampling:** Participants were purposively sampled. Screening and
50
51 inclusion criteria were: English speaking, a critical stay of +72 hours, capable of providing
52
53 informed consent determined using the Mental Capacity Act assessment²³, anticipated
54
55 to survive, aged over 18 and documented intensive care unit acquired weakness (this
56
57 was to ensure that the participants had exposure to rehabilitation interventions.)
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3 Relatives were also invited to be present in the interview to enable exploration and
4 elucidation of any ICU associated memory loss. As the study progressed participants
5
6 were selected to ensure a heterogeneous sample, with the aim of achieving thematic
7
8 saturation^{22,24-26}.
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13
14 **Ethics:** This study was granted approval by the East of England Ethics committee (REC
15
16 reference number 14/EE/1027) and from the Research and Development Department at
17
18 the study site.
19
20

21
22 **Data collection methods:** The clinical team identified potential participants against the
23
24 broad criteria to ensure that it was appropriate for them to be approached by the
25
26 research team. Notes were screened with the aim of purposively selecting a varied
27
28 sample of participants that could speak to the breadth of emerging themes. If
29
30 participants were appropriate they were approached by the lead researcher (EJC) and
31
32 provided with written information. If they had capacity to consent and agreed to
33
34 participate, written informed consent was gained. The semi-structured interviews were
35
36 conducted by EJC. For reflexivity, EJC is research physiotherapist with expertise in critical
37
38 care and prior training in qualitative methods research. EJC also has personal experience
39
40 of major injury and as a close relative of a critically ill patient.
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47
48 The interviews followed a topic guide designed with input from the Intensive Care
49
50 Society Patient and Relatives Group (Figure 1). The questions in the topic guide focused
51
52 on the memory of the admission to ICU, any physical weakness that they encountered,
53
54 and patients' experience of rehabilitation in the ICU and following discharge. The
55
56 questions were intentionally left open to initiate reflections and to allow subsequent
57
58 detailed exploration of the issues that appeared important to the interviewee. The first
59
60

1
2
3 interview was used as a pilot, however as no changes were made and those data
4
5 collected from this interview were rich and informative, it was retained and analysed in
6
7 the results.
8
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10
11 As the study progressed and themes emerged, participants were asked to elaborate and
12
13 probed on specific issues in line with the constant comparison technique. Namely; how
14
15 the perception of the physiotherapist's strength influenced their rehabilitation
16
17 experience; how they perceived their body now; what differences there were between
18
19 their current and previous physical function; how they saw their future; and what they
20
21 defined as rehabilitation.
22
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24
25
26 The interviews were carried out either in the hospital or in the community after ICU
27
28 discharge. Enrolment and interviews continued until thematic saturation was reached
29
30 i.e. no new ideas were emerging, as per the criteria outlined by Bonde (2013)²⁶, this was
31
32 to challenge the emergent theory and ensure credibility. The interviews were
33
34 anonymised, recorded and transcribed *verbatim*. All transcripts were double-checked for
35
36 accuracy by EJC.
37
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39

40
41
42 All interviewees were given pseudonyms to ensure anonymity. Further demographic and
43
44 clinical data were also collected from the case notes: age, critical care and hospital
45
46 length of stay, APACHE II score, admission diagnosis, residence prior to admission, pre-
47
48 morbid functional level, and hospital discharge destination.
49
50

51
52
53 **Data processing and analysis:** Transcripts were uploaded onto Nvivo® software (QSR
54
55 International, Doncaster, Australia) for analysis. They were read and reread by EJC to
56
57 ensure full immersion in the data. Memo writing was used throughout. The first stage of
58
59
60

1
2
3 the analysis process is 'open coding', which is the identification of primary broad
4
5 categories; these may be around a theme or topic, or more conceptual, such as emotion
6
7 or attitude. The second stage is 'axial coding'; here categories are clustered together into
8
9 meaningful, related groups. The third stage is 'selective coding', where core themes are
10
11 identified. Lastly, the themes are used to generate a theoretical framework to explain
12
13 the data^{22,24-26}. Data collection and analysis occur concurrently, so that constant
14
15 comparison was made between emerging themes (both within and between narratives),
16
17 and the literature, allowing theory refinement. After the fourth interview had been
18
19 transcribed and open coding had been completed, axial codes began to form. These
20
21 ideas were then discussed in detail with the research team. This was followed by a
22
23 dynamic process of reflection after each interview to develop and refine the axial codes
24
25 into selective codes until a theory encompassing all elements was developed. The last
26
27 interviews were used to challenge this theory and to assess for data saturation. This
28
29 process allowed a central phenomenon to emerge from the data^{22,24-26}.
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38 **Techniques to enhance trustworthiness:**

39 **Peer debriefing:**

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42 Peer debriefing was completed via in depth discussion with SJB and EJM. This was done
43
44 regularly throughout the course of the study.
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50 **Triangulation:**

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53 Triangulation and sense checking was completed through presentation to an ICU
54
55 survivor support group with subsequent dialogue to assess the dependability,
56
57 confirmability and credibility of the theory (this did not include interview participants).
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3 At the support group the theoretical framework was presented and then there was
4 opportunity for questions and answers with the researcher (EJC). The group were then
5 left to discuss the study between themselves and feedback to the research team with
6 any thoughts at a later date to allow them to speak openly and frankly with each other.
7
8 The group lead fed back those participants resoundingly agreed with the concepts and
9 felt that the work '*encompassed all the areas that were important and relevant to those
10 who have experienced critical illness*'. The presentation also led to a very tearful
11 response from some attendees who reported to have felt 'understood'.
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23 **Results:**

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27 Eleven hours of qualitative data from 15 participants (with 4 additional relatives present)
28 were collected; the *patients* are described in Table 1.
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33 *[Insert table 1: Patient demographics]*
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35

36 The median ICU and hospital length of stay were 19 days (IQR 8-33) and 63 days (IQR 34-
37 107) respectively. The median time between ICU discharge and interview was 56 days
38 (IQR: 36-80). Ten (66.6%) of the interviews took place at the hospital whilst the patients
39 were still inpatients, and five (33.3%) took place after discharge in the patient's home
40 (n=2), work (n=1), or in a clinic room (n=2). The interviews lasted a median of 39
41 minutes (IQR: 28-50).
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50
51 The central phenomenon grounded in these data was *recalibration of the self*. There
52 were three themes contributing to this: *mental representation of prior self; current self,*
53 *and construction of the future self*. The interaction between these themes and their
54 contribution to the overall theory is displayed graphically in Figure 2.
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3 When questioned about early physical function and mobilisation patients recalled a
4 discrepancy at the time of recovering awareness between their *current self*, which
5 incorporates their physical dependency, fatigue, clarity of mind, and self-image; and the
6 mental representation of themselves, which is still consistent with their *preadmission*
7 *self*. This discrepancy seemed due to episodic memory loss of their admission period.
8
9 Additionally, patients lacked some of the cognitive requirements for prospection at this
10 point²⁶ and therefore they struggled to envisage a compelling future self. This appears to
11 lead on to a period of *recalibration*.
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23 Although this central phenomenon of *recalibration* may seem distinct from the early
24 rehabilitation experience which was the focus of this study, it was quite the opposite,
25 with the process of *recalibration* seeming inextricably linked to the rehabilitation
26 experience. Rehabilitation should push people physically, this helps patients to challenge
27 and explore their current functional level, thereby reconciling the difference between
28 their physical self and the cognitive image of themselves. The process of therapy goal
29 setting also challenges their capacity to think about the future; discussing goal setting
30 with participants therefore elucidated the difficulties they may have in constructing a
31 compelling future to act as a motivational force.
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46 The rationale and contributing themes are presented below. Supporting evidence is
47 presented in Table 2.
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51 **Episodic memory loss**

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55 Fundamental to the patient experience of rehabilitation, and underpinning the
56 theoretical interpretation was patients' episodic memory loss (i.e. loss of a specific
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3 autobiographical event) of their admission to ICU, regardless of their admission
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5 background or diagnosis. In some cases this memory gap lasted weeks, with some
6
7 participants unable to recall any rehabilitation sessions on ICU at all, citing their ward
8
9 rehabilitation sessions as their first experiences. The first clear memory *for all*
10
11 participants was a family member at the bedside. This frequently elicited a tearful
12
13 response, George: *"(my first memory on awakening) was my mother stroking my arm,*
14
15 *saying 'Mum's here'... that was some 30 days after my admission"*. This memory loss is
16
17 of paramount importance, as it made it difficult for participants to rationalise and
18
19 understand their current situation.
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26 **Hallucinations and delusions**

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29 All patients' experienced vivid hallucinations that often involved torture and trying to
30
31 escape; some however were pleasant experiences, such as a friendly dog in the ICU.
32
33 Those with a history of recreational drug use seemed less shocked by hallucinations and
34
35 able to rationalise their mental state, John: *"you're pumped full of so many drugs, it*
36
37 *doesn't surprise me that you're tripping out."* Perceived stigma influenced patients'
38
39 comfort in discussing hallucinations with staff, EJC: *"Did you tell anyone about the*
40
41 *hallucinations at the time?"* Tom: *"No... I just felt a bit silly"*.
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48 **Weakness**

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50 On awakening patients reported frustration at their inability to communicate and were
51
52 shocked by the severity of their weakness, as mentally they still saw themselves as
53
54 capable of the physical tasks they were able to do pre-admission; Sasha: *"I didn't realise I*
55
56 *couldn't walk. I thought I could and I tried to get out of bed loads of times, but up here I*
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3 was weak (legs) and the top of my arms were weak as well. I couldn't do it." Their actual
4 physical-self and cognitive representation of themselves did not match, Sarah "I just
5
6 happened to catch sight of my whole body (in the mirror) and I nearly died. I thought;
7
8 'that doesn't resemble the person that I am'." However, it was the psychological
9
10 symptoms that were of the greatest concern to patients initially, Evan: "oh there were
11
12 tubes all over the place... but that was the least of my worries. The specialists were there,
13
14 and my son. I said 'I don't know who that is (son)'. My son came back on the Monday,
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16 then I recognised him and things started falling back into place."
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23 **"Noxious cycle" of ICU**

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27 Overwhelming fatigue, insomnia (due to noise and disruption), boredom and the
28
29 inability to concentrate were prevalent, which had a negative impact on the ability to
30
31 engage in both physical rehabilitation and cognitive tasks, and made many fear early
32
33 rehabilitation, John: "Physically tiring, emotionally, you're like "sh*t, really? I've got to do
34
35 it (physiotherapy) now. I haven't got any energy at all." Procedural pain was reported in
36
37 only a few instances, but discomfort was problematic, for example, from being
38
39 'swaddled' in blankets (John). For many this seemed to form a "noxious cycle" (Figure 3).
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45 **Humanisation of care**

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47
48 Participants' valued "humanised" care, often remembering the staff members who
49
50 made them laugh and feel safe, Caroline: "I remember one bloke, one nurse, who- he
51
52 would come in and smile, and I said 'Oh, you're always smiling. You make me so happy'."
53
54
55 Trust in the clinical team was also important; if trust was compromised then it had a
56
57 negative impact on their engagement with rehabilitation. Trust seemed dependent on
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1
2
3 the rapport the staff member developed with the patient, including their ability to
4
5 communicate, honestly and to maintain patient's hope, Michelle: *"I trust him... because*
6
7 *when Tom (physiotherapist) says something, it's true. Everything he said was true."*

8
9
10 However, the staff patient interaction was not always positive, with many patients
11
12 describing examples of *de-humanised care*²⁹. This included loss of agency: *"I feel so not*
13
14 *free, everyone is doing what they want, I'm like a puppet and I hate that"* (Michelle); and
15
16 feeling isolated: *"I don't think I had a voice at one point, which was probably one of the*
17
18 *most difficult things to experience, because you can't talk to people"* (Richard).
19
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22
23 The physical attributes of staff also influenced patients' rehabilitation experience, if
24
25 physiotherapists looked small, young, and weak, then patients had less trust in their
26
27 physical ability to keep them safe during early mobilisation, David: *"He (the physio) was*
28
29 *strong of course. One admires that. It's an ability, you know; and of course, not*
30
31 *everybody's going to have that ability."*
32
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36 **Recognising milestones to recovery and goal setting**

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38
39 This vulnerability described by patients and relatives seemed to lead to a sense of
40
41 desired paternalism in the early days; they did not feel ready to be in control. This was
42
43 further perpetuated by a lack of understanding of the stages of recovery. Michelle; *"The*
44
45 *other day the whole ward congratulated me- and even now I feel embarrassed – because*
46
47 *I washed myself. I didn't wait until now to know how to wash myself; I thought it was so*
48
49 *stupid."* The memory loss of their admission meant that patients did not recall their
50
51 acute stages of illness, and hence their physical decline: the weakness that they were
52
53 experiencing did not make sense, and was often so severe that it made it difficult to
54
55 envisage the next steps in their recovery. As a result, patients did not always recognise
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3 basic functional tasks as rehabilitation or indeed their achievements as progress. Tom:
4
5 *“how you are improving may not be quite so obvious to the patient”*. Therapeutic
6
7 adjuncts, such as the use of a bed bike or tilt table, were more commonly recalled as
8
9 rehabilitation.
10
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14 As patients had limited understanding of the recovery milestones early on, they wanted
15
16 the multi-disciplinary team to set their rehabilitation goals as...*“they did not know what*
17
18 *goals to set”* (Jim). Patient involvement in early goal setting was described as like *“being*
19
20 *in a car crash and someone asking you how you want to be cut out.”* Most patients had a
21
22 ‘just get on with it’ approach to rehabilitation. Martin: *“I just blind folded said, ‘if this is*
23
24 *what I am supposed to do, I will do it.”* However, despite desiring early clinician led
25
26 rehabilitation, all patients identified a high-level goal that aligned to the core values of
27
28 who they are, examples include, returning to work on oil rigs, going on holiday, finishing
29
30 a PhD, and getting married.
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36 As patients progressed through the stages of recovery, they started to recognise smaller
37
38 functional gains as improvement and engaged more in the goal-setting and
39
40 rehabilitation planning process, Sarah: *“Well, I was shocked at how little I could do, but*
41
42 *now, it's the other way, I'm actually shocked at how much I can do and I am doing. It's*
43
44 *really good.”* Their yardstick for comparison now became who they were on awakening,
45
46 and not who they were prior to admission; they were recalibrating.
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52 This is encapsulated in one key quote:
53

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55 Ben: *“The first days when I couldn't move... I was disillusioned with the whole thing, and I*
56
57 *thought, ‘This is never going to work’... I couldn't see how anything could turn round, but*
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3 *I was told just to trust. But that period was very difficult because when you don't see any*
4 *light at the end of the tunnel, it's difficult to sort of engage with it, and it's difficult to*
5 *trust... There was plans in my head, but it's difficult to kind of have them if you think it's*
6 *just a waste of time what you're doing. Now I know that there is (light at the end of the*
7 *tunnel)... and I believe I'll be walking next week, they've (physiotherapists) let me believe*
8 *that".*
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18 **Discussion**

21
22 This work focused on exploring the experience of rehabilitation after critical illness,
23 however as with inductive research, what transpired was a complex theory of recovery
24 extending beyond the physical. Patients demonstrated an interruption to personal
25 narrative, a lost sense of self associated with loss of autonomy, temporary desired
26 paternalism and gave examples of accidental dehumanised care (albeit mostly non-
27 maleficent in intent). Delirium, sleep deprivation, fatigue and memory loss acted as
28 potent mediators between the patients' physical impairments, and their ability to
29 recalibrate to their new disability, and engage in rehabilitation.
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42 It is interesting to consider these findings in the context of established psychological
43 theory. Deci & Ryan's Self-Determination Theory^{30,31} attempts to explain why people
44 engage in goal-orientated behaviour, exploring how this leads to well-being and personal
45 growth. Its three core concepts are: *autonomy* (the ability to be in control of oneself),
46 *competence* (the ability to manage the situation they are in) and *relatedness* (the ability
47 to have an emotional connection with others). Only when these needs are met can
48 intrinsic motivation flourish. Critical illness strips patients of *autonomy* and *competence*,
49 and perhaps for a shorter period, *relatedness*. Critical care patients are unable to
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3 communicate, move, talk, make decisions, and may have hallucinations and be too
4
5 fatigued to engage in decision making. Hence, loss of *autonomy* and *competence* are key
6
7 features of the patient experience. *Relatedness* which may recover earlier (or be
8
9 encouraged) is of paramount importance to them, and was a motivator to engage in
10
11 rehabilitation.
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15
16 Markus and Nurius (1986) developed a theory called “The Possible Self”³²; they contend
17
18 that humans have different cognitive representations of who we are (*current self*) and
19
20 who we could be (*possible self*). *Possible selves* drive behaviour. A notion of the *possible*
21
22 *self* helps us to assess our *current self*; by creating a comparison for self-evaluation;
23
24 therefore this concept is innately linked with goal setting.
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29 *The possible self* and goal setting also rely heavily on temporality, therefore requiring
30
31 narrative of the past, and the capacity to prospect. Physiologically, prospection depends
32
33 on episodic memory, prospective memory, emotional stability and hypothetical
34
35 thinking²⁸; some of which can be impaired in critical illness due to sleep deprivation,
36
37 fatigue and delirium.
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42 On awakening, patients’ immediate cognitive representation of their *current self*
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44 matched their pre-admission self because they do not remember their functional
45
46 decline; however, their body had changed. Their mental image of their *current self* and
47
48 their *physical self* are not aligned. Furthermore, patients could not remember the
49
50 totality of their past, they did not recognise their present, and they struggled to
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52 construct a compelling future self. This impaired their ability to engage in rehabilitation
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54 goal setting and led to a sense of vulnerability, desired paternalism and emphasis on
55
56 *relatedness*.
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3 This theory of *recalibration* ties these established psychological ideas together, reflecting
4 the need for patients to explore their new self, adapt to it and allow it to become their
5 new yardstick. When this was achieved, smaller milestones in recovery became
6 meaningful goals. Others have described similar concepts as a *liminal* state. Liminality is
7 an anthropological term from the Latin word *līmen*, meaning threshold³³. It refers to
8 someone who is transitioning. It is often associated with a change in role/identity; or a
9 loss of one self, to be replaced with another. This can create inner turmoil, especially if
10 that change is not invited.
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15 This idea of liminality in ICU has been touched upon by a number of authors^{27,33-36}. Kean
16 and colleagues²⁷ identified 'unscheduled status passage' from *prior self* to *critically ill self*
17 as a theme in a longitudinal study of ICU survivorship. They found that this unscheduled
18 liminal stage is worsened by memory loss and delirium; and that this process of change
19 is temporal in nature, both progressing and regressing (in the event of decline). In order
20 to move on, patients need to regain autonomy.
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24
25 Lindberg and colleagues³⁵ described what recovering autonomy looks like, suggesting
26 that patients go through four stages; the first is to acknowledge their dependence (or
27 paternalism), then they strive to be recognised as a person ("humanised" care). These
28 two stages echo the findings of this study. The latter two stages are 'invited participation
29 in care', and 'becoming a co-partner in the decision-making'. These stages describe how
30 staff coach patients to take control again through mutual trust, understanding and co-
31 determination.
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36 Although these may seem like abstract concepts, it is the authors' view that they have
37 direct relevance to clinical practice; especially as early rehabilitation becomes a key
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3 aspect of acute care. The reason for this is because perception of self and engagement
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5 in rehabilitation and goal setting are inextricably linked²⁶.
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9 If a person's mind is telling them one thing about who they are and what they are
10
11 capable of doing, and their body is telling them another, they cannot start thinking about
12
13 the future until they reconcile that difference. They cannot reconcile that difference with
14
15 delirium, hallucinations and lack of episodic memory to justify their current situation and
16
17 facilitate hypothetical thinking and prospection²⁹.
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22 Goal setting depends on the capacity to prospect; it is also a key recommendation in the
23
24 UK National Institute for Health and Care Excellence (NICE) Guidelines for Rehabilitation
25
26 after Critical Illness³⁷, and NICE Quality Standards³⁸. The Quality Standards state that
27
28 rehabilitation goals should be set within 4-days of admission, and ideally should be
29
30 patient agreed. These data would suggest that asking *patients* to set goals at day 4 may
31
32 for many be premature. Further research exploring the application of the model of
33
34 recovering autonomy described by Lindberg³⁵, may assist in tailoring rehabilitation
35
36 guidelines to the specific needs of the critically ill.
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42 Further focus on *how* rehabilitation is delivered, not just *what* is delivered could also be
43
44 instructive. The impact of the dynamic between a sports coach and the players is well
45
46 known; yet this coaching dynamic is neglected somewhat in ICU rehabilitation. If
47
48 clinicians are able to assist patients in recalibrating to their *new current self*, and the
49
50 reconstruction of a compelling *future self*, it may improve patient care and outcome.
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53 Further research will be needed to confirm the concepts identified in this initial
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55 exploratory study. However, we believe the concepts identified are sufficiently plausible
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3 and robust to pose challenges to clinicians working with recovering critically ill patients
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6 (outlined in Box 1).
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9 **Box 1: Key observations and challenges to practice.**
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11 **Key observations**

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13 ❖ Patients recovering consciousness during or after a critical illness are likely to be
14 shocked by the transition through which they have gone; part of that shock is the
15 restoration of their autobiographical story after a largely unplanned interruption.
16
17 ➤ How can you help to fill the gaps in autobiographical memory?
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22 ❖ Patients' immediate memory is of who they were and what they were able to do
23 before their critical illness; this is in collision with what they can actually do and a
24 period of recalibration is needed to allow people to align the two and develop
25 reasonable ambitions and goals.
26
27 ➤ How can you support patients to explore their current function and settle the
28 discrepancy between expectations and reality?
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35 ❖ This recalibration is the development of an understanding of the relationships
36 between their past, present and possible futures selves.
37
38 ➤ How can you help patients to envisage a compelling future?
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42 ❖ Because of this need for recalibration along with delirium and impaired cognition
43 patients may need, and wish for, very significant assistance in planning early
44 rehabilitation; as autonomy recovers, so patients can become fully involved.
45
46 ➤ How can you recognise and support recovering autonomy?
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51 ❖ Motivation and engagement are crucial in maximising the benefits of rehabilitation;
52 leveraging human relationships (relatedness) and encouraging autonomy are likely to
53 be helpful, care that is de-humanising, even if "efficient" is likely to impair recovery.
54
55 ➤ How can humanisation of care be optimised in your ICU?
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5
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References:

1. Puthuchearry ZA, Rawal, JR, McPhail M, Connolly B, Ratnayake G, Chan P, Hopkinson NS, Phadke R, Dew T, Sidhu PS, Velloso C, Seymour A, Agley CC, Selby A, Limb M, Edwards LM, Smith K, Rowlerson A, Rennie MJ, Moxham J, Harridge S, Hart N, Montgomery HE. Acute Skeletal Muscle Wasting in Critical Illness. *JAMA*, 2013; 310 (15), 1591-1600.
2. Friedrich O, Reid MB, Van den Berge G, Vanhorebeek I, Hermans G, Rich MM, Larsson L. The sick and the weak: Neuropathes/myopathies in the critically ill. *Physiol Rev*. 2015; 95 (3), 1025-109.
3. Hermans G, & Van den Berghe G. Clinical review: intensive care unit acquired weakness. *Crit Care*. 2015; 5 (19), 274.
4. Cavalazzi R, Saad M, Marik PE. Delirium in the ICU: an overview. *Ann Intensive Care*. 2012; 2 (49).
5. Kress JP & Hall JB. Intensive care unit acquired weakness and recovery from critical illness. *N Eng J Med*. 2014; 370, 1626-1635.
6. Cuthbertson BH, Elders A, Hall S, Taylor J, MacLennan G, MacKirdy F, Mackenzie SJ, and the Scottish Critical Care Trials Group and the Scottish Intensive Care Society Audit Group. Mortality and quality of life in the five years after severe sepsis. *Critical Care*. 2013; 17, R70.
7. Kaukonen K-M, Bailey M, Suzuki S, Pilcher D, Bellomo R. Mortality related to severe sepsis and septic shock among critically ill patients in Australia and New Zealand, 2000-2012. *JAMA*. 2014; 311 (13), 1308-1316.
8. Hill AD, Fowler RA, Pinot R, Herridge MS, Cuthbertson BH, Scales DC. Long-term outcomes and healthcare utilization following critical illness – a population-based study. *Critical Care*. 2016; 20, 76.
9. Pandharipande P, Girard TD, Jackson JC, Morandi A, Thompson JL, Pun NE, Brummel CG, Highes EE, Vasilevskis AK, Shintani KG, Moons SK, Geevaghese A, Canonico RO, Hopkins RO, Bernad GR, Dittus RS, Ely EW. Long-Term Cognitive Impairment after Critical Illness. *N Engl J Med*. 2013: 369, 1306-1316.
10. Nydahl P, Sricharoenchai T, Chandra S, Kundt FS, Huang M, Fischill M., Needham D.M. Safety of Patient Mobilization and Rehabilitation in the Intensive Care Unit.

- 1
2
3 Systematic Review with Meta-Analysis. *Annals of the American Thoracic Society*.
4 2017; 14 (5).
5
6
7 11. Castro-Avila AC, Seron P, Fan E, Gaete M, Mickan S. (2015) Effect of early
8 rehabilitation during Intensive Care Unit stay on functional status: systematic review
9 and meta-analysis. *PLoS ONE*. 2015; 10 (7), e0130722.
10
11 12. Balas MC, Burke WJ, Gannon D, Cohen MZ, Colburn L, Bevil C, Franz D, Olsen KM, Ely
12 WE, Vasilevski EE (2013) Implementing the awakening and breathing coordination,
13 delirium monitoring/management, and early exercise/mobility bundle into everyday
14 care: opportunities, challenges, and lessons learned from implementing the ICU
15 pain, agitation and delirium guidelines. *Crit Care Med*. 2013; 41: S116-S127.
16
17 13. Balas MC, Vasilevskis EE, Olsen KM, Schmid KK, Shostrum V, Cohen MZ, Peitz G,
18 Gannon DE, Sisson J, Sullivan J, Stohtert JC, Lazure J, Nuss SL, Jawa RS, Freihurt F, Ely
19 EW, Burke WJ. (2014) Effectiveness and safety of the awakening and breathing
20 coordination, delirium monitoring/management, and early exercise/mobility bundle.
21 *Crit Care Med*. 2014; 42:1024-1036.
22
23 14. Connolly B, Douiri A, Steier J, Moxham J, Denehy L, Hart N. A UK survey of
24 rehabilitation following critical illness: implementation of NICE Clinical Guidance 83
25 (CG83) following hospital discharge. *BMJ Open*. 2014; 4; e004963.
26
27 15. Jensen JF, Thomsen T, Overgaard D, Bestle MH, Christensen D, Egerod I. Impact of
28 follow-up consultations for ICU survivors on post-ICU syndrome: a systematic review
29 and meta-analysis. *Intensive Care Med* (2015) 41:763–775
30
31 16. Nydahl P, Parker RA, Bartoszek G, Dubb R, Filipovic,S, Flohr H-J, Kaltwasser A, Mende
32 H, Rothaug O, Schuchhardt D, Schwabbauer N, Needham D. Early Mobilization of
33 Mechanically Ventilated Patients: A 1-Day Point-Prevalence Study in Germany.
34 *Critical Care Medicine*. 2014; 42 (5), 1178-1186.
35
36 17. Berney SC, Rose JW, Bernhardt J, Denehy L, Prospective observation of physical
37 activity in critically ill patients who were intubated for more than 48 hours. *Journal*
38 *of Critical Care*. 2015; 30(4), 658-663.
39
40 18. Hodgson CL, Stiller K. Needham D, Tipping CJ, Harrold M, Baldwin CE, Bradley S,
41 Berney S, Caruana LR, Elliott D, Green M, Haines K, Higgins AM, Kaukonen KM,
42 Leditschke IA, Nickels MR, Paratz J, Patman S, Skinner EH, Young PJ, Zanni JM,
43 Denehy L, Webb SA. Expert consensus and recommendations on safety criteria for
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 active mobilisation of mechanically ventilated critically ill patients. *Critical Care*.
4 2014; 16:658.
5
6
7 19. Parry S, Knight LD, Connolly B, Baldwin C, Puthuchery Z, Morris P, Mortimore J, Hart
8 N, Denehy L, Granger CL. Factors influencing physical activity and rehabilitation in
9 survivors of critical illness: a systematic review of quantitative and qualitative
10 studies. *Intensive Care Med*. 2017; 43, 531–542.
11
12
13 20. Wright SE, Thomas K, Watson G, Baker C, Bryant A, Chadwick, TJ, Shen J, Wood R,
14 Wilkinson J, Mansfield L, Stafford V, Wade C, Furneal J, Henderson A, Hugill K,
15 Howard P, Roy A, Bonner S, Baudouin S. Intensive versus standard physical
16 rehabilitation therapy in the critically ill (EPICC); a multicentre, parallel-group,
17 randomised controlled trial. *Thorax*. 2017; (5).
18
19
20 21. Sottile PD, Nordon-Craft A, Malone D, Schenkman M, Moss M. Patient and family
21 perceptions of physical therapy in the medical intensive care unit. *Journal of Critical*
22 *Care*. 2015; 30, 891-895.
23
24 22. Mills, J., Bonner, A., Francis, K. (2006) The development of constructivist grounded
25 theory. *International Journal of Qualitative Research Methods*. 5 (1).
26
27 23. Mental Capacity Act (2005). UK legislation. Available at:
28 <https://www.legislation.gov.uk/ukpga/2005/9/contents>
29
30 24. Corbin, J. & Strauss, A. (2015) *Basics of qualitative research: techniques and*
31 *procedures for developing grounded theory*. 4th edition. London
32
33 25. Heath H, Cowley S. Developing a grounded theory approach: a comparison of Glaser
34 and Straus. *International Journal of Nursing Studies*. 2004; 41, 141-150.
35
36 26. Bonde, D. (2013) *Qualitative Interviews: When enough is enough*. Research by
37 Design.
38
39 27. Kean S, Salisbury LG, Rattray J, Walsh TS, Huby G, Ramsey, P. 'Intensive Care Unit
40 (ICU) Survivorship' – a constructivist grounded theory of surviving critical illness.
41 *Journal of Clinical Nursing*. 2017. [online].
42
43 28. Osman M. What are the essential cognitive requirements for prospection (thinking
44 about the future)? *Frontiers in Psychology*. 2014;5, 626.
45
46 29. Todres L, Galvin KT, Holloway I. The humanisation of healthcare: a value framework
47 for qualitative research. *International Journal of Qualitative Studies on Health and*
48 *Well-being*. 2009; 4, 68-77.
49
50
51
52
53
54
55
56
57
58
59
60

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2
3 30. Deci EL, Ryan RM. Intrinsic motivation and self-determination in human behavior.
4 New York, NY: Plenum. 1985.
5
6
7 31. Deci EL, Ryan RM. (2017) <http://selfdeterminationtheory.org/theory/> (Accessed:
8 30th March 2017)
9
10 32. Markus H & Nurius P. Possible Selves. *American Psychologist*. 1986; 41 (9), 954-969
11
12 33. Johnston LB. Surviving Critical Illness: A Case Study in Ambiguity. *Journal of Social*
13 *Work in End-of-Life & Palliative Care*. 2011; 7 (4), 363-382.
14
15 34. Darbyshire JL, Greig PR, Vollaam S, Young DJ, Hinton L. "I Can Remember Sort of Vivid
16 People... but to Me They Were Plasticine." Delusions on the Intensive Care Unit:
17 What Do Patients Think is Going on? *PLoS ONW*; 11 (4): e0153775.
18
19 35. Lindberg C, Sivberg B, Willman A, Fagerstrom C. A trajectory towards partnership in
20 care – patients perspective of autonomy in intensive care: A qualitative study.
21 *Intensive and Critical Care Nursing*. 2015;31: 294-302.
22
23 36. Craig A, Tran Y, Middleton J. (2017) Chapter Three: Theory Of Adjustment Following
24 Severe Neurological Injury: evidence Supporting The Spinal Cord Injury Adjustment
25 Model. *Horizons*. In: Andres Costa, A & Villalba, E. (eds) *Neuroscience Research*.
26 Volume 29. Nova Science Publishers, Inc., New York.
27
28 37. National Institute for Health and Clinical Excellence. Great Britain. *Rehabilitation*
29 *After Critical Illness Great Britain*. Available at: www.nice.org.uk. 2009.
30
31 38. National Institute for Health and Clinical Excellence (2017). *Rehabilitation after*
32 *Critical illness in adults: Quality Standard*. Published 7th September 2017. Available
33 online: nice.org.uk/guidance/qs158. (Accessed: 13th September 2017)
34
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36
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Table 1: Summary of each participant

Pseudonym (male/female [M/F])	Relative present?	APACHE II	Diagnosis	Length of stay, ICU (days)	Length of stay, hospital (days)	Discharge location
Richard (M)	No	17	Acute porphyria	9	102	Long-term, inpatient rehabilitation
Martin (M)	No	14	Drug overdose, aspiration pneumonia, rhabdomyolysis	26	32	Home, outpatient rehabilitation
Sadiq (M)	No	22	Exacerbation of COPD	33	34	Home, full care package
Sarah (F)	No	24	Open hernia repair- post operative MOF	115	197	Long-term, inpatient rehabilitation
Tom (M)	No	10	Pneumonia and pulmonary embolism	10	16	Home, outpatient rehabilitation
Evan (M)	No	15	Acute bowel obstruction- colon cancer	5	48	Home, no rehabilitation.
Sasha (F)	Yes, daughter	10	Neuromyelitis optica	19	98	Long-term, inpatient rehabilitation
John (M)	No	27	Influenza	33	71	Long-term, inpatient rehabilitation
George (M)	No	12	Drug overdose- respiratory failure	25	36	Home, no rehabilitation
Michelle (F)	No	14	Exacerbation of COPD	6	42	Declined inpatient rehabilitation- home, full care package
Jim (M)	Yes, wife	11	Food poisoning- MOF	10	18	Home, no rehabilitation
Matthew (M)	No	18	Hospital acquired pneumonia- fractured NOF	5	178	Nursing home
Caroline (F)	Yes, husband	22	Anterior resection for bowel cancer	13	63	Short-stay, inpatient rehabilitation.
Ben (M)	No	15	Drug overdose	65	107	Home, care package
David (M)	Yes, wife present	21	Influenza	150	232	Long-term, inpatient rehabilitation

(NOF-neck of femur; MOF-multi-organ failure; COPD-chronic obstructive pulmonary disease)

Table 2: Supporting data

Recalibration of the self	
Interruption in memory	<p>ICU admission</p> <p>Sasha: "...that's when I don't know, it's a real black after that (the emergency room)"</p> <p>Sadiq: "That is a black. That is a blank. Totally blank"</p> <p>John: "I must have been in and out of consciousness, because I don't remember anything"</p> <p>Ben: "I had a bad fall, collapsed... that's all I remember"</p> <hr/> <p>Rehabilitation and mobilization</p> <p>EJC: "what was your memory of getting moving after you woke up with the tubes attached?" Ben: "I don't really have much memory of it."</p> <p>EJC: Do you remember any of the rehab on ICU?" Martin: "Not to start with, no."</p> <p>David: "It was Dan (ward physiotherapist) who taught me to sit on the edge of the bed."</p> <p>EJC: "Do you remember getting into the chair for the first time?" Michelle: "It was with Tom (the ward physical therapist)."</p>
Hallucinations	<p>John: "I kept thinking I could see like people with hoodies and they were like assassins, trying to get in."</p> <p>David: "I was taken into Soho (Central London) by some people and stuck under a glass floor, lying under a glass floor with formaldehyde around me. I was encased."</p> <p>Ben: "I operated on Margaret Thatchers cat and there was eight other people in the house and three of them got shot... I remember waking up with the fear that I was going to get shot."</p> <p>Carolyn: "I was trying to use my mobile (to escape), and the same number kept on pressing and I remember panicking"</p>
Weakness	<p>George: "Nothing, I couldn't move my hand. I couldn't move and that was really scary. Really scary."</p> <p>Richard: "I couldn't do anything. I was paralyzed from the neck down... I still felt like I had sensation in my legs and my arms, I just couldn't move them."</p> <p>Carolyn: "I couldn't even stand up. I was really very, very weak."</p> <p>John: "I couldn't do anything. I mean literally, I couldn't move, I could just barely</p>

	<p>move my fingers.”</p> <p>David: “I couldn’t move. I couldn’t move at all. I could blink, that’s about it.”</p> <p>Martin: “...couldn’t walk, couldn’t do nothing.”</p>
<p>Noxious cycle of ICU</p>	<p>Sarah: “I didn’t want to do it (physiotherapy). I used to dread them coming, any excuse to get out of it. I was just so tired.”</p> <p>John: “Physically tiring, emotionally... you’re like ‘sh*t really? I’ve got to do it (mobilization) now? I haven’t got any energy at all.”</p> <p>George: “There were some days when they’d (physiotherapist) come and they’d get me into the chair, and they’d want to do some work on the zimmer frame. They’d come back (from getting the zimmer frame) and I’d be asleep.”</p> <p>Sarah: “People kept telling me to read, but I couldn’t. I couldn’t’ actually physically read. They’d bring me the menu and I just couldn’t do it, and then I’d fall asleep”</p>
<p>Relatedness</p>	<p>Researcher: “What have been the things that have kept you going?” Sasha: “I think Gemma (daughter) and her dad, they’ve been so supportive. He’s been down every day, and Gemma sometimes twice a day *starts crying* ... sorry...I suppose if it wasn’t for them, I wouldn’t be... *crying- unable to finish sentence*</p> <p>Sarah: “I cry a lot...something helped me to keep going, an inner strength came...the kids...”</p> <p>Richard: “Obviously I was doing it (rehab) for me primarily, but knowing how much concern and love she has for me, and knowing how much it would mean to her and how much of a relief it would be to her... The fact that she was, you know with me for as long as she was, and as strong as she was... I don’t know. I never thought my mum was that strong.”</p>
<p>Loss of autonomy and competence</p>	<p>Richard: “You are reliant entirely on the people around you, for everything really... that’s difficult.”</p> <p>Sarah: “...then I just accepted it (weakness), going...on the hoist and, you lose all dignity when you’re in that state you just accept it, and you just let them help you as much as possible and when you’ve done your, you know bits of physio, exhausted, you go back to bed again, sleep again. You know it tended to be like that.”</p>
<p>Recovery milestones and goal setting</p>	<p>Matthew: “Let the patient realize that he is not capable of doing that, or this, or whatever... don’t tell him”</p> <p>Tom: “Everyone’s functions, and how they are improving, might not be quite so obvious to the patient.”</p>

	<p>Carolyn: "The other day the whole ward congratulated me- and even now I feel embarrassed – because I washed myself. I didn't wait until now to know how to wash myself; I thought it was so stupid."</p> <p>Jim's wife: "We didn't want to set the goals, because we didn't know what goals to set"</p> <p>Sadiq:"It depends on the person. If a person is shooting to the high, they might do it (achieve their goal), but sometimes shooting too much to the high might break your neck. If they are too sick, they cannot talk, you are in the dark and you have to put your own objectives."</p>
<p>Conflict between current self and cognitive representation of the self</p>	<p>Sasha: "I didn't realize I couldn't walk. I thought I could and I tried to get out of bed loads of times, but up here I was weak (legs) and the top of my arms were weak as well. I couldn't do it."</p> <p>Sarah: "I don't ever look at myself in the mirror and there is a mirror in that bathroom, I just happened to catch sight of my whole body almost and I nearly died. I thought; that doesn't resemble the person that I am."</p>

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3 Figure legends
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6 **Figure 1: Interview topic guide**
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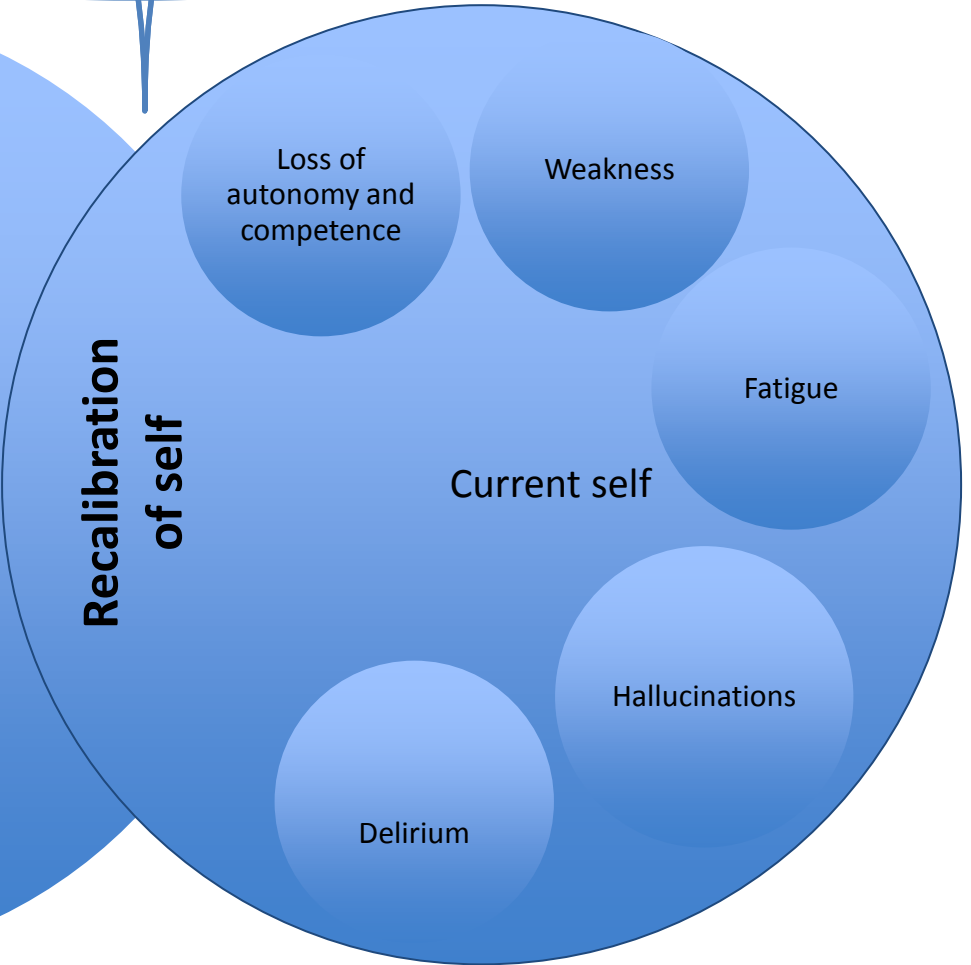
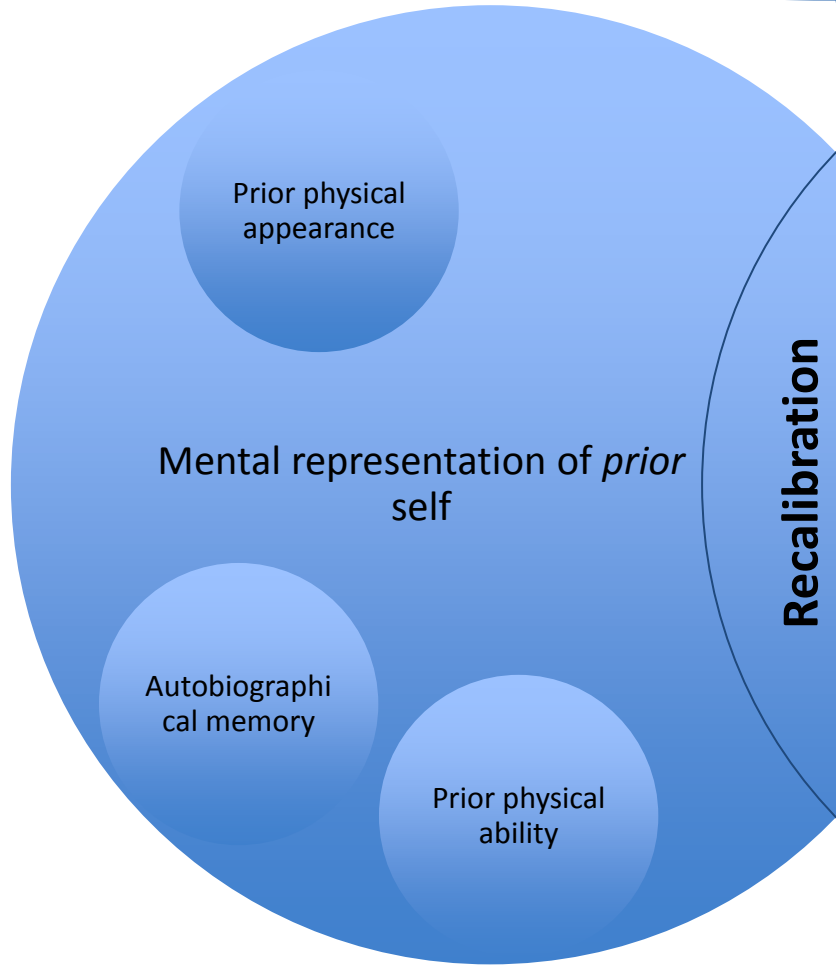
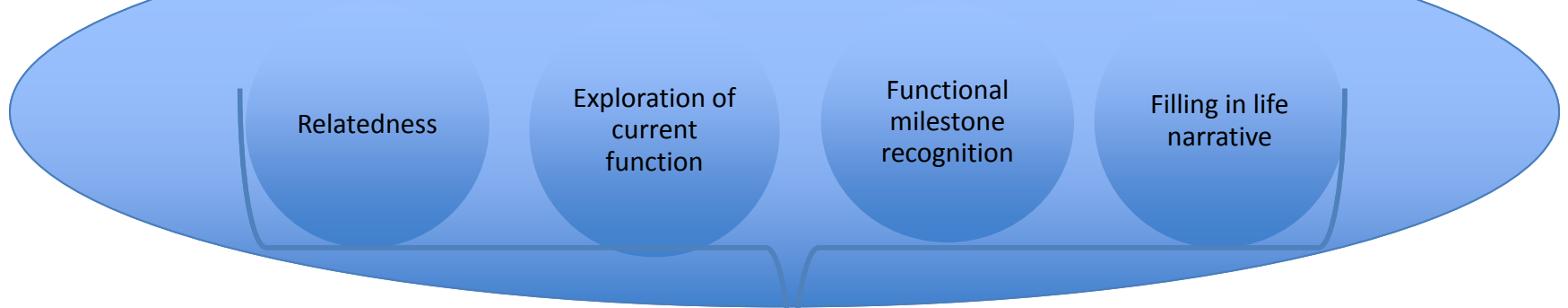
8 **Figure 2: Recalibration of the self:** A theory of rehabilitation and recovery from critical illness. This
9 figure demonstrates the how prior physical appearance and ability, and autobiographical memory
10 feed into a patient's mental representation of their prior self on ICU awakening. However, the
11 current physical self differs- this is informed by symptoms of weakness, fatigue, hallucinations,
12 delirium, and loss of autonomy and competence. Episodic memory loss creates a divide between
13 these two selves (represented by the two way arrow). Recalibration is when the physical self and the
14 cognitive self align. This process of recalibration is facilitated by reconstruction of the future self.
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18 **Figure 3: The noxious cycle of critical illness.**
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Figure 1: Interview topic guide

<p>Topic guide</p> <p>Opening</p> <p>1. Introduction</p> <p>2. Consent confirmed.</p> <p>Questions</p> <p>3. Do you have any questions about the about the patient information sheet?</p> <p>4. Could you tell me about the events leading up to your admission to the ICU?</p> <p>5. Could you summarize, as you remember it, your stay on the ICU including the length of your stay and the procedures you experienced (e.g. surgery, tracheostomy etc)?</p> <p>6. Could you describe any physical problems that you had during and after your stay, such as weakness, pain, joint stiffness etc?</p> <p>7. Could you describe your rehabilitation experience?</p> <ul style="list-style-type: none">- Memories of rehabilitation- Rehabilitation equipment- Interaction with the therapist- Intensity of rehabilitation- Rehabilitation goal setting <p>Closing</p> <p>8. Do you have any additional information you would like to add?</p> <p>9. Do you have any questions?</p> <p>End</p>

Reconstruction of the future self



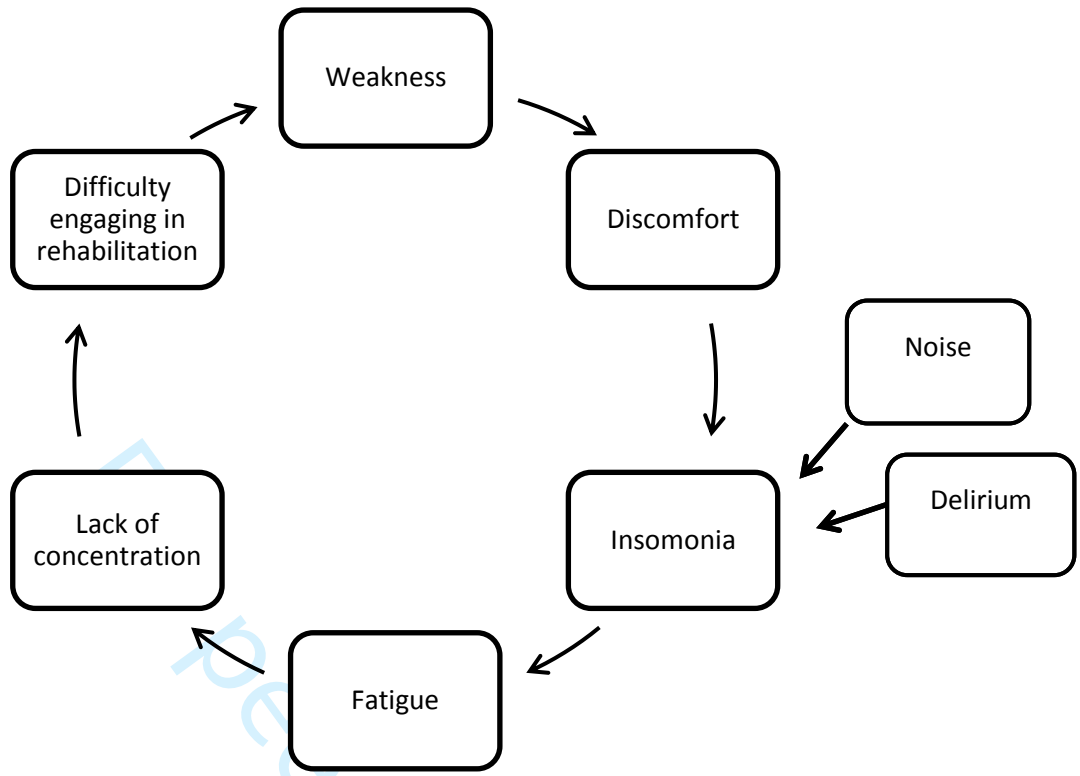


Figure 3: Noxious cycle of ICU

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BMJ Open

A Qualitative, Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery after Critical Illness.

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Title: A Qualitative, Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery after Critical Illness.

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1
2
3 views of The Health Foundation. SJB acknowledges the support of the National Institute for
4
5 Health Research Imperial Biomedical Research Centre
6
7

8
9 **Competing interests:** No competing interests to declare.
10

11
12 **Authors contribution to the study:** EJC, SJB and EJM were involved in the methodological
13
14 design, data analysis and writing and reviewing the manuscript. EJC did all of the interviews and
15
16 data collection.
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20 **Data sharing statement:** All available data can be obtained by contacting the corresponding
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22 author.
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Abstract

Rationale: Physical rehabilitation (encompassing early mobilisation) of the critically ill patient is recognized best practice, however further work is needed to explore the patients' experience of rehabilitation qualitatively; a better understanding may facilitate implementation of early rehabilitation, and elucidate the journey of survivorship.

Objectives: To explore patient experience of physical rehabilitation from critical illness during and after a stay on ICU.

Design: Exploratory grounded theory study using semi-structured interviews.

Setting: Adult medical/surgical ICU of a London teaching hospital.

Participants: A purposive sample of ICU survivors with intensive care unit acquired weakness (ICUAW) and an ICU length of stay of >72 hours.

Analysis: Data analysis followed a four-stage constant comparison technique: open coding, axial coding, selective coding, and model development, with the aim of reaching thematic saturation. Peer debriefing and triangulation through a patient support group were carried out to ensure credibility.

Main results: Fifteen people were interviewed (with four relatives in attendance). The early rehabilitation period was characterized by episodic memory loss, hallucinations, weakness, and fatigue, making early rehabilitation arduous and difficult to recall. Participants craved a paternalised approach to care in the early days of ICU.

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3 The central idea that emerged from this study was recalibration of the self. This is driven by
4
5 a lost sense of self, with loss of autonomy and competence; dehumanized elements of care
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7 may contribute to this. Participants described a fractured life narrative due to episodic
8
9 memory loss, meaning that patients were shocked on awakening from sedation by the
10
11 discrepancy between their physical form and cognitive representation of themselves.
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16 **Conclusions:** Recovery from ICUAW is a complex process that often begins with survivors
17
18 exploring and adapting to a new body, followed by a period of recovering autonomy.
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20 Rehabilitation plays a key role in this recalibration period, helping survivors to reconstruct a
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22 desirable future.
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3 **Key words:** critical care, early mobilisation, rehabilitation, patient experience, recovery,
4 physical therapy.
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7 **Abstract word count:** 298
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13 **Strengths and Limitations of this study**

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16
17 1. This was an exploratory qualitative grounded theory study using semi structured
18 interviews with survivors of critical illness to explore their experience of physical
19 rehabilitation after critical illness; the approach adopted, and the data generated
20 provided an extremely rich source of individual experience with many consistent
21 features.
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23
- 24 2. A constant comparison technique of data analysis was used, and enrolment
25 continued until thematic saturation was reached.
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27
- 28 3. Triangulation and peer debriefing were completed to ensure credibility of the
29 study findings that clearly resonated with an independent group of critical illness
30 survivors.
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- 33 4. The patients were all recruited from one centre, which may limit transferability
34 of findings. Qualitative studies of this kind innately have a small sample size,
35 however, the richness of the data produced allows deep exploration of meaning
36 and model development and thematic saturation was also reached.
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- 39 5. The variation in time to interview may be considered a limitation of this study in
40 view of impaired recall for longer gaps, however, there was no notable
41 difference in the richness of memories and insight provided by those interviewed
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3 at different time points. The variation in time to interview also elucidated the
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5 process of recovery over time.
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11 **Introduction:**

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15 The sequelae of critical illness are well documented with some patients experiencing rapid
16 muscle wasting^{1,2}, which can lead to weakness and functional decline³; coupled with the
17 cognitive consequences of delirium⁴ the result can be a prolonged period of weaning from
18 mechanical ventilation, disability, reduced endurance, anxiety, and depression⁵⁻⁹. To combat
19 this mobilisation, minimising sedation and spontaneous breathing should be instigated early,
20 with research demonstrating safety and likely efficacy¹⁰⁻¹³. Furthermore, on-going
21 rehabilitation following discharge from critical care, and attendance at ICU follow up clinics
22 are also advocated, although research showing direct benefit of these interventions is
23 limited¹⁴⁻¹⁵.
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38 Although implementation of early mobilisation protocols and post-ICU rehabilitation is
39 inconsistent^{14,16-17}, early adopters of these strategies are striving for them to become the
40 norm^{12,13,18}. In such centres, it is not uncommon for patients to receive active out of bed
41 physical rehabilitation whilst receiving full mechanical ventilation, renal replacement therapy,
42 and inotropic support¹⁸. Due to the severity of weakness that can be associated with
43 prolonged critical illness, these rehabilitation sessions are often delivered by two or more
44 therapists/nurses, and can require technical equipment and physical handling. It is perhaps
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3 unsurprising that pain, fatigue, weakness, anxiety, fear, lack of motivation and patient
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5 confidence are reported as barriers and reasons for cessation of early rehabilitation^{19, 20}.

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9 Sottile and colleagues (2015)²¹ completed a survey of patient experience of early mobilisation
10
11 in ICU concluding that patients recognized the importance of early mobilisation, but found it
12
13 difficult, tiring and uncomfortable.
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15
16
17 In spite of current enthusiasm, there is a paucity of literature exploring survivors' experience
18
19 of early mobilisation and physical rehabilitation during and after a stay on ICU in an in-depth
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21 manner. For the purpose of this manuscript, the term 'rehabilitation' is used to encompass
22
23 early mobilisation and physical rehabilitation implemented by physiotherapists from
24
25 admission to ICU.
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30 **Aim:** To explore the patient experience of recovery from critical illness, with emphasis on
31
32 their experience of rehabilitation, and to develop a theoretical model grounded in these data.
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34

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36 **Methods:**

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38
39 **Qualitative approach and research paradigm:** Constructivist grounded theory study²² using
40
41 semi-structured interviews with a purposive sample of adult ICU survivors. Constructivism
42
43 contends that individuals' views are directly influenced by their experiences, and it is these
44
45 individual experiences and views that shape their perspective of reality. Constructivists
46
47 believe that individuals have different realities that will be influenced by context- this is a
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49 'relativist' ontological stance²².
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3 Constructivist grounded theory is an appropriate methodology for this study because it allows
4
5 the researcher to develop a theoretical model to explain the data based on an iterative
6
7 process of data emersion, analysis and interpretation, which recognises and accounts for
8
9 contextual factors.²²
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14 **Setting:** Participants were recruited from the adult medical/surgical ICU of a 430 bedded
15
16 London teaching hospital between November 2015 and September 2016.
17

18
19 **Participants and sampling:** Participants were purposively sampled. Screening and inclusion
20
21 criteria were: English-speaking, a critical stay of >72 hours, capable of providing informed
22
23 consent determined using the Mental Capacity Act assessment²³, anticipated to survive, aged
24
25 over 18 and documented ICUAW determined via case note review (this was to ensure that
26
27 the participants had exposure to rehabilitation interventions.)
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31
32 The clinical team identified potential participants against the broad inclusion criteria stated
33
34 above to ensure that it was appropriate for them to be approached by the research team.
35
36 Notes were screened with the aim of purposively selecting a varied sample of participants
37
38 that could speak to the breadth of emerging themes. If deemed appropriate participants
39
40 were then approached by the lead researcher (EJC) and provided with written information. If
41
42 they had capacity to consent and agreed to participate, written informed consent was gained.
43
44
45 Participants that could not provide informed consent were excluded.
46
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49
50 At the discretion of the participant, relatives were also invited to be present in the interview
51
52 to enable exploration and elucidation of any ICU associated memory loss. As the study
53
54 progressed participants were selected to ensure a heterogeneous sample, with the aim of
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3 achieving thematic saturation^{22,24-26}, for example, targeting varying degrees of ICUAW,
4
5 different genders, and specific age categories.
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8
9 **Ethics:** This study was granted approval by the East of England Ethics committee (REC
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11 reference number 14/EE/1027) and from the Research and Development Department at the
12
13 study site.
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16
17 **Data collection methods:** The semi-structured interviews were conducted by EJC. For
18
19 reflexivity, EJC is research physiotherapist with expertise in critical care and prior training in
20
21 qualitative methods research. EJC also has personal experience of major injury and as a close
22
23 relative of an ex ICU patient. SJB is an ICU medical consultant and is involved with ICU follow
24
25 up clinics, and EJM is a researcher focusing on management and change in the health sector,
26
27 with expertise in qualitative methodology.
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30

31
32 The interviews followed a topic guide designed with input from the Intensive Care Society
33
34 Patient and Relatives Group (Table 1). The questions in the topic guide focused on the
35
36 memory of the admission to ICU, any physical weakness that they encountered, and patients'
37
38 experience of rehabilitation in the ICU and following discharge. The questions were
39
40 intentionally left open to initiate reflections and to allow subsequent detailed exploration of
41
42 the issues that appeared important to the interviewee. The first interview was used as a pilot,
43
44 however, as no changes were made and those data collected from this interview were rich
45
46 and informative, it was retained and analysed in the results.
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52 As the study progressed and themes emerged, participants were asked to elaborate and
53
54 probed on specific issues in line with the constant comparison technique, for example: how
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3 the perception of the physiotherapist's strength influenced their rehabilitation experience;
4
5 how they perceived their body now; what differences there were between their current and
6
7 previous physical function; how they saw their future; and what they defined as physical
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9 rehabilitation.
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14 The interviews were carried out either in the hospital or in the community after ICU discharge.
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16 Enrolment and interviews continued until thematic saturation was reached i.e. no new ideas
17
18 were emerging, as per the criteria outlined by Bonde (2013)²⁶, this was to challenge the
19
20 emergent model and ensure credibility. The interviews were anonymised, recorded, and
21
22 transcribed *verbatim* by a professional transcription company. All transcripts were double-
23
24 checked for accuracy by EJC.
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29 All interviewees were given pseudonyms to ensure anonymity. Further demographic and
30
31 clinical data were also collected from the case notes: age, critical care and hospital length of
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33 stay, APACHE II score, admission diagnosis, residence prior to admission, pre-morbid
34
35 functional level, and hospital discharge destination.
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40 **Data processing and analysis:** Transcripts were uploaded onto Nvivo® software (QSR
41
42 International, Doncaster, Australia) for analysis. They were read and reread by EJC to ensure
43
44 full immersion in the data. Memo writing was used throughout. The first stage of the analysis
45
46 process is 'open coding', which is the identification of primary broad categories; these may
47
48 be around a theme or topic, or more conceptual, such as emotion or attitude. The second
49
50 stage is 'axial coding'; here categories are clustered together into meaningful, related groups.
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52 The third stage is 'selective coding', where core themes are identified. Lastly, the themes are
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3 used to generate a theoretical framework to explain the data^{22,24-26}. Data collection and
4
5 analysis occur concurrently, so that constant comparison was made between emerging
6
7 themes (both within and between narratives), and the literature, allowing model refinement.
8
9
10 After the fourth interview had been transcribed and open coding had been completed, axial
11
12 codes began to form. These ideas were then discussed in detail with the research team. This
13
14 was followed by a dynamic process of reflection after each interview to develop and refine
15
16 the axial codes into selective codes until a model encompassing all elements was developed.
17
18 The last interviews were used to challenge this model and to assess for data saturation. This
19
20 process allowed a central phenomenon to emerge from the data^{22,24-26}. The words used for
21
22 coding were based on the lead researchers interpretation and terms in related literature.
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28 **Techniques to enhance trustworthiness:**

31 **Peer debriefing:**

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35 Peer debriefing was completed via in-depth discussion with SJB and EJM. This was done
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37 regularly throughout the course of the study.
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39

41 **Patient and public involvement**

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44 A patient representative from an ICU support group was consulted in the development of the
45
46 topic guide. An initial draft of the topic guide was developed by the research team and it was
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48 then sent to the patient representative for review and modification, all of their recommended
49
50 changes were made. Patients and public were not involved in the recruitment or conduct of
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3 the study. Participants were given the opportunity to receive information on the results of
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5 the study at their request.
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8 9 **Triangulation**

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12 Triangulation and sense checking was completed through presentation to an ICU survivor
13
14 support group with subsequent dialogue to assess the dependability, confirmability and
15
16 credibility of the model (this did not include interview participants).
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19
20 At the support group the model was presented and then there was opportunity for questions
21
22 and answers with the researcher (EJC). The group were then left to discuss the study between
23
24 themselves and feedback to the research team with any thoughts at a later date to allow
25
26 them to speak openly and frankly with each other. The group lead fed back those participants
27
28 resoundingly agreed with the concepts and felt that the work '*encompassed all the areas that*
29
30 *were important and relevant to those who have experienced critical illness*'. The presentation
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32 also led to a very tearful response from some attendees who reported to have felt
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36
37 'understood'.
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40 41 **Results:**

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44 Eleven hours of qualitative data from 15 participants (with 4 additional relatives present)
45
46 were collected. The *patients* are described in Table 2.
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50 *[Insert table 2: Patient demographics]*
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53 The median ICU and hospital length of stay were 19 days (IQR 8-33) and 63 days (IQR 34-107)
54
55 respectively. The median time between ICU discharge and interview was 56 days (IQR: 36-
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3 80). Ten (66.6%) of the interviews took place at the hospital whilst the patients were still
4 inpatients, and five (33.3%) took place after discharge in the patient's home (n=2), work (n=1),
5 or in a clinic room (n=2). The interviews lasted a median of 39 minutes (IQR: 28-50).
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11 The central phenomenon grounded in these data was *recalibration of the self*. There were
12 two themes contributing to this temporal model of recovery: the transition '*from prior self to*
13 *current self*', and the transition '*from current self to construction of the future self*'. When
14 questioned about early physical function, patients recalled a discrepancy at the time of
15 recovering awareness between their *current self*, which incorporates their physical
16 dependency, fatigue, clarity of mind, and self-image, and the mental representation of
17 themselves, which is still consistent with their *preadmission self*. This discrepancy seemed to
18 be due to episodic memory loss of their admission period. Additionally, patients lacked some
19 of the cognitive requirements for prospection at this point²⁶ and therefore they struggled to
20 envisage a compelling future self. This appears to lead on to a period of *recalibration*.
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36 Although this central phenomenon of *recalibration* may seem distinct from the early physical
37 rehabilitation experience that was the focus of this study, it was quite the opposite, with the
38 process of *recalibration* seeming inextricably linked to the rehabilitation experience. Physical
39 independence and function are core components of the concept of *self*. When physical ability
40 deteriorates so unexpectedly, rapidly, and without obvious causation (as in ICUAW) it comes
41 a shock to the patient blurring their sense of self. Physical rehabilitation aims to improve
42 impairments and function by challenging patients' physical ability thereby, in this extreme
43 context, inadvertently challenging their self-perception as well.
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3 This model suggests that physical rehabilitation within ICU helps patients to challenge and
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5 explore their current functional level and reconcile their self-discrepancy i.e. difference
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7 between their physical self and the cognitive image of themselves. The process of therapy
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9 goal-setting also challenges their capacity to think about the future; discussing goal setting
10
11 with participants therefore elucidated the difficulties they may have in constructing a
12
13 compelling future to act as a motivational force.
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18 The rationale and contributing themes are presented below. Supporting evidence is
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20 presented in Table 3.
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31 ***'From prior self to current self'***

32 33 34 **Episodic memory loss**

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37 Fundamental to the patient experience of rehabilitation, and underpinning the theoretical
38
39 interpretation was patients' episodic memory loss (i.e. loss of a specific autobiographical
40
41 event) of their admission to ICU, regardless of their admission background or diagnosis. In
42
43 some cases this memory gap lasted weeks, with some participants unable to recall any
44
45 rehabilitation sessions on ICU at all, citing their ward rehabilitation sessions as their first
46
47 experiences. The first clear memory *for all* participants was a family member at the bedside.
48
49 This frequently elicited a tearful response, for example, George stated: "*(my first memory on*
50
51 *awakening) was my mother stroking my arm, saying 'Mum's here'... that was some 30 days*
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3 *after my admission*". This memory loss is of paramount importance, as it made it difficult for
4
5 participants to rationalise and understand their current situation.
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8 9 **Hallucinations and delusions**

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11 All patients' experienced vivid hallucinations that often involved torture and trying to escape
12
13 some, however, were pleasant experiences, such as a friendly dog in the ICU. Those with a
14
15 history of recreational drug use seemed less shocked by hallucinations and able to rationalise
16
17 their mental state, for example, John stated: "*you're pumped full of so many drugs, it doesn't*
18
19 *surprise me that you're tripping out.*" Perceived stigma influenced patients' comfort in
20
21 discussing hallucinations with staff, for example, EJC asked Tom: "*Did you tell anyone about*
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23 *the hallucinations at the time?*" Tom replied: "*No... I just felt a bit silly*".
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33 **Weakness**

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35 On awakening patients reported frustration at their inability to communicate and were
36
37 shocked by the severity of their weakness, as mentally they still saw themselves as capable of
38
39 the physical tasks they were able to do pre-admission, for example, Sasha stated: "*I didn't*
40
41 *realise I couldn't walk. I thought I could and I tried to get out of bed loads of times, but up here*
42
43 *I was weak (legs) and the top of my arms were weak as well. I couldn't do it.*" Their actual
44
45 *physical-self* and cognitive representation of themselves did not match, for example, Sarah
46
47 said: "*I just happened to catch sight of my whole body (in the mirror) and I nearly died. I*
48
49 *thought; 'that doesn't resemble the person that I am'.*" However, it was the psychological
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3 symptoms that were of the greatest concern to patients initially, for example, Evan felt that:
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5 *“there were tubes all over the place... but that was the least of my worries. The specialists*
6
7 *were there, and my son. I said ‘I don’t know who that is (son)’. My son came back on the*
8
9 *Monday, then I recognised him and things started falling back into place.”*
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11

12 13 14 **“Noxious cycle” of ICU**

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16
17 Overwhelming fatigue, insomnia (due to noise and disruption), boredom and the inability to
18
19 concentrate were prevalent, which had a negative impact on the ability to engage in both
20
21 physical rehabilitation and cognitive tasks, and made many fear early rehabilitation, for
22
23 example, John stated: *“Physically tiring, emotionally, you’re like “sh*t, really? I’ve got to do it*
24
25 *(physiotherapy) now. I haven’t got any energy at all.”* Procedural pain was reported in only a
26
27 few instances, but discomfort was problematic, for example, from being ‘swaddled’ in
28
29 blankets (John). For many this seemed to form a “noxious cycle” (Figure 1).
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38 39 **Humanisation of care**

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41 Participants’ valued “humanised” care²⁷, often remembering the staff members who made
42
43 them laugh and feel safe, for example, Caroline said: *“I remember one bloke, one nurse, who-*
44
45 *he would come in and smile, and I said ‘Oh, you’re always smiling. You make me so happy’.”*
46
47
48 Trust in the clinical team was also important; if trust was compromised then it had a negative
49
50 impact on participants’ engagement with rehabilitation. Trust seemed dependent on the
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52 rapport the staff member developed with the patient, including their ability to communicate,
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3 honestly and to maintain patient's hope, for example, Michelle stated: *"I trust him... because*
4 *when Tom (physiotherapist) says something, it's true. Everything he said was true."* However,
5
6 the staff-patient interaction was not always positive, with many patients describing examples
7
8 of de-humanised care²⁷. This included loss of agency: *"I feel so not free, everyone is doing*
9
10 *what they want, I'm like a puppet and I hate that"* (Michelle); and feeling isolated: *"I don't*
11
12 *think I had a voice at one point, which was probably one of the most difficult things to*
13
14 *experience, because you can't talk to people"* (Richard).
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21 Although not related to humanisation of care, the physical attributes of staff also influenced
22
23 patients' rehabilitation experience, if physiotherapists looked small, young, and weak, then
24
25 patients had less trust in their physical ability to keep them safe during rehabilitation, an
26
27 example came from David: *"He (the physio) was strong of course. One admires that. It's an*
28
29 *ability, you know; and of course, not everybody's going to have that ability."*
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34 ***'From current self to construction of the future self'***

35 36 37 **Recognising milestones to recovery and goal setting**

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40 The vulnerability described by patients and relatives seemed to lead to a sense of desired
41
42 paternalism in the early days; they did not feel ready to be in control. This was further
43
44 perpetuated by a lack of understanding of the stages of recovery, for example, Tom stated:
45
46 *"how you are improving may not be quite so obvious to the patient"*. The memory loss of their
47
48 admission meant that patients did not recall their acute stages of illness, and hence their
49
50 physical decline; the weakness that they were experiencing did not make sense, and was
51
52 often so severe that it made it difficult to envisage the next steps in their recovery. As a result,
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3 patients did not always recognise basic functional tasks as rehabilitation or indeed their
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5 achievements as progress, for example, Michelle stated: *"The other day the whole ward*
6 *congratulated me- and even now I feel embarrassed – because I washed myself. I didn't wait*
7 *until now to know how to wash myself; I thought it was so stupid."* Therapeutic adjuncts, such
8
9 as the use of a bed bike or tilt table, were more commonly recalled as rehabilitation.
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16 As patients had limited understanding of the recovery milestones early on, they wanted the
17
18 multi-disciplinary team to set their rehabilitation goals as *"they did not know what goals to*
19 *set"* (Jim). The main thing that kept them focused on engaging in rehabilitation at this point
20
21 was their family and loved ones, Sarah described this: *"I cry a lot...something helped me to*
22 *keep going, an inner strength came...the kids..."*
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29 Patient involvement in early goal setting was described as like *"being in a car crash and*
30 *someone asking you how you want to be cut out."* Most patients had a 'just get on with it'
31
32 approach to rehabilitation. Martin: *"I just blind folded said, 'if this is what I am supposed to*
33 *do, I will do it.'" However, despite desiring early clinician-led rehabilitation, all patients*
34
35 identified a high-level goal that aligned to the core values of who they are; examples include,
36
37 returning to work, going on holiday, finishing a PhD, and getting married.
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44 As patients progressed through the stages of recovery, they started to recognise smaller
45
46 functional gains as improvement and engaged more in the goal-setting and rehabilitation
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48 planning process, for example, Sarah stated: *"Well, I was shocked at how little I could do, but*
49 *now, it's the other way, I'm actually shocked at how much I can do and I am doing. It's really*
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3 *good.*" Their yardstick for comparison now became who they were on awakening, and not
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5
6 who they were prior to admission; they were recalibrating.
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8 9 Discussion

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12 This work focused on exploring the experience of physical rehabilitation after critical illness,
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14 however, as with inductive research, what transpired was a complex model of recovery
15
16 extending beyond the physical. Patients demonstrated an interruption to personal narrative,
17
18 a lost sense of self associated with loss of autonomy, temporary desired paternalism and gave
19
20 examples of accidental dehumanised care (albeit mostly non-maleficent in intent). Delirium,
21
22 sleep deprivation, fatigue and memory loss acted as potent mediators between the patients'
23
24 physical impairments, and their ability to recalibrate to their new disability, and engage in
25
26 rehabilitation.
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32 It is interesting to consider these findings in the context of established psychological theory.
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34 Deci & Ryan's Self-Determination Theory^{28,29} attempts to explain why people engage in goal-
35
36 orientated behaviour, exploring how this leads to well-being and personal growth. Its three
37
38 core concepts are: *autonomy* (the ability to be in control of oneself), *competence* (the ability
39
40 to manage the situation they are in) and *relatedness* (the ability to have an emotional
41
42 connection with others). Only when these needs are met can intrinsic motivation flourish.
43
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46
47 Critical illness can strip patients of *autonomy* and *competence*, and perhaps for a shorter
48
49 period, *relatedness*. In the initial stages of critical illness, patients may be unable to
50
51 communicate and talk, be unable to move easily due to weakness, may have hallucinations,
52
53 and be too fatigued to engage in decision making. Hence, loss of *autonomy* and *competence*
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3 are key features of the patient experience. *Relatedness*, which may recover earlier (or be
4 encouraged) is of paramount importance to them, and was a motivator to engage in
5 rehabilitation.
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11 Markus and Nurius (1986) developed a theory called "The Possible Self"³⁰. They contend that
12 humans have different cognitive representations of who we are (*current self*) and who we
13 could be (*possible self*). *Possible selves* drive behaviour. A notion of the *possible self* helps us
14 to assess our *current self*; by creating a comparison for self-evaluation; therefore this concept
15 is innately linked with goal setting. *The possible self* and goal setting also rely heavily on
16 temporality, therefore requiring narrative of the past, and the capacity to prospect.
17 Physiologically, prospection depends on episodic memory, prospective memory, emotional
18 stability and hypothetical thinking³¹, some of which can be impaired in critical illness due to
19 sleep deprivation, fatigue and delirium.
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34 On awakening, patients' immediate cognitive representation of their *current self* matched
35 their pre-admission self because they do not remember their functional decline, however,
36 their body had changed. Their mental image of their *current self* and their *physical self* are
37 not aligned. Furthermore, patients could not remember the totality of their past, they did not
38 recognise their present, and they struggled to construct a compelling future self. This
39 impaired their ability to engage in rehabilitation goal setting and led to a sense of
40 vulnerability, desired paternalism and emphasis on *relatedness*.
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52 This model of *recalibration* ties these established psychological ideas together, reflecting the
53 need for patients to explore their new self, adapt to it and allow it to become their new
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3 yardstick. When this was achieved, smaller milestones in recovery became meaningful goals.

4
5 Others have described similar concepts as a *liminal* state. Liminality is an anthropological
6
7 term from the Latin word *limen*, meaning threshold³². It refers to someone who is
8
9 transitioning. It is often associated with a change in role/identity, or a loss of one self to be
10
11 replaced with another. This can create inner turmoil, especially if that change is not invited.
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15
16 This idea of liminality in ICU has been touched upon by a number of authors³²⁻³⁵. Kean and
17
18 colleagues³² identified 'unscheduled status passage' from *prior self* to *critically ill self* as a
19
20 theme in a longitudinal study of ICU survivorship. They found that this unscheduled liminal
21
22 stage is worsened by memory loss and delirium, and that this process of change is temporal
23
24 in nature, both progressing and regressing (in the event of decline). In order to move on,
25
26 patients need to regain autonomy.
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30
31 Lindberg and colleagues³⁵ described what recovering autonomy looks like, suggesting that
32
33 patients go through four stages: the first is to acknowledge their dependence (or
34
35 paternalism), and then they strive to be recognised as a person ("humanised" care). These
36
37 two stages echo the findings of this study. The latter two stages are 'invited participation in
38
39 care', and 'becoming a co-partner in the decision-making'. These stages describe how staff
40
41 coach patients to take control again through mutual trust, understanding and co-
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43 determination.
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50 Although these may seem like abstract concepts, it is the authors' view that they have direct
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52 relevance to clinical practice, especially as early rehabilitation becomes a key aspect of acute
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3 care. The reason for this is that perception of self and engagement in rehabilitation and goal-
4
5 setting are inextricably linked.
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9 If a person's mind is telling them one thing about who they are and what they are capable of
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11 doing, and their body is telling them another, they cannot start thinking about the future until
12
13 they reconcile that difference. They cannot reconcile that difference with delirium,
14
15 hallucinations and lack of episodic memory to justify their current situation and facilitate
16
17 hypothetical thinking and prospection³¹. Combining psychological intervention with
18
19 physiotherapy intervention may help to address this.
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24 Goal-setting depends on the capacity to prospect, it is also a key recommendation in the UK
25
26 National Institute for Health and Care Excellence (NICE) Guidelines for Rehabilitation after
27
28 Critical Illness³⁶ and NICE Quality Standards³⁷. The Quality Standards state that rehabilitation
29
30 goals should be set within 4-days of admission, and ideally should be patient-agreed. These
31
32 data would suggest that asking *patients* to set goals at day 4 may be premature. Further
33
34 research exploring the application of the model of recovering autonomy described by
35
36 Lindberg³⁵ may assist in tailoring rehabilitation guidelines to the specific needs of the critically
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38 ill.
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45 Further focus on *how* rehabilitation is delivered, not just *what* is delivered could also be
46
47 instructive. The impact of the dynamic between a sports coach and the players is well known,
48
49 yet this coaching dynamic is neglected somewhat in ICU rehabilitation. If clinicians are able to
50
51 assist patients in recalibrating to their *new current self*, and the reconstruction of a compelling
52
53 *future self*, it may improve patient care and outcome. Further research will be needed to
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confirm the concepts identified in this initial exploratory study. However, we believe the concepts identified are sufficiently plausible and robust to pose challenges to clinicians working with recovering critically ill patients (outlined in Box 1).

Box 1: Key observations and challenges to practice.

Key observations

- ❖ Patients recovering consciousness during or after a critical illness are likely to be shocked by the transition through which they have gone; part of that shock is the due to the unplanned interruption of their autobiographical story.
 - How can you help to fill the gaps in autobiographical memory?
- ❖ Patients' immediate memory is of who they were and what they were able to do before their critical illness; this is in collision with what they can actually do and a period of recalibration is needed to allow people to align the two and develop reasonable ambitions and goals.
 - How can you support patients to explore their current function and settle the discrepancy between expectations and reality?
- ❖ This recalibration is the development of an understanding of the relationships between their past, present and possible futures selves.
 - How can you help patients to envisage a compelling future?
- ❖ Because of this need for recalibration along with delirium and impaired cognition patients may need, and wish for, assistance in planning early rehabilitation. As autonomy recovers, patients desire to become fully involved increases.
 - How can you recognise and support recovering autonomy?

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2
3 ❖ Motivation and engagement are crucial in maximising the benefits of rehabilitation.
4 Leveraging human relationships (relatedness) and encouraging autonomy are likely
5 to be helpful; care that is de-humanising, even if “efficient” is likely to impair
6 recovery.
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10 ➤ How can humanisation of care be optimised in your ICU?
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17 London) for their input into the theoretical interpretation of these data. Thank you to
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19 with the study.
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References:

1. Puthuchery ZA, Rawal, JR, McPhail M, Connolly B, Ratnayake G, Chan P, Hopkinson NS, Phadke R, Dew T, Sidhu PS, Velloso C, Seymour A, Agle CC, Selby A, Limb M, Edwards LM, Smith K, Rowleron A, Rennie MJ, Moxham J, Harridge S, Hart N, Montgomery HE. Acute Skeletal Muscle Wasting in Critical Illness. *JAMA*, 2013; 310 (15), 1591-1600.
2. Friedrich O, Reid MB, Van den Berge G, Vanhorebeek I, Hermans G, Rich MM, Larsson L. The sick and the weak: Neuropathes/myopathies in the critically ill. *Physiol Rev*. 2015; 95 (3), 1025-109.
3. Hermans G, & Van den Berghe G. Clinical review: intensive care unit acquired weakness. *Crit Care*. 2015; 5 (19), 274.
4. Cavalazzi R, Saad M, Marik PE. Delirium in the ICU: an overview. *Ann Intensive Care*. 2012; 2 (49).
5. Kress JP & Hall JB. Intensive care unit acquired weakness and recovery from critical illness. *N Eng J Med*. 2014; 370, 1626-1635.
6. Cuthbertson BH, Elders A, Hall S, Taylor J, MacLennan G, MacKirdy F, Mackenzie SJ, and the Scottish Critical Care Trials Group and the Scottish Intensive Care Society Audit Group. Mortality and quality of life in the five years after severe sepsis. *Critical Care*. 2013; 17, R70.
7. Kaukonen K-M, Bailey M, Suzuki S, Pilcher D, Bellomo R. Mortality related to severe sepsis and septic shock among critically ill patients in Australia and New Zealand, 2000-2012. *JAMA*. 2014; 311 (13), 1308-1316.
8. Hill AD, Fowler RA, Pinot R, Herridge MS, Cuthbertson BH, Scales DC. Long-term outcomes and healthcare utilization following critical illness – a population-based study. *Critical Care*. 2016; 20, 76.
9. Pandharipande P, Girard TD, Jackson JC, Morandi A, Thompson JL, Pun NE, Brummel CG, Highes EE, Vasilevskis AK, Shintani KG, Moons SK, Geevaghese A, Canonico RO, Hopkins RO, Bernad GR, Dittus RS, Ely EW. Long-Term Cognitive Impairment after Critical Illness. *N Engl J Med*. 2013: 369, 1306-1316.

10. Nydahl P, Sricharoenchai T, Chandra S, Kundt FS, Huang M, Fischill M., Needham D.M. Safety of Patient Mobilization and Rehabilitation in the Intensive Care Unit. Systematic Review with Meta-Analysis. *Annals of the American Thoracic Society*. 2017; 14 (5).
11. Castro-Avila AC, Seron P, Fan E, Gaete M, Mickan S. (2015) Effect of early rehabilitation during Intensive Care Unit stay on functional status: systematic review and meta-analysis. *PLoS ONE*. 2015: 10 (7), e0130722.
12. Balas MC, Burke WJ, Gannon D, Cohen MZ, Colburn L, Bevil C, Franz D, Olsen KM, Ely WE, Vasilevski EE (2013) Implementing the awakening and breathing coordination, delirium monitoring/management, and early exercise/mobility bundle into everyday care: opportunities, challenges, and lessons learned from implementing the ICU pain, agitation and delirium guidelines. *Crit Care Med*. 2013; 41: S116-S127.
13. Balas MC, Vasilevskis EE, Olsen KM, Schmid KK, Shostrum V, Cohen MZ, Peitz G, Gannon DE, Sisson J, Sullivan J, Stohtert JC, Lazure J, Nuss SL, Jawa RS, Freihurt F, Ely EW, Burke WJ. (2014) Effectiveness and safety of the awakening and breathing coordination, delirium monitoring/management, and early exercise/mobility bundle. *Crit Care Med*. 2014; 42:1024-1036.
14. Connolly B, Douiri A, Steier J, Moxham J, Denehy L, Hart N. A UK survey of rehabilitation following critical illness: implementation of NICE Clinical Guidance 83 (CG83) following hospital discharge. *BMJ Open*. 2014: 4; e004963.
15. Jensen JF, Thomsen T, Overgaard D, Bestle MH, Christensen D, Egerod I. Impact of follow-up consultations for ICU survivors on post-ICU syndrome: a systematic review and meta-analysis. *Intensive Care Med* (2015) 41:763–775
16. Nydahl P, Parker RA, Bartoszek G, Dubb R, Filipovic,S, Flohr H-J, Kaltwasser A, Mende H, Rothaug O, Schuchhardt D, Schwabbauer N, Needham D. Early Mobilization of Mechanically Ventilated Patients: A 1-Day Point-Prevalence Study in Germany. *Critical Care Medicine*. 2014; 42 (5), 1178-1186.
17. Berney SC, Rose JW, Bernhardt J, Denehy L, Prospective observation of physical activity in critically ill patients who were intubated for more than 48 hours. *Journal of Critical Care*. 2015; 30(4), 658-663.

18. Hodgson CL, Stiller K, Needham D, Tipping CJ, Harrold M, Baldwin CE, Bradley S, Berney S, Caruana LR, Elliott D, Green M, Haines K, Higgins AM, Kaukonen KM, Leditschke IA, Nickels MR, Paratz J, Patman S, Skinner EH, Young PJ, Zanni JM, Denehy L, Webb SA. Expert consensus and recommendations on safety criteria for active mobilisation of mechanically ventilated critically ill patients. *Critical Care*. 2014; 16:658.
19. Parry S, Knight LD, Connolly B, Baldwin C, Puthuchery Z, Morris P, Mortimore J, Hart N, Denehy L, Granger CL. Factors influencing physical activity and rehabilitation in survivors of critical illness: a systematic review of quantitative and qualitative studies. *Intensive Care Med*. 2017; 43, 531–542.
20. Wright SE, Thomas K, Watson G, Baker C, Bryant A, Chadwick, TJ, Shen J, Wood R, Wilkinson J, Mansfield L, Stafford V, Wade C, Furneal J, Henderson A, Hugill K, Howard P, Roy A, Bonner S, Baudouin S. Intensive versus standard physical rehabilitation therapy in the critically ill (EPICC); a multicentre, parallel-group, randomised controlled trial. *Thorax*. 2017; (5).
21. Sottile PD, Nordon-Craft A, Malone D, Schenkman M, Moss M. Patient and family perceptions of physical therapy in the medical intensive care unit. *Journal of Critical Care*. 2015; 30, 891-895.
22. Mills, J., Bonner, A., Francis, K. (2006) The development of constructivist grounded theory. *International Journal of Qualitative Research Methods*. 5 (1).
23. Mental Capacity Act (2005). UK legislation. Available at: <https://www.legislation.gov.uk/ukpga/2005/9/contents>
24. Corbin, J. & Strauss, A. (2015) *Basics of qualitative research: techniques and procedures for developing grounded theory*. 4th edition. London
25. Heath H, Cowley S. Developing a grounded theory approach: a comparison of Glaser and Straus. *International Journal of Nursing Studies*. 2004; 41, 141-150.
26. Bode, D. (2013) *Qualitative Interviews: When enough is enough*. Research by Design.
27. Todres L, Galvin KT, Holloway I. The humanisation of healthcare: a value framework for qualitative research. *International Journal of Qualitative Studies on Health and Well-being*. 2009; 4, 68-77.

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28. Deci EL, Ryan RM. Intrinsic motivation and self-determination in human behavior. New York, NY: Plenum. 1985.
 29. Deci EL, Ryan RM. (2017) <http://selfdeterminationtheory.org/theory/> (Accessed: 30th March 2017)
 30. Markus H & Nurius P. Possible Selves. *American Psychologist*. 1986; 41 (9), 954-969
 31. Osman M. What are the essential cognitive requirements for prospection (thinking about the future)? *Frontiers in Psychology*. 2014;5, 626.
 32. Kean S, Salisbury LG, Rattray J, Walsh TS, Huby G, Ramsey, P. 'Intensive Care Unit (ICU) Survivorship' – a constructivist grounded theory of surviving critical illness. *Journal of Clinical Nursing*. 2017. [online].
 33. Johnston LB. Surviving Critical Illness: A Case Study in Ambiguity. *Journal of Social Work in End-of-Life & Palliative Care*. 2011; 7 (4), 363-382.
 34. Darbyshire JL, Greig PR, Vollam S, Young DJ, Hinton L. "I Can Remember Sort of Vivid People... but to Me They Were Plasticine." *Delusions on the Intensive Care Unit: What Do Patients Think is Going on?* *PLoS ONW*; 11 (4): e0153775.
 35. Lindberg C, Sivberg B, Willman A, Fagerstrom C. A trajectory towards partnership in care – patients perspective of autonomy in intensive care: A qualitative study. *Intensive and Critical Care Nursing*. 2015;31: 294-302.
 36. National Institute for Health and Clinical Excellence. Great Britain. *Rehabilitation After Critical Illness* Great Britain. Available at: www.nice.org.uk. 2009.
 37. National Institute for Health and Clinical Excellence (2017). *Rehabilitation after Critical illness in adults: Quality Standard*. Published 7th September 2017. Available online: nice.org.uk/guidance/qs158. (Accessed: 13th September 2017)

Table 1: Topic guide

Topic guide
Opening
1. Introduction
2. Consent confirmed.
Questions
3. Do you have any questions about the about the patient information sheet?
4. Could you tell me about the events leading up to your admission to the ICU?
5. Could you summarize, as you remember it, your stay on the ICU including the length of your stay and the procedures you experienced (e.g. surgery, tracheostomy etc)?
6. Could you describe any physical problems that you had during and after your stay, such as weakness, pain, joint stiffness etc?
7. Could you describe your rehabilitation experience?
- Memories of rehabilitation
- Rehabilitation equipment
- Interaction with the therapist
- Intensity of rehabilitation
- Rehabilitation goal setting
Closing
8. Do you have any additional information you would like to add?
9. Do you have any questions?
End

Table 2: Summary of each participant

Pseudonym	Relative present?	Age range (years)	APACHE II	Diagnosis	Length of stay, ICU (days)	Length of stay, hospital (days)	Discharge location
Richard	No	30-39	17	Acute porphyria	9	102	Long-term, inpatient rehabilitation
Martin	No	30-39	14	Drug overdose, aspiration pneumonia, rhabdomyolysis	26	32	Home, outpatient rehabilitation
Sadiq	No	50-59	22	Exacerbation of COPD	33	34	Home, full care package
Sarah	No	60-69	24	Open hernia repair- post operative MOF	115	197	Long-term, inpatient rehabilitation
Tom	No	60-69	10	Pneumonia and pulmonary embolism	10	16	Home, outpatient rehabilitation
Evan	No	60-69	15	Acute bowel obstruction- colon cancer	5	48	Home, no rehabilitation.
Sasha	Yes, daughter	50-59	10	Neuromyelitis optica	19	98	Long-term, inpatient rehabilitation
John	No	40-49	27	Influenza	33	71	Long-term, inpatient rehabilitation
George	No	50-59	12	Drug overdose- respiratory failure	25	36	Home, no rehabilitation
Michelle	No	80-89	14	Exacerbation of COPD	6	42	Declined inpatient rehabilitation- home, full care package
Jim (M)	Yes, wife	50-59	11	Food poisoning-	10	18	Home, no

				MOF			rehabilitation
Matthew (M)	No	70-79	18	Hospital acquired pneumonia-fractured NOF	5	178	Nursing home
Caroline (F)	Yes, husband	70-79	22	Anterior resection for bowel cancer	13	63	Short-stay, inpatient rehabilitation.
Ben (M)	No	40-49	15	Drug overdose	65	107	Home, care package
David (M)	Yes, wife present	63	21	Influenza	150	232	Long-term, inpatient rehabilitation

(NOF-neck of femur; MOF-multi-organ failure; COPD-chronic obstructive pulmonary disease; APACHE II- acute physiology and chronic health evaluation II; ICU – Intensive Care Unit)

Table 3: Supporting data

Central phenomenon: Recalibration of The Self	
Main theme 1: "From prior self to current self"	
<p><i>Sasha: "I didn't realize I couldn't walk. I thought I could and I tried to get out of bed loads of times, but up here I was weak (legs) and the top of my arms were weak as well. I couldn't do it."</i></p> <p><i>Sarah: "I don't ever look at myself in the mirror and there is a mirror in that bathroom, I just happened to catch sight of my whole body almost and I nearly died. I thought; that doesn't resemble the person that I am."</i></p>	
Episodic memory loss	<p>ICU admission</p> <p>Sasha: "...that's when I don't know, it's a real black after that (the emergency room)"</p> <p>Sadiq: "That is a black. That is a blank. Totally blank"</p> <p>John: "I must have been in and out of consciousness, because I don't remember anything"</p> <p>Ben: " I had a bad fall, collapsed... that's all I remember"</p>
	<p>Rehabilitation and mobilization</p> <p>EJC: "what was your memory of getting moving after you woke up with the tubes attached?" Ben: "I don't really have much memory of it."</p> <p>EJC: Do you remember any of the rehab on ICU?" Martin: "Not to start with, no."</p> <p>David: "It was Dan (ward physiotherapist) who taught me to sit on the edge of the bed."</p> <p>EJC: "Do you remember getting into the chair for the first time?" Michelle: "It was with Tom (the ward physical therapist)."</p>
Hallucinations and delusions	<p>John: "I kept thinking I could see like people with hoodies and they were like assassins, trying to get in."</p> <p>David: "I was taken into Soho (Central London) by some people and stuck under a glass floor, lying under a glass floor with formaldehyde around me. I was encased."</p> <p>Ben: "I operated on Margaret Thatchers cat and there was eight other people in the house and three of them got shot... I remember waking up with the fear that I was going to get shot."</p>

	<p>Carolyn: "I was trying to use my mobile (to escape), and the same number kept on pressing and I remember panicking"</p>
<p>Weakness</p>	<p>George: "Nothing, I couldn't move my hand. I couldn't move and that was really scary. Really scary."</p> <p>Richard: " I couldn't do anything. I was paralyzed from the neck down... I still felt like I had sensation in my legs and my arms, I just couldn't move them."</p> <p>Carolyn: "I couldn't even stand up. I was really very, very weak."</p> <p>John: "I couldn't do anything. I mean literally, I couldn't move, I could just barely move my fingers."</p> <p>David: "I couldn't move. I couldn't move at all. I could blink, that's about it."</p> <p>Martin: "...couldn't walk, couldn't do nothing."</p> <p>Richard: "You are reliant entirely on the people around you, for everything really... that's difficult."</p>
<p>Noxious cycle of ICU</p>	<p>Sarah: "I didn't want to do it (physiotherapy). I used to dread them coming, any excuse to get out of it. I was just so tired."</p> <p>John: "Physically tiring, emotionally... you're like 'sh*t really? I've got to do it (mobilization) now? I haven't got any energy at all.'"</p> <p>George: "There were some days when they'd (physiotherapist) come and they'd get me into the chair, and they'd want to do some work on the zimmer frame. They'd come back (from getting the zimmer frame) and I'd be asleep."</p> <p>Sarah: "People kept telling me to read, but I couldn't. I couldn't' actually physically read. They'd bring me the menu and I just couldn't do it, and then I'd fall asleep"</p> <p>Sarah: "...then I just accepted it (weakness), going...on the hoist and, you lose all dignity when you're in that state you just accept it, and you just let them help you as much as possible and when you've done your, you know bits of physio, exhausted, you go back to bed again, sleep again. You know it tended to be like that."</p>
<p style="text-align: center;">Main theme 2: "From current self to construction of the future self"</p> <p>Ben: <i>"The first days when I couldn't move... I was disillusioned with the whole thing, and I thought, 'This is never going to work'... I couldn't see how anything could turn round, but I was told just to trust. But that period was very difficult because when you don't see any light at the end of the</i></p>	

tunnel, it's difficult to sort of engage with it, and it's difficult to trust... There was plans in my head, but it's difficult to kind of have them if you think it's just a waste of time what you're doing. Now I know that there is (light at the end of the tunnel)... and I believe I'll be walking next week, they've (physiotherapists) let me believe that"

Recovery milestones and goal setting

Matthew: "Let the patient realize that he is not capable of doing that, or this, or whatever... don't tell him"

Tom: "Everyone's functions, and how they are improving, might not be quite so obvious to the patient."

Carolyn: "The other day the whole ward congratulated me- and even now I feel embarrassed – because I washed myself. I didn't wait until now to know how to wash myself; I thought it was so stupid."

Jim's wife: "We didn't want to set the goals, because we didn't know what goals to set"

Sadiq: "It depends on the person. If a person is shooting to the high, they might do it (achieve their goal), but sometimes shooting too much to the high might break your neck. If they are too sick, they cannot talk, you are in the dark and you have to put your own objectives."

Researcher: "What have been the things that have kept you going?" Sasha: "I think Gemma (daughter) and her dad, they've been so supportive. He's been down every day, and Gemma sometimes twice a day *starts crying*... sorry... I suppose if it wasn't for them, I wouldn't be... *crying- unable to finish sentence*

Richard: "obviously I was doing it (rehab) for me primarily, but knowing how much concern and love she has for me, and knowing how much it would mean to her and how much of a relief it would be to her... The fact that she was, you know with me for as long as she was, and as strong as she was... I don't know. I never thought my mum was that strong."

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Figure legends

Figure 1: The noxious cycle of critical illness.

For peer review only

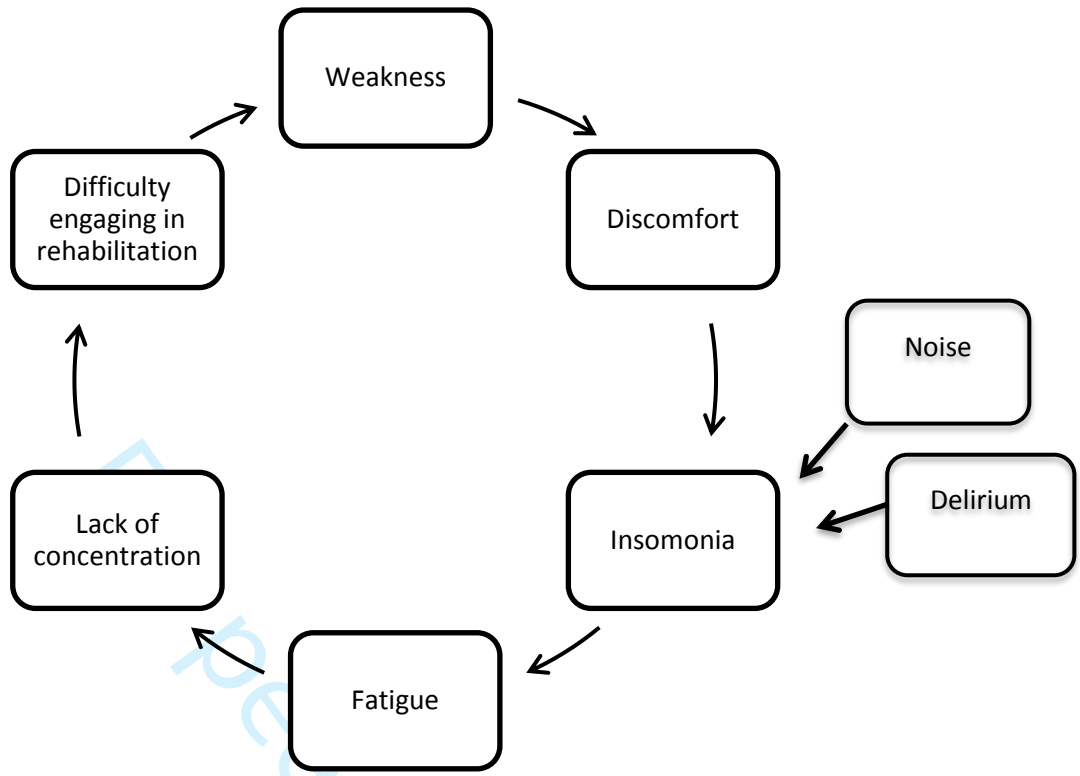


Figure 1: noxious cycle of ICU

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Title: A Qualitative, Grounded Theory Exploration of Patients' Experience of Early Mobilisation, Rehabilitation and Recovery after Critical Illness.

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2
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4
5 Department of Health.
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8
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11
12 **Authors contribution to the study:** EJC, SJB and EJM were involved in the methodological
13
14 design, data analysis and writing and reviewing the manuscript. EJC did all of the interviews
15
16 and data collection.
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20 **Data sharing statement:** All available data can be obtained by contacting the corresponding
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22 author.
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Abstract

Rationale: Physical rehabilitation (encompassing early mobilisation) of the critically ill patient is recognized best practice, however further work is needed to explore the patients' experience of rehabilitation qualitatively; a better understanding may facilitate implementation of early rehabilitation, and elucidate the journey of survivorship.

Objectives: To explore patient experience of physical rehabilitation from critical illness during and after a stay on ICU.

Design: Exploratory grounded theory study using semi-structured interviews.

Setting: Adult medical/surgical ICU of a London teaching hospital.

Participants: A purposive sample of ICU survivors with intensive care unit acquired weakness (ICUAW) and an ICU length of stay of >72 hours.

Analysis: Data analysis followed a four-stage constant comparison technique: open coding, axial coding, selective coding, and model development, with the aim of reaching thematic saturation. Peer debriefing and triangulation through a patient support group were carried out to ensure credibility.

Main results: Fifteen people were interviewed (with four relatives in attendance). The early rehabilitation period was characterized by episodic memory loss, hallucinations, weakness, and fatigue, making early rehabilitation arduous and difficult to recall.

Participants craved a paternalised approach to care in the early days of ICU.

The central idea that emerged from this study was recalibration of the self. This is driven by a lost sense of self, with loss of autonomy and competence; dehumanized elements

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3 of care may contribute to this. Participants described a fractured life narrative due to
4
5 episodic memory loss, meaning that patients were shocked on awakening from sedation
6
7 by the discrepancy between their physical form and cognitive representation of
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9 themselves.
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13
14 **Conclusions:** Recovery from ICUAW is a complex process that often begins with
15
16 survivors exploring and adapting to a new body, followed by a period of recovering
17
18 autonomy. Rehabilitation plays a key role in this recalibration period, helping survivors
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20 to reconstruct a desirable future.
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53 **Key words:** critical care, early mobilisation, rehabilitation, patient experience, recovery,
54 physical therapy.
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56 **Abstract word count:** 298
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Strengths and Limitations of this study

1. This was an exploratory qualitative grounded theory study using semi structured interviews with survivors of critical illness to explore their experience of physical rehabilitation after critical illness; the approach adopted, and the data generated provided an extremely rich source of individual experience with many consistent features.
2. A constant comparison technique of data analysis was used, and enrolment continued until thematic saturation was reached.
3. Triangulation and peer debriefing were completed to ensure credibility of the study findings that clearly resonated with an independent group of critical illness survivors.
4. The patients were all recruited from one centre, which may limit transferability of findings. Qualitative studies of this kind innately have a small sample size, however, the richness of the data produced allows deep exploration of meaning and model development and thematic saturation was also reached.
5. The variation in time to interview may be considered a limitation of this study in view of impaired recall for longer gaps, however, there was no notable difference in the richness of memories and insight provided by those interviewed at different time points. The variation in time to interview also elucidated the process of recovery over time.

Introduction:

Rapid muscle wasting^{1,2}, functional decline³ and delirium⁴ are common consequences of critical illness. In the long term, they can lead to prolonged periods of weaning from mechanical ventilation, disability, reduced endurance, anxiety, and depression⁵⁻⁹. To combat these issues mobilisation, minimising sedation and spontaneous breathing should be instigated early, with research demonstrating safety and likely efficacy¹⁰⁻¹³. Furthermore, on-going rehabilitation following discharge from critical care, and attendance at ICU follow up clinics are also advocated, although research showing direct benefit of these interventions is limited¹⁴⁻¹⁵.

Although implementation of early mobilisation protocols and post-ICU rehabilitation is inconsistent^{14,16-17}, early adopters of these strategies are striving for them to become the norm^{12,13,18}. In such centres, it is not uncommon for patients to receive active out of bed physical rehabilitation whilst receiving full mechanical ventilation, renal replacement therapy, and inotropic support¹⁸. Due to the severity of weakness that can be associated with prolonged critical illness, these rehabilitation sessions are often delivered by two or more therapists/nurses, and can require technical equipment and physical handling. It is perhaps unsurprising that pain, fatigue, weakness, anxiety, fear, lack of motivation and patient confidence are reported as barriers and reasons for cessation of early rehabilitation^{19, 20}.

Sottile and colleagues (2015)²¹ completed a survey of patient experience of early mobilisation in ICU concluding that patients recognized the importance of early mobilisation, but found it difficult, tiring and uncomfortable.

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2
3 In spite of current enthusiasm, there is a paucity of literature exploring survivors'
4 experience of early mobilisation and physical rehabilitation during and after a stay in ICU
5
6 in an in-depth manner. For the purpose of this manuscript, the term 'rehabilitation' is
7
8 used to encompass early mobilisation and physical rehabilitation implemented by
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10 physiotherapists from admission to ICU.
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16 **Aim:** To explore the patient experience of recovery from critical illness, with emphasis
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18 on their experience of rehabilitation, and to develop a theoretical model grounded in
19
20 these data.
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24 **Methods:**

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27 **Qualitative approach and research paradigm:** Constructivist grounded theory study²²
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29 using semi-structured interviews with a purposive sample of adult ICU survivors.
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31 Constructivism contends that individuals' views are directly influenced by their
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33 experiences, and it is these individual experiences and views that shape their perspective
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35 of reality. Constructivists believe that individuals have different realities that will be
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37 influenced by context- this is a 'relativist' ontological stance²².
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43 Constructivist grounded theory is an appropriate methodology for this study because it
44
45 allows the researcher to develop a theoretical model to explain the data based on an
46
47 iterative process of data immersion, analysis and interpretation, which recognises and
48
49 accounts for contextual factors.²²
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53 **Setting:** Participants were recruited from the adult medical/surgical ICU of a 430 bedded
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55 London teaching hospital between November 2015 and September 2016.
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3 **Participants and sampling:** Participants were purposively sampled. Screening and
4 inclusion criteria were: English-speaking, a critical stay of >72 hours, capable of providing
5 informed consent determined using the Mental Capacity Act assessment²³, anticipated
6 to survive, aged over 18 and documented ICUAW determined via case note review (this
7 was to ensure that the participants had exposure to rehabilitation interventions.)
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16 The clinical team identified potential participants against the broad inclusion criteria
17 stated above to ensure that it was appropriate for them to be approached by the
18 research team. Notes were screened with the aim of purposively selecting a varied
19 sample of participants that could speak to the breadth of emerging themes. If deemed
20 appropriate participants were then approached by the lead researcher (EJC) and
21 provided with written information. If they had capacity to consent and agreed to
22 participate, written informed consent was gained. Participants that could not provide
23 informed consent were excluded.
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36 At the discretion of the participant, relatives were also invited to be present in the
37 interview to enable exploration and elucidation of any ICU-associated memory loss. As
38 the study progressed participants were selected to ensure a heterogeneous sample, with
39 the aim of achieving thematic saturation^{22,24-26}, for example, targeting varying degrees of
40 ICUAW, different genders, and specific age categories.
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49 **Ethics:** This study was granted approval by the East of England Ethics committee (REC
50 reference number 14/EE/1027) and from the Research and Development Department at
51 the study site.
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3 **Data collection methods:** The semi-structured interviews were conducted by EJC. For
4
5 reflexivity, EJC is research physiotherapist with expertise in critical care and prior training
6
7 in qualitative methods research. EJC also has personal experience of major injury and as
8
9 a close relative of an ex ICU patient. SJB is an ICU medical consultant and is involved with
10
11 ICU follow up clinics, and EJM is a researcher focusing on management and change in the
12
13 health sector, with expertise in qualitative methodology.
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17
18 The interviews followed a topic guide designed with input from the Intensive Care
19
20 Society Patient and Relatives Group (Table 1). The questions in the topic guide focused
21
22 on the memory of the admission to ICU, any physical weakness that they encountered,
23
24 and patients' experience of rehabilitation in the ICU and following discharge. The
25
26 questions were intentionally left open to initiate reflections and to allow subsequent
27
28 detailed exploration of the issues that appeared important to the interviewee. The first
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30 interview was used as a pilot, however, as no changes were made and those data
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32 collected from this interview were rich and informative, it was retained and analysed in
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34 the results.
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41 As the study progressed and themes emerged, participants were asked to elaborate and
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43 probed on specific issues in line with the constant comparison technique, for example:
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45 how the perception of the physiotherapist's strength influenced their rehabilitation
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47 experience; how they perceived their body now; what differences there were between
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49 their current and previous physical function; how they saw their future; and what they
50
51 defined as physical rehabilitation.
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56 The interviews were carried out either in the hospital or in the community after ICU
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58 discharge. Enrolment and interviews continued until thematic saturation was reached
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3 i.e. no new ideas were emerging, as per the criteria outlined by Bonde (2013)²⁶. This was
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5 to challenge the emergent model and ensure credibility. The interviews were
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7 anonymised, recorded, and transcribed *verbatim* by a professional transcription
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9 company. All transcripts were double-checked for accuracy by EJC.
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14 All interviewees were given pseudonyms to ensure anonymity. Further demographic and
15
16 clinical data were also collected from the case notes: age, critical care and hospital
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18 length of stay, APACHE II score, admission diagnosis, residence prior to admission, pre-
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20 morbid functional level, and hospital discharge destination.
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23
24 **Data processing and analysis:** Transcripts were uploaded onto Nvivo® software (QSR
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26 International, Doncaster, Australia) for analysis. They were read and reread by EJC to
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28 ensure full immersion in the data. Memo writing was used throughout. The first stage of
29
30 the analysis process is 'open coding', which is the identification of primary broad
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32 categories; these may be around a theme or topic, or more conceptual, such as emotion
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34 or attitude. The second stage is 'axial coding'; here categories are clustered together into
35
36 meaningful, related groups. The third stage is 'selective coding', where core themes are
37
38 identified. Lastly, the themes are used to generate a theoretical framework to explain
39
40 the data^{22,24-26}. Data collection and analysis occur concurrently, so that constant
41
42 comparison was made between emerging themes (both within and between narratives),
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44 and the literature, allowing model refinement. After the fourth interview had been
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46 transcribed and open coding had been completed, axial codes began to form. These
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48 ideas were then discussed in detail with the research team. This was followed by a
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50 dynamic process of reflection after each interview to develop and refine the axial codes
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52 into selective codes until a model encompassing all elements was developed. The last
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3 interviews were used to challenge this model and to assess for data saturation. This
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5 process allowed a central phenomenon to emerge from the data^{22,24-26}. The words used
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7 for coding were based on the lead researchers interpretation and terms in related
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9 literature.
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13 14 **Techniques to enhance trustworthiness:**

15 16 17 **Peer debriefing:**

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20 Peer debriefing was completed via in-depth discussion with SJB and EJM. This was done
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22 regularly throughout the course of the study.
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25 26 **Patient and public involvement**

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29 A patient representative from an ICU support group was consulted in the development
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31 of the topic guide. An initial draft of the topic guide was developed by the research team
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33 and it was then sent to the patient representative for review and modification, all of
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35 their recommended changes were made. Patients and public were not involved in the
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37 recruitment or conduct of the study. Participants were given the opportunity to receive
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39 information on the results of the study at their request.
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44 45 **Triangulation**

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48 Triangulation and sense checking was completed through presentation to an ICU
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50 survivor support group with subsequent dialogue to assess the dependability,
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52 confirmability and credibility of the model (this did not include interview participants).
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56 At the support group the model was presented and then there was opportunity for
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58 questions and answers with the researcher (EJC). The group were then left to discuss the
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3 study between themselves and feedback to the research team with any thoughts at a
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5 later date to allow them to speak openly and frankly with each other. The leader of the
6
7 support group fed back to the research team that the participants resoundingly agreed
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9 with the concepts and felt that the work '*encompassed all the areas that were important*
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11 *and relevant to those who have experienced critical illness*'. The presentation also led to
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13 a very tearful response from some attendees who reported to have felt 'understood'.
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17 18 19 **Results:**

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22 Eleven hours of qualitative data from 15 participants (with 4 additional relatives present)
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24 were collected. The *patients* are described in Table 2.
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28 *[Insert table 2: Patient demographics]*
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31 The median ICU and hospital length of stay were 19 days (IQR 8-33) and 63 days (IQR 34-
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33 107) respectively. The median time between ICU discharge and interview was 56 days
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35 (IQR: 36-80). Ten (66.6%) of the interviews took place at the hospital whilst the patients
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37 were still inpatients, and five (33.3%) took place after discharge in the patient's home
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39 (n=2), work (n=1), or in a clinic room (n=2). The interviews lasted a median of 39
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41 minutes (IQR: 28-50).
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46 The central phenomenon grounded in these data was *recalibration of the self*. There
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48 were two themes contributing to this temporal model of recovery: the transition '*from*
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50 *prior self to current self*', and the transition '*from current self to construction of the*
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52 *future self*'. When questioned about early physical function, patients recalled a
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54 discrepancy at the time of recovering awareness between their *current self*, which
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56 incorporates their physical dependency, fatigue, clarity of mind, and self-image, and the
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3 mental representation of themselves, which is still consistent with their *preadmission*
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5 *self*. This discrepancy seemed to be due to episodic memory loss of their admission
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7 period. Additionally, patients lacked some of the cognitive requirements for prospection
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9 at this point²⁶ and therefore they struggled to envisage a compelling future self. This
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11 appears to lead on to a period of *recalibration*.
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16 Although this central phenomenon of *recalibration* may seem distinct from the early
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18 physical rehabilitation experience that was the focus of this study, it was quite the
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20 opposite, with the process of *recalibration* seeming inextricably linked to the
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22 rehabilitation experience. Physical independence and function are core components of
23
24 the concept of *self*. When physical ability deteriorates so unexpectedly, rapidly, and
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26 without obvious causation (as in ICUAW) it comes as a shock to the patient blurring their
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28 sense of self. Physical rehabilitation aims to improve impairments and function by
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30 challenging patients' physical ability thereby, in this extreme context, inadvertently
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32 challenging their self-perception as well.
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39 This model suggests that physical rehabilitation within ICU helps patients to challenge
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41 and explore their current functional level and reconcile their self-discrepancy i.e.
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43 difference between their physical self and the cognitive image of themselves. The
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45 process of therapy goal-setting also challenges their capacity to think about the future;
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47 discussing goal setting with participants therefore elucidated the difficulties they may
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49 have in constructing a compelling future to act as a motivational force.
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54 The rationale and contributing themes are presented below. Supporting evidence is
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56 presented in Table 3.
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'From prior self to current self'

Episodic memory loss

Fundamental to the patient experience of rehabilitation, and underpinning the theoretical interpretation, was patients' episodic memory loss (i.e. loss of a specific autobiographical event) of their admission to ICU, regardless of their admission background or diagnosis. In some cases this memory gap lasted weeks, with some participants unable to recall any rehabilitation sessions on ICU at all, citing their ward rehabilitation sessions as their first experiences. The first clear memory *for all* participants was a family member at the bedside. This frequently elicited a tearful response, for example, George stated: *"(my first memory on awakening) was my mother stroking my arm, saying 'Mum's here'... that was some 30 days after my admission"*. This memory loss is of paramount importance, as it made it difficult for participants to rationalise and understand their current situation.

Hallucinations and delusions

All patients experienced vivid hallucinations that often involved torture and trying to escape some of the hallucinations, however, were pleasant experiences, such as a friendly dog in the ICU. Those with a history of recreational drug use seemed less shocked by hallucinations and able to rationalise their mental state, for example, John stated: *"you're pumped full of so many drugs, it doesn't surprise me that you're tripping out."* Perceived stigma influenced patients' comfort in discussing hallucinations with

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2
3 staff, for example, EJC asked Tom: *“Did you tell anyone about the hallucinations at the*
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5 *time?”* Tom replied: *“No... I just felt a bit silly”*.
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11 **Weakness**

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15 On awakening patients reported frustration at their inability to communicate and were
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17 shocked by the severity of their weakness, as mentally they still saw themselves as
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19 capable of the physical tasks they were able to do pre-admission, for example, Sasha
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21 stated: *“I didn't realise I couldn't walk. I thought I could and I tried to get out of bed loads*
22
23 *of times, but up here I was weak (legs) and the top of my arms were weak as well. I*
24
25 *couldn't do it.”* Their actual *physical-self* and cognitive representation of themselves did
26
27 not match, for example, Sarah said: *“I just happened to catch sight of my whole body (in*
28
29 *the mirror) and I nearly died. I thought; ‘that doesn't resemble the person that I am’.”*
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31 However, it was the psychological symptoms that were of the greatest concern to
32
33 patients initially, for example, Evan felt that: *“there were tubes all over the place... but*
34
35 *that was the least of my worries. The specialists were there, and my son. I said ‘I don't*
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37 *know who that is (son)’. My son came back on the Monday, then I recognised him and*
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39 *things started falling back into place.”*
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48 **“Noxious cycle” of ICU**

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51 Overwhelming fatigue, insomnia (due to noise and disruption), boredom and the
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53 inability to concentrate were prevalent, which had a negative impact on the ability to
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55 engage in both physical rehabilitation and cognitive tasks, and made many fear early
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57 rehabilitation, for example, John stated: *“Physically tiring, emotionally, you're like “sh*t,*
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3 *really? I've got to do it (physiotherapy) now. I haven't got any energy at all.*" Procedural
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6 pain was reported in only a few instances, but discomfort was problematic, for example,
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8 from being 'swaddled' in blankets (John). For many this seemed to form a "noxious
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10 cycle" (Figure 1).
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17 **Humanisation of care**

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20 Participants valued "humanised" care²⁷, often remembering the staff members who
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22 made them laugh and feel safe, for example, Caroline said: *"I remember one bloke, one*
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24 *nurse, who- he would come in and smile, and I said 'Oh, you're always smiling. You make*
25
26 *me so happy'.*" Trust in the clinical team was also important; if trust was compromised
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28 then it had a negative impact on participants engagement with rehabilitation. Trust
29
30 seemed dependent on the rapport the staff member developed with the patient,
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32 including their ability to communicate honestly and to maintain patient's hope, for
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34 example, Michelle stated: *"I trust him... because when Tom (physiotherapist) says*
35
36 *something, it's true. Everything he said was true.*" However, the staff-patient interaction
37
38 was not always positive, with many patients describing examples of *de-humanised*
39
40 *care*²⁷. This included loss of agency: *"I feel so not free, everyone is doing what they want,*
41
42 *I'm like a puppet and I hate that"* (Michelle); and feeling isolated: *"I don't think I had a*
43
44 *voice at one point, which was probably one of the most difficult things to experience,*
45
46 *because you can't talk to people"* (Richard).
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55 Although not related to humanisation of care, the physical attributes of staff also
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57 influenced patients' rehabilitation experience, if physiotherapists looked small, young,
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3 and weak, then patients had less trust in their physical ability to keep them safe during
4 rehabilitation, an example came from David: *“He (the physio) was strong of course. One*
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8 *admires that. It’s an ability, you know; and of course, not everybody’s going to have that*
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10 *ability.”*

14 ***‘From current self to construction of the future self’***

17 **Recognising milestones to recovery and goal setting**

20 The vulnerability described by patients and relatives seemed to lead to a sense of
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The vulnerability described by patients and relatives seemed to lead to a sense of
desired paternalism in the early days; they did not feel ready to be in control. This was
further perpetuated by a lack of understanding of the stages of recovery, for example,
Tom stated: *“how you are improving may not be quite so obvious to the patient”*. The
memory loss of their admission meant that patients did not recall their acute stages of
illness, and hence their physical decline; the weakness that they were experiencing did
not make sense, and was often so severe that it made it difficult to envisage the next
steps in their recovery. As a result, patients did not always recognise basic functional
tasks as rehabilitation or indeed their achievements as progress, for example, Michelle
stated: *“The other day the whole ward congratulated me- and even now I feel
embarrassed – because I washed myself. I didn’t wait until now to know how to wash
myself; I thought it was so stupid.”* Therapeutic adjuncts, such as the use of a bed bike
or tilt table, were more commonly recalled as rehabilitation.

As patients had limited understanding of the recovery milestones early on, they wanted
the multi-disciplinary team to set their rehabilitation goals as *“they did not know what
goals to set”* (Jim). The main thing that kept them focused on engaging in rehabilitation

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2
3 at this point was their family and loved ones, Sarah described this: "I cry a
4
5 lot...something helped me to keep going, an inner strength came...the kids..."
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9 Patient involvement in early goal setting was described as like "*being in a car crash and*
10
11 *someone asking you how you want to be cut out.*" Most patients had a 'just get on with
12
13 it' approach to rehabilitation. Martin: "*I just blind folded said, 'if this is what I am*
14
15 *supposed to do, I will do it.*" However, despite desiring early clinician-led rehabilitation,
16
17 all patients identified a high-level goal that aligned to the core values of who they are;
18
19 examples include, returning to work, going on holiday, finishing a PhD, and getting
20
21 married.
22
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25
26 As patients progressed through the stages of recovery, they started to recognise smaller
27
28 functional gains as improvement and engaged more in the goal-setting and
29
30 rehabilitation planning process, for example, Sarah stated: "*Well, I was shocked at how*
31
32 *little I could do, but now, it's the other way, I'm actually shocked at how much I can do*
33
34 *and I am doing. It's really good.*" Their yardstick for comparison now became who they
35
36 were on awakening, and not who they were prior to admission; they were recalibrating.
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41 42 **Discussion**

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45 This work focused on exploring the experience of physical rehabilitation after critical
46
47 illness, however, as with inductive research, what transpired was a complex model of
48
49 recovery extending beyond the physical. Patients demonstrated an interruption to
50
51 personal narrative, a lost sense of self associated with loss of autonomy, temporary
52
53 desired paternalism and gave examples of accidental dehumanised care (albeit mostly
54
55 non-maleficent in intent). Delirium, sleep deprivation, fatigue and memory loss acted as
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3 potent mediators between the patients' physical impairments, and their ability to
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5 recalibrate to their new disability, and engage in rehabilitation.
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9 It is interesting to consider these findings in the context of established psychological
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11 theory. Deci & Ryan's Self-Determination Theory^{28,29} attempts to explain why people
12
13 engage in goal-orientated behaviour, exploring how this leads to well-being and personal
14
15 growth. Its three core concepts are: *autonomy* (the ability to be in control of oneself),
16
17 *competence* (the ability to manage the situation they are in) and *relatedness* (the ability
18
19 to have an emotional connection with others). Only when these needs are met can
20
21 intrinsic motivation flourish. Critical illness can strip patients of *autonomy* and
22
23 *competence*, and perhaps for a shorter period, *relatedness*. In the initial stages of critical
24
25 illness, patients may be unable to communicate and talk, be unable to move easily due
26
27 to weakness, may have hallucinations, and be too fatigued to engage in decision making.
28
29 Hence, loss of *autonomy* and *competence* are key features of the patient experience.
30
31 *Relatedness*, which may recover earlier (or be encouraged) is of paramount importance
32
33 to them, and was a motivator to engage in rehabilitation.
34
35

36
37 Markus and Nurius (1986) developed a theory called "The Possible Self"³⁰. They contend
38
39 that humans have different cognitive representations of who we are (*current self*) and
40
41 who we could be (*possible self*). *Possible selves* drive behaviour. A notion of the *possible*
42
43 *self* helps us to assess our *current self* by creating a benchmark for comparison for self-
44
45 evaluation. It can also provide tangible rehabilitation goals. *The possible self* and goal
46
47 setting also rely heavily on temporality, therefore requiring narrative of the past, and the
48
49 capacity to prospect. Physiologically, prospection depends on episodic memory,
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3 prospective memory, emotional stability and hypothetical thinking³¹, some of which can
4
5 be impaired in critical illness due to sleep deprivation, fatigue and delirium.
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7

8
9 On awakening, patients' immediate cognitive representation of their *current self*
10
11 matched their pre-admission self because they do not remember their functional
12
13 decline, however, their body had changed. Their mental image of their *current self* and
14
15 their *physical self* were not aligned. Furthermore, patients could not remember the
16
17 totality of their past, they did not recognise their present, and they struggled to
18
19 construct a compelling future self. This impaired their ability to engage in rehabilitation
20
21 goal setting and led to a sense of vulnerability, desired paternalism and emphasis on
22
23 *relatedness*.
24
25
26
27

28
29 This model of *recalibration* ties these established psychological ideas together, reflecting
30
31 the need for patients to explore their new self, adapt to it and allow it to become their
32
33 new yardstick. When this was achieved, smaller milestones in recovery became
34
35 meaningful goals. Others have described similar concepts as a *liminal* state. Liminality is
36
37 an anthropological term from the Latin word *līmen*, meaning threshold³². It refers to
38
39 someone who is transitioning. It is often associated with a change in role/identity, or a
40
41 loss of one self to be replaced with another. This can create inner turmoil, especially if
42
43 that change is not invited.
44
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48
49 This idea of liminality in ICU has been touched upon by a number of authors³²⁻³⁵. Kean
50
51 and colleagues³² identified 'unscheduled status passage' from *prior self* to *critically ill self*
52
53 as a theme in a longitudinal study of ICU survivorship. They found that this unscheduled
54
55 liminal stage is worsened by memory loss and delirium, and that this process of change
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1
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3 is temporal in nature, both progressing and regressing (in the event of decline). In order
4
5 to move on, patients need to regain autonomy.
6
7

8
9 Lindberg and colleagues³⁵ described what recovering autonomy looks like, suggesting
10
11 that patients go through four stages: the first is to acknowledge their dependence (or
12
13 paternalism), and then they strive to be recognised as a person (“humanised” care).
14
15 These two stages echo the findings of this study. The latter two stages are ‘invited
16
17 participation in care’, and ‘becoming a co-partner in the decision-making’. These stages
18
19 describe how staff coach patients to take control again through mutual trust,
20
21 understanding and co-determination.
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26 Although these may seem like abstract concepts, it is the authors’ view that they have
27
28 direct relevance to clinical practice, especially as early rehabilitation becomes a key
29
30 aspect of acute care. The reason for this is that perception of self and engagement in
31
32 rehabilitation and goal-setting are inextricably linked.
33
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35

36
37 If a person’s mind is telling them one thing about who they are and what they are
38
39 capable of doing, and their body is telling them another, they cannot start thinking about
40
41 the future until they reconcile that difference. They cannot reconcile that difference with
42
43 delirium, hallucinations and lack of episodic memory to justify their current situation and
44
45 facilitate hypothetical thinking and prospection³¹. Combining psychological intervention
46
47 with physiotherapy intervention may help to address this.
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51
52 Goal-setting depends on the capacity to prospect. It is also a key recommendation in the
53
54 UK National Institute for Health and Care Excellence (NICE) Guidelines for Rehabilitation
55
56 after Critical Illness³⁶ and NICE Quality Standards³⁷. The Quality Standards state that
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2
3 rehabilitation goals should be set within 4 days of admission, and ideally should be
4 patient-agreed. These data would suggest that asking *patients* to set goals at day 4 may
5
6 be premature. Further research exploring the application of the model of recovering
7
8 autonomy described by Lindberg³⁵ may assist in tailoring rehabilitation guidelines to the
9
10 specific needs of the critically ill.
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16 Further focus on *how* rehabilitation is delivered, not just *what* is delivered could also be
17
18 instructive. The impact of the dynamic between a sports coach and the players is well
19
20 known, yet this coaching dynamic is neglected somewhat in ICU rehabilitation. If
21
22 clinicians are able to assist patients in recalibrating to their *new current self*, and the
23
24 reconstruction of a compelling *future self*, it may improve patient care and outcome.
25
26 Further research will be needed to confirm the concepts identified in this initial
27
28 exploratory study. However, we believe the concepts identified are sufficiently plausible
29
30 and robust to pose challenges to clinicians working with recovering critically ill patients
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32 (outlined in Box 1).
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39 **Box 1: Key observations and challenges to practice.**

40
41 **Key observations**

- 42
43 ❖ Patients recovering consciousness during or after a critical illness are likely to be
44 shocked by the transition through which they have gone. Part of that shock is the
45 due to the unplanned interruption of their autobiographical story.
46
47 ➤ How can you help to fill the gaps in autobiographical memory?
48
49
50
51
52 ❖ Patients' immediate memory is of who they were and what they were able to do
53 before their critical illness. This is in collision with what they can actually do and a
54 period of recalibration is needed to allow people to align the two and develop
55 reasonable ambitions and goals.
56
57 ➤ How can you support patients to explore their current function and settle the
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discrepancy between expectations and reality?

- ❖ This recalibration is the development of an understanding of the relationships between their past, present and possible futures selves.
 - How can you help patients to envisage a compelling future?
- ❖ Because of this need for recalibration along with delirium and impaired cognition patients may need, and wish for, assistance in planning early rehabilitation. As autonomy recovers, patients desire to become fully involved increases.
 - How can you recognise and support recovering autonomy?
- ❖ Motivation and engagement are crucial in maximising the benefits of rehabilitation. Leveraging human relationships (relatedness) and encouraging autonomy are likely to be helpful; care that is de-humanising, even if “efficient” is likely to impair recovery.
 - How can humanisation of care be optimised in your ICU?

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References:

1. Puthuchery ZA, Rawal, JR, McPhail M, Connolly B, Ratnayake G, Chan P, Hopkinson NS, Phadke R, Dew T, Sidhu PS, Velloso C, Seymour A, Agley CC, Selby A, Limb M, Edwards LM, Smith K, Rowlerson A, Rennie MJ, Moxham J, Harridge S, Hart N, Montgomery HE. Acute Skeletal Muscle Wasting in Critical Illness. *JAMA*, 2013; 310 (15), 1591-1600.
2. Friedrich O, Reid MB, Van den Berge G, Vanhorebeek I, Hermans G, Rich MM, Larsson L. The sick and the weak: Neuropathes/myopathies in the critically ill. *Physiol Rev*. 2015; 95 (3), 1025-109.
3. Hermans G, & Van den Berghe G. Clinical review: intensive care unit acquired weakness. *Crit Care*. 2015; 5 (19), 274.
4. Cavalazzi R, Saad M, Marik PE. Delirium in the ICU: an overview. *Ann Intensive Care*. 2012; 2 (49).
5. Kress JP & Hall JB. Intensive care unit acquired weakness and recovery from critical illness. *N Eng J Med*. 2014; 370, 1626-1635.
6. Cuthbertson BH, Elders A, Hall S, Taylor J, MacLennan G, MacKirdy F, Mackenzie SJ, and the Scottish Critical Care Trials Group and the Scottish Intensive Care Society Audit Group. Mortality and quality of life in the five years after severe sepsis. *Critical Care*. 2013; 17, R70.
7. Kaukonen K-M, Bailey M, Suzuki S, Pilcher D, Bellomo R. Mortality related to severe sepsis and septic shock among critically ill patients in Australia and New Zealand, 2000-2012. *JAMA*. 2014; 311 (13), 1308-1316.
8. Hill AD, Fowler RA, Pinot R, Herridge MS, Cuthbertson BH, Scales DC. Long-term outcomes and healthcare utilization following critical illness – a population-based study. *Critical Care*. 2016; 20, 76.
9. Pandharipande P, Girard TD, Jackson JC, Morandi A, Thompson JL, Pun NE, Brummel CG, Highes EE, Vasilevskis AK, Shintani KG, Moons SK, Geevaghese A, Canonico RO, Hopkins RO, Bernad GR, Dittus RS, Ely EW. Long-Term Cognitive Impairment after Critical Illness. *N Engl J Med*. 2013: 369, 1306-1316.
10. Nydahl P, Sricharoenchai T, Chandra S, Kundt FS, Huang M, Fischill M., Needham D.M. Safety of Patient Mobilization and Rehabilitation in the Intensive Care Unit.

- 1
2
3 Systematic Review with Meta-Analysis. *Annals of the American Thoracic Society*.
4 2017; 14 (5).
5
6
7 11. Castro-Avila AC, Seron P, Fan E, Gaete M, Mickan S. (2015) Effect of early
8 rehabilitation during Intensive Care Unit stay on functional status: systematic review
9 and meta-analysis. *PLoS ONE*. 2015; 10 (7), e0130722.
10
11 12. Balas MC, Burke WJ, Gannon D, Cohen MZ, Colburn L, Bevil C, Franz D, Olsen KM, Ely
12 WE, Vasilevski EE (2013) Implementing the awakening and breathing coordination,
13 delirium monitoring/management, and early exercise/mobility bundle into everyday
14 care: opportunities, challenges, and lessons learned from implementing the ICU
15 pain, agitation and delirium guidelines. *Crit Care Med*. 2013; 41: S116-S127.
16
17 13. Balas MC, Vasilevskis EE, Olsen KM, Schmid KK, Shostrum V, Cohen MZ, Peitz G,
18 Gannon DE, Sisson J, Sullivan J, Stohtert JC, Lazure J, Nuss SL, Jawa RS, Freihurt F, Ely
19 EW, Burke WJ. (2014) Effectiveness and safety of the awakening and breathing
20 coordination, delirium monitoring/management, and early exercise/mobility bundle.
21 *Crit Care Med*. 2014; 42:1024-1036.
22
23 14. Connolly B, Douiri A, Steier J, Moxham J, Denehy L, Hart N. A UK survey of
24 rehabilitation following critical illness: implementation of NICE Clinical Guidance 83
25 (CG83) following hospital discharge. *BMJ Open*. 2014; 4; e004963.
26
27 15. Jensen JF, Thomsen T, Overgaard D, Bestle MH, Christensen D, Egerod I. Impact of
28 follow-up consultations for ICU survivors on post-ICU syndrome: a systematic review
29 and meta-analysis. *Intensive Care Med* (2015) 41:763–775
30
31 16. Nydahl P, Parker RA, Bartoszek G, Dubb R, Filipovic,S, Flohr H-J, Kaltwasser A, Mende
32 H, Rothaug O, Schuchhardt D, Schwabbauer N, Needham D. Early Mobilization of
33 Mechanically Ventilated Patients: A 1-Day Point-Prevalence Study in Germany.
34 *Critical Care Medicine*. 2014; 42 (5), 1178-1186.
35
36 17. Berney SC, Rose JW, Bernhardt J, Denehy L, Prospective observation of physical
37 activity in critically ill patients who were intubated for more than 48 hours. *Journal*
38 *of Critical Care*. 2015; 30(4), 658-663.
39
40 18. Hodgson CL, Stiller K. Needham D, Tipping CJ, Harrold M, Baldwin CE, Bradley S,
41 Berney S, Caruana LR, Elliott D, Green M, Haines K, Higgins AM, Kaukonen KM,
42 Leditschke IA, Nickels MR, Paratz J, Patman S, Skinner EH, Young PJ, Zanni JM,
43 Denehy L, Webb SA. Expert consensus and recommendations on safety criteria for
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 active mobilisation of mechanically ventilated critically ill patients. *Critical Care*.
4 2014; 16:658.
5
6
7 19. Parry S, Knight LD, Connolly B, Baldwin C, Puthuchery Z, Morris P, Mortimore J, Hart
8 N, Denehy L, Granger CL. Factors influencing physical activity and rehabilitation in
9 survivors of critical illness: a systematic review of quantitative and qualitative
10 studies. *Intensive Care Med*. 2017; 43, 531–542.
11
12
13
14 20. Wright SE, Thomas K, Watson G, Baker C, Bryant A, Chadwick, TJ, Shen J, Wood R,
15 Wilkinson J, Mansfield L, Stafford V, Wade C, Furneal J, Henderson A, Hugill K,
16 Howard P, Roy A, Bonner S, Baudouin S. Intensive versus standard physical
17 rehabilitation therapy in the critically ill (EPICC); a multicentre, parallel-group,
18 randomised controlled trial. *Thorax*. 2017; (5).
19
20
21
22
23 21. Sottile PD, Nordon-Craft A, Malone D, Schenkman M, Moss M. Patient and family
24 perceptions of physical therapy in the medical intensive care unit. *Journal of Critical*
25 *Care*. 2015; 30, 891-895.
26
27
28
29 22. Mills, J., Bonner, A., Francis, K. (2006) The development of constructivist grounded
30 theory. *International Journal of Qualitative Research Methods*. 5 (1).
31
32
33 23. Mental Capacity Act (2005). UK legislation. Available at:
34 <https://www.legislation.gov.uk/ukpga/2005/9/contents>
35
36
37 24. Corbin, J. & Strauss, A. (2015) *Basics of qualitative research: techniques and*
38 *procedures for developing grounded theory*. 4th edition. London
39
40
41 25. Heath H, Cowley S. Developing a grounded theory approach: a comparison of Glaser
42 and Straus. *International Journal of Nursing Studies*. 2004; 41, 141-150.
43
44 26. Bonde, D. (2013) *Qualitative Interviews: When enough is enough*. Research by
45 Design.
46
47 27. Todres L, Galvin KT, Holloway I. The humanisation of healthcare: a value framework
48 for qualitative research. *International Journal of Qualitative Studies on Health and*
49 *Well-being*. 2009; 4, 68-77.
50
51
52 28. Deci EL, Ryan RM. *Intrinsic motivation and self-determination in human behavior*.
53 New York, NY: Plenum. 1985.
54
55
56 29. Deci EL, Ryan RM. (2017) <http://selfdeterminationtheory.org/theory/> (Accessed:
57 30th March 2017)
58
59
60 30. Markus H & Nurius P. Possible Selves. *American Psychologist*. 1986; 41 (9), 954-969

- 1
2
3 31. Osman M. What are the essential cognitive requirements for prospection (thinking
4 about the future)? *Frontiers in Psychology*. 2014;5, 626.
5
6
7 32. Kean S, Salisbury LG, Rattray J, Walsh TS, Huby G, Ramsey, P. 'Intensive Care Unit
8 (ICU) Survivorship' – a constructivist grounded theory of surviving critical illness.
9 *Journal of Clinical Nursing*. 2017. [online].
10
11
12 33. Johnston LB. Surviving Critical Illness: A Case Study in Ambiguity. *Journal of Social
13 Work in End-of-Life & Palliative Care*. 2011; 7 (4), 363-382.
14
15
16 34. Darbyshire JL, Greig PR, Vollaam S, Young DJ, Hinton L. "I Can Remember Sort of Vivid
17 People... but to Me They Were Plasticine." *Delusions on the Intensive Care Unit:
18 What Do Patients Think is Going on?* *PLoS ONW*; 11 (4): e0153775.
19
20
21 35. Lindberg C, Sivberg B, Willman A, Fagerstrom C. A trajectory towards partnership in
22 care – patients perspective of autonomy in intensive care: A qualitative study.
23 *Intensive and Critical Care Nursing*. 2015;31: 294-302.
24
25
26
27 36. National Institute for Health and Clinical Excellence. Great Britain. *Rehabilitation
28 After Critical Illness* Great Britain. Available at: www.nice.org.uk. 2009.
29
30
31 37. National Institute for Health and Clinical Excellence (2017). *Rehabilitation after
32 Critical illness in adults: Quality Standard*. Published 7th September 2017. Available
33 online: nice.org.uk/guidance/qs158. (Accessed: 13th September 2017)
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Topic guide**Opening**

1. Introduction
2. Consent confirmed.

Questions

3. Do you have any questions about the about the patient information sheet?
4. Could you tell me about the events leading up to your admission to the ICU?
5. Could you summarize, as you remember it, your stay on the ICU including the length of your stay and the procedures you experienced (e.g. surgery, tracheostomy etc)?
6. Could you describe any physical problems that you had during and after your stay, such as weakness, pain, joint stiffness etc?
7. Could you describe your rehabilitation experience?
 - Memories of rehabilitation
 - Rehabilitation equipment
 - Interaction with the therapist
 - Intensity of rehabilitation
 - Rehabilitation goal setting

Closing

8. Do you have any additional information you would like to add?
9. Do you have any questions?

End**Table 1: Topic guide**

Table 2: Summary of each participant

Pseudonym	Relative present?	Age range (years)	APACHE II	Diagnosis	Length of stay, ICU (days)	Length of stay, hospital (days)	Discharge location
Richard	No	30-39	17	Acute porphyria	9	102	Long-term, inpatient rehabilitation
Martin	No	30-39	14	Drug overdose, aspiration pneumonia, rhabdomyolysis	26	32	Home, outpatient rehabilitation
Sadiq	No	50-59	22	Exacerbation of COPD	33	34	Home, full care package
Sarah	No	60-69	24	Open hernia repair- post operative MOF	115	197	Long-term, inpatient rehabilitation
Tom	No	60-69	10	Pneumonia and pulmonary embolism	10	16	Home, outpatient rehabilitation
Evan	No	60-69	15	Acute bowel obstruction- colon cancer	5	48	Home, no rehabilitation.
Sasha	Yes, daughter	50-59	10	Neuromyelitis optica	19	98	Long-term, inpatient rehabilitation
John	No	40-49	27	Influenza	33	71	Long-term, inpatient rehabilitation
George	No	50-59	12	Drug overdose- respiratory failure	25	36	Home, no rehabilitation
Michelle	No	80-89	14	Exacerbation of COPD	6	42	Declined inpatient rehabilitation- home, full care package
Jim (M)	Yes, wife	50-59	11	Food poisoning- MOF	10	18	Home, no rehabilitation
Matthew (M)	No	70-79	18	Hospital acquired pneumonia- fractured NOF	5	178	Nursing home
Caroline (F)	Yes, husband	70-79	22	Anterior resection for bowel cancer	13	63	Short-stay, inpatient rehabilitation.
Ben (M)	No	40-49	15	Drug overdose	65	107	Home, care package
David (M)	Yes, wife present	63	21	Influenza	150	232	Long-term, inpatient rehabilitation

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7 (NOF-neck of femur; MOF-multi-organ failure; COPD-chronic obstructive pulmonary disease; APACHE II- acute
8 physiology and chronic health evaluation II; ICU – Intensive Care Unit)
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For peer review only

Table 3: Supporting data

Central phenomenon: Recalibration of The Self	
Main theme 1: "From prior self to current self"	
<p><i>Sasha: "I didn't realize I couldn't walk. I thought I could and I tried to get out of bed loads of times, but up here I was weak (legs) and the top of my arms were weak as well. I couldn't do it."</i></p> <p><i>Sarah: "I don't ever look at myself in the mirror and there is a mirror in that bathroom, I just happened to catch sight of my whole body almost and I nearly died. I thought; that doesn't resemble the person that I am."</i></p>	
Episodic memory loss	<p>ICU admission</p> <p>Sasha: "...that's when I don't know, it's a real black after that (the emergency room)"</p> <p>Sadiq: "That is a black. That is a blank. Totally blank"</p> <p>John: "I must have been in and out of consciousness, because I don't remember anything"</p> <p>Ben: " I had a bad fall, collapsed... that's all I remember"</p> <p>Rehabilitation and mobilization</p> <p>EJC: "what was your memory of getting moving after you woke up with the tubes attached?" Ben: "I don't really have much memory of it."</p> <p>EJC: Do you remember any of the rehab on ICU?" Martin: "Not to start with, no."</p> <p>David: "It was Dan (ward physiotherapist) who taught me to sit on the edge of the bed."</p> <p>EJC: "Do you remember getting into the chair for the first time?" Michelle: "It was with Tom (the ward physical therapist)."</p>
Hallucinations and delusions	<p>John: "I kept thinking I could see like people with hoodies and they were like assassins, trying to get in."</p> <p>David: "I was taken into Soho (Central London) by some people and stuck under a glass floor, lying under a glass floor with formaldehyde around me. I was encased."</p> <p>Ben: "I operated on Margaret Thatchers cat and there was eight other people in the house and three of them got shot... I remember waking up with the fear that I was going to get shot."</p> <p>Carolyn: "I was trying to use my mobile (to escape), and the same number kept on pressing and I remember panicking"</p>

<p>Weakness</p>	<p>George: "Nothing, I couldn't move my hand. I couldn't move and that was really scary. Really scary."</p> <p>Richard: " I couldn't do anything. I was paralyzed from the neck down... I still felt like I had sensation in my legs and my arms, I just couldn't move them."</p> <p>Carolyn: "I couldn't even stand up. I was really very, very weak."</p> <p>John: "I couldn't do anything. I mean literally, I couldn't move, I could just barely move my fingers."</p> <p>David: "I couldn't move. I couldn't move at all. I could blink, that's about it."</p> <p>Martin: "...couldn't walk, couldn't do nothing."</p> <p>Richard: "You are reliant entirely on the people around you, for everything really... that's difficult."</p>
<p>Noxious cycle of ICU</p>	<p>Sarah: "I didn't want to do it (physiotherapy). I used to dread them coming, any excuse to get out of it. I was just so tired."</p> <p>John: "Physically tiring, emotionally... you're like 'sh*t really? I've got to do it (mobilization) now? I haven't got any energy at all.'"</p> <p>George: "There were some days when they'd (physiotherapist) come and they'd get me into the chair, and they'd want to do some work on the zimmer frame. They'd come back (from getting the zimmer frame) and I'd be asleep."</p> <p>Sarah: "People kept telling me to read, but I couldn't. I couldn't' actually physically read. They'd bring me the menu and I just couldn't do it, and then I'd fall asleep"</p> <p>Sarah: "...then I just accepted it (weakness), going...on the hoist and, you lose all dignity when you're in that state you just accept it, and you just let them help you as much as possible and when you've done your, you know bits of physio, exhausted, you go back to bed again, sleep again. You know it tended to be like that."</p>
<p style="text-align: center;">Main theme 2: "From current self to construction of the future self"</p> <p>Ben: <i>"The first days when I couldn't move... I was disillusioned with the whole thing, and I thought, 'This is never going to work'... I couldn't see how anything could turn round, but I was told just to trust. But that period was very difficult because when you don't see any light at the end of the tunnel, it's difficult to sort of engage with it, and it's difficult to trust... There was plans in my head, but it's difficult to kind of have them if you think it's just a waste of time what you're doing. Now I know that there is (light at the end of the tunnel)... and I believe I'll be walking next week, they've (physiotherapists) let me believe that"</i></p>	

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Recovery milestones and goal setting

Matthew: "Let the patient realize that he is not capable of doing that, or this, or whatever... don't tell him"

Tom: "Everyone's functions, and how they are improving, might not be quite so obvious to the patient."

Carolyn: "The other day the whole ward congratulated me- and even now I feel embarrassed – because I washed myself. I didn't wait until now to know how to wash myself; I thought it was so stupid."

Jim's wife: "We didn't want to set the goals, because we didn't know what goals to set"

Sadiq: "It depends on the person. If a person is shooting to the high, they might do it (achieve their goal), but sometimes shooting too much to the high might break your neck. If they are too sick, they cannot talk, you are in the dark and you have to put your own objectives."

Researcher: "What have been the things that have kept you going?" Sasha: "I think Gemma (daughter) and her dad, they've been so supportive. He's been down every day, and Gemma sometimes twice a day *starts crying*... sorry... I suppose if it wasn't for them, I wouldn't be... *crying- unable to finish sentence*

Richard: "obviously I was doing it (rehab) for me primarily, but knowing how much concern and love she has for me, and knowing how much it would mean to her and how much of a relief it would be to her... The fact that she was, you know with me for as long as she was, and as strong as she was... I don't know. I never thought my mum was that strong."

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6 **Figure 1: The noxious cycle of critical illness.**
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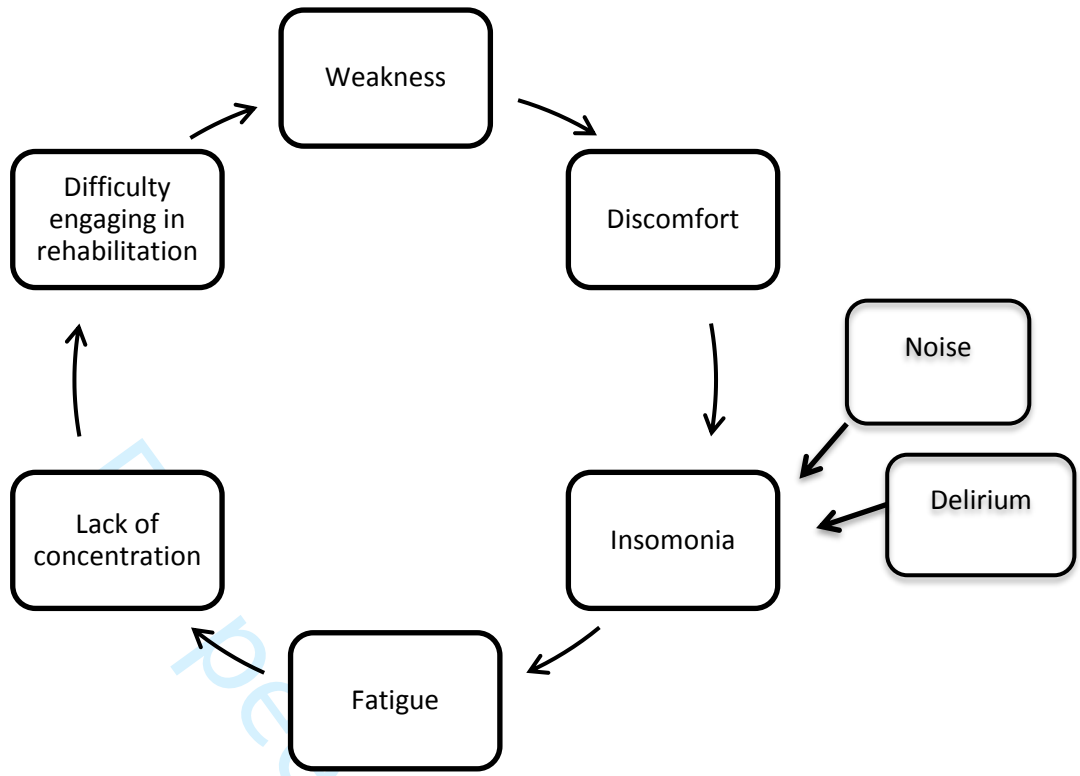


Figure 1: noxious cycle of ICU