

# UNPLANNED EARLY HOSPITAL READMISSION AMONG CRITICAL CARE SURVIVORS: A MIXED METHODS STUDY OF PATIENTS AND CARERS

## Running title:

Early unplanned hospital readmissions following critical illness

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## Conflicts of Interest

The authors have no conflicts of interests to declare.

## Authors' contributions

All authors contributed to conception and design of the work. ED and LS undertook interviews and focus groups, contributed to data acquisition and analysis. All authors contributed to interpretation of data for the work. ED and TW drafted the manuscript. All authors revised it critically for important

intellectual content. All authors gave final approval of the version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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# Abstract

## Background

Many intensive care (ICU) survivors experience early unplanned hospital readmission, but the reasons and potential prevention strategies are poorly understood. We aimed to understand contributors to readmissions from the patient/carer perspective.

## Methods

Mixed methods study with qualitative data taking precedence. Fifty-eight ICU survivors and carers who experienced early unplanned rehospitalisation were interviewed. Thematic analysis was used to identify factors contributing to readmissions, and supplemented with questionnaire data measuring patient comorbidity and carer strain, and importance rating scales for factors that contribute to readmissions in other patient groups. Data were integrated iteratively to identify patterns, which were discussed in five focus groups with different patients/carers who also experienced readmissions. Major patterns and contexts in which unplanned early rehospitalisation occurred in ICU survivors were described.

## Results

Interviews suggested ten themes comprising patient- and system-level issues. Integration with questionnaire data, pattern exploration, and discussion at focus groups suggested two major readmission contexts. A 'complex health and psychosocial needs' context occurred in patients with multi-morbidity and polypharmacy, who frequently also had significant psychological problems, mobility issues, problems with specialist aids/equipment, and fragile social support. These patients typically described inadequate preparation for hospital discharge, poor communication between secondary/primary care, and inadequate support with psychological care, medications, and goal-setting. This complex multidimensional situation contrasted markedly with the alternative 'medically unavoidable' readmission context. In these patients medical issues/complications primarily resulted in hospital readmission, and the other issues were absent or not considered important.

## Conclusions

Although some readmissions are medically unavoidable, for many ICU survivors complex health and psychosocial issues contribute concurrently to early rehospitalisation. Care pathways that anticipate and institute anticipatory multifaceted support for these patients merit further development and evaluation.

**275 words**

## Keywords

**Intensive care; critical illness; readmission; re-hospitalisation; recovery; post-intensive care syndrome.**

## Introduction

Survivors of critical illness frequently report poor quality of life (QoL), with functional and psychological disability.<sup>1-4</sup> Unpaid carers also experience stress and long-term mental health problems.<sup>5-7</sup> Although rehabilitation for critical care survivors is recommended<sup>8</sup>, the determinants of long-term health are poorly understood and rehabilitation trials have been largely ineffective for the outcomes measured.<sup>9-10</sup> Although the term ‘post-intensive care syndrome’ has been widely adopted<sup>2</sup>, recent studies show that health status among ICU survivors is strongly influenced by pre-critical illness health as well as new disabilities following acute illness.<sup>11</sup> These findings suggest health and social care needs are complex and multifactorial. The need to support ICU survivors and their families is increasingly recognised in policy<sup>12</sup>, and in 2017 the UK National Institute for Health and Care Excellence (NICE) made rehabilitation following critical illness a quality standard. However, there are few detailed studies of the needs of ICU survivors from a patient and carer perspective, and evidence to inform the optimum design of care pathways and their clinical and cost-effectiveness is weak.

In addition to disability, critical care survivors have high ongoing healthcare costs.<sup>13</sup> We recently reported that 25% of intensive care (ICU) survivors in Scotland experienced unplanned rehospitalisation within 90 days of hospital discharge,<sup>14</sup> a rate comparable to conditions such as heart failure, chronic respiratory disease, and pneumonia.<sup>15-16</sup> Early rehospitalisation is a widely used healthcare quality indicator that is linked to financial penalisation in some healthcare systems.<sup>17</sup> Although financially important, the validity of this metric is controversial, in part because the proportion of readmissions that are preventable (as opposed to appropriate) is uncertain, and the causes complex and incompletely understood.<sup>18</sup> <sup>19</sup> Understanding the complexity of ICU survivorship, and specifically the reasons patients experience unplanned hospital readmission following critical illness, could inform evidence-based development of clinically and cost-effective interventions and care pathways. We therefore carried out a mixed methods study to understand contributors to unplanned hospital readmission in this population from a patient and carer perspective.

## Methods

This study formed part of a larger research programme with a published protocol.<sup>20</sup> The local Research Ethics Committee provided approval. In this study qualitative methods took

precedence, but were supplemented with questionnaires and rating scales to support interpretation. The overall approach is summarised in figure S1 (electronic supplement).

## Sources of Data

### Individual interviews with patients/carers requiring emergency hospital readmission

Between January-August 2015 we recruited 58 participants (29 patients; 29 relatives/carers) from three Scottish Health Boards, including rural/urban areas and a range of socio-economic status. No patients dropped out following recruitment. Patient inclusion criteria were: mechanical ventilation (MV) for  $\geq 48$  hours and aged  $\geq 18$  years. This cut-off for MV has been widely used to identify patients with more prolonged critical illness (typically 40-50% of MV patients in UK ICUs). Patients who required unplanned hospital readmission within 3 months of index ICU hospitalisation were identified from ICU/hospital information systems within 3 months of the readmission event. The patient and a relative/carer were invited to participate. No financial or other incentive was offered. Exclusions were: organ transplantation; primary neurological admission diagnosis; palliative care; unable to speak English; lacking capacity; and too ill to participate. Purposive sampling was used to achieve a range of age, gender, socio-economic status, social situation (living alone versus partner), primary ICU admission diagnosis, illness severity, duration of ICU stay, duration of MV, and pre-existing co-morbidity. Patient characteristics are shown in table 1.

A researcher with experience of acute and community based qualitative research within NHS settings (ED; research fellow; social scientist) undertook interviews in the patients' home, mostly with the relative/carer and patient together (20/29) or individually according to their preference. Interviews were semi-structured using a taxonomy informed by literature review (see table S1; eSupplement), and lasted around 60 minutes (range 45-80 minutes).

Participants were invited to discuss issues which they felt contributed to their (or their relative's) readmission event and locate the event in their personal health and social circumstances and their interaction with health and social care services across acute and primary care. They were asked to group issues together if appropriate, and suggest what they felt might have helped prevent their readmission. Field notes were made to support interpretation of transcribed recordings.

### Questionnaires and rating scales

Following interview, participants completed several structured questionnaires and rating scales. These were a measure of multi-morbidity (completed by patients), the Functional

Comorbidity Index (FCI)<sup>21</sup>, to quantify the burden of co-morbidity for each patient, and a measure of caregiver strain (completed by caregivers), the Modified Caregiver Strain Index (MCSI)<sup>22</sup>. These were included because co-morbidity burden is associated with readmissions<sup>14</sup>, and caregiver strain and psychological morbidity have been highlighted as prevalent among ICU survivors' carers.<sup>7</sup>

Patients also rated the importance to their readmission of nine factors identified from a pre-study literature review as potentially important readmission drivers (see figure 1). A visual analogue scale (VAS) was used with anchor quotes (0 “none” to 10 “very large part”). These quantitative data were cross-checked with qualitative data for consistency and validity of responses in relevant areas, and helped during iterative development of themes and patient phenotypes.

### Focus groups

Focus groups were conducted after initial analysis and integration of the interview and questionnaire data. These aimed to provide independent validation for initial findings, refinement and confirmation of overall data saturation in a new population with wider national representation. Using the same recruitment strategy, participants who had not been previously interviewed were identified in five of the fourteen regional Scottish Health Boards and invited to take part; these ranged in rural/urban and socioeconomic status, and population density. There were 43 participants in 5 focus groups (20 ICU survivors; 22 carers/relatives), which were facilitated by two researchers (ED; LS (Research Fellow; academic physiotherapist), recorded, and transcribed verbatim. Focus groups lasted on average 2 hours. Patient characteristics are shown in Table 1.

Emergent data from the interviews was presented and participants invited to discuss this in relation to their own experience of readmission, as an ICU survivor (or carer). Any discordance from the initial analysis of data or need for modification was specifically sought and explored.

Table 1: Characteristics of the patients who experienced unplanned hospital readmission and participated in the interviews and focus groups. Patients (and their carers) were only invited to participate in either individual interviews or focus groups.

<b>Individual Patient Interviews</b>	
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Sex (number (%))	Male	18 (62)
	Female	11 (38)
Age range (years; number)	18-24	1
	25-34	2
	35-44	3
	46-54	8
	55-59	5
	60-64	2
	>65	8
Social deprivation status (number (%))		
Most Deprived		13 (45)
Mid Deprived		10 (34)
Least Deprived		6 (21)
Multimorbidity status (number (%))		
Multi-morbid		18 (62)
Not multi-morbid		11 (38)
Polypharmacy status (number (%))		
Polypharmacy		21 (72)
No polypharmacy		8 (28)
Drug and/or alcohol misuse (number (%))		
Present		8 (28)
Not present		23 (72)
Treatment for depression and/or anxiety (number (%))		
Present		13 (45)
Not present		16 (55)
Major mobility problems (number (%))		
Present		10 (34)
Not present		19 (66)
<b>Focus groups</b>		
Sex (number (%))	Male	9 (45)
	Female	11 (55)
Age range (years; number)	18-24	0
	25-34	1
	35-44	1
	45-54	6
	55-59	5
	60-64	4
	>65	3
Social deprivation status (number (%))		
Most Deprived		10 (50)
Mid Deprived		4 (20)
Least Deprived		6 (30)
Multimorbidity status (number (%))		
Multi-morbid		15 (75)
Not multi-morbid		5 (25)

Polypharmacy status (number (%))	
Polypharmacy	15 (75)
No polypharmacy	5 (25)
Drug and/or alcohol misuse (number (%))	
Not Recorded in Focus Groups	-
Treatment for depression and/or anxiety (number (%))	
Present	8 (40)
Not present	16 (60)
Major mobility problems (number (%))	
Present	10 (50)
Not present	10 (50)

## Analysis

### Qualitative interviews

Interviews were digitally recorded, transcribed verbatim, and entered into a qualitative data analysis tool (NVIVO 10). Thematic content analysis was used, an analytical approach that uncovers the most significant issues that arise from a particular group of respondents and for identifying typical responses. This approach allows researchers to analyse data for meanings in specific circumstances and experiences.<sup>23 24</sup> This focus on the explicit description of the interview data was considered particularly suited to this study, because we sought patient/carer views and experiences of their unplanned hospital readmission and the type of support that they felt they needed in the community following discharge home. Two authors (ED and LS) undertook independent thematic analysis of the first six patient/relative interviews to assess consistency of interpretation; interview transcripts were frequently read through before being cross-matched to classify emerging themes and issues, and at variance cases (differences of interpretation). Remaining interviews were analysed by one author (ED).

### Integration of qualitative themes and quantitative measures

Meetings of all co-investigators took place every 6-8 weeks during iterative analysis to discuss the emerging data and reach consensus on interpretation. Once preliminary themes were identified, the relevance of each to individual patients was assessed from transcripts by the researcher who undertook the interviews (ED). A checkerboard for all patients was created for pattern assessment, and the relevance of each theme to each patient was dichotomised based on interview transcripts. The quantitative responses to questionnaires and rating scales were added to the checkerboard tables to enable cross-tabulation. For the nine pre-defined potential contributors to readmission, the VAS rating scale data were further

processed to enable integration with the other data by creating a 'traffic light' with responses categorised as 'green' (score 0-3; little/no part), 'amber' (score 4-6; some part), and 'red' (score 7-10; important part). These data were added to the checkerboard data for themes. At the co-investigator meetings we iteratively grouped data to see if patterns emerged that usefully described different contexts in which patients experienced unplanned hospital readmissions. The qualitative data were cross-checked subjectively for consistency with the quantitative questionnaire and VAS 'traffic light' data, for example in relation to multimorbidity, social support, communication between services, and psychological issues. Discussion and re-analysis were used to reach consensus when disagreements occurred.

In-depth thematic analysis of focus group data was undertaken using a similar approach to individual interviews by a single researcher (ED). Analysis was iterative and enduring as the data were gathered and any emergent themes were identified and further discussed among the researchers. In this way the focus group data were integrated into the individual patient data, and used to confirm and refine the emerging themes and contexts in which readmissions occurred, with a focus on searching for discordant cases or themes.

The final themes presented and contexts in which unplanned readmissions occurred represented the integration of all data sources collected in the study.

## Results

### Themes that emerged from analysis of individual patient/carer interviews

Patients were interviewed a median (1<sup>st</sup>, 3<sup>rd</sup> quartile; range) 11 weeks (4, 9; 15-31 weeks) after the readmission event. At interview, patients had experienced a median 1 (1, 2; 1-5) separate readmissions. Despite wide variation in patient characteristics, diagnoses, and readmission circumstances common themes emerged. Based on-going analysis we considered data saturation occurred after 55 interviews, but completed all arranged interviews. Patients generally identified a readmission trigger, typically a medical condition or complication, but many described other issues that they felt contributed to being unable to remain at home. These included issues pre-dating ICU admission, direct consequences of their critical illness, and organisational issues around their experience of recovery. Ten themes captured the major issues described by patients and carers surrounding their unplanned readmission. These were not always explicitly or directly linked to rehospitalisation, but were described as important

in the context of the readmission event. We grouped these into ‘patient-level factors’ and ‘system-level factors’. These are summarised, together with illustrative quotes, in table 2.

### Patterns and contexts that emerged from integration of data

Data integration suggested patterns of clinical interest and importance. Cross checking the ten themes against individual patient/carer accounts and the quantitative measures indicated substantial concordance between the different data. Specifically, qualitative descriptions of the importance of multi-morbidity were consistent with the multimorbidity scores, and accounts of carer stress were consistent with the MCSI scores. When we tabulated the traffic light categorisation for the nine predefined readmission drivers, these were generally consistent with the thematic analysis of individual interviews.

Examination, organisation, and discussion of tabulated data for the individual patients according to whether interviewees described each theme as important in their accounts led to us grouping the patients into two major categories (table 3). For one group, patients described almost all of the ten themes as relevant in the context of their readmission; these patients reported high co-morbidity scores, and their carers reported high levels of strain. For the other group, most patients attributed few themes as important to their readmission, and they typically had lower co-morbidity scores; most (but not all) carers described lower levels of strain. Only three patients did not clearly fall within one of these categories, but they were not sufficiently different to justify a discrete category. We presented these patients as an ‘intermediate’ group.

Further tabulation to include the ‘traffic light’ presentation of VAS responses to the potentially important contributors to readmission further supported the categorisation into two major groups and contexts (table 4). Although all patients had discrete medical conditions or complications, those describing multiple contributing themes generally rated many of the pre-defined contributors as playing some part in their readmission. A feeling of inadequate support from general practitioners, nurses, and social services were rated as particularly important, and insufficient information about what to expect. Patients who rated support for psychological issues as insufficient were all in this group. The exceptions were for ‘social support from family and friends’ which most patients rated as unimportant as a readmission driver, and ‘support in the community from physiotherapy’ which had mixed responses. In marked contrast, those patients who described few themes as important to their readmission also rated the nine potential contributors as unimportant.

The analysis of focus group transcripts suggested participants' experiences strongly resonated with those of the individual interviewees. Data saturation occurred by the fifth focus group. No new important patient or system level themes emerged from these data, which were largely confirmatory, and consistent across all 5 focus groups. The data also suggested that the broad dichotomy into two major readmission contexts was valid based on the focus group discussions.

Across all patients and carers participating in the study there appeared approximately equal numbers within each of the two readmission context groupings. We used the terms 'complex health and psychosocial needs' and 'medically unavoidable' for these contexts and analysed data to describe them in detail.

Table 2: The five patient-level and five system-level themes that emerged as being important to readmission for many patients. Illustrative quotes from individual patients and carer interviews are included as supporting evidence.

<b>Theme</b>	<b>Description</b>	<b>Illustrative quote</b>
<b>Patient-level themes</b>		
<b>Multi-morbidity and polypharmacy</b>	Many patients directly linked their readmission to co-existing chronic conditions and the burden of multi-morbidity, specifically a “struggle” to self-manage chronic illnesses following hospital discharge. Polypharmacy, typically associated with multi-morbidity, was an issue and medication problems were considered by some to have contributed to readmission.	<i>I have Fibromyalgia, Diabetes, Diabetic Neuropathy, Sciatica, nerve damage at the base of my back and crumbling discs, Arthritis, Hidradenitis Supportiva, an underactive thyroid, depression, loads of hormonal problems, which is why I’m going through the menopause. I’m on 12 different types of medication. I have to monitor everything. One small change, like forgetting to take one of my medications or running out, or the consequences of getting a cold can set off a chain of other problems. I’ve been readmitted (to acute bed) with blood pressure problems due to changes in my medication. It’s a struggle just to get by. I’m housebound without my mum.</i>
<b>Problems with specialist equipment</b>	Issues related to specialist equipment contributed to readmission, for example stoma bags, feeding tubes, or Hickman lines. Some patients considered problems were unpredictable and/or unavoidable, but others felt inadequate training prior to hospital discharge or support in the community in maintaining specialist equipment contributed to the complication.	<i>My (unplanned) readmissions have been to do with a dislodged or blocked nephrostomy tube. I’ve got three bags and drains and stuff. I don’t get any warning. This one got quite blocked and got very smelly and I get a lot of infections. I either stop passing urine or I’ll just end up in real bad renal pain and I have to take it out because it’s all pus and stuff like that. There should be better training in managing these things.</i>
<b>Psychological problems and alcohol/drug dependency</b>	Many patients described psychological issues, which for many pre-dated their critical illness, but were often exacerbated by the ICU illness. Patients were often receiving treatment for pre-existing or new mental health problems. Other issues included the emotional strain of coming to terms with near death experiences, adapting to major lifestyle changes, relationship difficulties, and feeling socially isolated. Pre-existing drug and alcohol dependency or misuse was a problem for some patients, who often noted the impact of this on self-management, psychological status, and recovery.	<i>I’ve been a drinker since I was 16. That’s 40 years. I was diagnosed with diabetes at 52. I’ve been unemployed for 7 years and my wife keeps saying you are not looking after yourself. I stopped taking my insulin for months. By not taking that I was really giving up ...it was depression. I was feeling very low, very depressed. But not getting support. That’s when they (the hospital) thought I was trying to commit suicide which I was kind off. I saw a psychiatrist who said ‘you’ve got issues’ but I didn’t get the counselling. I got a card for the Samaritans. But that’s the last resort</i>
<b>Poor Mobility</b>	Mobility problems were prevalent among patients, often requiring crutches and/or a wheelchair. This preceded critical illness in many, but was either significantly worsened or was a direct consequence of critical illness in others.	<i>I’m on crutches or the walker just to get around the house. I’m totally reliant on my husband 24/7. If he wasn’t here I couldn’t cope. I need him to help get up the stairs to the toilet. They (social services) said you can have a handrail or walk in shower so I chose the shower. I’m high risk for a fall.</i>
<b>Fragile Social Support</b>	Many patients described heavy reliance on one unpaid carer for support with activities of daily living, and many unpaid carers described high levels of strain. Patients highlighted reliance on a single carer as a major risk to managing at home, especially in combination with social isolation, poor mobility or psychological problems. In some cases, removal of unpaid carers was a significant contributing factor in rehospitalisation.	<i>I have good support from my husband but totally rely on him. Then he wasn’t here. He had two weeks work at the mail centre with the Post Office at Christmas. He does the housework and cooking. I was on my own. Not eating properly. I think that’s how I ended up in hospital (early unplanned readmission) at Christmas, because I wanted the house looking nice so was cleaning. I was doing washing. I was pushing it down the stairs, and then dragging it from the bottom of the stairs to the washing machine. I wasn’t really ready to do that I was too weak, I ended up collapsing.</i>
<b>System-level themes</b>		

<b>Poor preparation for hospital discharge</b>	The information received to prepare for discharge, and in particular what to expect and do in the community to support recovery, was thought by many to not meet their needs especially for the wide range of physical, psychological, and social problems faced by ICU survivors. Patients/carers described being uncertain of expectations for recovery and recalled limited guidance about how to deal with common post-ICU problems.	<i>When I was in the High Dependency Dr X said you will have to take things very easy, softly, slowly. Okay. I understand that. But I didn't have anybody come and say to me exactly what that meant. Like, 'look you're going to be feeling like this for this amount of time. That's normal. And this might happen and if it does you need to do this exactly if that happens. Things will be like this for the next 3-4 months so take these steps, do this to help you get better' type thing. But no. Back home the GP didn't know I'd been in ICU.</i>
<b>Poor communication between acute and community based care</b>	Many patients/carers felt communication between hospital and community based services had been poor around the time of their discharge, and community services were unaware they had been discharged, and/or lacked relevant information. Community support was frequently perceived as reactive rather than anticipatory, despite poor health status at hospital discharge. When multiple services were needed, they were perceived by some to act independently without coordination.	<i>I don't think he (the ICU patient) had an actual consultation with the GP until he asked for one when he got unwell again. Given that he was so ill, I expected that once back home somebody would have come to see him, especially because of his age (69yrs) and he lives alone. That never happened. When he became unwell again he went back to the practice and the doctor asked 'are you here for your flu jab'? They didn't know he'd been in intensive care. I'm not blaming them, but that information should have been passed on to the people in the community, they should have known.</i>
<b>Inadequate psychological care</b>	The provision and timing of psychological support was highlighted in many interviews. Several patients were on a waiting list for counselling or psychologist review. Uncertainty how to seek support and its accessibility and timeliness, especially long waiting times, were described by several participants.	<i>I struggled coming to terms with the (bowel) cancer and having this stoma bag. I've suffered with depression for over 20 odd years, on and off. It's reactive depression and this whole thing's been so traumatic. When I got out of hospital it was a downward spiral, basically I got to the point... it was quite suicidal. I just..... I'd lost the will, I'd lost it. I'm still waiting on this psychology appointment, it's been months and months, it's pretty poor.</i>
<b>Inadequate medication support</b>	Many patients described drug treatment-related problems that they believed negatively affected their recovery, especially when they were receiving polypharmacy. These included changes to treatment, inadequate explanation, poor communication with community services, delays in receiving new medication, and/or continuation of medication that should have been stopped in hospital or after discharge home.	<i>Before my dad got out of hospital he was told he'd have to stop taking some of the drugs he'd been taking and start new ones when back home. I went down to the chemist to get the new prescription and said to the pharmacist the hospital have said to stop this one and the GP said start this new one. The pharmacist was angry – no one had told them. It turned out that one of the drugs my dad had been taking when he got home he shouldn't have been taking. It meant he had terrible diarrhoea, he was losing weight, feeling sick, not eating and getting dehydrated. I think that's why he ended up back in the (acute) hospital.</i>
<b>Lack of goal Setting</b>	A lack of and/or unrealistic recovery goals was highlighted as important. Accounts ranged from 'pushing themselves too far', to those for whom unclear goals were thought to have 'stagnated' their recovery. Uncertainty in relation to participation in previously important activities, including employment, was described.	<i>As far as goals are concerned? I didn't know what to expect. The nearest I get to that is when I meet some of the consultants, if I'm there for appointments. And they go, wow, you know you're doing really well. But apart from that, I don't know if I've set my goals too high, or if I've set them too low. I think I've got to that stagnant point, where I'm saying to myself, now - what next? I've lost the muscles in my legs, there's nothing there. I've no backside left. I don't know how to build them up again. You need targets and goals.</i>

Table 3: Check box chart to show the prevalence of the different emergent themes, functional comorbidity index score (co-morbidity count; range 0-18; counts are for the number of co-morbidities), and modified carer strain index score (range 0-10; higher scores indicate greater strain) for carers after grouping according to the suggested contexts. For patient IDs: letters refer to health board region (T, Tayside; L, Lothian; F, Fife) and numbers to study participant within each region. N/A, no carer available or no questionnaire data. Where the theme was considered important for an individual case the cell is shaded grey.

Patient ID	Weeks from discharge to interview	Number of unplanned readmissions to hospital	Poor preparation for hospital discharge	Poor communication between acute and community based care	Inadequate psychological care	Inadequate medication support	Lack of goal setting	Multi-morbidity and polypharmacy	Problems with specialist equipment	Psychological problems and drug dependency	Poor mobility	Fragile social support	Functional comorbidity index score	Carer strain Index Score
<b>“COMPLEX HEALTH AND PSYCHOSOCIAL NEEDS” CONTEXT</b>														
T1	31	5											5	7
T 2	26	2											2	8
T4	11	1											3	4
T8	20	1											1	3
L1	4	3											2	N/A
L2	5	2											1	8
L3	7	3											4	N/A
L7	9	2											4	5
L14	16	1											4	7
F1	15	2											1	6
F2	15	3											4	5
F6	15	3											4	7
F7	10	3											4	6



<b>“INTERMEDIATE” CONTEXT</b>														
L4	12	2											2	2
L12	11	1											2	1
F5	14	1											1	5
<b>“MEDICALLY UNAVOIDABLE” CONTEXT</b>														
T3	23	2											0	3
T5	15	1											0	3
T6	6	1											0	N/A
T7	10	1											2	5
L5	9	1											0	N/A
L6	10	1											1	1
L8	6	1											0	2
L9	20	1											1	2
L10	11	1											3	2
L11	10	1											0	7
L13	12	1											0	7
F3	6	1											1	3
F4	10	1											4	1

Table 4: Grading by patient from their perspective of the importance of factors to their acute readmission. Patients self-reported what part they felt each factor played in their readmission on a scale of 0 (“no part”) to 10 (“very large part”). Responses were categorised as “green” (score 0-3; little/no part), “amber” (score 4-6; some part), and “red” (score 7-10; important part). For patient IDs: letters refer to health board region (T, Tayside; L, Lothian; F, Fife) and numbers to study participant within each region.

Patient ID	Medical diagnoses associated with unplanned readmission	Health care support from General Practitioner in the community	Health care support from nurses in the community	Psychological issues being addressed	Support in the community from social services	Support in the community from physiotherapy	Social support from family and friends	Communication between Hospital and General Practitioner after discharge	Communication between hospital and family	Quality of information provided on what to expect or do after discharge home
<b>“COMPLEX HEALTH AND PSYCHOSOCIAL NEEDS” CONTEXT</b>										
T1	Blocked nephrostomy bag; urinary infection.	Red	Red	Red	Red	Yellow	Green	Red	Red	Red
T2	Diabetic coma and pneumonia; severe depression.	Red	Green	Red	Red	Green	Green	Green	Green	Yellow
T4	Stoma bag blockage; infection.	Red	Red	Red	Red	Yellow	Green	Red	Red	Red
T8	Adverse drug event.	Red	Yellow	Red	Red	Red	Green	Red	Red	Red
L1	Seizures. Heroin withdrawal.	Green	Green	Green	Red	Green	Green	Red	Green	Red
L2	Collapsed; constipation attributed to pharmacy regimen.	Red	Red	Red	Red	Red	Green	Yellow	Red	Red
L3	Collapse. Major mobility and breathing problems.	Red	Red	Red	Yellow	Red	Yellow	Yellow	Yellow	Red
L7	Pleuritic pain.	Green	Green	Green	Red	Yellow	Green	Green	Green	Green
L14	Vomiting and diarrhoea; attributed to drug regimen.	Yellow	Yellow	Green	Red	Green	Green	Green	Red	Red
F1	Adverse drug event; urinary retention.	Red	Red	Green	Yellow	Green	Green	Red	Yellow	Red
F2	Stoma bag malfunction.	Red	Red	Red	Red	Green	Green	Yellow	Red	Red
F6	Diabetic ketoacidosis.	Red	Red	Yellow	Red	Yellow	Green	Red	Red	Red

F7	Pneumonia.																			
<b>“INTERMEDIATE” CONTEXT</b>																				
L4	COPD exacerbation; technical problems with NIV mask.																			
L12	Seizure.																			
F5	Auto-antibody syndrome.																			
<b>“MEDICALLY UNAVOIDABLE” CONTEXT</b>																				
T3	Fall, unconscious																			
T5	Diarrhoea; co-existing IBS.																			
T6	Infection, following burst stiches.																			
T7	Low Magnesium.																			
L5	Pneumonia.																			
L6	Blocked NG tube; infection																			
L8	Bleeding from ileostomy site.																			
L9	Collapse; hypotension secondary to medication.																			
L10	Breathing problems/anxiety.																			
L11	Food poisoning; co-existing myasthenia Gravis.																			
L13	Cellulitis left ankle.																			
F3	Pulmonary embolism.																			
F4	Low Magnesium.																			

### The 'complex health and psychosocial needs' context

We used the term 'complex health and psychosocial needs' because, although a medical event occurred, it was a multiplicity of circumstances and events that patients and carers felt contributed to their readmission. Patients typically had significant general health, psychological and social problems prior to ICU admission, and required support from unpaid carers, health and social care services. Multi-morbidity and polypharmacy were prevalent, as were concurrent psychological, drug and/or alcohol problems and significantly impaired mobility (see table S2). Patients frequently came from socioeconomically deprived areas, were unemployed, and socially isolated. Most patients' carers reported high levels of strain. During transitions of care from ICU until the readmission event, the system-level themes all seemed important to patients in this group, and they rated these as important contributors (for illustrative quotes see table S3). A striking feature of the accounts was the accumulation and interaction between these issues. Although we did not include any formal measurement of resilience or coping many patients described 'struggling to cope' after returning home (for illustrative quotes see table S4). Importantly, patients felt timely anticipatory care, preparing them for what to expect when they got home, and early rapid responses to address their complex needs after discharge, could have prevented or reduced their risk of readmission. Of relevance, many patients had experienced multiple readmissions by the time of interview (median 2 (1, 3; 2-5)).

### The 'Medically Unavoidable' context

We used the term 'medically unavoidable' because these patients felt few of the themes were present or important in relation to their readmission. Typically, pre-existing health was better, social/carer support stronger, and reliance on health/social care services was low (see table S2). Younger patients were more likely to be in employment, and less carer strain was reported. Most patients considered their readmission due to medical issues complicating their recovery, and all but one experienced only one readmission (one patient 2 readmissions). These patients usually praised the support received from health and social services and believed there was no alternative but to be readmitted to hospital. Although three patients were classified as 'intermediate' in the analysis, we did not consider them dramatically different or discordant. Overall, the dichotomisation of the patient/carer accounts into the two general readmission contexts was consistent through the analysis. Illustrative case histories for a patient from each group are included in table S5. An infographic summarising our findings is shown in figure 1.

## Discussion

This first detailed mixed methods study exploring patient and carer perspectives of early unplanned hospital readmission following critical illness identified ten patient- and system-level themes. Patient-level themes related to chronic problems (multi-morbidity and polypharmacy; drug/alcohol dependency), new or significantly worse psychological and mobility problems, fragile social or unpaid carer support, and specific issues with specialist equipment. System-level themes related to preparation for hospital discharge, communication between healthcare teams/professionals, and timely access to support and advice after going home (particularly medication and psychological issues, and setting goals). Although some themes clearly related to both system and patient-level issues, this construct could underpin future health and social care improvements. Using comprehensive iterative integration of our data sources, primarily driven by the qualitative analysis of patient/carer accounts and confirmatory focus groups, we felt two distinct readmission contexts emerged. This dichotomisation was unexpected, but the integration of the mixed data supported the patterns. For a 'medically unavoidable' group readmission seemed unavoidable and related mainly to medical problems and complications. In these cases, the prevalence of the ten contributing themes was low. In contrast, other patients/carers described many medical, psychological, social, and organisational issues co-existing and interacting, resulting in a 'complex health and psychosocial needs' construct. For these patients, issues often pre-dated ICU admission and/or were significantly worse following the episode of critical illness. These patients had often experienced multiple readmissions and carers described high levels of strain.

A controversy in the readmission literature is whether events are avoidable or modifiable, and whether patients could be identified at an appropriate time in their care pathway. In other hospital populations around 25% of readmissions have been considered avoidable, and a wide range of predictive factors suggested and used in statistical prediction models.<sup>25</sup> Some of the themes that emerged from our study have been associated with readmissions in non-critical care populations, especially multi-morbidity and polypharmacy.<sup>26</sup> Similar associations have been reported among sepsis survivors (who often require ICU admission).<sup>27</sup> The prevalence of co-morbidity is high in general ICU populations; for example, we recently found a median 2 pre-existing comorbidities using the FCI among ICU survivors.<sup>28</sup> These observations, and our accounts from patients and carers who experienced readmissions, suggest that for many chronic ill health pre-dating ICU admission is an important driver for subsequent

rehospitalisation. This is supported by quantitative analyses of large critical care data sets showing comorbidity counts and previous unplanned hospitalisations are strongly associated with both readmission rates and ongoing hospitalisation costs.<sup>14 29</sup> We also found that measures of pre-existing health status were associated with early unplanned readmission risk in the quantitative population-based cohort study that comprised the other strand of our mixed-methods research programme.<sup>30</sup> Measures of pre-existing health had greater predictive value than both demographics and measures of ICU illness severity. Some other themes that emerged from our data are known to be prevalent among critical care survivors, such as mobility or functional impairment (from ICU-acquired weakness)<sup>31</sup> and psychological problems (especially anxiety, depression, cognitive impairment, and post-traumatic stress).<sup>32</sup> Psychological problems, in particular, seemed important to our participants because they magnified the impact of other factors, and because timely access to psychological care was difficult. Social support needs are poorly understood among ICU survivors, but some qualitative and quantitative studies have highlighted the importance of social issues during ICU survivorship and recovery<sup>33-35</sup>. Many of our participants highlighted ‘fragile social support’ and limited access to social service support as relevant to their readmission event, potentially because the multiple concurrent physical and psychological problems place high demands on patients themselves and their unpaid carers. This finding concurs with studies of patients with heart failure and pneumonia.<sup>36</sup> What was striking in our data was the severity, co-existence, and likely interaction of these multiple issues that typified the context we called ‘complex health and psychosocial needs’. This probably represents a greater overall burden of problems than faced by most other hospitalised patients, and involved contributors that pre-dated critical illness, occurred as a direct result of it, and was exacerbated by the ‘system-level’ issues that magnified the impact on individuals. This is a potentially useful construct on which to base risk assessment prior to hospital discharge, because many of the issues could be identified or anticipated at this time.

The term ‘post-hospital syndrome’ has been used by others to describe a period of generalized risk for a range of adverse health events following an acute hospital admission, which commonly results in rehospitalisation.<sup>37</sup> We believe the ‘complex health and psychosocial needs’ context represents a severe form of this concept. Improved anticipatory care planning and pre- and post-hospital discharge care might reduce rehospitalisations in this group; some of our participants expressed this view. In the United Kingdom rehabilitation after critical illness is recommended by the National Institute for Health and Care Excellence

(NICE)<sup>8</sup> and is a quality standard for critical care services<sup>12</sup>. However, there is wide variation in the provision of post-ICU care and the service models used.<sup>38</sup> Our data support a coordinated multi-faceted approach that recognises the diverse needs of some patients that relate to both pre-existing health and the consequences of a critical illness episode. It is notable that post-ICU survivors do not have a clear visible care pathway in health and social care services, at least in the United Kingdom where our study was undertaken. Typically, after ICU discharge patients are managed by ‘parent specialities’ on general wards, and discharge planning occurs according to specialty-based teams that may not fully recognise the needs of ICU survivors or have the resource to address them. More than 70% of ICU survivors are discharged directly home from the acute hospital<sup>28</sup>, without access to specialist rehabilitation facilities, and thereafter are managed by community based health and social care services that lack knowledge or expertise of ICU survivorship. Some patients may be offered attendance at an ICU follow-up clinic, but this is not universal. This care pathway contrasts with more ‘disease-focussed’ groups such as stroke, cancer, and myocardial infarction. The patient themes we identified could potentially be used to screen for high-risk patients at ICU discharge, and care pathways developed to support these patients and carers through subsequent hospital stay, discharge planning, and early community living. In this way, increased support could be focussed on those ICU survivors at greatest risk of being readmitted. Individualised discharge planning decreases hospital readmissions in medical patients<sup>39</sup>, and could address many of the issues occurring in the ‘complex health and psychosocial needs’ context if introduced at system-level. Screening for low resilience and intervening to support patients might also be a useful part of this process,<sup>40</sup> and could address the ‘struggling to cope’ described by many participants. This is recognised as useful in other populations such as cancer.<sup>41</sup>

Current post-ICU pathways, typified by discharge to ‘parent’ specialties, mean there is a progressive dilution of the multiple physical, psychological and social sequelae of critical illness<sup>42</sup>. This may explain why patients and carers highlighted poor communication, goal setting, and psychological support issues in our study. These omissions of care may explain, in part, the disappointing results of ICU rehabilitation trials, in which chronic disease-related issues and other issues such as social support were not specifically addressed.<sup>9 43 44</sup> Our data suggest that interventions and service re-design should also include a strong focus on non-medical issues such as social support. The active management of transitions, including timely and accurate information, good communication between hospital and primary care

physicians, and a single point of co-ordination has been shown to be effective for reducing readmissions in general hospital populations.<sup>45</sup> Provision of detailed information about expectations of recovery has been also shown to improve patient experience following ICU discharge.<sup>46</sup> Focussing on these approaches has potential to benefit ICU survivors, especially those at risk of the ‘complex health and psychosocial needs’ context following discharge.

Strengths of our study include the inductive data acquisition, the large sample to achieve data saturation, purposive sampling to maximise transferability, the inclusion of patients and unpaid carers, and confirmatory focus groups. Qualitative methods took precedence in the analysis, but the quantitative questionnaires provided objective confirmatory data that was especially useful in exploring and illustrating the two phenotypes. We cannot exclude some inclusion bias, as not all invited patients agreed to participate, and recall bias was also possible. The majority of the qualitative analysis and coding was also done by a single researcher. Findings may also not be generalisable to other healthcare systems.

In conclusion, we have identified issues considered important by patients and unpaid carers who experienced early unplanned hospital readmission following a critical illness, which may have contributed in many cases. Multiple interacting factors relating to pre-existing poor health, social status, the physical and psychological sequelae of critical illness, and system-level failures combined to create a ‘complex health and psychosocial needs’ context that is a potential target for screening and intervention. Novel complex healthcare interventions aimed at decreasing rehospitalisation following critical illness should address these issues concurrently to maximise the chance of effectiveness.



## Figures

Figure 1: Infographic illustrating the two major contexts in which unplanned hospital readmissions occurred, and how the ten themes that described the patient- and system-level issues described by patients interacted during the patient journey to contribute to the readmission event.

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THE TWO MAJOR CONTEXTS IN WHICH UNPLANNED REHOSPITALISATION OCCURRED AFTER INTENSIVE CARE TREATMENT

