



**University of Dundee**

**'Intensive Care Unit Survivorship' - a constructivist grounded theory of surviving critical illness**

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*“There is nothing so practical as a good theory.”* (Lewin, 1951)

## **1. Introduction**

Critical care practice and research has traditionally focused upon “survival” in its most literal and biomedical sense (Ridley, 2002). More recently, however, there has been increasing awareness of the diverse physical, psychosocial and economic sequelae of critical illness, and a growing appreciation that care needs to extend beyond the critical illness episode in order to support patients and families in the subsequent reclamation of their lives (Govindan et al., 2014).

Survivorship has been identified as a defining challenge of critical care in the 21st century (Iwashyna, 2010). The evidence is, however, limited. In this paper, we present our findings from a longitudinal qualitative study of recovery at up to one year following hospital discharge and posit a grounded theory (GT) of critical illness survivorship as a foundation for future research and improved health and social care provision among this patient group.

## **2. The physical, psychological, social and economic legacy of critical illness**

The emerging picture of critical illness survivorship is unsettling (Iwashyna, 2010). A host of “legacies” interact to produce highly complex conditions which Intensive Care (ICU) survivors and their families have to negotiate in order to rebuild their lives.

### **2.1 Physical legacies**

The physical legacy of critical illness is well documented and includes generalized weakness, muscle wasting, fatigue, weight loss, joint pain/stiffness and breathlessness, (Herridge, 2009), (Griffiths and Hall, 2010), all of which prolong recovery and can result in chronic functional impairment (Desai et al., 2013). Many survivors are slow to return to work, leisure and social activities, or may do so altered or diminished

capacity. Other physical sequelae include hair loss, voice changes and skin changes, the impact of which can be underestimated by healthcare professionals.

## **2.2 Psychological legacies**

The psychological legacy of critical illness is similarly well documented. Amnesia and delirium (an acute confusional state) are common during the ICU stay, resulting from sedation (to facilitate mechanical ventilation) or the nature or severity of illness. Importantly, survivors frequently remember little of their time in ICU and/or report on the “reality” of (often persecutory) dreams. Many struggle to make sense of the ICU experience, often reporting a limited understanding of the nature and severity of their critical illness. This can manifest in unrealistic expectations of recovery and psychological distress around unexplained sequelae and the protraction and potential limits of the recovery process (Ramsay, 2010).

Rates of anxiety, depression and post-traumatic stress symptomatology (broadly characterized by intrusive and distressing flashbacks) are high (Myhren et al., 2010), (Jackson et al., 2014)) and are associated with delayed recovery and late return to work (Rothenhausler et al., 2001), (Brenes et al., 2005). Cognitive impairment (impaired short-term memory, attention and decision-making) is also prevalent, interfering with everyday activities such as managing money, shopping, driving and return to work (Hopkins et al., 2005)

## **2.3 Social and economic legacies**

Social and economic legacies include reduced social participation among survivors and the burden of care upon family members, often disrupting family life and work, social or leisure activities (Paul and Rattray, 2008), (Abdalahim and Zeilani, 2014). The economic impact of critical illness relates to survivors’ delayed return to work, often in an altered or reduced capacity and to family members’ altered employment status in relation to care-giving activities (Griffiths et al., 2013), (Agard et al., 2014).

## **3 The emergence of survivorship**

The complex interacting legacies of critical illness result in an inherently social process of re-engagement with prior roles and activities, but with and through a body and sense of self that may be significantly transformed. This process has predominantly been described in terms of “recovery”, implying a return to pre-illness states (Frank, 2002). “Survivorship”, we contend, is a more appropriate term for this temporal, multi-dimensional and open-ended process, wherein survivors must live with, through and beyond the illness experience (Blows et al., 2012).

The literature on survivorship among other patient populations, most notably cancer, suggests a number of themes that resonate with recovery and survivorship following critical illness. These include, for example, the confrontation of one’s own mortality, the search for meaning, the transformative potential of a life-threatening illness, and a continued sense of vulnerability (Doyle, 2008), (Peck, 2008). Liminality has emerged as a central component of this process, and is broadly understood in terms of the disruption, social ambiguity and uncertainty brought about by illness. This work has served as a key conceptual model for the commissioning and provision of long-term health and social care among this patient group (Little et al., 1998), (Ringash, 2015) including, for example, substantive care planning, policy and research initiatives in the UK and internationally.

The experiential proximity and theoretical potential of the cancer literature presents the critical care community with an opportunity to empirically enhance its currently limited (i.e. essentially biomedical) understanding of survivorship and to address calls for the development of a critical illness-specific pathway of care and support (National Institute for Health and Care Excellence 2012), (Reay et al., 2014). There are nonetheless important differences between these patient groups that require exploration and development. Our GT of ICU survivorship uses survivors’ experiences as a foundation on which to explore these differences, develop a theoretical understanding and identify clinical and practical implications for long-term support.

## **4 Study design/methods**

As outlined in our published protocol, this is a longitudinal qualitative study of recovery among survivors of critical illness, at up to one year following hospital discharge (Ramsay et al., 2012). Based on locally conducted qualitative research (Ramsay 2010) and conventional time points in critical care outcomes research, we interviewed participants at four time points: (1) prior to hospital discharge and (2) 4-6 weeks, (3) 6 months and (4) 12 months after hospital discharge.

### *Setting*

Participants were recruited from two general combined ICU/High Dependency Units in University-affiliated teaching hospitals in the East of Scotland. ICU A is an 18-bed Unit admitting approximately 1100 patients annually. ICU B is a 16-bed Unit, admitting approximately 750 patients annually.

### *Inclusion and exclusion criteria*

Inclusion criteria comprised survival following  $\geq 48$  hours' mechanical ventilation in an ICU. Exclusion criteria comprised: a primary neurological diagnosis; referral for palliative care or patients currently receiving or referred to home ventilation services.

### *Participants*

Seventeen participants took part in interview prior to hospital discharge. Loss to follow-up occurred due to death (n=3), loss to contact (n=4) and withdrawal (n=1), resulting in a total of 47 interviews, and nine full cases (interviews at all four time-points). Participant characteristics are summarized in table 1.

### *Ethics*

The South East Scotland Research Ethics Committee granted ethical approval (10/S1101/45). Participants were approached on the general wards and assessed for delirium (a prevalent confusional state in early recovery), before providing a study-specific Information Sheet and seeking informed consent. Phase 1 interviews were conducted in a private room on the hospital ward. Participants' general practitioners were

contacted before arranging subsequent interviews, thereby avoiding distressing the families of participants who died following hospital discharge.

### *Data collection*

The majority of post-hospital discharge interviews were conducted in participants' homes. In some cases, a family member ((marital) partner or adult child) was present, for which additional consent was sought from both patient participants and family members. A small minority participated at one of the study hospitals. Interviews were digitally (voice) recorded, transcribed verbatim and checked for accuracy. Interviews lasted between x and y minutes. Data were stored and analysed using computer software (NVivo 9).

## **5 Analytical approach: construction of a Grounded Theory**

A constructivist grounded theory (GT) approach (Charmaz, 2006), (Charmaz, 2014) was chosen to develop a theoretical understanding of the journeys ICU patients embark on post-critical illness. GT's inductive approach fosters theory development by identifying action/interaction, behaviors and processes from participants' perspectives (Corbin and Strauss, 2008) and is of particular relevance to practice and policy where theoretical understandings of a phenomenon are limited or absent.

A constructivist epistemological stance holds that reality is constructed over time, and influenced by various social and cultural factors that lead to shared social constructions (Howell, 2012). Applying this approach to our data resulted in a co-constructed reality between researcher and researched, about "what it's like" to survive critical illness. GT fosters these processes of construction through its methods of constant comparison and simultaneous data collection and analysis, guided by identifying 'what is going on' in the data (Glaser, 1992), (Glaser, 2013). Consequently, interview questions iteratively developed over time in response to ongoing analysis.

Essential for theory development are activities that foster seeing possibilities, establishing connections, and asking questions; reaching down to fundamentals, up to abstractions, and probing into experience (Charmaz, 2006). Theory construction in GT also requires an abductive logic i.e. a shifting engagement with (theoretical) literature over time (Reichert, 2007). We initially explored the literature on “recovery”, for example, but it became evident throughout the iterative processes of data collection and analysis that participants were both “recovering” *and* “surviving”, and in very different ways. The analyst then probed alternative literatures, including cancer survivorship, drawing on abstractions from our data and ‘using those to formulate working hypotheses that in turn were tested against new cases and observations’ (Atkinson et al., 2003)

The longitudinal approach added significant analytical complexity, given that there are no standardized analytical methods (Saldaña, 2003), but also to its *potential*. The focus of longitudinal data analysis rests on change; the strategies individuals use to manage both change in their lives and the structural factors that shape change (Neale and Flowerdew, 2003). The analytical strategy was therefore usefully guided by GT’s iterative processes and strategies, which pay attention, specifically, to time and context (Strauss and Corbin, 1998).

The longitudinal approach resulted in recruiting participants in overlapping phases. Accordingly, insights gained in later interviews informed their exploration among participants in earlier interviews. This dynamic analytical strategy allowed the identification of shifting foci within participants’ survivorship journeys over time. To elicit these insights, participants were asked about the changes in their lives since the previous interview and about anticipated future challenges. Change was further explored through (1) re-reading individual participants’ previous transcript(s) prior to each interview and exploring changes therein (2) comparing changes in experiences, both within and across participants’ successive accounts.

In summary, construction of the theory followed the iterative processes of GT: simultaneous data collection and analysis; open coding i.e. the emergence of codes, their evolving abstraction and exploration of the relationships between them; comparative analysis (within and across cases and the articulation of key codes in different contexts); referral to new and relevant literatures, theoretical sampling (testing and refining

theoretical ideas against the data); and, finally, the identification of a core category. Survivorship emerged from the data as the core category or theoretical ‘fit’; one that explains the complexity of participants’ journeys and draws on the extant literature to enhance the theory’s depth and explanatory power (Strauss and Corbin, 1998).

This approach allowed to mine the analytical potential of the longitudinal data; exploring, in detail, what survivorship was “like” for participants, and its evolution over time. For example, at the beginning of the analytical process ‘negotiated order’, how social order is maintained in the face of change (Strauss, 1978), appeared to be a major explanatory concept. It was duly tested, but side-lined due to its inconsistency throughout participants’ journeys; whilst important at the beginning of the journey, participants’ foci later shifted to other matters, for example, towards re-engaging in social life.

These shifting foci inevitably implicated analytical concepts such as time, temporality and transitions. Transitions were further analysed and theorized into different dimensions as they are evident in “status passages” (Glaser and Strauss, 2011) and “liminality (Gennep, 1960, Turner, 1969) Transitioning through different status passages is not a passive process, but one in which individuals actively engage by bringing their experience, knowledge and aspirations to bear. Agency is thus an underlying dimension of the theory.

## **6 Findings and discussion: Transitions in ICU survivorship**

The following presents a GT of ICU survivorship as it emerged from participants’ accounts of their journeys over the year following critical illness. The use of transitions/temporality, status passages and liminality helped to understand the journey as life moving and changing towards unknown ends, with survivors and their family members acting as active agents in the process. The journey could at times be seen in terms of *desirable* progress, but was sometimes beset with *reversals*.



Status passages involve passing through states of *liminality*, which include an ‘undercurrent of uncertainty’ (Sheilds et al., 2015); where it becomes evident that the previous life has ended but where a life post-critical illness has yet to emerge. The GT centers on the concept of status passages, in order to draw out the detail on liminality inherent in status passages. Liminality in cancer survivorship is drawn on to explicate its meaning and significance in relation to critical illness.

## 6.1 Unscheduled status passages and liminality

The sudden onset of life-threatening illness and admission to ICU constitutes an *unscheduled status passage* (Glaser and Strauss, 2011). The term “status passage” captures the significance of the event, denoting transformations beyond health and including inter-related physical, psychological, social and material changes that imply a change in social status. The term “unscheduled” denotes an unexpected and unscripted transition.

### 6.1.1 Liminality; development and evolution

The concept of “*liminality*” helps to understand the transformative power of a status passage. The term was first used by the anthropologist, van Gennep (Gennep, 1960) in highlighting the importance of social ritual in marking these changes. To mark a person’s change of status, he or she is ritually removed from society, cleansed of a previous status, placed in a state of liminality to be taught a new role, and then ritually reintroduced as a different person. Coming of age rituals are well known examples of such passages. In van Gennep’s work, liminality incorporates three stages: (1) pre-liminal: rites of separation, (2) liminal: rites of transition, and (3) post-liminal: rites of incorporation.

Turner (Turner, 1969) extended the notion to encompass a range of situations in which roles are ritually inverted or challenged, emphasizing that the liminal state can also be unstructured, ambiguous, disruptive or transformative in its consequences. Liminality has since been used to understand status passages in a range of health contexts (Hockey, 2002), notably the socially disruptive effects of illness (Frankenberg, 1986) and disability as a state of ambiguity between health and illness and social in/exclusion (Murphy et al., 1988).

Thus, Van Gennepe's model has been extended and developed, with particular reference to the demarcation of the stages, and the social scripts that structure the passage.

In cancer survivorship, for example, Little et al (Little et al., 1998), posit two stages of liminality; an acute and a sustained phase, the latter beginning in convalescence, but potentially lasting until death. A cancer diagnosis sets in motion a powerful system of medical surveillance which, in turn, involves active engagement by the sufferer and their family members in a culturally and medically scripted process. Importantly, it is this common cultural paradigm that can lock survivors in states of liminality e.g. an ambiguous state of "cancer patientness" in both diagnosis and remission. We draw, therefore, on the use of liminality in cancer survivorship to explicate its critical illness-specific features and processes.

### *6.1.2 Liminality in critical illness*

Unlike Little et al's cancer survivors, participants' journeys were largely open-ended and unscripted. Critical illness does not confer a diagnosis with strong cultural connotations that elicits particular reactions and expectations, nor is there currently a pathway of care and follow-up that structures the survivorship journey. Participants and their family members therefore improvised as they went along. Exploring their experiences and improvisations within the context of liminality may, however, help inform the "script" for improved healthcare and support among this patient and family group.

Entrance into liminality can be said to occur when critical illness severs a connection with previous social states (here, comparative health). Recovery pitches survivors into a state of liminality, given that they find themselves between health and illness and at odds with the social and economic circumstances that a particular health status confers (Scott et al., 2005). It ends with a re-incorporation into society, sometimes in an altered social position due to a profound change in health, and often with a significantly altered relationship with life, body and self. It is this *post liminal* stage which is key to understanding critical illness survivorship, as it is here that the strands of a life that has been unravelled have to be picked up and (re)fashioned.

It is not suggest any clear demarcation between van Gennep's three stages of the passage through liminality, nor was there necessarily a clear end point, given that few of the participants could say with any great conviction that they "had recovered." As will be demonstrate, the ways in which they integrated the legacies of critical illness into "a life beyond" (Frank, 2002) varied significantly, as did the pace and directions of their survivorship journeys. In order to appreciate the complexity of refashioning a life post-critical illness, it must be first understood in which way participants negotiated movement into and through alternative states of liminality; often without, as the data demonstrates, a cohesive narrative around the nature and severity of their critical illness.

For many, the first sign that a health transition was in progress was the often vague realization that something was "not quite right", and of life's ordinariness being dramatically interrupted. In the following instance, for example, "a bad stomach", rapidly deteriorated into a life-threateningly serious infection caused by gallstones. Participants are referred to with their anonymized study code, followed by the phase (1,2,3 or 4) an their gender.

"I had a bad stomach on the Saturday- can't remember what day would that be, but I put that down to other things because - I was taking a lot of medication, different stuff. I remember on the Saturday morning having a bad stomach." (11057.1M)

For others, an unscheduled status passage emerged as an unexpected complication of routine elective surgery, and deterioration on a hospital ward

"Well, I was sore the first day and in and out of sleeping. The next day I was okay and I got up and had a shower with somebody's help, and the next day I was okay, and then I was sick. I was very sick and *I don't remember anything after that*" (our emphasis). (12016.1F)

The routine use of sedation in ICU (drugs to facilitate mechanical ventilation) imposes a likely unique existential separation from reality and from time/temporality. Whilst most of our participants could recall the onset of critical illness, few could recall their time in ICU with any great clarity.

“Not really...A couple of wee (small) things - but really not much at all. I could remember sort of wakening up. Well, at some point thinking for some reason or other I was in (city)”. (11010.1M)

The use of sedation induces both a lack of factual recall (amnesia) and also bizarre and often frightening “unreal memories” (delirium). Here, liminality is evidenced by participants’ accounts of “being in a world of my own” or being “not-really-there”.

“I went all sorts of different places mentally. I mean, the sort of memories that I have is that I was in a dark cellar and either a cellar, a dungeon or a drain, and being snatched at and fighting, cursing, swearing, biting, scratching because I wouldn't go... it was very, very frightening.” (11055.1M)

Some participants explicitly alluded to the proximity to death during their ICU admission

“I can remember one night I was sort of lying there gasping and thinking: ‘I want to die, I can't cope with this, you know. I can't cope with this fighting for breath.’” (11026.1F)

One explanation may be that the receipt of sedation spared them from a sense of death’s proximity. Another is Thompson’s (Thompson, 2007) notion of “communicative alienation”: the inability to articulate experience due to the existential and emotional impact of an acutely life threatening illness. Others, in contrast, appeared to underplay the seriousness of their illness, preferring to focus instead on the recovery process:

“As long as I'm okay. I mean, I just know that the nurses and doctors were working hard at keeping me alive and there was nothing that I could do for (myself). I was very dependent on them, so it doesn't

really bother me that I don't know (what happened).” (11013.1 F)

Our participants emerged from a liminal period in ICU with varying degrees of physical depletion and mental scarring, but also with limited direct experience, memory of or involvement in the events that had taken place in ICU. With due caution to over interpretation, we suggest that this biographical rupture may inform the way participants faced the uncertainty of life post-critical illness. A consistent finding, for example, was that participants often held somewhat unrealistic expectations regarding the rate and outcome of the recovery process. One participant, for example, expected to return to work (as a ticket inspector in a railway company) within 6 months. When asked about anticipated challenges on getting home, however, he said that

“Hmm, well, we have steps at my front and back door but it is only a couple of steps, so I don't see that as being too much of a problem... The thing is well, my toilet is upstairs... at the moment it's a challenge. I know I couldn't go home (just) now.” (11010.1 M)

Whilst many later conceptualised the unexpected protraction of the recovery process in terms of having been very ill. Much like those who appeared to underplay the severity of their illness, others often explained away their ongoing limitations in terms of “getting older”.

## **6.2 The post liminal examined 1: Desirability, reversibility and agency**

Our participants' survivorship journeys were shaped by the desirability and/or reversibility of progress over time, and also by the extent to which they were able to exercise a degree of control, self-determination or *agency*. The *desirability* of a status passage makes visible the motivational basis that shapes the passage (Glaser and Strauss 1971/2010); the aspirations held and the efforts made by participants towards recovering their lives, both forward looking and rooted in a perceived a sense of control. Participants often set themselves small incremental goals, tasks or targets. Strikingly, these often revolved around the small details of everyday life, which invariably took on a different meaning, because they were no longer taken-for-granted, but were a means to arriving somewhere.

“My little targets - yes, and I'm cooking now because when I first came home, (husband) was doing all the cooking, but I was sort of giving myself little tasks. I'll just peel potatoes and then he can get on with it and then I'll do whatever.” (11026.2 F).

Participants actively negotiated the direction and pace of their journeys using a range of strategies. In the following instance, for example, Betty emphasised her independence when she got out of bed and went downstairs in her own time instead of awaiting the support of community nurses.

“I used to try and get myself out of bed - which you weren't supposed to do - but I did and I changed all my clothes and everything. Because they (nurses) were supposed to help me up in the morning. She says ‘we're supposed to be helping’. I said ‘I know. I wouldn't do it unless I thought I could do it’, you know?” (11079.4 F)

Other examples include the active negotiation of mobility aids or home adaptations before hospital discharge, negotiating antibiotics from GPs ‘just in case’, independently arranging social care or resuming control of financial responsibilities from family members. Family members often actively engaged in or supported the process:

“My priority is to make mum independent. So, I am there and I support her to encourage her to do that. You know, it is not for me just to go and do it, so mum doesn't have to do it. It's to get mum to do it.” (Daughter of 12017.3F)

*Reversibility*, in contrast, denotes a negative directional change which can halt or hinder the status passage and introduce additional states of liminality. Some status passages require constant progress in order to counterbalance the pull backward, while others may overshadow the central passage, thus invoking a state of reversibility (Glaser and Strauss, 2011). Sources of reversibility included pre-existing illness, the latent legacies of critical illness, the development of unrelated conditions, or as we later demonstrate, asynchronies in biomedical, organisational and experiential timelines (Forss et al., 2004).

“I mentioned it (issues with balance) to my Consultant when I went for my cancer check-up a couple of months ago, and...he thought I might have had some nerve damage as a result of the (critical) illness and that could have affected the balance nerves, which are quite sensitive you know, or it could just be that you have still got a bit of muscle weakness and it will gradually sort of improve the more you do.” ((11079.3 F)

An example of the complexity of reversibility as it intersects with *multiple status passages* is for example a participant’s (11057 M) lingering gallbladder disease resulted in several reversals due to: surgical management of his abdominal wound, the interference of his health status on treatment for pre-existing prostate cancer and the wait for surgery to remove his gallbladder. Participants generally managed reversibility in much the same way as they managed desirable progress; by “taking it easy”, “keeping going”, seeking support from family members and consulting healthcare professionals, etc.

Thus, these strategies identified *agency* as an underlying factor in negotiating both desirable progress (recovery) and managing reversibility (setbacks), either simultaneously or in turn. The inherent tension between them had to be (re)negotiated throughout the journey and over time, in addition to negotiating, as we outline below, asynchronies in biomedical, organizational and experiential timelines. The pace and direction of travel was thus determined by the success with which participants negotiated a multitude of simultaneously occurring liminal states.

### **6.3 The post-liminal examined 2: temporality and timelines**

Temporality is another dimension of survivorship; it relates to the rate, pace or speed of the journey, and also to the expectations of where the journey will end (Glaser and Strauss, 2011). Time is directional and forward looking, given that moments passed cannot be lived again (Adam, 2013). Time’s passage is also multidimensional, given the multitude of timelines that interrelate and permeate social lives (Adam et al., 2000). For the participants, the task of rebuilding a life post-critical illness was one of integrating different times that had unravelled to a lesser or greater extent during their journeys.

Across the sample, there was a clear focus on and successive movement through physical, emotional and social recovery. The vast majority of participants, however, underestimated the rate and duration of the process, impeded as it was by the impact of pre-existing conditions, the lingering “legacies” of critical illness, or the acquisition of seemingly unrelated conditions. Their impact on social re-engagement and ultimately, sense of self was keenly felt. Several participants, for example, described a lack of confidence in engaging with other people, in resuming independent activities or returning to work. Others, however, had resumed previous social activities and hobbies (albeit in a sometimes altered or diminished capacity) and a very small number had actively engaged in new ones.

“If somebody said ‘how are you?’ I would have said I was fine, I have recovered”. (11013.4 F)

She went on, nonetheless, to describe a number of “loose ends” and their impact on previously enjoyed activities

“I suppose my leg is one of them. My concentration, my enthusiasm (chuckles) for life! And getting up and doing all the things I should be doing...like doing my photography and doing all the other things”. (11013.4 F)

When asked about the difference between physical and psychological or emotional aspects of recovery, she responded that

“They are all interlinked. You can’t really put them into their own wee (little) boxes. They are all in one big box”. And later, “Not that I am a weepy, self-pitying person but - kind of - I suppose (one’s mental state) it affects physical recovery.” (11013.4 F)

Asynchronies between organizational and body time sometimes impacted negatively on the recovery process, including, for example, included difficulty securing an appointment with a familiar GP, GPs’ late or non-



receipt of hospital discharge letters and failure to arrange follow-up or out-patient appointments. Commonly, community support (e.g. domiciliary physiotherapy), home aids or adaptations were not in place at the time of hospital discharge as arranged, or arrived when no longer required.

“They promised everything (would be in place) the day before (I got home)”. (11079.2 F)

“And the shower - which I couldn’t use because there was no handles in that either...And then, the lady came in the afternoon when - and my son started shouting. She brought two commodes and that thing (tea trolley) in (chuckles)...Just last week they came with the banisters, after I can walk up (stairs) myself.” (11079.2 F)

In the following excerpt, Jean had visited her GP to request domiciliary physiotherapy (which, although arranged prior to hospital discharge, had not transpired), whilst withholding that she had been using a static bicycle (home trainer) to expedite her recovery. When asked why, she responded:

“Well, I suppose as a matter of principle. Because I felt that he might say ‘you don’t need to have any physio’. And I just think I should see somebody”. (12016.2 F)

These data, in summary, usefully explore the detail of post-liminality through the alternative analytical “lenses” of desirability, reversibility, agency, temporality and timelines and draw out their directional properties and complex inter-relatedness.

### **6.3 Four broad patterns of ICU survivorship**

Four *over-arching* patterns of survivorship were identified, which are describe here and returned to in the discussion: survivorship; recovery towards survivorship; survivorship towards new onset disability and survivorship towards palliation.

### 6.3.1 *'Survivorship' and 'recovery towards survivorship'*

The pace at which participants transitioned towards survivorship varied enormously. A year on from their critical illness, some participants considered themselves “(fully) recovered”.

“Now that I am fully recovered, I wouldn't think of going along and feeding the ducks, but on the road to recovery it was a good incentive, to take a bag of breadcrumbs and go and feed the swans.” (11055.4 M)

Mary had had a very active social life prior to critical illness and, at six months post-hospital discharge, had resumed almost all of her previous activities.

“I'm out most days doing something at the moment because I've gone back to my other activities. I went back to my Tai Chi class last week for the first time. I could have gone back earlier but I was just doing lots of other things over the summer, so I just thought I'll wait and go back in September.” (11026.3 F)

Reflecting, however, the individual's perceived clarity of the signs of passage (Glaser and Strauss, 2011), others might be described (or describe themselves) as “recovered, but not quite recovered” (Luxford, 2003). Many described, for example, residual physical and/or psychological/emotional impairments and their impact upon social markers of recovery. The difference between participants who remained “between recovery and survivorship” (liminal) and those who had integrated any ongoing impairment into their everyday lives, discovering ‘a life on the other side’ (Frank, 2002) (post-liminal) should not be overplayed. “The post liminal phase” in critical care survivorship has no clear cut off point, and “recovery”, was conceptualized as a continuous process of change and integration of change (Little et al., 1998).

### 6.3.2 *'Survivorship towards disability' and 'survivorship towards palliation'*

‘Survivorship towards disability’ and ‘survivorship towards palliation’ are two additional patterns that were evident in our data. In healthcare practice and research, *disability* denotes a functional classification and relates to pre-existing impairment and/or the physical legacies of critical illness. Reflecting Glaser and Strauss’

(Glaser and Strauss, 2011) assertion that some status passages require a form of legitimation, none of our participants described themselves as “disabled” and the term only arose within the context of discussing disability benefits.

Robert, for instance, had survived severe smoke inhalation, resulting in acute lung damage and a subsequent diagnosis of chronic respiratory disease. His initial recovery progressed well and he was hopeful of returning to work within ‘three or four weeks’ of our 4-6 weeks interview. At the final interview, however, his physical recovery had clearly undergone significant reversal and chronic disability was emerging.

“I think my chest is getting worse than what it was before. Because before I could walk. No problem! When I came out of the hospital, I was able to walk further. I was not so out of puff, which I am now.”

(11014.4 M)

This reversal was augured at the six month interview when he said that:

“The Consultant that I see in the hospital, he says it could be a year, a couple of years even longer. Before the lungs get better what they are like. My mate says ‘you might never get back to (type of work)’” (11014.2 M)

In between interviews, he had begun to realize that he might not recover well enough to return to work and, with the support of friends, had applied for disability benefits. This reversal had implications for his emotional and social recovery, in that his deteriorating lung function prevented him from social interaction, resulting in an expressed sense of boredom, loneliness and depression.

*Survivorship towards palliation* was directional pattern for some participants, evidenced in our data by acute exacerbations of chronic illness, and/or hospital re-admissions with subsequent partial recoveries. James, for example (a sufferer of chronic respiratory disease) described his recovery at 4-6 weeks post-hospital discharge in the following terms;

“I would say half way to where I have been. I think it is getting harder and harder.” (11048.2 M)

At six months he said:

“I’ve just no strength in my body. But seemingly that’s just all part of the illness now.” (11048.4 M)

By the final interview, he had had several hospital admissions, and had entered a liminal state of ‘lingering’; a status passage in which the individual is ‘certain to die but unknown when’ (Glaser and Strauss, 1965). ‘Lingering’ was evident when he spoke of his GP and Marie Curie (cancer support service) urging him to write his Will and consider funeral arrangements

“The doctor was down yesterday and she started talking about my Will. And I thought ‘Jesus Christ.’ What I wanted to happen when it comes. Marie Curie will go through it when I am getting near the end. If I want to die in there, in the hospital or in the Marie Curie (hospice). If I’m wanting buried or I want cremated, they will see that that’s all done and everything. What hymns you want and everything.” (11048.4 M)

He had not, however, addressed the issue of his Will but spoke openly about death and dying in the near future, reflecting on his life and family. A similar trajectory, albeit with intermittent partial recovery, was evident in Sheila’s journey with frequent hospital readmissions, increasing dependence on (domiciliary) oxygen and decreasing mobility. Sadly, she passed away shortly before our final interview. Importantly, in both of these survivorship patterns, severe chronic illness was an underlying factor.

These four broad patterns, in summary, usefully move beyond the complex underlying directional properties of liminality in ICU survivorship to provide an overarching framework within which to apply our theory to the organization of health and social support.

## **CONCLUSION**

This GT is the first longitudinal, theorized understanding of ICU survivorship. It adds significantly to the understanding of the implicitly social processes and complexities of the survivorship journey, which was previously conceptualized in entirely biomedical or functional terms. Its explanatory power lies in the use of patient experience to explore the literature on (cancer) survivorship, notably status passages as the key underlying theoretical dimension. The longitudinal approach, moreover, underpins the explication of four directional elements; desirability, reversibility, agency and temporality/timelines and four broad patterns of ICU survivorship (notwithstanding the underlying movement through physical, emotional and social recoveries). The contribution is twofold, to: (i) survivorship theory generally and specific to critical illness and (ii) the healthcare implications of supporting ICU survivors with and throughout their journeys.

The findings support and extend the understanding of survivorship more generally, through applying successive iterations of liminality; from early anthropological conceptualizations on social ritual to modern conceptualizations in health, illness and cancer survivorship. These findings, like others', explores alternative definitions and demarcations of a post-liminal state, and raises key questions around how and when it is defined, by whom, and in what context. The data also underlines not only the importance of a cohesive illness narrative, but also the centrality of a common cultural paradigm of the illness experience in shaping expectations of recovery and healthcare organizational support. Finally, the data supports Blows et al's (Blows et al., 2012) call for additional research on liminality in "long-term survivorship", in order to examine its implications in survivors' everyday lives and wider life course, with particular attention to whether, when and how long-term survivors reincorporate into society.

With regard, specifically, to the implications for healthcare delivery and support in ICU survivorship, the explication of four directional properties and four directions of ICU survivorship adds significant experiential detail to an "implicit mental model" of critical illness recovery and survivorship (Iwashyna, 2012). Here, the trajectory is defined in terms of "The Big Hit" (critical illness with a relatively linear, sustained recovery), "The Slow Burn" (critical illness followed by persistent decline) and "Relapsing Recurrence" (critical illness followed by recurrent exacerbations and incomplete recovery). Iwashyna's model, however, is based

exclusively on biomedical models of cognitive and functional impairment with an explicit focus on developing end-points in clinical trials, as opposed to supportive interventions (Iwashyna, 2012).

The GT, in contrast, makes visible the inherently *social* response to the uncertainty that is evoked by the critical illness experience itself and by the complex interaction of personal times (physical and social) and their potential asynchronies with those of the healthcare system. Crucially, considerable ambiguity is identified regarding the *demarcations* of a post-liminal state in ICU survivorship, given the consistency with which the participants might be described as “recovered-but-not-quite-recovered”.

The implications for health and social care are significant, in terms of access to support for needs that are essentially hidden from professional view, unexplored or inadequately legitimized by either the individual and/or the healthcare system (Scott et al., 2005). It is noted that recent developments in oncology support including for example, the National Cancer Survivorship Initiative in the UK with its empirically supported holistic needs assessment, educational, supportive and care commissioning initiatives, and national strategies for the improvement of outcomes (Department of Health, 2011). This GT theory, with its directional properties and broad patterns constitutes a unique and important resource with which to translate these developments into an experientially sensitive and responsive healthcare service for survivors of critical illness.

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