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'ICU Survivorship' - a constructivist grounded theory of surviving critical illness

Abstract

Aims & objective: To theorise ICU survivorship after a critical illness based on longitudinal qualitative data.

Background: Increasingly patients survive episodes of critical illness. However, the short and long term impact of critical illness include physical, psychological, social and economic challenges long after hospital discharge. An appreciation is emerging that care needs to extend beyond critical illness to enable patients to reclaim their lives post-discharge with the term 'Survivorship' being increasingly used in this context. What constitutes critical illness survivorship has, to date, not been theoretically explored.

Design: Longitudinal-qualitative and constructivist Grounded Theory. Interviews (n = 46) with 17 participants were conducted at four time points: (1) before discharge from hospital, (2) 4-6 weeks post-discharge, (3) 6 months and (4) 12 months post-discharge across two adult intensive care setting.

Method: Individual face-to-face interviews. Data analysis followed the principles of Charmaz's Constructivist Grounded Theory. 'ICU survivorship' emerged as the core category and was theorised using concepts such as Status Passages, Liminality and Temporality to understand the various transitions participants made post-critical illness.

Findings: Intensive care survivorship describes the unscheduled status passage of falling critically ill and being taken to the threshold of life and the journey to a life post-critical illness. Surviving critical illness goes beyond recovery; surviving means 'moving on' to life post-critical illness. 'Moving on' incorporates a re-definition of self that incorporates any lingering intensive care legacies and being in control of one's life again.

Relevance to clinical practice: For healthcare professionals and policy makers it is important to realise that recovery and transitioning through to survivorship happens within an individual's time frame, not a schedule imposed by the healthcare system. Currently there are no care pathways or policies in place for critical illness survivors that would support ICU survivors and their families in the transitions to survivorship.

Keywords: Longitudinal, constructivist grounded theory, interviews, critical illness, intensive care, survivorship, recovery, status passages, liminality, temporality

Summary Box:

What does this paper contribute to the wider global clinical community?

- Intensive care survivorship is a future challenge worldwide and this longitudinal grounded theory offers a theorised understanding of surviving critical illness, adding significantly to our current understanding of ICU patients' survivorship.
- Transitioning from critical illness to recovery to survivorship is a long-term process involving physical, psychological/ mental and social transitions.
- The pace and direction of a survivorship journey is unique to each individual, but framed within known patterns of physical, psychological/ mental and social adjustments, providing

healthcare professionals and policy makers with an essential insight for any future development of support services.

‘ICU Survivorship’ - A constructivist grounded theory of surviving critical illness

“There is nothing so practical as a good theory.” Kurt Lewin

INTRODUCTION

Research and practice in intensive care management and rehabilitation has until recently focused on physical survival of critical illness. Lately, there has been a perceptible shift identifying critical illness *survivorship* as the future challenge for healthcare (Elliott 2011, Iwashyna 2010, Needham *et al.* 2011). Where before patients’ survival, understood as discharged alive from intensive care (ICU), was a measure of success (Ridley 2002), there is now an appreciation that care needs to extend beyond the critical illness episode for patients to reclaim their lives post-discharge (Desai *et al.* 2011, Govindan *et al.* 2014, Griffiths & Jones 2011). The evidence base for management of post critical illness is however lacking.

BACKGROUND

The emerging picture of critical illness survivorship is an unsettling one (Iwashyna 2010) with the impact of critical illness now being referred to under the unifying term Post Intensive Care Syndrome (PICS) and Post Intensive Care Syndrome -Family (PICS-F) (Davidson *et al.* 2012, Harvey & Davidson

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2016, Khan *et al.* 2015). PICS and PICS-F acknowledges the impact of critical illness on the (1) physical, (2) psychological, (3) social and (4) economic consequences on ICU survivors and their families. The physical and psychological aspects of post-critical illness have received extensive international research attention, often by utilising standardised measures of psychological outcome or quality of life (Cuthbertson *et al.* 2010, Davydow *et al.* 2008, Parry *et al.* 2015, Schandl *et al.* 2011). In contrast, social and economic impacts of critical illness on patients and families are under-researched and little understood, and we have little understanding of how different dimensions of critical illness interact to produce far reaching changes to survivors' lives. This is a critical omission if we are to develop appropriate services to support this patient group.

Physical, psychological and economic impact

Our understanding of the physical and psychological consequences of critical illness has improved significantly and there is a strong body of evidence that details these. Physical recovery is compromised in many ICU patients because of a complex phenomenon of muscle wasting during critical illness (Griffiths 2010, Herridge 2009). This is termed ICU acquired weakness that leads to long-term physical impairment and fatigue, prolonging recovery trajectories (Desai *et al.* 2013). ICU patients can lose 2% of muscle mass per day (Alamdari *et al.* 2013), with muscle wasting setting in rapidly after admission to ICU and is more pronounced in patients experiencing multiorgan failure (Puthuchery *et al.* 2013). The impact of these symptoms can often be underestimated by healthcare professionals.

The psychological impact of critical illness on patients and families is multidimensional. Patients may experience problems with short and long-term anxiety, depression and posttraumatic stress that may be associated with the ICU admission or critical illness experience itself (Azoulay *et al.* 2005,

Fumis *et al.* 2015, Parker *et al.* 2015). Delirium and cognitive impairment have been recognised as problems during and after ICU (Girard *et al.* 2016) and approximately 30-70% of ICU survivors experience cognitive impairment during the first year after discharge (Hopkins & Jackson 2013). Many patients remember little about their time in ICU but what is remembered are often unpleasant rather than factual events (Bélanger & Ducharme 2011). All these problems have the potential to negatively affect patients' recovery.

Negative economic consequences for families were established in a multicentre study back in the 1990s in the United States (US) (Covinsky *et al.* 1994) and more recently in the United Kingdom (UK) (Griffiths *et al.* 2013) and in Denmark (Ågård *et al.* 2014). These studies note that family members had reduced or stopped working to provide care for an ICU survivor. This is an unintended societal consequence of shifting-the-balance-of-care policies that essentially leaves patients and families without a clear provision of care creating a family care dependency (Chaboyer & Grace 2003, Haycock-Stuart & Kean 2013, Swoboda & Lipsett 2002). Family care dependency, in turn, has adverse short and long-term effects on family income and financial stability (Simon *et al.* 2013). Further, ICU survivors have higher rates of unemployment or reduced employment following critical illness (Norman *et al.* 2016).

Social impact, recovery and survivorship

Physical, psychological and economic effects of critical illness on patients' lives interlink to produce the conditions under which ICU survivors continue life after critical illness. Social recovery refers to the re-engagement with roles and activities following illness (Thomas 2004). It is about re-engaging with life and oneself after critical illness and is an aspect of recovery that remains relatively unexplored. If we are to understand and manage the complexity and multidimensionality of critical illness survivorship, this needs to be addressed in future research.

Despite the long standing prominence of 'survivorship' in the health literature, in particular for cancer, there is surprisingly little theoretical work on the topic. Recently, liminality is emerging as a theoretical lens in cancer survivorship (Blows *et al.* 2012, Bruce *et al.* 2014, Little *et al.* 1998). Nevertheless, what constitutes a cancer survivor and survivorship has been debated for decades but with no evidence of a consensus (Hewitt *et al.* 2006). The idea of 'cancer survivorship' has emerged from biomedical models of illness and healthcare (Feuerstein 2007). Notably, cancer survivorship has become an arena of contest between proponents of biomedical models of disease and writers advocating the role of social factors in shaping health and illness (Bell & Ristovski-Slijepcevic 2013).

In critical care, the term 'survivorship' is increasingly being used. The term 'survivor' is applied in its literal sense for someone having survived critical illness whilst 'survivorship' refers to an ICU survivor who is affected by aspects of critical illness legacies. To date, in the field of critical illness there has been no theoretical work exploring the concept of 'survivorship'.

Objective

Grounded theory (GT) methodology was used to generate a substantive GT of 'ICU survivorship' and which is based on material collected about survivors' strategies of adaptation to life after critical illness, and their experience of this process, over a period of one year.

STUDY DESIGN

The study (RELINQUISH) is a nested longitudinal qualitative study within RECOVER, a randomised control trial (RCT), evaluating a complex rehabilitation intervention for ICU patients post-ICU discharge (Walsh *et al.* 2015). Inclusion and exclusion criteria are identical in both studies (Table 1) and study protocols have been published elsewhere (Ramsay *et al.* 2012, Walsh *et al.* 2012).

A constructivist grounded theory (GT) approach Charmaz's (2000, 2006, 2014) was chosen to develop a theoretical understanding of the processes and transitions ICU patients embark on post-critical illness. The GT inductive approach to theory construction identifies action and interaction, behaviours and processes from the perspective of participants (Artinian *et al.* 2009, Corbin & Strauss 2008). GT is of particular interest and relevance to practice and policy in an area where a theoretical understanding about a phenomenon is absent.

The constructivist approach to GT was adopted as this epistemological stance holds that reality is developed over time and given meaning to the world by individuals (Howell 2013). Realities are viewed as constructed by individuals 'under the influence of a variety of social and cultural factors that lead to shared constructions' (Howell 2013, p. 90). Applying this stance to this study resulted in a shared, constructed reality between researcher and researched bringing about an understanding of what it is like to survive critical illness for participants. GT fosters these processes of construction through its methods of constant comparison and simultaneously collecting and analysing data. This is guided by identifying 'what is going on here?' in the data (Glaser 1992, 2013, Noerager Stern & Porr 2011). Consequently, interview questions changed and developed over time in response to on-going data analysis.

Theorising and theory construction in Grounded Theory

Essential for theory development are activities that 'foster *seeing* possibilities, *establishing* connections, and *asking* questions. [] When you theorize, you reach down to fundamentals, up to abstractions, and probe into experience' (Charmaz 2006, p. 135, Italics in original). Theorising is an iterative process that is integral and essential in developing theoretical sensitivity (Charmaz 2006, Dey 2004).

Theorising goes beyond induction and includes abductive logic on which, subsequently, theory construction in GT rests (Atkinson *et al.* 2003, Bryant & Charmaz 2007, Dey 2004, Reichertz 2013, Timmermans & Tavory 2012). Abductive reasoning involves ‘the analyst in “drawing out” possible abstractions from observed cases, and using those to formulate working hypotheses that can in turn be tested against new cases and observations’ (Atkinson *et al.* 2003, p. 149). This way of thinking is supported by and links to various iterative processes in GT; simultaneous collecting and analysis of data, constant comparisons, developing theoretical sensitivity, saturation and identification of a core category.

Sample and settings

Participants were recruited from two adult general ICUs of a major teaching hospital in the central belt of Scotland. The units are similar in size (18 vs 16 beds) and care for approximately 1150 mechanically ventilated patients per annum. All participants were emergency admissions and were general medical or surgical ICU patients. The sample includes two distinct groups: (1) acute critically ill patients and (2) chronically ill persons experiencing an exacerbation requiring ICU treatment.

The sample for this GT consists of 17 participants resulting in 47 interviews. Interviews were conducted at four time points: (1) before discharge from hospital (17 interviews), (2) 4-6 weeks post-discharge (11 interviews), (3) six months and (10 interviews) (4) 12 months post-discharge (9 interviews) from the original critical illness related hospital discharge. The loss to follow-up during the year was due to death (3), lost to contact (4) and one withdrawal resulting in nine full cases (interviews at all four time-points). As this study was situated within an RCT, participants were recruited from both arms.

Ethics

The Lothian Research Ethics committee granted ethical approval (S1101/45). Participants were approached and recruited shortly before hospital discharge by either SK or PR. Prospective participants received written study information and written consent was obtained at least 24 hours prior to the first interview. First phase interviews were conducted in the clinical area in a private room (single bedroom or family room on wards). Participants' General Practitioners (GP) were contacted before arranging interviews for phases 2-4. This safeguard ensured that researchers knew when a participant had been re-admitted to hospital or had died in between interviews therefore protecting bereaved families. Interviews for phases 2-4 were predominantly conducted in participants' homes. Only a minority of participants preferred the clinical setting in which case transport and a private room for interviews was organised.

Data collection and analysis

Data were collected through individual face-to-face semi-structured interviews. In some cases, a family member ((marital) partner or adult child) was present at follow-up interviews for which additional consent was sought from participants and family members. Family members added another perspective on critical illness experiences (Cypress 2011) which enriched contextualisations of participants' survivorship experiences over time. Interviews were digitally recorded, transcribed verbatim and checked for accuracy. Computer software (NVivo 9) was used in managing data and analysis - coding, memo writing, modelling change over time and checking saturation of categories. Data were collected and analysed by the first author.

Data analysis followed iterative strategies in GT: simultaneous collection and analysis of data, two-step coding process (open-focused), comparative analysis (within cases and across cases),

theoretical sampling to refine theoretical ideas, memo writing and the integration of theoretical frameworks into the developing GT (Charmaz 2000, Glaser 1978). Embedded in these strategies are processes of reflexivity, Gray (2014) distinguishes between epistemological and personal reflexivity. In this study, processes of personal reflexivity are evident in the re-reading of interview transcripts, adaptation of interview follow-up questions and also informal conversations that happened with each participant before, after and at times in-between interviews. Epistemological reflexivity is embedded in the various GT strategies such as memo writing, theoretical sampling and constant comparative method (Charmaz 2014, Mills *et al.* 2006) and is evident in the process of theorizing below.

The longitudinal nature of this study added significantly to its analytical complexity. The focus of longitudinal data analysis rests on change and the mechanisms and strategies individuals use to manage change in their lives as well as structural aspects of social life that impact on change (Neale & Flowerdew 2003). There are no standardized methods for longitudinal qualitative data analysis (Saldaña 2003). However, GT strategies and a focus on processes, paying specific attention to time and context (Strauss & Corbin 1998) guided analysis. Data were gathered and analysed simultaneously. The multi-phased nature of this study resulted in recruiting participants in overlapping phases. Accordingly, insights gained from participants in later interviews (Phases 3 & 4) informed probing of participants in earlier phases. This dynamic and reflective analytical strategy allowed the identification of shifting foci within participants' survivorship journeys over time and lead to explicit probing of experiences thus aiding theoretical coding.

In addition, the modelling function in NVivo 9 was used to visualise the increasing abstraction of the analysis, allowing insights into how, what and where changes happened over time. To elicit this information, all participants were asked: (1) what has changed? (then – now) and (2) what are your future challenges?, which allowed an understanding of survivorship to evolve. Change was further

explored through: (1) re-reading previous interviews (within case) before follow-up interviews exploring individual's changes over time, (2) probing into experiences (within and across cases) and (3) looking for processes using visual colour coded diagrams tracking and exploring change over time across data. Modelling was used as a tool to reflect on emerging insights, aiding understanding of data saturation and developing theoretical ideas.

Following an abductive logic for theory construction also requires a shift in engagement with (theoretical) literature over time. We engaged with literature at the beginning (grant application) and then explored theoretical literature (probing ideas) at a later stage after having inductively developed codes and categories to allow for the processes of abductive reasoning to develop, leading eventually to the identification of survivorship as core category and its underpinning theoretical foundations.

Theorising ICU survivorship

Theorising is a process not a step. It is messy, non-linear and requires flexibility, reflexivity and an open mind on the part of the analyst. It is about trying out how the analytical pieces of a puzzle fit together into a coherent explanation of what is going on in the data. Theorising is the analyst's forwards and backwards interaction with data, memos, (theoretical) literature and thinking about the data that allows explanations to arise, to be tried out and tested 'until the pieces of the puzzle fit' (Spencer *et al.* 2014). In GT this 'fit' is expressed in a core category.

The development of this constructivist GT 'ICU survivorship' underwent such an analytical journey. For example, at the beginning of the data analysis 'negotiated order' (Strauss 1978) appeared to be a

major concept that might explain what was going on. This construct was tried out, tested and dismissed. Over time, aided by the process of reflection, simultaneously collecting and analysing data, it became evident that 'negotiations' played an important part in a survivor's journey but it was not the central point of the story. Whilst negotiations were important at the beginning of the journey, by phase 3 (6 months) participants' foci had shifted to other matters, for example, towards re-engaging in social life for which this concept did not fit. This insight raised the issue of time, which in turn led to exploring the idea of transitions, and so the analytical focus shifted towards these concepts. Transitions were further analysed and theorised exploring different dimension as they are evident in status passage (Glaser & Strauss 1971/2010). It was evident in the data that specific analytic attention was required to the dimensions of liminality and temporality in status passages. In relation to liminality, Van Gennep's (1908/1960) and Turner's (1969/ 2008) work was used to further theorise whilst temporality was theoretically advanced by drawing on Adam's (1990) work. This then is the theoretical 'fit' with the data which explains the complexity of participants' journey from critical illness to ICU survivorship (Figure 1).

Limitation

The aim of GT is the development of a situation-specific middle range theory. This GT is in line with this aim and therefore its applicability is limited to ICU survivors. Future research will need to clarify the transferability of this GT to other long-term critical/ chronic illness survivors.

FINDINGS AND DISCUSSIONS: TRANSITIONING TO ICU SURVIVORSHIP

The following presents a GT of ICU survivorship as it emerged from ICU survivors' multiple transitions over a period of one year. Some transitions, such as being admitted to ICU, were sudden and unscheduled *status passages* while others reflected progress and were *desired* status passages

or a *reversal*, for example hospital re-admissions requiring a re-evaluation of goals and the idea of progress. During transitions, ICU survivors moved through different states of *liminality*. By definition, liminal states include an 'undercurrent of uncertainty' (Sheilds *et al.* 2015) where it becomes evident that the previous life has ended but where life post-critical illness has yet to emerge. Transitions happen over time and therefore *temporality* is an underlying dimension of transitions, involving a life moving and changing towards unknown ends.

Importantly, the outcome of these processes is not recovery but survivorship. Recovery often implies getting back to the pre-illness state (Frank 2002). In contrast, survivorship makes visible the active processes of re-engaging with a different, post-illness self. It draws attention to the fact that transitioning through different status passages is not a passive event, but one in which ICU survivors actively engage in by bringing their experience, knowledge and aspirations to the process. In essence, ICU survivors shaped their survivorship journeys through their agency.

Anonymised participant codes are explained in Table 2.

Unscheduled Status passages and liminality

A sudden critical illness and admission to ICU constitutes an unscheduled status passage, symbolising the observable starting point of a person's transition from health or a stable chronically ill health state to critical illness. Transitions in status passages are understood as 'movements into a different part of a social structure; or a loss or gain of privilege, influence, or power and a changed identity and sense of self, as well as changed behavior' (Glaser & Strauss 1971/2010, p. 2). The first signs that a health transition was in progress, and with it a transition from person to patient, was often the realisation that something was not quite right.

11057.1MC: 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.

Wife 11057.1MC: [] What happened was - two weeks previous I took a funny stomach. I was sick and all the rest of it - and he thought that was what he was taking, when this came on him. [] And that's what we treated, and you were up all night then.

The bad stomach turned out to be a sepsis triggered by gallbladder stones prompting a rapid deterioration and admission to ICU. For others, an unscheduled status passage emerged as post-operative complications. The following participant had undergone scheduled bowel cancer surgery.

12016.1FC: [] 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.

Across interviews most participants could remember the onset of critical illness. However, when asked few could recall their time in ICU:

11010.1MI: Not really. No, no not really. A couple of wee things - but really no much at all. [] I could remember sort of wakening up. Well, at some point thinking for some reason or other I was in (city).

Moving through different status passages is conceptually linked to liminality. Van Gennep (1908/1960, p. 2-3) defines liminality as 'transition[s] from one state to another [that] is literally equivalent to giving up the old life and "turning over a leaf"'. People in a liminal state are understood as being 'neither here nor there; they are betwixt and between' (Turner 1969/ 2008, p. 95). Liminality includes three stages: (1) pre-liminal: rites of separation, (2) liminal: rites of transition, and (3) post-liminal: rites of incorporation. Turner (1969/ 2008) and Van Gennep (1908/1960) describe liminality as a highly organised and ritualised processes of transitions. Critical illness, in contrast, is marked by unscheduled status passages. Liminality in critical illness corresponds to falling critically ill and therefore to the separation from life (pre-liminal) as it existed pre-critical illness, whilst the liminal state refers to the time and processes of recovering, with the post-liminal state signifying survivorship and life post-critical illness in which any long-term consequences of illness have been incorporated into one's life. In essence, liminality explicates the experiences of ICU survivors' transitions, including their inherent uncertainty and it is this aspect that is of interest to ICU survivorship. Interestingly, whilst living in and through a liminal time can be very challenging for ICU survivors, the inherent uncertainty also creates space and opportunities for growth and personal development (Johnston 2011).

This study included only patients that had been ventilated for at least 48 hours. Ventilated patients are routinely sedated, inducing a state of reduced consciousness to allow ventilation and in an effort to control anxiety and distress (Laws & Rudall 2013). Mechanical Ventilation (MV), illness severity and sedation are all factors linked to ICU delirium and these patients have fewer factual recalls but more delusional memories (Myhren *et al.* 2009, Ringdal *et al.* 2010, Wade *et al.* 2012). Delirium is an example in which ICU survivors' experiences of liminality was evident when participants spoke of 'being in a world of my own' (11057.1MC) or that they:

11055.1MI: [] 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. And I was telling them that I wasn't going and it was very, very frightening.

Sedation is existential in that it places the self in a state of liminality between the person that was and the patient that is. The existential dimension is apparent in Rier's account, comparing his critical illness with biographical disruption (Bury 1982) and asserting that critical illness is unlike a biographical disruption 'because my illness seemed simply to replace my earlier life, rather than compete with it. I was spared the stress (so prominent in accounts of chronic illness) of trying to manage my normal obligations while ill' (Rier 2000, p. 72). This experience is more in line with a biographical abruption (Locock *et al.* 2009) underlining that passages are transitions from one state into another: critical illness forces patients to relinquish their pre-illness lives to be replaced by a different one that is yet unknown. This insight emphasises the differences between recovery and survivorship; life did not return to the pre-illness state but to a different post-liminal life.

Directionality: desirability, reversibility and temporality

All transitions are directional. Consequently, transitions are shaped by their (1) degree of desirability and/ or (2) reversal of progress and (3) over time. Essentially, directionality and time shape status passages. *Desirability* of a status passage makes visible the 'motivational basis that shapes the passage' (Glaser & Strauss 1971/2010, p. 89). Desirability here captures hopes and efforts made by participants and family members towards recovering their lives.

11026.2FC: 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.

Daughter of 12017.3FI: 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 me just to go and do it, so mum doesn't have to do it. It's to get mum to do it.

Many participants set themselves some goals, for example, gradually increasing their walking distance, often doing so initially with a friend or family member. Setting very deliberate tasks and targets was a strategy some participants used, including social recovery aimed at re-engaging in previous hobbies and interests. The desire for recovery is often linked to getting back to where one was before (Frank 2002). Given the Post Intensive Care Syndrome and its long-term impact, recovery is perhaps better reframed in a mental health sense that views recovery as an on-going process aiming at recovering a meaningful and valuable life (Repper & Perkins 2003, Secker *et al.* 2002). Particularly for chronically ill participants the emphasis on recovering *with* not *from* illness was relevant. This understanding of recovery reflects how participants viewed recovery but is distinctly different from a clinical perspective that hinges on measurable functional outcomes. Participants, who defined themselves as recovered after one year, often did so acknowledging that their physical abilities were not the same post critical illness.

Reversibility, in contrast, denotes a directional change. Implicit in reversibility is the assumption that there is a direct passage towards recovery by those involved in transitions, excluding the possibilities of byways. Across the sample, hospital re-admissions were visible indicators of reversibility in status

passages and often linked to participants' chronic illness trajectories, illuminating directional highways and byways survivorship journeys can take.

Status passages happen over *time* and time too is directional. The directionality of time is emphasised by Adam (1990, p. 9) asserting that 'there can be no un-living, re-juvenating, or un-knowing [] since moments past cannot be lived again.' Time's passing is a future directed movement. Time is also multidimensional as there is no single time but a multitude of times that interrelate and permeate social lives (Adam 1995). The existentiality of temporality might be a given, but time itself is socially shaped and contextualised within the multitudes of times relating, for example, to body, social and organisational times. Asynchronies in these times resulted in challenges for ICU survivors.

In ICU survivorship *temporality* relates to rate, pace, or speed of the passage but also to the degree of certainty with which temporal expectations can be known (Glaser & Strauss 1971/2010). For example, many participants had an unrealistic expectation of how fast they would recover. It was only over time that participants realised the long-term nature of recovery. Intertwined with temporal aspects of recovery is the patient's pre-critical illness health status. A 'Big Hit' trajectory, a term Iwashyna (2012) uses to describe an otherwise healthy person falling critically ill, has a different recovery trajectory compared to someone experiencing a chronic illness exacerbation. Chronically ill patients differ in that their health is declining over time (slow burn) and this trajectory may be interrupted by acute events requiring ICU treatment (MacIntyre 2012). Pre-existing illnesses impact significantly on aspects of ICU mortality (Rubenfeld 2012). These differences between acute critical illness and chronic illness exacerbation have implications for survivorship trajectories.

Further, asynchronies between organisational and body time sometimes impacted negatively on ICU survivors' recovery efforts when, for example, promised occupational therapy (OT) material was not in place at the point of discharge.

11079.2FI: [] They promised that everything had been on the day before.

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 in (chuckles). (*Tea trolley*). [] Just last week they came with the banisters, after I can walk up myself.

Hart's (2001) concept of system induced setbacks applies here since asynchronies of organisational and personal/ body times sometimes hindered participants' recovery efforts.

In essence, temporality in ICU survivorship is evident in the directional processes of living through critical illness and is contextualised within the multitudes of times relating to body, social and organisational times. Survivorship journeys include a degree of uncertainty towards life post-critical illness but with identifiable broad patterns, in that the initial focus was on physical recovery before moving on to emotional/ psychological recovery which became intertwined with aspects of social recovery over time.

Agency: negotiations and control

Transitioning through different status passages is not a passive event but one in which ICU survivors actively engage in shaping their survivorship journeys. Agency refers to individuals' abilities to exert autonomy (Dillon 2014) and was evident in participants' negotiations and taking control of the

survivorship's direction. For instance, the following participant went to her GP asking for physiotherapy, withholding that she had been cycling (home trainer) to boost her recovery. When asked why, she responded:

12016.2FC: 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.

In this case, the participant was promised community physiotherapy at discharge that failed to materialise, so she negotiated access through her GP because she felt she needed it. Another participant emphasised her independence when she got out of bed and downstairs in her own time (personal time) instead of waiting for the community nurse (CN) (organisational time).

11079.4FI: 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 (CN) 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.

Other examples include the negotiations of OT materials before discharge, negotiating 'just in case antibiotics' with their GPs, additional support services (e.g. stair lifts) or taking back control of financial responsibilities from other adult family members. Conceptually, negotiations are linked to control. Controlling the passage is, in turn, linked to directionality and temporality of transitions (Glaser & Strauss 1971/2010). It was this interplay of negotiating and controlling directions by participants with others (e.g. GP, family members, CNs and so on) that actively shaped individual's survivorship journeys.

Directionality in ICU Survivorship

Transitioning from critical illness to ICU survivorship took four general directions: (1) survivorship, (2) recovery towards survivorship, (3) survivorship towards new-onset disability and (4) survivorship towards palliation. An underlying identifiable pattern across these directions was participants' initial focus on physical recovery before they moved on to emotional/ psychological recovery and eventually social recovery. Failure to recover sufficiently physically impacted on this onwards direction: delays or reversals became evident.

'Survivorship' and 'recovery towards survivorship'

The speed at which participants recovered and transitioned through to survivorship differed significantly. A year on from their critical illness some participants considered themselves as recovered. When asked typical responses were:

11055.4MI: Now that I am fully recovered, I wouldn't think of going along and feeding the ducks but on the road to recover it was a good incentive, take a bag of breadcrumbs and go and feed the swans.

11079.4FI: I think I've recovered, you know. I'm trying to think back what I used to do. I've not been on a bus to go into (city).

Though participants asserted that they had recovered, the interplay between physical, emotional and social recovery was evident at year one interviews and the following excerpt is an example.

11013.4 FC: If somebody said 'how are you?' I would have said I was fine, I have recovered.

I: I sense a 'but'?

11013.4: I would still say there were kind of some loose ends that were not fully recovered.

I: What are these loose ends?

11013.4: 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.

I: What should you be doing that you are not doing?

11013.4: Like doing my photography and doing all the other things. []

I: Do you think there is a difference between physical recovery and emotional, mental health recovery?

11013.4: They are all interlinked. You can't really put them into their own wee boxes. They are all in one big box.

I: So what is influencing what?

11013.4: Probably emotional and - Not that I am a weepy, self-pitying person but - Kind of - I suppose it affects physical recovery.

Over the follow-up year and in each case participants had times of reflection and the impact of the critical illness experience on their 'self' became apparent. The male participant (11055) had 'sorted himself out' after reflecting on the importance of his family and was now involved in volunteer work whilst both female participants reflected on a loss of confidence that was evident when they spoke about becoming 'quite quiet and I didn't bother speaking to people' (11013) or 'not having been on a bus' to the next town (11079) from what was otherwise a very independent lady. Social recovery, the re-engagement with their previous lives (Thomas 2004) came at different time points but after participants had made a sufficient physical and emotional recovery. The following participant 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.

11026.3FC: 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.

This then is the difference between 'survivorship', where participants truly had moved on and established a life post-critical illness (e.g. 11055, 11026) and those who were on the road from 'recovery to survivorship' (e.g. 11013, 11079). Recovery was a gradual process and for some participants (e.g. 11026, 11013, 11079) took byways (reversibility) such as falling ill in the follow-up year. Across the sample recovery was not to the pre-critical illness state. The critical illness left participants with some ICU related health issues or a new diagnosis such as Chronic Obstructive Pulmonary Disease (COPD - 11055), neuropathy in one leg (11013), memory problems (11079) or walking restrictions due to an ICU acquired weakness (11026). Conceptually, participants' view of having recovered despite some remaining ICU legacies signifies the post-liminal state. They have

achieved a life after critical illness in which any long-term consequences of their illness were integrated, allowing them to move on. They had, in Frank's (2002, p. 28) words discovered 'a life on the other side.'

'Survivorship towards disability' and 'survivorship towards palliation'

'Survivorship towards disability' and 'survivorship towards palliation' are the other two directions that were evident in the data. In critical care practice (and research), *disability* refers to a functional classification, describing 'a spectrum of disability after critical illness' (Kress & Herridge 2012) or 'new-onset disability' (Brummel *et al.* 2015) following critical illness. It is worth noting that none of the participants defined themselves as 'disabled' and the term only emerged in interviews where disability benefits came up (11014, 11041). For instance, participant 11014 had survived severe smoke inhalation which resulted in lung damage and subsequently in a COPD diagnosis. His initial post-critical illness recovery went well and he was hopeful to be back at work within 'three or four weeks' (11014) at the 4-6 weeks' interview. At the last interview (one year) it became evident that his physical recovery had reversed and a disability scenario was emerging.

11014.4MI: 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. []

This reversal of direction was foreshadowed at the six-month interview when he said that:

11014.3MI: 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).'

In-between these two time points, he started to realise that he might not get back to work and, with the help of friends, had applied for disability benefits. This recovery reversal had implications for his emotional and social recovery in that his failing lung function prevented him from going out resulting in feelings of boredom and loneliness and getting 'a wee bit depressed' (11014).

Other examples include previously independent living older participants (age range 70-88) who alluded to some long-term cognitive impairment. These participants described losing concentration whilst doing cross-word puzzles (12017), reading a book (12007, 11079) or forgetting to take medication (12017,11079) as changes from pre to post-critical illness. Older people have fewer physiological reserves to cope with stressors of critical illness and so the complex relationship between ageing, pre-illness vulnerability and critical illness can lead to new-onset disabilities (Bagshaw *et al.* 2015, Brummel *et al.* 2015).

Survivorship towards palliation was yet another directional change for some ICU survivors. In these cases (11041, 11048) a 'relapsing recurrent trajectory' (Iwashyna 2012) was evident through acute chronic illness exacerbations, frequent hospital re-admissions followed by partial recoveries. This is, for example evident in a participant with COPD. When asked at the 4-6 weeks' interview where he was in terms of recovery he said:

11048.2MC: I would say half way to where I have been. [] I think it is getting harder and harder.

By six months he said:

11048.3MC: I've just no strength in my body. But seemingly that's just all part of the illness now.

At the one-year follow-up interview, he spoke about having been in and out of hospital. In-between these two time points (6 months – 1 year) he had entered a liminal state of a 'lingering' pattern in which the patient stays in the 'certain to die but unknown when' status (Glaser & Strauss 1965, p. 50). The 'lingering' pattern was evident when he spoke of others urging him to write his Will:

11048.3MC: Aye, because Marie Curie (*charity*) talked about my Will. 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. They say if I tell them, they say they will see me. 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.

By the time of the last interview (one year) he had not addressed the issue of his Will but spoke about death and dying, reflecting on his life and family. Though still uncertain of the 'when', death had become the near future. A similar 'relapsing recurrent trajectory' was evident in the female participant (11041) with frequent re-admissions throughout the follow-up period, an increasing need for oxygen (home oxygen therapy) and decreasing mobility levels (partial recovery patterns). This participant passed away shortly before the one-year interview. In essence, these survivorship journeys were characterised by down-spiralling chronic illness progressions.

CONCLUSION

'Critical illness offers the experience of being taken to the threshold of life, from which you can see where life could end. From that vantage point you are both forced and allowed to think in new ways about the value of life. Alive but detached from everyday living, you can finally stop to consider, if any future is possible. Illness takes away parts of your life, but in doing so gives you the opportunity to choose the life you will lead, as opposed to living to choose the life you have simply accumulated over the years.' (Frank 2002, p. 1)

Frank's insight nicely sums up what ICU survivorship is about: the unscheduled status passage of being taken to the threshold of life and the transitions to a life post-critical illness. What this post-liminal life looks like is linked to the individual's pre-illness health status and the severity of critical illness experienced. Iwashyna (2012) has described these different recovery trajectories as: (1) the 'Big Hit', (2) the 'slow burn' and (3) 'relapsing recurrence' with each carrying a different expectation of recovery outcomes ranging from a full recovery to one where ICU survivors recover *with* and not *from* their illness.

Theorizing ICU survivorship through the lenses of status passages (Glaser & Strauss 1971/2010) that incorporates dimensions of liminality (Van Gennep 1908/1960) and time/ temporality (Adam 1995) advances data analysis beyond description and offers a way of understanding not only what ICU survivorship is but also the complexity and different directions these journeys can take.

The longitudinal nature of this GT allows a theorised understanding of surviving critical illness beyond the initial recovery period of critical illness and thus adds significantly to our understanding of patients' ICU survivorships. Surviving critical illness goes well beyond recovery; surviving means 'moving on' in life post-critical illness. As is evident in this GT, 'moving on' incorporates a re-definition of self that incorporates any lingering Post Intensive Care Syndrome issues and being in control of one's life again. ICU survivors have undergone or are undergoing a number of transitions

that are characterised by the intersection of different interdependent transitions relating to (1) liminal transitions; (2) recovery trajectories evident in the dimensions of status passages such as desirability, reversibility, control and negotiations and (3) the interplay of multiple times such as individual, body and organizational times.

RELEVANCE TO PRACTICE AND POLICY

Essential insights from this GT for healthcare professionals and policy makers are the realisation that the paces of recovery and transitioning through to survivorship happen within an individual's time frame. The temporal dissonance between organisational times and personal/body times needs to be addressed since healthcare system inflexibility is at times counterproductive to recovery efforts by patients and family members. Further, the current focus on functional outcomes after critical illness misses the complexity of the illness-recovery-survivorship trajectory including its unintended social and economic consequences for patients, their families and society at large. In contrast to cancer survivorship (Hewitt *et al.* 2006, NHS Improvement 2012), there are no policies or care pathways in place to address ICU survivorship issues and this work is urgently needed. In addition, the emerging evidence on the negative impact critical illness has on ICU survivors and their employment status (Norman *et al.* 2016) is another area requiring immediate political action and policy interventions.

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Table 1: Inclusion/ Exclusion criteria

Inclusion criteria	Exclusion criteria
> 48 h continuous ventilation via endotracheal and/ or tracheostomy tube	Primary neurological admission diagnosis (e.g. brain trauma, stroke, intracerebral bleed)
Consultant in charge considers patients fit for discharge from ICU	Patients for whom a dedicated rehabilitation programme exists (e.g. transplantation, stroke, post-cardiac surgery)
	Provision of palliative care
	Patients receiving home ventilation
	Patients discharged from ICU to a non-study hospital
	Patient is enrolled in another randomized controlled trial
	Communication difficulties (e.g. language)
	Patients below the age of 18 years

Table 2: Participant identifier codes explained

Study number	Phases 1 - 4	Gender	Group assignment	Appears in text as:
11013*	1	F	C(ontrol)	11013.1FC
11014	2	M	I(ntervention)	11014.2MI
12007*	3	M	C	12007.3MC
12017	4	F	I	12017.4FI
*Participants' study numbers are separated into locations: numbers starting with 11 standing for one ICU and numbers starting with 12 for the other participating ICU				

Figure 1: Theoretical foundations of ICU survivorship

