ORIGINAL ARTICLE

WILEY *Journal of* Clinical Nursing

Constructing a grounded theory of critical illness survivorship: The dualistic worlds of survivors and family members

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Abstract

Aim of the study: To understand the critical illness trajectory from patient and relative perspectives.

Background: In the context of increasing survivorship from critical illness, it is important to enhance our understanding of the subjective experience of survivors and their families. The need to consider the legacy of critical care beyond physiological survival is imperative.

Methods: Using a constructivist grounded theory methodology, in-depth interviews were undertaken with survivors of critical illness ($n = 16$) and family members ($n = 15$). Constant comparative analysis and data collection occurring concurrently with theoretical sampling commencing from the outset. EQUATOR guidelines for qualitative research (COREQ) applied.

Findings: Survivors of critical illness invariably experienced vivid, hallucinatory experiences which placed them in a different world or liminal space. The core difficulty can be summarised as follows: Survivors have little recall of the factual events of their critical illness but relatives have lived the whole event in a very real and ingraining manner. This can result in family members and survivors experiencing different versions of the critical illness episode.

Conclusion: Survivors of critical illness, together with family members, experience challenges when endeavouring to readjust to life post critical care. This study has identified a middle range theory of dualistic worlds between and within the survivor and family member experiences. Exploring the dynamic interplay between intrapersonal, interpersonal and societal factors has provided theoretical insights with practice implications in relation to surviving critical illness.

Relevance to clinical practice: The findings from this study highlight the need for a rehabilitation infrastructure following critical illness to support the existing UK national guidance, ensuring the individual and holistic needs of survivors and their families are met. Conversations with survivors and their families around critical illness survivorship are frequently absent and needed early in the recovery period.

1 | INTRODUCTION

Twenty-five years ago, we could not even quantify how many people survived admission to Critical Care (Kings Fund, 1989). Subsequently, we have gained quantitative knowledge of the survival rates of patients (Endacott, 2011; ICS, 2015). Survival is, however, a far more complex phenomenon; surviving the stay within intensive care is just one milestone on a much longer journey (Iwashyna, 2010). In the 21st century, we are beginning to discover, and understand, the longer term sequelae of critical illness for both patient and family members with consequential effects on physical and psychological function and the social landscape (Govindan, Iwashyna, Hyzy, Miller, & Watson, 2014; Hart, 2014). Studies have indicated that in patients surviving critical illness, physical, psychological and cognitive dysfunction is significant for up to two years following discharge from critical care (Cuthbertson, Scott, Strachan, Kilonzo, & Vale, 2005) and for some survivors this can last for much longer (Barnett, 2006; Storli, Lindseth, & Asplund, 2008). The potential for a significant societal and individual socioeconomic burden following critical illness has also been confirmed (Griffiths et al., 2013).

A driving imperative for this study was to develop a greater knowledge of the experience of survivors of critical illness and their families. This study gave survivors and family members a voice and vehicle to inform clinical practice. As Catherine White a survivor of critical illness and founder member of the charity ICU Steps states:

> As an ICU [Intensive care unit] patient, you have no voice (you are often unable to communicate and are confused), so many patients are therefore unable to contribute to their care and express their wishes while in intensive care. This is why it is so vital that the voices of former patients and relatives are heard at all levels to help fill this gap. (White, 2016 p. 50)

Millions of people now physiologically survive critical illness around the world (Iwashyna, 2010; Lasiter, Oles, Mundell, London, & Khan, 2016); however, there is a deficit both in knowledge and in provision around critical care survivorship which may be contrasted with that of cancer survivors, from whence the term survivorship developed (Blows, Bird, Seymour, & Cox, 2012; Govindan et al., 2014). This research provides novel perspectives on the relational effects of critical illness between survivors and family members. Data from this study additionally augment the growing corpus of knowledge around the long-term sequalae of critical illness.

The subjective experience of critical illness is poorly understood by healthcare professionals, survivors and their families (Stevens, Hart, & Herridge, 2014; White, 2016). In addition, the critical illness experience is enormously complex, varied and multifaceted. This study seeks not to medicalise this experience rather to provide an understanding of the dynamic interplay during the illness trajectory. The focus is away from illness affecting organs and systems and seeks to illuminate the embodied suffering that can occur as a consequence of surviving critical illness.

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

- Survivors of critical illness invariable experience a liminal space between life and death.
- The transitional period to a *new normal* following physiological survival requires support from practitioners and family members.
- Regaining family homeostasis can be a challenging journey for both survivor and family member.

The study aimed to formulate a substantive (middle range) theory in relation to patient and family's critical illness trajectory. Specifically asking, how do patients and family members experience their critical illness trajectory? The importance of conducting research on illness experiences has been well documented (Frank, 2004; Sakellariou, Boniface, & Brown, 2013). Illness is rarely experienced as a solely individual experience; illness is lived and co-constructed within the social context that people inhabit (Sakellariou et al., 2013) providing further justification for the dyadic approach of this study. Whilst health care per se does not always provide solutions, the process of health care should allow understanding of the positions of everyone involved (Mol, 2008). Such understanding may be achieved through the synthesis of different voices and by making sense of the intersubjective and heteroglossic world of illness (Good, 1994). By listening and co-constructing the stories from survivors and family members, the intersubjective nature of the illness trajectory is embraced, and subsequently, knowledge is enhanced.

2 | METHODS

To explore the research question a qualitative methodology, constructivist grounded theory was selected to yield rich, in-depth descriptions and theoretical insights into patients' and family members' experiences of critical illness. Kathy Charmaz's constructivist approach provides a major redefinition of grounded theory (Higginbottom & Lauridsen, 2014). A central tenet of constructivist grounded theory, and of this research study, is to give voice to participants (Charmaz (2006). This has encouraged grounded theorists to incorporate the multiple voices, views and visions of participants in rendering their experiences. In so doing, constructivist grounded theory has moved significantly from the original intent of the classic methodology (Breckenridge, Jones, Elliott, & Nicol, 2012; Cutcliffe, 2005).

This study was undertaken within an 800 bed district general hospital (DGH) in the UK. The DGH operates as an acute hospital providing elective and emergency services to 380,000 people from rural, semi-rural and urban areas. The unit had 14 Critical Care beds. The survivor population was heterogeneous with the causation for

admission being varied (see Table 1). The age range of survivors from the sample was 42–75 years (mean 61 years). The critical care unit typically saw more emergency than elective admissions with retrospective 1-year data showing 700 admissions of which 490 were emergency in nature, accounting for 70% of all admissions to critical care.

The study was reported followed the COREQ checklist as advocated by Tong, Sainsbury, and Craig (2007).

Ethical approval for this research was applied for and granted via the Integrated Research Application System (IRAS) administered by the National Research Ethics Services as part of the National Health Service (UK). Evidence of indemnity was provided and following a formal application to the Research and Development department of the National Health Service Trust, a Letter of Access was issued.

The ethical concerns around this research centred on informed consent, anonymity, confidentiality, and harm or benefit to participants. A fundamental aspect of demonstrating respect for others is to gain their consent to actions that will impact on them. A definition of informed consent is provided by Holloway and Wheeler (2002 p. 286) as "a voluntary agreement made by participants after having been informed of the nature and the aims of the study." Thirty-six letters of invitation were sent out, of which sixteen survivors indicated that they were happy to be interviewed. Five actively responded stating they did not want to participate, of which four of them kindly detailed the reasons why they had declined. There were no responses received from the remaining fifteen patients, and it is not known why they did not respond to the invitation letter. The reasons provided by non-participants revealed a desire not to revisit a painful episode in life.

Survivors and family members, gave written consent, having had the opportunity to read relevant participant information sheets. To ensure participation was voluntary, the researcher did not make the initial approach to potential participants with formal written consent undertaken at the outset of the interview by the lead author with the ongoing option to withdraw at any point during the course of the interview. Participant information sheets made clear that the researchers were not members of the clinical team and were not known to survivor and family member participants. Purposive sampling was undertaken progressing latterly to theoretical sampling. Constant self-awareness and reflexivity were maintained throughout the interview process to minimise potential bias. This was achieved through reflective, analytical and theoretical memo writing and maintaining a reflective diary.

Data were collected via in-depth interviews, aided by prompts and probes, and recorded verbatim. Subsequently, data were analysed using constructivist grounded theory coding, namely initial coding, focused coding and theoretical coding employing the constant comparative method (Charmaz, 2014). The process of coding was undertaken by the lead author and aided by the software ATLAS ti. During initial coding, fragments of data were studied and coded, adopting participants language as an initial code where appropriate, for example, "losing control." Initial coding being an interactive and analytical process where the researcher responds to the data. It allows categorising segments of data with a short name that both summarises and accounts for the data. If analytical ideas occur during this process, memos are written so that ideas can be developed and checked against more data or literature. When initial coding was completed, the second phase involved categorising significant initial

TABLE 1 Patient participant characteristics—interviewed at clinic

Research code	Gender	Age (years)	Pseudonym	Medical diagnosis	Length of time in critical care (days)	Duration from discharge to interview (months)
P01	F	65	Annie	Flu and pneumonia	17	6
P02	M	75	Charles	#humerus, GI bleed, respiratory failure	(3 admissions) 40	9
PR03	M	59	Andy	Emergency GI surgery	10	5
P04	F	52	Linda	Pneumonia and respiratory failure	4	5
PR05	M	55	David	Pancreatitis and rupture of biliary tract	17	10
PR06	M	58	Mark	Pancreatitis	29	6
P07	F	61	Judith	GI bleed and rheumatoid arthritis	6	6
P08	M	72	Richard	Anaphylaxis	4	6
PR09	F	54	Jane	Sepsis and breast reconstruction	16	6
PR10	F	72	Sharon	Sepsis and GI surgery	24	7
P11	F	46	Joy	Crohn's disease and GI surgery	5	7
PR12	M	69	James	Emergency bowel cancer surgery and sepsis	16	11
PR13	M	42	Kevin	Necrotising fasciitis and L arm amputation	13	4
PR14	M	63	Alan	Emergency aortic aneurysm repair and cardiac arrest	10	8
PR15	M	70	Barry	Peritonitis and cardiac arrest	6	8
PR16	M	69	Harry	Biliary peritonitis	15	8

Note. P: Patient; R: relative; PR: patient+relative.

codes to a smaller number of focused codes. "Critical junctures" as an example of a focused code with several open codes scaffolding the concept and the underpinning quotations for one of the initial codes "limited follow up." The third phase was to relate the focused codes together with theoretical relationships; this process of identifying the characteristics, properties and dimensions allowed the naming of a selective or theoretical code. These theoretical codes were few in number and formed the core concepts of the account in relation to the body of data (Charmaz, 2014; Eaves, 2001; Woolf, 2014).

3 | RESULTS

This section commences by introducing the participant characteristics to give context to the findings of the research. The five focus codes of the patient and family interviews are explored in detail through the use of quotations from participants. All participant names are pseudonyms.

Tables 1–3 illustrate a variety of mono, dyadic and triadic interviews. Such an approach presented both opportunity, and methodological threat and is an acknowledged underexposed dilemma between ethics and methodology in nursing research (Norlyk, Haahr, & Hall, 2016). However, there is epistemological congruence with interviewing relational selves as Mead (cited by Bjørnholt and Farstad (2014)) views the self as "inherently relational" (p4). There is further evidence in the literature that such an approach provides rich and valid data related to both couples and individuals (Bjørnholt & Farstad, 2014). Indeed, illness is experienced, lived and understood within a particular social context, and as such, joint interviews of illness experience are supported by Sakellariou et al. (2013). It is clear from the data that perspectives of survivors and their partners do not always coincide but that they can have access to each other's life world and can perhaps start to understand it. This understanding may never be complete, but this may not deny reconciliation. It is acknowledged that interviewing participants with or without family members may have offered a different understanding and produced differing storylines; however, the aim was to explore how survivors and family members experienced critical illness and to explore life post critical illness in their own relational context. All participants made reference to family relationship.

Five focus codes were constructed from 68 initial codes identified via line by line coding of 16 patient interviews and 15 family member interviews. This process enhanced the construction, conceptualisation and abstraction of the selective code or core category. The five focus codes being

- Ambiguous loss
- Dreams and hallucinations
- Physical and cognitive sequelae
- Sense-making
- Critical junctures

3.1 | Ambiguous loss

The premise that ambiguity combined with loss can create a powerful barrier to coping and bring conflict to human relationships has been explored by Boss (2006). Ambiguous loss is a loss that occurs without closure or understanding. This can leave a person searching for answers and thus complicate recovery and reduce resilience (Boss, 2006; Oakley, 2007). Participants' spoke of "loss" in differing ways: physical, temporal and relational. Survivors, in particular, revealed a loss of identity. According to Boss (2006), persistent ambiguity defies resolution and can cause serious relational disorders. The naming of this focus code was driven by the initial codes from the data and influenced by researching literature around "loss." The following vignettes exemplify the initial codes and collectively build to the overarching focus code.

Loss of time frequently caused a disconnect with reality, particularly when associated with delirium. Andy was in hospital for three months most of which he had no recollection:

Andy "Yeah, three months, and most of it I can't remember"… "it was such a blur and the moments of sanity were not many…". (PR03)

James articulated a similar experience over a shorter period of time:

James I have no recollection at all. I know I was in the living room one minute and the next I was on a trolley or something being taken to a ward, so that two weeks, in my mind, is a complete blank to me.
Researcher Blank, yes.
James But as far as my wife's concerned it's totally different…because she was there all the time. She says that she had conversations with me I don't recall, I had conversations with Dr this and Dr that. The visual was that I didn't know where I was. (PR12)

These complex and complicated "memories" augment the notion of ambiguous loss as they mitigate against making sense of what actually happened. Sharon spoke of her prolonged stay in critical care, which included readmission. She also had very little recollection of her stay; however, her family member filled in some of the gaps:

Researcher And you said your daughter and your husband have filled in some of the gaps…
Sharon Oh yes. I wouldn't know if they hadn't told me because I wasn't here. Well, I was, but I weren't, was I?

Sharon effectively summarised the notion of "being there, but not." Being alive in the real word but living in an unreal world of dreams, delirium or simply unable to recall any memory of real events. She went on to say:

Sharon   It feels weird because you often think about, well, what happened, and you have to sort it out in your mind by what my husband and my daughter's told me. But you just think it don't seem true, you know, because you weren't there to know.   (PR10)

The notion of "being there, but not" contributed and helped construct the core category (or selective code) of "dualistic worlds" where the critical illness experience can be very different between family member and survivor. Relatives experienced acutely the emotional trauma of admission to the critical care unit (CCU) and the subsequent days were tortuous and yet the survivor frequently had little or no recollection of this period of illness.

Facing death and confronting one's own mortality frequently prompted the phrase "lucky" to be alive. This was heard recurrently but, at the same time, there was acknowledgement that life was not the same as prior to critical illness. This combined *grief and gratitude*, expressed simultaneously, was evident in several interviews.

Jenny spoke openly and honestly about the enormous pressures of living with and through critical illness as a family member and provided a further insight into the different worlds experienced by patients and family members in critical care:

Jenny   I will be honest, because I have spoken about this to David, our two kids were superb and very supportive and the eldest son said, I've got to say something to you mum, and I knew what he was

going to say, if Dad's going to die, let it happen now, don't keep putting us through… So from that side of it, I don't know if David to this day, will ever know what the family goes through, but there he is sitting there.   (PR05)

Such insights provided by family members enhanced my theoretical sensitivity to the developing theory of *dualistic worlds* experienced by survivor and family members. There is also a sense of temporality, that is being bounded by time. The temporal processes of adaptation in response to (chronic) illness are well documented by Bury (1982), Charmaz (1995) and others but not so within acute and critical illness.

3.2 | Dreams and Hallucinations

All sixteen survivors of critical illness experienced either unusual, recurring dreams and/or hallucinations or nightmares. This study adds to the growing body of knowledge around the psychological problems experienced by patients both during their stay in critical care and following discharge. Survivors commonly reported that nurses were trying to harm or kill them. When asked what the hallucinations were like Alan replied:

Alan   I was convinced she was trying to kill me and as I say, it was really, really vivid, and it went on, it wasn't just a one off thing, it went on for a couple

TABLE 2 Family member characteristics interviewed on critical care unit

Research code	Gender	Pseudonym	Relationship	Medical diagnosis of patient and demographics	Admission time within CCU
R01	F	Wendy	Partner	Bowel obstruction and sepsis, male aged 82	72 hr
R02	M	John	Son		
R03	F	Susan	Mother	Pneumonia, male aged 24	72 hr
R04	F	Penny	Partner	Respiratory failure, bronchiectasis, male aged 68	10 days
R07	F	Anthea	Mother	Status epilepticus, cardiac arrest, aspiration pneumonia, male 24	7 days

Note. R: relative.

TABLE 3 Family member characteristics

Research code	Gender	Pseudonym of family member	Relationship	Medical diagnosis of patient and demographics	Duration from discharge to interview (months)
PR03[a]	F	Lucy	Partner (Andy)	Emergency GI surgery, male aged 59	5
PR05[a]	F	Jenny	Partner (David)	Pancreatitis and rupture of biliary tract, male aged 55	10
PR06[a]	F	Hazel	Partner (Mark)	Pancreatitis, male aged 58	6
PR09[a]	M	Gary	Partner (Jane)	Sepsis and breast reconstruction, female aged 54	6
PR10 + 11[a] (PRR)	M	Arthur	Partner (Sharon)	Sepsis and GI surgery, female 72	7
	F	Gill	Daughter (Sharon)		
PR12[a]	F	Carol	Partner (James)	Emergency bowel cancer and sepsis, male, 69	11
PR13[a]	F	Sarah	Partner (Kevin)	Necrotising fasciitis and L arm amputation, male 42	4
PR15[a]	F	Emily	Partner (Barry)	Peritonitis, heart failure and diabetes, male 70	8
PR16[a]	F	Sandra	Partner (Harry)	Biliary peritonitis male 69	8

Notes. P: patient; R: relative; PR: patient+relative.
[a]Interviewed with patient at clinic.

of days, and I was convinced, because I think one day I actually hit one of the nurses because I thought she was joining in, you know. (P14)

It is hard, if not impossible, to imagine that your life is in constant danger and you are lying, probably naked, in a hospital bed, with tubes and lines "tying you down" but this is the physical reality of being critically ill and necessary for physical survival. It is perhaps not surprising that connections have been made with the experiences of survivors of war and other atrocities and that post-traumatic stress symptoms or disorder can and does develop as a consequence (Tembo, Higgins, & Parker, 2015). The combative behaviour described by Alan (above) is a daily event for most critical care nurses, and indeed ward nurses, yet it is far from normal for the individual patient concerned.

Family members were aware of their relative's paranoid delirium. Hazel (wife of Mark) spoke of the care that he received from critical care nurses and in particular how they had listened to what he was saying whilst being in a delirious state:

Hazel   A couple of the nurses came and spoke to him, you know, and they were really listening to him as if he was making a lot of sense, and I was kind of thinking, why are you, you know, why are you… he's just… but they were like really listening to him, because he accused one of the boys of putting bananas down his tube and trying to kill him, and this particular ICU lad was special, he was lovely, he did an awful lot for you, and, yeah, he's trying to kill me! He's trying to kill me! (PR06)

Hazel as a relative was acutely aware of her husband's confrontation with mortality and recalled when "… I remember one night it was 100% oxygen. There was actually nowhere to go from there." In contrast, Mark had little if any recollection of his critical care stay, his wife Hazel saying that "when I talk to him about it he doesn't really remember." Naturally, there are consequences to such information dissonance and relational change was apparent in several participants.

3.3 | Physical and cognitive sequelea

There are multiple factors that lead to physical and cognitive sequelae following critical illness, that is, a condition which is the consequence of a previous disease or injury. All survivor participants expressed their surprise and dismay at the significant muscle loss and consequential debilitation with loss of independence whilst within critical care and on transfer to the ward. The physical debilitation remained on discharge from hospital:

Jane   the first few weeks were very hard, and things are still hard now, I mean I still have the thing in the shower cubicle, because I'm just frightened, because I haven't got my balance, it's just not as good as it used to be…. (PR09)

Changes in physical appearance often came as a shock where explanations were either not forthcoming, or had been forgotten, as James explains:

James   …I found out that I'd had a tracheotomy when I first went upstairs, I went for a shave, I thought, what the bloody hell's that? In fact only two, three days ago I found out from a conversation that I actually had a tube going in there (points to neck) as well, and so forth, but I didn't know. (PR12)

This lack of knowledge mitigated against the survivor's ability to make sense of the critical illness experience and may perpetuate differences between the family member and survivor's experience as they have witnessed events first hand.

The loss of a limb is a profound and very visual physical consequence of critical illness but Kevin and his wife Sarah discussed how Kevin denied the loss of his arm:

Sarah   But you couldn't understand why we were feeding you or doing things for you, could you?
Kevin   No. My brother in law, he was feeding me and I thought that was a bit strange, but I was eating it, and my sister said… they brought me a magazine and she sat on this side and I remember her saying, this was in X ward, so I was sort of coming back to… she said, when you want to turn the page just ask, and I… turn the page? I can turn the page myself!
Sarah   But he couldn't, could he? One arm up and the other arm was not there, he wasn't comprehending that at all. (PR13)

Making sense of critical illness, from both a patient and family member perspective, developed as a focus code. Access to information, and learning to manage a roller coaster of emotions, was key initial codes.

3.4 | Sense-making

This focus code relates to the process of making sense of a changing reality, namely, encountering and making sense of the critical illness trajectory from both survivor and family member perspectives. Sense-making is the interplay of action and interpretation that is instigated whenever the current state of the world is perceived to be different from the expected state (Weick, Sutcliffe, & Obstfeld, 2005).

Access to information is central to sense-making. Participants who received (or perceived they had received) high quality and accessible information felt greatly reassured. Access to information from medical consultants was valued by Sarah (PR13) after delayed diagnosis within the primary care setting.

Sarah   But I mean once we got to ITU, to that stage, I really felt that he [Kevin] was in the best possible hands. I

did feel reassured by him, Dr X was just amazing, and he always kept me informed, he even phoned me at home, so I didn't feel out of the loop at all, ever, and every time I went in to see him they would fill me in on what had happened since I last saw him and I could phone in the morning and speak to him.   (PR13)

Sense-making by survivors occurred later in the critical illness trajectory, as would be expected. Family members were central to providing information and often filling in gaps and correcting misconceptions. Linda spoke of the fear that her ventilator was being tampered with during her stay in critical care. It was only upon recent discussion with her son that it became clear to her that indeed this was not the case. It does indicate that for some patients returning to the intensive care unit may be beneficial in making sense of their critical care experiences:

Linda   …because although you've been in there [CCU], you don't know what it looks like. I always thought that… and this, again, this only came to light a couple of weeks ago when we were having dinner one night and a chat, I imagined on a couple of occasions that some of the nurses were going behind my bed and that was a big curtain behind me with all machinery behind that, and that they were going behind there and tampering with my oxygen and everything, and it wasn't until a couple of weeks ago that my son said to me, well no, the back of your bed was actually against a window.   (P04)

Linda went on to explain why this sense-making was important for her; "…so then there's no more lying in bed at night time trying to think of it…" (P04).

The notion of bringing about closure of the critical illness trajectory is evident here, and the importance of filling in the memory gaps and making sense of the whole experience was a recurring theme in the data.

3.5 | Critical junctures

The final focus code presented in relation to patient and family member data is entitled critical junctures. The critical junctures identified by participants are:

- Admission to critical care
- Discharge from critical care
- Discharge home/primary care setting

For the majority of family members, admission to critical care was a time of overwhelming shock, learning that their relative was critically ill and may not survive. For Susan, this emotion was exacerbated by poor communication when trying to locate her son within the hospital:

Susan   "to begin with we weren't even told that he was in Intensive Care,… I phoned the ward that he'd been in and they didn't know where he was and they said they would find out and phone me back and they didn't. And so that wasn't the best way to find out because when I spoke to someone from the Intensive Care Unit they assumed that I knew X's state, so they said, well, you know that he's on a respirator and da da da, and actually I didn't, so that was stressful…the shock, well, the whole thing that day was a real shock.   (R03)

All patient participants had no recollection of their admission to critical care and were reliant on staff and family members to fill the memory gaps. In contrast, admission to CCU is highly anxiety provoking for family members as demonstrated above.

For survivors, the next significant juncture was leaving critical care. For some, this involved transfer to a high dependency care setting for others this was a direct transfer to an acute medical and surgical ward. Several patients spoke of their desire to move out of critical care only to regret the transfer later. Many spoke of the lack of staff on the wards, and facing the reality of the extent of their debilitation and associated dependence. Jane was desperate to regain some independence but this did not come to fruition:

Jane   I couldn't wait to get off ICU because of one thing, you couldn't go to the bathroom… I'm going to be allowed to go to the bathroom, because I asked, is there bathrooms there, you know. I thought in my head that I would just get out of bed, be able to walk to the bathroom. It didn't happen, obviously, it didn't happen, and I was a bit dis…[appointed] nothing to do with the staff, you know, and I'm thinking, I'm still exactly the same as I was when I was in ICU, you know, still having to use bed pans, still having to do this, they're still having to wash me. I remember not being able to do the smallest of things.   (PR09)

Jane articulated, very clearly, her profound vulnerability on the general ward. She recalled how the nurses on high dependency care had advocated on her behalf to prevent an earlier discharge to the ward. The consultant later apologised, explaining that he was under pressure for the bed.

Transitioning from critical care to the ward was challenging for Judith but for different reasons:

Judith   … there wasn't room in the ward they wanted to send me to, so I was sent to another ward and then I was sent to another ward after that, you know, it sort of… I didn't feel as though I belonged

anywhere, if you know what I mean, you know, whereas I'd felt really supported in the Unit. (P07)

The winter bed pressures were a feature at the time of data collection and may have contributed to Judith's experience. However, it is a well-documented, distressing phenomenon researched by Maben, Adams, Peccei, Murrells, and Robert (2012) seminal research "'Poppets and parcels': the links between staff experience of work and acutely ill older peoples' experience of hospital care" that patients are moved from ward to ward losing their sense of identity along the way. In addition, the transition from 1:1 care by registered nurses in ICU to general ward staffing levels is well recognised as problematic.

Both survivors and their relatives described the overwhelming desire to go home, but frequently the reality of coming home following critical illness was challenging: physically and psychological for both survivor and family member. Annie described the impact of profound weight and muscle loss in terms of attempting daily activities of living within her own home:

Annie	And so I wanted to come home, I come home and I was about 7 stone 3 when I got home, so I obviously couldn't do anything. But that made it even worse because I couldn't even get to the toilet… (P01)

David was desperate to come home too but, in hindsight, recognised he had requested discharge home too early:

David	Well, I wasn't mobile enough really, the physiotherapist, she had started to come round and got me up and that, but I wasn't really mobile enough and as I say, and the sister of the ward, because it was a Friday, and she still wanted me to stay, but I said to A that I want to come home. I mean I didn't actually discharge myself, and in the end she said, OK, you can go. But I wasn't mobile enough, and I wasn't mobile enough when I got home, because unfortunately I developed…
Jenny	DVT. (PR05)

Jane described the challenges of getting through her own front door following discharge from hospital. Despite living in a bungalow she describes access in and out as a "nightmare". Having successfully navigated the front door, she felt trapped inside her own home:

Jane	…but you've got to get from the front door, from outside into the front door, that was a… nightmare, I think I couldn't… I can't even get into the front door, I can't even get through the door, you know… I couldn't get out the front… it wasn't… like I thought I'm in, now I've got to go out, you know? It's been an experience I don't want to repeat…. (PR09)

Family members spoke of their own anxiety when their relative returned home initially:

Lucy	Well I did worry when you came home…
Andy	Oh yeah…
Lucy	…I kept listening to see if you were breathing! [laughs]. I know it's ridiculous. I'd think, God, are you breathing? (PR03)

James recalled how on return home he had to sleep in a bed in the dining room and the vulnerability and associated change in relationship with his wife:

James	I was having to sleep in the dining room, you know, and that was awful. … but where she was asleep upstairs and I was asleep downstairs, and I couldn't get out of bed because I had no legs, I have all these pipes and bags and so forth, so if she decided to have a lie in, say 9 o'clock, if I woke up at 7.00… It was awful! [laughs]. (PR12)

Whilst discharge home is an obvious goal for survivor, family member and healthcare professional, it is evident from these transcripts that there is very limited support to help negotiate the "new normal" way of life and to come to terms with the different experiences that survivor and family member have suffered. The following vignette supports the theory of dualistic worlds:

David	I think the hardest thing is accepting what will become the new normal which can be very difficult to come to terms with in the early days after ICU, in the beginning family and friends are there to support you but often slowly drift away never really understanding how traumatic a life threatening illness can change your life forever, with comments like "it's time to move on and put it all behind you" words that cut through you like a knife with their lack of empathy. (PR05)

The preceding vignettes have provided insight into this separate reality that frequently is out of reach to family members and healthcare professionals. The voice of one survivor summarises the key dimension of the two different experiences:

Jane	It has been hard to reconcile the two separate lives that we lived during that time, and neither of us will ever be able to fully comprehend what the other went through. (PR09).

4 | DISCUSSION

Maintaining the centrality of the enquiry on the survivors of critical illness and family members has provided novel understanding of the longer term well-being of survivors and the legacy of critical care. The transcripts of survivors and family members revealed a complex interrelationship of identities that have changed as a consequence of critical illness. Contemplation and confrontation with mortality of

themselves and others have been part of the pathway of survival. This provoked anxiety and worry for some, and a new zest for life for others.

Survivors experienced changing and dynamic identities as they transition and transform along the critical illness trajectory, a health trajectory being defined as an understanding of the course and causes of changes in health over time, which may allow enhancements by health professionals and through self-care (Henly, Wyman, and Findorff (2011). This study reveals an evident, and evolving, interplay between emotional, psychological and social identities accompanying a quest for normality albeit a "new normal" in many cases. There are a number of critical junctures that survivors and their families have to negotiate, making the trajectory a non-linear process. Despite the individual, and context bound stories, commonalities have been revealed through constant comparison of data. Original insights into the complexity of the survivor experience and their family's lives have been elucidated across contexts. Whilst Bury's work focused on chronic illness, there are comparable biographical disruptions identified in the findings within the critical illness context. For the critical illness survivor, this can be due, in part, to amnesia of the critical illness episode and subsequent biopsychosocial sequalae; such disruptions include the struggle to transition to a "new normal." It is clear from this study, and the wider literature, that there are critical junctures to be negotiated. The challenges of regaining muscle mass to achieve mobility and adapting to the profound fatigue commonly experienced are just two examples from this study. There are also parallels with cancer survivors. Trusson, Pilnick, and Roy's (2016) study explored the way in which women engaged with and managed the myriad of challenges, in what it is to live in the afterlife of breast cancer. The study revealed a continual process of renegotiation of identities, daily lives and futures as time passes and lives evolve. The emphasis is on moving to a "new normal" rather than returning to a "normal" pre cancer self. Whilst physical sequelae were clearly evident, the psychological and cognitive sequelae were more dominant in the empirical data. There were also consistent accounts of amnesia as a critical illness survivor indicates:

> I have no recollection of being found or my stay in X but when I was in Y I had such incredibly crystal clear dreams that I could even write down every one of them a year on. I now feel as if I was put through a tunnel scanner and came out the other end a different person. I feel my personality has changed. I am still weepy at times and always feeling down most of the time. I know I think differently. (Critical illness survivor, ICU Steps blog 2016)

The sequelea of critical illness limits the ability of patients to navigate their own biography and post critical illness life course. This can exacerbate the sense of loss which includes what Charmaz (1995 p. 660) refers to as loss of "body-self unity." For the relative, confrontation with the mortality of their family member can also create indirect biographical disruption through relationship transition and change. This may manifest itself as a changed relationship. Mark and Hazel's narratives clearly revealed identity and relationship change. Navigation out of the disrupted state is, of course, highly individual, and the findings suggest that family members may move through this phase ahead of the survivor. This can potentiate disruptions in the relationship, as changed perspectives and uneven experiences introduce a change of step or rhythm between partners and family members. Despite the contextual homogeneity of environment, disparities exist between survivors' stories and their family members stories.

This corresponds with a study of stroke survivors reported by Faircloth, Boylstein, Rittman, Young, and Gubrium (2004 p. 244) who considers that "not all physiological illness or disease will have the same impact on lives" and urges consideration of different lenses to perceive, experience and story the same phenomenon. It is therefore important to stress that these findings do not suggest a single trajectory of survival that illuminates the course of biopsychosocial well-being. This is, partially, because survivors of critical illness and family members form a very heterogeneous group that vary in chronological age, gender, ethnicity, cause of admission, social class, health status and recovery time. More significantly, dynamic and evolving constructions of well-being emanate from an inter-relational and fluid state that transcends individual, social and societal domains (Sarup, 1993;).

The importance of sense-making as a strategy of biographical repair is identified in this study, as it has been previously in the context of critical illness (Bury, 1982 and Charmaz, 1995). Whilst the literature focuses on individuals navigating from a state of disruption, it is clear from the findings that both survivors and families strive to regain homeostasis, achieve a normalised state, albeit a "new normal" (Atkins, Colville, & John, 2012 p. 133). Some survivors were forced to conform to different identities. Kevin, for example, had developed an explicit disabled identity through limb loss. Having a visibly altered body image provided immediate images of change. The term appearance can also be considered symbolically, as well as in the literal sense, since knowledge of loss can construct new self-images upon individuals (Charmaz, 1995).

There is evidence within this study and others (Stayt, 2012) that during critical illness the bodies of survivors become alien terrain to themselves. Survivors are transported into unfamiliar worlds where body and self become estranged. Stayt (2012 p. viii) refers to "My Useless Body" where the body is disassociated and invaded by technology. Both studies reveal patients experiencing emotions, and exhibiting behaviours, that are uncharacteristic and unfamiliar to them. This suggested a division between body and self which subsequently underwent a journey of transition and transformation. In parallel, Frank (1993) refers to May's work (1991) who considers the self-change of a burns survivor (albeit from a practitioner perspective):

> If the patient revives after such [life threatening] events, he must reconstruct afresh, tap new power, and appropriate patterns that help define a new

existence …a new Phoenix must emerge from the
ashes….   (Frank, 1993 p. 40)

The journey to such reconciliation of self and body can, however, be tortuous, and there may be little support along the way to reconcile grief and gratitude, as the following vignette clearly illustrates.

…unfortunately many people never get the psychological support they need and are left not knowing why they feel so bad, when they've just survived a near death experience and everyone tells them how happy they should be, if only it could be like that.
(Critical Care survivor ICU Steps blog 2016)

The findings from this study clearly illustrate that survivors within critical care can, within themselves, experience dualistic worlds that imposes flux and disassociation from the real world; this can vary from a near death experience and oscillation between delirium and normality (all survivors). It is suggested that this is an internal "dualistic world." Charmaz (1995) claims that illness (not specifically critical illness) can be such an assault upon the self that the person views his, or her, bodily changes as unreal. Kevin's reaction to limb loss is a good example of evidence of this unreality where there was no self-acknowledgement of the loss of his arm. The notion of "being there, but not" so evident within the transcripts of survivors in this study confirms further biographical disruption that is experienced by survivors in isolation, that is, not shared with family or practitioners.

4.1 | Study limitations

It is important to place this study in to context and consider its limitations. This was a single-centred study conducted in the UK. The sample consisted of white Europeans, which whilst reflective of the local population, may not reflect other regions in the UK and further afield. The study sample of survivors was further restricted, as only those who agreed to attend a follow-up clinic were recruited. Survivors who chose not to attend, or did not have the opportunity to attend, may have contributed rich and varied data. Nevertheless, discussion of the study population's experience does resonate with published research and with local, national and international audiences suggesting the concepts and theories may "travel" (Charmaz, 2014).

5 | CONCLUSION

This study has explored the adult critical illness trajectory from a dyadic perspective and focused on the longer term biopsychosocial impact of survivorship following critical illness. Understanding the survivorship perspective from differing viewpoints has provided a holistic view of the complex and fluid nature of this journey. The study identified dualistic worlds between survivor and family member, and within the survivor. These temporal events occur during and after critical illness and expose a non-linear, fluid journey towards a "new normal." Theoretical insights in to the legacy of critical care have been revealed.

6 | RELEVANCE TO CLINICAL PRACTICE

The findings of this study have implications for practice and demonstrate a clear need to provide support for survivors of critical illness and their relatives, beyond critical care both within secondary and primary care settings. The need for support is established from this study and case studies from the Netherlands (van Mol et al., 2016). Support to come to terms with critical illness was largely absent from within the population studied, with the exception of a single follow-up appointment, available to only a very small percentage of survivors. The findings also highlight the need for a rehabilitation infrastructure to support the existing national guidance, ensuring the holistic needs of survivors and their families are met (Intensive Care Society, 2015, Connolly et al., 2014; Cotton, 2013; NICE, 2009). In comparison with cancer survivors, there is very limited and often no follow-up care or support pathway for critical illness survivors and their families within the UK health systems nor globally (Iwashyna, 2010; Wright et al., 2015). Further specific recommendations for clinical practice include the need to have early conversations with survivors and their families around critical illness survivorship. This study and Govindan et al. (2014) have confirmed that issues arising from surviving critical illness are rarely addressed during hospital stays and beyond. There is a paucity of support structures and no dominant model available to be tested or compared against. Unlike in Cancer Care, there is no emerging framework of "aftercare" services being developed. The recommendation from this study is to avoid a "one size fits all" approach, given the heterogeneous nature of the population. Instead, a personalised (person centred), tailored and risk-stratified approach is proposed. Providing information around life after critical illness, both in paper and in web-based formats, together with access to self-help groups, in both physical and virtual form is sensible and achievable starting points. As a consequence of this study, a support group has been set up in conjunction with critical illness survivors and is meeting bimonthly. Access to a key worker, such as a clinical nurse specialist in critical illness, as a point of contact, is a model taken from cancer care survivorship and worthy of evaluation within the context of critical illness survivorship. Finally, knowledge of the post critical illness sequelae within primary care is acknowledged to be poor (Wong & Wickham, 2013) and further confirmation is provided in this study. There is an urgent need to provide support and co-ordinate rehabilitation for both survivor and family members within the primary care setting.

CONFLICT OF INTEREST

No conflict of interests have been declared by the authors.

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