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**Bearing witness and being bounded; the experiences of nurses in adult critical care in relation to the survivorship needs of patients and families.**

**Running Title**

*Bearing witness and being bounded.*

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#### **Conflict of interest**

No conflicts of interest have been declared by the authors.

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#### **Abstract**

##### **Aim**

To discern and understand the responses of nurses to the survivorship needs of patients and family members in adult critical care units.

##### **Background**

The critical care environment is a demanding place of work which may limit nurses to immediacy of care, such is the proximity to death and the pressure of work.

##### **Design**

A constructivist grounded theory approach with constant comparative analysis.

## **Methods**

As part of a wider study and following ethical approval, eleven critical care nurses working within a general adult critical care unit were interviewed with respect to their experiences in meeting the psychosocial needs of patients and family members. Through the process of constant comparative analysis an overarching selective code was constructed. EQUATOR guidelines for qualitative research (COREQ) applied.

## **Results**

The data illuminated a path of developing expertise permitting integration of physical, psychological and family care with technology and humanity. Gaining such proficiency is demanding and the data presented reveals the challenges that nurses experience along the way.

## **Conclusion**

The study confirms that working within a critical care environment is an emotionally charged challenge and may incur an emotional cost. Nurses can find themselves bounded by the walls of the critical care unit and experience personal and professional conflicts in their role. Nurses bear witness to the early stages of the survivorship trajectory but are limited in their support of ongoing needs.

## **Relevance to Clinical Practice**

Critical care nurses can experience personal and professional conflicts when caring for both patients and families. This can lead to moral distress and may contribute to compassion fatigue. Critical care nurses appear bounded to the delivery of physiological and technical care, in the moment, as demanded by the patient's acuity. Consequentially this limits nurses' ability to support the onward survivorship trajectory. Increased pressure and demands on critical care beds has contributed further to occupational stress in this care setting.

## **What does this paper contribute to the wider global clinical community**

- Nursing within critical care is an emotional charged encounter.
- Critical care nurses live and experience intense and overpowering moments of questioning, generating personal and professional conflicts.

- Nursing care appears bounded to the *here and now* as nurses *bear witness* to the early stages of survivorship but are unable to support the onward survivorship journey.

## Introduction

The registered nurse, working in critical care, cares for critically ill patients and their families who have been suddenly, and unexpectedly, thrust into an alien technological environment as well as confronted with a life-threatening illness. Patient acuity is progressively higher as technology blurs the boundaries between life and death (Siffleet et al, 2015). This can cause both moral distress and compassion fatigue for nurses (van Mol et al, 2015). Millions of people are admitted with critical illness around the world (Iwashyna, 2010, Lasiter et al, 2016) and the demand for critical care nurses continues to grow in a climate of an ongoing nursing shortage (Waldmann, 2018).

## Background

Maintaining the emotional literacy of practitioners is an important and contemporary theme in the wake of the Report of the Gosport Independent Panel (Parliament, House of Commons, 2018). Further, the extent of failures at Mid Staffordshire NHS Foundation Trust in the UK, investigated and reported by Robert Francis led to 290 recommendations including first and foremost that patients are at the centre of the care system (Francis, 2013). There are however challenges confronting practitioners when caring for both patients and families in critical care. There is evidence that registered nurses face a fundamental conflict both between role expectations and patient care, and between professional ideals and being a human (Stayt, 2007). This potentially leads to a disparity between nurses' everyday patient and family care practice in terms of what they *can* achieve and what they would *like* to achieve. This can contribute to both occupational stress and compassion fatigue (Siffleet, 2015). Whilst it is imperative that practitioners are enabled to meet the needs of patients and family members this should not be at the expense of their own emotional wellbeing or the development of burnout (Stayt, 2007, Agard & Maindal 2009, Agard & Lomborg 2011, Morley et al, 2017). Furthermore, registered nurses in critical care are required to develop technical expertise in safely caring for patients, while sustaining emotional literacy to demonstrate compassion with family members and patients (Ball & McElligot, 2003, Almerud et al, 2007, McGrath, 2008). Further understanding of the emotional labour of caring, and supporting both family members and patients, in critical care is needed given the evidence that registered nurses feel unprepared for these roles (Williams, 2005).

### *Context of study*

Currently there are 223 Adult Critical Care units in England; as of November 2017, there were 4,070 adult Critical Care beds with bed occupancy rates of 85% (NHS England, 2017). Survival rates have risen steadily since 1992 when only 68% of patients admitted to Critical Care survived to leave hospital; mortality rates are currently between 15-20% (van Beusekom et al, 2016). According to the Intensive Care Society (ICS), Critical Care unit size can vary from four to over fifty beds (ICS, 2015). Participants in this study were recruited from an 800-bed district general hospital (DGH) in England with fourteen Critical Care beds. This is considered to be a medium sized Critical Care unit (CCU), typical of many in England.

### **The Study**

This paper is derived from a larger constructivist grounded theory study that aimed to formulate a substantive (middle range) theory in relation to patient and family's critical illness trajectory, and to discern and understand the response of nurses to survivorship needs. The specific aim of this paper is to comprehend the responses of nurses to the survivorship needs of patients and family members in adult critical care units. The term 'survivorship' is increasingly being used within the context of critical illness. The term 'survivor' is applied in the literal sense, whilst 'survivorship' refers to the individual who is affected by the legacy of critical illness (Kean et al 2017).

### **Methods**

This qualitative study applied Charmaz's (2006) constructivist approach to grounded theory. A central tenet of constructivist grounded theory (GT), and of this research study, is to give voice to participants. Charmaz (2006) 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 GT methodology (Breckenridge et al, 2012, Cutcliffe, 2005). Given that the world of critical care is complex and involves multiple social interactions, a constructivist rather than objectivist approach is justified. Within the context of an inductive and constructivist paradigm, the researcher becomes the research instrument through which data are collected.

The study is reported followed the COREQ checklist as advocated by Tong et al (2007) (see supplementary File 1).

### **Participants**

At the time of data collection there were 71 Registered Nurses (RN) working within the critical care unit (CCU). Registered nurses who had worked within the CCU for more than one year were invited to discuss their experiences. This period of time ensured regular exposure to both critically ill patients and family members and completion of initial clinical competencies. Letters of invitation detailing the purpose of the research together with information sheets with contact details of the researcher were provided to all team leaders. This negated direct access of the researcher to the potential participant. For interested nurses, a convenient time to conduct the interview was arranged. Written consent was requested and obtained prior to interview.

The biographical details of RN participants, length of critical care experience and qualification are provided in Table1.

### **Data Collection**

Data collection was undertaken through individual in-depth semi-structured interviews by the primary author. Face-to-face interviewing, as opposed to telephone interviews, had the added advantage of being able to pick up on non-verbal cues which may enhance the well-being of participants (Birks & Mills 2011). The subjective nature of the interview and the active co-construction of data and knowledge is congruent with both the chosen paradigm and the methodology. Interviews can, and do, lay open thoughts, feelings, and emotions that create emotional discomfort and distress.

All interviews were digitally recorded with the participant's permission. Interviews took place in a private room adjacent to the critical care unit. Following interviews, field notes were recorded to capture non-verbal cues along with thoughts, insights, and reflections. Interview recordings were listened to post-interview and transcribed within three to five working days; this process was critical to becoming immersed in the data. Transcriptions were checked against audio files to verify accurate transcription and anonymised to ensure confidentiality.

## **Ethical considerations**

Ethical approval via Integrated Research Application System (IRAS) was gained prior to data collection. Participants were recruited to discuss their own experiences of working in critical care and knowledge of the critical illness trajectory. This data collection was part of a wider study also interviewing survivors and family members during and post critical illness. All participant data were stored electronically on a password protected computer. All transcripts were anonymised and coded to further protect confidentiality.

## **Data analysis and theory construction**

Constant comparison has been a standard method of analysis in constructivist grounded theory and grounded theory methods (Urquhart, 2013). The concurrent nature of data collection and analysis are distinguishing methods of grounded theory permitting the initial generation of codes (Birks & Mills 2011). The process involves comparing data with data, data with codes, and codes with categories which are also compared with new codes. The computer assisted qualitative data analysis software Atlas ti assisted with this process. This iterative method of comparison at differing conceptual levels drives “*abstract categories rich with meaning*” (Birks & Mills 2011 pg. 94). It is through this process of abstraction and creativity that the theoretical code of ‘*bearing witness and being bounded*’ was constructed (see figure 1). Literature also contributed as a conceptual lever. To limit ‘*forcing theory*’ (Glaser, 1998); (a long-standing criticism of grounded theory) strategies such as staying close to the data, keeping an open mind and writing reflexive memos to note influence and interrelationships with the data were undertaken (Charmaz, 2014). Mindful of the goal of grounded theory being the generation of a new substantive theory and not the verification of an existing theory. Critically, the focus being a mutual construction of knowledge, by the researcher and the participant, and the aptitude to develop subjective understandings of participants meaning (Fram, 2013).

## **Rigour and trustworthiness**

Several strategies were used to enhance the credibility of the study. Namely; allowing participants to guide the inquiry process through reflexive, in-depth interviews where issues raised by participants were further explored with subsequent participants. Clearly the only people with authority to comment on phenomenon are the research participants. During

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interviews, we actively sought to develop trustful, researcher-participant relationships to construct rich, meaningful co-produced data.

Recording and transcribing interviews, together with providing an audit trail of processes, was central to ensuring confirmability. Use of participants' actual words is a central tenet of the grounded theory method at all levels of coding which adds to the credibility of the study findings (Chiovitti & Piran 2003). Care was taken to ensure meaning was not distorted by the extrapolation of single words and the researcher being alert to misinterpretation. It is also worth noting, that whilst the research findings may be dependable, they are not directly reproducible as the context and data are unique.

## Results

Five focus codes (second level coding) were constructed from the data, namely personal and professional challenges, delirium assessment and management challenges to humanising critical care, family presence, crafting specialist knowledge and skill, and challenges in care transition. These are explored using quotations from participants, utilising pseudonyms. The focus codes have no particular hierarchy as they contribute equally but differently in providing insights into critical care nurses' experience of the critical illness trajectory.

### *Personal and professional challenges*

Several interviews demonstrated how nurses consistently oscillated between their personal and professional selves – this can and does, according to the literature, contribute to occupational and sometimes moral distress. This focus code adds to the growing corpus of knowledge which reveals role ambiguity and role conflict when caring for patients and families within critical care.

Gail, an experienced critical care nurse of some 11 years, spoke of how she personally identified with patients and their families experiences and situations:

*Gail: 'what I find difficult is when I've looked after patients with bowel cancer, my dad had bowel cancer, so you can relate to things, and when relatives have got small children, I've got small children, and seeing what they're going through, that's quite challenging and hard emotionally...'. (S01)*

Mary invested her personal self in the relationship with families, going beyond the perceived notion of it being '*just a job*' or being '*professional*' and illustrates a potential 'cost' of emotional investment in terms of occupational stress.

Mary: '*...we are emotional people and we are professionals ...one relative the other day, when her loved one died, she fell to the ground, and so I sat on the ground with her, ...sometimes we cannot want to... it's hard to go to that place, but it's vital for the families that we do*' (S01).

Amanda after working in critical care for 18 years appeared to be struggling with the emotional challenges of working in an environment where proximity to death is ever present. The two vignettes from Amanda reveal the emotional cost of long-term exposure to critical illness and the challenge or conundrum of advancing technology.

Amanda: '*I'm sick of death, I am sick of death, I went through a phase, about six months ago I thought, I am just so sick of death, not necessarily that we had a big patch of people dying, we're either stopping somebody dying, they're dying, ...perpetual death, isn't it? Perpetual death, and I have had enough now, I have had enough. I've got another year and I'll be happy to go.*' (S02).

Amanda seriously questioned the appropriate use of technology that may prolong life, which in her view, was of very poor quality:

'*I think medical science is absolutely fantastic, but it needs to be used properly and I don't think necessarily these days it is, and that's why we've got the problems that we've got.*' (S02)

Working within an environment caring for people, literally fighting for their life, is evidently challenging at every level for the bedside nurse.

Aricha '*...it can be stressful because of workload, it can be stressful because of your emotions, you sometimes just have horrible, horrible days that you run all day and you don't get anywhere with a patient, you don't see the patient getting any better, actually sometimes just see the person going backwards and you just feel frustrated.*' (S03).

Aricha's narrative conveyed evident stress and frustration. The transition from active, aggressive intervention with complex technical and pharmacological approaches, into palliation or death, is extremely stressful for the bedside nurse as well as the family. Aricha

went on to explain the personal cost of working in Critical Care in contrast to the ward environment:

*'When I used to work on the wards and now, I see the difference, I can't actually go home and switch off.'* (S03)

In contrast Mary who had 25 years of bedside critical care nursing experience spoke of her ability to 'switch off' having done all that she could to care for both patient and family member in the fullest sense of the word. There was one caveat:

*Mary: "I think I'm able to switch off at the end of the day, I do my best while the patient is here, I do anything, I've taken a patient to a wedding, I've done all sorts, I take them out for walks and really tried to do my best while the patient's here. But once they've gone [died].... then that's it...I don't go to patient's funerals..."* (S08)

This quotation suggests evidence of an individual strategy to ensure resilience when confronting mortality on a regular basis.

Kay, a senior nurse, articulated the daily pressures on beds with the resultant occupational stress and the continual oscillation between personal and professional selves.

*Kay: "... the emotional challenges are the pressures, we cancelled an elective yesterday, you've got the consultant having a go at you because you're cancelling someone who's got cancer... they've got three consultants coming in for a cancer surgery and that patient's obviously geared up... and then it doesn't go ahead, like it's your fault. How is that my fault, we had 12 patients yesterday, and they don't want to hear it, and I totally get they're the ones that have got to go and face the patient at the end of the day, so I understand that, but that is awful, it makes you feel bad,* (S05).

Amanda clearly articulated the depersonalisation that can occur on admission to critical care:

*Amanda: "...when somebody is lying in a bed and they can't talk and you know nothing about them, you project your own theories of who they are, and it's like when they first talk and when you just hear their voice it's so amazing, and it adds a totally different dimension to them. But I think what we put them through ...some patients equate it to having been tortured, but I don't feel that in the immediate time they're here that we truly see the psychological impact that it has on them, and I think that as a national critical care service it's sadly lacking because I think it really damages some of them so very much"* (S02)

The inference that she may be complicit in the “*torture*” is alluded to, both an awareness of the psychological effects of critical care illness, and its treatments.

*Delirium assessment and management Challenges to humanizing critical care*

The data presented here illustrates deficits in health care professionals’ knowledge of the pathology of delirium. Jane, a clinical facilitator with 11 years of critical care experience recognised that formal assessment of delirium was missing:

Jane: *“I think that they’re a very missed set of patients and actually thinking about it, even today I think maybe we had a patient that was probably a little bit hypo alert and you could almost say that, you could argue that we were misdiagnosing them as being maybe a little withdrawn or just uncomfortable about the situation, or depressed or something...”* (S09)

Interestingly, Karen who had worked within the CCU for 27 years commented on learning from her mentees on a post-registration Critical Care course.

Karen: *“I’m mentoring at the moment A and B on the course, and I’ve learnt a lot [about delirium] and I think it is something we need to work on quite a lot. I didn’t know all the sorts of delirium there are and I thought I did but I didn’t know anything.”* (S06)

Some nurses spoke of striving to humanise an environment that appeared depersonalised by technology and medicalisation, an important strategy in trying to ensure the patient’s identity:

Cathy: *“...And also I see doctors who enter the bed spaces who start taking a limb and trying to cannulate it, ...what I would normally do is just speak over the doctor and say to the person X ‘The doctor’s going to just...’ and then usually they think, oh, yeah, I should have said that, and carries on! [laughs]* (S10)

Cathy also discussed the loss of control that patients experience during critical illness and the vulnerability they experience. She emphasised the importance of continuing orientation and communication together with acknowledging the privilege of caring for dependent patients and their families.

Cathy: *“... we’re in a privileged position and we forget this because we enter the space of an individual and we can do quite intimate things with them, and I don’t just mean catheter care, but actually mouth care, eye care, fiddling around with their hair,*

*brushing it, moving limbs, you know, and I think we have to continue to explain to people what's happening around them" (S10)*

The data revealed a varied knowledge base around delirium as a challenge to humanising the critical care environment, which is consistent with the literature. They also revealed a sensitive and humane approach to patients and their families in the 'here and now' of critical care.

### *Family presence*

Providing family centred care in critical care is a central tenet of holistic care. There is increasing recognition of the importance of family members presence in critical care and there are compelling reasons that nurses should include family members in the provision of critical care. Critical illness has a significant effect on family members of the patient, with up to 50 percent experiencing significant psychological symptoms, including acute stress, post-traumatic stress, anxiety, and depression both during and after the critical illness of their relative. The consequential question is what effect this presence has on the bedside critical care nurse. This section provides registered nurses' experiences of having family members present at the bedside. Participants spoke of the challenges of caring for the patient and meeting the needs of their relatives concurrently at the bedside. Some participants reported that they were torn between caring for the patient, which they perceived to be their priority, and recognising their responsibility towards the family. Gail describes how family presence can be challenging because of this.

*Gail: "especially when the patient's very sick and you're torn between... obviously you've got your job to do as looking after the patient and then you've got relatives asking you questions all the time... But we do our best! [laughs]" (S01)*

Amanda recalled occasions where family members were perceived as delaying care and expressed her concern in the interview:

*Amanda: "...sometimes there is so much happening. And I did have a few experiences of patients deteriorating and needing to go to theatre, and I do understand that family gets anxious, and they are deteriorating there, and they see us rushing around and they know that something is wrong. But at the same time, I found a couple of times that it wasn't really in the best interest of the patient for them to be there because we were being delayed," (S02).*

This account again reveals the reality of working in situations where there is a real tension in balancing physical survival with psychological needs of patients and their families, which in turn can cause personal and professional conflict for the bedside nurse.

Kay acknowledged the challenges faced by nurses at all levels in what she describes as, “... *the goldfish bowl scenario, you're very much embroiled in it and there's no escape, and so relatives will ask probing questions, they will challenge, they will test, and so it's very challenging for even experienced nurses*”. (S05).

Kay talked about some of the challenges she had experienced with family members, who in her view, resented not having access to their relative.

*Kay: “I don't think family members can appreciate the need to carry on with activities and get the job done and how, it isn't very private, is it, and washes and care have to be done, and people resent being kept waiting outside,... that's your visiting hours so the patient should be ready, and unfortunately if they've had their bowels open five minutes before visiting that has to be sorted, ...And I find that hard to rationalise, I don't understand why people don't get it,... So I'm not against open visiting if I thought that people would be understanding of the need to do what has to be done, ...people are obstructive, because I think more and more people have had suboptimum experience... And some people are blatantly rude and abusive...”* (S05)

The language used in this vignette reveals a frustration in families not understanding that care needs to be delivered in a way that attempts to give the patient some dignity and privacy. It also conveys a note of authority and may be illustrative of the ‘work’ family members must undertake to gain access to their relative. The unit in this study had fixed visiting hours that have in recent years been further curtailed, this was also an area of contention amongst staff.

Cathy suggested that the stress of having a relative critically ill is very likely to cause people to behave differently and that health care professionals should not be quick to judge:

*Cathy: “I think we're quite quick to make a judgement but not necessarily coming up with the right analysis of an individual really, because they're in a crisis, aren't they, and the person that knocks on the door, the person that rings at the other end of the phone isn't always the person who they really are...”* (S10).

There are variable visiting practices in adult critical care, both in the UK and globally. Participants in this study generally favoured restricted visiting but with flexibility. Some of the participants who had undertaken their pre-registration nurse education outside of the UK

(S03, S04, S07 and S11) found even flexible visiting an unusual concept. They were more familiar with a more prescriptive, authoritative approach. Although Clarin (S07) commented, conversely, on the lack of visibility and involvement of family members in supporting bedside care.

Karen, however, objected quite strongly to the visiting regime in place at the time of interviews:

*Karen: "I don't like it... if this was my family member in here, I would feel very restricted to come in. I understand not being able to visit in the mornings, we have physio, we have ward rounds, we've lots of procedures going on, but surely we could have visiting from 12 'til 9 or 10 o'clock at night... I'd want it for my family so I don't like it..."* (S06).

Cathy also expressed concern over the restricted visiting hours:

*Cathy: "Currently our visiting hours are limited to two hours in the early afternoon and then four hours later on in the day. I think they should be a bit more flexible to the patients' needs actually... especially if they have delirium, because often it's their loved ones that bring them back to where they need to be"* (S10).

Amanda recognised the very alien world that family members find themselves in and how nurses can orientate them and facilitate communication between doctors and families:

*Amanda: "...it's a totally alien environment so you have to draw them into the environment and help them to... adapt to coming into it on a frequent basis. It's our role to be an adjunct between the medical staff and the relatives, and also just to make what can be an absolutely appalling episode more tolerable to deal with".* (S02)

These data illustrate critical care nurses' experiences of the benefits and challenges of family presence in adult critical care although with limited consensus.

#### *Crafting specialist knowledge and skill*

The care that patients and family members receive in the CCU requires specialised nursing knowledge and skill. This in turn requires interaction with technology, complex pharmacology and significant efforts to humanise an alien environment. This section of data illustrates the reasons that nurses work in critical care and their experience of the effects of critical illness

on both patients and families. Experienced nurses appear more able to transcend the intrusive nature of technology. There appears to be evidence of a journey that junior nurses travel to gain specialised knowledge and skill in developing the craft of person-centred critical care nursing. Such expertise can be of comfort to both survivors and family members when they reflect on their time spent in the CCU, although the contrast between care provision in CCU and the wards can be a stark contrast and cause distress to both patient and family member. This may negatively impact on their survivorship journey.

Many nurses spoke of their passion for nursing on a 1:1 basis and being able to support families in addition to providing high quality nursing care. Senior nurses also spoke of the opportunity to continue to deliver ‘hands on’ care. This was clearly important to Karen who had spent 27 years in critical care:

*Karen: “I like bedside nursing, I like the hands-on nursing that you do, and I feel that you can achieve that here ...in my position now I’d be more of a paper-based nurse and I like the hands on”. (S06)*

Similarly, Kay expounded her ‘love’ of delivering high quality nursing care.

*Kay: “I love it! [laughs] I still love it, I just like being able to do everything, and even though it’s obviously a lot more acute and a lot busier than it was, ...you’re not leaving people in wet beds, [their] mouth’s attended to, and you have the time to talk to families, to spend with the patient, it’s still a luxury”.(S05).*

Several staff contrasted this with their experience of delivering care in a ward environment. Providing holistic care was clearly important to Jane; getting to know the patient and the family provided her with a sense of satisfaction which was important to her own wellbeing:

*Jane: “... being able to provide holistic care for a patient, knowing them very well, and being able to deliver very individualised care, just being able to do everything for them, you’re part of their family and just be able to care for them and know what their face looks like at handover. That was probably very important, you know, from working on a ward that sounds very callous in a way, but it’s not, just being able to know exactly what’s going on with them, I think, is really, really important to me”. (S09)*

The more junior staff also expressed great satisfaction in being able to deliver care in a timely and individualised manner. Clarin refers to the support that she received, and this was also a recurring theme from the interviews with more junior members of staff.

Clarín: *"Since I started in Critical Care I actually go home saying, I've done it, another day, tick, like really, really big and proud, because we've got the time to actually go and do it. Whereas on the wards it was like, it's just really, really stressful, really, really stressful..."* (S07)

Some senior staff also referred to the intellectual stimulation of working in an environment that provided and supported learning opportunities:

Paco, as a newer member of the team, also saw a direct association between knowledge and confidence and, by inference, competence.

Paco: *"I think this is the biggest benefit which you can get on ITU really, the knowledge. And after, when you've got the knowledge, you can build in confidence, you can deal with the patient. We are very close with the patients, not the same like on the wards, you're more close because you spend 12 hours with the same person,*

Kay, as a senior nurse, referred to instinctive, or tacit knowledge in advocating for patients to stay longer within critical care, acknowledging the vulnerability of patients particularly at the very early stages of the survivorship journey.

Kay: *"...a lot of our patients are vulnerable and you know what they're going out to [wards]... they don't know how frequent their suction is, they might cough on the ward round and then that might be it for the day, they're totally shattered, and there's just some people, from a nursing point of view, an instinct, call it whatever, but you just know that it's all going to go wrong if they... and sometimes it's just 24 hours but it's just that little bit longer they need here...."* (S05).

The detail provided in these vignettes illustrate the complexities that bedside critical nurses must manage alongside the competing roles of supporting family members and junior staff. This is an example of the boundary of influence nurses have in supporting the survivorship journey.

#### *Challenges in care transition*

The final section discusses nurses' experience of patients and families transitioning to the next stage of their journey beyond critical care. The data presented provides some stark illustrations as to why it is a challenging juncture in the survivorship journey. Nurses within this critical care unit appear grounded in the *'here and now'* of caring for critically ill patients and their families, often with evident compassion, and struggle to foresee what lies ahead for both survivor and their family. Given the pressures on beds, and the high demand of the

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service this is not surprising, but it does have obvious consequences for the survivor and their family. Staff had limited knowledge of patients' progression beyond Critical Care and some regretted not being able to close the loop in terms of patient outcome. There appeared to be little in the way of formal mechanisms to gain feedback.

Gail expressed pleasure on gaining information about the positive outcome of survivors of critical illness, however this was via a personal, rather than professional, route.

Gail: "...it would be nice to hear how people are doing, I had another person from my church, her daughter was here, and she's updated me and it's been really nice actually to know how well she's doing..." S01.

Amanda's perspective was slightly different with the pressure of work preventing her having time to reflect on what will happen beyond the 'doors' of critical care.

Amanda: "I think we've got a mentality up here that once you're out of the doors you're onto the next anyway. But I do feel to make us more rounded practitioners, if we knew then we could improve how we treat people, especially with the juniors, I think they don't... they need to know more about the psychological point of view of what we do, and I don't think we have time to teach it". (S02)

Kay referred specifically to the word 'closure' which may be valuable to practitioners in making sense of the care they have delivered.

Kay: "...there'll be a ring on the door bell and they'll come up, and you might not even know who they are, that's the awful thing, people that have been here ages because they look so different. But sometimes even when patients have passed for us it's quite important to know what they died of, and you don't get any feedback of what the mortuary report was..., it is about closure, isn't it?" (S05)

Karen commented that seeing people in a normalised psychological state was beneficial for her "especially if they've had the psychosis while they're up here and everything, it's nice to see people when they're not in that state" (S06).

Jane also referred to a nurse-led follow up team that for a short while allowed critical care nurses to follow up their patients on the wards. This had been abandoned as the service was never funded and pressure on critical care resources and specifically nurses required the initiative to stop, yet from Jane's perspective there were benefits.

Researcher: *“Do you get to hear about how patients are doing post-discharge?”*

Jane: *“No, not at all, and that’s a real shame, I was part of the follow up team and that was a real asset..., it was positive and negative going and seeing these poor patients, no, not all poor patients, but it does seem a little bit sad that there may be... there was more that we could have done, and it definitely opened my eyes to a world outside of ICU. It isn’t enough just to survive ICU, is it?”*

The benefit of gaining closure of the critical care experience is likely to be mutual to survivors, relatives and nurses as Clarin describes:

Clarin: *“...a patient who was with us for two months, and we discharged him to the ward and he came over a couple of weeks ago... he was in a wheelchair and he stood up and that was really, wow, because obviously I mean we saw him intubated, we saw him with the trachy, getting delirious,..., and he wasn’t very good, we actually thought [he was going to die], and he was between 30 and 40, so he came in, he knew us all, every single one of us. Thank you very much for what you guys have done for me, I wouldn’t have made it without you, and that was like, wow.” (S07).*

## Discussion

The level of empathy evident in the responses of the nurses in this study illustrates the emotional weight of caring and how caring may become a burden on the personal lives of professionals. This raises questions around the emotional wellbeing of staff working in critical care where severe vulnerability and death are ever present and is echoed in van Mol et al’s (2015) systematic review of the prevalence of compassion fatigue and burnout within intensive care professionals. In addition, caring for patients with profound delirium was also seen as emotional work exacerbated by an awareness of both knowledge and practice deficits in this area, a finding substantiated by Elliott (2014). The emotional toll appears to have been exacerbated further by the increased bed pressures aggravated by current austerity measures (Roberts et al, 2012, Waldmann, 2017).

In this study and the wider literature, visiting and the presence of family members remains a much-contested area of practice with a global call to ‘*open the doors*’ of critical care units, and the suggestion that restricting visiting in critical care is neither caring, compassionate nor necessary (Giannin et al, 2014). Some form of restrictive visiting is however the dominant model in Europe, including the UK (Hunter, 2010), the Netherlands (Cappellini et al, 2014, Spreen & Schuumans, 2011), and Greece (Plakas ,2014). Evidence of cultural

variation in nursing practice is well documented in the literature (Capellinie et al, 2013). However, the impact of open visiting on the bedside adult critical care nurse requires further research here in the UK. Giannin et al (2014) accepts that such liberalisation may cause some psychological distress to staff, but no mitigation is provided.

The personal and professional challenges experienced by nurses in this study are undoubtedly a consequence of acting in the human mode of coexistence. They are present at the bedside, listening and being with both survivors of critical illness and their family members. The core of this discussion centres on the novel theoretical construction that nurses bear witness to early survivorship, in particular, the precarious nature of physiological survival. Caring for people on the boundaries of life and death. Witnessing can be understood as a personal experience, "*the direct, personal apprehending of something in the moment*" (Cody, 2001, p.289). This is extended further by Cody (2001), Naef (2006) and Webb (2016) to the concept of bearing witness or "*attesting to the veracity or authenticity of something through one's personal experience*" (Cody, 2001, p. 289). Naef (2006) argues further that such presence is a central concept in nursing. The data from this study shows that nurses chose to bear witness rather than to not bear witness but with the consequential effect of emotional disquiet for some. Further, they appear bounded by the walls of the critical care unit due to the acuity of illness and the pressure on bed availability and the associated nursing resource. This limits nurses' ability to support the onward survivorship journey of both patients and family members. Nurses show insight into the challenges that survivors and their family members may encounter but are unable to support survivorship needs beyond the walls of critical care. This is not a criticism but an observation of nurses in critical care being forced to live and remain in the moment by the pressure of clinical work. These finding echoes Govindan et al (2014) study from the USA which confirmed that issues of survivorship are rarely addressed during critical care stays.

There is however no question of the significant intersubjective support that nurses provided at the outset of the survivorship journey to patient and family member alike. There is also evidence of emotional sequelea for nurses as well as for survivors of critical illness and their relatives.

Nurses are further challenged since the boundary between life and death has been changed by modern scientific developments. Physiological limits can be stretched with techniques such as extra corporeal membrane oxygenation (ECMO) allowing the nature and trajectory of lives to be reshaped. The form and trajectory of human life no longer has clear biological limits; beginnings and endings of life are no longer fixed but fluid (Blows et al, 2012). The

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decision to place patients in acute liminal or 'in-between' spaces, delicately balanced between life and death, can be problematic for nurses to fathom.

Such moral dilemmas are just one example of personal and professional challenges experienced by nurses interviewed in this study. The data constructs a picture of oscillation between personal and professional identities when delivering and managing care. Daily confrontation with death, or the potential for death, creates a significant amount of emotional work. In common with Stayt's phenomenological study of death, empathy and self-preservation in adult critical care (Stayt, 2009), some participants exhibited a preoccupation with death, the extent to which this impacts on the individual nurses requires further study but there is evidence that such exposure generates moral distress.

Whilst the concept of moral distress remains ambiguous with multiple conceptual foundations noted by Morley et al (2017), there is consensus in the literature that moral distress negatively affects nurses and can generate a broad range of psychological and physical effects. This may then lead to compassion fatigue defined as a state of physical or psychological distress in caregivers (van Mol et al, 2015). Compassion fatigue is a recognised source of suffering among critical care nurses, but the field of study remains lacking in terms of both conceptual clarity and theoretical grounding as to how to best identify and respond to this (Webb, 2016). Therefore, to support nurses through their experiences of moral distress and consequential compassion fatigue we need further understanding of the phenomena and the contextual setting.

Despite the personal and professional challenges articulated by many participants, nurses continued to demonstrate a passion for learning and appreciated the ability to deliver holistic nursing care afforded by the (largely) 1:1 ratio of staff to patients.

### **Limitations**

It is important to place this study in context and consider its limitations. This study was conducted in a single centre 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. A multi-site study may have increased the diversity of the population.

A further limitation relates to the method of data collection used in the study, for example observation may have provided greater illumination. The choice of interviews as the data collection tool was congruent with a subjectivist epistemology and undoubtedly allowed participants to reflect deeply on their experiences. The data collected was rich in both detail

and emotion, providing poignant insights and revealing the impact of confronting mortality and the challenges to crafting person centred care within an adult critical care environment.

## **Conclusions**

This study confirms that working within a critical care environment is an emotionally charged encounter. Specifically, this study has constructed novel theory in relation to critical care nurses' experiences of supporting the survivorship journey of patients and family members. Critical care nurses experience personal and professional challenges in the delivery of increasingly complex care. Nurses can be limited to the immediacy of care in the *here and now* or *in the moment* as they bear witness to both survivors and family members experiencing profound changes in health and confrontation with mortality. The specialist knowledge and skills that nurses provide are central to physiological survival and they also provide psychological support to patients and families, but they are unable to support the onward survivorship trajectory. They are, metaphorically, bounded by the walls of critical care.

## **Relevance to Research, Practice and Policy**

There is a clear need to support critical care nurses by providing effective policy and leadership, as their role is undoubtedly challenging and there is a requirement to maintain and grow a sustainable workforce in the face of a global shortage of qualified nurses. The data from this study and the wider literature reveals significant personal and professional pressures that may be relieved through clinical supervision, debriefing and working within a culture of care. (Siffleet et al, 2015, Baggett et al, 2016). These interventions may (subject to evaluation) help limit compassion fatigue and moral distress, thereby sustaining person and family centred care. Nurses thrive in a practice environment and culture that allows them to be seen, heard and understood. Transformational leaders who demonstrate empathy and engage with staff have been shown to evoke the human emotion of feeling cared for in the workplace (Baggett et al 2016). This may help build resilience against moral distress and compassion fatigue (van Mol 2015) and ultimately prevent the development of PTSD (Mealer 2012). The recommendation is for transformational leadership within critical care settings, to facilitate connection with staff and foster a healthier practice environment.

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## Conflict of interest

No conflicts of interest have been declared by the authors.

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| Research code | Gender | Pseudonym | Years of CCU experience | Post registration education in CC | Band* |
|---------------|--------|-----------|-------------------------|-----------------------------------|-------|
| S01           | F      | Gail      | 11                      | Yes                               | 6     |
| S02           | F      | Amanda    | 18                      | Yes                               | 7     |
| S03           | F      | Aricha    | 1.5                     | No                                | 5     |
| S04           | M      | Paco      | 4                       | Yes                               | 5     |
| S05           | F      | Kay       | 24                      | Yes                               | 7     |
| S06           | F      | Karen     | 27                      | Yes                               | 6     |
| S07           | F      | Clarín    | 3                       | No                                | 5     |
| S08           | F      | Mary      | 25                      | Yes                               | 5     |
| S09           | F      | Jane      | 11                      | Yes                               | 6     |
| S10           | F      | Cathy     | 11                      | Yes                               | 6     |
| S11           | M      | Velta     | 1.5                     | No                                | 5     |

**Table 1. Registered Nurse Characteristics**

\*Band – pay banding reflecting seniority within the UK National Health Service, Band 5 equates to entry level registration.

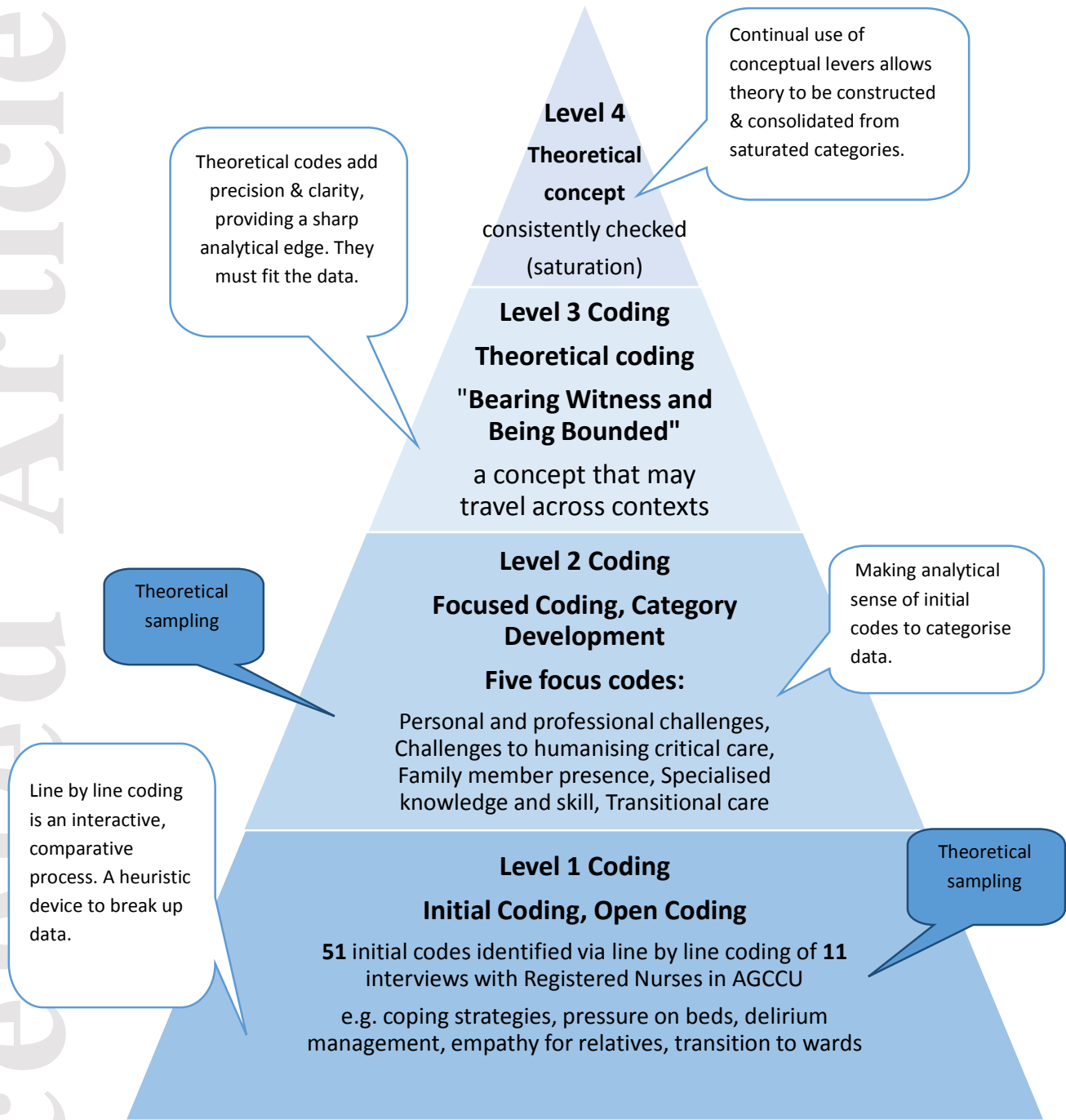


Figure 1. Progressive coding construction in relation to overarching theoretical code explaining RNs experiences of survivorship in adult critical care units (adapted from Hamm 2015).