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Living after confronting death; story telling during the recovery trajectory of intensive care unit survivors: An interpretive biographical approach

Beverley Anne Ewens
Edith Cowan University

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LIVING AFTER CONFRONTING DEATH; STORY TELLING DURING THE RECOVERY TRAJECTORY OF INTENSIVE CARE UNIT SURVIVORS: AN INTERPRETIVE BIOGRAPHICAL APPROACH

BEVERLEY ANNE EWENS

(BSc Hons, PG Diploma Critical Care, ICU Cert, DPSN, PGCE, PG Cert
Management Studies)

This thesis is presented for the degree of Doctor of Philosophy

School of Nursing and Midwifery

Faculty of Health, Engineering and Science

Edith Cowan University September 2015

ABSTRACT

Aim: To create new meaning of the experiences of intensive care survivors during early recovery and the meaning of "self" during this time. To add to the understanding of how support should be focussed for survivors during recovery.

Background: Survival from a critical event/illness and intensive care unit experience is increasing, as is associated physical and psychological complications. Complications are due to the severity of illness, the intensive care experience itself and the nature of the treatments which promote survival. If complications remain untreated increased health care service uptake and reduced quality of life can ensue. Despite the potential impact upon individuals and beleaguered health care systems, inadequate support service provision in Australia and across the world persists.

Design and participants: An interpretive biographical exploration of intensive care survivors experiences of recovery following hospital discharge. Nine participants were recruited from a single centre in metropolitan Perth, Western Australia. All participants had been ventilated for a minimum period of twenty four hours following a critical event/illness.

Methods: Data were collected from diaries, face to face interviews, memos and field notes. Participants diarised for three months commencing two months after hospital discharge. At five months following discharge participants were interviewed about the content of their diaries and the symbols and signifiers within them to create a shared meaning of their experiences. Analysis of diaries and interviews were undertaken using two frameworks. This process enabled the identification of themes throughout participants' stories and offers a unique portrait of recovery through their individual lens.

Findings: All of the participants considered their lives had irreparably changed as a result of their experience. The biographical methods provided a safe and creative way to reveal inner thoughts and feelings which may not have been revealed using other methods. This unique view through the lens of the survivor identified how unsupported by health care professionals they felt following discharge. Turmoil existed between survivors' surface and inner worlds as they struggled to conform to the constraints of what recovery should be; imposed by the biomedical model. The process of

constructing their stories enabled participants to reflect upon their experiences of recovery and bring a sense of coherence to their experiences.

Conclusion: The use of the biographical method gave the participants a voice through which they could be heard and a way to bring clarity to their experiences. The process of constructing their stories was considered important to their recovery process, and in particular in enabling reflection on how far they had traversed. Often survivors are unable to articulate their inner most thoughts and experiences for fear of being misinterpreted. The methods reported here gave them an opportunity to do so through non-verbal techniques. Analysis of diary entries may also identify maladaptation in survivors and enable interventions to be individually targeted before chronicity is established. The findings from this study may lead to a greater awareness among health care providers of the problems survivors face, and improved support services more broadly, based on frameworks more appropriate for this population.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;
- (ii) contain any material previously published or written by another person except where due reference is made in the text; or
- (iii) contain any defamatory material.

I also grant permission for the Library at Edith Cowan University to make duplicate copies of my thesis as required.

ACKNOWLEDGEMENTS

The completion of this thesis has been a challenging journey for my family and me. I have been an absent wife, mother, grandmother and friend. Without the selfless support of my husband Perry and our precious children: Lucas, Samuel and George; I would not have been able to continue and complete this journey.

To my primary supervisor Dr Joyce Hendricks, my mentor, who started this journey with me; my immeasurable thanks go to her for her unwavering, often tested, belief in me. She has been a wealth of knowledge and inspiration throughout many challenging times. To Dr Deb Sundin who has been my supervisor in the latter years for her supportive, nurturing and patient nature. As well as a content expert she is a master editor for which I am really grateful. I couldn't have completed this without you both – thank you.

Thank you to Linda King for her unwavering support and encouragement and for the endless cups of coffee and gorgeous food which have kept me going.

My thanks to Professor Di Twigg, Head of School, who has supported me in many ways; not least through the provision of study time and writing retreats which have been integral to my progress.

To all my colleagues at ECU, many of whom have been on their own PhD journeys at the same time but have always given me space when I needed it but also shared their own experiences with me.

To the Graduate Research School at ECU, especially Heather Williams and Tash Ayres who have provided endless support, encouragement and research training opportunities for me.

To Lisa Self and all my colleagues at the study site. My thanks go to them for their ongoing support and dedication to providing ICU diaries to their patients.

To my friends, who are still my friends despite my years of hibernation and absence at social events.

To my mother, sisters, family and friends in the UK who have supported me from afar.

Lastly, to my participants: Sam, Luke, Bella, Chloe, Phoebe and Olivia who have all been on their own, often difficult journeys and who I cannot thank enough. They have all been incredibly supportive of this study and have given their time selflessly. It has been an honour and a privilege to work with them all and an experience I shall always treasure.

DEDICATION

This work is dedicated to my dear friend Mary Rees who would have loved to have seen this thesis completed. I hope she is watching from afar.

RIP

STATEMENT OF CONTRIBUTION BY OTHERS

This thesis is my own composition, all sources have been acknowledged and my contribution has been clearly identified and supported as at least 50% by my co-authors. All co-authors have given their permission for me to include the publications in the thesis.

Beverley Ewens (PhD Candidate)

Dr Joyce Hendricks (Supervisor)

SUMMARY OF PUBLICATIONS

This thesis is presented in the format of a PhD with publication. The following chapters have been completed as papers for publication. To date three have been published in high impact journals and two are currently undergoing peer review. The papers are presented below:

CHAPTER TWO

Ewens, B., Hendricks, J., Sundin, D. (2015). The use, prevalence and potential benefits of a diary as a therapeutic intervention/tool to aid recovery following critical illness in ICU: a literature review. *Journal of Clinical Nursing*, 24(9-10), 1406-1425. doi: 10.1111/jocn.12736

CHAPTER THREE

Ewens, B., Hendricks, J., & Sundin, D. Biographical diarising in ICU recovery: Research practice implications.

CHAPTER FOUR

Ewens, B., Chapman, R., Tulloch, A., & Hendricks, J, M. (2013). ICU survivors' utilisation of diaries post discharge: A qualitative descriptive study. *Australian Critical Care*, 27, 28-35. doi: 10.1016/j.aucc.2013.07.001

CHAPTER FIVE

Ewens, B., Hendricks, J., & Sundin, D. Coming out of the mad house: survivors' stories of intensive care and recovery.

CHAPTER SIX

Ewens, B., Hendricks, J., Sundin, D. (2014). Never ending stories: Visual diarizing to recreate autobiographical memory of intensive care unit survivors. *Nursing in Critical Care* published online 6 October 2014. doi: 10.1111/nicc.12093

*Story makes the implicit explicit, the hidden
seen, the unformed formed and the confusing
clear*

Robert Atkinson

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CHAPTER ONE: GENERAL INTRODUCTION

*Stories are the creative conversion of life itself
into a more powerful, clearer, more
meaningful experience. They are the currency
of human contact*

Robert McKee

INTRODUCTION TO CHAPTER ONE

I came out and everyone was just talking like you're alright, we won the FA cup, you know they were all talking to me about football and I'd just lost a child (in my head). Oh you're doing alright about it they said ... People have no idea what you've been through. You're all sorted, you're all fixed up, they've no idea what's really happened or what's really going on underneath. When I first went back to work there was so much information coming in, overload, but I just couldn't remember anything. I'd come out of a meeting not really taking a bullet point, not really following everything up, not being organised and not being the person that I normally am. I just almost needed to get these pictures down about how I was thinking. I'm 38, I don't want to be a liability and I felt like a bit of a liability. I can't share what's going on in my head; every so often, I throw a few of the funny ones [delusions] out to people and tell them stuff that goes on in there but it's pretty disturbing you know (Sam's verbatim transcript).

Over the last two decades there has been an emergence of interest and associated examination of, the significant long term impact of a critical, which is, a life threatening illness and/or event and subsequent ICU admission, upon the lives of survivors and their families. This evolving body of evidence has confirmed that significant percentages of ICU survivors are frequently and profoundly affected by their ICU experience (Jones, 2013b; Woon, Dunn, & Hopkins, 2012). To be stricken with any illness/event which impacts upon the physical, psychological and social self creates a biographical disruption (Soklaridis, Cartmill, & Cassidy, 2011). A critical illness/event is no different to any other significant event and the biographical disruption to the self, can have powerful long lasting life altering consequences (Woon et al., 2012), accompanied by the grief and anguish that goes with becoming recovered. This biographical disruption was first described by Bury (1982) who coined the term in relation to those suffering a chronic illness. Biographical disruption occurs because the illness/event is unanticipated and the structures in daily lives become disordered (Bury, 1982). This disruption is so apparent that the individual cannot engage in activities which they could in their former lives (Asbring, 2001) bringing a disconnect between

the past and the present. Most people consider discharge from an ICU and consequently from hospital as a signifier of wellness and being recovered. However, for people like Sam, coming home following discharge from ICU left him in a state of disturbance and turmoil as he tried to meld people's perceptions of him being recovered with the disruption to his life and therefore his biographical account.

This disruption to self has been described as living with another self who is not known to them. Asbring (2001) asserts this juxtaposition as striving to reconcile with a pre-event identity which has been forever altered following a biographical disruption. The person experiencing this disruption has not been able to incorporate who they now are with who they once were, nor have they been provided with the means to do so. This disjunction between who Sam was and who Sam believes himself to be, creates a "space for thought" (Asbring, 2001 p. 317), which may create a positive or negative experience with long term effects on life trajectory. This 'space for thought' may lead to a reflection of life before illness and a change to life, now necessary, which were linked to that time.

The notion of this 'space for thought' has not been explored in those that have been to ICU or captured in research related to ICU. It is acknowledged that there has been significant investigation of ICU recovery per se but this is not the intent of this study. The purpose of this study was to illuminate that 'space in thought' which occurs from hospital discharge in order to focus upon the emotional recovery of ICU survivors.

Around the world intensive care units (ICU) are established to provide advanced technologies and high nurse patient ratio to care for patients with multi-system failure (Prin & Wunsch, 2012). The care of the critically ill person is highly resource intensive (Checkley et al., 2014) and it has been acknowledged that ICUs which deliver evidence based therapies can improve outcomes for the critically ill (Bauman & Hyzy, 2014). During 2010-2011 in Australia alone, over 131,000 people were considered ill enough to warrant ICU care (Australian and New Zealand Intensive Care Society, 2013). This is expected to rise with increases in population and life expectancy (Kahn & Angus, 2007). In tandem with this, the standard and capability of clinical care provided in ICUs has improved significantly over the last three decades. Patients who would not have survived a critical health event 30 years ago now survive; with the concomitant rise of survivors the potential for developing emotional sequelae leading to chronic illness increases with only a few returning to pre-morbid life-styles (Lane et al., 2013; Moran, Bristow, Solomon, Hgeorge, & Hart, 2008). The experience of an ICU admission is

clearly a stressful, potentially traumatic event for survivors and their families. The agreed definition of a traumatic event is one where individuals are confronted with unusual stress and are forced to cope with an unexpected and unfamiliar situation and which is an overwhelming, physical, emotional or social experience (American Psychiatric Association, 2013). In this instance, ICU survivors may experience a level of trauma where the individual either perceives a risk of death to themselves or witnesses this in others. The events which are categorised as having the potential to precipitate psychological distress include threatened or actual physical assault, threatened or actual sexual violence, exposure to natural or human made disasters, incarceration as a prisoner of war, severe motor vehicle accidents and being taken hostage, kidnapped or tortured (American Psychiatric Association, 2013). The nature of the traumatic event has been acknowledged as correlating with the development of anxiety, depression or PTSD, with traumas of an interpersonal nature i.e. sexual violence, being held captive are more likely to be associated with psychological complications (Kilpatrick, Resnick, Milanak, Keyes, & Friedman, 2013), as is multiple exposure to traumatic experiences (Pfeiffer & Elbert, 2011; Suliman et al., 2009). In health care it has been recognised that cancer diagnoses and treatment are also traumatic stressors with similar sequelae to recognised traumatic events (Andrykowski, Steffens, Bush, & Tucker, 2015) however, this is not recognised as such in the diagnostic criteria.

The recognition that ICU survivors face a very difficult recovery period has given rise to the exploration of many interventions (Aitken, 2010), yet the widespread application of such interventions is not apparent in practice. As a result of their experiences ICU survivors may develop anxiety related disorders during admission or after discharge, the most severe of which is Post Traumatic Stress Disorder (PTSD). The incidence of psychological complications in survivors is higher than the general population (Kowalczyk, Nestorowicz, Fijalkowska, & Kwiatosz-Muc, 2013) and is thought to be related to the ICU admission itself (O'Donnell et al., 2010), the interventions necessary to sustain life (Davydow, Desai, Needham, & Bienvenu, 2008) and delusional recall of events in ICU (Kiekkas, Theodorakopoulou, Spyrtatos, & Baltopoulos, 2010; Svenningsen et al., 2013).

Symptoms of PTSD usually become apparent within the first three months following exposure to the traumatic event but may be delayed for months or even years (American Psychiatric Association, 2013). The coping process following a traumatic event of whatever origin is recognised to commence within the first weeks

and months following the trauma (Studley & Chung, 2014). A delay in diagnosis can occur however, if all of the diagnostic criteria are met (American Psychiatric Association, 2013). Accordingly, it is possible that survivors who have been recently discharged from hospital are vulnerable during this early period when symptoms may be emerging and support should be available to them. Support during recovery and in particular during this early period is not routinely offered for survivors. This lack of support and the identification of early symptoms does nothing to halt the tide of chronicity which may develop (Lane et al., 2013) if no action is undertaken to support the sufferer in this transient time. Furthermore, it may be extrapolated that the number of individuals at risk for developing chronicity underpinned by unresolved anxiety and failure to develop a new self –identity will also rise. Unresolved anxiety may evolve to PTSD which involves psychological and pharmacological interventions the cost of which, in financial and human terms, is significant. This ‘after thought space’ or the initial three months following discharge, may be critical to recovery. However, this space has not been studied with the voices of those who have lived the experiences at the forefront.

BACKGROUND

It has become increasingly evident that significant physical and psychological morbidity befalls many survivors of a critical illness/event (Asimakopoulou & Madianos, 2014; Jones, 2013a). These life threatening incidents may have long term consequences post discharge from hospital (National Institute for Health and Care Excellence, 2009; Oeyen, Vandijck, Benoit, Annemans, & Decruyenaere, 2010). A reduction in the quality of life (Clavet, Doucette, & Trudel, 2015; Soliman et al., 2015; Stergiannis et al., 2014) and an augmented risk of physical and psychological complications as a consequence of these experiences has been reported (Hermans et al., 2014; Honselmann et al., 2015; Jones, 2013b). However, a consensual agreement related to the most appropriate management and treatment modalities which may avert or moderate the risk of psychological complications developing into chronic illnesses, does not currently exist. Identification of those at risk of psychological sequelae is not routinely undertaken in ICU patients and support for ICU survivors during recovery is not typically offered (Endacott, 2011). This is postulated to be because the appropriate timing of support and components of this are not well defined (Walsh et al., 2015). This lack of support provision determines that survivors are left alone to seek support independently or only receive non-expert support from family and friends. Thus, it is

unknown to what extent those affected by their ICU experiences are dealing with the potential implications these experiences may have on their recovery trajectory. These survivors, if not understood and supported in the three to four months following discharge, or in the “space for thought” confer a higher financial burden on already beleaguered health and social care systems (Adhikari, Fowler, Bhagwanjee, & Rubenfeld, 2010; Needham, Feldman, & Kho, 2011) in the long term.

In Australia, approximately 94% of people will survive ICU and 90% of these will survive to hospital discharge (Australian and New Zealand Intensive Care Society, 2013). The increased utilisation of ICUs and the associated complex interventions necessary for survival can only result in more vulnerable people following discharge from ICU. Notably, not all of those admitted to ICU will encounter a disruption to self which is manifested in psychological problems. But, for those who do the risk of subsequent health and social costs to themselves and their families is increased. Yet this is not being addressed and increasing number of survivors are cast adrift to embark on their recovery alone.

To compound the experience of recovery for ICU survivors, associated with the traumatic experience is peri-traumatic dissociation. Those who experience this dissociation are unable to create a coherent narrative of what happened to them and this is thought to be a predictor of the development and continuation of PTSD (Otis, Marchand, & Courtois, 2012). The process of peri-traumatic dissociation is associated with how the critical illness/event was encoded when the memory of it was formatted. It is this inability to remember the critical event which may lead to the development of PTSD (Otis et al., 2012; Werner & Griffin, 2012).

Another compelling reason for early support during recovery for survivors is the identification of acute delirium, which if manifested in ICU, yields significant consequences for ICU survivors as a result. A causal relationship has been demonstrated between delirium and significant deleterious outcomes such as psychological and physical morbidity, increased length of hospital stay and even mortality (Brummel et al., 2013; DiMartini, Dew, Kormos, McCurry, & Fontes, 2007; Girard et al., 2010). Therefore, the risk of developing psychological complications during recovery is increased for those diagnosed with acute delirium in ICU.

Acute delirium in ICU is not the only precipitating factor for psychological complications for survivors as other aetiologies have been proposed. Significant levels

of physiological disturbance are apparent in ICU patients as they experience at least one, and frequently more body system/s failure that usually require invasive therapies to promote survival. Invasive therapies often include deep sedation, ventilation and a variety of other invasive procedures, which in themselves are known to precipitate adverse physical and psychological consequences (Carr, 2007; Davydow et al., 2009; Jones et al., 2007). As a result of these interventions, and in particular sedation, survivors experience an enforced disconnection from reality and are unable to reconcile their memories with what actually happened to them. This state can endure for weeks and even months in some instances. The consequences of this twilight existence and the associated invasive therapies have been likened by some patients to a torture-like existence (Clukey, Weyant, Roberts, & Henderson, 2014). The sequelae of these experiences can include anxiety, depression and acute stress responses or the most severe consequence PTSD (Wade, Hardy, Howell, & Mythen, 2013).

Disorders such as PTSD, in the general population, as a consequence of a traumatic experience are uniquely associated with a specific psychosocial stressor (American Psychiatric Association, 2013). These stressors are not the same for all and the response to them also differs from individual to individual (Bryant et al., 2010). Acknowledged triggers for the development of PTSD are witnessing and, or involvement in terrifying events. A traumatic life experience such as this may yield a catastrophic effect on the physical and psychological integrity of the self (Kilpatrick et al., 2013). Typically ICU patients' bodies and minds also undergo overwhelming physical and emotional strain and are subjected to unfamiliar stressors in an 'alien' environment. These experiences lead one to conclude that the ICU experience is as traumatic as exposure to general trauma and raises an important question surrounding the management of survivors. In particular, to the emotional and psychological health of the person once they have left hospital and in the initial three to five months at home when they are deemed to be physically recovered and yet this is just the beginning of the recovery journey for them (Endacott, 2011).

The degree to which an individual approaches and achieves recovery has been attributed to individual beliefs, attitude and behaviour (Petersen, Heesacker, & Schwartz, 2010). This implies that the individual still retains some control over their own recovery but it is how this autonomy can be empowered which remains undefined and elusive in the current understanding of being recovered. Missing from the research related to ICU recovery is how those who share this experience of recovery

generate meanings to *being and feeling recovered* when discharged, in order to understand those experiences that have altered their lives and preconceived notion of self. During a critical illness/event and an ICU experience survivors are faced with their own mortality. Often, they struggle to understand what happened to them as they cannot construct a biographical account of it and memories are either fragmented or delusional. This creates a biographical disruption where they struggle to reconcile life as it is compared to their pre-morbid state.

This is crunch time- when the ICU survivor or care professional is faced with a *fork in the road*: one road leads to a meaningful recovery; the other to a life tainted by psychological problems which may become chronic if they go unnoticed and untreated.

Although studies have identified the ICU experience for survivors, there has been limited research which provides an insight into survivors' experiences during recovery through their individual lens. Identifying the unique perspective of survivors during recovery, support strategies can be implemented which address this disruption to the self and aid a meaningful recovery. The study acknowledges, however, the role played by researchers who have used trauma narratives and life review.

The therapeutic benefits of narrative discourse in trauma survivors have been well recognised (Chaitin, 2014; Jaeger, Lindblom, Parker-Guilbert, & Zoellner, 2014). Writing a coherent story following a traumatic experience is positively linked to improved coping and recovery (Liu, 2013) and enabling the individual to re-create their stories brings about positive change and healthier outlook of the self (Wilson, 2011). In the health care context storytelling has been explored in many areas of practice including dementia care, chronic illness management and maternal health. Storytelling in these settings has been linked to maintaining dignity (Heggestad & Slettebø, 2015), being emancipatory (Grassley & Nelms, 2009) and increasing coping (Lucius-Hoene, Thiele, Breuning, & Haug, 2012). Despite applications of storytelling elsewhere in health care it has not been widely reported in the study of ICU survivors although there has been some application with family members and their role in limiting treatment (Schenker et al., 2015). Notably, Williams (2009) (n=11) concluded that ICU survivors have difficulty in constructing a narrative of their experience because of enforced pharmacological amnesia and severity of illness and suggest that offering support with self-story construction may be beneficial to recovery. This is supported by the literature; that ICU

survivors experience partial or total memory loss of their ICU experience and the precipitating events (Chahraoui, Laurent, Bioy, & Quenot, 2015; Guttormson, 2014).

An application of storytelling; life review has also been used with positive outcomes for ICU survivors with reported positive effects upon depression, low self-esteem and future optimism in young men (Jones, Lyons, & Cunningham, 2003). Life review is a method whereby an ordered review of life events is constructed from childhood to the current time. It is postulated that life review facilitates dialogue between individuals and creates a temporary escape from reality by reflecting back upon happier times (Jones et al. 2003). The researchers concluded that the adaptation process following a critical event and an ICU experience was a multi-faceted and complex, with no one factor more influential than others in recovery. However, despite acknowledging the benefits of (Jones et al., 2003) research, using life review or storytelling for ICU survivors has not been explored further or adapted widely in practice. A gap in the knowledge remains relating to experiences of recovery following discharge from ICU despite an awareness of the significant psychological complications which may develop and the problems that can arise from lack of support. If this lack of support continues, the incidence of PTSD and risk of chronicity is likely to escalate.

The need to tell one's story of recovery arises for many reasons but the process is well reported to possess therapeutic properties (Charmaz, 1999; Moya & Arnold, 2012; Pennebaker, 1993). Significantly, the process of writing a coherent story following a trauma has been positively linked to improving the recovery and coping skills of survivors (Parker & Wampler, 2006; Pennebaker & Seagal, 1999; Wimberly, 2011). Stories always exist within a context and the nature of the story is shaped by many different factors (Blythe, Wikles, Jackson, & Halcomb, 2013). The use of guided reflection in the initial months following discharge from ICU creates a story which enables survivors to harness this 'space for thought' to provide a way forward from their trauma event or life disruption. Capturing survivors during this vulnerable period and enabling them to reflect upon their experiences and pre-morbid lives assists them to re-focus upon the here and now as they recover and to reconcile the space between who they once were and who they are now.

PURPOSE OF THE RESEARCH

The purpose of this research is to explore the recovery stories of people who have been discharged from ICU during the first five months of recovery following a critical illness or event.

THE SIGNIFICANCE OF THIS STUDY

The significance of this study is summarised below:

- 1) There is limited research on the recovery experiences of ICU survivors in the Australian context.
- 2) This study seeks to explore the experiences of ICU survivors during early recovery and to gain an understanding of their life experience.
- 3) To date, limited studies have considered the experiences of this group by identifying the significant events and key moments during their experiences of recovery a greater depth of understanding can be gleaned.
- 4) This study will add to the understanding of how survivors navigate their recovery and allow recommendations for the care, counselling and support of ICU survivors.

AIMS OF THE RESEARCH

The aims of this study are to:

- 1) To explore the experiences of ICU survivors during the early stages of recovery.
- 2) To expand the knowledge related to ICU survivors' experiences during recovery.
- 3) To develop an understanding of the ways in which meaning is attributed to the *self* during recovery following discharge from ICU.
- 4) To create new meaning regarding the recovery process.
- 5) To add to the current understanding of how support should be focussed and make recommendations for the care, counselling and support of survivors.

- 6) To explore the use of diarising as a tool to capture life disruptions in the ICU environment following a biographical disruption.

METHOD CHOSEN

An understanding of recovery following a critical illness or event following discharge from ICU, and the life stories of those recovering, presupposes that the ICU sufferer is able to use a language which is shared and understood by all. To be recovered, is an inner experience which requires a *self* that is able to reconcile with the perceptions of others and with beliefs about one's pre-morbid self, and is always described in the language of experience. The language of recovery is a complex, learned and culturally determined behaviour which reflects the medical parameters for discharge from hospitalised care, and therefore articulates an understanding of the experience of recovery which is shaped by the ways in which society understands the concept of recovery which may only be authenticated through, and by the use of language. ICU survivors use language as a tool to convey their recovery. That is, the form of language used by the ICU survivor translates their personal meanings of recovery into a textual medium of, first the signified (voice), and then the social text or narrative. This text is again translated by the reader and the listener. Language as a social medium is established within the discursive elements of the dominant culture, and therefore by creating its understanding, legitimates being recovered as a cultural and personal experience which is encountered alone, but which also encompasses pervasive meaning.

Charon (2009) asserts that the handling of encounters with others is clearly an interpretive process. The researcher defines the utterances of the ICU survivor and actively responds on the basis of these interpretations. There is an acknowledgment that all people have a past, with life experiences which form the backdrop for their lives. Hence, the personal experience and meaning of recovery from a critical illness or event arise from the past as well as the present. Moreover, meaning is changeable in context and over time and therefore must be interpreted and understood within the historical timeframe - theological, social, economic, scientific, and psychological - in which it is being shaped. This interpretation and subsequent action forms the fabric of the ICU survivor's life and the telling of their story the narrative of their life. Hence, recovery from a critical illness or event becomes the subject of understanding and interpretation. Through guided reflection, the event may drop its original air of

meaninglessness and expose an unseen chain of events, difficult to remember with significant biographical points into a transformation in the life of the ICU survivor.

It may be seen from the above discussion that an understanding of the role of being recovered would best be known through a methodology which highlights the essence of the recovery experience and the significance of this experience to the life trajectory of the person considered recovered. The interpretive process and more significantly 'interpretive biography', as described by Denzin (1989), are such methodologies. The interpretive biography illuminates an understanding of being recovered from a critical illness/event as a personal experience.

The biographical method Denzin (1989) exerts is a distinct approach to the study of the human experience where the tangible experiences of real people are formed. Denzin (1989) identified the significance of turning point moments in people's lives which are moments that leave an indelible mark on individuals' lives which are changed forever (Denzin, 1989). The intent of investigation, in this case, the recovery trajectory of those who survive ICU and the use of story in this context enabled the guided reflection and re-ordering of ICU survivor's life experiences (Suarez-Ortega, 2013) into a self-validating meaningful account (Frank, 1995) using narrative. This approach enhances an understanding of the essence of the recovery experience and the significance of this experience to the life trajectory of the ICU survivor because it provided the ICU survivor with a voice in telling their own story as it unfolded through events in time. Brown (1985:573) suggests it is through the narrative provided that the "the essential features of human existence are expressed through specific events".

Survivors' experiences of their time in ICU and their sequelae can be of an intensely personal and sensitive nature. Unique to each individual, sequelae may include persistent and vivid persecutory dream recall, acute stress responses, anxiety, depression and sexual dysfunction (Griffiths et al., 2006a; Jones & Griffiths, 2013; Roberts, Rickard, Rajbhandari, & Reynolds, 2006). Not surprisingly, survivors find the psychological complications they experience very difficult to acknowledge and share (Ewens, Hendricks, & Sundin, 2014).

It may be contended that the process of re-visiting the ICU experience, filling the memory gaps or re-defining factual memory from delusional might reduce the incidence of psychological complications (Guttormson, 2014; Knowles & Tarrier, 2009; Roulin, Hurst, & Spirig, 2007). An initiative designed to provide coherence to the ICU

experience and fill the reported memory gaps has been the implementation of patient diaries in ICU (Åkerman, Ersson, Fridlund, & Samuelson, 2013; Engström, Grip, & Hamren, 2009; Hale, Parfitt, & Rich, 2010). Diaries created in ICU for patients are commenced at varying times, constructed by nursing staff and family members and designed to be an accurate, chronological record in words and photographs of the patient's experiences and have been welcomed by survivors and their families (Egerod & Bagger, 2010; Egerod, Christensen, Schwartz-Nielsen, & Agard, 2011a; Ewens, Chapman, Tulloch, & Hendricks, 2013). Initially developed in ICUs in Sweden during the 1980s there has been sporadic implementation in the UK and areas of Europe with varying levels of success. One recent study has explored the impact of ICU diaries upon the reduction in new onset PTSD (Jones et al., 2010). This randomised controlled trial demonstrated a reduction in the incidence of new onset PTSD in a diary group compared to a control group. The optimal way of using diaries in the recovery phase is still to be established, however, and there is no standard format for their implementation, content and structure (Ewens, Hendricks, & Sundin, 2014).

Despite the acceptance of diaries by survivors and their families and emerging evidence of their potential efficacy during recovery (Jones et al., 2010) they remain an account of events and experiences through the lens of others and not through that of the survivor. The uniqueness of the methods in this study and the application of diarising in the context of recovery allowed the survivors' own voices to be heard; to let them tell their stories of recovery through their individual lens. Creating a story following a life disruption can enable survivors to share their experiences which may be beneficial to them but also offer insight to create a greater depth of understanding for others. The strengths of this study lies in the unique application of methods to provide a safe environment through which survivors could create their personal stories of ICU and recovery through their individual lens.

To enable this process participants were provided with blank journals, art materials and a disposable camera with which to construct their diaries. They were encouraged to record their recovery experiences over a period of three months in any way they wished to represent their personal story. To aid the participants in the diarising process written information was provided to offer guidance about diary construction and in essence to reiterate that the participants should approach diarising in any way they felt would illustrate their individual stories.

THE RESEARCHER'S POSITION

The issue of how the researcher positions her or himself within the research and their active involvement within it, is at the forefront of qualitative research (Band-Winterstein, Doron, & Naim, 2014). Band-Winterstein et al. (2014) assert that research is the product of the relationship between the researcher and the participants and how experiences are interpreted in relation to each other but also of the shared meaning that is created. Reflexivity ensures that the researcher reflects upon how their own values, beliefs and experiences impact on their interpretation of the data. This is a conscious process where the researcher moves from outside and inside of the phenomena under exploration (Ben-Ari & Enosh, 2011). This was critical to the research process as the researcher has an extensive history of ICU nursing in both the UK and Australia in a variety of roles which could have influenced the process. This extensive experience has contributed to the development of this project and personal passion to improve recovery for ICU survivors which created the incentive for the inception of the project.

During the 1980s and 1990s, the ICU community recognised that survivors faced significant physical and psychological complications during their recovery phase. This was apparent in practice when survivors frequently returned to ICU and relayed their experiences to the clinical staff. These experiences mirrored those still reported in the literature including physical debilitation (Fan et al., 2013), sleep disturbances (Boyko, Riding, & Jennum, 2012), vivid delirious recall (Guttormson, 2014)(refs) and anxiety and depression (Asimakopoulou & Madianos, 2014). The incidences and categories of complications relayed by survivors almost became 'the norm' as there were seldom any survivors who visited the unit, who did not report an element of physical or psychological disorder. Unit staff became well versed in framing questions to elicit information about issues survivors were facing and suggest various support mechanisms they could access.

ICU survivors were often invited to return their ICU for a visit. Those survivors who accepted the invitation to visit the unit were motivated to do so not only to visualise it from a different perspective but also to take the opportunity to discuss their experiences with those who had cared for them and who could potentially understand what they had experienced. Many survivors declined the invitation to return to the unit. The reasons for this were not explored but can only be postulated to be due to an unwillingness to re-visit their experiences.

Often it would be necessary to spend significant periods of time with survivors who visited to recount their memories of the experience and reflect on their recovery to date. It became obvious that survivors were in need of a variety of focussed support mechanisms which were unavailable at that time. This dialogue with survivors was a powerful trigger for the researcher and ignited a passion to explore potential strategies to support survivors during their recovery. In 2000, as a UK Consultant Nurse in Critical Care and shortly following the publication of the UK seminal report about critical care service redesign (Audit Commission, 1999) the researcher established a follow up clinic for survivors and their families and negotiated the right of referral with all of the hospital and primary health consultants and services. Survivors were offered clinic appointments at six weeks, six months and a year following hospital discharge; or more frequently if they wished. The purpose of this clinic was to offer survivors an opportunity to discuss their experiences, identify any issues they were encountering and receive referrals to other services as appropriate.

Many survivors who attended the clinic were troubled by their recollection of dreams and delirious memories they experienced in ICU. In particular they were troubled by the genre of these recollections which was often of a sensitive nature including sexual, violent or persecutory, far removed from their everyday life experiences. All of the survivors were unprepared that this recall could persist during their recovery and it was important for them to be reassured that this was not an infrequent event and also for others and that the recovery challenges they were experiencing were also not unusual. Often simple confirmation from those who understood what had happened to them in ICU and what they were experiencing during recovery was normal was all that was required to enable them to move forward. These discussions with survivors also afforded the opportunity to recommend they seek help if this recall became intrusive and affected their everyday lives before chronicity could establish.

Whilst conducting the study detailed in this thesis the researcher acknowledged the potential for bias in the desire to support survivors and enable them to overcome the challenges they described. A conscious effort was made to not influence participants' recovery by developing a therapeutic relationship with them thereby detracting from the significance of the methods applied. On one occasion the researcher was professionally obligated to encourage a participant to seek

psychological support following disclosure of new onset psychological distress which was agreed to by the participant.

It quickly became apparent through the study that the participants' experiences were no different from those of the survivors who attended the UK clinic over a decade earlier. This was a sobering experience that although the plight of many survivors is recognised in the literature, in Australia and in other parts of the world, support is not offered to enhance recovery and quality of life. This was the motivator to continue with this study and in particular to publish concurrently to raise awareness and actively participate in the debate surrounding ICU survivorship.

Through this research process the intent was to emphasise the plight of this overlooked population who remain inadequately provided for during the recovery period in the Australian context. The application of interpretive biographical methods may have the potential to assist in the recovery of this and other populations and should be further explored. It has been the focus of this study that survivors will have a voice through which they may be heard and stimulate debate within this neglected discourse.

ETHICAL CONSIDERATIONS

All research involving human participants must adhere to fundamental ethical. The researcher has the responsibility of ensuring that the participants do not come to any harm (National Health and Medical Research Council, 2007). This principle was always at the forefront during this study and which the researcher adhered to throughout the research process.

Ethical approval was gained from the Human Research Ethics Committees of the study site and the University where the researcher is undertaking doctoral studies. All participants gave their written consent voluntarily and possessed an autonomous reasoning capacity (Epright, 2010). Participants were approached by telephone by the researcher to consider their participation in the study when they were discharged from hospital as the researcher was cognisant that whilst still within the hospital setting the participants may have felt obliged or coerced to participate in the study by family members grateful for their survival, therefore the researcher considered the motives of the participants to take part in the study as a matter of good practice (Clandinin, 2007). Supportive written information was provided to the participants which detailed in lay terms the purpose and structure of the study. During the consent process the

researcher made it explicit to the participants that they could leave the study at any time without affecting their current or any future treatment. See appendix 1 for a copy of consent/information form.

The application of the value of beneficence in research ensures that any risk to participants is identified and minimised but above all the proposed benefits of the research justify those risks (National Health and Medical Research Council, 2007). The researcher was aware from past experiences with survivors that there was a potential that they could experience distress when recounting their stories. To that end the researcher ensured that a collation of self-referral agencies were made available to participants should this be necessary. Participants were informed at the beginning of the study about the possibility of them experiencing distress when re-visiting events and elements of their recovery process. The researcher minimised the risks to participants by the sensitive manner in which the interviews and any communication with participants were conducted.

Anonymity of participants was assured by the allocation of pseudonyms and the de-identification of their presenting conditions in this thesis and associated publications. All data were de-identified, stored in a password protected computer and a locked cupboard which were only available to the researcher. Following a period of five years following completion of the study all data will be destroyed.

STRUCTURE OF THE THESIS

This thesis does not follow a traditional format and is reported in a thesis with publication. Chapter one provides a background to and rationale for the study as well as describing the researcher's position. The following chapters and evolving thesis are underpinned by papers peer reviewed for publication. In this case, three papers are published in peer reviewed journals and the remaining two are under peer review (to date). These papers are then interwoven by introduction, discussion and conclusion chapters which link the thesis together to form a cohesive account of the research undertaken.

It was vital that this study was underpinned by a rigorous and systematic synthesis of all available and applicable evidence. Chapter two details a thorough synthesis of the literature which was undertaken, the purpose of which was to ensure that all existing literature was identified, assimilated into the project and direction/s for further research identified (Im & Chang, 2012).

The methodological processes utilised in the subsequent study are described in chapter three, in particular how this method was applied to enable the participants to recreate their stories through diarising and face to face interviews allowing triangulation of data to ensure the trustworthiness of the study. Chapter five provides a detailed analysis of the interviews undertaken and the emergent themes including the challenges participants encountered during their recovery trajectories and the revelation of turmoil as they struggled to conform to the shared understanding of being recovered.

Chapter four details a qualitative descriptive study exploring ICU survivors' utilisation of dairies following discharge from hospital. The purpose of this study was to explore ICU survivors' and family members' perceptions and utilisation of ICU dairies following discharge from hospital. In the course of the implementation process and in particular when handing over their ICU dairies to survivors, anecdotal feedback was overwhelmingly positive and prompted a further exploration of survivors' utilisation of dairies during recovery.

In chapter five the findings from the participants' interviews are detailed. Several themes emerged from the interviews which were undertaken so that a shared meaning of the dairies and their recovery trajectories could be established and shared.

The following chapter, chapter six discusses one participant's unique diary. Sam's diary stood out as unique in its scope and construction. Sam chose to represent his story through the use of digital media combined with text which enabled him to produce a diary burgeoning with imagery and rich description. The researcher considered that his diary and the depicting of turning point moments were so significant that chapter six is devoted to his story.

Chapter seven concludes the thesis and provides a discussion and conclusion which integrate key findings from this research relating to the specific aim of this study, whilst highlighting the impact and implications of the findings to education, research and clinical practice. This chapter concludes by recommending areas for consideration and future investigation.

SUMMARY OF CHAPTER

This chapter has introduced the key concepts of recovery in the ICU context and identified that survivorship from an ICU experience is increasing and potentially the numbers of survivors requiring emotional support. A brief discussion of the literature

confirmed that ICU survivorship can be at a high emotional and psychological cost for many. Survivors experience a biographical disruption of the self where they struggle to reconcile their life as it is now compared to their former selves. It is at this time that support is crucial to them to prevent complications becoming established and yet this is neither recognised nor professional support provided.

CHAPTER TO FOLLOW

The following chapter provides a critical synthesis of the literature which underpins the study and the research process undertaken. This chapter is presented as a paper which has been published in *The Journal of Clinical Nursing*.

CHAPTER TWO: THE USE, PREVALENCE AND
POTENTIAL BENEFITS OF A DIARY AS A
THERAPEUTIC INTERVENTION/TOOL TO AID
RECOVERY FOLLOWING CRITICAL ILLNESS IN ICU:
A LITERATURE REVIEW

INTRODUCTION TO CHAPTER TWO

The focus of the literature review presented here determined the use, prevalence and potential benefits of ICU diaries for survivors within an international context. The 12 step process espoused by Kable, Pich, and Maslin-Prothero (2012) structured the literature review. This review identified gaps in the literature and suggests areas for future investigation related to this field of nursing.

The purpose of this review was not to explore the interpretive biographical method but to determine the use and prevalence of diaries in the ICU context and to identify if diarising as method during the recovery trajectory of ICU survivors had been previously been undertaken or investigated. However, no studies were identified either from published or grey sources which explored diarising during recovery for ICU survivors.

The literature retrieval process did not yield a large quantity of sources, in particular with respect to original research papers. After scrutinising the retrieved sources and excluding those which did not meet the criteria, 22 original research papers were retained for critical analysis. Most significantly the review determined that although ICU diaries have been in existence for over three decades in some units with positive anecdotal feedback from survivors and their families this review highlighted the paucity of rigorous studies exploring the use, prevalence and potential benefits of diaries for ICU survivors. Congruent with the prevalence of ICU diaries within Scandinavia the majority of the published work originates from that geographical region.

The focus and approach of the studies identified aligned with the history and evolution of the implementation of diaries in ICU. The earlier studies which coincided with the emergence of ICU diaries in practice focussed on their prevalence and operational use. This period also saw beginning exploration of survivors' perceptions of their potential benefit. These early studies were predominantly descriptive in design but nevertheless presented some useful findings. Overall there were minimal sources of empirical evidence to support the use or potential benefits of ICU diaries for survivors and their families. Recent evidence has emerged which has demonstrated the potential of ICU diaries upon the reduction of new-onset PTSD for ICU survivors and

improvements in quality of life for survivors and this is anticipated to be an increasing focus over time.

Ewens, B., Hendricks, J., Sundin, D. (2014). The use, prevalence and potential benefits of a diary as a therapeutic intervention/tool to aid recovery following critical illness in ICU: a literature review. *Journal of Clinical Nursing*, 24(9-10), 1406-1425. doi: 10.1111/jocn.12736

ABSTRACT

Aims and objectives: To critically appraise the available literature and summarise the evidence related to the use, prevalence, purpose and potential therapeutic benefits of ICU diaries following survivors' discharge from hospital and identify areas for future exploration.

Background: Intensive care unit survivorship is increasing as are associated physical and psychological complications. These complications can impact on the quality of life of survivors and their families. Rehabilitation services for survivors have been sporadically implemented and lack an evidence base. Patient diaries in intensive care have been implemented in Scandinavia and Europe with the intention of filling memory gaps, enable survivors to set realistic recovery goals and cementing their experiences in reality.

Design: A review of original research papers.

Methods: The review used key terms and Boolean operators across a thirty four year time frame in: CIHAHL, Medline, Scopus, Proquest and Informit and Google Scholar for research reports pertaining to the area of enquiry. Twenty two original research papers met the inclusion criteria for this review.

Results: The review concluded that diaries are prevalent in Scandinavia and parts of Europe but not elsewhere. The implementation and ongoing use of diaries is disparate and international guidelines to clarify this have been proposed. Evidence which demonstrates the potential of diaries in the reduction of the psychological complications following intensive care has recently emerged. Results from this review will inform future research in this area.

Conclusions: Further investigation is warranted to explore the potential benefits of diaries for survivors and improve the evidence base which is currently insufficient to inform practice. The exploration of prospective diarising in the recovery period for survivors is also justified.

Relevance to clinical practice: Intensive care diaries are a cost effective intervention which may yield significant benefits to survivors.

INTRODUCTION

The incidence of intensive care unit (ICU) admissions is increasing with an associated reduction in mortality. Successful patient outcomes from ICU though, are measured in terms of survival to discharge in accordance with state and national reporting mechanisms. Thus, what is not captured in these corporate KPIs is when and if survivors return to a pre-morbid life circumstance. A significant number of survivors struggle to achieve their pre-morbid health status with an associated reduction in their quality of life, because of adverse physical and or psychological effects of a critical illness and ICU stay (Hofhuis et al., 2008; Jackson, Mitchell, & Hopkins, 2009). While the recognition of these consequences of critical illness is well documented; service provision to address them remains inadequate and lacks an evidence base. This paper discusses one intervention; the concept of diarising as a strategy for ICU survivors and the potential impact this may have following a critical illness.

BACKGROUND

Hundreds of thousands of people are admitted to ICUs annually across the world and these rates are increasing as are survival rates. Discharge from ICU is frequently misconstrued as a return to pre-morbid physical and emotional health for the survivor and both health professionals and consumers may subscribe to this misconception, perpetuating the notion that surviving critical illness and a return to pre-illness life circumstance signifies the return to a pre-morbid state. However, this is not the case for many survivors who may appear physically recovered but remain psychologically affected to varying degrees by their experience (Ewens, Hendricks, & Sundin, 2015) which may be irreversible (Unroe et al., 2010; Wilcox et al., 2013).

The result of this increase in quantity of ICU survivors who are not necessarily fully fit physically and psychologically is an ever increasing pressure on the health debt

and health care systems (Lone et al., 2013; Unroe et al., 2010). These human and health care associated costs of ICU survivorship is significant as evidenced by an increased uptake of health care services following hospital discharge (Lone et al., 2013; Williams, Leslie, Brearley, & Dobbs, 2010).

Since the recognition of significant morbidity following critical illness there has been extensive exploration of interventions which may support survivors during the recovery phase of their illness and reduce the incidence of complications (Cuthbertson et al., 2007; Dammeyer et al., 2013; Ramsay et al., 2014). These initiatives began with ICU follow up clinics which were developed in the United Kingdom (UK) and Scandinavia in the 1990s. These clinics were usually nurse-led with or without multi-professional input and with the broad aims of screening survivors for complications and providing or referring them to specialist services as necessary (Egerod et al., 2013; Griffiths, Barber, Cuthbertson, & Young, 2006b; Modrykamien, 2012). However, this model has not demonstrated tangible benefits (Cuthbertson et al., 2009) despite being well received by survivors and their families (Engström, Andersson, & Söderberg, 2008; Peterssen, Bergbom, Brodersen, & Ringdal, 2011). The standardised provision of rehabilitation initiatives which address psychological and physical domains with the intention of improving long term outcomes for survivors are still required (Jackson et al., 2012; Rubenfeld, 2007).

A diary written for patients whilst in ICU by nursing staff and families has been an area of interest for some time and is beginning to show potential as an aid to recovery in this population (Jones et al., 2010). It is apparent that ICU survivors have no, or delusional recall of their stay in ICU, both of which have been associated with psychological complications (Granja et al., 2008; Griffiths & Jones, 2007a; Kiekkas et al., 2010). Diaries commenced in ICU are designed to help fill this reported memory gap and recreate a biographical account of factual events for survivors with the aim of reducing the reported morbidity associated with memory loss or delusional recall of their experience. Evaluation of the diary initiative has been predominantly descriptive; although recent empirical evidence from a comparative study indicated that ICU diaries may reduce new-onset Post Traumatic Stress Disorder (PTSD) in comparison with a non-diary group (Jones et al., 2010). However, the potential use of diaries following discharge from hospital is largely unexplored and it has been highlighted that survivors do not actively diarise following discharge from hospital and their use of diaries i.e. reading and reflecting on events reduces over time (Ewens et al., 2013).

Nurses have been identified as the principal authors of diaries with some units actively discouraging relatives and patients to contribute (Egerod & Christensen, 2009). Elsewhere, family members and friends were actively encouraged to contribute to the living document (Engström et al., 2008; Ewens et al., 2013; Robson, 2008). Family members were also encouraged to write separate accounts which were added to the diary at a later date however, the rationale for this process was not justified (Gjengedal, Storli, Holme, & Eskerud, 2010).

DESIGN

A review and synthesis of the literature followed by a discussion on the key issues, implications for practice and recommendations for future research are presented. The design of this review is based on the structured approach described by Kable et al (2012) which enabled a rigorous search strategy and synthesis of relevant original research papers.

AIM AND OBJECTIVES

The aim of this review is to critically appraise the available literature and summarise the evidence related to the prevalence, use and potential therapeutic benefits of ICU diaries following survivors' discharge from hospital and identify areas for future exploration.

The objective of this literature review is to determine if there are potential therapeutic benefits of using a diary for ICU survivors post hospital discharge. Therefore the question is posed: What are the potential benefits of ICU diaries to survivors of a critical illness following discharge from hospital?

METHODS

This review was conducted using a 12 step approach described by (Kable et al., 2012). Adapting this framework enabled the researcher to undertake a thorough search process, refinement of papers retrieved and a critical review and synthesis of the literature which is detailed here. The literature was searched in the following databases: CINAHL, Medline, Scopus, Proquest and Informit and conducted October 2013 and updated in July 2014 for the purpose of locating published original research related to the use of patient diaries in ICU. A Google Scholar search was also conducted to identify any grey literature which may become apparent. To ensure that no studies were overlooked during this process, key literature retrieved was hand searched to

identify any other literature not previously identified. Repeated searches of several databases yielded the same sources so the researcher was confident that saturation had been achieved.

INCLUSION CRITERIA

Papers were included if they were:

- In English
 - Original research papers and or discussion papers about adult ICU diaries
 - An evaluation of the papers limited to the patient experience
 - Published between January 1980 and July 2014
 - Papers were excluded if they were commentaries, editorials, discussion papers, letters or focussed on the populations of children and young people, family members' and health care providers' perceptions of diaries and other areas of specialty care such as mental health, neonatal care and cancer care. Previously published literature reviews were also excluded as they were not primary sources of data. However, one review was identified
- Dates for the search were limited to January 1st 1980 to the present date (July 2014) to ensure all studies related to ICU diaries were identified.

Boolean operators were included in search terms:

- Intensive care unit AND diaries
- Intensive care recovery AND diaries
- Intensive care follow up
- Diaries OR journal
- Intensive care narratives OR stories
- Intensive care stories
- Diaries and recovery
- Intensive care AND memory

The search was conducted sequentially and papers were excluded which did not meet the initial inclusion criteria. The term "journal" was also used but excluded after a review of the retrieved papers. Forty six papers were consequently identified which met the inclusion criteria; of which 13 were excluded following a review of their titles and abstracts. Thirty two papers were therefore retained for an evaluation of the full text

and of those, 11 did not meet the inclusion criteria and 22 were included in this review (Fig 1). Of these 22 papers six originated from Sweden, five from Denmark, three from the United Kingdom (UK), two from Australia, one from Norway and one each from Germany, Scandinavia, Switzerland, France and Europe.

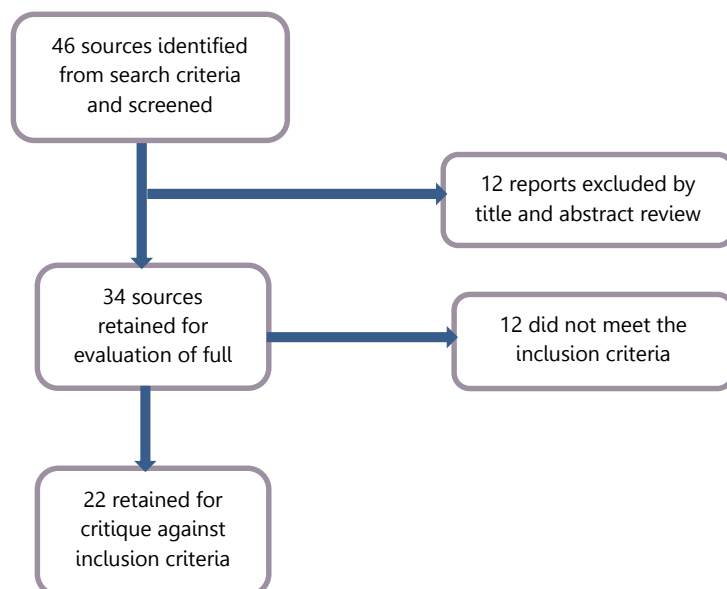


Figure 1 Flowchart of literature screening process

ASSESSMENT OF THE ARTICLES

An assessment of papers was undertaken using three recognised approaches appropriate for the types of studies included in the review. These were the Cochrane Method Guidelines for Systematic Reviews (van Tulder, Furlan, Bombadier, & Bouter, 2003); the Strengthening the Reporting of Observational Studies in Epidemiology statement (STROBE) checklist (von Elm et al., 2008) for observational studies (quantitative) and the Qualitative Research Guidelines Project (Malterud, 2001) for qualitative papers.

Table 1 Scoring categories to assess methodological quality of papers

Checklist	Quality of papers		
	High (✓✓✓)	Medium (✓✓)	Low (✓)
Cochrane Guidelines	6-11		0-5
STROBE	15-22	8-14	0-7
Guideline of qualitative research	18-25	9-17	0-8

The quality of each paper was assessed in accordance with the criteria associated with each of the approaches determined by their methodology (Table 1). A score was allocated to each paper based on the criteria and then classified as high, medium or low methodological quality, apart from the Cochrane Guidelines which only stipulates high or low classifications. Of the papers reviewed three used a quantitative methodology, 18 a qualitative and the remaining study mixed methods. Qualitative methodologies used in the studies included grounded theory but predominantly comprised descriptive or observational studies varying in methodological rigour. This lack of rigour was in relation to sample size, single site studies and trustworthiness of the data generated.

Table 2 Analysis of literature retrieved

	Author (year), Country	Study design	Sampling and sites	Data collection	Data analysis	Comments/ key findings	Limitations	Quality appraisal
1	(Nydahl, Knüick,& Egerod, 2010) Germany	Qualitative exploratory multi-centre design using mail or telephone survey from Egerod et al. (2007) to examine the extent and prevalence of diaries in adult ICUs in 2008.	All ICUs in two federal states of Germany (n=120)	Telephone interviews	Descriptive statistics	Survey replicated and translated from a previous Danish study (Egerod, Schwartz-Nielsen, Hansen, & Laerkner, 2007) and assumption made that diaries were being used in German ICUs. No units used diaries but email and telephone contacted indicated interest from nurses. Language barrier postulated as reason for the lack of implementation of diaries; nurses do not migrate from Scandinavia to Germany and most journal articles about diaries are written in English.	Potential bias from translation of the term intensive care diary to German. Not clear if two states chosen were representative of all states in Germany. Confusion with participants about terminology re: diaries. Not explicitly stated how many nurses responded.	✓✓ 15/25
2	(Gjengedal, Storli, Holme,& Eskerud 2010) Norway	Qualitative descriptive design using semi structured telephone interviews of ICU nurses experienced in the use of diaries (n=30) to explore the background, extent and application of patient diaries in ICUs.	Thirty units used diaries from a total of 70, 31 use diaries and 30 of those participated in the study	Telephone interviews	Template organising model	Survey adapted from a previous Danish study (Egerod et al., 2007). Almost half of the units used diaries and commenced between 1991 and 2000. Motivation to commence diaries from national and local pioneers, conferences and published papers. Nurses the main authors of the diaries and entries not compulsory. Nurses were main authors and only a few encouraged other professions to contribute to diaries. Family members encouraged to write their own	Translation of the data collection tool did not take into account the Norwegian nursing context.	✓✓ (17/25)

3	(Egerod, Schwartz-Nielsen, Hansen, & Lærkner, 2007) Denmark	Qualitative explorative descriptive design to describe the extent and application of patient diaries in Danish ICUs in 2006. Semi-structured telephone interviews.	Purposive sampling of one nurse in each ICU using diaries (n=19).	Telephone interviews	Template organising model	<p>diaries or on sheets to be added to the patient's diary later. Most had a diary team responsible for coordinating and QA of the process but expressed a need for national guidelines. Two purposes – therapeutic and caring. Also used in follow-up in >50% of the units.</p> <p>19 out of 49 (40%) Danish ICUs use diaries and in use from 0-17 years. Implemented because of networking, education exchange programs, and conferences and published paper. No uniformity for initiation of diaries or structure.</p> <p>No units had a plan for measuring the efficacy of diaries. Some units kept the diaries and some gave to the patients. No systematic plan for follow up with diaries. Small sample and all respondents involved with diaries – bias</p>	✓✓✓ (20/25)	
4	(Åkerman, Granberg-Axéll, Ersson, Fridlund, & Bergbom, 2010). Sweden	Descriptive explorative design – a replication study of (Egerod et al., 2007) to describe and compare the extent and application of ICU diaries in Sweden.	Nurses with experience in using diaries (n=65)	Telephone interviews	Descriptive statistics and content analysis.	<p>65 (76%) of all units used diaries most for an average of 6.9 years. Six (9.2%) handed over the diary to the patient at a follow up clinic the rest on discharge from the unit. Follow up most commonly 2 months after discharge. Majority 46 (70%) had a diary group who took responsibility for them.</p>	Different levels of experience with diaries from respondents may have biased responses. Translation from Danish to Swedish may have incurred some inaccuracies.	✓✓✓ (21/25)

5	(Egerod, Storli, & Åckerman,2011) Denmark, Norway and Sweden	Multinational comparative review of qualitative secondary data to describe and compare the emergence and evolution of ICU diaries in Scandinavia. Original data from studies in Denmark (2006). Norway (2008) and Sweden (2008).	Nurses with experience of diaries in ICU (n=114). All sites used the same translated surveys	Original data generated from telephone interviews with ICU staff.	Secondary analysis	<p>Seven (8%) had developed a questionnaire for evaluation by patients, 28 (43%) had no formal evaluation and 61 (94%) stated that the patients thought the diary was important.</p> <p>Incentive to commence diaries came from colleagues, conferences or patients and relatives.</p> <p>Diaries common practice in Sweden. Paucity of scientific evidence re: the use of diaries recognised.</p> <p>ICUs using diaries Denmark 19 (40%), Norway 31 (44%), Sweden 65 (76%).</p> <p>Initiated via a "bottom up" process and inspiration in Sweden and Norway by academic nurses.</p> <p>Local guidelines existed mostly but national guidelines identified as a need. Main objective was to ensure the patients to view their ICU experience in context which may facilitate coping.</p> <p>Initially kept for long term ventilated patients but considered may help non ventilated patients in the future.</p> <p>Different styles of content in all of the countries – factual, empathic style and a refined art of wondering.</p> <p>Photographs taken in all countries but concern over ethical considerations –</p>	Preconceptions of researchers noted in only one study. Original studies only interviewed nurses who were enthusiastic about the diary concept – potential bias.	✓✓✓ (21/25)
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6	(Bäckman, & Walther, 2001). Sweden	Observation study to explore the use of a diary in debriefing patients and relatives.	Single centre (n=51) (41 survivors and 10 relatives). Diaries given to patient or relative of deceased patients at follow up two weeks after discharge. Mailed questionnaire six months later. Six patients died before the questionnaire was sent to them but questionnaire answered by relatives.	Postal questionnaire.	Descriptive statistics (SD, means, interquartile ranges)	continued because of positive patient feedback. No follow-up in Denmark but diaries used regularly in Norway and Sweden. Conclusion diaries used as a therapeutic instrument, an act of caring, an expression of empathy or a combination. Recommend national guidelines be developed. Every patient except one and all relatives had read the diaries. 26 (13%) diaries read more than 10 times. All respondents had shared the diary with relatives and or friends and considered that it helped them to understand their time in ICU. All supported the use of photographs in diaries and none had difficulty in understanding what was written.	Single site with a small sample.	✓✓✓ (21/25)
7	Ewens, Chapman, Tulloch, & Hendricks, 2013). Australia	Qualitative descriptive study to explore survivors' and relatives perceptions and utilisation of diaries following discharge from hospital	Purposive sampling in one West Australian ICU (n=18)	Postal survey.	Thematic analysis.	Many continued reading the diaries but few wrote in them. Themes were: gaining a sense of reality, feeling cared for and maintaining a connection with loved ones through the diary.	Single centre, small sample, low response rate and non-respondents not followed up to ascertain reasons for lack of response. Demographic data not collected.	✓✓✓ (21/25)

8	(Roulin, Hurst, & Spirig, 2007). France	Explorative descriptive qualitative design to analyse the content of ICU diaries.	Convenience sample of ICU survivors' diaries (n=8). Single site 18 bed ICU in 2005.	164 diary entries by health care providers and relatives. Demographic data also collected.	Content analysis.	Four themes: sharing the story (ICU events and at home), sharing the presence (time, date and who was present), shared feelings and sharing through support. Not just a story of events but a way of communicating.	Small sample at a single site. Did not investigate survivors' opinions of diaries and assumed they would be a source of comfort to patients but not evidenced. Demographic data collected but not cross referenced against diary content.	✓✓✓ (20/25)
9	(Egerod & Christensen, 2009). Denmark	Descriptive and explorative qualitative design to analyse content of ICU diaries.	Purposive sampling of ICU survivors' diaries (n=25) at single site in 2007.	Diary entries by nurses only. Demographic data.	Interpretive; narrative and content analysis.	Three stages of the narrative identified: crisis, turning point and normalisation. Also identified description of dynamic nursing care. All were ICU survivors so plots were similar in the diaries - would have been different plots if patients had died.	Single site. Only written by nurses so do not ascertain the relatives' narratives. Data taken from pervious study – not identified.	✓✓✓ (23/25)
10	(Egerod & Christensen 2010) Denmark	Qualitative, descriptive and comparative design of secondary data previously analysed by the researchers (Egerod & Christensen, 2009) to investigate the structure and content of diaries and examine the potential contribution of charts and diaries to recovery.	Convenience sampling at a single site ICU in 2007 (n=10) same sample as (Egerod & Christensen 2009)	Interviews, hospital charts	Narrative analysis of diaries and interview of survivors.	Diaries and charts have different purposes. Nurses' notes fragmented, impersonal and technical whereas diaries coherent, personal and supportive.	Single centre small sample. Unclear why interviews were undertaken and what the finding were.	✓✓✓ (18/25)

11	(Åkerman, Ersson, Fridlund, & Samuelson, 2013) Sweden	Descriptive and exploratory cohort with mixed method design to identify the preferred content and usefulness of an ICU diary by ICU survivors.	Participants from a previous study with length of ICU stay 4-10 days (n=409) of those who had received a diary identified (n=115) had photos in diary (n=15)	Six months after ICU discharge interviews at home, hospital or by phone, postal questionnaires and ICU database (demographic data).	Inferential and descriptive statistics and content analysis.	Medical information and details of daily activities deemed important and in chronological order to construct a story. Missing photographs led to incomplete information and considered important to have an accurate record in the diary. Diaries enhanced communication. Guidelines on preferred content called for.	Previous study sample obtained source not identified. Survivors interviewed in hospital setting gave different answers to those interviewed elsewhere. Questionnaire not piloted. Limited discussion about the impact of photographs as potential tool for survivors.	✓✓✓ (21/25) ✓✓✓ (19/22)
12	(Bäckman, Orwelius, Fredriksson, & Walther, 2010) Sweden	Non randomised prospective study. Hypothesis that diaries would improve quality of life by filling in memory gaps.	Convenience sampling 2002-2004 (N=449). Component of a larger study exploring QoL (Orwelius et al., 2005) and data from one site analysed. Diary group and follow up visit (n=40) no diary group (N=224) received questionnaire not follow up visit.	SF36 mailed at 6, 12, 24 and 36 months after hospital discharge.	MANOVA	No differences in patient characteristics between the two groups but diary group were younger and greater severity of illness and stayed in hospital longer. Scored better in general health, physical component and vitality.	Non-randomised design and small sample. Unsure if the follow up visit influenced QoL or was the diaries. As the diary group was younger would be expected to score better in vitality and physical component score – so unsure if it was the diary which influenced this. Significant drop out in non-diary group, reason not clarified.	✓✓✓ (18/22)

13	(Bergbom, Svenssen, Beggren, & Kamsula, 1999) Sweden	Pilot study qualitative descriptive design to ascertain views on the content of diaries.	Convenience sample of ICU patients who were expected to stay longer than seven days and had a diary kept for them in 1996 (n=18). Ten survived and eight died. Questionnaires completed by relatives of those who died.	Postal questionnaire	Unclear	All had read their diaries; two thought the diaries did not help them, to remember their ICU experience seven said that it did. Reading the diaries they could connect with events that they remembered. Diaries gave them security and permission to rebuild their lives after illness. Had difficulty remembering what they looked like and would have liked photos in the diaries.	Unclear at what stage post ICU the questionnaires were sent. Small sample and a pilot study. Unclear methodology reduces transferability.	✓✓ (14/25)
14	(Combe, 2005) UK	Qualitative descriptive design	Convenience sample during 2001 ICU stay of >4 days, sedated and ventilated and given diaries, photographs included written by nurses and family members.	Interviews at a follow up clinic 2, 6, and 12 months post hospital discharge conducted in an interview room close to the ICU	Unclear	Photographs useful to set recovery goals. Open communication channels between survivor and relatives. Enabled them to move on from the experience.	Small study, single site, data collection tool not discussed or data analysis.	✓✓ (10/25)
15	(Egerod, Christensen, Schwartz-Nielsen, & Ågård, 2011) Denmark	Qualitative grounded theory sequel to a previous study RACHEL trial (Jones et al., 2010) to how patients and relatives use a diary in the context of the illness trajectory.	Convenience sample of ICU survivors at two ICUs during 2007 and 2008 (n=32). Diaries established practice in both units and written by nurses.	Interviews – six individual and 13 with survivors and relatives in their homes.	Constant comparative analysis	Diaries didn't re-establish memories but helped fill the gap. Diaries were an inconsistent source of information restricted by what people chose to put in them. Patients needed to construct their illness in the context of onset of illness and recovery not just the ICU experience. Photos were deemed confrontational but also a valuable source of information. Helped them to	Small sample but two centred increased the transferability of findings. Diary entries from nurses not family which may have influenced the survivors' perceptions of them.	✓✓✓ (21/25)

16	(Egerod, & Bagger, 2010). Denmark	Qualitative subsidiary study from RACHEL trial (Jones et al, 2010) Qualitative study to ascertain survivors' experiences of ICU diaries.	Purposive sample (n=4) at 11 bed surgical thoracic unit discharged within last 6-12 months and been in the RACHEL study.	Focus groups in a room near the ICU.	Inductive coding technique.	<p>appreciate how ill they had been and set realistic goals for recovery. Some gender differences identified with the diaries – females more receptive.</p> <p>Narrative process crisis, turning point and normalisation (Egerod & Christensen, 2009). Diary was not a reliable record of events, did not enhance recall but enabled them to complete their story, photos essential component, needed to know how they behaved, said and experienced, family should be able to write in the diary and different times when ready to read their diaries.</p>	<p>Single site and low participant numbers possibly due to time elapsed between RACHEL study and this study. Suboptimal numbers for a focus group could limit quality of data generated.</p> <p>Participants may not have been able to disclose details of a personal nature in a focus group leading to potential bias.</p>	✓✓ (14/25)
17	Engström,, Grip & Hamrén, 2009). Sweden	Qualitative descriptive design	Convenience sample of ICU survivors in ICU ≥ 72 hours discharged ≥ 2 months from hospital and one year since discharge from ICU	Interviews	Qualitative content analysis.	<p>Four categories: being afraid, being deeply touched, appreciating close relatives' notes, a feeling of unreality and gaining coherence.</p>	<p>Small sample, single site study. Lengthy period of time following discharge from ICU – recall may be less – potential for bias. Interviews translated from Swedish to English – open to misinterpretation. Trustworthiness of data questionable.</p>	✓✓ (14/25)

18	(Garrouste-Orgeas, Coquet, Timsit, Pochard, Lancrin, Philippart, Vesin, Bruel, Angeli, Cousin, Carlet, & Misset 2012). France	Mixed methods prospective single centre study with an intervention period between two control periods pre and post diary during 2009.	Convenience sample of ICU patients admitted for at least four days. Pre diary group (n=48), diary period (n=49) and post diary period (n=46). Diary maintained by ICU staff and family members – no photos whilst in ICU only of equipment.	On discharge from ICU relative completed HADS, Critical Care Family Needs Inventory. HADS and PDEQ. Three months after discharge survivors and relatives completed HADS and PDEQ. After 12 months survivors and relatives completed IES.	Descriptive statistics and qualitative analysis of diaries	Less symptoms of PTS in post diary group than pre-diary group – most prevalent in relatives than survivors at 12 months. Reduction in avoidance in survivors only category which reached statistical significance.	Unclear methods section describing the purpose of the intervention group and when intervention occurred. Cannot be sure that the diary was causal factor in reduction of PTS in relatives at 12 months – may have just been time factor. Interviewers may not have been blinded during interviews introducing potential bias.	✓✓✓ (17/22)
19	(Jones, Bäckman, Capuzzo, Egerod, Flaatten, Granja, Rylander, & Griffiths, 2010). Europe	RCT to examine if the use of diaries in ICU survivors during the convalescence period in reducing new onset PTSD.	Randomised sample in 6 ICUs (n=352) ventilated for >24 hours. LoS in ICU >72 hours. No history of psychotic disease, PTSD or inability to give consent.	All had diaries and completed ICUMT at 1-2 weeks post discharge and PTSS-14 prior to randomisation. Randomised at one month. Intervention	Non parametric statistics	5% of intervention group had PTSD compared to 13.1% of the control group (P=0.02)	Discussion of diary with participants could have biased the results. Unable to blind the investigators also leading to potential bias.	✓✓✓ (7/11)

20	(Knowles & Tarrier, 2009). UK	Pragmatic RCT to evaluate the effectiveness of an ICU diary on affective symptomology at 1 month post ICU discharge.	Randomised sample in 1 ICU comparing diary and verbal feedback group with a control non diary group (n=18) and a diary group (n=18). In ICU for >48 hours with no existing psychological morbidity or suicidal ideation.	group had the diary when they wanted and the control after completed PTSS-14 at 3 months. Completed HADS at one month post discharge and given their diary then repeated HADS 3 weeks later.	Parametric and non-parametric testing.	Less anxiety and depression in the intervention group than the control group.	?long enough period of time lapsed for assessment when PTSD can develop a year after trauma. Not clear if the discussion with the ICU nurse in the intervention group or the diaries influenced results. Single centre small numbers. Does not state how sample size was calculated.	✓✓✓ (19/22)
21	(Robson, 2008). UK	Observational. To ascertain diary content, how often they had read the diary and opinions about them.	Purposive sample (n=20) in single site. Diaries been in use there for two years and nurses, families and occasionally medical staff and physiotherapists made entries. Photographs were included and guidelines on	Postal questionnaire and interviews up to two years post discharge.	Unclear	Sixteen (80%) considered the time they received the diary was appropriate. All considered diaries helped them make sense of the experience and helped them understand how ill they had been. All had read the diaries after discharge. Seventeen (85%) felt that the diary should have been continued after discharge from ICU in HDU and wards. Eleven (55%) found it distressing to see	Single centre small sample. Questionnaire not validated or piloted. Composition of photographs not detailed. Eight (40%) had been discharged for 18-24 months who could have had reduced recall of feelings about the	✓✓ (16/25)

			diary composition and photographs developed.			the diary for the first time. Two participants were unhappy with the content from friends. Suggestions for improvement: a happy ending photo, prevent gaps in content and continue throughout hospital stay.	diary. Unclear if reading the diary reduced over time. Significant differences in scope of diaries as well as reported gaps in content could bias findings.	
22	(Ewens, Hendricks, & Sundin, 2014). Australia	Qualitative interpretive biographical account of one participant's visual diary.	Purposive sampling	Visual diaries and interviews at two and five months post ICU discharge.	Interpretive analysis of interviews and diaries	Was unprepared for severity of debilitation following critical illness. Still had recollection of delusional dreams whilst in ICU. Ensured that good came from his experience in ICU. Considered visual diary aided his recovery.	Single site small study	✓✓✓ (22/25)

RESULTS

USE OF DIARIES IN ICU BY SURVIVORS AND FAMILIES

The intended use and purpose of diaries is varied with similarities across studies. The intended use of diaries was to fill the memory gap which survivors reported however; with their evolution other potential benefits have emerged. There is evidence to suggest that reading their diaries enabled survivors to gain coherence and understanding of their experience (Backman, Orwelius, Sjoberg, Fredrikson, & Walther, 2010; Combe, 2005; Engström et al., 2008) as well as linking visits from family and friends recorded in their diaries with their memories (Engström et al., 2008).

The use of diaries following discharge from hospital by survivors and their families varied across studies but was predominantly high (Backman et al., 2010; Bergbom, Svensson, Berggren, & Kamsula, 1999; Jones et al., 2010) with reports that some survivors repeatedly read their diary searching out new information (Backman & Walther, 2001). Most survivors were prepared to share the content of their diaries with family and friends (Backman & Walther, 2001). It is acknowledged that reading diaries for the first time can be distressing for survivors (Ewens et al., 2013) and one survivor addressed this by reading his diary from the end to the beginning (Engström et al., 2008). In one study survivors and their families and carers continued to diarise whilst on the ward (Backman & Walther, 2001) and at home (Ewens et al., 2013) although this was not prevalent across studies and survivors in one study considered they would have liked the opportunity to do this (Robson, 2008).

Family members considered that writing in the diaries enabled them to express their feelings to loved ones whilst they were in ICU, to share experiences, connect them with normal family events, express emotions and maintain a connection with them (Ewens et al., 2013; Roulin et al., 2007). These often poignant entries also enabled survivors to understand how difficult this time had been for their families (Robson, 2008) and how much they were loved and cared for in ICU and how many people were urging them to recover (Ewens et al., 2013; Ewens et al., 2014).

Any potential benefits to nurses and practice development through the use of diaries has not been extensively explored but in one study nurses reviewed the diaries and based improvements in their care on the content (Åkerman, Granberg-Axéll, Ersson, Fridlund, & Bergbom, 2010).

During their recovery phase survivors may be unable to talk about and share their experiences with their friends and families. In this instance diaries have been used as a conduit for these discussions to occur between survivors and their families and friends (Combe, 2005; Egerod et al., 2011a; Ewens et al., 2013).

PREVALENCE OF DIARIES IN ICU

Diaries in ICU were developed in the 1990s in Scandinavia. Their use is now predominantly within Sweden but they are also in use in Denmark, Norway (Egerod, Storli, & Åkerman, 2011b), Switzerland and the UK (Egerod et al., 2011b) although implementation has been sporadic in other parts of Europe and the rest of the world (Ewens et al., 2013; Nydahl, Knuck, & Egerod, 2010).

Feedback from patients and their families was identified as a significant driver in the implementation or ongoing use of patient diaries (Åkerman et al., 2010). In many instances but not all, the operational aspects of ICU diaries were based on locally developed guidelines (Robson, 2008). Importantly, the development of national or international guidelines for diary use has been called for (Egerod et al., 2011b; Ewens et al., 2013; Gjengedal et al., 2010). Inconsistencies exist regarding the optimum time to commence diaries; most commonly though this occurs at day three when ventilation is considered to be ongoing (Egerod et al., 2011b; Gjengedal et al., 2010). However, this criterion extended at some sites to include patients ventilated for a minimum of 24 hours and those receiving non-invasive ventilation with an associated shorter length of ICU stay (Egerod et al., 2011b). Investigation into the outcomes of diarising for patients who receive non-invasive ventilation only is yet to be conducted.

The main purpose of ICU diaries for survivors was identified as assisting to fill the perceived memory gaps, cementing their experiences in reality and helping them to understand the severity of their illness and to set realistic recovery goals (Combe, 2005; Egerod & Bagger, 2010). From the perspective of the survivors the diaries were considered an act of support and caring by nursing staff in addition to their usual duties (Ewens et al., 2013).

In all studies the diaries were deemed the survivors' personal property and not a component of hospital records. Diaries were returned to survivors or relatives of the deceased at various time points; either on discharge from ICU (Åkerman et al., 2010; Ewens et al., 2013; Robson, 2008) or at a follow up visit following hospital discharge if this was available (Backman & Walther, 2001; Combe, 2005; Gjengedal et al., 2010).

There was no consensus in the literature about the optimum point at which to return diaries to survivors or family members and this process appeared to be based upon custom and practice. If units conducted follow up clinics the diaries were often returned at that point and used as a springboard for discussion about the ICU experience (Backman et al., 2010; Combe, 2005).

CONTENT AND STRUCTURE OF DIARIES

All studies undertaken to explore the preferred content and structure of diaries were from Scandinavia and Switzerland (Åkerman et al., 2013; Egerod & Christensen, 2009, 2011; Roulin et al., 2007). Survivors acknowledged the supportive nature of diaries, not merely as an information giving exercise but because of the specific content and the way this was expressed (Roulin et al., 2007). In two studies diaries were viewed as both a means of maintaining a link with loved ones whilst they were unable to communicate and facilitating the construction of a coherent story of the ICU experience for the survivor (Roulin et al., 2007). Content analysis of a small sample of survivors' diaries demonstrated similarities in the structure of the stories portrayed in the diaries from crisis, turning point to normalisation (Egerod & Christensen, 2009). In order to construct a realistic story of their experience in ICU, survivors considered that events should be written in chronological order in their diaries (Åkerman et al., 2013) as omissions had been identified which detracted from the flow of the narrative (Åkerman et al., 2013; Robson, 2008).

The inclusion of patient photographs in diaries has been considered important by survivors in augmenting the written content (Åkerman, Ersson, Fridlund, & Samuelson, 2012; Backman & Walther, 2001; Egerod et al., 2011a) and in helping them to realise the severity of their illness. The inclusion of photographs is widespread (Egerod et al., 2011b) however, their potential impact remains relatively unknown. If photographs are included in diaries there is an inconsistent approach to their specific content. This varies between the inclusion of staff and family members with patients (Backman & Walther, 2001; Combe, 2005) to one instance where photographs comprised ICU equipment only without the patient in view (Garrouste-Orgeas et al., 2012). The recovery trajectory is often underestimated by survivors (Deacon, 2012b) and being able to visualise themselves in photographs has aided some survivors to understand the severity of their illness and therefore to set realistic recovery goals (Combe, 2005).

Nurses in Scandinavia expressed concern about the ethical issues associated with patients' photographs in diaries; in particular the practice of photographing patients

without their consent, but continued to do so because of positive patient feedback (Egerod et al., 2011b). This issue has been addressed elsewhere by securely storing the photographs and including them in the diary when the patient gave consent to do so (Ewens et al., 2013; Jones, Griffiths, Humphris, & Skirrow, 2001). However, the use and potential effect of patients' photographs in ICU diaries has not been extensively explored in the literature (Åkerman et al., 2013).

A comparison of ICU diary content and ICU observation/flow charts has been undertaken (Egerod & Christensen, 2011) to ascertain the contribution of these charts and diaries to the construction of survivors' stories. The findings confirmed that the content of diaries was very different to patients' charts and are of little value in constructing the stories of survivors because of their different purposes (Egerod & Christensen, 2011).

PERCEIVED BENEFITS OF ICU DIARIES

Intensive care diaries are well received by survivors and their families (Backman & Walther, 2001; Combe, 2005; Ewens et al., 2013) and have many perceived benefits which are related to their underpinning philosophy. A holistic style of composition is encouraged with families often providing the backdrop of normality through their entries within the diaries. The concept of diaries has demonstrated benefits for survivors, their family members but also to families of non survivors (Backman & Walther, 2001; Combe, 2005). Diaries are viewed as an act of caring evidenced by the entries of ICU staff and family members which are often expressions of love and hope; and survivors have reported many emotions when reading these types of entries (Engström et al., 2008; Ewens et al., 2013; Ewens et al., 2014). Making diary entries enables family members to maintain a connection and a sense of normalcy with their loved ones whilst offering them focus and purpose (Ewens et al., 2013). Diaries are also an information giving exercise of events in ICU for the survivor. These entries have been credited as enabling survivors to come to terms with what has happened to them and are therefore able to re-author their story and develop insight into their experiences (Egerod et al., 2011a). The therapeutic benefits of diaries to survivors and their families is emerging however there is little evidence to support any benefit for nursing staff as primary authors.

Diaries are attributed with filling memory gaps and enabling survivors to form a coherent story of their ICU stay as well as maintaining the human connection between them and their family members (Åkerman et al., 2013; Bergbom et al., 1999; Ewens et

al., 2013). Diaries, particularly if they contain photographs, demonstrate to survivors the severity of their illness which enables them to set realistic recovery goals (Bergbom et al., 1999; Combe, 2005; Egerod et al., 2011a).

Early studies focussed on general feedback from survivors and their families about the benefits of diaries without tangible endpoints and there are only four studies which have focussed on the impact of diaries on anxiety, depression, PTSD and quality of life (Backman et al., 2010; Garrouste-Orgeas et al., 2012; Jones et al., 2010; Knowles & Tarrier, 2009). In a multi-national RCT, diaries were attributed to reducing new-onset PTSD in the convalescence period in a significant sample (Jones et al., 2010). Diaries have also been identified as reducing Post-traumatic Stress (PTS) symptoms in survivors (Garrouste-Orgeas et al., 2012) although it was unclear if diaries alone were the causative factor or due to elapsed time since hospital discharge. Diaries have also been attributed with a reduction in anxiety and depression (Knowles & Tarrier, 2009) and improvements in quality of life (Backman et al., 2010) however, in both studies it was unclear if discussion with nursing staff after discharge biased the findings.

DISCUSSION

This literature review has indicated that ICU diaries are a low cost, grass roots initiative which have demonstrated potential therapeutic benefit in a population recognised to be at significant risk of psychological morbidity (Capuzzo et al., 2008; Jackson et al., 2009; Peris et al., 2011). A significant finding of this review has been the lack of rigorous research to inform the use of ICU diaries as a therapeutic intervention despite their application in some countries for more than two decades. There has been a substantial focus on the prevalence of diaries compared to the potential impact of diary use. The Scandinavian studies aimed at establishing the prevalence of ICU diaries using the same survey were reliant upon individual responders who were deemed experienced in the use of ICU diaries (Gjengedal et al., 2010; Nydahl et al., 2010). While this use of a valid tool enhances rigor, the survey required translation, both of terms and into a different context. This may have led to potential bias from misinterpretation of terms via translation cannot be excluded in some of the studies (Gjengedal et al., 2010; Nydahl et al., 2010).

This evidence establishing the prevalence of diaries in Scandinavia is now dated mainly because of the use of secondary data from one study (Egerod et al., 2007; Egerod et al., 2011b; Gjengedal et al., 2010), therefore it is unclear whether this practice

has become more prevalent, although there is limited application in Australia (Ewens et al., 2013). However, it is apparent that the implementation of diaries and investigation into diaries is most prevalent in Scandinavia which may be due to the development of dedicated teams responsible for diaries in their units (Gjengedal et al., 2010) which could be adopted elsewhere to sustain the practice of ICU diaries.

There has been limited exploration of the preferred content of diaries from the survivors' perspectives to guide practice. Studies in Scandinavia which have analysed the purpose and content of ICU diaries have been via secondary analysis (Åkerman et al., 2012; Egerod & Christensen, 2011) or further investigation using the same sample (Egerod & Bagger, 2010) from previous studies (Egerod & Christensen, 2009) which has limited the generalisability of findings and the contemporaneous nature of the data.. Photographs are widely used in ICU diaries and were positively received by survivors as a means to supplement the text within them (Backman & Walther, 2001; Combe, 2005). Despite photographs evoking a range of emotions in survivors and their families, this did not detract from their perceived benefit (Ewens et al., 2013; Robson, 2008). There remains inconsistency about the agreed content of photographs and whether they should be used at all within diaries; as nursing staff have raised concerns about the ethics of doing so without the patient's consent (Egerod et al., 2011b). Photographic imagery is a powerful medium and as such the potential in this context is probably underestimated. The inclusion of photographs in diaries enables the survivor to visualise themselves often at their most vulnerable. If photographs were taken sequentially and at turning point moments in their ICU journey a visual record of progress to accompany the written text would be created. Inconsistencies may be due to the lack of evidence which supports the use of photographs but could also be attributed to nurses' reservations and this is an area which requires further clarification

Reports from survivors and their families about ICU diaries have been predominantly positive. Many survivors and their family members have recounted the ways in which diaries assisted in filling memory gaps and maintaining communication with loved ones through the supportive nature of the diaries (Roulin et al., 2007). Survivors were deeply moved by the statements of love, support and encouragement to overcome their illness from their relatives (Engström et al., 2009; Ewens et al., 2013) who themselves considered diaries a way in which they could communicate with their loved ones during this time (Roulin et al., 2007). Diaries also revealed to survivors how

they were cared for by nursing staff, which was often considered above and beyond their usual nursing duties (Ewens et al., 2013).

The body of literature has focussed upon the use, prevalence, content, structure and potential benefits of ICU diaries for survivors and their families. However, nurses play a crucial role in operationalising diaries in the clinical setting and yet there has been no examination of the potential benefits that diaries may have for the nurses who construct them and this should be considered.

Survivors have reported a reluctance to share their experiences with family members following discharge for fear of causing them stress and re-visiting events themselves (Griffiths & Jones, 1999). Diaries have been credited with enabling difficult conversations to occur by acting as a springboard for discussion (Backman & Walther, 2001; Ewens et al., 2013). Reading their diaries evoked powerful emotions for survivors however, this did not detract from the positive experiences that have been reported in the literature (Egerod et al., 2011a; Ewens et al., 2013).

The commencement of diaries differs from day one to three of admission during which time a significant amount of critical data could be lost leading to fragmented narrative which has been identified as undesirable by survivors (Egerod & Christensen, 2011; Robson, 2008). Survivors were not encouraged to continue diarising following intensive care either whilst in hospital or following discharge home, although some felt that this would be beneficial (Robson, 2008). Prospective diarising may benefit survivors as they become active participants in their recovery journey but this is yet to be explored and should be the focus of future investigation.

Specific interventions to promote ICU recovery should be targeted to those who will benefit most from them (National Institute for Health and Care Excellence, 2009). Studies within this review contained demographic and severity of illness data but there have been no inferences drawn from this data about the relevance of this for targeting diary use other than gender preferences (Egerod et al., 2011a) and this should be a focus of future research.

STRENGTHS AND LIMITATIONS

The strength of this literature review is the systematic review of relevant research papers guided by an answerable question. Papers were reviewed both for their methodological rigour and their contribution to practice. The papers were reviewed in

relation to the review question and a conclusion reached. The review was limited by the exclusion of three papers which were not in English. The quantity of papers generated from the Google Scholar search prohibited further exploration and this may have limited the collection of pertinent studies as yet unpublished in scientific journals.

CONCLUSION AND RELEVANCE TO PRACTICE

The prevalence and range of psychological morbidity is well evidenced in ICU survivors however rehabilitation services are still evolving and their application remains limited. Patient diaries are a cost effective intervention which has shown potential in the reduction of psychological morbidity during the recovery period for survivors of critical illness. The focus of research should now be upon establishing evidence based practice standards for the implementation of diaries and further exploration of their potential impact upon psychological morbidity during the recovery period. It has been acknowledged that because of the diversity of the complications of critical illness strategies to support survivors should be targeted appropriately and to those who need it most. There has been no exploration of who would benefit most from receiving diaries and this should also be undertaken. The use of prospective diarising during the recovery period for survivors may also have potential and this should be further explored in this population.

CONTRIBUTION OF THIS CHAPTER TO THE THESIS

The preceding chapter presented a synthesis of all the appropriate literature underpinning this study. This review clarified that the implementation of ICU patient diaries remains sporadic, flourishing in Scandinavia relative to parts of Europe but much less in Australia where only one study originated. There was a dearth of studies within the review which had explored survivors' use of their ICU diaries during the recovery period. Essentially this is when diaries would be used by survivors and potentially useful for survivors; to help them to understand what happened to them during their time in ICU. The review indicated that survivors' valued the diaries created for them whilst in ICU and they did serve the broad purpose for which they were intended; namely to help fill memory gaps, concrete the survivors' experience in reality and help them to understand how compromised they had been and set realistic recovery goals as a consequence. There is limited exploration though of how survivors use their diaries during recovery and whether there may be other applications for diaries during this time.

Notwithstanding the positive reception from survivors about their ICU diaries and their potential usefulness it is indisputable that these diaries remain an account of experiences through the lens of others and not through those of the survivor. Those who create the diaries cannot know what the survivor is feeling and experiencing during their time in ICU; they can only assume. This review identified a gap in the literature. The use of diarising during recovery to enable survivors to portray their experiences through their individual lens and provide an authentic story of their experiences has not been explored. Despite interpretive biography as method not being the intended focus of the literature review the findings from the review guided the development of the method. The findings prompted the researcher to identify a method which could enable survivors' to recreate and share their individual stories of recovery in order to shed light on their unique experiences and contribute to the existing body of knowledge about survivors' recovery trajectories.

CHAPTER TO FOLLOW

The following chapter three discusses the methodological approach for this study and details the philosophical underpinnings of this approach. It was crucial to apply a methodological approach which would enable the participants to illuminate their experiences and the disruption which an ICU admission brought to their lives. The biographical approach and the use of innovative methods gave the participants the opportunity to share their experience in a safe and secure way. This chapter has been prepared as a paper for publication and is currently undergoing peer review in the journal: Nurse Researcher.

CHAPTER THREE: BIOGRAPHICAL DIARISING IN ICU RECOVERY: RESEARCH PRACTICE IMPLICATIONS

*Stories matter. They shape our lives, expectations,
and dreams. They are the wrap and weave of our
human existence, binding us into a fabric far
stronger than any individual element*

Bascomb James

INTRODUCTION TO CHAPTER THREE

In order to arrive at an appropriate methodological approach to the study aims developed from a review of the literature, it was necessary to undertake a process of epistemological and ontological reflection. This process enabled me to reflect upon how things are really known in the world of the ICU survivor and what are the characteristics, principles and assumptions that guide this in order to form a theoretical perspective and position myself in relation to the research. My personal research paradigm is underpinned by a subjective ontology, to elucidate meaning and make sense of existence. Therefore I adopted an interpretive biographical approach to this study to enable the interpretation of survivors' stories from their unique, individual perspective; to give meaning to their experiences and share those with others in order to create a mutual understanding of recovery. My intention was that this epistemological approach would ensure that the research process would be shared with, and ultimately repeated by others in order to assess the quality of this study. This reflection process then drew me towards an appropriate methodology i.e. the tools required to elicit meaning from ICU survivors' experiences, described here.

This chapter describes the methodological approach which underpins the study and the methods chosen which provided a different lens through which to view ICU recovery trajectories from the perspective of survivors.

Ewens, B., Hendricks, J., & Sundin, D. Biographical diarising in ICU recovery: Research practice implications.

ABSTRACT

Aims and objectives: The aim of this study was to explore the application of a biographical approach to create and interpret stories of recovery through the lens of intensive care unit survivors.

Background: Intensive care survivors may be affected physically and psychologically by their illness experience and intensive care unit stay. Despite decades of investigation, support provision during recovery remains disparate and lack an evidence base.

Data sources: This paper draws upon the experiences of the researcher within a particular study as well as relevant literature.

Review Methods: This is a methodology paper that details the application of an interpretive biographical approach, in particular diarising, with individuals who have survived a critical illness/event and stay in intensive care.

Discussion: The application of interpretive biography through diarising enabled participants to reveal their deep inner worlds and the conflict between those and their surface worlds. Participants revealed their experiences of intensive care and recovery through their individual lens.

Conclusion: This study applied interpretive biographical methods to create stories of individuals who survive intensive care. The unique application of this method has not been undertaken in this population before and enabled the participants to construct their story of intensive care and recovery and reflect upon their experiences. Diarising may have potential in the recovery of this population.

Implications for research/practice: This method offers an opportunity to explore the experiences of those who survive ICU and shed light on their experiences through their individual lens. Diarising in this population should be further explored as a potential therapeutic intervention.

Key words: nursing, intensive care, recovery, storytelling, diarising, interpretive biography

INTRODUCTION

This paper outlines an interpretive biographical approach to creating, reading and understanding the stories of those individuals who survived an intensive care unit (ICU) experience following a critical illness/event. The participants in the study had all experienced such an event requiring admission to ICU and ventilation for a minimum period of 24 hours. When well enough to be discharged from ICU and eventually hospital, they were deemed recovered enough to do so. The legacy of an ICU experience goes far beyond the physical and this outward appearance of being recovered is not a true reflection of the individual as a whole. This outward appearance which is visible for others to witness is merely the tip of the iceberg and does not represent the whole self. In the fathoms below there is a storm brewing, a disruption to the whole self which is rarely revealed to others but kept hidden below. To achieve a point in recovery where survivors are comfortable with their selves may have no end point. This juxtaposition between the deep and the surface worlds of survivors creates a dissonance which many find difficult to manage as they struggle to conform to the expectations of others and the meaning of what it is to be recovered which is the reality of others but not theirs.

It is this approach and the methods used in the study as described here which make possible the revelation of this inner self, not captured before through other methods. A brief background to the study follows but the focus of this paper is to introduce a synthesis of Denzin (1989) method to enable the unique experiences of those who survive ICU to be revealed within their wider social, cultural, and historical contexts in this case during their experiences of recovery.

BACKGROUND

The experiences of ICU survivors during recovery have not been captured before using the methods applied in this study; methods which have enabled experiences to be brought up from the depths and to the forefront. Survivors have reported an inability to share their inner most thoughts and feelings which simmer below the surface, for fear of being judged or causing distress to those closest to them (Ewens et al., 2014). Creating a safe environment to share stories of ICU recovery has enabled these inner thoughts and experiences to be captured to create a deeper understanding of recovery experiences through their individual gaze. The use of innovative methods such as diaries in this study ensured the collection of rich and evocative data enabling

individual stories to be crafted as a result, which would not have been possible through other means.

Earlier studies with ICU survivors explored recall of ICU events during recovery including dreams and delusional memories (Lof, Berggren, & Ahlstrom, 2007; Magarey & McCutcheon, 2005; Minton & Carryer, 2005), the persistence of these memories over time (Zetterlund, Plos, Bergbom, & Ringdal, 2012) and the incidence of associated psychological sequelae (Roberts & Chaboyer, 2004). These studies were predominantly descriptive in nature applying methods such as semi structured interviews and surveys and recovery from ICU was not the focus.

Recovery from ICU in other studies has focussed upon recovery of the physical self and interventions to promote it (Agard, Egerod, Tonnesen, & Lomborg, 2012; Kelly & McKinley, 2010; Ramsay et al., 2014). Capturing these experiences of recovery has predominantly been through the application of semi structured interviews, surveys or focus groups which do not necessarily offer participants a safe way in which to share sensitive thoughts and feelings leading to limited disclosure by participants. This existing research has not brought the survivors' experiences to the forefront as achieved in this study. The application of storytelling based on the biographical approach described here has captured the unique experiences through the gaze of survivors.

The therapeutic benefits of creating stories for general trauma survivors are well recognised in the literature (Chaitin, 2014; Jaeger et al., 2014). In health care the application of storytelling for those recovering from cancer, helps to bring coherence to the remainder of their lives following the disruption of diagnosis and treatment (Knox & Svendsen, 2015) and increasing coping (Lucius-Hoene et al., 2012). Storytelling as a method is not well evidenced with ICU survivors. Williams (2009) concluded that ICU survivors are unable to construct a cohesive narrative as they do not have accurate recall of events in ICU because of pharmacologically induced amnesia compounded by severity of illness and suggest that guided story construction may be beneficial to recovery. This notion; that ICU survivors experience partial or total memory loss of their ICU experience and of the precipitating events is well reported in the literature (Dowdy et al., 2009; Granja et al., 2008).

An alternative to storytelling; life review and reminiscence therapy have been used with success in the elderly population with reported positive effects upon

depression by enabling reflection on the fabric of one's life (Chan, Ng, Tien, Man Ho, & Thayala, 2013; Daniels, Boehnlein, & McCallion, 2015). Life review is a method whereby an ordered review of life events is constructed from childhood to the current time. It is postulated that life review facilitates dialogue between individuals and creates a temporary escape from reality by reflecting back upon happier times (Jones et al. 2003). The method of life review is similar to a biographical approach and was considered by Jones et al. (2003) to be of potential benefit to ICU survivors and worthy of further investigation. Life review however, has not been explored further in this population or adapted broadly into clinical practice.

The potential therapeutic benefits of storytelling in this study were based upon the biographical approach which was extended to Denzin's biographical event; to capture turning point moments in the recovery of ICU survivors, create a shared understanding of recovery and bring meaning to their experiences.

THE AIM OF THE STUDY

The aim of this study was to explore the application of a biographical approach to create and interpret the stories of recovery through the lens of ICU survivors.

KEY ASSUMPTIONS UNDERPINNING THE METHODOLOGY

This has been a qualitative project guided by postmodern values. The postmodern researcher acknowledges the existence of multiple realities in any given situation and thus cannot expect any text to be telling the 'truth'. Rather, they strive to build a picture of a particular phenomenon within its context from the perspectives of many individuals (Sundin-Huard & Fahy, 2008). Biographical methods, specifically diarising in this study, allowed the researcher to capture many views of a situation/ process/ phenomenon which in this context is the recovery trajectory of ICU survivors.

Biographical methods is the encompassing term for the collection and interpretation of various life documents including life history, storytelling, auto/biography and reminiscence enabling a unique understanding and interpretation across cultural, traditional and national boundaries to identify turning point or epiphany moments in individuals' lives (Bornat, 2012). Initially explored in the 1920s the biographical method has grown in popularity (Denzin & Lincoln, 1998; Denzin & Lincoln, 2011), blossomed during the 1970s and has now become increasingly recognised as a construct of social reality rather than merely an informative account of life events (Rosenthal, 2004).

In this study a biographical approach was used to reveal patterns and meanings within the stories of the participants and to illuminate their experiences by enabling a “distinct approach to the study of human experience” (Denzin, 1989, p7). The biographical method Denzin (1989) describes exerts a different approach to a life where the tangible experiences of real people are formed. Denzin (1989) identified the significance of turning point moments in people’s lives as moments that leave an indelible mark on individuals’ lives which as a consequence are changed forever (Denzin, 1989). The focus in this study was the recovery trajectory of those who survived ICU. The use of story-telling in this context enabled the reflection and re-ordering of ICU survivor’s life experiences (Suarez-Ortega, 2013) into a self-validating meaningful account (Frank, 1995) using biographical methods. The methods used to create stories can differ. In this study the stories were created from participants’ diaries and interviews to make sense of an individual’s life rather than to merely describe it (Denzin & Lincoln, 2008).

MEANING VS REALITY

Interpretive researchers face many challenges in their quest for meaning however, the researcher agrees to accept the accountability for the choice and interpretation of stories told (Holloway & Biley, 2011). The stories of the participants in this study highlighted the co-existence of multiple realities for them, as their visual and oral narratives detailed their experiences of ICU, their possibly delusional realities at the time of ICU and during recovery and how these realities sometimes co-existed within the ‘*true*’ reality of the here and now. Together, through the creation of diaries and their interpretation via face to face interviews, wealth of rich data were gathered. This process enabled the participants and the researcher to create an understanding of the realities they were experiencing set within the context of their natural world. The researcher here identified turning point moments in the participants’ lives (Table 3) which emerged through the interpretation of their stories and through which Denzin (1989) the researcher can capture, and bring coherence to the experiences people encounter.

BIOGRAPHICAL APPROACHES

Denzin (1989) argued that biographies and autobiographies must be organised and interpreted and that the strategies for facilitating such organisation fell into one of two categories: objective or interpretive formats. The objective format category he further delineated into classic (objective, natural history approach) and the objective

(hermeneutic approach). Both of these approaches Denzin critiques for their logicocentric view of the human psyche, the exclusion of subjectivity (potentially multiple influences on a person's or people's' perspective of a given situation) and thus multiple realities. The traditional users of these objective approaches adjudge their efforts (the rigor of their findings) in terms of validity, reliability, truth, bias, generalisability, hypothesis (Denzin, 1989). Denzin (1989) acknowledges that the interpretation of stories can be biased and sometimes the storyteller may neglect structural factors which have had an effect on their lives; this is the storyteller's truth and researchers trust these accounts whether or not evidence exists to support it. The truth in creating stories is dependent upon the storyteller's relationship with the experiences and Denzin (1989) contests that the truth differs each time it is revisited; can be incomplete and fluid. The diaries in this study enabled the teller to redefine and reshape personal interactions to make sense of their experience. The delusional recall and persecutory dreams experienced and illustrated by the participants reflects the interpretive stance that there are multiple realities and contextual truths for survivors, reflecting diverse and unique patterns captured within the individual stories. Interpretive researchers search biographies for the stories they tell and the meanings within those stories. For the reasons outlined here, this project has been guided by Denzin's (1989) discussion of the features of interpretive biographical strategies.

Interpretive biographical strategies begin with life experiences which are given meaning by those being studied, in this case the experiences captured during recovery (Denzin, 1989). Biographical materials are then gathered which recount individual's experiences to create a story. The creation of stories relies on subjective oral and written expressions by the participants being studied and these expressions offer a window into their lives. These windows are filtered through the lens of language, signs and the process of denotation to give expression to life experiences. The lived experience of the lives being studied is the focus and the meaning of these experiences is best portrayed by those who experience them. How these stories are constructed can extend into other realms such as visual and auditory methods as was used in this research. The methods of diarising and interviews enabled the researcher to encourage the participants to expand on certain points identified in their stories as an interpretive strategy. To further illustrate the applicability of this method to ICU survivors, Denzin (1989) considers (self) stories as a method which comprises several taken for granted

assumptions, all of which are thematic in this study but three of which are particularly pertinent:

Knowing authors – the assumption that in biography there is an outside author who records and makes sense of the life being studied

Objective markers – subjects live lives with meaning and have subjective and objective markers which reflect key, critical events in their lives and give coherence to the life in question

Turning points – lives are shaped by epiphany moments which are turning points and leave indelible marks. Typically biographies are structured by these turning point moments in an individual's life as a distinct approach to the human experience.

Interviews offer an opportunity to tell one's story and the data derived from them are interactional set within the historical, cultural, social and political context of the individual. Once materials are captured the story is carefully read and interpreted with patterns and meanings explored. Triangulation of the data ensures that different perspectives on life experiences are captured as the researcher moves back and forth, extracting different meanings and creating a broader picture of a life through individual voices. In this study the turning point moments which structured the stories of the participants were revealed (Table 3).

CREATING A STORY

The creation of stories is one of the first forms of discourse learned as a child and remains an integral component of daily life however, the importance of this is sometimes lost (Atkinson, 1998; Kohler Riessman, 1993). Narrating a self story can be considered the most significant medium through which a person defines and shapes cultural and personal interactions; a means through which the individual defines their life, identity, culture and society (Bingley, Thomas, Brown, Reeve, & Payne, 2008).

Diaries, interviews, memos and field notes were all used to create the stories. Participants were requested to begin their stories at a point of their choosing and to illustrate their experiences of recovery in any way they felt appropriate. These methods combined enabled the participants to create stories which entwined their deep and surface worlds to promote harmony and congruence in both parts of their lives.

DIARIES

All participants were supplied with a blank journal comprising removable pages and gender neutral art materials, such as shapes and letters, which they could use to illustrate their story in any form they wished. They were also supplied with pens and a disposable camera. The participants were encouraged to utilise any media they felt appropriate to capture memories, thoughts and feelings which they may not be able to articulate through other means. The application of diarising in this study has been discussed in detail elsewhere (Ewens et al., 2014).

INTERVIEWS

Following three months of diarising participants were visited at a time and in a setting of their choosing. The interviews lasted for up to 90 mins and were digitally recorded. A rapport had already been established between the participants and the researcher at the initial contact visit and this enabled the free sharing of information by participants in a safe environment. Interviews were semi structured to ensure the aims of the research were addressed. Questions were asked in any order and the researcher was able to seek clarification from the participants' answers if necessary and enabled a flexibility to the interviews. This flexible approach allowed the participants to speak freely about their experiences and the way they had depicted these in their diaries. which provided another means to guide the interview. The participant in responding to questions were able to use the diary to highlight or make explicit the way in which they had recalled their experience their by word or imagery. Each interview commenced with the researcher inviting the participants to tell their stories starting at a point in time of their choosing and clarify how they had depicted their stories within the diaries as an account of their biographical event. During the interviews the researcher prompted the participants to describe significant events or turning point moments of their recovery experience. At this time participants referred to their diaries to show how they had captured the event or experience. This often provided an opportunity to seek clarity and greater depth of the experience. This technique empowered participant a set the flow of the interview. Thus the context of the interviews was one in which the participants felt comfortable exploring their feelings and experiences giving truthfulness to the derived data. This approach to data collection captured the two worlds within which each of the participants were enmeshed.

FIELD NOTES

Field notes and memos were used following each contact with participants. The researcher composed reflective remarks about the process of data collection to further inform the analysis of the interviews and supplement the diaries. This process enabled the researcher to develop a greater depth of understanding. In particular the researcher reflected upon visual and oral cues offered by the participants but also on the interview process and the framing of these for future interviews. The interviews were transcribed verbatim and the transcripts were read and re-read whilst listening to the recordings to ensure immersion in the data.

As trauma memories are very different to everyday experiences they are well integrated into the autobiographical memory and as such can be very central to the individual's sense of self (Smeets, Giesbrecht, Raymaekers, Shaw, & Merckelbach, 2009). The delusional recall and persecutory dreams described by the participants reflects the interpretive stance that there are multiple realities and contextual truths. The use of interpretive biographical methods in this study gave voice to the participants and brought their experiences from the backdrop to the forefront. One of the benefits of interpretive biography is the necessity to consider that a teller's story is context bound, so in order to interpret stories the researcher must consider the historical, cultural, social and political context when seeking to understand the stories told. This innovative approach to developing biographical materials and the interpretive process adopted enabled a holistic interpretation of the stories of those who survive a life threatening event in ICU. Interpretive researchers face many challenges in their quest for meaning but the researcher agreed to accept the accountability for the choice and interpretation of data generated (Holloway & Biley, 2011) as it was anticipated that multiple realities could emerge from the data obtained from the diaries and subsequent interviews. The stories told did reveal the co-existence of multiple realities for survivors, as their visual and oral narratives detailed their experiences of ICU, their delusional reality and how this reality sometimes co-existed with the true reality of the here and now. The unique application of this method identified the individual needs of participants which could enable support to be shaped to meet their needs. The diaries in that context highlighted potential maladjustment for two participants who revealed that their delusional dreams could still be replayed at will which is a strong predictor of psychological distress (American Psychiatric Association, 2013). Arguably this potential maladaptation may not have been identified through other means and gone untreated.

The shared interpretation process created an understanding of these realities which participants described set within the context of their natural world.

DATA ANALYSIS

Analysis was twofold and guided by Etherington (n.d.) and Kucera, Higgins, and McMillan (2010) frameworks which enabled the researcher to identify turning point moments in the participants' lives and capture them in text (Table 3). The purpose of the interviews was to create a shared meaning of the stories of recovery depicted in the diaries. In particular a clear understanding of what the symbols and signifiers represented for the participants was established in order to be shared accurately with others. It was integral to the interpretive process that the researcher and the participants read the diaries together and the experiences that the diaries were intended to illustrate were clearly captured. The interviews were transcribed verbatim by the researcher as a component of the analysis process; read and re-read combined with listening to the recordings to ensure immersion in the data. Data were coded at the initial level and then pattern coded to enable sub themes to emerge to identify words which linked the themes together (Miles & Huberman, 2014).

TRUSTWORTHINESS

Trustworthiness of the data derived from the participants comprised the constructs of: credibility, transferability dependability and confirmability (Guba & Lincoln, 2005). Credibility was ensured by data immersion and member checking; transferability by wide dissemination of the study's findings; dependability by triangulation of data from diaries, interviews, memos and field notes and confirmability by ensuring a transparent process to data collection and analysis as well as a rigorous audit trail.

RELEVANCE OF APPROACH

An interpretive biographical approach elucidates the interrelationships between private lives and public responses (Denzin, 2001; Holt, Tamminen, Tink, & Black, 2009). The application of biographical methods including diarising, in this study, offered those who survived ICU the means to express memories and experiences which they were often unable or reluctant to disclose to others; therefore, establishing a juxtaposition between the deep and the surface worlds. In this study survivors revealed that they wanted others to believe they were returning to *normal*; to portray normalcy and to prove they had emerged unscathed from their experience because this was expected of

them. Those who survive an ICU illness/experience frequently describe an existence which outwardly appears normal; they are getting physically stronger and gradually re-entering their lives however, below the surface there is turmoil. They do not feel normal; they still have vivid, disturbing recollections; are searching for meaning from their experience, unable to discuss these to protect themselves and those closest to them; climaxing in a biographical disruption of the self. This dissonance complicates the ability to determine and create a shared understanding of recovery in order to provide support for this population. To be able to support survivors in their recovery journey requires a shared understanding of what recovery is and what it means to different people, yet the notion of recovery and how it is perceived differs across health care systems and cultures, creating anomalies in service provision and health targets (Slade, 2012). Viewing recovery from the perspective of those who are recovering revealed that ICU survivors do not fit with the accepted understanding of recovery. Therefore, when one is "recovered" and discharged home, the wider population considers the recovered person should behave in a particular way, so that they can exist in the wider socio-economic context. Individuals feel that they should be recovered by a period in time, as is the recognised understanding but when their self-identity does not fit with their former self-identity there is a disconnect which can lead to mental health issues. Therefore if this dissonance highlighted by this method were to be recognised by health care professionals support could be focussed appropriately. It is a challenge for many survivors to move forward and come to terms with what is happening in their deep self until they can reveal and share the experiences which shaped it.

The biographical approach and the methods described here provided a multi-dimensional insight into recovery in this population which captured the social, cultural and historical context in which the participants were situated. Capturing stories through an alternative lens as described here ensured that those who survived became the foci of the research thereby allowing their voice to be at the forefront.

All of the participants were affected in various way by their ICU experience and recovery journey and as a result had experienced many turning points in their lives.. This method offered participants the opportunity to recreate their stories in a safe non-judgemental space and to be empowered to divulge their personal and inner most thoughts through diarising. Although all participants had the opportunity to diarise only three chose to supplement their diaries with imagery, remarking that this method

assisted them to reflect upon how ill they had been in ICU and how far they had traversed since their critical illness/event.

All of the participants considered that their ICU experience was life changing for them. In a positive way Bella considered the experience had given her another chance at life and she had changed her entire focus as a result. However, Phoebe experienced social isolation for the first time because of her reluctance to be with groups of people which resulted in a reclusive existence for her which was in contrast to her pre-illness way of life.

Frustration at protracted and unexpected recovery times was also a dominant theme with many participants describing how they struggled to maintain an outward appearance of being recovered whilst experiencing an inner turmoil they were hesitant to expose.





This biographical approach; has a basis in the ontological substance of multiple realities; each person has their own reality none of which is more important than the other. Viewing the meaning of recovery through the participants' lens revealed the dissonance between the two worlds in which they exist: the deep world which may not be revealed to others and the surface world which they tried to portray to others as being wholly recovered. Enabling participants to reveal this dissonance and have this acknowledged was empowering and legitimised their relative and absolute realities. In this study, giving the opportunity to use symbols and signifiers in diaries enabled participants to share traumatic thoughts and feelings and to integrate significant events into their lives as empowering. Disclosing their stories intertwined the disruption between the deep and the surface worlds and participants found they were able to move forward thus bringing and giving new meaning to their recovery journey.








CONCLUSION

The interpretation of stories offers a unique method to reveal the inner lives of those who survive ICU and give voice to their experiences; whilst enabling them to make sense of what happened. This unique focus revealed multiple realities for the participants captured through the use of a diary as a tool. This method of capturing stories through diaries offered a safe way in which participants could unburden their thoughts and feelings which many could not articulate through oral means alone. When viewed in this way different ways of being recovered were portrayed, reflecting diverse and unique patterns. In order to make personal sense, survivors had to consider

what they had experienced outside of the dominant way of thinking about *being recovered*.

Table 3 Biographical event timeline from one participant's diary

Epiphany moments	Chronological trajectory	Discourse	Power
<p>May</p> <p>Feeling judged</p>	<p>Sam was upset and angry that the nursing and medical staff had because of his illness labelled him as an alcoholic. He made repeated reference to this in his diary and interviews.</p>	<p>Categorised due to the discourse of the institution</p>	<p>Power regulates human thoughts and behaviour to control the people to get the most out of human resources available</p>
			
<p>June</p> <p>Released from the madhouse</p> 	<p>Sam was severely debilitated at discharge home and realised that he had been too ill to understand the magnitude of his illness. However, there was also relief for him as he now understood why he had been ill for the last few years. He was feeling good in himself and had a determination to get better and follow advice about health and diet to enable this. Each day he saw an improvement which took away his concerns, however despite this physical improvement he remained very tearful and viewed his discharge from the hospital as being released "from the madhouse".</p>	<p>The discourse dictates health advice based on scientific evidence</p> <p>Knowledge of recovery not offered to him because to share the knowledge may enable him to challenge the body of knowledge and therefore power</p>	<p>Physical bodies are subjugated and made to behave in certain ways as a regime of truth</p>
			
<p>July</p> <p>Determined to make a positive out of the experience</p> 	<p>Two months following discharge from hospital Sam was feeling fantastic and achieving the lifestyle goals he had set himself. He had commenced a phased return to work. Everyone had commented on how well he was looking but inside he was experiencing a dichotomy. He realised he was struggling, that his brain was tired conflicting with his physical appearance. He was struggling to perform simple tasks at work and found himself looking for places to hide and crying in the car on the way home.</p>	<p>Goals based on the values and determinants of the discourse but beneath that he was struggling because he was not achieving what he perceived to be normal.</p>	<p>No realisation that he could challenge the discourse and ask for help.</p>

			
<p>August</p> <p>Everything coming together</p> 	<p>By August Sam was improving his fitness and was able to run 7kms in 30 minutes – he was proud of this achievement. He was managing better at work but was still not quite back to normal. Because of this residual difficulty he did consider that he had sustained brain damage in ICU but would be able to hide it.</p>	<p>Society said he was recovered</p>	<p>He was afraid to ask for help for fear of being exposed as abnormal</p>
			
<p>September</p> <p>Fears for the future</p> 	<p>Sam was re-admitted to hospital for a procedure which was complicated by infection and was unexpectedly off work for 6 weeks. His mood was low as he had no control over his health, was worried about his job and feared for the future. He feared returning to work as he didn't want to feel helpless; work is important to him.</p>	<p>Conforms to biomedical model for treatment and had pathology to support this</p>	<p>Decisions/treatment in houses of professionals, sick role played</p>
			
<p>October</p> <p>Needing to prove himself</p>	<p>In October Sam again returned to work at 60 hours per week; trying to prove himself competent in his role. This left him exhausted at the end of each day and he was afraid to undertake the exercise which had been such an integral component of his physical recovery.</p>		<p>Functioning at work is a measure of success and return to normal. Returns to productivity</p>
			
<p>November</p> <p>I'm back</p> 	<p>Seven months after his admission to ICU Sam was eventually feeling healthy and achieving his goals at work. He considers the future is bright.</p>	<p>Conforms to the idea of "being well"</p>	

CONTRIBUTION OF THIS CHAPTER TO THE THESIS

This chapter has given a clear account of the methodological underpinnings of this study and the approach that was taken to elicit the stories of ICU survivors from their individual gaze during the early months of recovery. The application of biographical methods and the interpretation process offers valuable insight into the journeys of those who survive an ICU experience. The methods chosen for this study; the diaries and interviews enabled the participants to articulate their experiences through guided reflection of their diaries. The benefit of diaries was that participants were free to diarise whenever they wished; giving them the freedom and a space for thought to reflect upon their experiences.

CHAPTER TO FOLLOW

The following chapter describes a preliminary study which explored the use of ICU patient diaries by survivors post hospital discharge. The findings from this study informed the larger study, detailed in forthcoming chapters. This chapter was prepared as a paper for publication and has been published in the journal: Australian Critical Care.

CHAPTER FOUR: ICU SURVIVORS' UTILISATION OF DIARIES POST DISCHARGE: A QUALITATIVE DESCRIPTIVE STUDY

*After nourishment, shelter and
companionship, stories are the thing we need
most in the world.*

Philip Pullman

INTRODUCTION TO CHAPTER FOUR

The literature review described in chapter two identified that there had been minimal exploration of survivors' utilisation of their ICU diaries during the recovery period throughout the world. The application of ICU diaries in Australia is a relatively novel concept and to date their prevalence is relatively unknown. Although the review highlighted that ICU diaries had been well received in Scandinavia and parts of Europe there had been no exploration of the utilisation and perception of ICU diaries in the Australian context. This prompted the researcher to establish survivors' perceptions and utilisation of ICU diaries during recovery in the Australian context. This chapter details a study undertaken at the same site as the larger study and where ICU patient diaries had been successfully implemented.

The processes the researcher developed to implement diaries in the unit were drawn from the extensive review of the literature described in chapter two. These methods included the preparation of staff, patients and families as well as the operational processes necessary to optimise the integrity and quality of the diaries constructed. All of the study participants received a diary created for them whilst in ICU by nursing staff as well as their families and friends and as reflected in the literature were intended to be a factual record of events in ICU.

Ewens, B., Chapman, R., Tulloch, A., & Hendricks, J. M. (2013). ICU survivors' utilisation of diaries post discharge: A qualitative descriptive study. *Australian Critical Care*, 27, 28-35. doi: 10.1016/j.aucc.2013.07.001

ABSTRACT

Background: A growing body of evidence has confirmed that intensive care unit survivors encounter myriad of physical and psychological complications during their recovery. The incidence of psychological morbidity in intensive care survivors is increasingly being recognised. The causes of psychological morbidity are multi-factorial but may be associated with a complete lack of, or delusional recall of events in intensive care. Intensive care unit diaries are an initiative designed to enable survivors to help restore factual memories and differentiate those from delusional.

Purpose: To explore survivors' and family members' perceptions and utilisation of diaries following discharge from hospital.

Method: A single centre qualitative descriptive study was undertaken in a general intensive care unit in Western Australia. Participants were surveyed three, six and twelve months following discharge from hospital. Eighteen participants completed one or more surveys.

Findings: Many of the participants who completed the surveys read their diaries but few made entries in them following discharge. Reading the diaries evoked mixed emotions for these participants; however they still viewed the diaries as a positive initiative in their recovery. Diaries enabled survivors to fill the memory gaps, make sense of their experience and reinforced the human connection when they were immersed in a technological environment.

Conclusion: Use of patient diaries was received positively by the participants in this study. Diaries are a simple, cost effective initiative which enabled survivors to piece together the time they had lost, concreted their experience in reality and enabled them to retain a connection with their loved ones whilst immersed in a technological environment.

Key words: Intensive care unit, diaries, recovery, post-discharge

INTRODUCTION

The impact of a critical illness and consequent intensive care unit (ICU) stay upon patients and their families cannot be underestimated. The ICU experience and its aftermath are described by some survivors as traumatic and life changing; and is associated with a significant risk to short and long term physical and psychological morbidity, reduced quality of life (QoL) and delays in optimal functional recovery for a significant percentage of survivors (Corrigan, Samuelson, Fridlund, Thomas, & Thome, 2007; Davydow et al., 2008; Granja et al., 2008; Griffiths & Jones, 2007a; Hofhuis et al., 2008; Hopkins & Jackson, 2006; Iwashyna, Ely, Smith, & Langa, 2010; Jubran et al., 2010; Kapfhammer, Rothenhausler, Krauseneck, Stoll, & Schelling, 2004; Myhren, Ekeberg, Toien, Karlsson, & Stokland, 2010b; Oeyen et al., 2010; Peris et al., 2011; Rattray, Crocker, Jones, & Connaghan, 2010; Rattray & Hull, 2008; Skinner, Warrillow, & Denehy, 2011; Talisayon, Buckley, & McKinley, 2011; Volk & Grassi, 2009; Zetterlund et al., 2012).

Complications reported include sleep disturbance, anxiety, depression and Post Traumatic Stress Disorder (PTSD) (Corrigan et al., 2007; Granja et al., 2008; Jubran et al., 2010; Myhren et al., 2010b; Talisayon et al., 2011; Van Loey, Maas, Faber, & Taal, 2003; Volk & Grassi, 2009). However, the prevalence of psychological complications reported is variable but is postulated to range from 24 – 44% of survivors with some evidence to support that up to 64% of survivors report symptoms of Post-Traumatic Stress. This variance has been attributed to endogenous patient characteristics as well as the ICU experience itself. A pessimistic outlook, a pre-ICU history of mental health disorders, intrusive memories, memories of pain and longer duration of sedation have all been recognised as independent risk factors for the development of PTSD (Davydow et al., 2009; Jubran et al., 2010; Myhren et al., 2010b; Schelling et al., 2003; Wade et al., 2012). The wider implications of the trauma of an ICU experience and associated complications is a higher burden of ill-health and an associated increase in the use of health care resources (Adhikari et al., 2010; Cheung et al., 2006; Cuthbertson, Scott, Strachan, Kilonzo, & Vale, 2005; Iwashyna, 2012; Needham et al., 2011; Unroe et al., 2010; van der Schaaf, Beelen, Dongelmans, Vroom, & Nollet, 2009).

The concept of trauma is defined in the literature as any unexpected and unfamiliar experience, during which unusual and extreme stress is experienced (American Psychiatric Association, 2013). Exposure to a trauma may generate feelings of intense fear, horror and/or helplessness caused by subjection to the threat of actual or potential death or serious injury, or bearing witness in others (American Psychiatric

Association, 2013). Traumatic events, which have been identified and which may precipitate psychological distress in some individuals, include exposure to military conflict, torture and physical and sexual violation (Krans, Naring, Becker, & Holmes, 2009). The effects of such trauma, can be so powerful as being recognised as capable of tearing the protective fabric of one's self apart (Reisner, 2002). There are many similarities between the psychological distress associated with "conventional" trauma exposure and that experienced by survivors of a critical illness and an ICU experience.(Deacon, 2012b; Granja et al., 2008; Griffiths & Jones, 2007a; Jubran et al., 2010; Myhren et al., 2010b; Rattray & Hull, 2008; Talisayon et al., 2011; Zetterlund et al., 2012) This could be because the reports of a critical illness and ICU experience are similar to that of other trauma survivors and, therefore, similar sequelae could be anticipated. Similar to other trauma exposures, it may be asserted that a critical illness is often unexpected, patients are rendered helpless in an unfamiliar environment, confronted by extreme stress and frequently report recollections of persecution and impending death, despite their apparent subconscious state (Kiekkas et al., 2010; Lof et al., 2007; Magarey & McCutcheon, 2005; Roberts et al., 2006; Samuelson, 2011; Storli, Lindseth, & Asplund, 2008).

The realisation of short and long term physical and psychological morbidity associated with ICU survivorship, has led to an exploration and identification of both the precipitating factors and interventions which could reduce the incidence and severity of complications (Cheung et al., 2006; Engström et al., 2008; Hale et al., 2010; Iwashyna et al., 2010; Needham et al., 2011; Papathanassoglou, 2010; Rubenfeld, 2007; Volk & Grassi, 2009; Williams & Morrow, 2009; Williams & Leslie, 2011; Wunsch & Angus, 2010). An association between psychological morbidity in ICU survivors and absent or delusional recall of the ICU experience or the presence of delirium has been postulated (Granja et al., 2008; Griffiths & Jones, 2007b; Kiekkas et al., 2010). Rates of delirium in Australia have been estimated to be 45% (Roberts et al., 2005) compared to higher rates reported in the rest of the world (Wells, 2012). Delirium is characterised by a fluctuating mental state, inattention, disorganised thinking and altered level of consciousness (First, 2000; Ouimet, Kavanagh, Gottfried, & Skrobik, 2007; Page & Katawala, 2011; Vasilevskis et al., 2010). The process of re-defining and clarifying the experience and filling the memory gap or re-defining true memory from delusional, may impact upon the incidence of psychological morbidity and recovery (Knowles & Tarrier, 2009; Roulin et al., 2007). Despite the realisation of the scale of complications which ICU survivors face, a lack of consensus regarding the most appropriate focus and

structure of programs to assist survivors to regain their pre-morbid functionality and QoL persists (Griffiths & Jones, 2007a; Jackson et al., 2012).

Survivors of a critical illness display a unique assortment of atypical and complex problems which often require specialised and individualised support to enable recovery. As the recovery trajectory is not homogenous, the duration and extent of recovery are difficult to predict, with many survivors never regaining their pre-morbid physical or psychological state (Jackson et al., 2012; Wunsch & Angus, 2010). The explanation for these inconsistencies in recovery trajectories is probably multi-factorial but may, in part, be attributed to the paucity of rigorous research to inform the provision of physical and psychological rehabilitation frameworks (Jackson et al., 2012).

Early interventions to improve the quality of life of ICU survivors initially focussed upon the implementation of ICU follow-up clinics. These clinics were pioneered in a UK centre in the 1990s as a treatment and support modality for ICU survivors (Griffiths & Jones, 2011). Evaluation of these clinics demonstrated high levels of user satisfaction and associated health service endorsement in the UK (Department of Health, 2000). Unfortunately, the model was plagued by sporadic implementation, disparate composition and inadequate methodological evaluation (Engström et al., 2008; Samuelson & Corrigan, 2009; Storli & Lind, 2008).

Another strategy which has attracted significant interest and associated investigation in Europe has been the implementation of patient diaries in ICU. Patient diaries have been used in follow up clinics as a springboard to promote discussion about the ICU experience and resulting recovery. Recent studies have demonstrated the potential of ICU diaries in assisting physical and psychological recovery in this population (Hale et al., 2010; Jones et al., 2010; Knowles & Tarrier, 2009).

Patient diaries are based on the premise that ICU survivors have difficulty in constructing a narrative of their experience because of enforced pharmacological amnesia and severity of illness and this may have detrimental effects upon their recovery (Jones et al., 2007; Jones et al., 2001). It has been suggested that providing a narrative of events of which the survivor has no recollection, may be beneficial to recovery (Hall, 2011; Williams, 2009).

Patient diaries are usually commenced in ICU after the patient is ventilated and entries are completed by relatives and ICU staff to serve as a factual record, in words and photographs of the survivors' ICU experience. ICU patient diaries emerged in

Scandinavia in the 1980s, with their implementation sporadically disseminating to the UK and Switzerland but not as yet further afield (Åkerman et al., 2010; Backman & Walther, 2001; Egerod et al., 2011b; Nydahl et al., 2010; Roulin, Hurst, & Spirig, 2007). Early examination of the benefit of diaries focused upon survivors' descriptive feedback, however recently, empirical methodologies have been employed exploring the benefit of diaries on QoL and the potential reduction of PTSD (Backman et al., 2010; Jones et al., 2010). A non-randomised study was conducted in Sweden to investigate if the use of diaries in ICU would improve patients' QoL (Backman et al., 2010). Diaries were commenced for thirty eight patients and anyone involved in patient care was encouraged to contribute. Questionnaires were sent to the patients post-discharge to measure survivors QoL at six, twelve, twenty four and thirty six month intervals. In addition to the diaries, as standard ICU practice, patients also received follow-up visits from staff. The findings of the study demonstrated that the use of diaries and the follow-up visits were associated with improved health-related QoL. However, it is not apparent if the non-diary group received a follow-up visit too. It is therefore not possible to attribute the improved quality of life in the diary group to the diaries alone. The single site, small sample size, the inability to compare pre-morbid quality of life and mental health status to post-morbid state and lack of information pertaining to how often the diaries were read by the participants, are further limitations of this study.

A UK randomised controlled trial (RCT) evaluated the effectiveness of patient diaries in ICU on levels of patient anxiety and depression (Knowles & Tarrier, 2009). Nursing staff kept diaries for ICU patients using a series of standardised headings and thirty six patients were recruited into the study. The findings demonstrated a reduction in anxiety and depression scores in the diary group survivors at two months post-hospital discharge (Knowles & Tarrier, 2009). Although the results of the study showed that the use of diaries in ICU may have a beneficial impact to reduce survivors' anxiety and depression, the authors highlighted limitations including the small number of participants and the time available to complete the study, making the findings less generalisable.

An RCT conducted across six European sites, evaluated the use of patient diaries following ICU discharge and the reduction of new onset PTSD. Nursing staff and family members were encouraged to make written and photographic entries in the diaries, which were constructed in a standard format across all sites. There were three hundred and fifty two participants recruited to the study who completed a validated screening

tool at one and three months post ICU discharge. The statistically significant results from the study indicated that the prevalence of new onset PTSD was reduced in the diary group (5%) compared to the control group (13%). The researchers concluded that reading the diaries may yield a similar effect as Cognitive Behavioural Therapy, in that diaries help survivors change the way they think about their illness and enable the recreation of an autobiographical memory.

Overall, the use of diaries has been positively evaluated by European survivors and their families and the diaries have also been acknowledged as giving nursing staff insight into the patients' experiences when utilised as a follow-up tool. Diaries have also been attributed contributing to the reduction in survivors' memory gaps, concreting their experiences in reality and enabling them to comprehend the severity of their illness and set realistic goals to achieve meaningful recovery (Bergbom et al., 1999; Gjengedal et al., 2010; Knowles & Tarrier, 2009; Roulin et al., 2007; Storli, Lind, & Viotti, 2002). Maintaining a diary for ICU patients and their families has been shown to provide a coherent narrative of the patient's ICU experience and nursing performance (Egerod & Christensen, 2009; Egerod et al., 2011a).

In a qualitative study (Roulin et al., 2007) several emergent themes were identified from patient diaries including; the sharing of daily events, confirming someone was always at the bedside and a vehicle for expressing feelings and support. The authors concluded that the diaries were a reflection of the care and contribution of staff and family. However, the impact and therapeutic benefit of specific content upon the survivors' recovery has yet to be defined and remains based on professional judgement (Åkerman et al., 2010).

Survivors have reported diaries helped them to recover the time they had lost, provided a sense of being loved when reading their family's diary entries, legitimised their experience and enabled them to come to terms with the severity of their illness (Bergbom et al., 1999; Combe, 2005; Egerod & Bagger, 2010; Engström et al., 2009). However, there is a paucity of studies exploring survivors' perceptions and utilisation of diaries post-discharge, although as it has been alluded that this may be an important support mechanism (Engström et al., 2009). Although the use of ICU diaries has been explored in the UK and Europe there has been limited use and therefore evaluation within Australia.

The study detailed in this paper explored survivors' use of an ICU diary as a post-discharge recovery tool in the Australian setting. The results of the study will provide clinicians, managers and educators with evidence to assist them to effectively implement ICU patient diaries in their own clinical setting.

METHOD

Diaries provided for participants were designed by the researchers and professionally printed. Nursing staff received education sessions about the construction of the diaries and written guidelines were distributed to reinforce these education sessions. Staff were encouraged to detail the participants' daily activities, how they were responding to treatment and who had visited them. Photographs were also taken of participants but withheld from them until they gave consent for their use in the diaries (Åkerman et al., 2013). Meaningless entries, for instance about the weather and any personal information about staff were discouraged. Family members were encouraged to make entries in the diaries in written or pictorial form, which many chose to do particularly if family members were children. When participants were clinically stable, had been extubated and were preparing for discharge to the wards, the primary researcher would approach them to discuss their diaries. This discussion was undertaken in a sensitive manner and a full explanation of the purpose and composition of the diaries was given to each participant prior to going through their diary with them. This was often an emotional time for the participants and the researcher ensured enough time was devoted to this initial diary discussion. None of the participants became unduly distressed when viewing their diary for the first time but support mechanisms had been identified if this should be the case. The research team visited all participants in the wards every two to three days until hospital discharge to monitor individual responses to their diaries and answer any questions which may have arisen as a result.

Following discharge from ICU the diaries become the property of the survivor who if they so wish, may read and make entries into them. However, the frequency of diary entries by survivors post discharge has not been investigated and it is therefore unknown if this is a frequent practice. This descriptive qualitative study was conducted in a general ICU in Western Australia. Participants were asked to complete a written open-ended survey at three, six and twelve months following hospital discharge. The survey aimed to elucidate the frequency of which they and their relatives had read their diaries and what thoughts and feelings this generated.

PARTICIPANT RECRUITMENT

Inclusion criteria for the study were adults aged 18 years and over, who were ventilated for at least twenty four hours and were receiving ongoing active treatment, had no new or pre-existing cognitive impairment and were English speaking. The next of kin of each eligible patient was approached by the ICU nursing staff to gain consent to commence a diary and a verbal explanation of the study was given to the relative. A written information sheet was then offered explaining that the diaries were a means of providing their relative with a factual record of events during their ICU stay. This explanation also included a description of the diaries and their purpose, who would make entries in them and the completion of the surveys post-discharge. Following discharge to a ward, patients who remained in a stable condition were offered verbal and written clarification of the study and if they were willing to participate, written consent was obtained. Surveys were distributed to participants' by post to their usual residences at three, six and twelve months post hospital discharge. A stamped addressed envelope was included for return of the surveys. If surveys had not been returned by participants within two weeks, the researchers contacted the participants by telephone once only to encourage them to do so.

Ethics approval was gained from the appropriate human research ethics committees. Confidentiality and anonymity were assured and all surveys were coded and de-identified. Participants were assured that they would not be identified by their comments, which may be included for publication or conference proceedings in the future. Only the researcher had access to the coding system and identification of participants, to be able to contact them if they had not returned surveys within the anticipated timeframe.

PARTICIPANTS

Thirty two patients were eligible to participate in the study. From these, four patients or their relatives declined to participate, ten withdrew from the study after initially agreeing to participate, seven completed all three surveys during the year following hospital discharge, six participants completed the first two surveys and five completed the first survey only.

Participants were classified as withdrawn from the study if they did not return their surveys within six weeks of receiving them. Participants were contacted by telephone on one occasion to remind them to complete the surveys but any further contact was deemed inappropriate in this group as potentially some may have been

experiencing complications of their critical illness. Reasons for relatives refusing to participate in the study were not explored at the time.

DATA COLLECTION

The surveys were developed by the researchers, as an existing suitable instrument could not be identified in the literature. The survey consisted of nine questions, some of which were multiple-choice eliciting how many times participants had read their diary since discharge; the remainder were open-ended questions which invited the participants to describe their feelings when reading diary entries. Three questions focussed upon the participants' families views of the diaries and in particular if they would recommend the use of diaries to others who had a family member in ICU.

The surveys were reviewed by a panel of three experts to establish face validity of the tool. The three experts met with the researchers to discuss the content and structure of the survey and changes were made to the structure of some questions in response to their feedback.

DATA ANALYSIS

Data collection and analysis were approached using a qualitative descriptive framework. This approach does not require a highly abstract rendering of the data, and is a method of choice when fundamental descriptions of phenomena are required (Sandelowski, 2000). Surveys were analysed using standard processes of qualitative analysis (Streubert Speziale & Rinaldi Carpenter, 2008) and included coding, finding categories, clustering and identifying patterns and meanings. The data were reflected on and coded line-by-line to identify significant meanings, that is, words or phrases that the participants used and which were identified as being of interest or importance (Strauss & Corbin, 1990). The coded meanings were categorised and clustered and the relationship between them identified, thus confirming that the themes which emerged were adequate and informative.

Trustworthiness was achieved by addressing credibility and transferability of the data (Fossey, Harvey, McDermott, & Davidson, 2002; Lincoln & Guba, 1985). Credibility was ensured by giving a sample of the transcribed surveys to two experts in qualitative data analysis who coded and categorised the data individually, with overall agreement and consistency found between the experts' and the researchers' analyses.

Transferability was established by developing rich descriptions and maintaining an audit trail to allow comparison of the study with those conducted in similar contexts.

The following section provides statements that illustrate the main categories. Statements are not identified by participant to preserve anonymity.

FINDINGS

The ICU survivors who participated in this study included nine males and nine females who were aged between forty four and eighty four years. The reasons for admission to the ICU included respiratory failure, intraoperative complications, septic shock and acute renal failure.

Themes that emerged from the data included: feelings generated from reading the diary; gaining a sense of reality; feeling cared for; sustaining human connection; and insight into their illness. Additional data collected included: the frequency survivors and their families made diary entries; the frequency they read and discussed the diaries; their views of the diaries and whether participants would recommend the use of diaries to others.

FREQUENCY OF READING THE DIARY SINCE DISCHARGE FROM ICU

Twelve participants read their diaries at least monthly at six months post discharge, however four of these participants recorded that this had reduced in frequency over this time period. For the remainder, four read the diary less frequently than two monthly and two had never read their diary after discharge. For those that did not read their diaries their reasons included feeling that their health had improved and one participant found the diary "too upsetting" to read.

WRITING IN THE DIARY POST DISCHARGE

Fifteen of the participants had not written in their diary since discharge. Of the four participants that had written in them, their reasons were; not only to fill in the gaps but also because they wanted to respond to the nurses' comments. For those few who continued to write in their diary post discharge they experienced mixed emotions. These emotions included fear "as the memories came flooding back" and a realisation that they could have died. Alternatively, some participants also reported feeling joy and happiness because writing in the diary helped them to remember their feelings when reading their families' entries.

DISCUSS THE DIARY

Seven of the participants did not discuss their diary with anyone whilst they were in hospital. Of the twelve that did talk about their diary, the majority (nine) discussed it

with their family, six with nurses, four with friends and one with other patients and non-nursing staff. As demonstrated by these results some participants' discussed the diary with more than one group of people.

FAMILY VIEWS OF THE DIARY

All participants considered that their family felt the diary was a good idea. Writing in the diary assisted the family to express their feelings and provided a quick reference for them. When family members visited they could read the entries and quickly catch up with their loved one's care requirements since the last time they had seen them. The families felt appreciative of and supported by the staff entries and these records provided a focal point to open up discussion with other family members. However, on some occasions family members were fearful for their loved one's welfare and their prognosis after reading some of the staff accounts.

FAMILY READING THE DIARIES

Twelve of the respondents stated that their family had never read the diary since being discharged from ICU. The reasons for this were not explored in the study however, this could be interpreted as avoidance behaviour by family members and a reluctance to re-visit their traumatic experience. Of those who had, two read it monthly or more often and the remainder less frequently than every two months.

FAMILY ENTRIES IN THE DIARY POST DISCHARGE

Sixteen of respondents' families had never written in the diary post discharge. The two respondents who had written in the diary had only done so on one occasion and the reasons given for these entries were to welcome their loved one home after discharge and because they had asked them to.

FEELINGS GENERATED FROM READING THE DIARY

Reading the diaries was reported to be an emotional experience for all of the participants and even if these were considered negative, they considered that this did not have a detrimental effect upon them but served to reinforce their experience. There were reports of both positive and negative emotions but despite this, there evolved a realisation of how critically ill they had been and how much their families and ICU staff cared for them. The diverse emotions experienced by the participants included humility because of the care they received and relief that they had survived the experience. Some however, experienced shock and fear when they read their diary entries, which

prompted one participant to explain: *"I don't often read my diary because it makes me feel very emotional"*.

GAINING A SENSE OF REALITY

Whilst being heavily sedated and ventilated, awareness of experiences and environment is lost. The diaries provided participants with details of what had happened to them and their family during this time. The diary entries demonstrated to the participants the severity of their illness, and that despite being immersed in a technological environment, the humanistic component of their care remained paramount. For others, the diaries made sense of what they remembered and recognised; that the information in the diary assisted them to "fill in the gaps" and to gain a better understanding of not only their illness but also the days they lost. One participant wrote: *"I still remember vividly my experience when conscious – most of which were hallucinations, so it helps reading it to get a sense of reality"*.

The following comment illustrates the potential of diaries to fill the memory gap: *"I had no recollection of anything ... it was only after I read the diary that I realised how seriously ill I was, also I could see the daily happenings and improvements"*.

FEELING CARED FOR

The theme of feeling cared for was a concurrent one for the participants and most stated they were grateful that although the staff were busy, they still found time to write in the diaries. They considered this to be above and beyond what was expected of the staff and was interpreted by participants as an act of caring. As one participant commented: *"I was being cared for by the most professional, caring and committed nursing staff"*. Another stated: *"makes me feel good – that somebody really cares"*. The notion of individualised care in ICU was also commented upon: *"I felt appreciative of the personal care...shampooing of hair, brushing of teeth, plaiting my hair ..."*

CONNECTION WITH LOVED ONES

The diary on some occasions provided the respondents with evidence of how their families, often in times of crisis, sustained a connection with them through the diaries. This was evidenced by expressions of support, love and hope articulated through their diary entries. One participant commented: *"They had a chance to communicate with me ... helpful to read about how much they cared ... revealed things they wouldn't normally talk about"*.

Another participant commented that: "*Seeing in writing how much I was treasured.....gave me a different perspective*"

Of the participants who responded and had read their diaries it was considered that the staff reports helped them gain a better insight into their illness, which was augmented by viewing diary photographs intended as a visual representation of their journey to recovery. Initial feelings of shock when seeing the photographs for the first time emerged, followed by a realisation of the severity of their illness.

Several of the participants were grateful to the staff for writing in their diaries as it provided them with an opportunity to "get to know" the staff who had cared for them which they were unable to do whilst were in hospital due to their illness and treatment.

RECOMMENDING OTHERS TO USE A DIARY IN ICU

Each survey included a question about whether the participants and their family members would recommend a diary to others who had loved ones in ICU. Despite the mixed emotions reported by survivors, all agreed that they would recommend the diary to someone they knew who had a family member in ICU. Despite some participants not reading the diary when at home, they had all read it whilst in hospital and considered that the diary provided them with an insight into their situation and assisted them with their recovery. Several participants mentioned that whilst in ICU and unable to communicate the diary helped their family members express their feelings.

DISCUSSION

The findings from this study have shown that within this small cohort many participants continued reading their diaries; however few made written entries following discharge. The diaries provided survivors with information about their illness, what had happened to them in ICU and affirmed the preservation of human connection when they were immersed in a technological environment. The diaries evoked myriad emotions for survivors and their families. Experiencing these emotions rather than suppressing them may have allowed survivors to re-process their thoughts about their experience. However, it was necessary to ensure survivors were supported by experienced ICU staff when they first read their diary and viewed the pictures within it, as it is acknowledged that this could be distressing for them. Participants were informed that reading their diaries may be difficult for them and that if they felt they wished to discuss their diaries following discharge from hospital that they could

contact the researchers at any time but none did. On discharge from hospital participants were also advised to contact their general practitioner if the memories of their experience did not fade e.g. recollections, dreams or if they experienced intrusive thoughts or distress about their ICU experience. The diaries further enabled them to build an accurate autobiographical story which may have enhanced their psychological recovery.

The participants in this study described a range of both positive and negative emotional responses to their diaries. An appreciation of the potential detrimental effect that diaries may have is not well illustrated in the literature. As such, clinicians should be cognisant of the risks and potential harm which may be associated with ICU diaries when considering implementing this initiative in their setting.

Participants viewed the nurses' entries as an emotionally moving act of caring which they considered to be above and beyond their expected duties. The diaries appeared to forge a humanistic bond between patient and carer, and as evidenced by the post-discharge reports, this bond prevailed long after discharge. The transfer from ICU, to ward care and eventually to home is known to be a difficult transition for ICU survivors (Unroe et al., 2010). This is probably due to the phenomenon of "separation anxiety" which occurs during transition from ICU to ward care and is well documented in the literature (Brodsky-Israeli & DeKeyser Ganz, 2011; Field, Prinjha, & Rowan, 2008; Forsberg, Lindgren, & Engström, 2011; Wu & Coyer, 2007). Diaries may reduce the effects of separation by endorsing the connection between patients and staff. The diary entries were a permanent testament to the enduring nurse-patient relationship, however this dimension has not been explored in the literature and is worthy of further investigation.

Similar to other studies diaries were found to have value, filling in the memory gap for these survivors and bringing a sense of coherence to their experience (Egerod & Bagger, 2010; Engström et al., 2008). The literature has shown that reading entries and viewing photographs may aid the survivor to come to terms with the severity of their illness and hence set realistic recovery goals (Combe, 2005). However, a number of eligible patients declined to participate in the study and therefore, did not have the opportunity to continue writing in their diaries during their recovery. It was beyond the scope of this current study to explore the reasons patients chose not to participate in the project. However, these reasons should be further explored in order to examine the nature of the relationship between non-use of diaries and PTSD which has recently

been alluded to in the literature (Jones et al., 2010). A major challenge for health care professionals is to develop and establish effective follow-up services for those survivors at risk of psychological co-morbidity. As clinicians become more aware of the associated risk factors, at-risk patients can be identified in ICU and targeted for intensive rehabilitation programs. The use of diaries may have an important role in the recovery of ICU patients and not just for those who are identified as being at risk of psychological complications. However, further investigation is required to determine which patients potentially benefit from diaries and those patients for whom diaries may be deleterious. Diaries are a generic tool which may transcend the diversity of complications in this population and the accompanying diffuse emotional response. The participants in this current study were grateful for the insight they developed regarding their illness from reading the diaries and looking at photographs of themselves whilst in ICU. The use of photographs has been shown to be a powerful tool to assist survivors to realise the severity of their illness and the need to set more realistic goals during their recovery (Backman et al., 2010; Combe, 2005; Egerod & Bagger, 2010; Hale et al., 2010). The effect of this visual media is yet to be evaluated and since photographs are widely used in ICU diaries, it is worthy of further detailed investigation.

A number of participants in this study did not access their diaries following discharge. The reasons for this may have been many and may be related to the lack of guidance provided to the participants regarding diary use after discharge. The impact of guided support for survivors on their diary use warrants further exploration. Participants may have been exhibiting avoidance behaviour, that is, avoiding stimuli associated with the traumatic event, which may have evoked flashbacks, memories and re-experiencing the primary trauma (Amir, Leiner, & Bomyea, 2010). Determining the reasons survivors and their families discontinued the diaries was beyond the scope of this study and requires further epistemological research.

LIMITATIONS AND FUTURE DIRECTIONS

Diaries are a cost effective tool which may have potential in enhancing the recovery of ICU survivors however, the impact of this intervention has not been evaluated in the Australian setting. The findings of this study suggest that survivors read their diaries following hospital discharge but did not actively diarise. The impact and use of diaries as a psychological intervention, including the use of prospective

diarising during the recovery phase has not been a focus of research and requires future in-depth exploration.

Currently in Australia, the provision of routine after-care for ICU survivors is rhetorical despite evidence to suggest forms of follow-up may have a place in improving physical and psychological outcomes for ICU survivors (Crabtree-Buckner & Kautz, 2012; Jackson et al., 2012; Papathanassoglou, 2010). Diaries could play a role as the foundation on which to build follow up services for ICU survivors and this is also worthy of further investigation.

Limitations of this study included the use of a small sample, low response rate from participants and the use of a single site. A single site was utilised for the study because there are no other units in Western Australia which advocate the use of diaries in ICU.

The reason for the low response rate to the surveys was not explored further by the researchers and therefore these remain unknown. It could be postulated that the low response rate resulted from avoidance behaviour, a possible consequence of PTSD or that the participants were in some way negatively affected by the diaries and did not articulate this for fear of offending the staff who had cared for them in ICU. Following up participants who did not respond, despite initially agreeing to do so and elicit the reasons for this, may have strengthened the findings of the study.

The data collection instrument was only subject to face validity and a greater depth of validation would have increased the reliability of the instrument. Therefore the applications of this study across multiple sites and the triangulation of data through a variety of data collection tools e.g. interviews or telephone surveys would strengthen the findings of this study and their application in other contexts.

Furthermore, demographic data, severity of illness, length of stay and presenting diagnosis were not collected therefore it is not possible to measure if these factors influenced participant responses or if the findings of this study may be applicable to other settings.

Diaries are a simple tool constructed by ICU staff which can be introduced with minimal time and cost implications in any ICU, or potentially in other clinical settings. The use of diaries in early post-discharge and beyond has received limited evaluation. In this study diaries were used as a tool by survivors as a medium to aid reconstruction

of events in ICU, of which survivors had limited recollection. The retrospective use of diaries and prospective diarising following a critical event, should be explored as a potential aid to recovery.

CONCLUSION

The focus of this research was to explore the perception and utilisation of diaries by ICU survivors and their families post-discharge. The results from this small study demonstrated that ICU patient diaries were considered to be a positive initiative by those who completed the surveys. Despite survivors experiencing mixed emotions when reading their diaries, this did not detract from the positive feelings they described. Survivors considered that the diaries served many purposes; helped fill their memory gaps, gave them an understanding of how ill they had been, concreted their experience in reality and enabled them to realise that during crisis they were still cared for by nursing staff and loved by their families. This human connection transcended the technology and de-humanised state which epitomises a critical illness.

CONTRIBUTION OF THIS CHAPTER TO THE THESIS

In the preceding chapter a study has been described which explored the utilisation and perceptions of ICU diaries during the recovery period for survivors. The findings from this study identified the many potential purposes of diaries not least by assisting survivors to comprehend the severity of their ICU event/illness and to aid them in establishing realistic recovery goals; and these findings have been echoed in the literature. The humanistic element of ICU diaries stood out in this study as the diaries enabled survivors to realise how much they had been cared for by staff and their families. They described how they felt that the human connection between them and their families and carers was maintained despite them being immersed in a technological environment unable to actively communicate. This study was an important precursor to the larger study as it identified that survivors in the Australian setting welcomed the notion of diaries and found them to be a valuable tool to refer to during their recovery; as they endeavoured to come to terms with what had happened to them in ICU and the disruption to their lives.

Few participants diarised during their recovery phase. One participant added entries to his diary as if to respond to the nurses' entries but none considered that the diaries were to be used in that way as they moved forward with their lives. This suggests that because diaries in ICU are constructed by others as a representation of

the survivors' experiences; this does not convey a sense of ownership of them by the survivor and hence the stories within them. Survivors' limited recall of events and subsequent inability to identify with their stories depicted within the diaries exacerbate this potential disengagement with their experiences. This notion prompted the researcher to review other means of re-creating survivors' stories through their individual lens building on the diary concept which the participants valued, but by using methods where survivors could take ownership of their stories.

It is now time to introduce the participants in this study.

PARTICIPANTS

Out of deep respect for the participants in this study and as an acknowledgement of their contribution to it I have dedicated this section to them. Here I introduce them, all of whom had experienced a critical event/illness and a subsequent ICU experience. The participants experienced a variety of critical illness/events which necessitated their admission to ICU. These included respiratory failure, sepsis, and traumatic injury related to a road traffic accident. The ages of the participants ranged from 32 to 84 years and all resided in the suburbs of Perth, Western Australia. The participants all presented with different conditions and experiences prior to their admission to ICU as well as a range of demographic and social contexts; however, their experiences of recovery were of a common currency. All of the participants gave their time to engage with the study and recreate their stories of recovery. This was not an easy process for some of the participants and yet they were willing to reveal their inner most thoughts and feelings without reservation. This supports the methods used in this study enabled this process of disclosure often about personal issues which were difficult to articulate. The interpretive biographical approach applied in this study and the engagement in this process by the participants has resulted in rich findings which give a unique insight into the recovery of ICU survivors.

It is without doubt that ICU survivors have suffered traumatic experiences as a result of their critical illness/event and ICU stay. At the time of recruitment to this study potential participants were in the early stages of their recovery journey and I did not have knowledge of the current physical and psychological state of potential participants who I approached. During the recruitment process it became apparent however, that recruiting participants for this study would be challenging. Twelve potential participants when initially approached by the researcher declined to take part in the study and three who had consented to participate withdrew from the study without notice; six completed the study. The initial contact with participants was made by telephone and it was at this point that these twelve potential participants declined to participate. If potential participants agreed to meet with the researcher to discuss the study, all of these agreed to participate. The potential vulnerability of the participants may also have impacted upon recruitment as the experience of a life threatening admission to ICU, for those who survive; arguably alters the course of their

lives leaving many survivors struggling to cope with residual challenges (Hermans et al., 2014; Jones & Griffiths, 2013) which may delay or even prevent meaningful recovery. Lasting complications could deem ICU survivors as vulnerable research participants and researchers should be cognisant of this to ensure they come to no harm as a result of their participation.

The reasons why participants withdrew or did not wish to participate in the study were not explored for fear of causing distress, therefore this can only be postulated to be related to their ICU experience. The presence of psychological distress in ICU survivors is well documented (Carr, 2007; Crabtree-Buckner & Kautz, 2012; Kiekkas et al., 2010) and a symptom of the most severe form of psychological distress Post Traumatic Stress Disorder (PTSD) is avoidance behaviour (American Psychiatric Association, 2013) i.e. any stimulus which may remind survivors of the traumatic precipitating event. The reasons why ICU survivors do not participate in research or engage in other activities related to their ICU experience should be explored as these are potentially the population who would benefit most from the experience.

The participants who completed the study who I present here were all allocated pseudonyms and the details of their presenting conditions withheld to guarantee their anonymity.

SAM

Sam was a 37 year old man who lived with his wife Grace and their three young children in the northern suburbs of Perth. The family had emigrated to Perth a few years earlier and had happily settled to an Australian way of life. Sam's wife did not work and he was employed full time as a supervisor in a warehouse. His job at the warehouse was very important to Sam and he worked long hours to ensure he met deadlines and achieved a high standard of performance. For some years Sam had been troubled by abdominal pain and general malaise. Despite ongoing investigation Sam had not been diagnosed with a cause of his symptoms. Over a period of days he became so unwell and with significant abdominal pain that he was admitted to hospital. He was admitted to a general medical ward where he underwent investigations and was consequently diagnosed. It was during this experience on the ward that Sam was asked by a nurse if he was an alcoholic, which greatly offended him and a condition which he vehemently refuted. This event significantly affected him and he relayed the details of it to me to me several times during the course of the study.

On the ward Sam's condition quickly deteriorated and after being reviewed by the critical care team he was admitted to ICU for further management. Sam was initially treated conservatively in ICU and closely monitored but his condition rapidly deteriorated and he was sedated and ventilated the same day. He remained ventilated for several days and as his condition did not improve, and extended ventilation time was anticipated, he was given a temporary tracheostomy to facilitate ventilation and future weaning. His condition continued to be labile over the following week but eventually began to improve. He was weaned from ventilation over a four day period at which point he began a stormy recovery period, complicated by acute delirium and profound physical disability. Sam stayed for another week in ICU during which time his delirium was pharmacologically managed. This was a stressful time for Grace and his parents who had travelled from his birth country because of his condition. They were troubled by his delirium but tried to orientate him during their frequent visits to ICU. Eventually Sam's physical condition improved so much that his tracheostomy was removed and he was transferred to a general ward. He was still experiencing some confusion however but was deemed well enough to be transferred. Sam was discharged home following several days on the ward and intensive physiotherapy. On discharge from hospital he remained significantly debilitated physically from his Critical illness.

Discharge from hospital was only the beginning of another challenging journey for Sam. He continued to experience delusional recall of events in ICU including vivid recall of disturbing dreams dominated by death and dying. This recall and most significantly being able to play his dreams out at will in waking hours, had a profound effect on him and they gradually became more intrusive during his recovery causing him psychological distress for which he sought treatment.

Sam also required ongoing medical management which culminated in the discovery of a genetic malformation of his biliary system which had predisposed him to illness. This was a great relief to him to receive a tangible reason for the years of pain and malaise.

When I met with Sam for the first time he was a warm and articulate man who was eager to share his story with me. He reflected on his journey with candour but also with relief that he had survived his experience. He often reflected upon how debilitated he had been and what a shock this had been to him but how he had changed his life to

incorporate an exercise regime and an overall healthy lifestyle. Sam exuded a sense of achievement and looked forward to the future.

CHLOE

Chloe, a 74 year old woman lived with her husband in a suburb of Perth. Chloe had two adult children, one of whom lived in the dwelling next door to her and as a result they had a very close, supportive relationship. Together with her husband they operated the family business and despite being past retirement age they both played an active role in the day to day running of it. Chloe was physically active and fully independent. She had been diagnosed with a chronic bowel disease which hitherto had been managed medically. She began to experience abdominal pain and vomiting unexpectedly which was so severe she was admitted to hospital. As this was an acute episode of her existing disease and resulted in an acute bowel obstruction and Chloe quickly deteriorated. She required emergency abdominal surgery which resulted in the formation of a temporary stoma. Postoperatively Chloe was transferred to ICU for overnight ventilation due to the extensive surgery, her age and potential sepsis. Unfortunately her condition deteriorated as she developed sepsis requiring vasoactive support and an extended period of ventilation. This period of ventilation was extended for ten days whilst the underlying sepsis resolved. She was weaned from the ventilator over a period of two days without the need for a tracheostomy. Chloe remained in ICU for three days following extubation as she experienced a period of confusion during that time. She was transferred to a ward following a further three days in ICU and required three weeks of in-patient rehabilitation because of her profound physical disability. Her debilitation was so severe at that point that she feared she may never walk again. Chloe did not recall being told that she had a stoma and that she discovered it herself; the shock of which she reiterated to me several times during her interview.

When I interviewed Chloe five months following hospital discharge she was still suffering residual issues related to her physical debilitation as a result of her ICU experience. She divulged that she still had some bad days related to her recovery and this was a source of constant frustration for her. She was eager to contribute fully to the family business and this was weighing heavily upon her. Chloe read her ICU diary frequently to find out what happened to her during that time as she had no recollection at all of events in ICU and didn't remember being so ill prior to her admission. She found it difficult to believe that she had been so ill without any

recollection of being so. She was however, reluctant to request any photographs to add to her diary that may be available of her in ICU and she was very definite about not wanting to see what she looked like at the time. Chloe had learned to adapt to life with a stoma and had no intention of undergoing reversal surgery as she feared that something may happen to her again.

Despite ongoing physical impairment the experience of a critical illness had changed Chloe's outlook on life. She found it difficult to comprehend that she had nearly died and expressed how precious life had become to her since.

PHOEBE

Phoebe was an 84 year old woman who lived in a separate dwelling at her daughter's house. She had two adult children and they had emigrated as a family several years before. Phoebe had been widowed for a long time but had remained independent and maintained an active social life with several groups of friends. Phoebe had an underlying chronic respiratory disease and following an exacerbation of this was admitted to hospital in acute respiratory failure. She was initially transferred from the emergence department to a ward for stabilisation and monitoring. However, Phoebe became confused and her respiratory failure worsened necessitating an admission to ICU. Phoebe's condition was deteriorating rapidly and she required ventilation shortly after her admission to ICU. She was ventilated for a period of four days and consequently weaned from it on days five and six. Phoebe experienced some confusion during this time but was stable enough to be transferred to a general ward on day seven.

Phoebe was very enthused about telling her story to me when I interviewed her. She was animated and articulate and appeared to enjoy conversing, even though her experiences had been challenging for her. She remained physically debilitated by her ICU experience and expressed disbelief that she could have been so ill without any physical signs i.e. injury as if that would justify how she was feeling. She also was having difficulty coming to terms with how long her recovery was taking as this was unexpected and physically she appeared recovered to herself and others. When prompted about her recollections she divulged that she had experienced persecutory dreams in ICU which had distressed her at the time and which she could still recall at will during waking hours. Similar to Sam she did not dream these during sleeping hours and the people who featured within them took on different, persecutory

personas. As with Sam; she was reluctant to share the content of many of the dreams with those closest to her for fear of their reaction and distressing them.

Phoebe had only read her ICU diary once since hospital discharge but felt it gave her an understanding of what had happened to her in ICU. Phoebe's life had also changed significantly; as the once active social life she had enjoyed had gone. She barely left the house and therefore did not socialise twice a week with friends as she did before. Phoebe was almost a recluse; a stark difference to her life prior to ICU. Following her discharge from hospital she became reclusive and reluctant to socialise even at family gatherings because of large crowds of people. When I offered Phoebe the details of services which may help her and offer psychological support she declined as if she accepted that this was how her life would be going forward.

LUKE

Luke was a 34 year old man who had emigrated to Australia four years before and lived alone in a suburb of Perth. He was fit and well and working full time in the building industry. An avid motorbike enthusiast for many years, he was involved in a collision with a car whilst riding his motorbike; the details of which he had accurate recall of. He sustained spinal and abdominal injuries and underwent an emergency laparotomy and bowel resection. Due to the nature of his injuries and potential complications he was transferred to ICU for postoperative ventilation. He was ventilated for two days in ICU and extubated without any issues. The remainder of his time in ICU was uneventful. Luke was transferred to a general ward two days following surgery and fitted with a brace to stabilise his spine. He required extensive physiotherapy on the ward as was discharged to home ten days following his accident.

When I met Luke for the first time he was very physically debilitated and unable to care for himself and this was a source of great frustration for him. He was also experiencing issues as a result of his bowel resection and accessing toilet facilities was a challenge to him with his limited mobility. When I returned to interview him about his diary three months later, his physical condition was much improved and his parents, who had travelled from his birth country to care for him, had returned home. His only recall of ICU was of being a dreamlike state and a sensation of drowning but these recollections did not trouble him at all. He was required to wear a back support following his injury and in addition to this continued to be physically debilitated as a result of his ICU experience. Luke was unable to work for some time following his

accident and financial issues became a significant stressor for him. He depicted these concerns in his diary through a series of "smiley faces" which portrayed his mood at the time of his entries. He treasured his diary and often read it to reflect upon how far he had traversed from his early days of recovery.

BELLA

Bella was a 32 year old lady who lived with her husband and young son in a Perth suburb. She was currently unemployed but had studied psychology and counselling in the past but was not actively looking for work. Bella had been diagnosed with a chronic mental health disorder many years before and the continuing management of this and stability of her mood was an ongoing challenge. Her son had been diagnosed with a learning difficulty and this had also contributed to her stress. Relationships at home had been under strain and after an altercation at home she attempted suicide. Shortly following admission to the emergency department her conscious level reduced and she was ventilated. Bella was then transferred to ICU for further management. She was admitted to ICU from the emergency department and ventilated for a period of 24 hours and a further day before being transferred to a general ward. She was transferred to the Mental Health Unit two days afterwards. She remained in the Mental Health Unit in a voluntary capacity for another week. When I met with Bella for the first time she was feeling positive about the future and was looking forward to diarising as she remarked that she had always used a diary up until recently. When I met her for the second time to interview her about her diary she asked if she could read it out loud to me. As I listened to Bella she punctuated her rendition with reflections of disbelief that this had been her just a few short months before. It was as if she was in awe of how she had felt during the dark times and how far she had journeyed; captured through the process of diarising.

Bella did not experience any physical debilitation following her short stay in ICU; nevertheless she had been profoundly affected by the experience in other ways. Prior to the critical event she had lacked confidence and fear had been a large part of her life. Now she considered that her life had changed forever because of the realisation that without help she would have died. This turning point moment had fundamentally affected her outlook on life and prompted her to re-evaluate it grateful to and how she was moving forward. She was now actively searching for employment; grateful to be alive. As the interview drew to a close she concluded that now her life was positive and that she looked forward to the future with her husband and son.

OLIVIA

Olivia was a 51 year old woman who lived with her husband and teenage son settling in Perth from overseas many years earlier. Prior to her illness Olivia had been fit and healthy and enjoyed her full time employment in the retail industry, where she often worked longer hours than was required of her. She had taken a holiday overseas with her husband and developed flu like symptoms shortly after returning home. Olivia was ill for several days with her condition progressively worsening before being admitted to hospital, by which time she was unconscious and significantly compromised. When the severity of her illness was recognised in the emergency department Olivia was quickly transferred to ICU. She was ventilated shortly following admission to ICU and thereafter began many days of cardiovascular instability due to septic shock. She required extensive pharmacological management to maintain her organ functioning and developed multi-system failure. This instability continued for a period of seven days when her condition slowly began to improve. At one point Olivia experienced a compromising cardiac arrhythmia secondary to her condition which required immediate management to reverse it and prevent complications.

When her condition had eventually stabilised Olivia was weaned from ventilation and remained on ICU for a further three days. It was during this period that Olivia was diagnosed with neurological deficit secondary to a stroke which had been caused by a blood clot from the cardiac arrhythmia. When I interviewed Olivia she continued to have a neurological deficit with visual impairment in one eye and significant loss of function in one hand.

When I met Olivia for the first time she was very motivated to tell me about her experiences in ICU and during recovery. She was unsure if she would be able to complete the diary because of her hand but that she would try. After I returned to interview Olivia she was again keen to share her story depicted in the diary and share her experiences with me. As she had no recollection of her time in ICU her husband had made entries about that time for her. He had also recorded entries about her recovery which she had dictated to him.

Olivia had no factual recall of events in ICU but vividly recalled the dreams she had in ICU although these did not trouble her during her recovery and she was not able to "play them out" at will; nor did she re-dream them during sleeping hours. Olivia repeatedly expressed her disbelief that at such a young age she had been left with a disability which had changed her life significantly. Simple tasks now took her hours to

complete and she was frequently reliant on others and this was a source of great frustration for her. She no longer slept for long periods and spent most of the night awake; exhausted during the day. She could no longer work and I could sense that this was a source of great sadness for her. She remained very angry and distrustful of the medical profession as despite saving her she now had a permanent disability as a result of her critical illness which had changed her life forever.

As the participants have now been introduced a detailed discussion of the findings from this study are detailed in the following chapters in relation to their individual experiences. The following chapter has been prepared as a paper for publication which is currently undergoing a peer review process in the journal: *Contemporary Nurse*.

CHAPTER FIVE: COMING OUT OF THE MADHOUSE: SURVIVORS' STORIES OF ICU AND RECOVERY

INTRODUCTION TO CHAPTER FIVE

In the following chapter the analysis of findings are discussed from one component of data collection: face to face interviews. These interviews were undertaken with the participants five months post discharge from hospital and following three months of diarising. During these interviews being cognisant of the personal nature of what was being disclosed the researcher was mindful to focus on what was not being said by the participants as they recalled their experiences of recovery as well as what was being said. This is where the field notes and memos were such an integral component of the data collection process and enabled the researcher to reflect upon the hidden elements of recovery and yet still remain connected to the participants throughout the interview process.

Ewens, B., Hendricks, J., & Sundin, D. Coming out of the mad house: survivors' stories of intensive care and recovery.

ABSTRACT

Intensive care survivors report physical and psychological problems during recovery phase which can adversely affect quality of life. A lack of rehabilitation services leads to delayed diagnosis of complications and protracted recovery in this population. Diaries created for survivors in intensive care depict events which occurred whilst they were immersed in a technological environment, often unaware of their surroundings. Fragmented or absent memory of the experience in intensive care has been identified and as a chronological record of events; diaries are intended to help fill memory gaps. Diaries are beginning to show promise as an intervention which may reduce the new onset of Post Traumatic Stress Disorder however, the evidence remains tentative. This interpretive biographical study explored the use of visual diarising with six participants recruited from a general intensive care unit in metropolitan Western Australia. This approach enabled survivors to re-create their story of intensive care and recovery. Survivors were interviewed about the diaries they constructed and their meaning interpreted together with the researcher. The significant themes identified in relation to the intensive care experience included: *life changing experience, expectations of recovery over time, support at home, ICU dreaming, unpleasant memories and, diarising in recovery*. Interpreting visual diaries in this population may identify those survivors experiencing emotional or psychological difficulties related to their experience. Diaries in intensive care used for some time arguably are not the survivors' stories but a perception of them by those who construct them. Survivors often have difficulty constructing a narrative of their experiences and this innovative method enabled them to re-construct their stories through their lens; to articulate what they were unable to, using other methods. This study identified that diarising during the recovery period may enable survivors to reflect upon their intensive care experience and how far they had traversed during their recovery.

INTRODUCTION AND BACKGROUND

A sudden and often unanticipated critical illness or event and associated intensive care unit (ICU) admission may result in life changing consequences for survivors. The prevalence of psychological and physical morbidity with associated reductions in quality of life has been reported in the literature (Cuthbertson et al., 2005; Dowdy et al., 2005; Wade et al., 2012). Individual presentations to ICU vary in complexity and severity yet the complications survivors experience have commonalities, many of which could have been ameliorated with early identification. The range of physical complications reported by survivors include extreme fatigue, reduced activity (Denehy, Berney, Whitburn, & Edbrooke, 2012) appetite suppression (Jones, 2012), sleep disturbances (Parsons et al., 2013) sexual dysfunction (Griffiths et al., 2006a) and a spectrum of neuromuscular problems termed polyneuropathy or neuropathy (Guarni, Bertolini, & Latronico, 2008; Jones, 2012; Needham et al., 2011) and neuro-psychological after effects.

Despite awareness of the difficulties survivors face and the potential burden on service provision, there remains a lack of congruence surrounding rehabilitation programs. Survivors of a critical event require psychological support and holistic rehabilitation following discharge (Griffiths & Jones, 2007b) which should commence in ICU (Peris et al., 2011; Rattray, 2013). The expansion of existing evidence to inform rehabilitation strategies and establish interventions for those who are considered most at risk has been advocated (Cuthbertson et al., 2009; Denehy & Elliot, 2012; Jones, 2014; Rattray, 2013).

One way to empower those with lived ICU experiences is to use diarising. This strategy for ICU patients revealed that some survivors experienced memory loss or delirious recall following an ICU experience and were thwarted in being able to recall a coherent account of their experience (Backman & Walther, 2001; Dowdy et al., 2009; Granja et al., 2008). This may be attributable to the severity of illness/event or pharmacologically induced amnesia (Wade et al., 2012).

Intensive care therapies aim to balance benefits against the risk of complications, both physical and psychological. Therefore, recent practice has seen a transition towards lighter sedation, or daily sedation interruption, with associated investigation of the impact of this on the patient experience (Tembo, Parker, & Higgins, 2013). However, the natural response to stress is the suppression of the physical and the emotional state, including memories, to enable survival. There has been limited

exploration of the role of sedation on memories but to date the therapeutic benefits of sedation regimes, that is; ease of intubation, amelioration of stress response, takes precedence over potential psychological complications.

Williams (2009) asserts that offering support with building a self-story may be beneficial to recovery in this population. This assertion is supported in the trauma literature where the ability to recount one's trauma story is reported to be therapeutic (O'Kearney & Perrott, 2006; Reisner, 2002; Tuval-Mashiach et al., 2004; Zoellner, Alvarez-Conrad, & Foa, 2002) and improve coping and overall recovery (Parker & Wampler, 2006; Pennebaker & Seagal, 1999; Wimberly, 2011). Telling a story about oneself is a means by which an individual defines their life, identity, culture and society (Bingley, et al., 2008). Self-stories examine an entire life or a segment of a life, considered significant by the teller set in relation to their experience (Denzin, 1989). The experience of a critical illness in an individual's life is a key event; and, Denzin refers to these as epiphany events and markers which have an impact upon life trajectory.

This paper discusses the analysis and implications of one component of data collection from an interpretive biographical study of ICU survivors in metropolitan Western Australia. The detailed analysis of the diaries, in this study, have been reported elsewhere (Ewens, Hendricks, & Sundin, 2014). Therefore, this paper focuses on the findings from the interviews conducted with participants.

RESEARCH AIM

To explore the application of a biographical approach to create and interpret the stories of recovery through the lens of ICU survivors.

DESIGN

An interpretive biographical approach enabled the researcher to interpret survivors' stories of their ICU experience and recovery. Interpretive biography enables individual experiences to be expressed and communicated to others and has been defined as: "...creating literary, narrative, accounts and representations of lived experiences" (Denzin, 1989, p. 11). Diaries, as the literary text, during the recovery period was chosen as method because it is an unexplored intervention in this population and empowered the participants to express thoughts, feelings and memories which they may be unable to articulate through discussion or writing alone.

SETTING AND ACCESS

The study was undertaken in a general ICU in metropolitan, Western Australia. This unit has approximately 400 general ICU patients admitted annually with a 1:1 nurse patient ratio. The case mix comprises medical and non-specialist surgical services. The use of patient diaries was an established practice for patients who have been ventilated for a period of 24 hours (Ewens et al., 2013).

ETHICAL CONSIDERATIONS

Ethical approval was granted from the University's Human Research Ethics Committee and at the study site and complied with the National Health and Medical Research Council Guidelines (2007). Contact details of potential participants who met the inclusion criteria was provided by the study site and initial contact was made with them by telephone within six weeks of discharge from hospital. All participants gave written consent after receiving verbal and written explanations. The researcher ensured that participants who may have experienced psychological distress as a result of diarising and talking about their experiences had access to local agencies to which participants could self-refer. Participants were informed they could leave the study at any time without recourse.

PARTICIPANTS

Purposive sampling ensured participants met the inclusion criteria to explore the phenomenon under investigation (Lopez & Whitehead, 2013). Inclusion criteria were: participants aged over 18 years, been ventilated for a minimum of 24 hours, understood and able to write in English with no new or pre-existing cognitive impairment recorded in their records. The criterion of 24 hours ventilation ensured that the participants had experienced sedation and were more likely to experience memory loss or impaired recall of their experience (Åkerman, 2010; Gjengedal, 2010).

Eighteen individuals met the inclusion criteria and were approached to participate in the study. Twelve declined to participate, three withdrew without notice and six completed the study. Of the remaining six, two were male and four female aged between 30 and 84 years with presenting conditions including respiratory failure, sepsis and intraoperative complications of abdominal surgery (Appendix 1). Participants' length of ICU stay was between three and 21 days and hospital stay was up to ten days following discharge from ICU. This ensured that participants did not have a protracted

overall length of stay and met the timeframe for the study. Participants were no longer recruited to the study when saturation was reached.

DATA COLLECTION

Data collection comprised visual diaries, interviews, memos and field notes. Initial face to face contact was made with participants within two months of discharge from hospital. This time period ensured that ICU experiences remained vivid as they commenced their recovery trajectory. The purpose of the initial visit was to provide details of the study, obtain written consent and provide diarising materials. This visit also served to establish rapport with participants and create a safe environment to encourage open disclosure.

Participants were encouraged to construct their diaries focussing on their experiences, thoughts and feelings of ICU and recovery. The researcher returned three months after the initial meeting to interview participants and share stories of their recovery. It was at this point that participant's visual diaries were shared with the researcher as supplemental to the interview. Participants were asked to describe their thoughts, feelings, memories and emotions from which their visual diaries evolved. Interviews were digitally recorded and lasted between 60 to 90 minutes.

DATA ANALYSIS

The purpose of qualitative analysis is to ensure that participants' experiences are illuminated and the richness of those experiences are shared through the interpretive process (Harding & Whitehead, 2013). To maintain the integrity of the study the researcher interpreted the meaning in the diaries with participants during the interviews as an integral component of analysis. Analysis of interviews and where applicable visual diaries, was conducted adapting Etherington's framework (Etherington, n.d.) and Kucera, Higgins and Macmillan's processes of interpretation (Kucera et al., 2010). Interviews were transcribed verbatim by the researcher as transcription was intended to be a component of the analysis process; the very beginning of the process to interpret the participant's story of recovery. Next, the researcher read and re-read the interviews as well as listening to the recordings to ensure she was fully immersed in the data. The story was then placed in chronological order and paraphrased to capture epiphany moments for each. Themes were identified between and within stories and similar themes and patterns were grouped together to provide shared experiences of the recovery trajectory. To uncover hidden meanings

contained within the stories propositions were identified which were comparable and categorised the aspects of the story. This process of interpretation was further supported by reflection on field notes and memos captured during and immediately following the interviews. Following this analytic step, the researcher consulted two other researchers, who were experts in thematic analysis to confirm thematic conclusions. This rechecking and verification of themes and aspects also ensured the integrity of the interpretative process. Interpretation allowed representation of memories, thoughts and emotions which the participant experienced during their ICU journey and recovery and the impact this had upon their lives.

Undertaking this structured approach to data analysis ensured that the integrity of the stories was maintained and trustworthiness achieved. Credibility of the researcher was established early as was a rapport with the participants and sufficient detail has been provided to ensure judgements can be made about the transferability of the findings. Dependability was maintained by ensuring that a consistent approach to data collection was maintained with an accompanying audit trail (Guba & Lincoln, 2005).

FINDINGS

Participants (see Appendix 1) described epiphany moments which left indelible marks on their lives and their stories were structured by them. Five main themes emerged from the interviews; and these will be discussed in turn.

LIFE CHANGING EXPERIENCE

Life changing for the participants meant that their lives had irreparably changed in positive but also negative ways. For Olivia a 52 year old, formerly active woman, life had changed forever because of a stroke and she was very frustrated that her physical limitations were not explained to her:

"I still feel very angry...they saved me one way but they... kind of damaged me the other way. You can't just unplug people from life support just because you don't know, make sure. If I died nobody was going to know anything but because I like to scratch the surface and ask people what's exactly happened to me I did and I learned the answer".

As a young woman she lamented she struggled with simple tasks she had once taken for granted:

"you know when you're making mash potato you, how long it take you, 10 minute maximum to peel the potato, it can take me up to an hour.

She vented her anger in the diary:

"you can imagine...what I put in that diary afterwards... I tried to limit and tried to use gentle words because if I was going to describe my case it was going to be with F, with a lot of bad [bitchy] words"

For some participants reduced social interaction was significant. Phoebe, an 84 year old woman had been independent and outgoing prior to her critical event. She described the initial elation of surviving as:

"I felt... well I did feel on top of the world I suppose after you go through all that sort of thing. But as I've got on I think with me, I mean not tell anybody, I think its nerves".

Phoebe described her reason for not reading her ICU diary or diarising as:

"Well I don't want to keep going over it, you know"

Phoebe declined to go on holiday with her daughter and was reluctant to attend family events; spending most of her time in the separate dwelling above her daughter's house.

Luke, a 34 year old man had been involved in a road traffic accident:

"I look at things different now... I think the consequence where before I wouldn't think and just do it... I thought I was a bit invincible but now I know I'm not and I think, I know as you get older you get a bit of fear and you know you're a bit more hesitant but I'm a lot more hesitant now... It's made me take a step back and reassess everything in life...I think I too much now. I'd rather be my old me than me as I am now".

Luke also commented that his experience had some positive aspects:

"I appreciate people more now...I surprise [sic] when people came to see me and I appreciate people around me a lot more...it's made me look at life a bit different...made me weigh things up."

Sam a 37 year old man experienced anxiety for the first time in his life on returning to work:

"It's like a blanket coming over me and you feel like cold and it's like 30 seconds and it's gone...when I feel anxious this veil just sort of comes over me".

He also described how things had changed since coming out of a coma:

"I think having come out of the mad house of the coma I don't think I really quite like losing the functions..."

However, Bella described a different view saying that her experience had changed her life only in a positive way. Prior to her critical event fear had been a large part of her life but now she considered she:

had never been such a confident, able person ever...nearly dying...holding back because I didn't think I could. Don't it all comes [sic] back to my internal world and my choices and the decisions that I made to become a better person. To realise that I could have died and I didn't so I should just go out there and do it... throw caution to the wind to a degree.

EXPECTATIONS OF RECOVERY OVER TIME

The notion of recovery differs within individuals and in this population the meaning of recovery cannot be quantified. Participants considered physical recovery represented their overall recovery but this was often not the case as some did not achieve psychological recovery. All of the participants held unrealistic perceptions of how long recovery trajectories would be and none of the participants received any verbal or written information about recovery trajectories or guidance and how they should be active in promoting their own recovery.

For Luke the impact of a critical illness was particularly profound:

"I thought when I woke up...I'd had an accident and I'd be alright. Every time I've hurt myself...you would get better and you just move on but it was the length of time... I think that's what affected me the most, the time it took to get better". It took so long for me to get better...you know the time frame... it wasn't just like getting over a cold or cough you know it's a lot longer".

The frustration because of this affected how he behaved with people close to him:

I was constantly tired, I was constantly on the settee, I felt a bit lazy...a bit grumpy about it with people because..., I couldn't do what I could normally do...it hit me for six how tired I was for a long time... often if I'd move my body it would zap so much energy and power.

Phoebe considered that because she had no visible injuries her recovery would be straightforward as she compared herself to those who had been physically injured:

"I'm sitting here and talking..., but you're not suffering like they are".

Sam when asked if he had neglected his psychological recovery at the expense of his psychological recovery said:

"Absolutely, absolutely. So being [sic], thinking about whether to see a psychologist... But if they can fix me up and just stop you know, make me focus a little bit more but then I felt good"

Chloe also commented that it had taken time for her to realise how long it would take her to recover and expressed her frustration at this:

"When I come out of the coma...probably about three weeks before I realised...I'm not very patient, I have good and bad days...I want to do things and I just can't 'cause I get tired and it's just frustrating. I'll get there but it's just going to take more time now".

Misconceptions about the time to experience being 'recovered' were evidenced by all participants in the study and for some this commenced whilst they were still in hospital indicating the longitudinal nature of recovery in this population.

SUPPORT AT HOME

All participants considered they would have benefited from support and reassurance from someone who could relate to their experience upon discharge from hospital. This need for an empathetic ear became evident once the *joy* of being home was replaced with feelings of isolation from their former selves. When prompted to define this support many participants reflected they needed someone to talk to who understood what they had experienced and could offer advice about recovery.

Chloe felt she was unprepared for the physical effects of a critical illness and had no-one to reassure her that this was a normal process:

"That was worse than the stoma because you can hide that (stoma) but you can't hide that (hair loss)".

Participants described the need for formal support by a visiting nurse or outreach service to assist them in adapting to a new image of themselves whilst on the recovery journey. Luke considered:

I think it'd be good to speak to people like that because I experienced like a moment...quite upset you know with it...I was feeling things which I didn't really know...things I didn't know how to deal with" ... "spoke to mum and dad or I spoke to close friends and got through it.

Sam reflected that even months after his discharge that:

"I'd take counselling now if it was offered".

All participants considered that it would have been beneficial when they were discharged from hospital to have someone to talk to about their experiences. Despite receiving routine follow up from their hospital teams to address their physical recovery none were offered specific ICU follow up or support their recovery.

ICU DREAMING

Most participants experienced dreaming. However, two of the participants were still able to vividly recall their dreams but did not dream them during sleeping hours. The dreams overall had commonalities of persecution and death with one participant confusing dreams in ICU with current reality. Sam commented that his dreams were:

"extremely vivid...it weren't [sic] a case of you were able to just screw your eyes and wakeup, you had to go through that...persecuted by people who were extremely supportive of me".

Phoebe recalled that her dreams were:

"...not like an ordinary dream where you like dream at night and then the next morning you think oh what did I dream about...they're not horrible dreams but I don't want to think about them."

However, she recalled a nurse (in a dream) who:

"...wouldn't let me go anywhere... there was something going on and she said you're not to go out...she was horrible...she put me in bed and pushed me down and made me stay there".

Sam also recalled a dream involving physical cruelty: *"...there was a time when they were beating me as part of my recovery and that seemed to work".*

When discussing her dreams Phoebe confirmed that they could be still played out before her:

"I could see them now if I think about it, if I like [sic] start talking to you I can visualise them. I can see all of one...quite vivid...different ones come up and I still haven't talked to (daughter) about it. They're not there all the time or at night".

Reluctance to discuss dreams with those closest to them was also echoed in Sam's story:

I tell the funny dreams...I throw a few of the funny ones out to people and tell them stuff that goes on in there but they're pretty disturbing you know...I like [sic] went on a journey and everything started off quite light hearted and nice until it all went a little bit nasty.

Sam recalled that he felt:

"very much abandoned" in his dreams and "was paralysed in some of them".

A dream which had a lasting effect on him and one he reiterated on several occasions:

"it was very difficult (wife) having a baby and it being stillborn... everybody was like quite cheery and I was sort of grieving because of this child that we'd lost".

Sam felt that some of his dreams conveyed a message to him:

"what have you become...what you were a few years ago...and I felt like I got a lot of that a real message..." Sam and Phoebe could still "play out" their dreams in waking hours and this is associated with extreme stress

symptoms and it was these two participants who appeared to suffer the greatest psychological stress following their experience.

UNPLEASANT MEMORIES

Two of the participants had no recollection of being in ICU. For the remainder, the memories of ICU were diverse and frequently confronting. Luke recalled:

"I can remember people talking to me but I can't remember what they were saying...I can just remember a pipe feeling, a drowning sensation...that's what stays with me".

Sam recalled that:

"I have memory, bad memory... I was obsessed with death, I don't know why... death, people on death row...people dying".

Olivia recalled that she thought that she had been transported back in time which increased her confusion:

"I was still living in (birth country) like 30 years ago...never once I was in Australia. They had to tell me no you're in Australia; Ah I'm on holiday." 'No, you've been living here for so many years'. It didn't make sense. Everything was many, many, many years ago for me...I blocked maybe 20, 30 years and I had to slowly talk to myself to, back to England, back to South Africa, back in here, back to (birth country)".

Chloe's only memory of her ICU experience was one of darkness tinged with anxiety:

"I haven't really got any bad memory...the only thing I was worried about was that I couldn't walk again, I was really worried about that".

Memories recalled from ICU were frequently disturbing for participants, many of whom had vivid recall of delusional memories.

DIARISING IN RECOVERY

All of the participants who diarised considered the use of diaries enabled thoughts to be captured on paper and therefore reflect on their experiences which they had been unable to do so using other means. Bella commented:

"Initially we wrote; that was really helpful but as time went on I found I just didn't need to use it and I was also speaking to a therapist at the time...it just gave me time to think about what I was, what I was writing, how I had felt, how I was feeling now".

Luke illustrated the way in which the diary enabled him to reflect on his progress:

"I look back and I can see where I've been, at times I've been happy...where I think of all my family and everyone come and see me and I just think...although I'm the other side of the world and like none of my family are here I've got a good niche of friends...and then I'd read it and some days and I can see... I went through really low patches but I wouldn't tell, I'd try and keep it to myself but I was like [sic] worry about stuff".

The reflective component of diarising was reiterated by Sam who considered that the diary not only enabled him to reflect on his progress but also that the actual process of diarising had a significant impact on his recovery. He considered that his wife may also have benefited from diarising when he was experiencing difficulties during recovery. Those participants who did diarise viewed this as a positive intervention, enabling them to reflect on their progress and disclose feelings surrounding their experiences.

DISCUSSION

This study found that the use of biographical events enabled the inner self of survivors to be revealed which may not have been apparent through alternative methods of data collection. This was illustrated by one participant who could talk about the images he had chosen to depict his story with the researcher but was unable to discuss some with his wife. The therapeutic benefits of writing following a traumatic event are well recognised (Pennebaker, 1993; Pennebaker & Seagal, 1999) and the use of visual materials to construct a story may have potential for ICU survivors.

The participants in this study considered their lives had changed – some for the better but frequently for worse and this is reflected in the literature (Elliott et al., 2011; Hofhuis et al., 2008). A preconception with previous ideas of self-differed from their current perceptions of how they perceived themselves. Participants were caught between how they were currently and their former selves; not reconciled by physical care that they had been given.

A dichotomy existed between the expectation of recovery over time and how long this process took. The notion “to be recovered” is nebulous and holds different meaning to different individuals. There is a mismatch between the biological model i.e. the expectation of recovery from disease within timeframes and the actual trajectories ICU survivors endure. As participants demonstrated here physical recovery did not equate to holistic recovery of the self and often participants were physically recovered but remained psychologically unwell and this is supported by the literature (Jones, 2012).

Those who did diarise identified significant benefits of doing so. Primarily, the diaries enabled survivors to reflect on how far they had traversed in their recovery trajectory and also provided an avenue to express their feelings and emotions which they may not have been able to articulate verbally. There has been some exploration about the impact of diaries on ICU survivors and compelling evidence has emerged which has identified that diaries may reduce the onset PTSD in survivors compared to a control group who did not receive diaries (Jones et al., 2010). However, ICU diaries have been a reconstruction of events from the perspective of those who diarised i.e. nursing staff and family members and not through the survivors’ lens therefore not providing a narrative from the survivors’ unique perspectives as has been undertaken here.

The selective uptake of diarising supports the notion that one intervention does not suit all and any intervention should be offered on an individual basis and targeted to those who are most likely to benefit. Those survivors who didn’t diarise could have experienced avoidance behaviour, as one participant alluded: “I didn’t want to go through it all again” and this was reflected in her social withdrawal. Another participant, however, considered the timing was too late to receive the diary when she did and ruminated that if it had been given it earlier she would have dictated entries to her husband despite having no recall at all of events in ICU. The content of diaries or a reluctance to diarise could be indicative of psychological morbidity and prompt further investigation before chronicity develops.

The participants in this study were unprepared for the challenges they faced during recovery. Nurses are ideally situated to provide written resources prior to discharge for survivors and their families about the potential challenges during recovery, enabling them to set appropriate goals. It is important to direct the information towards what the survivors and their families have identified as helpful (Bench, Day, & Griffiths, 2012; Lee, Herridge, Matte, & Cameron, 2009; Shehabi et al.,

2013) in contrast to what clinicians believed they require (Soltner et al., 2009). The lack of provision of information for survivors and their families infers that there is a lack of recognition of the sequelae of critical illness and this should be addressed.

Crucially, preferred support was not familial but professional; given by someone who understood the challenges survivors encounter during recovery and also the ICU experience. Often participants were unwilling to share their experiences with their families for fear of upsetting them or because of embarrassment. However, if this was professional support open disclosure could be maximised and the sharing of their lived experience of ICU and recovery promoted.

In Australia limited service provision exists for ICU survivors to assist them in recovery despite follow up services positively received by survivors (Engström et al., 2008; Peterssen et al., 2011; Prinjha, Field, & Rowan, 2009) and would have been welcomed by all participants in this study. Most of the participants were unprepared for the physical and psychological effects of a critical illness and would have appreciated verbal or written information about the potential physical and psychological issues they may encounter.

Anxiety and depression are significant complications for ICU survivors (Myhren et al., 2010b) and unanticipated complications could compound this anxiety further (Bench, Day, & Griffiths, 2013) although this has not been fully explored in the literature. Unanticipated physical side effects for two participants which caused them distress included temporary hair loss; a known effect of critical illness but a potential complication they had not been made aware of. Simple written information given on discharge could have reassured participants that this was usually a transient complication of critical illness. One participant was profoundly affected by physical debility but was able to set targets to regain his strength and fitness goals as a result of his internal motivation. For those who were unable to do so, simple written information about the process of physical recovery, promoting realistic goals and facilitating a plan may have brought clarity to their situation and relieved frustration. Participants, in this study, had no point of referral to discuss their individual circumstances apart from family members and their General Practitioners, some of whom may not have possessed sufficient experience of the challenges of ICU recovery to be able to offer appropriate advice. Two of participants appeared to experience psychological problems evidenced by being able to "replay" their delusional memories in waking hours which is an indicator of PTSD (American Psychiatric Association, 2013). One participant sought

treatment for this but only after the researcher provided him with appropriate access to resources. Another participant who could replay dreams in waking hours had become more socially isolated and reluctant to venture out alone or engage in social activities. In keeping with this was a reluctance to view her ICU diary and actively diarise as "*she didn't want to bring it up*" again and attributed her feelings and intrusive dream recall both alluded to psychological difficulties. Potentially these participants would have gone unchecked as neither had disclosed this to their families and if they had it is possible that they would not recognise the significance of it. It may be postulated that early and ongoing follow up may have identified these difficulties and any necessary treatment initiated to address their potential complications.

The genre of survivors' dreams depicted here share similarities and the contextualising image (the central powerful image of the dream) of terror and helplessness is evident in those who have suffered the most severe traumas (Hartmann, Zbrowski, Rosen, & Grace, 2001; Punamaki, Karzan, & Ismahil, 2005). Intensity of the central image is related to the power of the underlying emotion (Hartmann & Brezier, 2008). Therefore, the persecutory nature of the dreams experienced by some of the participants in this study is in keeping with this notion and alludes to the level of distress that some experience whilst in ICU. The presence of dreams indicates that there is a level of awareness during an unconscious state and one participant felt that his dreams were influenced by what people told him at the time. This insight may have relevance for future exploration in investigating the influence of auditory stimuli on the nature of patients' dreams.

Some participants reported reluctance to discuss their dreams with others; to the point of being unable to write about them in their diaries. Assistance to explore these dreams with an external, qualified therapist may assist with the process of adjustment as this has been utilised elsewhere (Kuiken, Dunn, & Lo Verso, 2008).

Acute delirium in ICU which has been linked to many factors including increased mortality (Lin et al., 2004; Pisani et al., 2009; Shehabi et al., 2013) and significantly for this population the probability of long term cognitive dysfunction up to twelve months following discharge (Girard et al., 2010; Gunther et al., 2012; van den Boogard et al., 2012). The causes of delirium are multifaceted but are thought to be related to severity of illness, delusional recall (Svenningsen et al., 2013), inflammatory status (Skrobik, Leger, Cossette, Michaud, & Turgeon, 2013) and sedation and analgesia regimes (Ouimet et al., 2007). Unfortunately delirium remains underestimated and

underdiagnosed in ICU and the acute setting (Collins, Blanchard, Tookman, & Sampson, 2009; Spronk, Riekerk, Hofhuis, & Rommes, 2009) and should be a focus of ongoing investigation.

Writing about traumatic events has been shown to be of therapeutic benefit and a trauma narrative is integral to the integration of thoughts and feelings into a meaningful experience (Kuiken et al., 2008; Pennebaker & Seagal, 1999). Writing expressively about dreams following trauma has also demonstrated benefit (Kuiken et al., 2008) however, this has not been explored in the ICU population. Despite widespread reporting of dream recall in the ICU survivor population there is a dearth of exploration into why this occurs so frequently and with a potentially detrimental effect. In some studies dream recall has been correlated with a lack of adjustment following trauma (Duval & Zadra, 2010; Kiekkas et al., 2010) as well as in the ICU population (Hauer et al., 2009).

Diarising during recovery may also provide a conduit for survivors to reconstruct their stories of ICU and recovery and reflect how far they have come in their recovery trajectory. This may enable survivors to divulge memories and dreams which they still find disturbing but are unable to articulate in other ways. The guided use of diarising during recovery by nurses may also have potential in the early detection of psychological morbidity.

RECOMMENDATIONS

It is recommended that this study is replicated with a larger cohort of participants and across multiple sites. It is also recommended that in future studies participants are assessed for psychological morbidity at the initial contact with researchers to identify morbidity in order for it to be managed and reduce the risk of chronicity in this population.

LIMITATIONS OF THE STUDY

This study was conducted at a single centre. Nonetheless, the findings are rich and open the debate surrounding the needs and support provision for ICU survivors in the Australian setting during recovery.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

The trauma of a critical illness and ICU stay yields life changing consequences for many survivors often leading to protracted and challenging recovery periods; yet service provision in Australia remains inadequate. In the general trauma population re-creating stories has been shown potential benefit during recovery and re-adjustment process. In this study participants were able to re-create their stories through the media of visual diarising and face to face interviews.

Clearly the participants were ill prepared for the length of their recovery trajectories as well as the debilitation associated with critical events and nurses are ideally placed to develop interventions to support survivors and their families. The consideration for professional support for survivors during recovery is urgently required as is the provision of written information prior to hospital discharge.

The use of diarising during recovery is a simple low cost intervention which can be implemented by nurses in practice. This intervention builds upon the concept of ICU diaries which are currently provided in many ICUs globally and have been well received by survivors and their families. Diarising during recovery for ICU survivors may have potential to aid in the identification of psychological morbidity before chronicity develops and this requires further exploration to establish best practice and the potential benefits it may yield.

CONTRIBUTION OF THIS CHAPTER TO THE THESIS

In the preceding chapter the findings from the interviews undertaken with participants have been detailed. These interviews enabled the participants' to reflect upon their experiences of recovery which they had depicted within their diaries. The interpretation of these interviews has elicited rich data which vibrantly illustrates ICU survivors' experiences. For the first time this biographical disruption to the self and the way in which survivors struggle to reconcile this has been clearly illustrated through their individual lens. The participants identified during this early phase of recovery how they struggled to come to terms with the self they were now compared to how they had been. This was clearly evident for Sam and Phoebe who could not share their inner most thoughts to those closest to them and struggled to maintain an outward appearance of normalcy. Many themes were reiterated from previous work but new themes and implications for the provision of specialised support from the perspective of the survivor during the crucial time during early recovery emerged.

Findings outlined in this chapter have indicated that despite advances in ICU practice aimed at reducing the psychological complications of ICU, including less invasive techniques, lighter sedation and the reduction in routine administration of neuromuscular blockade, the complications survivors experience remain consistent. From the participants' experiences in this study it is apparent that there is inadequate support provision during recovery and potentially this is echoed across Australia in both the public and private sectors. The participants identified low cost interventions which could support them during recovery. The provision of written information indicating what they could expect to encounter in the recovery period and when and where to access support was one such suggestion.

CHAPTER TO FOLLOW

The following chapter details the findings from one participant's diary. This diary illuminated Sam's experiences of recovery through the use of imagery, rich description and metaphor. The use of such imagery was so unique that this chapter is dedicated to Sam and his diary. The content of Sam's diary eloquently revealed the conflict he experienced between his two worlds; the deep and the surface. To all, he was fitter and slimmer than he had been for many years and therefore he was recovered- well enough to leave everything behind him. Sam could not do that as his delusional memories remained very real and were part of the here and now for him as he struggled to keep them below the surface; hidden from sight.

This chapter has been prepared as a paper for publication and has been published in the journal: *Nursing in Critical Care*.

CHAPTER SIX: NEVER ENDING STORIES: VISUAL DIARISING TO RECREATE AUTOBIOGRAPHICAL MEMORY OF ICU SURVIVORS

*A story has no beginning or end: arbitrarily
one chooses that moment of experience from
which to look back or from which to look
ahead.”*

Graham Greene

INTRODUCTION TO CHAPTER SIX

The focus of this chapter evolved from one participant's diary. Sam was the first participant in the study and proved to be the most complex in many ways. Sam had been unexpectedly taken critically ill and the psychological and physical ramifications of this illness profoundly affected him and his family during recovery. He experienced a stormy and protracted recovery period however, after significant reflection; he emerged from his experiences with great hope for the future.

At the commencement of the study Sam was provided with diarising materials i.e. a blank notebook, pens, colourful paper and a disposable camera to depict his story in the manner of his choosing. However, he chose not to use these and instead gathered electronic images from the internet to depict his thoughts and feelings during recovery. The result of this was the production of a visually engaging diary which was rich in symbolism and metaphor. These images captured Sam's experiences and the emotional and physical legacies of them so vividly that the researcher felt compelled to highlight these in a dedicated chapter in order to do them justice. The images in the diary eloquently depict Sam's story of ICU and recovery in a way that words alone could not. His diary portrays a powerful message to the ICU community of the challenges survivors face and the potential benefits of diarising as a method are eloquently demonstrated as a result. Here follows Sam's never ending story.

Ewens, B., Hendricks, J., Sundin, D. (2014). Never ending stories: Visual diarizing to recreate autobiographical memory of intensive care unit survivors. *Nursing in Critical Care* published online 6 October 2014. doi: 10.1111/nicc.12093

ABSTRACT

Aims: The aim of this study was to explore the potential use of visual diarising to enable intensive care unit survivors to create their story of recovery.

Background: An intensive care unit experience can have deleterious psychological and physical effects on survivors leading to reductions in quality of life which for some may be of significant duration. Although there has been exploration of many interventions to support recovery in this group, service provision for survivors remains inconsistent and inadequate.

Design and participants: A qualitative interpretive biographical exploration of the ICU experience and recovery phase of ICU survivors using visual diarising as method. This paper is a component of a larger study and presents an analysis of one participant's visual diary in detail.

Methods: Data collection was twofold. The participant was supplied with visual diary materials at two months post hospital discharge and depicted his story in words and pictures for a three month period, after which he was interviewed. The interview enabled the participant and researcher to interpret the visual diary and create a biographical account of his ICU stay and recovery journey.

Findings: The analysis of one participant's visual diary yielded a wealth of information about his recovery trajectory articulated through the images he chose to symbolise his story. The participant confirmed feelings of persecution whilst in ICU and was unprepared for the physical and psychological disability which ensued following his discharge from hospital. However, his story was one of hope for the future and a determination that good would come out of his experience. He considered using the visual diary enhanced his recovery.

Conclusions: The participant perceived that visual diarising enhanced his recovery trajectory by enabling him to re-create his story using visual imagery in a prospective diary.

INTRODUCTION

During the past two decades the advancement of intensive care medicine has resulted in a reduction in mortality rates. With increased numbers of survivors has emerged a realisation that survivors are at significant risk of physical and psychological morbidity as a consequence of their critical illness (Granja, Amaro, Dias, & Costa-Pereira, 2012; Moran et al., 2008; Needham et al., 2011). The intensive care unit (ICU) experience itself has been considered to predispose survivors to complications as well as the presenting condition which necessitated an ICU admission (Dowdy et al., 2009; O'Donnell et al., 2010; Scragg, Jones, & Fauvel, 2001). Morbidity resulting from a critical illness may be physical and/or psychological, difficult to predict and challenging to manage.

Literature reports that ICU survivors experience a reduced quality of life (QoL) compared to the general population, with an increased incidence of Post-Traumatic Stress Disorder (PTSD), anxiety and depression all of which inhibit functioning (Baker, 2006; Burnham et al., 2013; Davydow et al., 2008; Jones, 2012). In turn, these psychological factors are detrimental to health outcomes (Skinner, Warrillow, & Denehy, 2011; Wagner, Wolfe, Rotnitsky, Procter, & Erickson, 2000) reflected in the increased health seeking behaviours of this group of people (Unroe et al., 2010; Williams et al., 2010). It has been claimed that the overall increased encumbrance of ill health exerts a far reaching effect on health care systems as survivors may never regain their psychological and/or physical pre-morbid state (Cuthbertson et al., 2007; Myhren, Ekeberg, & Stokland, 2010a; Unroe et al., 2010).

BACKGROUND

The reasons that an ICU event has such a deleterious psychological effect on survivors is not fully understood but it has been postulated that exposure to stressors in ICU is one of the predetermining factors (Jones et al., 2001; O'Donnell et al., 2010; Schelling et al., 2003). This stress has been compared to that which can occur during and after exposure to traumas which are associated with the highest risk of PTSD (American Psychiatric Association, 2013; Frans, Rimmö, Åberg, & Fredrikson, 2005; Hetzel-Riggin & Wilber, 2010; Jackson et al., 2007). Of course, not every individual will develop psychological complications as a result of exposure to a particular stressor. The reasons for this have been proposed as being dependent upon pre-existing factors such as the presence of peri-traumatic dissociation at the time of the event, prior trauma, prior psychological adjustment, family history of psychopathology, perceived

threat to life during the trauma, post trauma social support and peri-traumatic emotional experiences (Ozer, Best, Lipsey, & Weiss, 2003; Werner & Griffin, 2012)

Despite evidence that confirms survivors are often confronted with psychological and physical complications which impact on their quality of life, the provision of rehabilitation programs is inconsistent, lacks an evidence base and have been described as inadequate and uncoordinated (Cotton, 2012; Jackson et al., 2012; National Institute for Health and Care Excellence, 2009). Furthermore, there is a lack of evidence to support particular interventions in enhancing the recovery of ICU survivors who, despite recovering from the most severe illnesses, may be affected for the remainder of their lives (Herridge, 2007; Rubenfeld, 2007). This deficit is in contrast to the services provided for survivors of other conditions such as heart disease pulmonary disease and stroke. For example, a significant body of evidence has confirmed that the provision of cardiac rehabilitation (CR) positively influenced the quality of life and lifestyle choices; with strength of influence directly related to length of exposure to the program (Beauchamp et al., 2013; Harwood et al., 2011; Rideout, Lindsay, & Godwin, 2011). These programs, in contrast to ICU rehabilitation programs have undergone rigorous and extensive evaluation internationally (Austin, Williams, Ross, & Hutchison, 2008; Listerman, Bittner, Sanderson, & Brown, 2011; West, Jones, & Henderson, 2013). It can be postulated that this may be due to the predictable progression of these diseases which is not the case for many ICU survivors who often face an unpredictable and unique recovery trajectory. As such, it is important to evaluate generic strategies which can be applied to ICU survivors which may assist in their recovery.

An intervention which has undergone evaluation in recent years and has demonstrated some potential in the reduction of new onset PTSD in ICU survivors has been the introduction of patient diaries. The premise of diaries is that ICU survivors have little or sometimes delirious memories of their ICU experience and as a result, experience a memory gap which is associated with an increased risk of psychological morbidity. The diaries are intended to fill this reported memory gap and are an account of events in ICU from the perception of those who complete them, usually nursing staff and family members. However, the composition of, and processes associated with the use of diaries in ICU lack consistency (Combe, 2005; Egerod & Christensen, 2009; Storli et al., 2002), making it difficult to evaluate them as a therapeutic intervention (Combe, 2005, Egerod and Christensen, 2009, Storli et al., 2002). The diaries are a secondary account of the survivors' experiences in ICU and as such are a representation of their stories; their perceptions of events as they saw, heard and experienced them. Therefore

in this study the concept of visual diarising i.e. the use of imagery and symbols with or without written word, aimed to give the survivors a voice from which to tell their own story through their unique lens. Furthermore, the use of visual signage has been used since the 1930s with or without written word (Mitchell, Theron, Stuart, Smith, & Campbell, 2011). It is thought that visual images promote the expression of that which may not easily be expressed in words and enables the understanding of human experience which may otherwise have been lost. The collaborative meaning making of analysing the visual images as in this study by the participant and researcher enables a greater depth of understanding. There remains a distinction between research that uses art as a means of expression and those which use drawing or other artistic approaches as more conventional forms of verbal data (Mitchell et al., 2011).

The use of storytelling as a legitimate means of research has now been recognised (Fraser, 2004). Stories are dynamic and the interaction between the storyteller and the listener shape how they are constructed: by telling our stories and therefore exposing them to interpretation our lives are changed (Lai, 2010). Storytelling has been identified as a means of validating and affirming experiences and sometimes providing an avenue for catharsis and instilling hope (Banks-Wallace, 1998; Chelf, Deshler, Hillman, & Durazo-Arvizu, 2000). The benefits of storytelling are underpinned by the notion that individuals seek to understand what has happened to them and gain meaning from it (Pennebaker & Kilihr Beall, 1986). By disclosing one's story the storyteller can confide about an event which enables them to find structure and therefore meaning and affirmation that others have been through the same experience (Pennebaker & Kilihr Beall, 1986; Restrepo & Davis, 2003).

Narrative is one way in which humans have learned to clarify and construct their experiences (De Silva, Gaudin, & Gaudin, 2007). Creative therapies such as writing and art have been shown to be beneficial in the treatment of those exposed to traumatic events and so organise complex emotional experiences (Pennebaker, Colder, & Sharp, 1990; Pennebaker & Seagal, 1999; Pizaro, 2011). Pennebaker, Colder and Sharp (1990) go as far as to describe this writing technique as a form of therapy. Emotional expression is necessary but not sufficient in itself to bring about emotional change (Smyth, 1998). Expressing emotions through writing transmutes the experience into words which can then be assimilated and made sense of (Pennebaker, Mayne, & Francis, 1997). Writing and so expressing emotions conveys significant health benefits in a healthy population (Smyth, 1998) and so can be postulated to be of benefit in a traumatised population. This paper is a component of a larger study which was

undertaken with ICU survivors using guided emotional expression of the recovery journey by applying Denzin's chronological series of events for storytelling. This paper focuses on the analysis of one participant's (Sam) visual diary. This diary was chosen as, unlike the other participants in the larger study, Sam did not use the hard copy materials given to him but chose to use the internet to source images which represented his story. His diary was so different in its construction compared to the other participants that the researcher considered it important to share this. The end result of this process was a chronological journey of ICU recovery depicted using rich, colourful and meaningful imagery.

AIM OF THE STUDY

The aim of the study was to explore the use of a visual diary to recreate the story of ICU survivors' experience and recovery. This is part of a larger study which explored the use of visual diarising as a potential intervention to aid recovery in ICU survivors.

DESIGN

An interpretive biographical exploration was used to analyse the visual diary of an ICU experience and recovery phase of one ICU survivor. Interpretive biography was selected because of the method's assumption that individuals experience pivotal (or epiphany) events in their lives which impact upon their future. The ICU experience may be seen as one such experience; and therefore is significant in the way an individual's life and their subsequent recovery may be impacted. The interpretive method enables the researcher to investigate, probe and capture data to enable an understanding of the epiphany moment (Denzin, 1989). Denzin (1989) describes the epiphany as: "interactional moments and experiences which leave marks on people's lives....they are often moments of crisis...their effects may be positive or negative"(p.70).

PARTICIPANTS

The ICU survivor who is the focus of this study was recruited using purposive sampling from a general ICU in Perth, Western Australia. Inclusion criteria for the larger study were that participants were aged over eighteen years; had been ventilated for a minimum period of twenty four hours; spoke and understood English and had no new or existing cognitive impairment.

ETHICAL CONSIDERATIONS

Ethical approval was obtained from the ethics committees at the study site and the university, at which the researcher is a student. Sam is a pseudonym to protect the identity of the participant.

DATA COLLECTION

Data collection was twofold and consisted of a visual diary constructed by the participant and recorded interviews over a period of five months. The participant was offered diary materials two months following hospital discharge and collected by the researcher after three months had elapsed. The diary and interview transcripts were stored on a password protected computer.

VISUAL DIARIES

The participant was supplied with materials to construct a diary which consisted of a journal, pens, art materials and a disposable camera. The diary was a blank canvas upon which Sam could draw or write his story. The art materials provided were deliberately gender and topic neutral to ensure that the materials did not influence how the images were constructed and shape the content of the visual diaries which could introduce bias to the study. The materials provided were merely a vehicle to promote expression and give memories and images a form. Although Sam had photographs taken by nursing staff with the consent of his family within his ICU diary, he chose not to include these in his visual diary.

INTERVIEWS

Two interviews were undertaken at two and five months following discharge from hospital. The first interview was used to clarify the aims of the research and to gain written consent. Sam was also provided with the materials for maintaining a diary. The intention of the second interview was to enable him participant to discuss the content of the visual diary with the researcher. The style of interview was creative with the researcher listening, understanding and facilitating the participant to interpret his story through the use of visual imagery in the diary. The researcher encouraged Sam to tell his story from the beginning, a point of his choosing, with a middle and an end as in Denzin's biographical method. During the interview Sam was prompted to describe the thoughts, feelings and emotions associated with the visual entries in his diary. The interviews lasted for up to an hour and were recorded.

DATA ANALYSIS

The participant's visual diaries initially proved problematic for analysis. Analysis could not be prescriptive and one-dimensional and had to be adapted to the situation in which the researcher is positioned (Fraser, 2004). The recovery story captured in the visual diary had to maintain the integrity of the participant's story and convey a sense of personal depth and colour. Using Etherington's framework (Etherington, n.d.) and Kucera, Higgins and Macmillan processes of interpretation (Table 4) (Kucera et al., 2010) to guide analysis and having the participant describe turning point moments, as captured in the visual diary, allowed the researcher to share in the world of the participant.

Table 4 Data analysis process

1.	Transcription of stories and primary analysis Stories were transcribed verbatim by the researcher as transcription was intended to be a component of the analysis process – the very beginning of the process to interpret the participant's story of recovery.
2.	Reading of stories Transcriptions were read to obtain an overall understanding of the participant's experience/life view.
3.	Paraphrasing Several paraphrases were constructed for each story to highlight the points being made.
4.	Identification of themes Taken from the paraphrases; themes were identified and similar themes and patterns were grouped together and common meanings and points of the story identified. Points were identified and grouped then collapsed into themes. The less common themes were grouped separately.
5.	Recheck and confirm The researcher re-visited of all the themes identified from the paraphrases and double checked for reliability.
6.	Hidden meanings/identification of narrative aspects The researcher identified what else the story was about apart from the ICU experience by identifying the propositions which were comparable and categorising the aspects of the story. Formalising the aspects in terms of what the ICU experience and recovery meant to the participant was integral to this process.
7.	Rechecking and confirm the resultant themes and aspects Paraphrases and themes were reviewed to ensure the most important themes, meanings and messages were identified. Links between themes were noted.
8.	Identity The researcher revisited the paraphrases and the story in its entirety. Interpretation allowed the development of a representation of the experiences, thoughts and emotions which the participant experienced during the journey of ICU and recovery and the impact this has upon his life.



Figure 2 Achievement

Further to this, the researcher listened as Sam explained and described his pictorial and written depictions and how these captured his feelings and experiences. This process also served as member checking. Coupled with this, the recordings of the interviews were listened to several times to enable interpretation of the messages within the transcript and their correlation with the pictures used to symbolise Sam's recovery trajectory. Barden and Williams (2006) assert that symbols are unique to the individual and this notion has been supported by the preliminary findings in this study.

TRUSTWORTHINESS

Trustworthiness in qualitative research refers to the rigor of the research and comprise four constructs of: credibility (truth value), transferability (applicability), dependability (consistency) and confirmability (neutrality) (Guba & Lincoln, 2005; Shenton, 2004). It is essential in qualitative research that the researcher builds a rapport with the participants as they have no control over what the participants are willing to share so establishing a rapport and building a trusting relationship early is essential. This basis of trust will encourage participants to disclose personal information they may only reserve for close confidants (Speziale-Streubert & Carpenter, 2003). The researcher endeavoured to build a rapport with Sam, taking time to discuss his overall experience of critical illness and his current situation making sure that he realised that the researcher was a nurse with many years' experience in ICU to create an environment of trust, safety and understanding. Reliability of data was ensured by the triangulation of data i.e. from different sources; the visual diaries and interviews combined with member checking with the participant and remaining in the setting until saturation was reached. To ensure transferability purposive sampling was utilised to ensure a representative sample from the general ICU population and sufficient detail has been included to allow for judgements about transferability to be made. The demonstration of credibility is sufficient to demonstrate dependability (Lincoln & Guba,

1985) but also satisfactory detail has been reported in this research study to ensure others may repeat the work and confirms the dependability of the study. The concept of confirmability is to ensure that the interpretation of the data is objective and not influenced by the bias of the researcher (Shenton, 2004). Lincoln and Guba suggest several measures to be undertaken to ensure confirmability of study findings and enable audit. To this end triangulation of data was achieved: an accurate audit trail of the research project was maintained to enable review if necessary. Interviews (raw data) were recorded and memos and process notes were maintained together with methodological reflections and notes.

FINDINGS AND DISCUSSION

SAM

Sam was a 37 year old man admitted to ICU with a history of abdominal pain. He was ventilated for several days and developed severe acute delirium during this time. A diary had been commenced for him by the nursing staff whilst in ICU which he continued to read following his discharge, about which he commented: "I could cry every time I read it... very strange to know how much people love you and want you to pull through". These feelings and emotions evoked by reading ICU diaries are typical of what have been evidenced previously (Ewens, Chapman, Tulloch, & Hendricks, 2013). For this study, the researcher built upon the concept of diarising for ICU patients and encouraged Sam to diarise in the recovery phase of illness. Sam had actively diarised electronically and produced a diary overflowing with vivid imagery and text which he described and interpreted with the researcher.

Sam began his story at the point where he had been admitted to hospital but not yet to ICU. He recalled how he had been severely affected by a comment from a nurse who inferred that because of his illness he must be an alcoholic, despite his protestations to the contrary. This assumption had a significant impact on him and he made repeated references to it during his interview and also in his visual diary: "I didn't like the way people talked about me about me in the hospital as if I had a drink problem ... how people have judged me through the whole process ... I was embarrassed when people said this ... I didn't have a drink problem and I've never had a drink problem ... it was OK, people were making me better so I'll go along with it ... it's quite funny how in the medical professions there's an awful lot of ignorance ... "He depicted this experience in his diary with a statement which said: "don't judge what you don't understand".

Sam was determined to make significant changes to his lifestyle so that something good would come from his experience "because I got through it ... I didn't want to lose sight of that, that even when I was in hospital ... I was determined that I was going to make something positive out of the whole issue; it's a good achievement, I came through it, fit enough. Sam was profoundly affected by the realisation of how critical illness had physically affected him and he reiterated how this had impacted on him throughout his story. He compared his recovery journey to the energy, dedication and perseverance required to climb a mountain, representing a super human effort (Figure 2). He was determined to regain his pre-morbid state and he described the early days of recovery: "it'd take me half an hour to get out of bed...I'd shower and shave and that's an hour, my body'd just shake, I'd be sweating... then I'd just try and walk to the park... I just walked around it and I'd just keep doing it". I was determined...it was painful... that was my goal I just wanted to get back".

However, despite noticeable improvements in his physical strength Sam struggled to maintain an appearance of normality: "I found myself trying to find a place to hide and nearly break down... sometimes I'd cry in the car on the way home...I felt like I was struggling to do simple things." He depicted these frustrations visually in Figures 3 and 4:

At one stage Sam was so concerned about his mental abilities he thought his brain may be damaged and "felt concerned but thought I would be able to hide it".



Figure 3 Spaghetti brain



Figure 4 Struggling to do simple things

The memories of his time in ICU were not always pleasant and describing his acute delirium shortly after he was extubated he recalled: "I have bad memory, I was very punchy when I came out of it and I'd start talking and you know you just couldn't get your words right it was like having a bit of Alzheimer's ... it still comes every so often when I'm tired". He still had difficulty talking about the vivid dreams he recalled and still found he struggled to talk to others about them and even to write them down. He described that he was "on a journey, everything started off quite light hearted and nice until it all went a bit nasty... weren't a case of just screw your eyes and wake up, you had to go through that and be persecuted by people who were extremely supportive of me...dreaming that Grace (wife) was trying to poison me... where people had taken on different personalities, even I had taken on a different persona".

Sam had no clear recollection of events as: "everything was confusing or mixed, you'd see people and then you'd be dreaming about them ... I was very much abandoned ... it was very difficult, Grace was having a baby and it being stillborn ... she was trying to poison me and my boss ... they've been supportive, have looked out for me, but they're against me, everything was really". Sam recounted his obsession with death whilst in ICU: "I was obsessed with death, I don't know why. Yeah death, people on death row ... people dying".

Sam described his feelings and depicted them in Figure 4 as he struggled to recover: "the black cloud was something that I'd never felt before ... I wouldn't say I was depressed ... every so often you'd just feel something like a blanket over your head ... God what was that it was awful ... I felt it when I first went back to work... whether it was just the anxiety of going into something unknown ...



Figure 5 Dark clouds

"I'd find myself in work and people wanted to come and see me and talk about it ... I was daunted, everyone staring at me and wanting to talk to me about it and just all feel goodwill and I remember finding myself once just going and seeing a mate in the stores and sat away from everything at work you know and it was like everybody's goodwill was just a little bit too over overbearing".

Prior to his illness Sam had worked full time as a manager. As his physical appearance improved his work colleagues presumed he had returned to his normal state in every aspect: "they see me looking physically better than I did when I went off and that's it, you've been to a health camp... they just don't know what you've gone through".



Figure 6 Been to a health farm

"I don't know what I've gone through at times ... people don't understand that you just can't understand things...how long is it going to be before sympathy's over and they know you're making mistakes". Work was a very important part of Sam's life;

something which he repeatedly referred to in his visual diary and interview and considered it “an important part of my make-up” and measured his recovery by how he functioned in his job.

Over the next month Sam suffered a relapse and was re-admitted to hospital which he described as having to “go through a bit of a grieving process”. He endured several weeks off work but by the end of the year, seven months after his original illness, he commented “I’m back – feel really good, healthy and achieving my goals at work, still a bit to go but the future is bright. I’m confident about my future...just trying to get myself to focus...”







The findings from this study have provided an insight into the recovery of an ICU survivor using prospective diarising. Sam was able to capture his thoughts and feelings with his choice of imagery via the internet which enabled him to choose which best represented what he was intending to express. The story of Sam’s recovery trajectory is underpinned by hope. He began his diary with an image which represented super human effort and this set the tone of his story. Despite the biographical events of physical setbacks and impairment accompanied by mental turmoil, his story is full of optimism, looking forward to the future and a determination to achieve positive change from such a deleterious and potentially life changing experience.

The way in which Sam chose to reconstruct his story using electronic media changed the way in which the researcher chose visual diary materials for other participants in the study. Electronic media had not been considered before and subsequent participants in the larger study were given an electronic storage device following this. This was a turning point for the researcher who had not considered that participants would be able, or wish to use electronic media to construct their diaries.

BIOGRAPHICAL EVENTS

A biographical event timeline incorporating epiphany or turning pointy moments have been extrapolated from Sam’s visual diary and interviews (Table 5).

Table 5 Biographical events in Sam's recovery

Epiphany moments	Chronological trajectory
May Feeling judged	Sam was upset and angry that the nursing and medical staff had labelled him as an alcoholic because of his illness. He made repeated reference to this in his diary and interviews.
	
June Released from the madhouse	Sam was severely debilitated at discharge home and realised that he had been too ill to understand the magnitude of his illness. However, there was also relief for him as he now understood why he had been ill for the last few years. He was feeling good in himself and had a determination to get better and follow advice about health and diet to enable this. Each day he saw an improvement which took away his concerns, however despite this physical improvement he remained very tearful and viewed his discharge from the hospital as being released "from the madhouse".
	
July Determined to make a positive out of the experience	Two months following discharge from hospital Sam was feeling fantastic and achieving the lifestyle goals he had set himself. He had commenced a phased return to work. Everyone had commented on how well he was looking but inside he was experiencing a dichotomy. He realised he was struggling, that his brain was tired conflicting with his physical appearance. He was struggling to perform simple tasks at work and found himself looking for places to hide and crying in the car on the way home.
	
August Everything coming together	By August Sam was improving his fitness and was able to run 7kms in 30minutes – he was proud of this achievement. He was managing better at work but was still not quite back to normal. Because of this residual difficulty he did consider that he had sustained brain damage in ICU but would be able to hide it.
	
September Fears for the future	Sam was re-admitted to hospital for a procedure which was complicated by infection and was unexpectedly off work for 6 weeks. His mood was low as he had no control over his health, was worried about his job and feared for the future. He feared returning to work as he didn't want to feel helpless; work is important to him.
	
October Needing to prove himself	In October Sam again returned to work at 60 hours per week; trying to prove himself competent in his role. This left him exhausted at the end of each day and he was afraid to undertake the exercise which had been such an integral component of his physical recovery.
	
November I'm back	Seven months after his admission to ICU Sam was eventually feeling healthy and achieving his goals at work. He considers the future is bright.

Sam's diary illustrated that neither he nor his family had been prepared for the physical and psychological aftermath of his critical illness. He had not been offered written or verbal information, links to resources or structured follow up which may have supported his recovery. There is evidence which suggest ICU survivors value and benefit from discharge information (Lee, Herridge, Matte, & Cameron, 2009) and there are a variety of interventions available which could be adopted to inform service provision. These initiatives include discharge information resources (Bench et al., 2012), psychological intervention techniques (Black & Parahoo, 2011; Peris et al., 2011) and comprehensive rehabilitation care pathways (National Institute for Health and Care Excellence, 2009). There are currently inadequate resources allocated to ICU survivors in Australia and further investigation into the application and evaluation of potential initiatives should be a high priority.

Sam recalled vivid, predominately persecutory dreams which as a phenomenon has long been recognised in ICU survivors and postulated to influence psychological morbidity (Kiekkas et al., 2010; Magarey & McCutcheon, 2005; Zetterlund et al., 2012). These dreams can be so intrusive and disturbing that many survivors are unable to share them, even with those closest as illustrated by Sam. The persecutory nature of these dreams is significant. This delusional memory is often the only reality survivors retain of their ICU experience and it could be argued that this is the biographical memory of their traumatic event, the nature of which i.e. perceiving a risk of death, is associated with a high risk of PTSD (American Psychiatric Association, 2013). Sam experienced a difficult recovery period and required psychological support for a short period of time. This psychological distress may have been identified earlier had he have been offered follow up of some description. In his diary and during the interview he repeatedly recalled feelings of persecution and a preoccupation with death; all of which have been identified as a determinant of PTSD (American Psychiatric Association, 2013; Hetzel-Riggin & Wilber, 2010). However, he did not know how to access this support and was guided by the researcher to access services.

Sam was highly motivated to regain his pre-morbid status and was able to set his own physical goals in his determination to achieve something positive from what had happened to him. He assumed that recovery entailed regaining the physical component of his health and that and it was only when he returned to work that he realised that mentally he "wasn't right". Sam was fortunate in that he had an inherent optimistic outlook and was able to set realistic goals for himself.

LIMITATIONS AND IMPLICATIONS FOR PRACTICE

This study was a small single site study and therefore the results are limited in terms of transferability to the wider context. Sam considered that diarising had aided his recovery: "I believe the research contributed to my successful recovery" and is a strong advocate of the diary concept. He still carries his original ICU diary with him on occasion. The application of prospective diarising has yet to be explored in the literature and may be worthy of further study.

CONCLUSION

It is apparent from the literature that ICU survivors often face a complex and challenging recovery process which for some may never be complete with an associated reduction in QoL (Karachi, hanekom, & Faure, 2011; Myhren et al., 2010a; Oeyen et al., 2010). Despite decades of exploration it is evident that evidenced based programs for ICU survivors during the recovery phase is not prevalent and are yet to be widely established. Diaries commenced in ICU have been explored as a potential aid to recovery in this population and recent studies have demonstrated promising results (Jones et al., 2010). However, this study has explored uncharted territory in developing the ICU diary concept further than before. Not only has this study explored prospective diarising but also introduced the concept of visual imagery to guide the storyteller in constructing their story. The findings from this study have indicated that this may have potential during recovery. Visual diarising enabled Sam to capture his recovery journey through powerful visual imagery. When he recounted his story and what the images portrayed for him he was able to reflect on what had happened to him and how much he had achieved during his recovery phase.

Currently there is no provision in Australia for ICU survivors to re-tell their stories and make sense of their experiences and recovery journey in a structured and guided way. Diarising for ICU patients and the impact of this is beginning to show promise. Prospective diarising for ICU survivors has not been explored in the literature and may warrant further investigation.

CONTRIBUTION OF THIS CHAPTER TO THE THESIS

In this chapter Sam's story has been illuminated and demonstrates how the unique data collection methods in this study and in particular diaries, can be an opportunity for survivors to reveal what is hidden below the surface, which he acknowledged was difficult to disclose through other means. This unique method of data collection enabled an insight into the experiences and identified the turning point

moments in his recovery. The data generated captured the life disruption that an ICU experience creates and how he struggled to come to terms with his inner and outer selves as he tried to meet the expectations of others and their perceptions what being recovered was. The process of diarising and guided reflection gave Sam a space for thought so that he could start to reconcile his former life and how that marries with his current life.

CHAPTER TO FOLLOW

In the preceding chapters a detailed overview of the processes undertaken during this research journey has been presented. The findings in relation to survivors' unique experiences which have emerged from it have also been discussed. In the following chapter an overview of the major findings from this study; the implications for practice, education and research are presented. Several recommendations are made and ways to address the deficit in support for survivors during recovery are also made.

CHAPTER SEVEN: DÉNOUEMENT

A man is a teller of tales; he lives surrounded by his stories and the stories of others; he sees everything that happens to him through them, and he tries to live his life as if he was recounting it

Jean Paul Sartre

INTRODUCTION TO CHAPTER SEVEN

This study explored ICU survivors' experiences of recovery during the first five months following discharge from hospital. An interpretive biographical approach was used to illuminate the stories of survivors through their individual lens and shed light on their unique experiences of recovery. This chapter revisits the methodology, the methods used in the collection of data, the key findings of the study and makes recommendations for practice and future research. Finally, an overview and conclusion to the project is presented.

CONTEXTUALISING THIS STUDY

There is now an extensive body of research related to ICU practice and outcomes. In recent years the focus of this research has shifted from battling mortality as an endpoint to an exploration of the outcomes of ICU and quality of life of ICU survivors (Jones, 2014). This change in research focus has yielded evidence that, globally, ICU survival comes at a high physical, psychological and emotional cost; that severity of the disease process and the interventions necessary to sustain life can leave a legacy of life changing complications. Psychological consequences can include anxiety, depression; at worst, PTSD. Any and each of these sequelae can become chronic, exerting life changing consequences on the survivor and their family as well as increasing an already significant health care debt.

The complications survivors may experience are of a common currency despite the heterogeneity of the population. This would suggest that complications are predictable and manageable (Crabtree-Buckner & Kautz, 2012; Wilcox et al., 2013). Early identification and intervention strategies to promote a meaningful recovery are vital to address these significant issues before chronicity is established (Griffiths & Jones, 2007, 2011; Jackson, Mitchell, & Hopkins, 2009). Despite the recognition of potential problems and an extensive exploration of interventions to promote recovery, follow up support services during recovery remain disparate, sporadically implemented and often lack an empirical evidence base (Egerod et al., 2013; Jensen et al., 2015; Prinjha, Field, & Rowan, 2009). Most significantly, support services for the individual surviving the ICU experience remain predominantly focused on the physical.

The determinants of this inadequate provision for the psychological needs of ICU survivors are potentially numerous. Leading factors though include limited recognition of the psychological consequences of a critical illness/event; no consensus around the terms of an evidence based approach and thus inadequate resourcing.

An intervention which has not been explored with ICU survivors is that of disclosing thoughts and feelings through other means rather than oral alone. The process of writing about deeply personal issues has been identified as exerting a positive bearing on health status (Pennebaker, 1993). It is the process of disclosing personal thoughts and in particular negative feelings, which exerts mental and physical health benefits (Pennebaker, 1993).

The experience of a critical illness/event and the associated de-humanising interventions can be so disturbing that they have been compared to a torture-like existence. Survivors' memories of their ICU experience are often of a persecutory or morbid nature indicating that there remains a level of awareness of risk to self, whilst in ICU despite, or perhaps because of, deep sedation and an inability to interact with surroundings or associated experiences. The disturbing nature of these recollections or dreams as the central powerful image i.e. the contextualising image has been correlated with those who suffer the most severe trauma (Duval & Zadra, 2010). This is congruent with the notion that an ICU experience is deeply disturbing and potentially traumatic with the potential to create a lasting legacy of psychological distress and potential psychological consequences. Notably, general trauma survivors are well recognised to be at risk of psychological sequelae because of their experiences and pre-emptive psychological interventions are routinely provided for them however, this pre-emptive approach is not extended to ICU survivors. This raises the debate that as ICU survivors manifest similar complications as general trauma survivors, trauma management strategies should be adopted in the ICU population of which the methods used in this study could be a component.

As illustrated in this project, survivors often appear physically recovered but remain psychologically unwell, often unable to reveal this even to those closest to them. Survivors experience a biographical disruption of the self and as Bury (2012) noted, the structure to their daily lives is disrupted by unanticipated events. This disruption unless reconciled can have long lasting implications for the identity of the self (Woon, Dunn, & Hopkins, 2012). The ICU survivors' psychological recovery is lost within the focus of the physical; the physical is tangible, relatively measurable and can

be outwardly recognised. This disruption to the self which survivors experience captured by the dissonance between the surface and deep worlds creates turmoil as they strive to conform to the expectations of what recovery is, perceived by the dominant discourse of biomedicine and society in general.

OUTLINE OF THE METHODOLOGY

An interpretive biographical approach enables the capture of lived events through the collection of life documents such as stories, diaries, obituaries and other artefacts. In this study the biographical approach enabled the illumination of real-life experiences by identifying patterns and meanings within the stories created by the participants. Importantly the method enabled the identification of turning point moments in the participants' lives; all of which were changed forever. The turmoil of the deep and the surface worlds was revealed, which hitherto they had consciously kept hidden from those closest to them. The use of innovative data collection methods gave the participants the opportunity to recreate their stories through their individual lens and share a unique insight into their experiences of recovery. Diaries supplemented the face to face interviews and gave the participants an opportunity for reflection, and to create stories which they may not have been able to articulate through oral methods alone. The interviews were integral to the interpretation process as participants reflected upon, and interpreted their stories of recovery with the researcher to establish a shared meaning and make sense of their experiences.

The concept of diarising in a health care context was already familiar to the participants. They had all received diaries created for them in ICU and were supportive of the notion of diaries during recovery. Anecdotal evidence and a paucity of published research suggests that ICU diaries are underutilised in Australia. The study reported in chapter three identified that ICU survivors in the Australian context valued their ICU diaries but did not continue to diarise during their recovery. They had not however, received encouragement or facilitation to do so. Significantly survivors considered the diaries cemented the nurse-patient relationship beyond their time in ICU as they continued to read their diaries during their recovery. Although the nature of the survivors' illness and condition at the time precludes their participation in diarising during ICU, the potential limitation of subjectivity on the part of those constructing the diaries for the survivors must be acknowledged. The diaries are only a depiction of survivors' stories as viewed by others so it can be argued that the diaries do not belong to survivors as they are outsiders in this process, looking in. As passive recipients in this

storytelling process, by actively diarising they take responsibility and ownership of their personal story and recovery journey. The study described in chapter four was therefore the impetus to explore the use of storytelling through diaries to recreate stories of recovery within the first months following discharge from hospital from a unique perspective.

The methodological approach for the second study was described in chapter three and provided a rationale for the choice of interpretive biography as method to underpin it. Biographical methods transcend national, cultural and social barriers (Bornat, 2008) and the versatility of this method enabled the researcher to explore and describe the human experience in the context of ICU survivors' stories. The analysis of interviews described in chapter five illuminated the experiences of the participants and identified that outwardly they appeared to have "recovered" but psychologically remained unwell. These findings gave a multi-dimensional view of recovery during the early stages and an insight into the incongruence which exists around the notion of recovery and the biographical disruption which existed for the participants. The accounts of the participants in this chapter also revealed how they struggled to conform to what the notion of recovery meant to and the expectations of health care providers and their families. It was apparent that a shared meaning of what recovery is does not exist and this was a source of angst for the participants.

The life documents as described by Denzin (1989) were the diaries which described turning point moments in the lives of the participants. These turning point moments were compellingly captured in chapter five through the stories of the participants. These accounts of turning point moments derived from the face to face interviews and diaries demonstrated the inherent power of the biographical method through the interpretation of life documents that separates the life being lived (i.e. the surface world) from the deep inner (hidden) self.

Storytelling as a research method has been validated as has the therapeutic benefits of individual or group storytelling. The opportunity to tell one's story can be both emancipatory and healing. These benefits were reflected in the accounts from the participants who considered that the opportunity to tell their story from their individual perspectives enabled them to reflect on their recovery journeys thus far. The cathartic process of survivors "unpacking" their stories through diarising and interviews was evident in this study and afforded meaning to their experiences.

The use of diaries as a data collection tool ensured that there were no constraints upon participants who had the flexibility to diarise when the time was right for them. This was important as the participants were vulnerable during the early stages of their recovery and this method gave them space and time to capture thoughts and feelings when they felt able to do so. This reflective process created a much needed space for thought wherein the participants could reflect upon what had happened to them and make sense of their experiences. This process enabled them to reflect on their lives as they were and begin to reconcile the biographical disruption they had experienced in order to look toward the future.

Importantly, the participants were able to describe the type of support they considered would have made a positive impact upon their recovery. The provision of written information upon discharge from hospital they considered would have been invaluable to inform them of what to expect during recovery; and how to seek support should they feel they needed. The participants also articulated that the provision of specialised support during recovery by someone who could identify with their experiences and guide them through recovery was crucial.

The final process in storytelling is recognised as moving forward in order to develop an understanding of experiences and to realise that the traumatic event was episodic rather than permanent (Wimberely, 2011) enabling survivors to look forward and move on with their lives.

Chapter six demonstrated the diarising process and the significant contribution to the project using the example of one participant's experience. Sam used vivid symbolism and metaphor in his diary to represent his story and journey of recovery. This chapter highlighted the power of this method and the ability to recreate individual stories and share experiences, if one is given the appropriate tools and support to do so. Sam considered the opportunity to be able to diarise and use imagery to illustrate his experiences as an important factor in his recovery journey. Thus this chapter allowed the reader to follow the process from diarising and story development (data collection) to analysis and interpretation. Sam's diary uniquely identified the turning point moments i.e. disruption of the self in his trajectory and how he struggled to reconcile his life as it had become compared to what it had been. His diary enabled him to illustrate how he struggled at work, desperately trying to conform to the expectations of others, afraid to disclose this dichotomy for fear of not conforming to the expectations of others. His diary also revealed the multiple realities in which he

existed; how he still grieved for his stillborn child which was his delusional reality. Sam was at the fork in the road during this early period of his recovery. Diarising enabled him to capture his thoughts and feelings which he had not been able to before and reconcile the disruption he experiences in order to look forward.

The participants' stories told here echo the plight of many ICU survivors which despite advances in ICU care, the experiences and challenges of recovery remain unchanged. These experiences are synonymous with those who experience trauma from other sources which threaten the integrity of the individual and cause a biographical disruption to the self (Hull, 2012; Kiekkas et al., 2010).

FINDINGS

The findings from this study were manifold and have implications for survivors, their families and for practice.

Significantly, this is the first study to explore ICU recovery to apply a biographical approach to aid story construction during the recovery of ICU survivors. Further to this, as the participants diarised during the five months immediately after their discharge from hospital, the study provided a unique window upon the recovery process during that early timeframe. This study identified that participants continued to experience delusional recall of ICU which they could control at will and which they had not previously disclosed to anyone. The innovative use of diaries and interviews helped to capture this.

The participants in this study experienced a biographical disruption to the self and were affected by their experiences and considered their lives had changed forever as a result. Dreams recalled by the participants were of a sinister and menacing nature indicating that there remains a level of awareness despite heavy sedation and a presumed unawareness of their surroundings in ICU. These findings confirm that the ICU experience is a traumatic event and consistent with general trauma survivors, they experience a threat to their own lives as a direct consequence of a traumatic event; in effect a threat to the integrity of the self. These psychological sequelae and the associated psychological consequences which include PTSD and potential therapeutic interventions offered here can no longer be ignored.

Many participants described that although outwardly their appearance represented to others that they were recovered, below the surface they did not feel

recovered and this was a source of great angst for them. This lack of understanding surrounding the notion of recovery and what this means to those who are recovering was a noteworthy finding of this study. The view of recovery through the lens of the survivor gave an insight into recovery trajectories and an understanding of the challenges survivors face but also the support they would value during this time. Participants considered that this support should commence with written discharge information about what survivors could expect to encounter during recovery and where and how to seek support should they feel this necessary. As well as written information support from a specialised support person was important rather than just from their family and friends who did not have a deep understanding of ICU experiences and recovery. The participants considered that this support person should be expert in ICU practice and able to identify with their experiences of ICU and recovery to offer the most appropriate support.

The unique application of diarising in this study permitted an insight into the recovery of ICU survivors and the challenges they face. The findings from this study have contributed to the existing body of knowledge by enabling survivors to portray their experiences of recovery through their individual lens, offering insight into the disruption to self that they encounter but also to determine the support which would be appropriate for them in the Australian setting.

RECOMMENDATIONS

There are several categories of recommendations which emerged from this study and encompass many areas of ICU recovery. These have been organised to reflect their diversity and include recommendations for practice, future research, education and support during recovery.

RECOMMENDATIONS FOR PRACTICE

RECOMMENDATION ONE

It was evident from the findings of this study that survivors were unprepared for the aftermath of their critical illness and ICU experience. These unanticipated consequences and protracted and uncertain recovery times can lead to anxiety and frustration for some survivors. To help counteract these effects it is recommended that survivors be offered verbal and written information, based on best available evidence, prior to their discharge from hospital. This information should include, but is not limited to, details about potential psychosocial/mental health sequelae and strategies

to ameliorate these via health care professional support skilled in the after care of ICU survivors. Written information about potential issues during recovery accompanied by advice about managing these have been successfully implemented in the UK and been well received by survivors.

RECOMMENDATION TWO

Participants in this study experienced severe acute delirium in ICU. The disturbing memories of this were clearly articulated in their diaries and interviews as well as the ability to recall them at will. Whilst it is known that the ability to control delusional recall is associated with psychological morbidity, in particular PTSD, these participants were not offered specialised support during their recovery. It is well established that the presence of ICU delirium and/or delirious recall is an independent risk factor for morbidity and mortality in ICU survivors (Svenningsen et al., 2014; van den Boogard et al., 2012) yet these participants were not identified as at risk or offered specialised support during their recovery. It is recommended that survivors who experience acute delirium in ICU are offered appropriate support to mitigate the potential sequelae of delirium following hospital discharge.

RECOMMENDATION THREE

The findings from this study have confirmed that a critical illness/event and subsequent ICU admission is a harrowing experience for survivors. These experiences are synonymous with those who experience trauma from other sources which threaten the integrity of the self and the potential effects of trauma exposure are analogous in both groups. The recommendations from this study therefore that there is open recognition and a shared understanding within the ICU community that this issue be debated. This debate should incorporate the potential of therapeutic techniques well established in the trauma population, be explored for and with ICU survivors.

RECOMMENDATIONS FOR FUTURE RESEARCH

Research undertaken to date has not listened to the voice of the survivor and brought their experiences to the fore front as has been achieved in this study. The following recommendations suggest appropriate research directions to achieve this.

RECOMMENDATION ONE

The therapeutic benefits of storytelling and disclosure of traumatic events have been acknowledged as validating and managing the impact of the experience as well

as offering an avenue to share information and emotions with others. Yet the notion of re-creating the experience of ICU for survivors has not been developed further from those authored by others in ICU. This new and innovative use of a biographical approach described here has potential to enable those who survive a critical illness/event to re-create their unique stories of survivorship and further inform the existing body of evidence and should be further built upon within other ICU contexts nationally and internationally.

RECOMMENDATION TWO

Survivors in the Australian context have been shown to be positive about the notion of diaries written for them whilst they were in ICU as was described in chapter four. The optimum processes and strategies surrounding the use of ICU diaries requires clarification and a standardised approach to include the optimum time to commence diaries in ICU requires clarification. Specifics around their construction and the optimum time and way to return them to survivors bear investigation as well.

RECOMMENDATION THREE

The findings from this study confirm that ICU survivors experience similar sequelae as those exposed to other trauma. It is recommended that future research should determine if the application of pre-emptive therapeutic interventions traditionally afforded the general trauma group, may have merit with ICU survivors in reducing the incidence of psychological consequences of a critical illness/event.

RECOMMENDATIONS FOR EDUCATION

Recommendations for education which have emerged from this study in the context of ICU recovery are wide ranging; pertain to health care practitioners, survivors and their families and have the potential to have a significant impact upon survivors.

RECOMMENDATION ONE

The consequences of a critical illness/event are well evidenced in the literature yet this has not translated to a grass roots level. The researcher contends that the incidence and significance of ICU sequelae for survivors is often underestimated in practice and there persists a lack of understanding of the difficulties survivors face during recovery. As a consequence health care practitioners are not providing information to survivors about the potential difficulties they may face and strategies to address these should they arise. In order to provide adequate education to survivors

and their families however, health care providers need to be educated themselves about ICU recovery and the potential difficulties survivors can encounter.

RECOMMENDATION TWO

Well educated health care providers can provide evidence based education to survivors, their families as well as to their colleagues. It is recommended that education for survivors should be an essential component to promote psychological health and well-being as they embark upon their recovery trajectories. This education provision should also be extended to family members of survivors.

RECOMMENDATIONS FOR HEALTH CARE PROFESSIONALS

Within Australia there is a lack of support for ICU survivors during recovery despite the wealth of evidence which confirms the prevalence of sequelae with an associated reduction in employment, increased health seeking behaviour and reduction in quality of life compared to the general population. Promotion of recovery of the physical self is usually addressed as this is tangible to see and measure. It is the recovery of the self which cannot be seen i.e. the emotional and psychological self where support is lacking. The timing of this support is crucial and should be commenced prior to the manifestation of significant psychological problems such as PTSD. It is recommended that health care providers recognise this and develop interventions targeted early during recovery and to those who would benefit most from them.

LIMITATIONS

This study was conducted at a single site thus reducing the transferability of its findings. This constraint was unavoidable as this was the only unit in Western Australia and potentially Australia routinely using ICU diaries. This has not detracted for the richness of the data generated and the potential impact of the findings.

This was a vulnerable group to study and the researcher encountered difficulties in recruiting and retaining participants as it was recognised that this was a population who had experienced significant life events. Interestingly, those vulnerable individuals who did not participate in this study may have benefited most from the methods applied here.

When potential participants were first approached by telephone, they were still in the early stages of their recovery journey. Approaching participants whilst they were in

hospital may have increased the number of participants willing to take part in the study. The researcher had limited knowledge of the participants' pre-morbid state and the events in ICU so their physical and psychological status could not be accurately determined at the time of recruitment into the study. It was important though to capture the experiences of survivors in the early recovery stages when they could potentially recall their experiences of ICU and diarise during recovery most accurately.

A limitation of the study was that the researcher did not offer alternative methods of diarising, such as taped diaries which could have further facilitated diarising in the study.

CONCLUSION

There is little doubt that ICU survivors face challenging and protracted recovery trajectories. With little or no professional support, survivors may be reliant upon family members closest to them who are unable to offer the specialised support they need. The irony remains that those who were the sickest and needed the costliest health care resources to survive are seemingly cast out without an afterthought by those who invested time and resources into their survival. This imbalance stems from a lack of understanding around what it means to be recovered, measuring being "recovered" by way of outward (physical) appearances with no consideration of what is bubbling beneath the surface. This is not holistic health care. In this study there was a lack of acknowledgement that an ICU experience is traumatic and life changing for many; reflected in the lack of support services for survivors and indeed, their families.

Survivors are a vulnerable population and describe feelings of anxiety and loneliness as they face an uncertain recovery trajectory. A lack of support during recovery can exacerbate these feelings. Issues for survivors are not always evident soon after discharge from hospital and can develop far into recovery; up to a year post ICU experience in some cases. This determines that the provision of support for survivors should commence early during recovery and target those who would benefit most from it, thereby reducing the risk of difficulties developing. At its worst the sequelae of ICU admission may be PTSD, a chronic condition which yields a significant effect on survivors' quality of life. Early implementation of appropriate support is vital to halt the sequelae of psychological difficulties before chronicity is established.

As a senior ICU nurse 20 years ago I experienced on a human level the early and late sequelae which a significant number of survivors faced. I was privileged to work

with these survivors and experiencing their issues at first hand ignited a passion within me to support them in whatever way I could; they had, I realised, suffered enough. Decades have since lapsed yet there remains limited recognition of the burden of ICU survivorship in the practice setting and it would appear a lack of intent to change this. As a nurse this has saddened and frustrated me and the desire to illuminate this inequity was the impetus for this study. All of the participants described here shared their experiences with me without reservation, for no other reason than to assist me and those who came after them. This study has given them a voice to tell their stories so they can be shared, heard and understood. I am confident that the findings from this study, shared through publications will contribute to the debate surrounding ICU survivorship so that others may be moved as I was and driven to rectify this deficit in care.

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APPENDICES

Ewens, B., Chapman, R., Tulloch, A., & Hendricks, J. M. (2013). ICU survivors' utilisation of diaries post discharge: A qualitative descriptive study. *Australian Critical Care*, 27, 28-35. doi: 10.1016/j.aucc.2013.07.001



ICU survivors' utilisation of diaries post discharge: A qualitative descriptive study



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ABSTRACT

Background: A growing body of evidence has confirmed that intensive care unit survivors encounter myriad of physical and psychological complications during their recovery. The incidence of psychological morbidity in intensive care survivors is increasingly being recognised. The causes of psychological morbidity are multi-factorial but may be associated with a complete lack of, or delusional recall of events in intensive care. Intensive care unit diaries are an initiative designed to enable survivors to help restore factual memories and differentiate those from delusional.

Purpose: To explore survivors' and family members' perceptions and utilisation of diaries following discharge from hospital.

Method: A single centre qualitative descriptive study was undertaken in a general intensive care unit in Western Australia. Participants were surveyed 3, 6 and 12 months following discharge from hospital. Eighteen participants completed one or more surveys.

Findings: Many of the participants who completed the surveys read their diaries but few made entries in them following discharge. Reading the diaries evoked mixed emotions for these participants; however they still viewed the diaries as a positive initiative in their recovery. Diaries enabled survivors to fill the memory gaps, make sense of their experience and reinforced the human connection when they were immersed in a technological environment.

Conclusion: Use of patient diaries was received positively by the participants in this study. Diaries are a simple, cost effective initiative which enabled survivors to piece together the time they had lost, concreted their experience in reality and enabled them to retain a connection with their loved ones whilst immersed in a technological environment.

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Introduction

The impact of a critical illness and consequent intensive care unit (ICU) stay upon patients and their families cannot be underestimated. The ICU experience and its aftermath are described by some survivors as traumatic and life changing; and is associated with a significant risk to short and long term physical and psychological morbidity, reduced quality of life (QoL) and delays in optimal functional recovery for a significant percentage of survivors.¹⁻¹⁹

Complications reported include sleep disturbance, anxiety, depression and Post Traumatic Stress Disorder (PTSD).^{4-7,14,15,20} However, the prevalence of psychological complications reported is variable but is postulated to range from 24 to 44% of survivors with some evidence to support that up to 64% of survivors report symptoms of PTSD. This variance has been attributed to endogenous patient characteristics as well as the ICU experience itself. A pessimistic outlook, a pre-ICU history of mental health disorders, intrusive memories, memories of pain and longer duration of sedation have all been recognised as independent risk factors for the development of PTSD.^{4,5,21-23} The wider implications of the trauma of an ICU experience and associated complications is a higher burden of ill-health and an associated increase in the use of healthcare resources.^{8,24-29} The concept of trauma is defined in the literature as any unexpected and unfamiliar experience, during which

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unusual and extreme stress is experienced.³⁰ Exposure to a trauma may generate feelings of intense fear, horror and/or helplessness caused by subjection to the threat of actual or potential death or serious injury, or bearing witness in others.³⁰ Traumatic events, which have been identified and which may precipitate psychological distress in some individuals, include exposure to military conflict, torture and physical and sexual violation.³¹ The effects of such trauma, can be so powerful as being recognised as capable of tearing the protective fabric of one's self apart.³² There are many similarities between the psychological distress associated with "conventional" trauma exposure and that experienced by survivors of a critical illness and an ICU experience.^{4–6,10,13,14,16,33} This could be because the reports of a critical illness and ICU experience are similar to that of other trauma survivors and, therefore, similar sequelae could be anticipated. Similar to other trauma exposures, it may be asserted that a critical illness is often unexpected, patients are rendered helpless in an unfamiliar environment, confronted by extreme stress and frequently report recollections of persecution and impending death, despite their apparent subconscious state.^{34–39}

The realisation of short and long term physical and psychological morbidity associated with ICU survivorship, has led to an exploration and identification of both the precipitating factors and interventions which could reduce the incidence and severity of complications.^{8,15,24,28,40–46} An association between psychological morbidity in ICU survivors and absent or delusional recall of the ICU experience or the presence of delirium has been postulated.^{14,16,39} Rates of delirium in Australia have been estimated to be 45%⁴⁷ compared to higher rates reported in the rest of the world.⁴⁸ Delirium is characterised by a fluctuating mental state, inattention, disorganised thinking and altered level of consciousness.^{49–52} The process of re-defining and clarifying the experience and filling the memory gap or re-defining true memory from delusional, may impact upon the incidence of psychological morbidity and recovery.^{33,54} Despite the realisation of the scale of complications which ICU survivors face, a lack of consensus regarding the most appropriate focus and structure of programmes to assist survivors to regain their pre-morbid functionality and QoL persists.^{16,55}

Survivors of a critical illness display a unique assortment of atypical and complex problems which often require specialised and individualised support to enable recovery. As the recovery trajectory is not homogenous, the duration and extent of recovery are difficult to predict, with many survivors never regaining their pre-morbid physical or psychological state.^{41,55} The explanation for these inconsistencies in recovery trajectories is probably multi-factorial but may, in part, be attributed to the paucity of rigorous research to inform the provision of physical and psychological rehabilitation frameworks.⁵⁵

Early interventions to improve the quality of life of ICU survivors focussed upon the implementation of ICU follow-up clinics. These clinics were pioneered in a UK centre in the 1990s as a treatment and support modality for ICU survivors.⁵⁶ Evaluation of these clinics demonstrated high levels of user satisfaction and associated health service endorsement in the UK.⁵⁷ Unfortunately, the model was plagued by sporadic implementation, disparate composition and inadequate methodological evaluation.^{44,58,59}

Another strategy which has attracted significant interest and associated investigation in Europe has been the implementation of patient diaries in ICU. Patient diaries have been used in follow up clinics as a springboard to promote discussion about the ICU experience and resulting recovery. Recent studies have demonstrated the potential of ICU diaries in assisting physical and psychological recovery in this population.^{54,40,60}

Patient diaries are based on the premise that ICU survivors have difficulty in constructing a narrative of their experience because of enforced pharmacological amnesia and severity of illness which

may have detrimental effects upon their recovery.^{61,62} It has been suggested that providing a narrative of events of which the survivor has no recollection, may be beneficial to recovery.^{45,63}

Patient diaries are usually commenced in ICU after the patient is ventilated and entries are completed by relatives and ICU staff to serve as a factual record, in words and photographs of the survivors' ICU experience. ICU patient diaries emerged in Scandinavia in the 1980s, with their implementation sporadically disseminating to the UK and Switzerland but not as yet further afield.^{64–68} Early examination of the benefit of diaries focused upon survivors' descriptive feedback, however recently, empirical methodologies have been employed exploring the benefit of diaries on QoL and the potential reduction of PTSD.^{60,69} A non-randomised study was conducted in Sweden to investigate if the use of diaries in ICU would improve patients' QoL.⁶⁹ Diaries were commenced for 38 patients and anyone involved in patient care was encouraged to contribute. Questionnaires were sent to the patients post-discharge to measure survivors' QoL at 6-, 12-, 24- and 36-month intervals. In addition to the diaries, as standard ICU practice, patients also received follow-up visits from staff. The findings of the study demonstrated that the use of diaries and the follow-up visits were associated with improved health-related QoL. However, it is not apparent if the non-diary group received a follow-up visit too. It is therefore not possible to attribute the improved quality of life in the diary group to the diaries alone. The single site, small sample size, the inability to compare pre-morbid quality of life and mental health status to post-morbid state and lack of information pertaining to how often the diaries were read by the participants, are further limitations of this study.

A UK randomised controlled trial (RCT) evaluated the effectiveness of patient diaries in ICU on levels of patient anxiety and depression.⁵⁴ Nursing staff kept diaries for ICU patients using a series of standardised headings and 36 patients were recruited into the study. The findings demonstrated a reduction in anxiety and depression scores in the diary group survivors at 2 months post-hospital discharge.⁵⁴ Although the results of the study showed that the use of diaries in ICU may have a beneficial impact to reduce survivors' anxiety and depression, the authors highlighted limitations including the small number of participants and the time available to complete the study, making the findings less generalisable.

An RCT conducted across six European sites, evaluated the use of patient diaries following ICU discharge and the reduction of new onset PTSD. Nursing staff and family members were encouraged to make written and photographic entries in the diaries, which were constructed in a standard format across all sites. There were 352 participants recruited to the study who completed a validated screening tool at 1 and 3 months post ICU discharge. The statistically significant results from the study indicated that the prevalence of new onset PTSD was reduced in the diary group (5%) compared to the control group (13%). The researchers concluded that reading the diaries may yield a similar effect as Cognitive Behavioural Therapy, in that diaries help survivors change the way they think about their illness and enable the recreation of an autobiographical memory.

Overall, the use of diaries has been positively evaluated by European survivors and their families and the diaries have also been acknowledged as giving nursing staff insight into the patients' experiences when utilised as a follow-up tool. Diaries have also been attributed to contributing to the reduction in survivors' memory gaps, concretising their experiences in reality and enabling them to comprehend the severity of their illness and set realistic goals to achieve meaningful recovery.^{53,54,70–72} Maintaining a diary for ICU patients and their families has been shown to provide a coherent narrative of the patient's ICU experience and nursing performance.^{73,74}

In a qualitative study⁵³ several emergent themes were identified from patient diaries including; the sharing of daily events,

confirming someone was always at the bedside and a vehicle for expressing feelings and support. The authors concluded that the diaries were a reflection of the care and contribution of staff and family. However, the impact and therapeutic benefit of specific content upon the survivors' recovery has yet to be defined and remains based on professional judgement.⁶⁸

Survivors have reported diaries helped them to recover the time they had lost, provided a sense of being loved when reading their family's diary entries, legitimised their experience and enabled them to come to terms with the severity of their illness.^{72,75–77} However, there is a paucity of studies exploring survivors' perceptions and utilisation of diaries post-discharge, although as it has been alluded that this may be an important support mechanism.⁷⁷ Although the use of ICU diaries has been explored in the UK and Europe there has been limited use and therefore evaluation within Australia.

The study detailed in this paper explored survivors' use of an ICU diary as a post-discharge recovery tool in the Australian setting. The results of the study will provide clinicians, managers and educators with evidence to assist them to effectively implement ICU patient diaries in their own clinical setting.

Method

Diaries provided for participants were designed by the researchers and professionally printed. Nursing staff received education sessions about the construction of the diaries and written guidelines were distributed to reinforce these education sessions. Staff were encouraged to detail the participants' daily activities, how they were responding to treatment and who had visited them. Photographs were also taken of participants but withheld from them until they gave consent for their use in the diaries.⁷⁸ Meaningless entries, for instance about the weather and any personal information about staff were discouraged. Family members were encouraged to make entries in the diaries in written or pictorial form, which many chose to do, particularly if family members were children. When participants were clinically stable, had been extubated and were preparing for discharge to the wards, the primary researcher would approach them to discuss their diaries. This discussion was undertaken in a sensitive manner and a full explanation of the purpose and composition of the diaries was given to each participant prior to going through their diary with them. This was often an emotional time for the participants and the researcher ensured enough time was devoted to this initial diary discussion. None of the participants became unduly distressed when viewing their diary for the first time but support mechanisms had been identified if this should be the case. The research team visited all participants in the wards every 2–3 days until hospital discharge to monitor individual responses to their diaries and answer any questions which may have arisen as a result.

Following discharge from ICU the diaries become the property of the survivor who if they so wish, could read and make entries into them. However, the frequency of diary entries by survivors post discharge has not been investigated and it is therefore unknown if this is a frequent practice. This descriptive qualitative study was conducted in a general ICU in Western Australia. Participants were asked to complete a written open-ended survey at 3, 6 and 12 months following hospital discharge. The survey aimed to elucidate the frequency of which they and their relatives had read their diaries and what thoughts and feelings this generated.

Participant recruitment

Inclusion criteria for the study were adults aged 18 years and over, who were ventilated for at least 24 h and were receiving

ongoing active treatment, had no new or pre-existing cognitive impairment and were English speaking. The next of kin of each eligible patient was approached by the ICU nursing staff to gain consent to commence a diary and a verbal explanation of the study was given to the relative. A written information sheet was then offered explaining that the diaries were a means of providing their relative with a factual record of events during their ICU stay. This explanation also included a description of the diaries and their purpose, who would make entries in them and the completion of the surveys post-discharge. Following discharge to a ward, patients who remained in a stable condition were offered verbal and written clarification of the study and if they were willing to participate, written consent was obtained. Surveys were distributed to participants by post to their usual residences at 3, 6 and 12 months post hospital discharge. A stamped addressed envelope was included for return of the surveys. If surveys had not been returned by participants within 2 weeks, the researchers contacted the participants by telephone once only to encourage them to do so.

Ethics approval was gained from the appropriate human research ethics committees. Confidentiality and anonymity were assured and all surveys were coded and de-identified. Participants were assured that they would not be identified by their comments, which may be included for publication or conference proceedings in the future. Only the researcher had access to the coding system and identification of participants, to be able to contact them if they had not returned surveys within the anticipated timeframe.

Participants

Thirty-two patients were eligible to participate in the study. From these, 4 patients or their relatives declined to participate, 10 withdrew from the study after initially agreeing to participate, 7 completed all three surveys during the year following hospital discharge, 6 participants completed the first two surveys and 5 completed the first survey only.

Participants were classified as withdrawn from the study if they did not return their surveys within 6 weeks of receiving them. Participants were contacted by telephone on one occasion to remind them to complete the surveys but any further contact was deemed inappropriate in this group as potentially some may have been experiencing complications of their critical illness. Reasons for relatives refusing to participate in the study were not explored at the time.

Data collection

The surveys were developed by the researchers, as an existing suitable instrument could not be identified in the literature. The survey consisted of nine questions, some of which were multiple-choice eliciting how many times participants had read their diary since discharge; the remainder were open-ended questions which invited the participants to describe their feelings when reading diary entries. Three questions focussed upon the participants' families views of the diaries and in particular if they would recommend the use of diaries to others who had a family member in ICU.

The surveys were reviewed by a panel of three experts to establish face validity of the tool. The three experts met with the researchers to discuss the content and structure of the survey and changes were made to the structure of some questions in response to their feedback.

Data analysis

Data collection and analysis were approached using a qualitative descriptive framework. This approach does not require a highly abstract rendering of the data, and is a method of choice when

fundamental descriptions of phenomena are required.⁷⁹ Surveys were analysed using standard processes of qualitative analysis⁸⁰ and included coding, finding categories, clustering and identifying patterns and meanings. The data were reflected on and coded line-by-line to identify significant meanings, that is, words or phrases that the participants used and which were identified as being of interest or importance.⁸¹ The coded meanings were categorised and clustered and the relationship between them identified, thus confirming that the themes which emerged were adequate and informative.

Trustworthiness was achieved by addressing credibility and transferability of the data.^{82,83} Credibility was ensured by giving a sample of the transcribed surveys to two experts in qualitative data analysis who coded and categorised the data individually, with overall agreement and consistency found between the experts' and the researchers' analyses. Transferability was established by developing rich descriptions and maintaining an audit trail to allow comparison of the study with those conducted in similar contexts. The following section provides statements that illustrate the main categories. Statements are not identified by participants to preserve anonymity.

Findings

The ICU survivors who participated in this study included nine males and nine females who were aged between 34 and 84 years. The reasons for admission to the ICU included respiratory failure, intraoperative complications, septic shock and acute renal failure.

Themes that emerged from the data included: feelings generated from reading the diary; gaining a sense of reality; feeling cared for; sustaining human connection; and insight into their illness. Additional data collected included: the frequency survivors and their families made diary entries; the frequency they read and discussed the diaries; their views of the diaries and whether participants would recommend the use of diaries to others.

Frequency of reading the diary since discharge from ICU

Twelve participants read their diaries at least monthly at 6 months post discharge, however four of these participants recorded that this had reduced in frequency over this time period. For the remainder, four read the diary less frequently than two monthly and two had never read their diary after discharge. For those that did not read their diaries their reasons included feeling that their health had improved and one participant found the diary "too upsetting" to read.

Writing in the diary post discharge

Fifteen of the participants had not written in their diary since discharge. Of the four participants that had written in them, their reasons were; not only to fill in the gaps but also because they wanted to respond to the nurses' comments. For those few who continued to write in their diary post discharge they experienced mixed emotions. These emotions included fear "as the memories came flooding back" and a realisation that they could have died. Alternatively, some participants also reported feeling joy and happiness because writing in the diary helped them to remember their feelings when reading their families' entries.

Discuss the diary

Seven of the participants did not discuss their diary with anyone whilst they were in hospital. Of the 12 that did talk about their diary, the majority (9) discussed it with their family, 6 with nurses, 4 with

friends and 1 with other patients and non-nursing staff. As demonstrated by these results some participants' discussed the diary with more than one group of people.

Family views of the diary

All participants considered that their family felt the diary was a good idea. Writing in the diary assisted the family to express their feelings and provided a quick reference for them. When family members visited they could read the entries and quickly catch up with their loved one's care requirements since the last time they had seen them. The families felt appreciative of and supported by the staff entries and these records provided a focal point to open up discussion with other family members. However, on some occasions family members were fearful for their loved one's welfare and their prognosis after reading some of the staff accounts.

Family reading the diaries

Twelve of the respondents stated that their family had never read the diary since being discharged from ICU. The reasons for this were not explored in the study however, this could be interpreted as avoidance behaviour by family members and a reluctance to re-visit their traumatic experience. Of those who had, two read it monthly or more often and the remainder less frequently than every 2 months.

Family entries in the diary post discharge

Sixteen of respondents' families had never written in the diary post discharge. The two respondents who had written in the diary had only done so on one occasion and the reasons given for these entries were to welcome their loved one home after discharge and because they had asked them to.

Feelings generated from reading the diary

Reading the diaries was reported to be an emotional experience for all of the participants and even if these were considered negative, they considered that this did not have a detrimental effect upon them but served to reinforce their experience. There were reports of both positive and negative emotions but despite this, there evolved a realisation of how critically ill they had been and how much their families and ICU staff cared for them. The diverse emotions experienced by the participants included humility because of the care they received and relief that they had survived the experience. Some however, experienced shock and fear when they read their diary entries, which prompted one participant to explain:

I don't often read my diary because it makes me feel very emotional

Gaining a sense of reality

Whilst being heavily sedated and ventilated, awareness of experiences and environment is lost. The diaries provided participants with details of what had happened to them and their family during this time. The diary entries demonstrated to the participants the severity of their illness, and that despite being immersed in a technological environment, the humanistic component of their care remained paramount. For others, the diaries made sense of what they remembered and recognised; that the information in the diary assisted them to "fill in the gaps" and to gain a better understanding of not only their illness but also of the days they had lost. One participant wrote:

I still remember vividly my experience when conscious – most of which were hallucinations, so it helps reading it to get a sense of reality

The following comment illustrates the potential of diaries to fill the memory gap:

I had no recollection of anything...it was only after I read the diary that I realised how seriously ill I was, also I could see the daily happenings and improvements

Feeling cared for

The theme of feeling cared for was a concurrent one for the participants and most stated they were grateful that although the staff were busy, they still found time to write in the diaries. They considered this to be above and beyond what was expected of the staff and was interpreted by participants as an act of caring. As one participant commented:

I was being cared for by the most professional, caring and committed nursing staff

Another stated:

makes me feel good – that somebody really cares

The notion of individualised care in ICU was also commented upon:

I felt appreciative of the personal care...shampooing of hair, brushing of teeth, plaiting my hair...

Connection with loved ones

The diary on some occasions provided the respondents with evidence of how their families, often in times of crisis, sustained a connection with them through the diaries. This was evidenced by expressions of support, love and hope articulated through their diary entries. One participant commented:

They had a chance to communicate with me...helpful to read about how much they cared...revealed things they wouldn't normally talk about

Another participant commented that:

Seeing in writing how much I was treasured...gave me a different perspective

Of the participants who responded and had read their diaries it was considered that the staff reports helped them gain a better insight into their illness, which was augmented by viewing diary photographs intended as a visual representation of their journey to recovery. Initial feelings of shock when seeing the photographs for the first time emerged, followed by a realisation of the severity of their illness.

Several of the participants were grateful to the staff for writing in their diaries as it provided them with an opportunity to "get to know" the staff who had cared for them which they were unable to do whilst were in hospital due to their illness and treatment.

Recommending others to use a diary in ICU

Each survey included a question about whether the participants and their family members would recommend a diary to others who had loved ones in ICU. Despite the mixed emotions reported by survivors, all agreed that they would recommend the diary to someone they knew who had a family member in ICU. Despite some participants not reading the diary when at home, they had all read it whilst in hospital and considered that the diary provided them with an

insight into their situation and assisted them with their recovery. Several participants mentioned that whilst in ICU and unable to communicate the diary helped their family members express their feelings.

Discussion

The findings from this study have shown that within this small cohort many participants continued reading their diaries, however few made written entries following discharge. The diaries provided survivors with information about their illness, what had happened to them in ICU and affirmed the preservation of human connection when they were immersed in a technological environment. The diaries evoked myriad emotions for survivors and their families. Experiencing these emotions rather than suppressing them may have allowed survivors to re-process their thoughts about their experience. However, it was necessary to ensure survivors were supported by experienced ICU staff when they first read their diary and viewed the pictures within it, as it is acknowledged that this could be distressing for them. Participants were informed that reading their diaries may be difficult for them and that if they felt they wished to discuss their diaries following discharge from hospital that they could contact the researchers at any time but none did. On discharge from hospital participants were also advised to contact their general practitioner if the memories of their experience did not fade, e.g. recollections, dreams or if they experienced intrusive thoughts or distress about their ICU experience. The diaries further enabled them to build an accurate autobiographical story which may have enhanced their psychological recovery.²⁸

The participants in this study described a range of both positive and negative emotional responses to their diaries. An appreciation of the potential detrimental effect that diaries may have is not well illustrated in the literature. As such, clinicians should be cognisant of the risks and potential harm which may be associated with ICU diaries when considering implementing this initiative in their setting.

Participants viewed the nurses' entries as an emotionally moving act of caring which they considered to be above and beyond their expected duties. The diaries appeared to forge a humanistic bond between patient and carer, and as evidenced by the post-discharge reports, this bond prevailed long after discharge. The transfer from ICU, to ward care and eventually to home is known to be a difficult transition for ICU survivors.²⁹ This is probably due to the phenomenon of "separation anxiety" which occurs during transition from ICU to ward care and is well documented in the literature.^{34–37} Diaries may reduce the effects of separation by endorsing the connection between patients and staff. The diary entries were a permanent testament to the enduring nurse-patient relationship, however this dimension has not been explored in the literature and is worthy of further investigation.

Similar to other studies diaries were found to have value, filling in the memory gap for these survivors and bringing a sense of coherence to their experience.^{44,76} The literature has shown that reading entries and viewing photographs may aid the survivor to come to terms with the severity of their illness and hence set realistic recovery goals.⁷⁵ However, a number of eligible patients declined to participate in the study and therefore, did not have the opportunity to continue writing in their diaries during their recovery. It was beyond the scope of this current study to explore the reasons patients chose not to participate in the project. However, these reasons should be further explored in order to examine the nature of the relationship between non-use of diaries and PTSD which has recently been alluded to in the literature.⁵⁹

A major challenge for health care professionals is to develop and establish effective follow-up services for those survivors at risk of

psychological co-morbidity. As clinicians become more aware of the associated risk factors, at-risk patients can be identified in ICU and targeted for intensive rehabilitation programmes. The use of diaries may have an important role in the recovery of ICU patients and not just for those who are identified as being at risk of psychological complications. However, further investigation is required to determine which patients potentially benefit from diaries and those patients for whom diaries may be deleterious. Diaries are a generic tool which may transcend the diversity of complications in this population and the accompanying diffuse emotional response. The participants in this current study were grateful for the insight they developed regarding their illness from reading the diaries and looking at photographs of themselves whilst in ICU. The use of photographs has been shown to be a powerful tool to assist survivors to realise the severity of their illness and the need to set more realistic goals during their recovery.^{40,69,75,76} The effect of this visual media is yet to be evaluated and since photographs are widely used in ICU diaries, it is worthy of further detailed investigation.

A number of participants in this study did not access their diaries following discharge. The reasons for this may have been many and may be related to the lack of guidance provided to the participants regarding diary use after discharge. The impact of guided support for survivors on their diary use warrants further exploration. Participants may have been exhibiting avoidance behaviour, that is, avoiding stimuli associated with the traumatic event, which may have evoked flashbacks, memories and re-experiencing the primary trauma.⁸⁸ Determining the reasons survivors and their families discontinued the diaries was beyond the scope of this study and requires further epistemological research.

Limitations and future directions

Diaries are a cost effective tool which may have potential in enhancing the recovery of ICU survivors however, the impact of this intervention has not been evaluated in the Australian setting. The findings of this study suggest that survivors read their diaries following hospital discharge but did not actively diarise. The impact and use of diaries as a psychological intervention, including the use of prospective diarising during the recovery phase has not been a focus of research and requires future in-depth exploration.

Currently in Australia, the provision of routine after-care for ICU survivors is rhetorical despite evidence to suggest forms of follow-up may have a place in improving physical and psychological outcomes for ICU survivors.^{43,55,89} Diaries could play a role as the foundation on which to build follow up services for ICU survivors and this is also worthy of further investigation.

Limitations of this study included the use of a small sample, low response rate from participants and the use of a single site. A single site was utilised for the study because there are no other units in Western Australia which currently advocate the use of diaries in ICU.

The reasons for the low response rate to the surveys was not explored further by the researchers and therefore these remain unknown. It could be postulated that the low response rate resulted from avoidance behaviour, a possible consequence of PTSD or that the participants were in some way negatively affected by the diaries and did not articulate this for fear of offending the staff who had cared for them in ICU. Following up participants who did not respond, despite initially agreeing to do so to elicit the reasons for this, may have strengthened the findings of the study.

The data collection instrument was only subject to face validity and a greater depth of validation would have increased the reliability of the instrument. Therefore the applications of this study across multiple sites and the triangulation of data through a variety

of data collection tools, e.g. interviews or telephone surveys would strengthened the findings of this study and their application in other contexts.

Furthermore, demographic data, severity of illness, length of stay and presenting diagnosis were not collected therefore it is not possible to measure if these factors influenced participant responses or if the findings of this study may be applicable to other settings.

Diaries are a simple tool constructed by ICU staff which can be introduced with minimal time and cost implications in any ICU, or potentially in other clinical settings. The use of diaries in early post-discharge and beyond has received limited evaluation. In this study diaries were used as a tool by survivors as a medium to aid reconstruction of events in ICU, of which survivors had limited recollection. The retrospective use of diaries and prospective diarising following a critical event, should be explored as a potential aid to recovery.

Conclusion

The focus of this research was to explore the perception and utilisation of diaries by ICU survivors and their families post-discharge. The results from this small study demonstrated that ICU patient diaries were considered to be a positive initiative by those who completed the surveys. Despite survivors experiencing mixed emotions when reading their diaries, this did not detract from the positive feelings they described. Survivors considered that the diaries served many purposes; helped fill their memory gaps, gave them an understanding of how ill they had been, concreted their experience in reality and enabled them to realise that during crisis they were still cared for by nursing staff and loved by their families. This human connection transcended the technology and de-humanised state which epitomises a critical illness.

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RESEARCH

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Never ending stories: visual diarizing to recreate autobiographical memory of intensive care unit survivors

Beverley A Ewens, Joyce M Hendricks and Deb Sundin

ABSTRACT

Aim: The aim of this study was to explore the potential use of visual diarizing to enable intensive care unit (ICU) survivors to create their story of recovery.

Background: An ICU experience can have deleterious psychological and physical effects on survivors leading to reductions in quality of life which for some may be of significant duration. Although there has been exploration of many interventions to support recovery in this group, service provision for survivors remains inconsistent and inadequate.

Design and participants: A qualitative interpretive biographical exploration of the ICU experience and recovery phase of ICU survivors using visual diarizing as method. This paper is a component of a larger study and presents an analysis of one participant's visual diary in detail.

Methods: Data collection was twofold. The participant was supplied with visual diary materials at 2 months post-hospital discharge and depicted his story in words and pictures for a 3-month period, after which he was interviewed. The interview enabled the participant and researcher to interpret the visual diary and create a biographical account of his ICU stay and recovery journey.

Findings: The analysis of one participant's visual diary yielded a wealth of information about his recovery trajectory articulated through the images he chose to symbolize his story. The participant confirmed feelings of persecution whilst in ICU and was unprepared for the physical and psychological disability which ensued following his discharge from hospital. However, his story was one of hope for the future and a determination that good would come out of his experience. He considered using the visual diary enhanced his recovery.

Conclusions: The participant perceived that visual diarizing enhanced his recovery trajectory by enabling him to recreate his story using visual imagery in a prospective diary.

Relevance to clinical practice: Prospective visual diarizing with ICU survivors may have potential as an aid to recovery.

Key words: Critical illness recovery • Intensive care diaries • Intensive care survivors • Recovery stories • Visual diaries

INTRODUCTION

During the past two decades the advancement of intensive care medicine has resulted in a reduction in mortality rates. With increased numbers of survivors has emerged a realization that survivors are at

significant risk of physical and psychological morbidity as a consequence of their critical illness (Moran *et al.*, 2008; Needham *et al.*, 2011; Granja *et al.*, 2012). The intensive care unit (ICU) experience itself has been considered to predispose survivors to complications as well as the presenting condition which necessitated an ICU admission (Scragg *et al.*, 2001; Dowdy *et al.*, 2009; O'Donnell *et al.*, 2010). Morbidity resulting from a critical illness may be physical and/or psychological, difficult to predict and challenging to manage.

Literature reports that ICU survivors experience a reduced quality of life (QoL) compared to the general population, with an increased incidence of post-traumatic stress disorder (PTSD), anxiety and depression, all of which inhibit functioning (Baker, 2006; Davydow *et al.*, 2008; Jones, 2012; Burnham

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et al., 2013). In turn, these psychological factors are detrimental to health outcomes (Wagner *et al.*, 2000; Skinner, 2011) reflected in the increased health seeking behaviours of this group of people (Urroe *et al.*, 2010b; Williams *et al.*, 2010). It has been claimed that the overall increased encumbrance of ill health exerts a far reaching effect on healthcare systems as survivors may never regain their psychological and/or physical pre-morbid state (Cuthbertson *et al.*, 2007; Myhren *et al.*, 2010; Urroe *et al.*, 2010a).

BACKGROUND

The reasons that an ICU event has such a deleterious psychological effect on survivors is not fully understood but it has been postulated that exposure to stressors in ICU is one of the predetermining factors (Jones *et al.*, 2001; Schelling *et al.*, 2003; O'Donnell *et al.*, 2010). This stress has been compared to that which can occur during and after exposure to traumas which are associated with the highest risk of PTSD (American Psychiatric Association, 2000; Frans *et al.*, 2005; Jackson *et al.*, 2007; Hetzel-Riggin and Wilber, 2010). Of course, not every individual will develop psychological complications as a result of exposure to a particular stressor. The reasons for this have been proposed as being dependent upon pre-existing factors such as the presence of peri-traumatic dissociation at the time of the event, prior trauma, prior psychological adjustment, family history of psychopathology, perceived threat to life during the trauma, post-trauma social support and peri-traumatic emotional experiences (Ozer *et al.*, 2003; Werner and Griffin, 2012).

Despite evidence that confirms survivors are often confronted with psychological and physical complications which impact on their QoL, the provision of rehabilitation programmes is inconsistent, lack an evidence base and have been described as inadequate and uncoordinated (NICE, 2009; Cotton, 2012; Jackson *et al.*, 2012). Furthermore, there is a lack of evidence to support particular interventions in enhancing the recovery of ICU survivors who, despite recovering from the most severe illnesses, may be affected for the remainder of their lives (Herridge, 2007; Rubinfeld, 2007). This deficit is in contrast to the services provided for survivors of other conditions such as heart disease pulmonary disease and stroke. For example, a significant body of evidence has confirmed that the provision of cardiac rehabilitation (CR) positively influenced the QoL and lifestyle choices; with strength of influence directly related to length of exposure to the programme (Harwood *et al.*, 2011; Rideout *et al.*, 2011; Beauchamp *et al.*, 2013). These programmes in contrast to ICU

rehabilitation programmes have undergone rigorous and extensive evaluation internationally (Austin *et al.*, 2008; Listerman *et al.*, 2011; West *et al.*, 2013). It can be postulated that this may be due to the predictable progression of these diseases which is not the case for many ICU survivors who often face an unpredictable and unique recovery trajectory. As such, it is important to evaluate generic strategies which can be applied to ICU survivors which may assist in their recovery.

An intervention which has undergone evaluation in recent years and has demonstrated some potential in the reduction of new onset PTSD in ICU survivors has been the introduction of patient diaries. The premise of diaries is that ICU survivors have little or sometimes delirious memories of their ICU experience and as a result experience a memory gap that is associated with an increased risk of psychological morbidity. The diaries are intended to fill this reported memory gap and are an account of events in ICU from the perception of those who complete them, usually nursing staff and family members. However, the composition of and processes associated with the use of diaries in ICU lack consistency (Storli *et al.*, 2002; Combe, 2005; Egerod and Christensen, 2009), making it difficult to evaluate them as a therapeutic intervention (Storli *et al.*, 2002; Combe, 2005; Egerod and Christensen, 2009). The diaries are a secondary account of the survivors' experiences in ICU and as such are a representation of their stories; their perceptions of events as they saw, heard and experienced them. Therefore in this study the concept of visual diarizing, i.e. the use of imagery and symbols with or without written word, aimed to give the survivors a voice from which to tell their own story through their unique lens. Furthermore, the use of visual signage has been used since the 1930s with or without written word (Mitchell *et al.*, 2011). It is thought that visual images promote the expression of that which may not easily be expressed in words and enables the understanding of human experience which may otherwise have been lost. The collaborative meaning making of analysing the visual images as in this study by the participant and researcher enables a greater depth of understanding. There remains a distinction between research that uses art as a means of expression and those which use drawing or other artistic approaches as more conventional forms of verbal data (Mitchell *et al.*, 2011).

The use of storytelling as a legitimate means of research has now been recognized (Praser, 2004). Stories are dynamic and the interaction between the storyteller and the listener shapes how they are constructed: by telling our stories and therefore exposing them to interpretation our lives are changed

(Lai, 2010). Storytelling has been identified as a means of validating and affirming experiences and sometimes providing an avenue for catharsis and instilling hope (Banks-Wallace, 1998; Chelf *et al.*, 2000). The benefits of storytelling are underpinned by the notion that individuals seek to understand what has happened to them and gain meaning from it (Pennebaker and Beall, 1986). By disclosing one's story the storyteller can confide about an event which enables them to find structure and therefore meaning and affirmation that others have been through the same experience (Pennebaker and Beall, 1986; Restrepo and Davis, 2003).

Narrative is one way in which humans have learned to clarify and construct their experiences (de Silva *et al.*, 2007). Creative therapies such as writing and art have been shown to be beneficial in the treatment of those exposed to traumatic events and so organize complex emotional experiences (Pennebaker *et al.*, 1990; Pennebaker and Seagal, 1999; Pizaro, 2011). Pennebaker *et al.* (1990) go as far as to describe this writing technique as a form of therapy. Emotional expression is necessary but not sufficient in itself to bring about emotional change (Smyth, 1998). Expressing emotions through writing transmutes the experience into words which can then be assimilated and made sense of (Pennebaker *et al.*, 1997). Writing and so expressing emotions conveys significant health benefits in a healthy population (Smyth, 1998) and so can be postulated to be of benefit in a traumatized population. This paper is a component of a larger study which was undertaken with ICU survivors using guided emotional expression of the recovery journey by applying Denzin's chronological series of events for storytelling. This paper focuses on the analysis of one participant's (Sam) visual diary. This diary was chosen as, unlike the other participants in the larger study, Sam did not use the hard copy materials given to him but chose to use the internet to source images which represented his story. His diary was so different in its construction compared with the other participants that the researcher considered it important to share this. The end result of this process was a chronological journey of ICU recovery depicted using rich, colourful and meaningful imagery.

AIM OF THE STUDY

The aim of the study was to explore the use of a visual diary to recreate the story of one ICU survivor's experience and recovery. This is part of a larger study which explored the use of visual diarizing as a potential intervention to aid recovery in ICU survivors.

Design

An interpretive biographical exploration was used to analyse the visual diary of an ICU experience and recovery phase of one ICU survivor. Interpretive biography was selected because of the method's assumption that individuals experience pivotal (or epiphany) events in their lives which impact upon their future. The ICU experience may be seen as one such experience, and therefore it is significant in the way an individual's life and his/her subsequent recovery may be impacted. The interpretive method enables the researcher to investigate, probe and capture data to enable an understanding of the epiphany moment (Denzin, 1989). Denzin (1989) describes the epiphany as: 'interactional moments and experiences which leave marks on people's lives . . . they are often moments of crisis . . . their effects may be positive or negative' (p.70).

Participants

The ICU survivor who is the focus of this study was recruited using purposive sampling from a general ICU in Perth, Western Australia. Inclusion criteria for the larger study were that participants were aged over 18 years, had been ventilated for a minimum period of 24 h, spoke and understood English and had no new or existing cognitive impairment.

Ethical considerations

Ethical approval was obtained from the ethics committees at the study site and the university, at which the researcher is a student. Sam is a pseudonym to protect the identity of the participant.

Data collection

Data collection was twofold and consisted of a visual diary constructed by the participant and recorded interviews over a period of 5 months. The participant was offered diary materials 2 months following hospital discharge and they were collected by the researcher after 3 months had elapsed. The diary and interview transcripts were stored on a password protected computer.

Visual diaries

The participant was supplied with materials to construct a diary which consisted of a journal, pens, art materials and a disposable camera. The diary was a blank canvas upon which Sam could draw or write his story. The art materials provided were deliberately gender and topic neutral to ensure that the materials did not influence how the images were constructed and shape the content of the visual diaries which could introduce bias to the study. The materials provided

were merely a vehicle to promote expression and give memories and images a form. Although Sam had photographs taken by nursing staff with the consent of his family within his ICU diary, he chose not to include these in his visual diary.

Interviews

Two interviews were undertaken at 2 and 5 months following discharge from hospital. The first interview was used to clarify the aims of the research and to gain written consent. Sam was also provided with the materials for maintaining a diary. The intention of the second interview was to enable him to discuss the content of the visual diary with the researcher. The style of interview was creative with the researcher listening, understanding and facilitating the participant to interpret his story through the use of visual imagery in the diary. The researcher encouraged Sam to tell his story from the beginning, a point of his choosing, with a middle and an end as in Denzin's biographical method. During the interview Sam was prompted to describe the thoughts, feelings and emotions associated with the visual entries in his diary. The interviews lasted for up to an hour and were recorded.

Data analysis

The participant's visual diaries initially proved problematic for analysis. Analysis could not be prescriptive and one-dimensional and had to be adapted to the situation in which the researcher is positioned (Fraser, 2004). The recovery story captured

in the visual diary had to maintain the integrity of the participant's story and convey a sense of personal depth and colour. Using Etherington's (nd.) framework and Kucera et al.'s (2010) processes of interpretation (Table 1) to guide analysis and having the participant describe turning point moments, as captured in the visual diary, allowed the researcher to share in the world of the participant. Further, the researcher listened as he explained and described his pictorial and written depictions and how these captured his feelings and experiences. This process also served as member checking. Coupled with this, the recordings of the interviews were listened to several times to enable interpretation of the messages within the transcript and their correlation with the pictures used to symbolise Sam's recovery trajectory. Barden and Williams (2006) assert that symbols are unique to the individual and this notion has been supported by the preliminary findings in this study (Table 1).

Trustworthiness

Trustworthiness in qualitative research refers to the rigor of the research and comprises four constructs: credibility (truth value), transferability (applicability), dependability (consistency) and confirmability (neutrality) (Shenton, 2004; Guba and Lincoln, 2005). It is essential in qualitative research that the researcher builds a rapport with the participants as they have no control over what the participants are willing to share, so establishing a rapport and building a trusting relationship early is essential. This basis of

Table 1 Data analysis process

1. <i>Transcription of stories and primary analysis:</i>	Stories were transcribed verbatim by the researcher as transcription was intended to be a component of the analysis process—the very beginning of the process to interpret the participant's story of recovery.
2. <i>Reading of stories:</i>	Transcriptions were read to obtain an overall understanding of the participant's experiential view
3. <i>Paraphrasing:</i>	Several paraphrases were constructed for each story to highlight the points being made
4. <i>Identification of themes:</i>	Taken from the paraphrases; themes were identified and similar themes and patterns were grouped together and common meanings and points of the story identified. Points were identified and grouped then collapsed into themes. The less common themes were grouped separately.
5. <i>Recheck and confirm:</i>	The researcher revisited all the themes identified from the paraphrases and double checked for reliability
6. <i>Hidden meanings/identification of narrative aspects:</i>	The researcher identified what else the story was about apart from the ICU experience by identifying the propositions which were comparable and categorising the aspects of the story. Formalising the aspects in terms of what the ICU experience and recovery meant to the participant was integral to this process.
7. <i>Rechecking and confirming the resultant themes and aspects:</i>	Paraphrases and themes were reviewed to ensure the most important themes, meanings and messages were identified. Links between themes were noted.
8. <i>Identify:</i>	The researcher revisited the paraphrases and the story in its entirety. Interpretation allowed the development of a representation of the experiences, thoughts and emotions which the participant experienced during the journey of ICU and recovery and the impact this has upon his life.

ICU, intensive care unit.

trust will encourage participants to disclose personal information they may only reserve for close confidants (Speziale-Streubert and Carpenter, 2003). The researcher endeavoured to build a rapport with Sam, taking time to discuss his overall experience of critical illness and his current situation making sure that he realized that the researcher was a nurse with many years' experience in ICU to create an environment of trust, safety and understanding. Reliability of data was ensured by the triangulation of data, i.e. from different sources; the visual diaries and interviews combined with member checking with the participant and remaining in the setting until saturation was reached. To ensure transferability purposive sampling was utilized to ensure a representative sample from the general ICU population and sufficient detail has been included to allow for judgements about transferability to be made. The demonstration of credibility is not only sufficient to demonstrate dependability (Lincoln and Guba, 1985) but also satisfactory detail has been reported in this research study to ensure others may repeat the work and confirm the dependability of the study. The concept of confirmability is to ensure that the interpretation of the data is objective and not influenced by the bias of the researcher (Shenton, 2004). Lincoln and Guba suggest several measures to be undertaken to ensure confirmability of study findings and enable audit. To this end triangulation of data was achieved: an accurate audit trail of the research project was maintained to enable review if necessary. Interviews (raw data) were recorded and memos and process notes were maintained together with methodological reflections and notes.

FINDINGS AND DISCUSSION

Sam

Sam was a 37-year-old man admitted to ICU with a history of abdominal pain. He was ventilated for several days and developed severe acute delirium during this time. A diary had been commenced for him by the nursing staff whilst he was in ICU which he continued to read following his discharge, about which he commented: 'I could cry every time I read it ... very strange to know how much people love you and want you to pull through'. These feelings and emotions evoked by reading ICU diaries are typical of what have been evidenced previously (Ewens *et al.*, 2014). For this study, the researcher built upon the concept of diarizing for ICU patients and encouraged Sam to diarize in the recovery phase of illness. Sam had actively diarized electronically and produced a diary overflowing with vivid imagery and text which he described and interpreted with the researcher.

Sam began his story at the point where he had been admitted to hospital but not yet to ICU. He recalled how he had been severely affected by a comment from a nurse who inferred that because of his illness he must be an alcoholic, despite his protestations to the contrary. This assumption had a significant impact on him and he made repeated references to it during his interview and also in his visual diary: 'I didn't like the way people talked about me in the hospital as if I had a drink problem ... how people have judged me through the whole process ... I was embarrassed when people said this ... I didn't have a drink problem and I've never had a drink problem ... it was OK, people were making me better so I'll go along with it ... it's quite funny how in the medical professions there's an awful lot of ignorance ...'. He depicted this experience in his diary with a statement that said: 'don't judge what you don't understand'.

Sam was determined to make significant changes to his lifestyle so that something good would come from his experience 'because I got through it ... I didn't want to lose sight of that, that even when I was in hospital ... I was determined that I was going to make something positive out of the whole issue; it's a good achievement, I came through it, fit enough'. Sam was profoundly affected by the realization of how critical illness had physically affected him and he reiterated how this had impacted on him throughout his story. He compared his recovery journey to the energy, dedication and perseverance required to climb a mountain, representing a super human effort (Figure 1). He was determined to regain his pre-morbid state and he described the early days of recovery: 'it'd take me half an hour to get out of bed ... I'd shower and shave and that's an hour, my body'd just shake, I'd be sweating ... then I'd just try and walk to the park ... I just walked around it and I'd just keep doing it. I was determined ... it was painful ... that was my goal I just wanted to get back'.



Figure 1 Achievement.



Figure 2 Spaghetti brain.



Figure 3 Struggling to do simple things.

However, despite noticeable improvements in his physical strength Sam struggled to maintain an appearance of normality: 'I found myself trying to find a place to hide and nearly break down... sometimes I'd cry in the car on the way home... I felt like I was struggling to do simple things'. He depicted these frustrations visually in Figures 2 and 3:

At one stage Sam was so concerned about his mental abilities that he thought his brain may be damaged and 'felt concerned but thought I would be able to hide it'.

The memories of his time in ICU were not always pleasant and describing his acute delirium shortly after he was extubated he recalled: 'I have bad memory, I was very punchy when I came out of it and I'd start talking and you know you just couldn't get your words right it was like having a bit of Alzheimer's ... it still comes every so often when I'm tired'. He still had difficulty in talking about the vivid dreams he recalled

and still found he struggled to talk to others about them and even to write them down. He described that he was 'on a journey, everything started off quite light hearted and nice until it all went a bit nasty... weren't a case of just screw your eyes and wake up, you had to go through that and be persecuted by people who were extremely supportive of me... dreaming that Grace (wife) was trying to poison me... where people had taken on different personalities, even I had taken on a different persona'.

Sam had no clear recollection of events as: 'everything was confusing or mixed, you'd see people and then you'd be dreaming about them... I was very much abandoned... it was very difficult, Grace was having a baby and it being stillborn... she was trying to poison me and my boss... they've been supportive, have looked out for me, but they're against me, everything was really. Sam recounted his obsession with death whilst he was in ICU: 'I was obsessed with death, I don't know why. Yeah death, people on death row... people dying'. Sam described his feelings and depicted them in Figure 4 as he struggled to recover: 'the black cloud was something that I'd never felt before... I wouldn't say I was depressed... every so often you'd just feel something like a blanket over your head... God what was that it was awful... I felt it when I first went back to work... whether it was just the anxiety of going into something unknown...'

'I'd find myself in work and people wanted to come and see me and talk about it... I was daunted, everyone staring at me and wanting to talk to me about it and just all feel goodwill and I remember finding myself once just going and seeing a mate in the stores and sat away from everything at work you know and it was like everybody's goodwill was just a little bit too over overbearing'.

Prior to his illness Sam had worked full time as a manager. As his physical appearance improved his



Figure 4 Dark clouds.



Figure 5 Been to a health fam.

work colleagues presumed he had returned to his normal state in every aspect: 'they see me looking physically better than I did when I went off and that's it, you've been to a health camp... they just don't know what you've gone through' (Figure 5).

"I don't know what I've gone through at times ... people don't understand that you just can't understand things... how long is it going to be before sympathy's over and they know you're making mistakes." Work was a very important part of Sam's life; something which he repeatedly referred to in his visual diary and interview and considered it 'an important part of my make-up' and measured his recovery by how he functioned in his job.

Over the next month Sam suffered a relapse and was readmitted to hospital which he described as having to 'go through a bit of a grieving process'. He endured several weeks off work but by the end of the year, 7 months after his original illness, he commented 'I'm back - feel really good, healthy and achieving my goals at work, still a bit to go but the future is bright. I'm confident about my future ... just trying to get myself to focus ...'

The findings from this study have provided an insight into the recovery of an ICU survivor using prospective diarizing. Sam was able to capture his thoughts and feelings with his choice of imagery via the internet which enabled him to choose which best represented what he was intending to express. The story of Sam's recovery trajectory is underpinned by hope. He began his diary with an image which represented super human effort and this set the tone of his story. Despite the biographical events of physical

setbacks and impairment accompanied by mental turmoil, his story is full of optimism, looking forward to the future and a determination to achieve positive change from such a deleterious and potentially life changing experience.

The way in which Sam chose to reconstruct his story using electronic media changed the way in which the researcher chose visual diary materials for other participants in the study. Electronic media had not been considered before and subsequent participants in the larger study were given an electronic storage device following this. This was a turning point for the researcher who had not considered that participants would be able, or wish, to use electronic media to construct their diaries.

Biographical events

A biographical event timeline incorporating epiphany or turning pointy moments have been extrapolated from Sam's visual diary and interviews (Table 2).

Sam's diary illustrated that neither he nor his family had been prepared for the physical and psychological aftermath of his critical illness. He had not been offered written or verbal information, links to resources or structured follow-up which may have supported his recovery. There is evidence which suggests ICU survivors value and benefit from discharge information (Lee *et al.*, 2009), and there are a variety of interventions available which could be adopted to inform service provision. These initiatives include discharge information resources (Bench *et al.*, 2012), psychological intervention techniques (Black and Parahoo, 2011; Peris *et al.*, 2011) and comprehensive rehabilitation care pathways (NICE, 2009). There are currently inadequate resources allocated to ICU survivors in Australia and further investigation into the application and evaluation of potential initiatives should be a high priority.

Sam recalled vivid, predominately persecutory dreams. This phenomenon in ICU survivors has long been recognized and postulated to influence psychological morbidity (Magarey and McCutcheon, 2005; Kiekkas *et al.*, 2010; Zetterlund *et al.*, 2012). These dreams can be so intrusive and disturbing that many survivors are unable to share them, even with those closest to them as illustrated by Sam. The persecutory nature of these dreams is significant. This delusional memory is often the only reality survivors retain of their ICU experience and it could be argued that this is the biographical memory of their traumatic event, the nature of which, i.e. perceiving a risk of death, is associated with a high risk of PTSD (American Psychiatric Association, 2000). Sam experienced a difficult recovery period and required psychological support for a short period of time. This psychological distress

Table 2 Biographical events in Sam's recovery

Epiphany moments	Chronological trajectory
May Feeling judged	Sam was upset and angry that the nursing and medical staff had labelled him as an alcoholic because of his illness. He made repeated reference to this in his diary and interviews.
June Released from the madhouse	Sam was severely debilitated at discharge home and realized that he had been too ill to understand the magnitude of his illness. However, there was also relief for him as he now understood why he had been ill for the last few years. He was feeling good in himself and had a determination to get better and follow advice about health and diet to enable this. Each day he saw an improvement which took away his concerns; however, despite this physical improvement he remained very fearful and viewed his discharge from the hospital as being released 'from the madhouse'.
July Determined to make a positive out of the experience	Two months following discharge from hospital Sam was feeling fantastic and achieving the lifestyle goals he had set himself. He had commenced a phased return to work. Everyone had commented on how well he was looking but inside he was experiencing a dichotomy. He realized he was struggling, that his brain was tired conflicting with his physical appearance. He was struggling to perform simple tasks at work and found himself looking for places to hide and crying in the car on the way home.
August Everything coming together	Sam was improving his fitness and was able to run 7 km in 30min—he was proud of this achievement. He was managing better at work but was still not quite back to normal. Because of this residual difficulty he did consider that he had sustained brain damage in ICU but would be able to hide it.
September Fears for the future	Sam was readmitted to hospital for a procedure which was complicated by infection and was unexpectedly off work for 6 weeks. His mood was low as he had no control over his health, was worried about his job and feared for the future. He feared returning to work as he did not want to feel helpless; work is important to him.
October Needing to prove himself	Sam again returned to work at 60 h/week; trying to prove himself competent in his role. This left him exhausted at the end of each day and he was afraid to undertake the exercise which had been such an integral component of his physical recovery.
November I'm back	Seven months after his admission to ICU Sam was eventually feeling healthy and achieving his goals at work. He considers the future is bright.

ICU, intensive care unit.

may have been identified earlier had he have been offered follow-up of some description. In his diary and during the interview he repeatedly recalled feelings of persecution and a preoccupation with death; all of which have been identified as a determinant of PTSD (American Psychiatric Association, 2000; Hetzel-Riggin and Wilber, 2010). However, he did not

know how to access this support and was guided by the researcher to access services.

Sam was highly motivated to regain his premorbid status and was able to set his own physical goals in his determination to achieve something positive from what had happened to him. He assumed that recovery entailed regaining the physical component of his health

and that and it was only when he returned to work that he realized that mentally he 'wasn't right'. Sam was fortunate that he had an inherent optimistic outlook and was able to set realistic goals for himself.

LIMITATIONS AND IMPLICATIONS FOR PRACTICE

This study was a small single site study and therefore the results are limited in terms of transferability to the wider context. Sam considered that diarizing had aided his recovery: 'I believe the research contributed to my successful recovery' and is a strong advocate of the diary concept. He still carries his original ICU diary with him on occasion. The application of prospective diarizing has yet to be explored in the literature and may be worthy of further study.

CONCLUSION

It is apparent from the literature that ICU survivors often face a complex and challenging recovery process which for some may never be complete with an associated reduction in QoL (Myhren *et al.*, 2010; Oeyen *et al.*, 2010; Karachi *et al.*, 2011). Despite decades of exploration it is evident that evidence-based programmes for ICU survivors during the recovery phase is not prevalent and are yet to be widely established. Diaries commenced in ICU have been explored as a potential aid to recovery in this

population and recent studies have demonstrated promising results (Jones *et al.*, 2010). However, this study has explored uncharted territory in developing the ICU diary concept further than before. Not only has this study explored prospective diarizing but also introduced the concept of visual imagery to guide the storyteller in constructing their story. The findings from this study have indicated that this may have potential during recovery. Visual diarizing enabled Sam to capture his recovery journey through powerful visual imagery. When he recounted his story and what the images portrayed for him he was able to reflect on what had happened to him and how much he had achieved during his recovery phase.

Currently there is no provision in Australia for ICU survivors to retell their stories and make sense of their experiences and recovery journey in a structured and guided way. Diarizing for ICU patients and the impact of this is beginning to show promise. Prospective diarizing for ICU survivors has not been explored in the literature and may warrant further investigation.

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WHAT IS KNOWN ABOUT THIS TOPIC

- ICU recovery is a challenging time for many survivors, a significant percentage of who never regain their pre-morbid health status.
- Rehabilitation services are sporadic and lack an evidence base.
- ICU diaries are designed to fill the reported memory gap that ICU survivors report which is associated with increased psychological morbidity.
- ICU diaries have demonstrated some potential in reducing new onset PTSD in survivors.

WHAT THIS PAPER ADDS

- Prospective visual diarizing has not been explored in this population and may offer some potential to aid in the recreation of ICU survivors' stories.

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ORIGINAL ARTICLE

The use, prevalence and potential benefits of a diary as a therapeutic intervention/tool to aid recovery following critical illness in intensive care: a literature review

Beverley A Ewens, Joyce M Hendricks and Deb Sundin

Aims and objectives. To critically appraise the available literature and summarise the evidence related to the use, prevalence, purpose and potential therapeutic benefits of intensive care unit diaries following survivors' discharge from hospital and identify areas for future exploration.

Background. Intensive care unit survivorship is increasing as are associated physical and psychological complications. These complications can impact on the quality of life of survivors and their families. Rehabilitation services for survivors have been sporadically implemented and lack an evidence base. Patient diaries in intensive care have been implemented in Scandinavia and Europe with the intention of filling memory gaps, enable survivors to set realistic recovery goals and cement their experiences in reality.

Design. A review of original research articles.

Methods. The review used key terms and Boolean operators across a 34-year time frame in: CINAHL, Medline, Scopus, Proquest, Informit and Google Scholar for research reports pertaining to the area of enquiry. Twenty-two original research articles met the inclusion criteria for this review.

Results. The review concluded that diaries are prevalent in Scandinavia and parts of Europe but not elsewhere. The implementation and ongoing use of diaries is disparate and international guidelines to clarify this have been proposed. Evidence which demonstrates the potential of diaries in the reduction of the psychological complications following intensive care has recently emerged. Results from this review will inform future research in this area.

Conclusions. Further investigation is warranted to explore the potential benefits of diaries for survivors and improve the evidence base which is currently insufficient to inform practice. The exploration of prospective diarising in the recovery period for survivors is also justified.

Relevance to clinical practice. Intensive care diaries are a cost effective intervention which may yield significant benefits to survivors.

Key words: intensive care diaries, recovery, survivorship, psychological morbidity

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What does this article contribute to the wider global community?

- Intensive care unit diaries have been sporadically implemented across the international ICU community but still lack a rigorous evidence base which informs their use.
- The use of diaries may have several benefits for survivors during their recovery period.
- Further exploration regarding preferred content and operational processes in the use of diaries within intensive care and during recovery is warranted.

Introduction

The incidence of intensive care unit (ICU) admissions is increasing with an associated reduction in mortality. Successful patient outcomes from ICU, however, are measured in terms of survival to discharge in accordance with state and national reporting mechanisms. Thus, what is not captured in these corporate Key Performance Indicators is when and if survivors return to a pre-morbid life circumstance. A significant number of survivors struggle to achieve their pre-morbid health status with an associated reduction in their quality of life, because of adverse physical and/or psychological effects of a critical illness and ICU stay (Hofhuis *et al.* 2008, Jackson *et al.* 2009). Whilst the recognition of the consequences of critical illness is well documented; service provision to address them remains inadequate and lacks an evidence base. This article discusses one intervention; the concept of diarising as a strategy for ICU survivors and the potential impact this may have following a critical illness.

Background

Hundreds of thousands of people are admitted to ICUs annually across the world and these rates are increasing as are survival rates. Discharge from ICU is frequently misconstrued as a return to pre-morbid physical and emotional health for the survivor and both health professionals and consumers may subscribe to this misconception, perpetuating the notion that surviving critical illness and a return to pre-illness life circumstance signifies the return to a pre-morbid state. However, this is not the case for many survivors who may appear physically recovered but remain psychologically affected to varying degrees by their experience (Ewens *et al.* 2014 – in press) which may be irreversible (Unroe *et al.* 2010, Wilcox *et al.* 2013).

The result of this increase in quantity of ICU survivors who are not necessarily fully fit physically and psychologically is an ever-increasing pressure on the health debt and healthcare systems (Unroe *et al.* 2010, Lone *et al.* 2013). These human and healthcare associated costs of ICU survivorship are significant as evidenced by an increased uptake of healthcare services by survivors following hospital discharge (Williams *et al.* 2010, Lone *et al.* 2013).

Since the recognition of significant morbidity following critical illness there has been extensive exploration of interventions which may support survivors during the recovery phase of their illness and reduce the incidence of complica-

tions (Cuthbertson *et al.* 2007, Dammeyer *et al.* 2013, Ramsay *et al.* 2014). These initiatives began with ICU follow-up clinics which were developed in the UK and Scandinavia in the 1990s. These clinics were usually nurse-led with or without multi-professional input and with the broad aims of screening survivors for complications and providing or referring them to specialist services as necessary (Griffiths *et al.* 2006, Modrykamien 2012, Egerod *et al.* 2013). However, this model has not demonstrated tangible benefits (Cuthbertson *et al.* 2009) despite being well received by survivors and their families (Engstrom *et al.* 2008, Peterssen *et al.* 2011). The standardised provision of rehabilitation initiatives which address psychological and physical domains with the intention of improving long-term outcomes for survivors are still required (Rubinfeld 2007, Jackson *et al.* 2012).

A diary written for patients whilst in ICU by nursing staff and families has been an area of interest for some time and is beginning to show potential as an aid to recovery in this population (Jones *et al.* 2010). It is apparent that many ICU survivors have no, or delusional recall of their stay in ICU, both of which have been associated with psychological complications (Griffiths & Jones 2007, Granja *et al.* 2008, Kielkas *et al.* 2010). Diaries commenced in ICU are designed to help fill this reported memory gap and recreate a biographical account of factual events for survivors with the aim of reducing the reported morbidity associated with lack of or delusional recall of their experience. Evaluation of the diary initiative has been predominantly descriptive; although recent empirical evidence from a comparative study indicated that ICU diaries may reduce new-onset Post-Traumatic Stress Disorder (PTSD) in comparison with a nondiary group (Jones *et al.* 2010). However, the potential use of diaries following discharge from hospital is largely unexplored and it has been highlighted that survivors do not actively diarise following discharge from hospital and their use of diaries, i.e. reading and reflecting on events reduces over time (Ewens *et al.* 2013).

Nurses have been identified as the principal authors of diaries with some units actively discouraging contributions from relatives and patients (Egerod & Christensen 2009). Elsewhere, family members and friends were actively encouraged to contribute to the living document (Engstrom *et al.* 2008, Robson 2008, Ewens *et al.* 2013). Family members were also encouraged to write separate accounts which were added to the diary at a later date, however, the rationale for this process was not justified (Gjengedal *et al.* 2010).

Design

A review and synthesis of the literature followed by a discussion of the key issues, implications for practice and recommendations for future research are presented. The design of this review is based on the structured approach described by Kable *et al.* (2012) which facilitated a rigorous search strategy and synthesis of relevant original research articles.

Aim and objectives

The aim of this review was to critically appraise the available literature and summarise the evidence related to the prevalence, use and potential therapeutic benefits of ICU diaries following survivors' discharge from hospital and identify areas for future exploration.

The objective of this literature review was to determine if there are potential therapeutic benefits of using a diary for ICU survivors posthospital discharge. Therefore, the question is posed: What are the potential benefits of ICU diaries to survivors of a critical illness following discharge from hospital?

Methods

This review was conducted using a 12 step approach described by Kable *et al.* (2012). Adapting this framework enabled the researcher to undertake a thorough search process, refinement of articles retrieved and a critical review and synthesis of the literature which is detailed here. The literature was searched in the following databases: CINAHL, Medline, Scopus, Proquest and Informat and conducted October 2013 and updated in July 2014 for locating published original research related to the use of patient diaries in ICU. A Google Scholar search was also conducted to identify any grey literature which may become apparent. To ensure that no studies were overlooked during this process, key literature retrieved was hand searched to identify any other literature not previously identified. Repeated searches of several databases yielded the same sources, at which point the researcher was confident that saturation had been achieved.

Inclusion criteria

Articles were included if they were:

- In English.
- Original research articles and/or discussion articles about adult ICU diaries.
- An evaluation of the articles limited to the patient experience.
- Published between January 1980–July 2014.

Articles were excluded if they were commentaries, editorials, discussion articles, letters or focussed on the populations of children and young people, family members' and health care providers' perceptions of diaries and other areas of specialty care such as mental health, neonatal care and cancer care. Previously published literature reviews were also excluded as they were not primary sources of data. However, one review was identified. Dates for the search were limited to January 1, 1980 to the present date (July 2014) to ensure all studies related to ICU diaries were identified.

Boolean operators were included in search terms:

- Intensive care unit AND diaries.
- Intensive care recovery AND diaries.
- Intensive care follow up.
- Diaries OR journal.
- Intensive care narratives OR stories.
- Intensive care stories.
- Diaries and recovery.
- Intensive care AND memory.

The search was conducted sequentially and articles were excluded which did not meet the initial inclusion criteria. The term journal was also used but excluded after a review of the retrieved articles. Forty-six articles were consequently identified which met the inclusion criteria; of which 13 were excluded following a review of their titles and abstracts. Thirty-two articles were therefore retained for an evaluation of the full text and of those, 11 did not meet the inclusion criteria and 22 were included in this review (Fig. 1). Of these 22 articles, six originated from Sweden, five from Denmark, three from the UK, two from Australia, one from Norway and one each from Germany, Scandinavia, Switzerland, France and Europe.

Assessment of the articles

An assessment of articles was undertaken using three recognised approaches appropriate for the types of studies included in the review. These were the Cochrane Method Guidelines for Systematic Reviews (van Tulder *et al.* 2003); the Strengthening the Reporting of Observational Studies in Epidemiology statement (STROBE) checklist (von Elm *et al.* 2008) for observational studies (quantitative) and the Qualitative Research Guidelines Project (Malterud 2001) for qualitative articles (Table 1).

The quality of each article was assessed in accordance with the criteria associated with each of the approaches determined by their methodology (Table 2). A score was

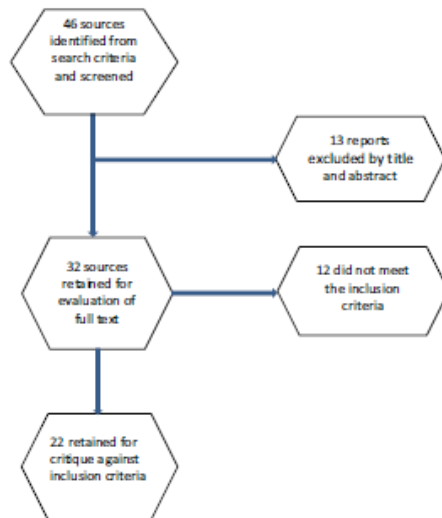


Figure 1 Flow chart of literature screening.

allocated to each article based on the criteria and then classified as high, medium or low methodological quality, apart from the Cochrane Guidelines which only stipulates high or low classifications. Of the articles reviewed, three used a quantitative methodology, 18 a qualitative and the remaining study mixed methods. Qualitative methodologies used in the studies included grounded theory, but predominantly comprised descriptive or observational studies varying in methodological rigour. This lack of rigour was in relation to sample size, single site studies and trustworthiness of the data generated.

Results

Use of diaries in ICU by survivors and families

The intended use and purpose of diaries are varied with similarities across studies. The intended use of diaries was to fill the memory gap which survivors reported; however, with their evolution other potential benefits have emerged. There is evidence to suggest that reading their diaries enabled survivors to gain coherence and understanding of their experience (Combe 2005, Engstrom *et al.* 2008, Backman *et al.* 2010) as well as linking visits from family and friends recorded in their diaries with their memories (Engstrom *et al.* 2008).

Table 1 Criteria used to assess methodological quality of articles

Checklist	Quality of articles		
	High (✓✓✓)	Medium (✓✓)	Low (✓)
Cochrane Guidelines	6–11		0–5
Strengthening the Reporting of Observational Studies in Epidemiology statement	15–22	8–14	0–7
Guideline of qualitative research	18–25	9–17	0–8

The use of diaries following discharge from hospital by survivors and their families varied across studies but was predominantly high (Bergbom *et al.* 1999, Backman *et al.* 2010, Jones *et al.* 2010) with reports that some survivors repeatedly read their diary searching out new information (Backman & Walther 2001). Most survivors were prepared to share the content of their diaries with family and friends (Backman & Walther 2001). It is acknowledged that reading diaries for the first time can be distressing for survivors (Ewens *et al.* 2013) and one survivor addressed this by reading his diary from the end to the beginning (Engstrom *et al.* 2008). In one study, survivors and their families and carers continued to diarise whilst on the ward (Backman & Walther 2001) and at home (Ewens *et al.* 2013), although this was not prevalent across studies and survivors in one study considered they would have liked the opportunity to do this (Robson 2008).

Family members considered that writing in the diaries enabled them to express their feelings to loved ones whilst they were in ICU, to share experiences, connect them with normal family events, express emotions and maintain a connection with them (Roulin *et al.* 2007, Ewens *et al.* 2013). These often poignant entries also enabled survivors to understand how difficult this time had been for their families (Robson 2008) and how much they were loved and cared for in ICU and how many people were urging them to recover (Ewens *et al.* 2013, 2014).

Any potential benefits to nurses and practice development through the use of diaries has not been extensively explored but in one study nurses reviewed the diaries and based improvements in their care on the content (Akerman *et al.* 2010).

During their recovery phase survivors may be unable to talk about and share their experiences with their friends and families. In this instance, diaries have been used as a conduit for these discussions to occur between survivors and their families and friends (Combe 2005, Egerod *et al.* 2011a, Ewens *et al.* 2013).

Table 2. Analysis of literature retrieved

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Nydhahl <i>et al.</i> (2010) Germany	Qualitative exploratory multi-centre design using mail or telephone survey from Egerod <i>et al.</i> (2007) to examine the extent and prevalence of diaries in adult ICUs in 2008	All ICUs in two federal states of Germany (<i>n</i> = 120)	Telephone interviews	Descriptive statistics	Survey replicated and translated from a previous Danish study (Egerod <i>et al.</i> 2007) and assumption made that diaries were being used in German ICUs. No units used diaries but email and telephone contacted indicated interest from nurses. Language barrier postulated as a reason for the lack of implementation of diaries; nurses do not migrate from Scandinavia to Germany and most journal articles about diaries are written in English	Potential bias from translation of the term intensive care diary to German. Not clear if two states chosen were representative of all states in Germany. Confusion with participants about terminology re: diaries. Not explicitly stated how many nurses responded	✓✓ 15/25
Gjengedal <i>et al.</i> (2010) Norway	Qualitative descriptive design using semi structured telephone interviews of ICU nurses experienced in the use of diaries (<i>n</i> = 30) to explore the background, extent and application of patient diaries in ICUs	30 units used diaries from a total of 70, 31 use diaries and 30 of those participated in the study	Telephone interviews	Template organising model	Survey adapted from a previous Danish study (Egerod <i>et al.</i> 2007). Almost half of the units used diaries and commenced between 1991 and 2000. Motivation to commence diaries from national and local pioneers, conferences and published papers. Nurses the main authors of the diaries and entries not compulsory. As main authors a few nurses encouraged other professions to contribute to diaries. Family members encouraged to write their own diaries or on sheets to be added to the patient's diary later.	Translation of the data collection tool did not take into account the Norwegian nursing context	✓✓ (17/25)

Table 2 (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Egerod <i>et al.</i> (2007) Denmark	Qualitative explorative descriptive design to describe the extent and application of patient diaries in Danish ICUs in 2006. Semistructured telephone interviews	Purposive sampling of one nurse in each ICU using diaries ($n = 19$)	Telephone interviews	Template organising model	Most had a diary team responsible for coordinating and QA of the process but expressed a need for national guidelines. Two purposes of diaries recognised therapeutic and caring. Also used in follow-up in >50% of the units 19 of 49 (40%) Danish ICUs used diaries and in use from 0–17 years. Implemented because of networking, education exchange programmes, and conferences and published papers. No uniformity for initiation of diaries or structure. No units had a plan for measuring the efficacy of diaries. Some units kept the diaries and some gave to the patients. No systematic plan for follow up with diaries. 65 (76%) of all units used diaries most for an average of 6–9 years. 6 (9.2%) handed over the diary to the patient at a follow up clinic the rest on discharge from the unit. Follow up most commonly two months after discharge. Majority 46 (70%) had a diary group who took responsibility for them.	Small sample and all respondents were involved with diaries – potential bias.	✓✓✓✓ (20/25)
Akerman <i>et al.</i> (2010) Sweden	Descriptive explorative design – a replication study of (Egerod <i>et al.</i> 2007) to describe and compare the extent and application of ICU diaries in Sweden	Nurses with experience in using diaries ($n = 65$)	Telephone interviews	Descriptive statistics and content analysis		Different levels of experience with diaries from respondents may have biased responses. Translation from Danish to Swedish may have incurred some inaccuracies	✓✓✓✓ (21/25)

Table 2. (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Egerod <i>et al.</i> (2011b) Denmark, Norway and Sweden	Multinational comparative review of qualitative secondary data to describe and compare the emergence and evolution of ICU diaries in Scandinavia. Original data from studies in Denmark (2006), Norway (2008) and Sweden (2008)	Nurses with experience of diaries in ICU (<i>n</i> = 114). All sites used the same translated surveys	Original data generated from telephone interviews with ICU staff	Secondary analysis	7 (8%) had developed a questionnaire for evaluation by patients, 28 (43%) had no formal evaluation and 61 (94%) stated that the patients thought the diary was important. Incentive to commence diaries came from colleagues, conferences or patients and relatives. Diaries common practice in Sweden. Paucity of scientific evidence re: the use of diaries recognised ICUs using diaries Denmark 19 (40%), Norway 31 (44%), Sweden 65 (76%). Initiated via a "bottom up" process and inspiration in Sweden and Norway by academic nurses. Local guidelines existed mostly but national guidelines identified as a need. Main objective was to ensure the patients to view their ICU experience in context which may facilitate coping. Initially kept for long term ventilated patients but considered may help nonventilated patients in the future. Different styles of content in all of the countries –	Preconceptions of researchers noted in only one study. Original studies only interviewed nurses who were enthusiastic about the diary concept – potential bias	✓✓✓ (21/25)

Table 2 (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Backman and Wälther (2001) Sweden	Observation study to explore the use of a diary in debriefing patients and relatives	Single centre ($n = 51$) (41 survivors and 10 relatives). Diaries given to patient or relative of deceased patients at follow up two weeks after discharge/death. Mailed questionnaire six months later. Six patients died before the questionnaire was sent to them but questionnaire answered by relatives	Postal questionnaire	Descriptive statistics (SD, means, interquartile ranges)	factual, empathic style and a refined art of wondering. Photographs taken in all countries but concern over ethical considerations – continued because of positive patient feedback. No follow-up in Denmark but diaries used regularly in Norway and Sweden. Concluded that diaries used as a therapeutic instrument, an act of caring, an expression of empathy or a combination. Recommended that national guidelines be developed	Single site with a small sample	✓✓✓✓ (21/25)

Table 2. (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal (2,1,2,5)
Ewens <i>et al.</i> (2013) Australia	Qualitative descriptive study to explore survivors' and relatives' perceptions and utilisation of diaries following discharge from hospital	Purposive sampling in one West Australian ICU (<i>n</i> = 18)	Postal survey	Thematic analysis	Many survivors continued reading the diaries but few wrote in them. Themes were: gaining a sense of reality, feeling cared for and maintaining a connection with loved ones through the diary	Single centre, small sample, low response rate and nonrespondents not followed up to ascertain reasons for lack of response. Demographic data not collected	✓✓✓✓
Roulin <i>et al.</i> (2007) Switzerland	Explorative descriptive qualitative design to analyse the content of ICU diaries	Convenience sample of ICU survivors' diaries (<i>n</i> = 8). Single site 18 bed ICU in 2005	164 diary entries by healthcare providers and relatives. Demographic data also collected	Content analysis	Four themes: sharing the story (ICU events and at home), sharing the presence (time, date and who was present), shared feelings and sharing through support. Not just a story of events but a way of communicating	Small sample at a single site. Did not investigate survivors' opinions of diaries and assumed they would be a source of comfort to patients but not evidenced. Demographic data collected but not cross referenced against diary content	✓✓✓✓ (2,0,2,5)
Egerod and Christensen (2009) Denmark	Descriptive and explorative qualitative design to analyse content of ICU diaries	Purposive sampling of ICU survivors' diaries (<i>n</i> = 25) at single site in 2007	Diary entries by nurses only. Demographic data	Interpretive; narrative and content analysis	Three stages of the narrative identified: crisis, turning point and normalisation. Also identified description of dynamic nursing care. All were ICU survivors so plots were similar in the diaries – would have been different plots if patients had died	Single site. Only written by nurses so did not ascertain the relatives' narratives. Data taken from previous study – not identified	✓✓✓✓ (2,3,2,5)
Egerod and Christensen (2011) Denmark	Qualitative, descriptive and comparative design of secondary data previously analysed by the researchers (Egerod & Christensen 2009)	Convenience sampling at a single site ICU in 2007 (<i>n</i> = 10) same sample as (Egerod & Christensen 2009)	Interviews, hospital charts	Narrative analysis of diaries and interview of survivors	Diaries and charts have different purposes. Nurses' notes fragmented, impersonal and technical whereas diaries coherent, personal and supportive	Single centre small sample. Unclear why interviews were undertaken and what the finding were	✓✓✓✓ (1,8,2,5)

Table 2 (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Åkerman <i>et al.</i> (2013) Sweden	Christensen 2009) to investigate the structure and content of diaries and examine the potential contribution of charts and diaries to recovery Descriptive and exploratory cohort with mixed method design to identify the preferred content and usefulness of an ICU diary by ICU survivors	Participants from a previous study with length of ICU stay 4–10 days (<i>n</i> = 409) of those who had received a diary identified (<i>n</i> = 115) had photos in diary (<i>n</i> = 15)	Six months after ICU discharge interviews at home, hospital or by phone, postal questionnaires and ICU database (demographic data)	Inferential and descriptive statistics and content analysis	Medical information and details of daily activities deemed important and in chronological order to construct a story. Missing photographs led to incomplete information and considered important to have an accurate record in the diary. Diaries enhanced communication. Guidelines on preferred content called for	Previous study sample obtained source not identified. Survivors interviewed in hospital setting gave different answers to those interviewed elsewhere. Questionnaire not piloted. Limited discussion about the impact of photographs as potential tool for survivors	✓✓✓ (21/25) ✓✓✓ (19/22)
Backman <i>et al.</i> (2010) Sweden	Nonrandomised prospective study. Hypothesis that diaries would improve quality of life by filling in memory gaps	Convenience sampling 2002–2004 (<i>n</i> = 449). Component of a larger study exploring QoL (Orwelius <i>et al.</i> 2005) and data from one site analysed. Diary group and follow up visit (<i>n</i> = 40) no diary group (<i>n</i> = 224) questionnaire not followed up visit	SE36 mailed at 6, 12, 24 and 36 months after hospital discharge	MANOVA	No differences in patient characteristics between the two groups but diary group were younger with greater severity of illness and stayed in hospital longer. Diary group scored better in general health, physical component and vitality	Nonrandomised design and small sample. Unsure if the follow up visit influenced QoL or the diaries. As the diary group was younger would be expected to score better in vitality and physical component score – so unsure if it was the diary which influenced this. Did not quantify how frequently participants read their diaries, if at	✓✓✓ (18/22)

Table 2. (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Bergbohm <i>et al.</i> (1999) Sweden	Pilot study qualitative descriptive design to ascertain views on the content of diaries	Convenience sample of ICU patients who were expected to stay longer than seven days and had a diary kept for them in 1996 (<i>n</i> = 18). Ten survived and eight died. Questionnaires completed by relatives of those who died	Postal questionnaire	Unclear	All had read their diaries; two thought the diaries did not help them to remember their ICU experience seven said that it did. Reading the diaries they could connect with events that they remembered. Diaries gave them security and permission to rebuild their lives after illness. Had difficulty remembering what they looked like and would have liked photos in the diaries	all. Significant drop out in nondiary group, reason not clarified Unclear at what stage post-ICU the questionnaires were sent. Small sample and a pilot study. Unclear methodology reduces transferability of findings	✓✓ (14/25)
Combe (2005) UK	Qualitative descriptive design	Convenience sample during 2001 of ICU stay of greater than four days, sedated and ventilated and given diaries, photographs included written by nurses and family members	Interviews at a follow up clinic 2, 6, and 12 months posthospital discharge conducted in an interview room close to the ICU	Unclear	Photographs useful to set recovery goals. Open communication channels between survivor and relatives. Enabled them to move on from the experience	Small study, single site, data collection tool not discussed or data analysis process	✓✓ (10/25)
Egerod <i>et al.</i> (2011a) Denmark	Qualitative grounded theory sequel to a previous study (Jones <i>et al.</i> 2010) to how patients and relatives use a diary in the context of the illness trajectory	Convenience sample of ICU survivors at two ICUs during 2007 and 2008 (<i>n</i> = 32). Diaries established practice in both units and written by nurses	Interviews – six individual and 13 with survivors and relatives in their homes	Constant comparative analysis	Diaries didn't re-establish memories but helped fill the gap. Diaries were an inconsistent source of information restricted by what people chose to put in them. Patients needed to construct their illness in the context of onset of illness and recovery not just the	Small sample but two centred increased the transferability of findings. Diary entries from nurses not family which may have influenced the survivors' perceptions of them	✓✓✓ (21/25)

Table 2 (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Egerod and Bagger (2010) Denmark	Qualitative subdiary study from RACHEL trial (Jones <i>et al.</i> 2010) Qualitative study to ascertain survivors' experiences of ICU diaries	Purposive sample ($n = 4$) at 11 bed surgical thoracic unit discharged within last 6–12 months and been in the RACHEL study	Focus groups in a room near the ICU	Inductive coding technique	ICU experience. Photos were deemed confrontational but also a valuable source of information. Helped them to appreciate how ill they had been and set realistic goals for recovery. Some gender differences identified with the diaries – females more receptive Narrative process crisis, turning point and normalisation (Egerod & Christensen 2009). Diary was not a reliable record of events, did not enhance recall but enabled them to complete their story, photos essential component, needed to know how they behaved, said and experienced, family should be able to write in the diary and different times when ready to read their diaries	Single site and low participant numbers possibly due to time elapsed between RACHEL study and this study. Suboptimal numbers for a focus group could limit quality of data generated. Participants may not have been able to disclose details of a personal nature in a focus group leading to potential bias Small sample, single site study. Lengthy period of time following discharge from ICU – recall may be less – potential for bias. Interviews translated from Swedish to English – open to misinterpretation.	✓✓ (14/25)
Engström <i>et al.</i> (2009) Sweden	Qualitative descriptive design	Convenience sample of ICU survivors in ICU ≥ 72 h discharged ≥ 2 months from hospital and one year since discharge from ICU	Interviews	Qualitative content analysis	Four categories: being a 'frakl', being deeply touched, appreciating close relatives' notes, a feeling of unreality and gaining coherence		✓✓ (14/25)

Table 2 (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
Garrouse-Orgues <i>et al.</i> (2012) France	Mixed methods prospective study with an intervention period between two control periods pre- and postdiary during 2009	Convenience sample of ICU patients admitted for at least four days. Pre diary group (<i>n</i> = 48), diary period (<i>n</i> = 49) and post diary period (<i>n</i> = 46). Diary maintained by ICU staff and family members - no photos whilst in ICU; only of equipment	On discharge from ICU relative completed HADS, Critical Care Family Needs Inventory. Three months after discharge survivors and relatives completed HADS and PDEQ. After 12 months survivors and relatives completed IES	Descriptive statistics and qualitative analysis of diaries	Less symptoms of Post-traumatic Stress (PTS) in postdiary group than pre-diary group - most prevalent in relatives than survivors at 12 months. Reduction in avoidance in survivors only category which reached statistical significance	Trustworthiness of data questionable Unclear methods section describing the purpose of the intervention group and when intervention occurred. Cannot be sure that the diary was causal factor in reduction of PTS in relatives at 12 months - may have just been time factor. Interviewers may not have been blinded during interviews introducing potential bias	✓✓✓✓ (17/22)
Jones <i>et al.</i> (2010) Europe	RCT to examine if the use of diaries in ICU survivors during the convalescence period in reducing new-onset Post-Traumatic Stress Disorder (PTSD)	Randomised sample in six ICUs (<i>n</i> = 352) ventilated for >24 h, LoS in ICU >72 h, no history of psychotic disease, PTSD or inability to give consent	All had diaries and completed ICUMT at one to two weeks postdischarge and PTSD-14 prior to randomisation. Randomised at one month. Intervention group had the diary when they wanted and the control after completed PTSD-14 at three months	Nonparametric statistics	5% of intervention group had PTSD compared to 13.1% of the control group (<i>P</i> = 0.02)	Discussion of diary with participants could have biased the results. Unable to blind the investigators also leading to potential bias	✓✓✓ (7/11)
Knowles and Tarrler	Pragmatic RCT to evaluate the effectiveness of an	Randomised sample in 1 ICU comparing diary and verbal	Completed HADS at one month postdischarge and	Parametric and nonparametric testing	Less anxiety and depression in the intervention group than the control group	Long enough period of time lapsed for assessment when	✓✓✓ (19/22)

Table 2. (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
(2009) UK	ICU diary on affective symptomology at one month post-ICU discharge.	feedback group with a control nondiary group (<i>n</i> = 18) and a diary group (<i>n</i> = 18). In ICU for >48 h with no existing psychological morbidity or suicidal ideation	given their diary then repeated HADS three weeks later			PTSD can develop up to a year after trauma. Not clear if the discussion with the ICU nurse in the intervention group or the diaries influenced results. Single centre small numbers. Does not state how sample size was calculated	✓✓ (16/25)
Robson (2008) UK	Observational. To ascertain diary content, how often survivors had read the diary and opinions about them	Purposive sample (<i>n</i> = 20) in single site. Diaries been in use there for two years and nurses, families, occasionally medical staff and physiotherapists made entries. Photographs were included and guidelines on diary composition and photographs developed	Postal questionnaire and interviews up to two years postdischarge	Unclear	Sixteen (80%) considered the time they received the diary was appropriate. All considered diaries helped them make sense of the experience and understand how ill they had been. All had read the diaries after discharge. Seventeen (85%) felt that the diary should have been continued after discharge from ICU in HDU and wards. Eleven (55%) found it distressing to see the diary for the first time. Two participants were unhappy with the entries from friends. Suggestions for improvement: a happy ending photo, prevent gaps in content and continue throughout hospital stay	Single centre small sample. Questionnaire not validated or piloted. Composition of photographs not detailed. Eight (40%) had been discharged for 18–24 months who could have had reduced recall of feelings about the diary. Unclear if reading the diary reduced over time. Significant differences in scope of diaries as well as reported gaps in content could bias findings	✓✓ (22/25)
Ewens <i>et al.</i> (2014)	Qualitative interpretive biographical account	Purposive sampling	Visual diaries and interviews at two and five months post-ICU discharge	Interpretive analysis of interviews and diaries	Survivor unprepared for severity of debilitation following critical illness. Still had recollection of	Single site small study	✓✓ (22/25)

Table 2. (Continued)

Author (year), country	Study design	Sampling and sites	Data collection	Data analysis	Comments/key findings	Limitations	Quality appraisal
	of one participant's visual diary				delusional dreams whilst in ICU. Ensured that good came from his experience in ICU. Considered visual diary aided his recovery		

Prevalence of diaries in ICU

Diaries in ICU were developed in the 1990s in Scandinavia. Their use is now predominantly within Sweden but they are also in use in Denmark, Norway (Egerod *et al.* 2011b), Switzerland and the UK (Egerod *et al.* 2011b), although implementation has been sporadic in other parts of Europe and rest of the world (Nydahl *et al.* 2010, Ewens *et al.* 2013).

Feedback from patients and their families was identified as a significant driver in the implementation or ongoing use of patient diaries (Akerman *et al.* 2010). In many instances but not all, the operational aspects of ICU diaries were based on locally developed guidelines (Robson 2008). Importantly, the development of national or international guidelines for diary use has been called for (Gjengedal *et al.* 2010, Egerod *et al.* 2011b, Ewens *et al.* 2013). Inconsistencies exist regarding the optimum time to commence diaries; although this most frequently occurs at day three when ventilation is considered to be ongoing (Gjengedal *et al.* 2010, Egerod *et al.* 2011b). However, this criterion extended at some sites to include patients ventilated for a minimum of 24 h and those receiving noninvasive ventilation with an associated shorter length of ICU stay (Egerod *et al.* 2011b). Investigation into the outcomes of diaring for patients who receive noninvasive ventilation only is yet to be conducted.

The main purpose of ICU diaries for survivors was identified as assisting to fill the perceived memory gaps, cementing their experiences in reality and helping them to understand the severity of their illness and to set realistic recovery goals (Combe 2005, Egerod & Bagger 2010). From the perspective of the survivors, the diaries were considered an act of support and caring by nursing staff in addition to their usual duties (Ewens *et al.* 2013).

In all studies, the diaries were deemed the survivors' personal property and not a component of hospital records. Diaries were returned to survivors or relatives of the deceased at various time points; either on discharge from ICU (Robson 2008, Akerman *et al.* 2010, Ewens *et al.* 2013) or at a follow-up visit following hospital discharge if this was available (Backman & Walther 2001, Combe 2005, Gjengedal *et al.* 2010).

There was no consensus in the literature about the optimum point at which to return diaries to survivors or family members and this process appeared to be based upon custom and practice. If units conducted follow up clinics the diaries were often returned at that point and used as a springboard for discussion about the ICU experience (Combe 2005, Backman *et al.* 2010).

Content and structure of diaries

All studies undertaken to explore the preferred content and structure of diaries were from Scandinavia and Switzerland (Roulin *et al.* 2007, Egerod & Christensen 2009, 2011, Åkerman *et al.* 2013). Survivors acknowledged the supportive nature of diaries, not merely as an information giving exercise but because of the specific content and the way this was expressed (Roulin *et al.* 2007). In two studies, diaries were viewed as both a means of maintaining a link with loved ones whilst they were unable to communicate and facilitating the construction of a coherent story of the ICU experience for the survivor (Roulin *et al.* 2007). Content analysis of a small sample of survivors' diaries demonstrated similarities in the structure of the stories portrayed in the diaries from crisis, turning point to normalisation (Egerod & Christensen 2009). To construct a realistic story of their experience in ICU, survivors considered that events should be written in chronological order in their diaries (Åkerman *et al.* 2013) as omissions had been identified which detracted from the flow of the narrative (Robson 2008, Åkerman *et al.* 2013).

The inclusion of patient photographs in diaries has been considered important by survivors in augmenting the written content (Backman & Walther 2001, Egerod *et al.* 2011a, Åkerman *et al.* 2012) and in helping them to realise the severity of their illness. The inclusion of photographs is widespread (Egerod *et al.* 2011b); however, their potential impact remains relatively unknown. If photographs are included in diaries, there is an inconsistent approach to their specific content. This varies between the inclusion of staff and family members with patients (Backman & Walther 2001, Combe 2005) to one instance where photographs comprised ICU equipment only without the patient in view (Garrouste-Orgeas *et al.* 2012). The recovery trajectory is often underestimated by survivors (Deacon 2012) and being able to visualise themselves in photographs has aided some survivors to understand the severity of their illness and therefore to set realistic recovery goals (Combe 2005).

Nurses in Scandinavia expressed concern about the ethical issues associated with patients' photographs in diaries; in particular the practice of photographing patients without their consent, but continued to do so because of positive patient feedback (Egerod *et al.* 2011b). This issue has been addressed elsewhere by securely storing the photographs and including them in the diary when the patient gave consent to do so (Jones *et al.* 2001, Ewens *et al.* 2013). However, the use and potential effect of patients' photographs in ICU diaries has not been extensively explored in the literature (Åkerman *et al.* 2013).

A comparison of ICU diary content and ICU observation/flowcharts has been undertaken (Egerod & Christensen 2011) to ascertain the contribution of these charts and diaries to the construction of survivors' stories. The findings confirmed that the content of diaries was very different to patients' charts and are of little value in constructing the stories of survivors because of their different purposes (Egerod & Christensen 2011).

Perceived benefits of ICU diaries

Intensive care diaries are well received by survivors and their families (Backman & Walther 2001, Combe 2005, Ewens *et al.* 2013) and have many perceived benefits which are related to their underpinning philosophy. A holistic style of composition is encouraged with families often providing the backdrop of normality through their entries within the diaries. The concept of diaries has demonstrated benefits for survivors, their family members and also to families of nonsurvivors (Backman & Walther 2001, Combe 2005). Diaries are viewed as an act of caring evidenced by the entries of ICU staff and family members which are often expressions of love and hope; and survivors have reported many emotions when reading these types of entries (Engstrom *et al.* 2008, Ewens *et al.* 2013, 2014). The process of making diary entries enables family members to maintain a connection and a sense of normality with their loved ones whilst offering them focus and purpose (Ewens *et al.* 2013). Diaries are also an information giving exercise of events in ICU for the survivor. These entries have been credited as enabling survivors to come to terms with what has happened to them and are therefore able to reauthor their story and develop insight into their experiences (Egerod *et al.* 2011a). The therapeutic benefits of diaries to survivors and their families is emerging; however, there is little evidence to support any benefit for nursing staff as primary authors.

Diaries are attributed with filling memory gaps and enabling survivors to form a coherent story of their ICU stay as well as maintaining the human connection between them and their family members (Bergbom *et al.* 1999, Åkerman *et al.* 2013, Ewens *et al.* 2013). Diaries, particularly if they contain photographs, demonstrate to survivors the severity of their illness which enables them to set realistic recovery goals (Bergbom *et al.* 1999, Combe 2005, Egerod *et al.* 2011a).

Early studies focussed on general feedback from survivors and their families about the benefits of diaries without tangible endpoints and there are only four studies which have focussed on the impact of diaries on anxiety, depression,

PTSD and quality of life (Knowles & Tariier 2009, Backman *et al.* 2010, Jones *et al.* 2010, Garrouste-Orgeas *et al.* 2012). In a multinational randomised controlled trial (RCT), diaries were attributed to reducing new-onset PTSD in the convalescence period in a significant sample (Jones *et al.* 2010). Diaries have also been identified as reducing Post-traumatic Stress (PTS) symptoms in survivors (Garrouste-Orgeas *et al.* 2012), although it was unclear if diaries alone were the causative factor or this was due to elapsed time since hospital discharge. Diaries have also been attributed with a reduction in anxiety and depression (Knowles & Tariier 2009) and improvements in quality of life (Backman *et al.* 2010); however, in both studies it was unclear if discussion with nursing staff after discharge biased the findings.

Discussion

This literature review has indicated that ICU diaries are a low cost, grass roots initiative which have demonstrated potential therapeutic benefit in a population recognised to be at significant risk of psychological morbidity (Capuzzo *et al.* 2008, Jackson *et al.* 2009, Peris *et al.* 2011). A significant finding of this review has been the lack of rigorous research to inform the use of ICU diaries as a therapeutic intervention despite their application in some countries for more than two decades. There has been a substantial focus in the literature on determining the prevalence of diaries compared to the potential impact of diary use. The Scandinavian studies aimed at establishing the prevalence of ICU diaries using the same survey were reliant upon individual responders who were deemed experienced in the use of ICU diaries (Gjengedal *et al.* 2010, Nydahl *et al.* 2010). While this use of a valid tool enhances rigour, the survey required translation, both of terms and into a different context. This may have led to potential bias from misinterpretation of terms through translation which cannot be excluded in some of the studies (Gjengedal *et al.* 2010, Nydahl *et al.* 2010).

The evidence establishing the prevalence of diaries in Scandinavia is now dated mainly because of the use of secondary data from one study (Egerod *et al.* 2007, 2011b, Gjengedal *et al.* 2010), therefore, it is unclear whether this practice has become more prevalent internationally, although there is limited application in Australia (Ewens *et al.* 2013). It is apparent that the implementation of diaries and investigation into diaries is most prevalent in Scandinavia which may be due to the development of dedicated teams responsible for diaries in their units (Gjengedal *et al.* 2010) and this could be adopted elsewhere to sustain the practice of ICU diaries.

There has been limited exploration of the preferred content of diaries from the survivors' perspectives to guide practice. Studies in Scandinavia which have analysed the purpose and content of ICU diaries have been via secondary analysis (Egerod & Christensen 2011, Åkerman *et al.* 2012) or further investigation using the same sample (Egerod & Bagger 2010) from previous studies (Egerod & Christensen 2009) which has limited the generalisability of findings and the contemporaneous nature of the data. Photographs are widely used in ICU diaries and were positively received by survivors as a means to supplement the text within them (Backman & Walther 2001, Combe 2005). Despite photographs evoking a range of emotions in survivors and their families, this did not detract from their perceived benefit (Robson 2008, Ewens *et al.* 2013). There remains inconsistency about the agreed content of photographs and whether they should be used at all within diaries; as nursing staff have raised concerns of doing so without the patient's consent (Egerod *et al.* 2011b). Photographic imagery is a powerful medium and as such the potential in this context is probably underestimated. The inclusion of photographs in diaries enables the survivor to visualise themselves often at their most vulnerable. If photographs were taken sequentially and at turning point moments in their ICU journey a visual record of progress to accompany the written text would be created. Inconsistencies in this practice may be due to the lack of evidence which supports the use of photographs but could also be attributed to nurses' reservations and this is an area which requires further clarification.

Feedback from survivors and their families about ICU diaries have been predominantly positive. Many survivors and their family members have recounted the ways in which diaries assisted in filling memory gaps and maintaining communication with loved ones through the supportive nature of the diaries (Roulin *et al.* 2007). Survivors were deeply moved by the statements of love, support and encouragement to overcome their illness from their relatives (Engström *et al.* 2009, Ewens *et al.* 2013) who themselves considered diaries a way in which they could communicate with their loved ones during this time (Roulin *et al.* 2007). Diaries also revealed to survivors how they were cared for by nursing staff, which was often considered above and beyond their usual nursing duties (Ewens *et al.* 2013).

The body of literature has focussed upon the use, prevalence, content, structure and potential benefits of ICU diaries for survivors and their families. However, nurses play a crucial role in operationalising diaries in the clinical setting and yet there has been no examination of the potential benefits that diaries may have for the nurses who construct them and this should be considered.

Survivors have reported a reluctance to share their experiences with family members following discharge for fear of causing them stress and revisiting events themselves (Griffiths & Jones 1999). Diaries have been credited with enabling difficult conversations to occur by acting as a springboard for discussion (Backman & Walther 2001, Ewens *et al.* 2013). Reading their diaries evoked powerful emotions for survivors however, this did not detract from the positive experiences that have been reported in the literature (Egerod *et al.* 2011a, Ewens *et al.* 2013).

The commencement of diaries differs from day one to three of admission during which time a significant amount of critical data could be lost leading to fragmented narrative which has been identified as undesirable by survivors (Robson 2008, Egerod & Christensen 2011). Survivors were not encouraged to continue diaring following ICU either whilst in hospital or following discharge home, although some felt that this would be beneficial (Robson 2008). Prospective diaring may benefit survivors as they become active participants in their recovery journey but this is yet to be explored and should be the focus of future investigation.

Specific interventions to promote ICU recovery should be targeted to those who will benefit most from them (NICE 2009). Studies within this review contained demographic and severity of illness data but there have been no inferences drawn from this data about the relevance of this for targeting diary use other than gender preferences (Egerod *et al.* 2011a) and this should also be a focus of future research.

Strengths and limitations

The strength of this literature review is the systematic review of relevant research articles guided by an answerable question. Articles were reviewed both for their methodological rigour and their contribution to practice. The articles were reviewed in relation to the review question and a conclusion

reached. The review was limited by the exclusion of three articles which were not in English. The quantity of articles generated from the Google Scholar search prohibited further exploration and this may have limited the collection of pertinent studies as yet unpublished in scientific journals.

Conclusion and relevance to practice

The prevalence and range of psychological morbidity is well evidenced in ICU survivors; however, rehabilitation services are still evolving and their application remains limited. Patient diaries are a cost effective intervention which has shown potential in the reduction of psychological morbidity during the recovery period for survivors of critical illness. The focus of research should now be upon establishing evidence-based practice standards for the implementation of diaries and further exploration of their potential impact upon psychological morbidity during the recovery period. It has been acknowledged that because of the diversity of the complications of critical illness strategies to support survivors should be targeted appropriately and to those who need it most. There has been no exploration of who would benefit most from receiving diaries and this should also be undertaken. The use of prospective diaring during the recovery period for survivors may also have potential and this should be further explored in this population.

Disclosure

The authors have confirmed that all authors meet the IC-MJE criteria for authorship credit (www.icmje.org/ethical_1author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, and (3) final approval of the version to be published.

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ETHICAL APPROVAL



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4 April 2011

Ms Beverley Ewens
50 Bayport Circuit
MINDARIE WA 6030

Dear Ms Ewens

I am pleased to write on behalf of the Research Students and Scholarships Committee who have approved your PhD research proposal: **Living after confronting death: does story telling influence the recovery trajectory of young ICU survivors.**

I also wish to confirm that your proposal complies with the provisions contained in the University's policy for the conduct of ethical research, and your application for ethics has been approved. Your ethics approval number is **5894** and the period of approval is: **1 April 2011 to 1 July 2013.**

Approval is given for your supervisory team to consist of:

Principal Supervisor: Dr Joyce Hendricks - ECU
Associate Principal: Dr Christopher Churchouse - ECU

The examination requirements on completion are laid down in *Part VI of The University (Admissions, Enrolment and Academic progress) Rules for Courses Requiring the Submission of Theses* available at:
http://www.ecu.edu.au/GPPS/legal_legis/uni_rules.html

Additional information and documentation relating to the examination process can be found at the Graduate Research School website: <http://research.ecu.edu.au/grs/>

Please note: the Research Students and Scholarship Committee has resolved to restrict doctoral theses to a maximum of 100,000 words with a provision that under special circumstances a candidate may seek approval from the Faculty Research and Higher Degrees Committee for an extension to the word length. (RSSC 99/24).

I would like to take this opportunity to offer you our best wishes for your research and the development of your thesis.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'P. Brown'.

Patricia Brown
Senior Student Progress Officer
Research Assessments – SSC

Principal Supervisor: Dr Joyce Hendricks - ECU
Associate Principal: Dr Christopher Churchouse - ECU
HDR Kristina Sfreddo

CONFERENCE PRESENTATIONS

CONFERENCE PRESENTATION: NARRATIVES AND RECOVERY IN ICU

Association for Qualitative Research: Embodying good research: What counts and who decides? Charles Darwin University, August 23-25, 2012.

ABSTRACT

ICU survival carries significant risk of long term physical and psychological morbidity, yielding a reduced quality of life for survivors and considerable economic burden upon a besieged health service. Screening for psychological complications in ICU survivors is infrequent and the provision and standardization of physical and psychological rehabilitation programs is inadequate, despite evidence of their benefit.

The purpose of this qualitative study is to determine whether constructing a self-story through diarising as visual narrative, has potential in the recovery of ICU survivors.

ICU survivors (n=10 or until saturation is reached) will describe the story of their ICU experience and recovery thus far at three months post hospital discharge. This narrative will be a continuation from the diary which was constructed for them in ICU. This narrative will then be reproduced in a diary using materials of their choice together with the researcher. The participants will be encouraged to continue to diarise their recollections of ICU and the course of their recovery for a further three months, when they will be invited to continue to narrate their story with the researcher.

Interpretive thematic analysis of the narratives and diaries will be performed with particular reference to the emergence and continuance of key themes. Comparison of the narratives and diaries' content will be compared to the survivors' perceptions of their recovery trajectory.

Studies have alluded to the positive impact that patient diaries may have upon psychological recovery in ICU survivors. The application of therapeutic narrative in trauma survivors is well established but this intervention has not been explored in ICU survivors. As yet there are no studies which have built upon and expanded the diary concept traversing the recovery trajectory using the visual imagery of diarising.

This paper will present the preliminary findings from this qualitative study and the perceived benefit for service development in this population.

CONFERENCE PRESENTATION: NEVER ENDING STORIES: RECONSTRUCTING THE STORIES OF INTENSIVE CARE UNIT SURVIVORS

British Association of Critical Care Nurses (BACCN) Conference 2014. Royal College of Music and Drama, Cardiff, Wales 8-9 September 2014.

ABSTRACT

Intensive care unit survival has increased significantly over the last few decades as has a realisation that survival carries significant risk of long term physical and psychological morbidity. Although it has been established that survivors often face a complex and uncertain recovery, rehabilitation interventions are inconsistent and lack an evidence base. Survivors report high levels of cognitive distortion and distress, often accompanied by feelings of persecution and fear of death or harm as they drift between reality and unreality. If survivors' recollections of their experiences are delusional, which typically are more vividly recalled, a higher incidence of psychological morbidity and associated reductions in quality of life have been identified. Emotional disclosure by writing or talking about traumatic events has been demonstrated to have a positive effect on health outcomes (Pennebaker & O'Heeren, 1984). Conversely, not confiding about experiences promotes behavioural inhibition and physiological arousal, which may be associated with psychological morbidity and in particular Post Traumatic Stress Disorder, postulated to be as high as 64% percent in this population. Therefore, interventions which enable survivors to re-create an accurate transcript of their experiences may have potential. The purpose of this qualitative study was to determine whether constructing a self-story through diarising as visual narrative, has an impact on the recovery of survivors. Intensive care unit survivors (n=7) constructed their individual stories of their intensive care unit experience and recovery using visual media. Participants diarised for three months following discharge from hospital when they were interviewed by the researcher focusing on the content and structure of their diaries to elicit meaning. Interpretive thematic analysis of the diaries with particular reference to the emergence and continuance of key themes was completed. This paper will focus on one survivors' visual diary and his use of images as vivid metaphor to illustrate his ICU experience and recovery journey.