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Making sense of it: Intensive care patients' phenomenological accounts of story construction

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Abstract

Background

Patients entering intensive care encounter physical and psychological stress which may lead to psychological morbidity such as depression, anxiety and post-traumatic stress. It has been suggested that constructing a story may assist psychological recovery however this has been minimally investigated in the intensive care patient.

Aim

The aim of this paper is to examine the process of story construction in patients' phenomenological accounts of being a patient in the technological environment of intensive care.

Study design

The study design was informed by Heideggerian phenomenology.

Methods

Semi-structured interviews were conducted in nineteen patients who had been in intensive care for at least four days. Interviews were digitally recorded, transcribed and analysed utilising Van Manen's framework for thematic analysis.

Findings

Making sense of their experiences in ICU appeared to be fundamental to story construction. Themes that arose were: "Why am I here?", "Filling in the gaps", "Sorting the real from the unreal" and "Searching for familiarity". These themes describe how participants sought temporal and causal coherence in order to construct their integrated and understandable story. Families appeared to play a critical role in assisting participants in filling in the gaps, sorting the real from the unreal and their subsequent psychological recovery.

Conclusions and relevance to clinical practice

The importance of early support from health care professionals to facilitate patients' story construction is highlighted. The study also emphasizes the role of families in supporting patients in making sense of their experiences and the associated psychological recovery process. Further research to evaluate methods of facilitating story construction such as nurse-led de-briefing, patient diaries, is recommended. In addition investigation of families' perceptions of their role in assisting patients to construct their story may facilitate health care professionals in developing strategies to effectively support families in their role.

INTRODUCTION

When entering the intensive care unit (ICU), patients endure physical and psychological stress (Samuelson 2011, Desai *et al.* 2011) which they report as being terrifying and traumatic (Fredriksen and Ringsberg 2007, Cypress 2011). Patients who survive ICU to discharge are at significant risk of developing psychological problems such as anxiety, depression and post-traumatic stress disorder (Jones 2014, Kowalczyk *et al.* 2013). The presence of memory gaps, delusions, and hallucinations may increase the likelihood of developing psychological problems (Ringdal *et al.* 2006, Griffiths and Jones 2011). In addition there is evidence that the presence of clear factual memories may offer protection against the development of PTSD (Jones *et al.* 2007, Jones *et al.* 2001).

Williams (2009) has suggested that the construction of a story may help the psychological recovery of a patient who has been in ICU. Williams (2009) conducted a hermeneutic study of five ICU patients one year after discharge and suggested that there is a cathartic benefit to constructing and telling their story as it may stabilize the patient's sense of self and improve their ability to cope with the traumatic event. Other authors have also theorised that constructing a meaningful story may facilitate the psychological recovery of the patient (Corrigan *et al.* 2007, Hupcey and Zimmerman 2000). McKinny & Deeny (2002) found that patients were eager to cognitively revisit their ICU experience in an attempt to re-frame their experiences and restore a sense of meaning. Indeed constructing an illness narrative is not a new phenomenon (Bury 2001). Story-telling or personal narratives are one way in which individuals can give meaning to what they experience (O'Brian and Clark 2010). Hyden (1997) describes illness narratives as being a powerful method of expressing experiences related to suffering. Frank (1995: Page 18) suggests that illness narratives 'attempt to give voice to an experience that medicine cannot describe'.

The potential benefits of creating an illness narrative has long been recognised in trauma patients where narrative re-constructions of the experience is considered to be a central component of the recovery process (Kaminer 2006). Tuval-Mashiach *et al.* (2004) suggest that narrative mechanisms play a crucial and interactive part in the early phase following trauma which is widely recognised as being the most critical in terms of coping and long term recovery (Shalev 2002). Kaminer (2006) in a review of the literature, suggested that trauma narratives are deemed to have psychotherapeutic benefits, including: emotional catharsis, an opportunity to create a linguistic representation of the event, development of an explanatory account, habituation of anxiety through exposure, empathic witnessing of injustice and identification of value or purpose in adversity. Furthermore, a coherent story after experiencing traumatic events is positively correlated with better recovery and coping (Gidron *et al.* 2002, Tuval-Mashiach *et al.* 2004).

The National Institute for Health and Care Excellence (NICE) have highlighted that optimisation of recovery should be the therapeutic objective and not merely the survival of the critical illness (NICE 2009). Therefore, research interest into the long-term emotional and psychological sequelae of critical illness and how best to support patients during their recovery has gathered apace. Rehabilitation strategies including critical care follow-up clinics and the use of patient diaries in particular have gathered much research attention. Follow-up clinics vary in their structure and format, however, typically include physical, psychosocial and cognitive assessments and a more informal discussion of the patients experiences (Modrykamien 2012, Griffiths *et al.* 2006). The impact of follow up clinics on physical and psychological outcomes has yet to be robustly demonstrated in the research literature, however patients report great satisfaction with follow-up services (Modrykamien 2012, Ågård *et al.* 2014, Cuthbertson *et al.* 2009). Patient diaries offer a factual summary of the patient's time in ICU, and aim to address gaps in patients' memory, clarify and explain delusions or hallucinations and assist patients to understand and rationalise their experiences of ICU (Ewens *et al.* 2014). The evidence supporting the use of patient diaries varies in quantity and quality however, there are tentative suggestions that patient diaries may have positive

effects on patients' psychological recovery (Aitken et al. 2013). Implicit within both rehabilitative interventions is the facilitation of patient story telling. However, the role and process of the construction of an illness narrative in patients who have been critically ill in ICU has only been minimally explored in the literature (Williams 2009, Williams 2010). The purpose of this article is to report the findings relating to the process of story construction from a larger phenomenological study exploring patients' experiences of being cared for in a technological environment such as ICU (Stayt *et al.* 2015).

AIM

The aim of this paper is to examine the process of story construction in patients' phenomenological accounts of being a patient in the technological environment of intensive care.

DESIGN AND METHODS

The design of this study was informed by Heideggerian phenomenology. Heidegger propounded the ontological perspective of *being-in-the-world*, which considers an individual's understanding, perceptions and experiences to be inseparable from their social, psychological and historical context (Mackey 2005, Earle 2010). Heideggerian phenomenology therefore allows a qualitative and holistic understanding of the individual experiences of ICU whilst acknowledging the multiple dimensions of being a patient in ICU.

Setting

The research was conducted in a university teaching hospital in the south of England in a general ICU which cares for level 3 patients who require advanced respiratory support or support of a minimum of two organs (Intensive Care Society 2009). The ICU operates a one to one nurse: patient ratio.

Sample

All patients who have been in ICU for four or more days are invited to a follow-up clinic 12 weeks after discharge. During periods of 2009-2011, convenience samples of these patients were invited by letter to participate in an interview either before or after their scheduled appointment. Patients, who were unable to consent to participate, did not feel well enough to be interviewed or who did not speak English, were excluded from this study.

Approximately ninety invitation letters were posted; nineteen patients responded and were subsequently recruited to participate. Data saturation was achieved at nineteen participants. It is not known why other invited participants did not respond to the invitation letter.

Data collection

Semi-structured interviews, lasting 45-90 minutes, were conducted in a private room within the hospital out-patients department. Participants were interviewed either alone or with a family member present. The interview commenced with the simple question "Tell me your story," however an interview topic prompt list was also utilised. Prompts included: memories prior to admission, first recollections of being in ICU, memories of ICU and discharge. Interviews were digitally recorded and transcribed *verbatim*. Reflexive field notes were made before, during and after the interview. Data were managed utilising QSR NVivo version 9.

Data Analysis

Transcripts were analysed utilising Van Manen's (1990) principles of thematic analysis. Preliminary themes were formed from the categorisation of significant phrases. Essential themes, and subsequently substantive themes, were identified by clustering, segregating, ordering and re-ordering categories with continual reference to the original transcripts and reflexive field notes. Participant quotations that exemplified the essential themes were selected. Consistent with

Heideggerian phenomenology, no attempt was made to 'bracket' the preconceptions of the researcher- rather the researcher's understandings were incorporated into the co-construction of meaning (Gelling 2010). Participants were not asked to validate the themes as this research integrated the accounts of participants enabling a more generalised, theoretical discussion of underpinning concepts. Morse (1998) argues that as theory is developed from a synthesis of the perspectives of a number of participants it is inappropriate to expect individual participants to have the ability to 'validate' the findings of the research as a whole.

ETHICAL AND RESEARCH APPROVALS

Ethical approval was gained from the National Health Service (NHS) Research Ethics Committee (REC No: 09/H0606/66) and the hospital Research and Development Department. Informed consent was gained from all participants. Confidentiality was maintained by allocating participants a code number which was then used to label all digital recordings, researcher notes and quotations included within reports and publications.

RIGOUR

Witt and Ploeg's (2006) expressions of rigour were applied as a framework for ensuring rigour. Heideggerian tenets were considered and incorporated into every stage of the study with the aim of achieving *Balanced Integration*. *Openness* was achieved by providing a clear audit trail of all decisions in a reflexive diary. *Concreteness* was demonstrated by the design of the study which aimed to strongly orientate the phenomenon into the broader context of ICU. *Resonance* of the study findings with readers will hopefully be achieved upon publication. According to de Witt and Ploeg (2006), *Actualisation* implies that phenomenological interpretation doesn't end when a study is finished as readers will continue to interpret findings in the future, therefore by definition has yet to be realised.

FINDINGS

Participant Characteristics

Participants had an average age of 57.5 years (+/-12.4 years) ranging from 32-86, the average length of stay was 2.1 weeks (+/- 0.9 weeks) ranging from 1-4 weeks. The average time since discharge from ICU at interview was 4.3 months (+/- 0.8 months) and ranged from 3-7 months. Participants were admitted to ICU for a wide range of reasons including elective post-operative admission, sepsis, pneumonia, and trauma. All participants were white, and English.

Making Sense of It

'Making sense of it' describes how participants sought explanation of their experiences in ICU by the rational construction of a story. It comprises of the subthemes 'Why I am here', 'Filling in the gaps', 'Sorting the real from the unreal', and 'Searching for familiarity' (figure 1).

Why am I here?

The process of story construction involved the participants providing a context to their ICU admission. Participants invariably started their story by describing the events leading up to their critical illness. Participants were able to describe clear memories up until a certain point where for what many of them described as rational thoughts or memories, stopped.

'Well I was home and I had cooked Christmas dinner for everybody... I don't remember much more of Christmas day... I was just so ill. And then the night of the 26th December the last thing I can remember is coming down stairs and sitting with my husband' (Participant 8)

When asked what had led to their admission to ICU, all participants, although not necessarily having a personal memory of the events or knowing the exact diagnosis, had a clear idea of the physical

reasons that had led to their ICU admission. A clear physical reason for their ICU admission seemed to be important for subsequent understanding of their experiences. Participants were often dispassionate when describing their illness- many reeled off a list of ailments as though they were reading a laundry list:

“I had ribs broken, sternum broken umm, crushed foot, wrist, cheek bone broken umm lip, cut lip, eye, puncture wound in my shin. Broken ankle... But my main problem was that I had a lacerated liver which wasn’t apparent at the time.” (Participant 4)

In describing the context of their admission, some participants appeared to emphasise the chronology of events and spent time making sure that the chronology was correct, often referring to a pocket diary or verifying with their relatives:

‘Well I was admitted on the Thursday, the Thursday before Easter. No wait a minute it was the Wednesday. That is right because I remember going to the meeting at work on the Wednesday. I didn’t go to ICU until the early hours of Friday. So that was Good Friday. Yes that is right, Good Friday.’ (Participant 18)

The complete, chronological account of events leading up to their ICU admission appears to be important to participants. Together with an understanding of their physical ailments, the chronological account appears to form a framework upon which the participants’ subsequent understanding of their experiences is based.

Filling in the gaps

Participants all describe having patchy memories and often expressed frustration at not having the complete picture.

‘My main feeling throughout it all was probably confusion. I didn’t know why I was there. I didn’t remember the accident. And it was only when I got to [Community Hospital] that [Husband] realised that I didn’t know either! ... I didn’t realise at that point that I had been in hospital for nearly a month’ (Participant 4)

In order to make sense of these incomplete memories, participants described the importance of having somebody, most commonly a family member, fill in the gaps.

‘So I don’t remember all the details, just snippets. My wife has told me some things...[Wife] filled me in on all the odds and ends. So [Wife] has helped a lot, she has been able to clarify the details.’ (Participant 2)

Sorting the real from the unreal

Just as participants can describe a definite time when clear memories disappear, most participants can distinguish a time when they are suddenly aware that they are fully conscious and subsequent memories are vivid and clear. In between these two time frames, participants describe different types of memories: some memories are hazy, some are based in reality, and others are based on their dream-like state or their distorted perception of events at the time.

It is clear from the participant’s dialogue that, during their recovery and the construction of their story, they spent a lot of time trying to distinguish which memories were real and which were part of their dream world- sorting the real from the unreal. Many participants described feeling as though reality and unreality were intermingled and sometimes inseparable. As such, participants often

expressed difficulty in separating what they perceived to be a dream and what were real events. Many relied upon family members to help them sort the real from the unreal:

'Because even now I have memories but I don't know whether they are real or not. And some of them are so bizarre I don't bother mentioning them to my husband.... So it is difficult finding out the reality and the dream world. You know trying to distinguish the two was the hardest thing for me.' (Participant 4)

'...My mum said do you mind if I go and get [stepfather], and I thought this happened in a tropical clinic somewhere in South America. But that was a real event that happened in [City in the UK] and I've since found out that Mum did come in and she remembers having this conversation. It is like having a small wedge or reality that gets put into your dream. This is why I have difficulty in deciphering what is real and what is imagined.' (Participant 12)

Frequently participant's real memories were of specific events or interventions such as a family members visit, replacement of an arterial line, or undergoing endotracheal suctioning. Participants appeared to be unable to accurately recall their environment or recall any details or memories of the people caring for them.

Searching for familiarity

In constructing their story, participants searched for and relied upon familiar factors that could provide a framework for their memories of their experiences in ICU. Such factors primarily included a sense of time and routine, familiar people and activities.

Participants described how they had little sense of time during their stay in ICU often unable to distinguish night from day. Participants described that knowing the time was important as it gave them a sense of orientation from which they could start to understand other less usual activities and events.

'Well before they moved my bed I couldn't see a clock or a window. But when they moved me, it was better because although there was no window at least I could get a sense of time ...' (Participant 11)

'Towards the end I became more aware. I started to be more aware of the daily routine and activity. In a way I started to know what to expect when.' (Participant 8)

Participants described how familiar people and activities provided a sense of reassurance and normality and helped them to situate their personal experiences.

'You just grasp to make sense of it all. The fact that friends and family visited reassured me... It made it feel more normal, like life goes on. Life isn't confined to the weird environment' (Participant 5)

'I clearly remember on Sunday night, because I think I was given a digital radio and I was listening to radio 4 and I finally, you know, this is awesome, because I can finally separate reality from not. I was doing something normal.' (Participant 12)

Participants described these familiar factors as comforting and reassuring as they assisted in formulating and understanding their experiences in ICU which were often unfamiliar, and terrifying.

DISCUSSIONS

Making sense of their experiences and constructing an integrated and meaningful story appeared to be fundamental to participants' understandings and their ability to make sense of what had

happened to them. Participants valued a chronologically and causally coherent comprehension of their experiences. It appeared that participants needed something tangible, a universally understandable concept such as time, on which to hang their experiences and formulate their understandings. Williams' (2009) qualitative study also found that the temporal coherence of the story is very important to the patient who is constructing their illness narrative. A story demonstrates temporal coherence when it has a logical and consistent chronology (Williams 2009).

The nature of critical illness means that the patient may spend expanses of time when they are unconscious and may have little or no memory of events. Constructing a chronologically accurate story may have been participants' attempts to re-orientate themselves and re-claim the lost time by accounting for it day by day, hour by hour, and minute by minute. Previous studies (Williams 2009, Corrigan et al. 2007, Hupcey and Zimmerman 2000) have investigated patients at a later stage in their recovery (at least one year post ICU discharge) in contrast to this study which interviewed patients 3-7 months after discharge. It is pertinent to note that participants value a meaningful and temporally cohesive story early on in their recovery process.

All participants were able to describe some factual memories of their ICU stay. Roberts *et al* (2007) and Ringdal *et al.* (2006) suggest that most patients (83%) in ICU have factual memories of their stay. In this study, factual memories were often of certain events such as family visits, technological procedures and interventions, however, participants were often unable to clearly describe their surroundings or the staff caring for them. A number of participants described staff as invisible or faceless. The significance of this previously unreported findings is unclear, however, fragmented or 'jigsaw puzzle' memories have been demonstrated in other studies (Löf 2006, Jones et al. 2007, Storli and Lind 2009, Granberg et al. 1999).

Participants recall therefore appears to be a complex mix of factual memories, missing or hazy memories, delusions and hallucinations. In making sense of their experiences and constructing their story participants attempted to fill in the gaps and sort the real from the unreal. Participants described how they had sometimes had difficulty in knowing what were real memories and which ones were dreams, delusions or nightmares. This was further complicated when real life events, people and objects entered into the participants dreams and nightmares. Participants described how reality and unreality were intermingled and inseparable. Other research studies have revealed similar complexities in patients' recall of ICU (Russell 1999, Corrigan et al. 2007, Jones et al. 2001). Storli *et al.* (2009) described patients' memories as chaotic mixtures of real events, dreams, hallucination and amnesia. Magaray and McCutcheon (2005) described how patients moved in and out of reality along a continuum and similarly, their patients reported difficulty in distinguishing between the two.

Participants in this study appeared eager to fill in the gaps and sort the real from the unreal by primarily gathering information from their family members in order to construct and make sense of their story. Participants appeared to be seeking what Williams (2009) describes as causal coherence where events are presented in such a way that makes sense. The process of sorting memories demonstrated by the participants is significant as the importance of having factual recall in patients' long-term recovery and wellbeing has been demonstrated in the literature. Ringdal *et al.* (2006) and Griffiths and Jones (2011) identified that patients with continued adverse and delusional memories reported lower quality of life, increased anxiety and depression and may even be predictive of later PTSD. In addition, Jones *et al.* (2001) postulate that clear factual memories may offer protection against the development of PTSD. Griffiths and Jones (2007) suggest that factual memories enable patients to recognise that their delusional memories are not real and therefore rationalise them.

Whilst the importance of filling in the gaps and sorting the real from the unreal has been clearly demonstrated in previous literature, little is written about how and when this process occurs. Consideration of the findings begins to demonstrate how patients approach this process. In addition the reliance on family members to fill in their memory gaps and rationalise memories has only been tentatively acknowledged in previous literature (Hupcey and Zimmerman 2000). However, the findings of this current study emphasize the family as an important information resource for the patients suggesting that participants found family accounts particularly accessible and meaningful.

LIMITATIONS

This study was a single centre study in the UK with the sample only consisting of white Europeans. The findings may therefore not reflect other regions within the UK and abroad. However detailed descriptions are given to enable to reader to assess the transferability of the findings to their setting. Only patients who attended follow-up clinic were recruited- participation of patients who potentially may have made rich contributions to the data, but did not want to attend clinic, may have been inadvertently restricted. In addition the self-selecting nature of the recruitment process meant that those who felt that they had memories of ICU and were willing and able to share them, may be more inclined to participate than those with limited memories or those too traumatised to share their experiences. The process of constructing a story may be different in these two groups.

CONCLUSIONS AND IMPLICATIONS FOR NURSING

The need to formulate an understandable and meaningful story early in their recovery process has been clearly demonstrated within this study. This is a new finding as the need has only previously been reported in patients at least one year post discharge. As well as the importance of constructing a story this study gives a preliminary insight into the mechanisms and processes by which the patient recovering from critical illness constructs that story, which has not previously been reported in the literature.

Of particular significance is that participants appeared to process their experiences and construct a story very early on in the recovery process. This finding supports the NICE (2009) directive that rehabilitation strategies ideally should be implemented early in the patient's recovery and should not wait, as it has done previously, until physical recovery. Early support from health care professionals to facilitate the construction of a temporally and causally coherent story may assist patients in both their long-term physical and psychological recovery after discharge from ICU and hospital.

These important new findings lead to several key suggestions for further research. Firstly, interventions that might facilitate story construction such as patient diaries or nurse-facilitated debriefing may be evaluated and compared. Secondly the extent to which the construction of a story is beneficial might be explored using a mixed method approach. A qualitative investigation may explore the patient perceived benefits of constructing their story, whilst a quantitative approach to evaluation might deduce exact outcomes such as incidence of anxiety, depression or PTSD. All of these measures have the potential to inform health care professionals of how best to support patients during their psychological recovery after critical illness and ICU admission. This study also highlighted that families' presence and support in constructing their story is of significance to patients. Exploration of families' perspectives on providing this supportive role would be beneficial. An assessment of families' needs during this time would enable healthcare professionals to facilitate strategies to supporting family members as they support their critically ill relative.

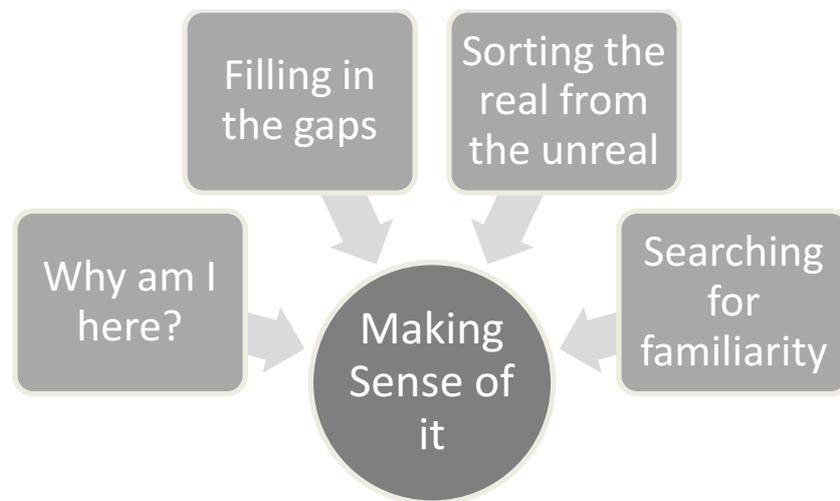
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Figure 1: Schema of Making Sense of It



Impacts

What is known about this topic:

- Patients in intensive care encounter physical and psychological stress and are at significant risk of psychological morbidity
- Story telling or constructing an illness narrative may assist psychological recovery of patients who have suffered a trauma
- Critical care follow-up clinics and patient diaries, both of which may implicitly facilitate patient story-telling, may have a positive impact on patients psychological rehabilitation

What this paper adds:

- Patients demonstrated a need to construct a meaningful story early on in their recovery process.
- Families play an important role in facilitating story construction and the patient's psychological recovery process.