

**University of  
South Wales**  
Prifysgol  
De Cymru

Cheryl Phillips, PhD student, RCBC Wales Fellowship, University of South Wales, in partnership with the Diary Team, Aneurin Bevan University Health Board, Critical Care Unit, Royal Gwent Hospital, Newport.

Critical care diaries: “being out of it” and seeking life story coherence

Acknowledging the hard work of the PhD supervision team:

Director of Studies: Professor Ruth Northway

Professor Marcus Longley, Dr Paul Gill

# Overview

- What is Grounded Theory
- Glaserian Grounded Theory
- The study
- Study findings
- Grounded Theory

# What is Grounded Theory?

- There is some debate about what constitutes grounded theory, but it is generally described as an approach for looking systematically at data, most often qualitative in nature (Suddary, 2006).
- The purpose of grounded theory is the discovery of theory from the data which is inductively derived from the study of phenomena and is discovered through systematic data collection and analysis (Glaser & Strauss, 1967).

# Contentions in use of Grounded theory

There are three main contentions that surround the different approaches to grounded theory.

1. The *role of induction* in grounded theory  
(abstraction, not description)

2. Emergence versus forcing, *discovery (or emergence) versus constructivism*

3. A *focus on social processes versus individual experience*

(Bryant & Charmaz, 2007).

GGT consists of the following stages of data analysis:

- Initial coding, which is substantive and data dependent
- Intermediate phase, continuation of above with constant comparative analysis.

Constant comparative analysis itself has four stages (Glaser, 2008):

1. Comparing incidents applicable to each category
2. Integrating categories and their properties
3. Delimiting the theory
4. Writing the theory

Emerging theory synchronised with the above processes through theoretical development, refitting and refining of categories which integrate around a core concern. The theory should have scope and modifiability (Adapted from Heath & Cowley, 2004, p.146).

## Memos

- Evolves into potential detachment from the situation! Consider this more. Loss of control over all this as no memory consider this.
- “My family talks to me obviously, but **they tell me** what’s happened” (Alice 2 months)
- **Family as a resource for information about what happened**
- “Which upset them obviously, more than me, cos they could see I was in pain, which I wasn’t feeling” (Alice 2 months)
- **Family going through more than the patient?**
- In vivo code: “**come to terms with**” or alter to **coming to terms with**
- “**It’s something I must know**” (Alice 2 months): Knowing what happened is important, seems to be relying on family as a source of information, but possibly feels this is not enough: ‘something **I got to know.**’

# The study

- Longitudinal
- Glaserian Grounded Theory (Classic GT)
- Serial Qualitative Interviews (2, 6 & 12 months post discharge from hospital home)
- 9 participants
- 27 interviews (6 women, 3 men)

## Study aim

- The aim of this study is to provide an in-depth insight into critical care survivor experiences and use (or not) of a critical care diary during the first 12 months of their recovery to inform development of theory and future diary use.



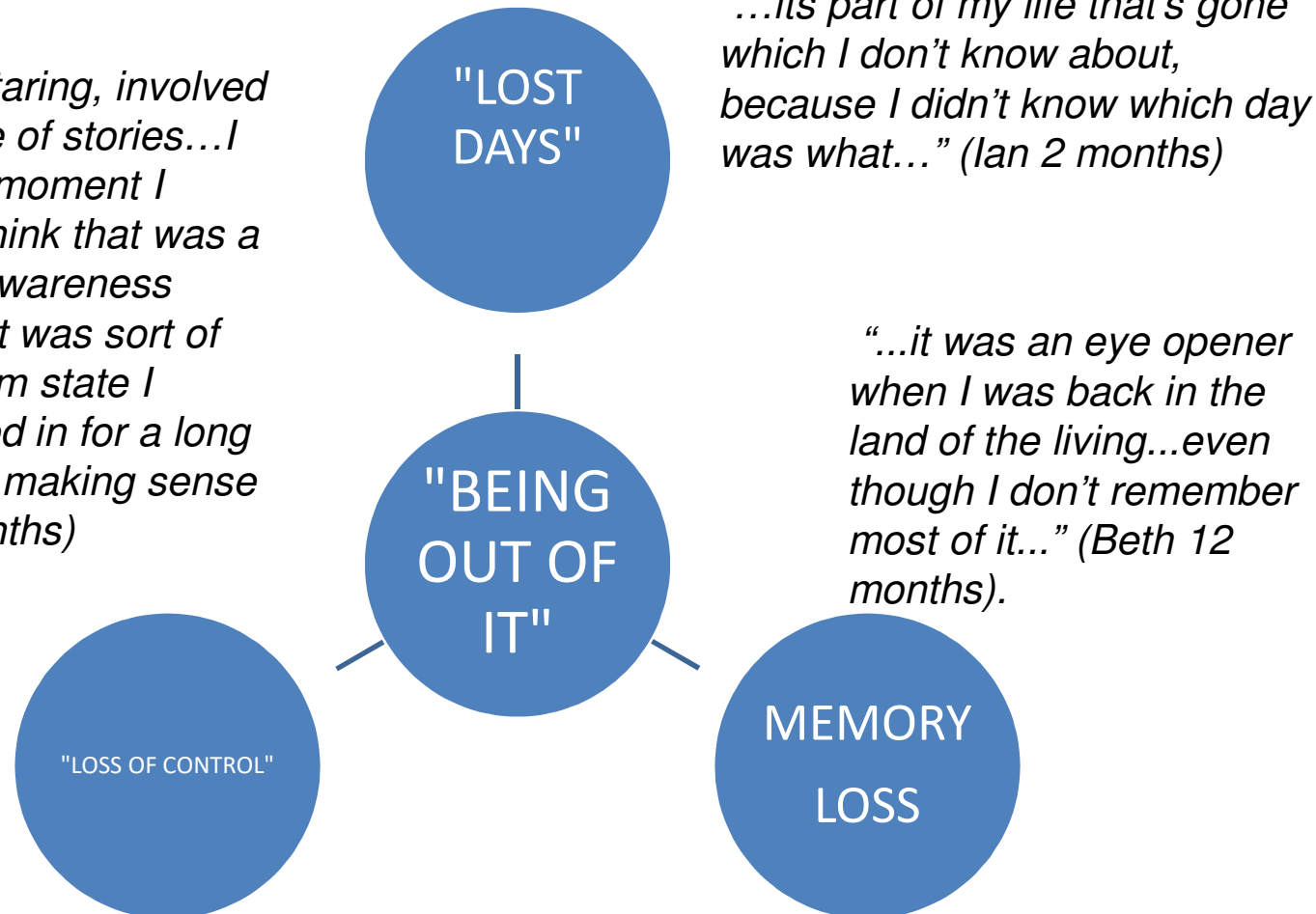
# Study objectives

- To critically explore participants':
  1. Experiences of critical illness and their ensuing recovery during the first 12 months.
  2. Use of their critical care diary (or not) including if, when, and how they used it and to elicit how diaries may be useful at different time points during their recovery and rehabilitation.
  3. Perceptions of diary content (type, breadth and depth), impact of this and role, if any, they felt their diary had for them during their recovery.
  4. Environmental and demographic factors that may impact on perceptions of the diary

*I was wide awake, staring, involved in this whole episode of stories...I don't remember the moment I actually woke up. I think that was a gradual process of awareness coming, but I know, it was sort of because of this dream state I suppose that I existed in for a long time. Things weren't making sense at all..." (Clara 2 months)*

*"It's not the first time I have done this for you, you know, washing me head to tail and well of course I didn't know who the hell he was, did I? It was my first time really awake." (Beth 12 months)*

## Study findings



# Study findings

*I suppose I don't really know how ill I was. Perhaps I haven't accepted that I was that ill, because I was out of it." (Graham 2 months)*

"MENTALLY  
WHAT A  
PATIENT HAS  
TO GO  
THROUGH"

*"...but I think it would have helped to have had something, don't get me wrong, the nurses are so busy...it's just routine, isn't it?...I don't think they realise mentally what a patient has to go through." (Emily 2 months)*

RECOVERY:  
"IS IT  
NORMAL TO  
FEEL LIKE  
THIS?"

*"I did feel...when I wasn't right as though I have been taken out of where I was and plonked in this end of life, because I am on the last lap now...that's how I felt...I just felt like I was trapped." (Fran 12 months)*

"REALISE  
HOW ILL I  
WAS"

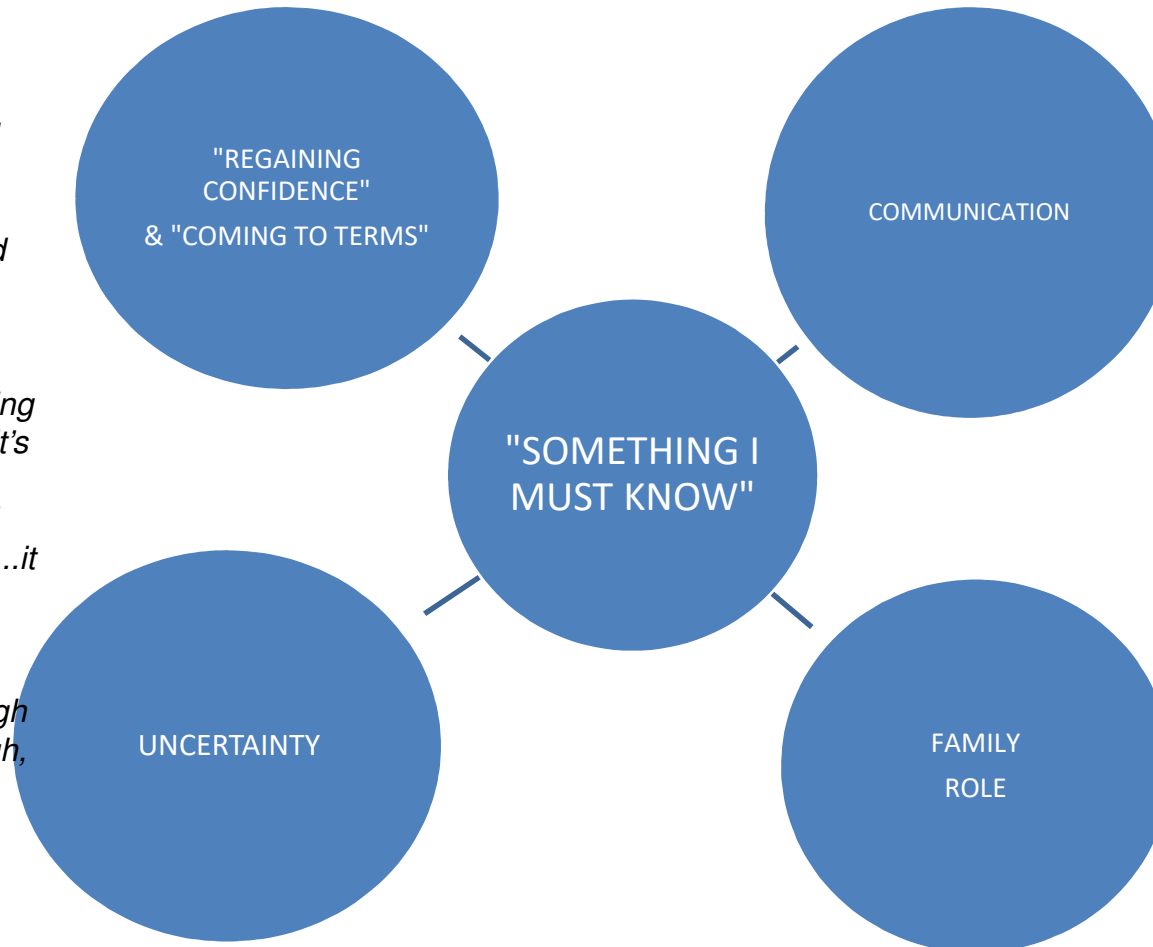
*"Anniversary"*

*Physically and mentally then I was fine, but my body had to catch up with it all." (Alice 6 months)*

RECOVERY &  
PROGRESS:  
"THE  
STRUGGLE"

# Study findings

*"but whether it could be something that a nurse or something that would come and see you from going into intensive care, coming out into the ward and maybe going through it, because it's not being taken in to hospital on a normal day to day thing is it...it was major and probably half the women in the ward didn't even go through what I'd gone through, but yet you was treated the same."  
(Emily 12 months)*



*"I literally couldn't move a thing and I think because that is a constant memory, there is part of me that's sort of thinks, when you come around someone needs to very quickly be able to say to somebody, this has happened to you. So don't panic now we will explain everything to you..." (Clara 2 months)*

*"because I have got my family and I have been able to talk it out with them and they've told me their opinions and things like that. So I have had all the support I've needed..." (Alice 12 months)*

# Study findings

*"They said read the diary a little at a time, but no I couldn't do that could I. So when I came home I sat in the front room and read the whole thing. I finished it. So maybe that was a bit of a mistake, because it was a bit of a shock. I didn't get upset, because I was out of it." (Beth 2 months)*

*"I can refer back to the days now, you know, when I was in there...telling me how bad I was and what the family was doing."(Alice 12 months)*

*"It's a piece of jigsaw I suppose and there is going to be pieces missing from that time, but I think it would be nice to look at what happened and when it happened and why it happened...that's the bit where the diary could help out...I suppose you do feel that you have lost that part of your life... So it would be nice to know what was going on... (Graham 2 months)*

THE DIARY  
PROCESS

*"Those two days that are missing. That was the one day that my grandson actually came in with my daughter. It doesn't say about him being there, as I say it's one of the days that was missing." (Alice 6 months)*

BENEFIT  
VERSUS  
HARM

"IT'S A  
PIECE OF  
JIGSAW"

CAPTURING WHAT  
HAPPENED

*"...they said I had pneumonia, but when my husband read on the internet, there are so many different types of pneumonia. I don't know what type I had. Will it come back again? Am I going to have weakness there? It would have been nice to have that explained to you." (Emily 2 months)*

CONSTRUCTING  
THE ILLNESS  
STORY

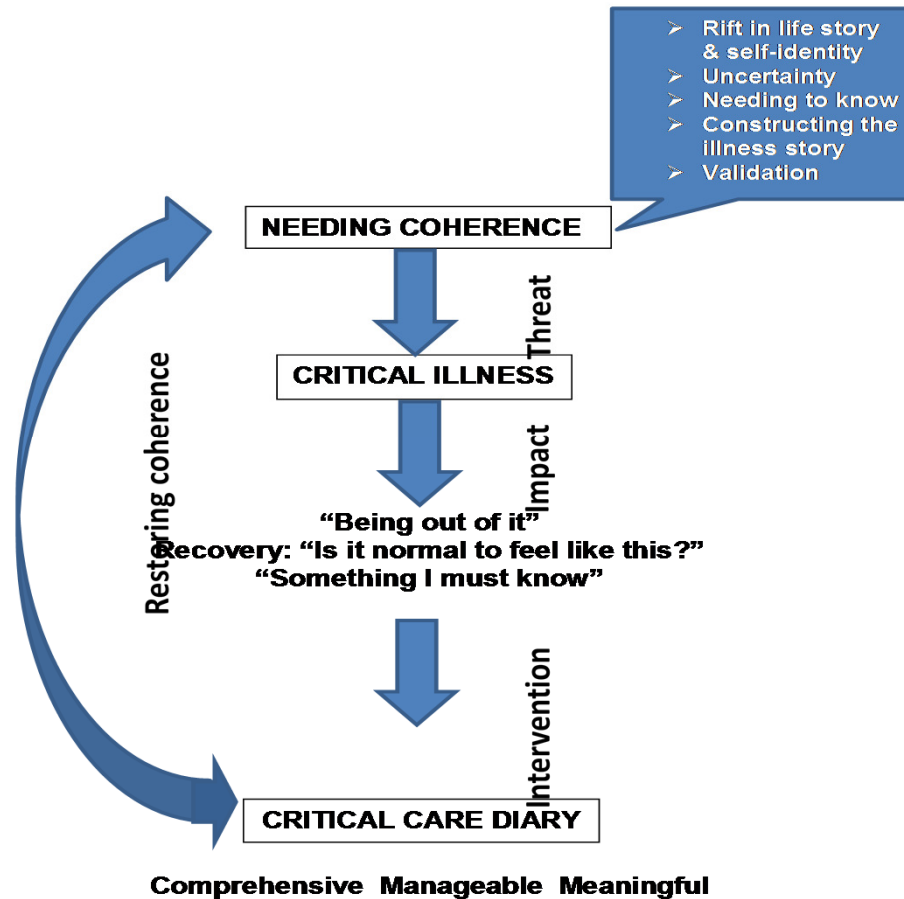
## Study findings

- *“...it is a journey and it’s a journey that’s continuing for me and you can’t sort of think right that’s over now...because it isn’t, when you have been through the trauma, major trauma, whatever you want to call it, there isn’t an end date with it, there is an acceptance of what you have been through...but you are never totally free of where you have been...life’s a journey anyway, but this has just been part of it. You know and the cliché, “what doesn’t kill you makes you stronger” is very true.” (Clara 12 months)*

Role the diary plays		
Comprehensibility	Manageability	Meaningfulness
Chronological	Answers & insight	Understanding & beliefs.
“Being out of it”; “lost days” and “memory loss”	Recovery: “Is it normal to feel like this?”	“Something I must know”
Regain control Confidence	Reality of illness Dates	Realistic about critical illness events & implications for recovery. Make sense & come to terms
When the diary is incomplete or does not say enough		
Loss of control persists	Overwhelmed with unanswered questions & uncertainty	Remain in a state of flux about what happened to them
Increased risk of psychological problems and reduced physical recovery		

# The emergent Grounded Theory

Theoretical model for a grounded theory of needing coherence: repairing the rift in life story and self-identity after critical illness





REASSURANCE, REPRESENT RELATIONSHIP AND TRUST	The way the diary is written matters. By using a personal approach it can demonstrate that they were cared for and treated as a human being. HCP's taking the time to write in the diary is valued by patients as showing commitment to their well-being and allows formation of a trusting nurse-patient relationship that was missing while the patient was unconscious.
CHRONOLOGICAL ACCOUNT OF MISSING TIME	There needs to be something written for each day, otherwise it can cause anxiety about what could not be said. The initial period of critical illness needs to be captured in some way, even if retrospectively as the initial few days may be the most life threatening and if this is not captured the mismatch between the diary and family portrayal can add to confusion.
CONFIRM OR VALIDATE ILLNESS	The diary needs to contain enough depth of detail to help the patient piece together key events or discussions that were held. It almost needs to reflect the salient points from the shift handovers. The diary plays an important role in validating or confirming how ill the patient actually was. By reading it they can gain acknowledgement and permission to feel the way they do during their recovery
MEANINGFUL CONTENT	The content of the diary is there to help the patient (in retrospect) feel part of something that happened to them. When writing entries the HCP needs to be mindful that the content will be used to form threads of the patients missing life story for that period of time so they can rebuild the coherence that they normally hold over their life.
LIFE STORY AND COHERENCE	The disruption to the normally intact notion of their life caused by critical illness is significant. Missing time is a vulnerability and a sense of loss of control is inevitable. Capturing enough detail to help form their own interpretation of events is important for peace of mind and moving forwards with recovery.
SELF-IDENTITY	The rebuilding of the missing storyline is important to the patients' sense of identity and well-being.

# Conclusions

- The original contribution to knowledge is in the provision of in-depth insight into critical care survivors' experiences of critical illness, recovery and use, or not, of their diary during this process.
- The theory that emerged is that humans seek coherence in their daily lives, but this is disrupted by critical illness. Restoring a sense of coherence to disrupted life and identity is important in the aftermath of critical illness and diaries, done well, have an important part to play.

- Aspiring to help patients' psychological well-being is a worthy position for nurses and other HCP's to hold.
- However providing a diary with lack of explanation or follow-up thereafter could have a detrimental impact.
- Therefore diary implementation requires strategic planning, education and preparation of those who wish to contribute. It also needs investment in follow-up provision.

Cheryl Phillips email: [cheryl.phillips@southwales.ac.uk](mailto:cheryl.phillips@southwales.ac.uk)

Thank you for listening  
**ANY QUESTIONS**

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