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# Constructing a grounded theory of the critical illness trajectory

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- Study aims & research questions
- Constructivist Grounded Theory method
- Ethical approval
- Coding & Atlas ti™ (initial, focus & selective codes)
- Findings
- Constructing mid range theory
- Discussion & conclusion



## Aims of the study

- To formulate a mid range theory in relation to patient and family's critical illness trajectory.
- (To discern and understand the response of nurses to survivorship needs in an adult critical care setting.)

## Research questions

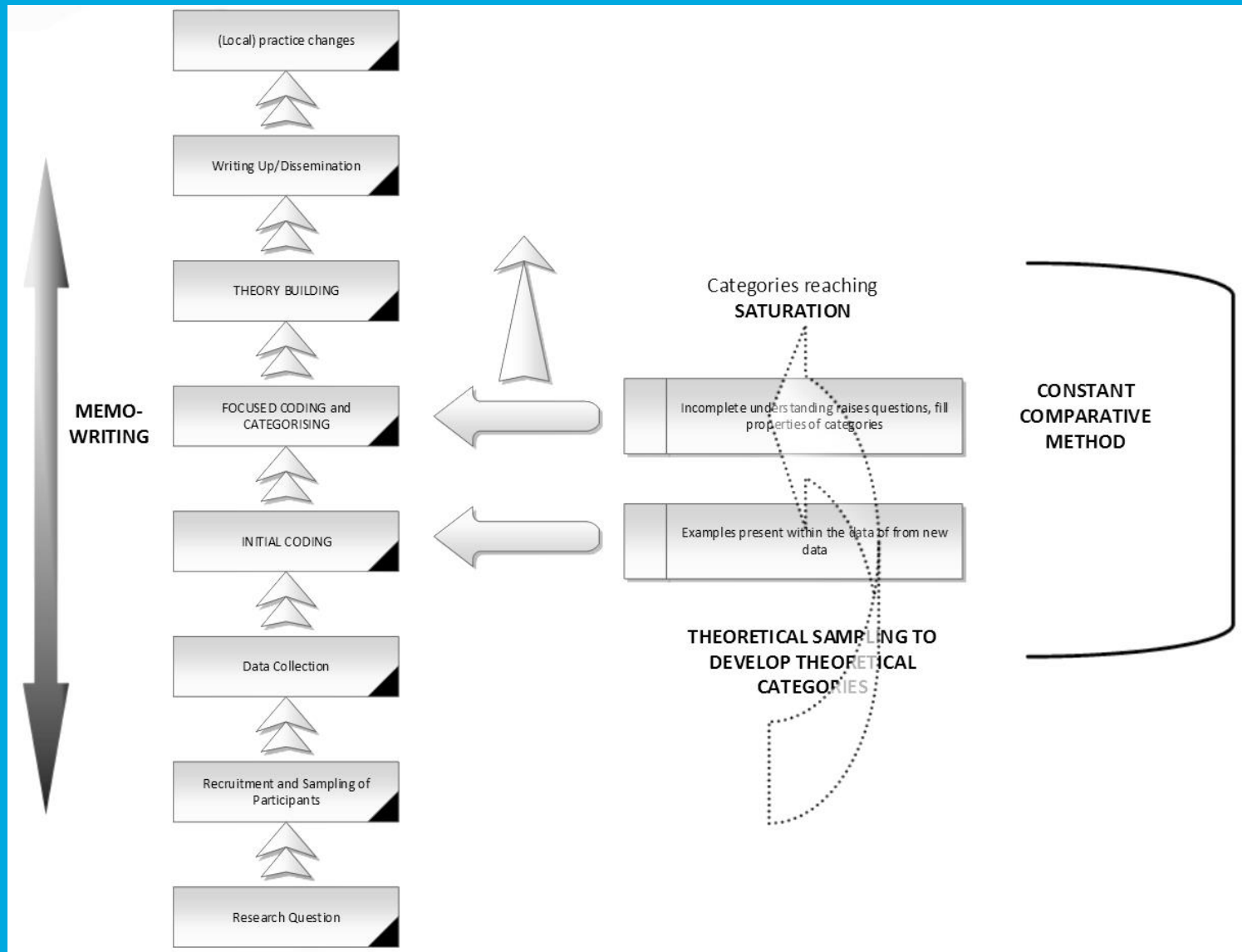
- How do patients and family members experience their critical illness trajectory?
- (How do RNs in critical care respond to the survivorship needs of patients and family members?)



## Drivers for the Study

A 35 year old professional women involved in a road traffic collision survived a prolonged stay including readmission to Critical Care. She describes the experience of surviving critical illness:

*"Emaciated, frail and unable to wash or dress myself I was discharged from hospital to the care of my parents. For those around me, leaving hospital was a milestone, a confirmation that I had survived. For me, it was a moment I had to face the skeleton in the mirror, an imposter masquerading as me. Where was the real me? Would I ever be me again? In my childhood bedroom, I sobbed silent tears. I had survived, but which part of me?"*





- IRAS approval gained via proportionate review (13/LO/0798)
- R&D approval gained at NHS Trust (R&D 936)
- 16 patient interviews, open to semi-structured
- 15 relative interviews (10 with patients), open to semi-structured
- (11 staff RNs interviews, semi-structured)



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# PIS, Consent, GP letter



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GP Address  
REC no[13/LO/0798]

Dear Dr. ....

Re:- A qualitative

I am writing to inform you of  
my experience as a patient with  
Essex Hospitals NHS Trust.

This interview is part of a  
critical care study. The study is  
being conducted at City University  
London.

**Who is organising the**  
Pamela Page is the principal  
researcher. The study will form part of  
a PhD thesis.

**Contact for further information**



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24<sup>th</sup> April 2013

## Participant Information Sheet for Patients

### A qualitative appraisal of visiting within adult critical care units.

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If there is anything you are not clear about or would like more information please feel free to contact **Pamela Page** (contact details overleaf).

#### **What is the purpose of the study?**

Patients admitted to Critical Care are extremely unwell. Given that the nurse-patient relationship has a central role in the care of patients, it is important that the concerns and needs of patients and families are recognised and addressed. Patients have a unique point of view of their experiences and it is hoped that by asking you directly, and listening to your experiences of being in critical care, we will get information and understanding that we may not otherwise have known. Discovering what issues were important to you will provide a better understanding of the situation so that relevant interventions might be taken by health care professionals to identify and address the needs of patients and their families within critical care.

**Do I have to take part?** Your participation in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep. You are under no pressure to take part and may withdraw from the study at any time without having to explain why. In the event you choose to withdraw, your interview data will be deleted. If you choose not to participate this will not influence the care you will receive.

#### **What will happen to me if I take part?**

If you agree to take part in the study, you will be interviewed about your experiences of in critical care.



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## CONSENT FORM for Patient

REC Reference Number: [13/LO/0798]

Title of Project: A qualitative appraisal of visiting within adult critical care units.

Please initial box

Information sheet dated 24<sup>th</sup> April  
I have read and understood the  
information and I am free to ask questions.

I understand that I am free to withdraw at  
any time without affecting my clinical care or legal rights

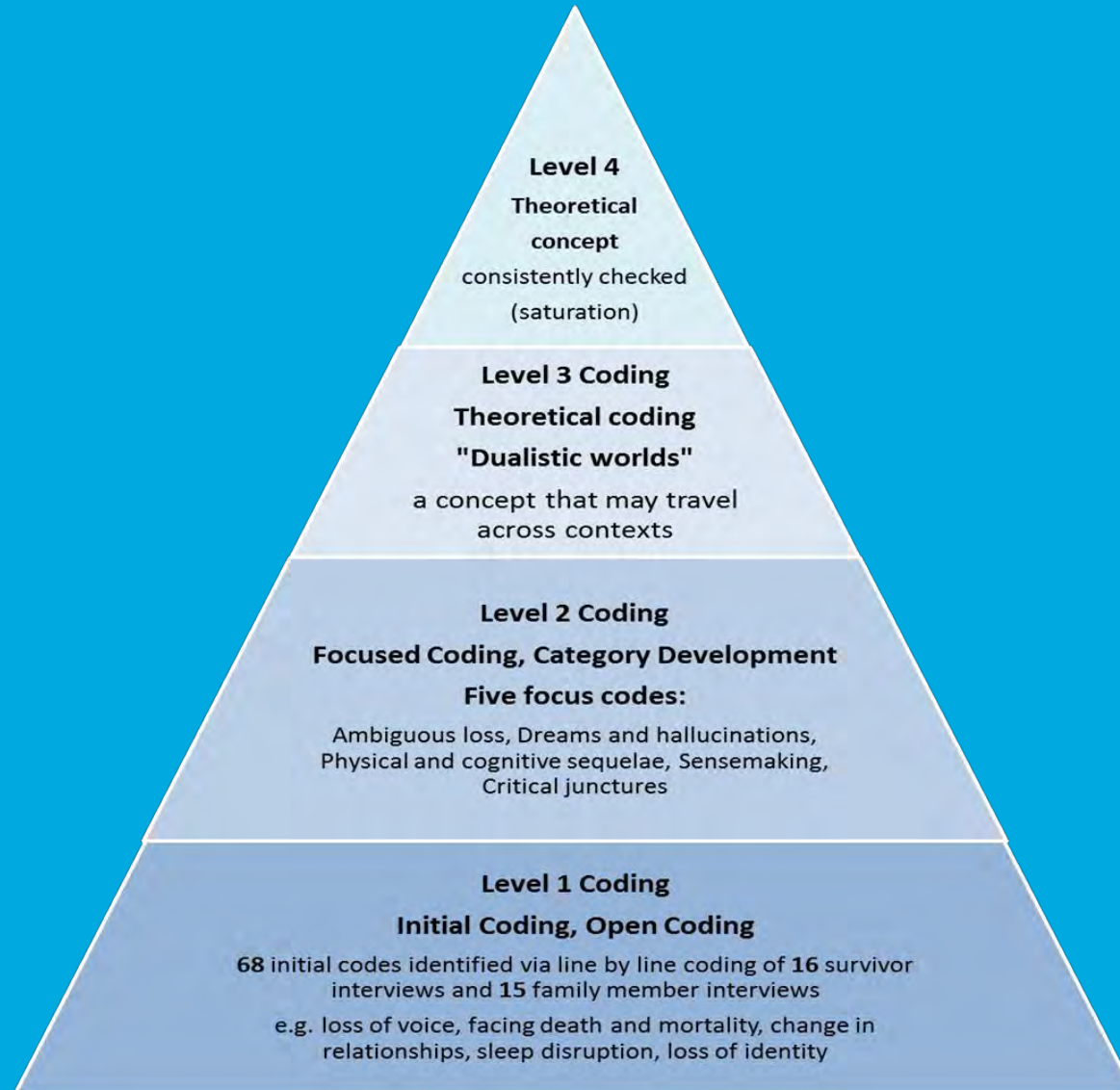
I have agreed to take part in the research.

I understand that my data may be looked at by  
other research groups or from the  
research. I give my consent to the  
use of my data.

I understand that my data will be used within the PhD thesis,



# Progressive Coding Construction







# Ambiguous loss

**Andy** *"I couldn't communicate with anybody, literally I'd basically vegetated" "When I finally did try and move it was more like going back to a baby"*

**Jane** *"I'm just not the person I was, I've got no patience with anybody. I don't like myself for that, I really dislike myself".*

Torpie (2014) speaks of loss of reality and identity *"I had lost not only my physical sense of myself – my vitality, mobility and appearance –but with it my way of relating to the world around me. I'd lost everything I ever held to be 'real', everything that who and how I am in the world had previously been based on. I had no idea how I would continue to function in a world with any authenticity without that to guide me".*



**Literature indicates delirium prevalence up to 83% of ventilated patients (Ely 2015)**

**Linda** *"I was convinced they were trying to kill me....fear they were trying to unplug my machinery"*

**Charles** *" I had very nasty, very nasty hallucinations, I was a drug runner, I was a booze runner, I was involved in money laundering.....is that odd? Is it me that's odd?"*

**Alan** *"I was convinced she was trying to kill me and as I say, it was really, really vivid, and it went on, it wasn't just sort of like a one off thing, it went on for days, ....and I was convinced, because I think one day I actually hit one of the nurses because I thought she was joining in,*



# Physical Debilitation

**Magnitude of debilitation post critical illness underestimated (Misak 2014, Kean 2013). Fatigue & weakness significant problems (Rattray 2013). Muscle wastage has been estimated at 2-4%/day during critical illness. All patients interviewed were unaware of this and couldn't understand their physical weakness.**

**Richard** *"I found it difficult to even pick up a cup of tea, and that's why I thought it was wrong to actually be sent home..."*

**Alan** *"my wife brought my Kindle in so I could read, I couldn't even turn it on. It took me about half an hour to turn it on by which time I was exhausted so I just turned it back off again, you know? I was so feeble, it was crazy."*

**Judith** *"I felt really, really weak when I was in the Unit and I was amazed how in four days how weak one can become and I found it difficult lifting a plastic cup half full of water...I was shaking"*

**Several patients spoke of hair and nail loss, substantial weight loss, change in taste, as well as lack of concentration, disrupted sleep patterns.**



# Psychological Sequelae

Some showed signs of depression and anxiety:

**Charles** *"I just felt life was a bit worthless" "..there were a couple of times when I was thinking, how can I die? I was thinking, how can I commit suicide without hurting myself too much"*

**Annie** *"it feels like pre-hospital everything was OK, post-hospital, even though I am here, thank God, I'm not as good as what I was and I can't do what I can't do – and it's awful to know I can't do it". "Everything is an effort .."*

**Jane** *"I do get very stressed and worried and....not in control". "People think, oh, you should be happy because you're alive. It doesn't quite work like that, you know, it doesn't."*



# Critical Junctures of Care

- Admission to critical care
- Transfer to ward
- Discharge home

## **Paranoid delusion often continued on discharge to the ward**

**Linda** *"I was in danger and that wasn't really very nice at all, it really wasn't"  
"I was too frightened to go to sleep on the ward..."*

## **The step down in dependency was frequently too great;-**

**Jane** *"I think there wasn't the same care.. I couldn't wait to get out of X ward..  
Maybe I shouldn't .. I am going to say it, I thought people on X ward were  
really bad, I mean there were other people in there that were ill pressing their  
buzzers and you could hear nurses laughing and joking, they didn't come..." "I  
was very frightened on X ward...once my catheter came out I had to keep  
ringing for the bell to go...feeling so, so dependent...like I think all my dignity  
went out of the window..."*



# Theoretical Sampling

Whilst recognising the individual experiences that survivors and family members feel and encounter, one constructed, abductive theory is that survivors of critical illness experience '*dualistic worlds*' alongside their family member. In addition the survivor may experience an internal *dualistic world* where a self-contained separate reality co-exists with one's own.

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

*"People don't understand...people can't understand. Though they've seen me go through it they can't understand what it is like to go through it..."* Annie

*"In a way I suppose that was a worse nightmare for them two (partner and daughter), than it was for me, because I didn't know too much, did I? It was a nightmare for me trying to get better because it was hard but that must have been a terrible nightmare for the family....**Two different nightmares**".* Sharon



# Scaling up theory

- Supporting theoretical lens –anthropological theory of liminality.
- Reflects the ambiguity and uncertainty of living '*betwixt and between*' different worlds (Blows et al 2012)
- Connectedness Vs disconnectedness
- Critical illness causes relational disruption
- Leading to *dualistic worlds*



# Middle Range Theory

- Evidence that relatives and survivors experience two different versions of the patient's critical illness.
- *Dualistic worlds* (between patient and relative experience) an abstract, explanatory concept that seeks to elucidate the critical illness trajectory.

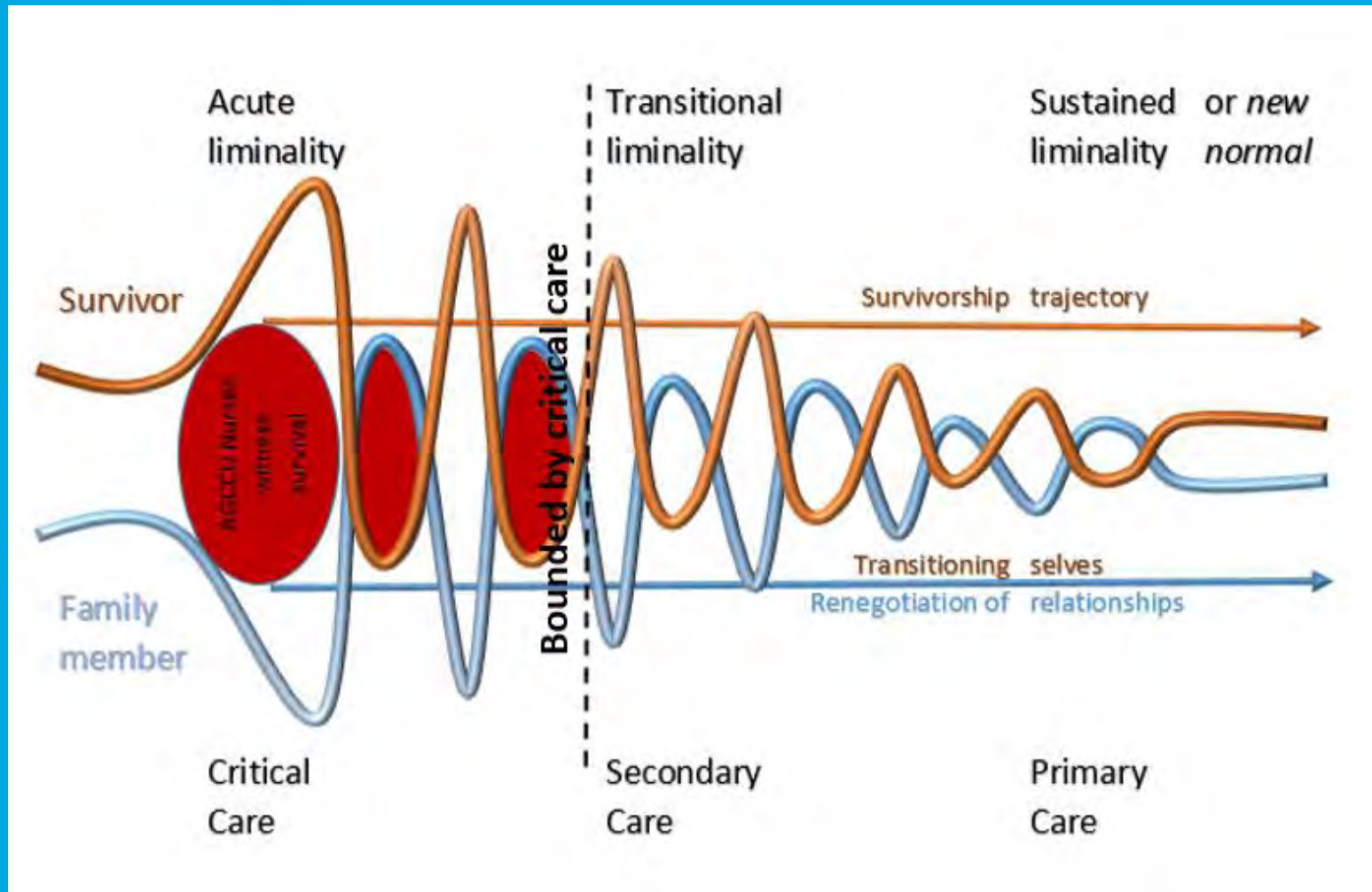
*"I think the hardest thing is accepting what will become the **new normal** which can be very difficult to come to terms with in the early days after ICU, in the beginning family and friends are there to support you but often slowly drift away never really understanding how traumatic a life threatening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





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# Dualistic Worlds – mid range theory





- Survivorship – the concept of moving from surviving to thriving is new within adult critical care and considered the greatest challenge for C21st critical care (Hart 2014, Kean et al 2017).
- Critical care medicine can, and does save lives but has to date, failed to understand the consequential effects on individuals and in particular how people ‘live’ (Oakey 2007 p 149) in their bodies.

*“You must decide what that life will be like. It will be different from before the ICU, because you are different. The people who care about you may not understand, but that’s OK. The only way to really understand it is to have lived through it”. (David PR05)*



# References

Blows E., Bird L., Seymour J., Cox K., 2012 Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *Journal of Advanced Nursing*, 2155-2164

Charmaz K., 2014 *Constructing Grounded Theory* (2nd Ed) SAGE.

Hart, N., 2014. *Therapeutic and Rehabilitation Strategies in the ICU*. In: R. Stevens, N. Hart and M. Herridge, eds. 2014. *Textbook of Post-ICU Medicine: The Legacy of Critical Care*. Oxford: Oxford University Press. Part 6, Ch. 37. pp. 419-420.

Kean S., 2013 Surviving Critical illness: Intensive Care and Beyond. *Journal of Clinical Nursing*, 23, 603-604

Kean, S., Salisbury, L. G., Rattray, J., Walsh, T. S., Huby, G. and Ramsay, P. 2017, 'Intensive care unit survivorship' – a constructivist grounded theory of surviving critical illness. *Journal Clinical Nursing*. doi:10.1111/jocn.13659

Misak, C., 2014. *Survival and Recovery: A Patient's Perspective*. In: R. Stevens, N. Hart and M. Herridge, eds. 2014. *Textbook of Post-ICU Medicine: The Legacy of Critical Care*. Oxford: Oxford University Press. Part 1, Ch. 10, pp.123-129.

Rattray J., 2013 Life after critical illness; an overview. *Journal of Clinical Nursing*, 23, 623-633.

Torpie, K.A. 2014, *Losing face : a memoir of lost identity and self-discovery*, 2nd edition. Auckland NZ : Huntingtree Press.