LA TROBE UNIVERSITY

Heightened Emotional Vulnerability and Regaining Control: A Grounded Theory of Family Resilience in an Australian ICU

Pauline Wong

PhD candidate
School of Psychology & Public Health
College of Science, Health & Engineering
La Trobe University, Melbourne, Australia
20 September 2016

latrobe.edu.au

CRICOS Provider 00115M

Acknowledgements

Family participants

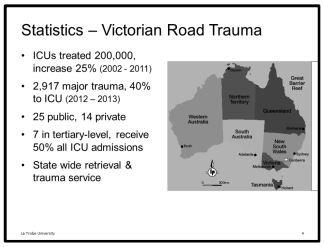
Social workers and Registered nurses

Supervisors

- Professor Pranee Liamputtong
  Western Sydney University
- Dr Helen Rawson
  Deakin University
- Associate Professor Susan Koch
  La Trobe University, University of Sydney, RDNS Institute

Overview

Setting the scene
Background and significance
Research aims
Methods
Findings
Recommendations for clinical practice



- Victoria - state situated in the south-eastern part of Australia
- Geographically - smallest state on the country's mainland
- Victoria and UK are about the same size (UK: 244.101 km² cf. Victoria: 237.629 km²)

- Australia's population is 24 million – 3 per km^2 Victoria's population is one quarter at almost 6 million (UK 65 million – 266 per km^2)
- Most densely populated state in Australia - 25 per km^2.
- Continues to have fastest population growth rate.

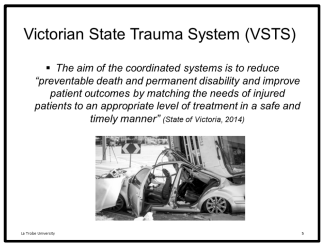
- Over 10-year period from 2002 to 2011, Victorian ICUs treated almost 200,000 patients, with average increase in admissions of 25 per cent over that time (State of Victoria, 2014a).

- 2012−2013: almost 3,000 (2917) patients admitted to hospital with major trauma and 40 per cent of these were admitted to ICU

- There are 25 public ICUs across Victoria and 14 in private health sector

- Of public ICUs, 7 located in tertiary-level hospitals and receive 50 per cent of all ICU admissions

- ICUs in Victoria are also part of a state-wide retrieval and trauma service that ensures the optimal management of critically ill patients regardless of their location.



The aim of VSTS

- to coordinate triage and transfer of patients who have sustained major trauma
- to ensure right patient delivered to right hospital in shortest time

- The VSTS has designated **two adult hospitals and one paediatric hospital as the states major trauma services (MTS) operating as the hub of the integrated system**

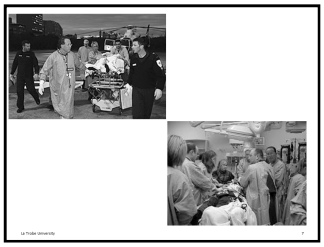
EMERGENCY ROAD TRANSPORT FEES* All users

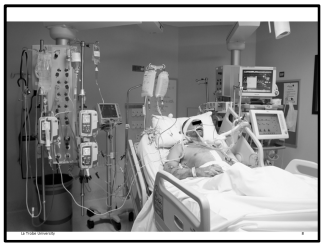
- Metropolitan Emergency Road $1,174
- Regional and Rural Emergency Road $1,732

AIR TRANSPORT FEES

- **Fixed wing** $2,816
- **Rotary** Fixed charge $23,842

Swap hats.





- When you are allowed to go in to ICU to see your loved one for the first time you are confronted by this scenario?
- As a family member, how would you be feeling?
- How could staff help you through this potentially traumatic experience?
- What would your role as a family member in the ICU be?

Role of family in ICU

- Patients suffer emotionally and psychologically
    - Patients: 50-87% anxiety, 50% delirium
    - Delirium - increased LOS, morbidity, mortality, prolonged weaning mechanical ventilation.
- Families provide emotional/psychosocial support:
    - Orientate patient
    - Familiar/caring presence
    - Reduce uncertainty, fear, anxiety associated with ICU.
- Valuable resource for pt care – staff know patient better through family
    - Sharing information - normal emotional/behavioural characteristics, smoking /alcohol use, medication history
    - Contribute to improving patient's health outcomes

Psychological impact of being family member in ICU

- Families ***also*** experience emotional burden – anxiety/depression.
- Similar levels of emotional distress as patient
- Task force SCCM PICS-F (anxiety, depression, ASD, PTSD, complicated grief) = group of adverse psychological complications attributed to the ICU experience
- Impact - ability to make decisions, process information, cope with situation and provide support to their relative.

Patient- and Family-centred care

- Philosophical model of care = family + patient
- Widely accepted in paediatric ICU settings.
- Although evidence to support FCC in adult ICU, most adult units in Australia and internationally do not integrate the family as the unit of care.

Family needs (CCFNI) and Family experiences

- Healthcare professionals – underestimate needs family considers important - information, emotional support, proximity to patient.
- Therefore, needs often go unmet.

Although we know families need information and uncertainty causes anxiety:

- Limited understanding of
    - nature of uncertainty and interventions, perceived by families to reduce uncertainty (beyond the provision of information)
    - families interactions more broadly in ICU - the environment, other staff (doctors, non health professionals), other family members, critically ill relative and families of other patients.
- A lack of theoretical frameworks to guide practice in this area may be a barrier to improving family-centred care in adult ICU.

Qualitative design – Constructivist grounded theory

Recruitment

•A third party recruitment process) to protect privacy of families and their critically ill relatives.

• Social workers and RNs

Participants

•25 participants of 21 critically ill patients

•diverse range of relationships to patient - spouses, parents, siblings, adult children.

Setting

•Tertiary-level ICU in Victoria.

Data collection

•In-depth interviews

Data analysis

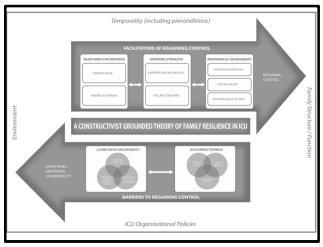
•Initial, focused and theoretical coding characteristic of grounded theory method

•Nvivo software – manage/store the data.

Ethics

IEC and UHEC

•governance authorisation - wide range of department heads across the health service organisational hierarchy



- Represents journey from: time informed of relative's critical condition to time ready for discharge

- Journey unique - diverse interactions with: environment; ICU staff, other families, their own family members and their critically ill relative.

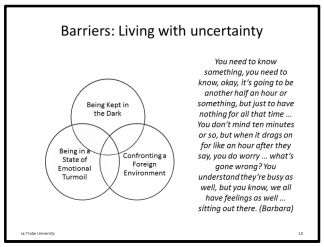
- Common experiences, interactions and emotional responses that signpost their journeys, represented by categories and themes that comprise my GT

- Contextual influences on their experiences: temporality (incl preconditional factors), environment, family structure/function, ICU policies

- Core category – Regaining control

- Four major categories: Heightened emotional vulnerability, Searching for Meaning, Drawing strength, Meaningful engagement

- Categories/themes represent barriers /facilitators to families' ability to regain control.



- Three major themes

- Each theme directly influenced nature of uncertainty - not mutually exclusive.

- Further understanding of uncertainty gained from interrelationships between themes.

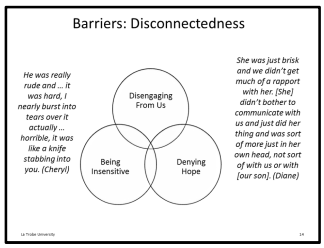
    - ***emotional turmoil***, (so overwhelmed with emotion) - unable to process information provided by staff. Perception of ***being kept in the dark***

    - Similarly, when ***kept in the dark*** if communication closed, added to ***emotional turmoil*** and their uncertainty.

    - ***Keeping them in the dark*** eg. failing to explain the technology added to ***uncertainty about their environment***.

Example

- Staff closed communication - tendency to imagine a scenario much worse than reality = added to their emotional burden



Disconnectedness = families' perception that staff failed to provide emotional support and in some cases caused further emotional distress.

- The themes are: disengaging from us etc.

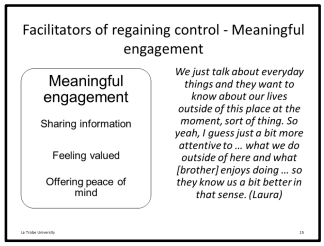
- Each theme directly contributed to families' perceptions of experiencing *Disconnectedness*.

- However, interrelationships between themes also identified.

- Eg. Families described staff that were ***disengaging*** as 'cold', 'clinical', 'aloof', but they were also perceived as ***insensitive***.

Example

- Cheryl's situation - elderly mother admitted following a MCA and doctors had planned to take her to theatre for eye operation.
- Cheryl concerned about operation, questioned doctor about whether it was too soon.
- The doctor responded in a condescending manner by looking her up and down, asking her who she was and what qualifications did she have?



- **Meaningful staff engagement** facilitated families ability move beyond their emotional vulnerability to regain control.

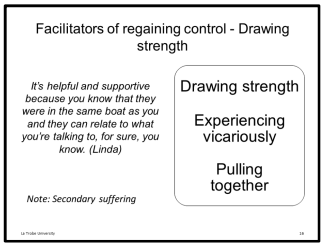
- Represented interactions - staff connected with families through information-sharing, making them feel valued and offering peace of mind.

- Strong SOC - necessary characteristic of resilient families in literature

- SOC applied to explain certain aspects of my framework.

- When families meaningfully engaged by sharing information that was clear and unambiguous – supported strong SOC

- Also when staff built rapport by learning families' personal details and interests families felt valued connection with staff.

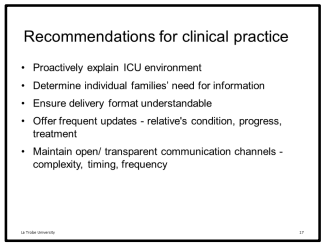


- Represents families interactions with families of other patients and with their own family members.

- A major finding in this study is a more in-depth understanding of interactions with families of other pts in ICU but limited in previous research.

- Families experienced vicariously due to prolonged periods of time in small confined space of waiting room.
- Drew strength from each other - validated each other's feelings/ concerns.
- Informational support - explaining procedures/ aspects of ICU they had already experienced

- IMPORTANT NOTE: NOT ALL families welcomed interactions with others:
- Some felt it caused further emotional burden – 'secondary suffering'
- Others had enough of their own stress and didn't want to deal with additional stress of other families.



- Staff should proactively explain the foreign nature of the ICU environment, including purpose and function of technology, to families.

- Staff should determine individual families' need for information and ensure it is delivered in a format they can readily interpret and understand.

- Staff should continue to offer frequent updates of their relative's condition, progress and treatment especially 24-72 hours

- Staff should maintain open and transparent communication channels and use language that families can comprehend, with consideration for the complexity, timing and frequency of the information provided.

Thank you

Email contact: p.wong@latrobe.edu.au

latrobe.edu.au

CRICOS Provider 00115M

Points for discussion

Translating these findings into clinical practice.

What might some of the barriers and enablers be?

Do these findings resonate with clinical practice in your workplace?