

THE EXPERIENCE OF COMMUNICATION DIFFICULTIES IN CRITICAL ILLNESS SURVIVORS IN AND BEYOND ICU - Findings from a larger phenomenological study

Agness C Tembo PhD, MSc, RM, RN. Conjoint Lecturer The University of Newcastle, Faculty of Health and Medicine. School of Nursing and Midwifery, Callaghan campus. NSW 2287, Australia



PRESENTATION OUTLINE

- Background
- Aim/Objective of Study
- Methodology
- Methods and Design
- Findings
- Discussion /Conclusion



BACKGROUND



- In the Cartesian driven technologically advanced animated Intensive Care Units (ICU) coupled with practice innovations the quest to improve patients' physical outcomes and efficiency, patients can be objectified and become invisible.
 - the patient is broken into biochemical and anatomical components as opposed to a whole person with existential needs.

BACKGROUND CONT'D



- Studies that have examined the impact of technology and ventilation for patients have demonstrated the distressing nature of being ventilated, either through an endotracheal tube (ETT) or tracheostomy.
- The distress is associated largely with the inability to speak and communicate effectively with staff and family.
- In addition, communication difficulties are related to feelings of powerlessness and vulnerability resulting in frustration, anxiety and possibly delirium (Happ, 2001).
- Compounding factors have been linked to nurses' busyness and inability to lip read, patients' personality and inability to write (ibid).

BACKGROUND... CONT'D



- Although Daily Sedation Interruption (DSI) has been associated with better physical outcomes, the meaning the patients attach to their experience in ICU has not been explored extensively.
- This presentation discusses communication difficulties as one of the major findings from a larger study which was conducted from an ICU in a rural referral hospital in Australia.



AIM / OBJECTIVES OF STUDY

The aim was to describe the experience of critical illness in ICU and beyond in the context of daily sedation interruption (DSI).

Objectives were to:

- Gain an understanding of the critical illness in ICU and beyond in the context of DSI which can lead to praxis in ICU practice.
- To establish if DSI has improved the experience of critical illness in ICU and beyond.

METHODOLOGY

- > Hermeneutic phenomenology was used to conduct the study.
 - > The question was: "What was it like to be critically ill in ICU and beyond?"
 - > In-depth face to face interviews two weeks then 6 -11 months
- > Selection Criteria
 - > 12 men and women: 20 76 years of age
 - Mechanically ventilated for > 24 hours
 - > Must have undergone DSI
 - > English speaking able to give informed consent
 - Not cognitively impaired





METHODS AND DESIGN

- Ethical approval 2007
- Data collection- interviews where audio recorded and transcribed verbatim
- > Analysis
 - Thematic highlighting based on Van Manen's (1990) six dynamic interplay activities was used.

FINDINGS



- Being in limbo was the overarching theme
- Under the Overarching theme were the following major themes:
 - Being imprisoned
 - > Being voiceless
 - being trapped and
 - > waiting for the familiar and reliable voice.

Being Imprisoned



Being imprisoned was associated with the verbal and physical restriction patients suffered while they were in ICU.

"But that tube in my throat that was shocking. I can still feel it at the back of my throat although it's not there now, I could still feel it there, but even just the thought of it...//...I couldn't talk and I couldn't move ...//...they had tied my arms to the bed...//...It was like a prison very scary"

(Monika 1st Int.)

Being Imprisoned...cont'd



Some participants were frightened to discover themselves in ICU without a voice to ask questions

"When I went to talk...I just couldn't talk. And I thought, 'what's happened to my throat,' like it is like someone's taken your voice off you. And that was the frightening part because I couldn't relate to anybody. When I went to write, I couldn't my hands were too weak I could only scribble...pretty frightening, because the questions you want to ask: what happened? What happened to me? What am I doing here? How did I get here?" (George 1st Int.)



Being Voiceless

Being voiceless represents the failure to communicate their feelings and intentions both to their family and medical staff

Being voiceless was associated with severance from the lived other; being annoyed and frustrated by the inability to communicate while others felt isolated.

"I couldn't talk, which was unfortunate, I had no voice and was just you know, what I wanted, trying to get my feelings across, but it was difficult. I knew what they were saying, but I couldn't respond, body movements and gestures... It was difficult. Knew what the daughter was saying: knew what the wife was saying, but it didn't mean a great deal to me because I couldn't respond in any way ... I was very frustrated."

(Keith 1st Int.)

Being Voiceless.. Cont'd



In addition, losing the voice was tantamount to losing control and being powerless and being subject to the ICU staff who had saved their life:

"They had that tube down my throat...//...I could not express myself...//... I guess you're at their mercy because they've got you plugged into all their equipment and they've just saved your life so you've got to do as you're told. "

(lan)



Being Trapped

Being trapped describes the way the participants felt about being in a body the could not talk properly after their ICU discharge. Their voice had become unreliable.

"Now and then my voice goes and I get very hoarse. ..//.. I can go alright but if I talk too much, my voice starts to go very croaky ..//.. But my voice has never really come back really clear. That's really hoarse type thing ..//.. It is strange."

(George 1st Int.)

Waiting for the familiar and reliable voice



Waiting for the familiar and reliable voice elucidates the participants' uncertainty and anticipation for their normal voice to return. They found being with a different voice strange.

"I am still waiting ... Now and then my voice goes and I get very hoarse. ... I can go alright but if I talk too much, my voice starts to go very croaky ... But my voice has never really come back really clear. That's really hoarse type thing ... It is strange."

(George 1st Int.)

Waiting for the familiar and reliable voice...Cont'd



Some participants called the process of waiting as being in limbo because they did not know when the waiting would end.

"So there we are-in limbo. Oh, it is annoying. You 're talking softly and people can't understand or hear you. You've got to sort of repeat yourself and you know that it's not your normal voice and I'll get that one day. They say its three to four months (oh God!) but it is so annoying for yourself because you haven't got your normal voice; you can't talk normal to people and they can't understand you a lot of the times ... That makes you become frustrated... Give me time. I'll talk properly, one day//Hopefully, one day too. I'll be free."

(Keith 1st Int.)

DISCUSSION/CONCLUSION



- Communication difficulties continue to affect patients up to eleven months after ICU hospitalisation.
- This leaves the people with a loss of identity and feelings of being in limbo not knowing when their voice will come back.
- This calls for further qualitative research into the experience of communication difficulties after ICU hospitalisation.
- It is hoped that it has challenged clinicians to treat patients as individuals with unique and ongoing needs resulting from their critical illness and ICU hospitalization (Tembo, 2012; Tembo et al., 2012).

REFERENCES



- Almerud-Österberg, S. (2010) Visualism and technification—The patient behind the screen. International Journal of Qualitative Studies on Health and Well-Being, 5, 5223.
- Caroll, S.M. (2007) Silent, slow life world: The communication experience of non-vocal ventilated patients. *Qualitative Health Research*, 17, 1165-1177. doi:10.1177/1049732307307334
- 3. S675. doi:10.1097/CCM.0b013e3181f203aa
- 4. Happ, M.B., Harrington, C. and Kluger, M. (2006) Non-speaking older adults in the ICU. *American Journal of Nursing*, 106, 30.
- 5. Happ, M.B., Garrett, K., DiVirgilio, D., Thomas, M., Tate, J., George, E., *et al.* (2011) Nurse-patient communication interactions in the intensive care unit. *American Journal* of Critical Care, 20, e28-e40. <u>http://www.ajcconline.org</u>, *Accessedon12/04/2011*
- 6. Khan, J.M., Benson, N.M., Appleby, D., Carson, S.S. and Iwashyna, T.J. (2010) Longterm acute care hospital utilisation after critical illness. *Journal of the American Medical Association*, 303, 2253-2259. <u>doi:10.1001/jama.2010.761</u>
- 7. <u>Tembo, A. C.</u> (2012) Being in Limbo: The experience of critical illness in ICU and Beyond. PhD Thesis. The University of Newcastle, Australia.



QUESTIONS

?