BEING IN LIMBO: THE EXPERIENCE OF CRITICAL ILLNESS IN INTENSIVE CARE AND BEYOND

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A thesis presented in fulfilment of the requirements for the Degree of Doctor of Philosophy in Nursing

The University of Newcastle, Australia
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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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This thesis is dedicated to the memory of my dearest father, John Chisanga, whose love and trust kept me focused on my goal.

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ABSTRACT

Daily sedation interruption (DSI) has been associated with improved physical outcomes such as short ventilator, intensive care unit (ICU) stay and increased number of survivors. To date, only one cohort study has investigated the long-term effects of DSI on critical illness and ICU survivors. However, numerous studies have argued that many survivors continue to suffer from the effects of their critical illness and the ICU treatment. There are no qualitative studies that have examined the experience of critical illness in ICU and beyond in the context of DSI and the meaning the patients attach to their experience.

The purpose of this study was to describe the lived experience of people who experienced critical illness in ICU and following discharge. The research question for the study asked: What is the experience of critical illness in ICU and how does it affect people's lives after discharge? Phenomenology was used as the methodological approach to this study. Participants aged between 20 and 76 years with an ICU stay ranging from 3 to 36 days were recruited from a 16 bed ICU in a large regional referral hospital in NSW, Australia. Participants were intubated and mechanically ventilated with DSI during their critical illness in ICU. In-depth face to face interviews with twelve participants were conducted at two weeks after discharge from ICU. A second interview was conducted with eight participants six to eleven months following the first interview. Interviews were audio taped and transcribed. Thematic analysis was conducted using van Manen’s six dynamic interplay activities. The main theme to emerge from the study was ‘being in limbo’. ‘Being disrupted’; ‘being imprisoned’ and ‘being trapped’ comprise the main subthemes of the study.

The findings of this study have the potential to increase understanding of the experiences of people during and following critical illness by nurses and other health care professionals. The experiences of the participants in this study suggest the use of DSI, considered an innovation in the treatment of critically ill patients with improved physiological outcomes, may not improve lived experiences of critical illness in ICU and beyond. Recommendations are made for new models of care and support to mitigate the patients’ experiences.

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1. Being on life support (breathing supported by the breathing machine)