

## Understanding recovery and survivorship after a prolonged critical illness

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Ongoing advancements in technology and treatments mean that many patients now survive critical illnesses that once would have been fatal. However, beyond survival lies recovery. A definition of recovery in health care is often referred to as the act of regaining or returning to a normal healthy state (Medline, 2019). Deegan (1996, p. 96) suggests:

recovery does not necessarily mean cure. Rather recovery is an attitude, a stance, and a way of approaching the day's challenges. It is not a perfectly linear journey. There are times of rapid gains and dis-appointing relapses ... Each person's journey of recovery is unique. Each person must find what works for them.

The trajectory of recovery is made even more unique because survival from critical illness involves patients from heterogeneous patient groups, and there is great variance in age, gender, culture and cause of admission. Survivors of critical illness cross the lifespan and have a range of roles and responsibilities within families and society.

Recovery from critical illness takes time, and many patients experience setbacks along the way. Critical illness recovery is characterised by decreased physical function, psychological problems, such as anxiety and depression, and various forms of cognitive impairment, some involving memory and executive function that significantly impact on patients long after discharge from the intensive care unit (ICU) (Jensen et al., 2015; Lasiter, Oles, Mundell, London, & Khan, 2016). Furthermore, the realisation that critical illness could have resulted in death can be profoundly confronting for patients and their families (Cutler, Hayter, & Ryan, 2013; Eriksson, Bergbom, & Lindahl, 2011; Samuelson, 2011). Dealing with this knowledge through the recovery process can result in days patients describe as 'dark' as they try to regain mental equilibrium (Nelderup, Simonsson, & Samuelson, 2018). Working through this can be facilitated through encounters with other people who understand the process of recovery. However, such people may not be available to patients and their family members during the recovery process (Palesjö, Nordgren, & Asp, 2015).

Patients can also experience a physiological cascade of events that results in increasing frailty, regardless of their previous health status and age, making for a complex and sometimes very protracted recovery trajectory. The concept of frailty has been linked to ageing, and however, it also has many common characteristics that are linked to patients post intensive care, such as multidimensional and multisystem decline in health status from impaired homeostatic reserve (fatigue, physical decline and cognition) which increases vulnerability to adverse outcomes from acute stress (Bagshaw & Muscedere, 2017). Loss of these reserves decreases a person's ability to withstand exposure to stress, increasing the risk of susceptibility to inflammatory insults and

nosocomial infection, resulting in worse health outcomes such as dependency, hospitalisation and mortality (Gibson & Crowe, 2018).

Although the problems of ICU recovery are well documented in the literature, there is a lack of understanding and services to meet the specialised needs of this group. Despite follow-up clinics and tele- phone services existing in various permutations for many years, formal follow-up is not common consistent practice of all ICUs internationally (Lasiter et al., 2016). There is increasing awareness within the literature of the need for ICU services to extend beyond the physical boundaries of the ICU (van Mol et al., 2016; Page, Simpson, & Reynolds, 2019).

Treatment in an ICU is psychologically and emotionally traumatic for patients and their families. An ICU experience does not end when a patient leaves the physical ICU environment; it is with them forever. Viewing a critical illness experience as an ongoing phenomenon reveals the many deficits that are missing as patients and their family's attempt to recast their biography after a life-changing event (Ewens, Hendricks, & Sundin, 2018; Page et al., 2019). Mental health conditions can arise after trauma, such as near-death experiences and severe illness, including anxiety, depression and post-traumatic stress disorder (König, Matt, Kortgen, Turnbull, & Hartog, 2019). Patients can re-experience the trauma through intrusive memories and vivid im- ages of the event during waking hours, and nightmares can also occur. Depression and anxiety can result because of the ongoing physical health problems (Wintermann et al., 2015). For example, dysthymia or a low mood and anxiety can develop due to the experience of continuing ill health, disability or inability to work, rather than the actual injury or insult itself. Providing opportunities to focus on strengths and hope is important, and people should be given opportunities to consider their future rather than be reminded that they are 'lucky to be alive'.

Recognition of diversity is important, and despite extensive research on recovery from critical illness, there has been little re- search into the experiences and outcomes of Indigenous peoples or other specific cultural groups. In Australia for example, there is no literature around postcritical illness experiences and recovery for Aboriginal and Torres Strait Islander Peoples and other minority groups. However, Australian residents born overseas account for nearly half of all sepsis admissions (Ore, 2015) and Aboriginal and Torres Strait Islander Peoples are admitted to intensive care at nearly double the rate of other Australians, at a younger age, with more severe illness and higher mortality (Trout, Henson, & Senthuran, 2015). There is also a dearth of literature on recovery from critical illness from a Māori perspectives in New Zealand, and however, a study to predict outcomes for ICU patient after a stay greater than seven days noted that Māori people only made up 3.8% of this group (Carden, Graham, McLennan, & Celi, 2008). This is well below the 15.4% of the Indigenous population proportion (Statistics NZ, 2015). Understanding the process and nature of recovery for patients, particularly when their critical illness has been prolonged, is essential if we are to support patients to deal with the complexity that critical illness has on their biography. Recovery from critical illness involves contextualising, coming to terms, reconstituting identity and recasting one's biography. However, while in the ICU patients are frequently to unwell to be able make sense of their illness experiences and it is often only through their physiological deconditioning that they know something dreadful has happened to them, often with memory blanks and altered memories from their time in ICU (Minton, 2017). Therefore, patients' temporal perceptions of their ICU experience can only be processed when they are well enough to have the ability to contextualise this process, which occurs after discharge from ICU. The ongoing prevalence of psychological and physiological morbidity in this population group reflects a medicalised model of recovery that does not recognise a person's individual biography that needs specialist assistance to be contextualised (Minton, 2017). Patients need written information about their ICU illness as well as specialised support from healthcare

professionals. It should not be left to family and friends to help patients understand their ICU experience and recovery. As technologies and treatments continue to advance for critically ill patients, nurses have a moral and ethical duty to promote recovery as defined by Deegan (1996) as an attitude and a stance, and a way of approaching challenges as they work individually with patients.

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