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## Understanding the process of recovery from critical illness from the patient perspective: A constructivist grounded theory

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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## Abstract

Critical illness creates long-term physical, psychological and cognitive deficits that negatively impact quality of life, persisting well beyond hospital discharge. The purpose of this constructivist grounded theory study is to understand and develop theoretical propositions on factors that patients perceive influence the process of recovery from critical illness in order to inform more comprehensive patient care management strategies.

Semi-structured interviews were conducted with 17 participants admitted to an ICU. All interviews were audio-recorded and transcribed verbatim. Data collection and analysis occurred concurrently using the constant comparative method. Data were analysed initially with line-by-line coding, then focused coding. Initial codes were collapsed and organized into categories and theoretical concepts that later informed theory construction.

Our data informed the generation of 2 theoretical concepts: 1) “critical illness and care environment”, sub-categories isolation, disempowerment, emotions, mental functions, human connection to people, home and outside world; and 2) “the person”, sub-categories mental health and personal traits. The relationships among the theoretical concepts and categories were explored with “The Person”, “Family” and “Care Environment” emerging as central to the process of recovery from critical illness.

The findings of this study suggest that patients perceive **f**amily, the **c**are **e**nvironment and aspects of **t**he person as central to the process of recovery from critical illness; forming the **FaCeT** grounded theory of recovery. This theory

aims to provide a greater understanding of factors perceived to influence the process of recovery and can be used to inform comprehensive patient care strategies aimed at optimizing long-term outcomes following critical illness.

## **Keywords**

critical care, critical illness, rehabilitation, outcomes, holistic patient care, family, environment, grounded theory

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## **List of Abbreviations**

ARDS: Acute Respiratory Distress Syndrome

ICF: International classification of functioning, disability and health

ICU: Intensive care unit

ICU-AW: Intensive care unit acquired weakness

LHSC: London Health Sciences Centre

LOS: Length of stay

MV: Mechanical ventilation

PICS: Post-intensive care unit syndrome

PICS-F: Post-intensive care unit syndrome family

PTSD: Post-traumatic stress disorder

WHO: World Health Organization



## Chapter 1

This chapter is intended to provide an overview of the evolution of critical care medicine, highlighting both the significant advancements in patient care to date as well as the challenges facing its continued evolution. Specifically, this chapter will address the poor long-term patient outcomes associated with surviving critical illness and explore complimentary patient care models that can inform more comprehensive and holistic practices seeking to optimize patient and family centered outcomes following survival.

### **Critical Illness and Critical Care Medicine**

Critical illness refers to episodes of life threatening organ dysfunction occurring as a result of catastrophic illness or injury. Critical care medicine is an evolving specialty dependent on understanding complex physiological processes and utilizing advanced technologies to assess, react and implement life sustaining therapies aimed at providing organ support and achieving stability in body systems during these acute episodes which would otherwise be fatal (Finfer & Vincent, 2013; Hill et al., 2016; Marini, Vincent, Annane, 2015; Moreno & Rhodes, 2010).

The heterogeneity of critical illness is such that each individual's experience of critical illness is unique and individual outcomes vary. Experiences of critical illness can range from less severe critical illness requiring only a few days in the intensive care unit (ICU) to more severe and prolonged courses of illness resulting in stays of weeks or even months. The need for mechanical ventilation (MV) is considered a hallmark of care for those with a critical illness.

Mechanical ventilation is a technology that provides a means of breathing when individuals can no longer independently support the work of spontaneous breathing. Patients who are mechanically ventilated are physically connected to this device through a tube that is inserted into their main airway (an endotracheal tube) that provides both oxygen and support for the work of breathing.

Accordingly, the length of time required to withdraw or 'wean' an individual from MV is paramount to determining length of stay (LOS) in the ICU. Prolonged weaning from MV is defined as requiring greater than seven days of MV after the initiation of independent breathing trials (Boles et al., 2007).

Severity of critical illness can be quantified using the Acute Physiology and Chronic Health Evaluation II (APACHE II) classification system which evaluates organ function to estimate severity of illness; increasing scores on the APACHE II indicate a greater severity of critical illness (Knaus, Draper, Wagner & Zimmerman, 1985). Greater severity of critical illness is associated with increased risk of mortality (Knaus et al., 1985; Naved, Siddiqui & Kahn, 2011), prolonged ICU stays (Naved et al., 2011) and longer term ICU acquired morbidity such as prolonged weaning from MV, muscle weakness, decreased activity tolerance, depression, anxiety, impaired cognition and a resultant decreased quality of life following survival and discharge home (Bigatello, Stelfox, Berra, Schmidt & Gettings, 2007; Gosselink et al., 2008; Jolley, Bunnell & Hough, 2016; Nelson, Cox, Hope & Carson, 2010).

This chapter provides an overview of the evolving paradigm shift in the discipline of critical care medicine. This shift began with acknowledging the multi-

dimensional sequelae associated with surviving critical illness to one where practice is continuing to evolve to a more holistic model of care aimed at improving long-term patient and family centered outcomes.

### **Critical Care Medicine: An Evolving Practice**

Critical care medicine has evolved such that advancements in technologies for assessment and treatment have resulted in decreases in mortality, with the majority of patients surviving critical illness (Desai, Law & Needham, 2011; Iwashyna, 2010; Nelson et al., 2010). Survival has long been considered the primary outcome in critical care (Oeyen, Vandijck, Benoit, Annemans & Decruyenaere, 2010), however, there is a growing awareness that repercussions of severe critical illness and the interventions associated with treatment of the illness extend well beyond ICU discharge and are often associated with long-term morbidity and mortality (Marini et al., 2015). As a result, critical care is continuing to evolve in its appreciation for the long term complications associated with surviving critical illness, creating a paradigm shift where goals of care extend beyond survival to encompass quality of life and long-term patient and family-centered outcomes (Desai et al., 2011; Iwashyna, 2010; Moreno & Rhodes, 2012; Oeyen et al., 2010).

### **Life Following Survival of Critical Illness**

Critical illness itself creates new cognitive, physical and functional disabilities that persist well beyond hospital discharge, culminating in significantly reduced quality of life following survival (Damm & Patel, 2015; Desai et al., 2011; Dowdy et al., 2006; Herridge & Cameron, 2013; Herridge et al., 2011; Iwashyna,

Ely, Smith & Langa 2010; Hill et al., 2016; Oeyen et al., 2010). Herridge and colleagues (2011) demonstrated that survivors of acute respiratory distress syndrome (ARDS) experience physical and psychological deficits with decreased quality of life up to five years post-discharge from ICU. Other studies have expanded on understanding the breadth and depth of the neurocognitive impairments associated with surviving critical illness, including impaired memory, verbal fluency and executive function, as well as significant psychiatric morbidity including depression, anxiety and post-traumatic stress disorder (PTSD) (Damm & Patel, 2015; Mikkelsen et al., 2012).

The acknowledgement of poor long term outcomes following survival of critical illness has prompted several stakeholder conferences to develop strategies to improve patient and family outcomes (Elliott et al., 2014; Needham et al., 2012). These stakeholder conferences have resulted in several initiatives that have increased awareness and understanding of this phenomenon among health care professionals. These initiatives include increasing understanding of factors contributing to long term morbidity, as well as the development of a standardized language to describe and identify these symptoms as a clinical syndrome (Hermans & Van den Berghe, 2015; Herridge & Cox, 2012; Kress, & Hall 2014; Elliott et al., 2014). The clinical syndromes used to describe the long term, multi-dimensional morbidity associated with surviving critical illness include ICU-Acquired weakness (ICU-AW) and Post-Intensive Care Syndrome (PICS) (Needham et al., 2012; Elliott et al., 2015). These two clinical syndromes are defined below.

**ICU-Acquired Weakness.** ICU-Acquired Weakness (ICU-AW) is a term used to describe muscle weakness developing as a complication of critical illness (Needham et al., 2012). Intensive care unit-acquired weakness is characterized by diffuse symmetric generalized muscle weakness affecting both respiratory and peripheral muscles (De Jonghe et al., 2002; Castro-Avila, Seron, Fan, Gaete & Micken, 2015). The peripheral muscles commonly affected include bilateral wrist extensors, elbow flexors, shoulder abductors, ankle dorsiflexors, knee extensors and hip flexors (De Jonghe et al., 2002; Castro-Avila et al., 2015). A diagnosis of ICU-AW is made by testing the aforementioned peripheral muscle groups bilaterally using the Medical Research Council (MRC) scale, with a score of less than 48 out of 60 constituting ICU-AW (De Jonghe et al., 2002).

Intensive care unit acquired weakness is a common complication of severe critical illness with it being present in over 60% of patients mechanically ventilated for more than 10 days (Castro-Avila et al., 2015). The pathophysiology of ICU-AW is thought to be a combination of muscle and nerve injury from systemic inflammation combined with deconditioning resulting from immobility as a result of prolonged ICU stays and resultant bed rest (Castro-Avila et al., 2015; Hermans & Van de Berghe, 2015; Kayambu, Boots & Patel, 2015). Patients diagnosed with ICU-AW were also found to experience prolonged MV, an associated loss of muscle mass and present with a decreased ability to tolerate physical activity (Castro-Avila et al., 2015; De Jonghe et al., 2002; Needham et al., 2012; Hermans & Van de Berghe, 2015; Stevens et al, 2009) likely occurring

as a result of impaired microcirculation throughout the course of critical illness (Kress & Hall, 2014).

Intensive care unit acquired weakness is considered an important contributor to poor functional outcomes in survivors of critical illness (Kress & Hall, 2014) and is associated with increased morbidity and mortality following ICU discharge (Herman & Van de Berghe, 2015) underscoring its impact on both short and long-term patient outcomes. The development of the term ICU-AW was a significant accomplishment in the evolution of critical care in that it provided a standardized language and definition for researchers and health care professionals alike to enable proper diagnosis, which is essential for conducting research on strategies to treat and prevent these complications.

**Post intensive care syndrome.** Post intensive care syndrome (PICS) is another term that has been adopted in the literature to describe a constellation of symptoms including new or increasing physical, cognitive and mental health impairments following recovery from critical illness that persist well beyond discharge home (Needham et al., 2012; Elliott et al., 2014). Although ICU-AW is a significant contributor to the development of PICS (Hermans & Van de Berghe, 2015), PICS is a distinct syndrome reflecting multi dimensional, longer term morbidity that manifests and persists, negatively impacting quality of life and meaningful patient outcomes such as return to work and social function following discharge. There is also recognition that not only survivors of critical illness, but their family members as well, can experience these symptoms; with PICS – Family (PICS-F) being adopted as the term to describe this phenomenon

(Davidson, Harvey, Schuller & Black, 2013; Davidson, Harvey, Bermis-Dougherty, Smith & Hopkins, 2013).

### **Factors Associated with Poor Long-Term Patient Outcomes**

Although the relationship between ICU-AW and PICS is not completely understood, together they represent a multitude of physical, cognitive and mental health impairments that contribute to poor long term patient outcomes following survival of critical illness. Despite numerous studies, there remains no definitive consensus on risk factors for ICU-AW (Jolley et al., 2016). The most consistently cited risk factor for ICU-AW is severity of illness (Jolley et al., 2016). Other possible and commonly cited risk factors for physical, cognitive and/or mental health impairments following critical illness include use of sedation, pre-existing mental and physical health status, acute delirium, anxiety, immobility, administration of corticosteroids and neuromuscular blockades, hyper- or hypoglycemia, hypotensive episodes and periods of hypoxemia during critical illness (Damm & Patel, 2015; Desai et al., 2011; Jolley et al., 2016; Hatch, McKechnie & Griffith, 2011; Mikkelsen et al., 2012; Nelson, Weinert, Bury, Marinelli & Gross, 2000; Peris et al., 2011). The presence of one or more of these factors has been associated with persistent disability following survival of critical illness.

Why is it important to understand factors that predict long term morbidity following survival of critical illness? While little can be done to change non-modifiable risk factors such as age, gender or pre-existing physical and mental health status, simply being aware of such risk factors allows for earlier

identification of individuals who may experience more protracted and complicated courses of recovery. Likewise, identification of potentially modifiable risk factors of long term morbidity allows for the development and earlier implementation of management strategies aimed at mitigating their effects; this might include ensuring proper glucose control, facilitating early mobility or exercise in the ICU, decreasing use of sedation and neuromuscular blockades where possible and employing strategies to minimize episodes of hypoxemia and hypotension. Identifying and understanding both modifiable and non-modifiable risk factors for long term morbidity following survival of critical illness is paramount to facilitating early detection and implementation of more comprehensive management strategies aimed at improving long-term patient-centered outcomes and overall quality of life.

### **Preventing Complications Associated with Critical Illness: What works?**

It is becoming increasingly apparent that survivors of critical illness experience not only physical disabilities, but longer term persistent psychological and neurocognitive disabilities culminating in decreased quality of life well beyond hospital discharge (Damm & Patel, 2015; Davydow, Desai, Needham & Bienvenu, 2008; Desai et al., 2011). In addition to early identification of patients most at risk for these complications, patient care management strategies need to evolve to address the multiple dimensions of disability produced by critical illness itself if there is any hope of improving long term patient outcomes. To date, the majority of rehabilitation related research in critical care has focused on interventions aimed at addressing the physical disability associated with surviving



critical illness; with the most prevalent intervention of study being physical therapy-led early mobility.

Early mobility in critical care refers to the commencement of some form of active or passive physical activity initiated immediately following stabilization of the body systems (Korupolu, Gifford & Needham, 2009), at a sufficient intensity to produce physiological benefits such as enhancing circulation, ventilation and central and peripheral perfusion, as well as increased muscle metabolism and mental alertness (Castro-Avila et al., 2015).

The earliest studies investigating the effectiveness of early mobility demonstrated that peripheral joint range of motion exercises and resistive muscle training in supine and sitting at the edge of the bed decreased hospital and ICU length of stay (Morris et al., 2008), facilitated weaning from MV and improved physical function at time of discharge (Schweikert et al., 2009) in patients who were critically ill. The work of Pohlman and colleagues (2010) further extended the definition of early mobility in the ICU to include higher intensity physical activities such as sitting, standing, walking and participating in activities of daily living such as grooming and self-care, as they demonstrated that these activities were safe, feasible and well tolerated even in the highest acuity patients. These studies were seminal in challenging the one-time dominant culture of bed rest and immobility in critical care, in favor of a movement towards a culture of activity and early mobility where even the sickest patients receive this intervention early on in ICU admission.

More recently, a systematic review and meta-analysis by Kayambu and colleagues (2013) found that physical therapy led early mobility, initiated early on in the ICU stay, improves muscle strength, physical function, quality of life, ventilator free days and length of stay in the ICU and hospital. In contrast, Castro-Avilla and colleagues (2015) in a systematic review failed to demonstrate the benefit of early 'rehabilitation' on functional status, muscle strength, quality of life and healthcare utilization citing limitations due to inconsistent definitions for usual care and early rehabilitation as well as heterogeneity in patient population, outcome measures and treatments provided.

Despite some discrepancy in the systematic reviews, there remains general consensus that early mobility is beneficial in addressing the physical impairments associated with critical illness and thus is becoming adopted as standard practice in critical care. This evolution in critical care medicine, although significant and worthy of praise, is simply not enough. Patient care management strategies need to continue to evolve beyond solely the physical impairments produced by critical illness. Patient care management strategies need to become more holistic and comprehensive by beginning to address the psychological and cognitive disability produced by critical illness; only then can there be a hope of improving long term patient outcomes.

What does more holistic and comprehensive critical care look like? Early literature exploring enhanced models of critical care have suggested that comprehensive interdisciplinary health care teams are essential to addressing the broad scope of long term morbidity associated with critical illness (Bailey,

Miller & Clemmer, 2009; Lingdren & Ames, 2005). At minimum, interdisciplinary critical care teams should consist of physiotherapists, respiratory therapists, nurses, physicians, dieticians and social workers (Korupolu et al., 2009; Nelson et al, 2010). There is also evidence to suggest that the addition of clinical psychology services early on in ICU admission improves long term mental health outcomes following survival of critical illness (Hatch et al., 2011; Peris et al., 2011). Just as critical care has evolved to consider physical therapists essential to managing the physical impairments associated with critical illness, it needs to continue to evolve to a point where psychological and cognitive rehabilitative strategies are considered equally essential. The addition of clinical psychologists to the interdisciplinary critical care teams is one small step in that direction. The specific benefits of such enhanced models of care will be discussed further on in this chapter.

### **Qualitative Accounts of Surviving Critical Illness**

The earliest qualitative research in critical care centered on understanding patient experiences of weaning from mechanical ventilation, long considered the most significant milestone of surviving critical illness. Jenny and Logan (1994) conducted a grounded theory study where they interviewed nurses assisting patients through the process of weaning as an initial step in better understanding the phenomenon of weaning from MV. This study developed a theoretical framework categorizing the work nurses engage in while helping patients wean from MV; this work included knowing the patient, knowing the work of weaning, and managing the patient's energy (Jenny & Logan, 1994). Logan and Jenny

(1997) also conducted a qualitative study where they interviewed hospitalized patients who had recently undergone the process of weaning from MV in order to better understand their perception of their role during the process. The results of this study suggested that patients perceive themselves to be active participants during the process, engaging in 'work' to facilitate weaning from MV but recommended that additional research is necessary to better understand the patients' 'work' (Logan & Jenny 1997).

Cook and colleagues (2001) published a systematic review of qualitative studies exploring the patient's experience of weaning from MV in order to describe and summarize the emotional and psychological effects patients report while undergoing this process. This systematic review highlighted the negative emotions patients experience throughout the process of weaning; including experiences of frustration, hopelessness, uncertainty and lack of mastery (Cook, Meade & Perry, 2001). While noteworthy for its contributions to better understanding the experience of weaning from MV, these accounts are limited to one discrete activity within a larger process of recovery and the extent to which these experiences contribute to outcomes of weaning success remain unclear.

Additional qualitative studies have explored the broader experience of surviving critical illness (Chaing, 2011; Kean et al., 2016). A grounded theory study exploring the influence of family support for patients while in ICU illustrated that critical illness is experienced both by patients and family, and survival is attributed to mutually being there together throughout the process (Chaing, 2011). A more recent grounded theory study demonstrated that patients

perceive surviving critical illness to encompass not only the acute episode itself but life post-acute critical illness as well (Kean et al., 2016). Patients perceived the period of surviving critical illness to include a period of time post-discharge from hospital where they need to redefine themselves by incorporating their ICU experience into their life post-critical illness in order to once again regain control over their life (Kean et al., 2016).

Qualitative studies have also examined the psychological needs of patients recovering from critical illness, identifying a strong need to know (Hupcey & Zimmerman, 2000) and an overwhelming need to feel safe (Hupcey, 2000) as beneficial throughout the process of recovery, both in ICU and post-discharge. Hupcey and Zimmerman (2000) identified that patients in the ICU specifically report a need to know information about what is happening to them and a need for reassurance and reorientation during and after confusing and difficult times (Hupcey & Zimmerman, 2002). Patients also identified family, friends, ICU staff, religious beliefs and feelings of knowing, regaining control, hoping and trusting as integral to fostering a sense of feeling safe throughout the process of recovery; all perceived as beneficial to the process of recovery. These studies combined contribute to a greater understanding of the needs of patients experiencing critical illness and have begun to help form the foundations of what more holistic and comprehensive critical care medicine entails from both the patient and family perspective.

## **Reflections from Practice in Critical Care**

I have worked as a physiotherapist in critical care for 14 years. Very early on in my career, I was drawn to patients with prolonged and complicated recovery courses, usually marked by an inability to wean from MV, preventing them from leaving the ICU despite achieving physiological stability, and experiencing subsequent protracted stays in our ICU with seemingly very poor quality of life. These patients were usually few in number at any given time, but consumed the majority of my attention, time and resources given their complexity. What I observed in practice was the following. Although these patients had survived the acute phase of their illnesses and now were quite medically stable, their profound global weakness prevented them from not only breathing independently but in some cases from even being able to sit independently, let alone participate in any functional mobility and activities of daily living.

My entry-level-to-practice training as a physiotherapist was largely grounded in empiricism. Moreover, working in an ICU, I was immersed in a culture largely grounded in the medical model of disability; one grounded in the biomedical model of disability, fostering the belief that medical care should be focused on fixing impairments and curing disease (Engel, 1977; WHO, 2001). These influences were formative in the way I initially approached clinical practice; if a muscle was weak, I would focus treatment on strengthening it and if a muscle was short, I would focus treatment on lengthening it.

Moreover, as a clinician working within the biomedical model, I regularly reviewed critical care literature and practice guidelines (which were largely focused on treating the physical impairments created by critical illness). In doing so, I endeavored to apply the recommendations to my daily practice in an effort to provide the best care possible for all my patients. I could easily recount the most up to date and evidence-informed physiotherapy treatments for rehabilitating patients who were critically ill, the problem was, I was rarely able to implement them in the majority of my caseload. My patients were either too old, had a variety of co-morbidities contraindicating 'best-practice' or patients did not tolerate, or just flat out refused to participate in treatment. Emphasis on the medical model alone encouraged overemphasis on impairment focused treatments (e.g., strengthening and stretching, etc.) with little appreciation for the individual as a whole or their environment. This, at the time, created a great deal of frustration in my everyday practice and is what largely motivated my return to graduate studies.

In hindsight, I now realize that the source of my frustrations at that time can be understood by appreciating that "the scientific world is not, of course, the everyday world that people experience" (Crotty 2003, p. 28). "The scientific world [empiricism] is an abstraction of the 'lived' world; it has been distilled from the world of everyday experiences...." (Crotty 2003, p. 28). This distilled version can yield results that are very often not generalizable to the real lived experiences of our patients and sometimes cannot explain all the nuances and complexities that are unique to each individual and their situation.

Through a series of false starts, some successes and many failures, I continued to evolve as a clinician; a clinician who was starting to see the bigger picture. A clinician who was starting to appreciate the effects of anxiety on recovery, a clinician who was starting to appreciate the cumulative toll of patient's daily struggles, a clinician who was starting to see the value in patient and family led care, and a clinician who was starting to realize that sometimes spending my hour reassuring and encouraging patients can be just as beneficial as any other evidence-informed treatment because it's simply what they needed at that time. What I started questioning several years ago was, if I could better 'understand' the unique needs and experiences of patients with critical illness, could that inform more individualized and comprehensive patient care, thereby improving meaningful long-term outcomes? And if so, how does this fit within the realm of 'science'?

### **Facilitating a Comprehensive Approach to Recovery**

Recovery from critical illness encompasses the entire process of surviving the acute phase of critical illness, successfully weaning MV, engaging in therapies to regain functional strength and independence, and ultimately extending to successful transition home with support to achieve positive long-term outcomes such as return to work and social function (Davydow et al., 2008; Herridge & Cameron, 2013; Herridge et al., 2011; Marini et al., 2015). As such, care must evolve to adopt successful management strategies to help facilitate patients and families through each stage of their journey with the understanding that determinants of recovery are multi-dimensional, extending beyond



physiological factors to include both personal and environmental factors (Blackwood, 2000; Lingren & Ames, 2005). Moreover, the heterogeneity of critical illness is such that each individual's experience is unique and individual outcomes vary suggesting that care must reflect patient individuality, as well as the multi-dimensionality of recovery in order to optimize long-term outcomes.

### **The Biopsychosocial Model: Accounting for the Complexity of Recovery**

The biopsychosocial model of patient care, as it eventually came to be called, was founded in the beliefs of George Engel. Engel believed that the biomedical model encouraged a reductionist view of medicine in that it assumed disease to be fully explained by deviations from normative biological data and treatment and cure of disease stemmed solely from correcting or alleviating these deviations (Engel, 1977). Engel argued that this model was reductionist in that it does not account for nor explain individual, context specific, subjective experiences of illness, nor does it account for the contribution of individual attributes to disease states (Borrell-Carrió, Suchman & Epstein, 2004; Engel 1977; Engel 1980). Engel argued for a more holistic, multi-system model that extended application of the scientific method to data of psychological or social nature; data obtained through a person's narrative where behaviors, experiences and influences of family and community may be considered as contributors to illness or disability (Borrell-Carrió, 2004; Engel, 1977; Engel, 1980). The biopsychosocial model of patient care emerged as an integration of the medical and social models of disability and ultimately informed development of a theoretical framework providing a more comprehensive view of health and

disability, the International Classification of Functioning, Disability and Health (ICF) (2001).

### **The International Classification of Functioning, Disability and Health**

The World Health Organization's ICF (2001) is a model of health and disability that is grounded in the biopsychosocial model (WHO, 2001) in that it provides a multi-dimensional view of health from multiple perspectives; the physiological, individual and social perspective (Engel, 1977; WHO, 2001). The ICF (2001) recognizes the importance of contextual factors such as personal and environmental factors, combined with body structures and functions, in determining health status. This conceptual framework allows for the meaningful exploration of contextual factors that may influence recovery from critical illness, thereby informing comprehensive, individualized patient-centered management strategies.

**Personal factors associated with recovery.** Personal factors comprise a variety of individual attributes and features inherent to a person and are independent of a health condition (WHO, 2001). Personal factors can predict, modify or even determine outcomes (Muller & Geyh, 2014). Although acknowledged as a contributor to outcomes of disability and health, personal factors are not classified under the ICF model and lack detailed conceptualization, unlike the other domains of the ICF (Muller & Geyh, 2014). The WHO (2001) lists gender, race, age, other health conditions, fitness, lifestyle, coping strategies, habits, upbringing, social background, education, profession, past and current experiences, behavior patterns, character style, and individual

psychological assets as personal factors that may influence outcomes of disability and health.

Personal factors can function clinically much like non-modifiable risk factors. With respect to recovery from critical illness, variables such as female gender, pre-existing psychiatric history, individual personality traits and educational status have been suggested specifically as possible non-modifiable risk factors for the development of mental health impairments following survival of critical illness (Hatch et al., 2011; Peris et al., 2011). Moreover, pre-existing underlying illness is also thought to potentially influence long term outcomes of recovery (Angus & Carlet, 2003). As previously stated, while little can be done to change a non-modifiable risk factor, simply being aware of such factors is useful in that it can alert health care professionals early on of individuals in the ICU who may experience longer and more complicated courses of recovery.

**Environmental factors associated with recovery.** Environmental factors encompass the immediate physical, social and attitudinal environment of an individual (Schneidert, Hurst, Millet & Ustin, 2003). Several environmental factors inherent to critical care have been suggested to influence both short and long-term outcomes of recovery. These factors include: 1) the ICU setting itself, 2) a multi-disciplinary critical care team, 3) specialized equipment to facilitate communication, 4) prevailing ICU attitudes and culture informing patient care and 5) family and social support for patients both in the ICU and following discharge.

***The ICU setting.*** A significant number of patients admitted to the ICU develop depression and symptoms of PTSD (Hatch et al., 2011; Peris et al.,

2011). The physical environment of the ICU itself, to some extent, is thought to contribute to the development of these negative psychological symptoms (Hatch et al., 2011; Peris et al., 2011). The physical environment of the ICU is characterized by equally negative conflicting experiences of sensory deprivation and sensory overload (Blackwood, 2000). Patients with prolonged ICU stays may experience sensory deprivation as a result of extended periods of time in their hospital room with limited interactions (Blackwood, 2000; Cook et al., 2001; MacIntyre 2001). Sensory overload is thought to occur as a result of the incessant light and excessive noise consistently present in the ICU, as well as established ICU routines of frequently turning patients and monitoring vital signs (Lingdren & Ames, 2005). These conflicting sensory experiences are thought to create sleep disturbances and psychological distress, all negatively influencing outcomes of recovery (Blackwood, 2000; Cook et al., 2001; Cooper et al., 2000; Lingdren & Ames, 2005; MacIntyre, 2001).

***Multi-disciplinary critical care team.*** The ability to provide comprehensive care to patients recovering from critical illness is dependent upon the assembly of collaborative multi-disciplinary health care teams with sufficient breadth of expertise to address the complex and unique needs of patients recovering from critical illness. Traditional critical care teams generally consist of social workers, physiotherapists, respiratory therapists, dietitians, nurses and physicians (Korpololu e al., 2009; Nelson et al., 2010). While traditional health care teams are equipped with the expertise to collectively manage acute episodes of critical illness including any associated physical disability, current

teams may lack sufficient expertise to manage the psychological morbidity associated with surviving critical illness.

Research has shown that clinical psychology services, initiated early on in ICU admission to conscious patients and their family members in the form of education, counseling and stress management interventions, decreased the risk of PTSD, anxiety and depression following discharge (Peris et al., 2011). Most interestingly, the benefits of these early in-ICU clinical psychology interventions were still evident 12 months post ICU discharge (Peris et al., 2011), suggesting that clinical psychologists may be integral to optimizing longer term mental health outcomes following critical illness. Similarly, Jones and colleagues (2010) found that the provision of an ICU diary describing the patient's ICU day-to-day experience, given to the patient one month into their recovery, was shown to reduce the incidence of new onset PTSD. Lastly, Cox and colleagues (2012) demonstrated that telephone-based coping skills training sessions for patients and families following discharge home was associated with reduced psychological distress in patients and families recovering from critical illness. These studies demonstrate the benefits of proactive psychological interventions for patients and family members both in ICU and following discharge, further supporting the addition of clinical psychologists to standard multi-disciplinary critical care teams.

***Specialized equipment to facilitate communication.*** Many patients in the ICU are mechanically ventilated or require a tracheostomy as part of their medical care, severely limiting their ability to speak. In these instances, patient

communications are usually limited to nodding 'yes' or 'no' (Pullen, 2007; Lingdren & Ames, 2005), leaving them with limited ability to communicate anything beyond binary answers to questions posed by their health care team. The inability to speak or communicate has been suggested as a possible contributor to patient anxiety during critical illness (Davidson et al., 2013; Lingdren & Ames, 2005). Some patients may be able to communicate by writing via large or easy grip pencils, text to speech communication aids or through picture communication boards (Pullen, 2007). Without specific technologies to enhance communication, patients may be left with little to no ability to communicate, potentially contributing to additional psychological distress during their ICU admission.

***Culture of the ICU.*** An ICU that ascribes to a culture of wakefulness and mobility (Herridge & Cameron, 2013) is thought favourable to one of heavy sedation and bedrest with the latter contributing to increased physical, cognitive and psychiatric morbidity following discharge (Angus & Carlet, 2003; Fan, 2010; Hatch et al., 2011). The use of heavy sedation has been associated with long term cognitive and mental health disability following survival of critical illness (Damm & Patel, 2015; Desai et al., 2011; Fan, 2010; Korupolu et al., 2009; Hatch et al., 2011). Moreover, heavy sedation, although necessary at times to facilitate medical interventions such as endotracheal intubation and mechanical ventilation (Korupolu et al., 2009), limits the ability to implement early mobility (Fan, 2010; Korupolu et al., 2009). Studies have demonstrated that sedation interruption (regular periods of time where sedation is discontinued allowing patients to wake

up) is safe and feasible for patients who are critically ill, allowing for effective implementation of early mobility (Pohlman et al., 2010). Moreover, sedation interruption allows for wakeful periods where patients have the ability to interact and communicate with others, likely compounding the positive benefits of early mobility (Fan, 2010) on patients' recovery. Adopting a culture of wakefulness and mobility is essential to optimizing long-term patient mental health outcomes and dependent upon a culture that values and prioritizes the implementation of this standard of care at all levels.

***Family and social support.*** Family integration into daily patient care is a novel strategy gaining credibility as an adjunct therapy in critical care medicine. Family members are increasingly occupying important roles in daily patient care (McAdam, Arai & Puntillo, 2008). These roles include: 1) an active presence that makes patient's feel safe and comfortable, 2) a protector who can advocate on their behalf, 3) a facilitator that can enhance communication between patient's and health care workers, 4) act as a historian for the health care team, 5) a coach providing daily encouragement and 6) an informal caregiver providing assistance as needed (McAdam et al., 2008). The integration of family members into daily patient care has demonstrated an increase in daily patient mobilization (Rukstele & Gagnon, 2013), as well as providing patients with a connection to loved ones (McAdam et al., 2008). Perceived social support from family and personal care givers during recovery is thought to improve patient coping skills with traumatic events encountered in the ICU (Deja et al., 2006). Moreover, patient recall of support and assistance from family and personal care givers in

the ICU was shown to positively influence subsequent mental health, reduce the risk of developing PTSD and positively improve long term outcomes such as employment status (Deja et al., 2006); underscoring the need to further explore the role of family and social support in optimizing outcomes following critical illness.

### **A Call to Arms: Challenges Facing the Evolution of Critical Care**

The evolution of critical care has brought several important developments in practice. This is realized in the collective increased understanding of the impairments, both short and long term, associated with surviving critical illness. It is also realized in the adoption of standardized nomenclature for identifying and diagnosing these phenomena, thereby improving practice and research. There is an increased appreciation for the multitude of pre- and post-ICU factors associated with poor long term outcomes as well as the development of innovative treatment strategies informing several clinical guidelines and protocols (Korupolu et al., 2009; Davidson et al., 2013) to help foster best-practice. As critical care continues to evolve, it will face new challenges with 'survivorship' and its associated physical, cognitive and psychological morbidities, defined as the next significant challenge in its evolution (Davidson et al., 2013; Iwashyna, 2010).

Researchers and health care providers working in critical care alike are being challenged to think beyond survival and expand goals of patient care to include meaningful long term patient- and family-centered outcomes such as quality of life and return to work and social function (Angus & Carlet, 2002; Elliott



et al., 2014; Herridge & Cox, 2012; Moreno & Rhodes, 2010; Needham et al., 2012). Understanding the experiences and perspectives of patients recovering from critical illness is essential to informing comprehensive, patient-centered care with the end-goal that seeks to improve long-term meaningful outcomes to patients and families.

### **The Research Question**

The initial purpose of this research was to understand and develop theoretical propositions on factors that patients perceive as influential in shaping the process of recovery from critical illness. True to the iterative nature of grounded theory, as this research progressed and evolved, so too did the research question. The current study addresses the following research questions:

- How do patients perceive environmental and personal factors influence the process of recovery from critical illness?
- How can better understanding the perceived influence of environmental and personal factors inform more comprehensive patient care during the process of recovery from critical illness?

## Chapter 2

### **Quantitative versus Qualitative Research Methods**

Quantitative research methods involve measurement, counting or the collection of numbers in some form to quantify observations through the use of controlled experiments designed to test a specific hypothesis and produce statements of causality (Ponterotto, 2005). Qualitative research methods involve the interpretation of text and dialogue obtained through interviews, conversations and observations systematically collected and interpreted in order to explore meaning and gain understanding of social phenomena (Malterud, 2001). Both quantitative and qualitative research methods are empirical and scientific in that they both employ systematic processes of data collection, interpretation and analysis of data however, the products and outcomes of research for either methodology are context specific and embedded in philosophical assumptions underpinning the process of inquiry; this is also called a research paradigm (Ponterotto, 2005).

### **Research Paradigms**

A research paradigm is a core set of beliefs that deal with non-negotiable, fundamental principles that represent how one views the world and his/her place in it (Guba & Lincoln, 1994). Inherent to a research paradigm is its own set of ontological and epistemological assumptions. Guba and Lincoln (1994) are among many scholars who have provided a concise representation of the major research paradigms, complete with their philosophical underpinnings. The core set of beliefs within a research paradigm deals with basic questions regarding:

1) ontology, the fundamental belief of the nature of reality and whether there is one common shared reality versus multiple context-specific realities; 2) epistemology, beliefs on how one can come to acquire knowledge including the relationship between the researcher and participant during the process, and 3) methodology, the procedure for conducting research (Guba & Lincoln, 1994; Ponterotto, 2005; Snape & Spencer, 2003). Guba and Lincoln (1994) illustrate the competing research paradigms in qualitative research: positivism, postpositivism, critical theory and constructivism. Table 1 provides an overview of the competing research paradigms and their associated underlying philosophical assumptions and beliefs (Guba & Lincoln, 1994; Kinsella, 2012; Ponterotto, 2005).

**Table 1****An overview of competing research paradigms\***

	Positivism	Post-Positivist	Critical Theory	Constructivism/ Interpretivism
Ontology	Realism - one common shared accessible reality	Critical realism - one common shared reality that is not perfectly accessible	Historical realism	Relativism – multiple context specific realities exist
Epistemology	Objectivist – uncovering ‘truths’	Objectivist – cannot actually ever know if findings are true, but probably true	Subjective – value mediated findings	Subjective – findings are created through interaction of viewer and observed
Methods	Primarily quantitative-measurement, verification of hypothesis	Modified experimental - may include quantitative or qualitative, falsification of hypothesis	Dialogic/dialectical – dialogue between researcher and participant aimed at transforming misconceptions and challenging status quo	Hermeneutic/ dialogical – interactions between researcher and observed that are interpreted for meaning

*\*Adapted from, Guba & Lincoln, 1994; Kinsella, 2012; Ponterotto, 2005.*

## **The Interpretivist Movement**

Key thinkers and philosophers such as David Hume and Auguste Comte are credited with laying the foundation for empirical research and the term 'positivism' as a research paradigm (Crotty, 2003; Snape & Spencer, 2003). Inherent to positivism, as suggested by Hume, is the idea that knowledge is gained inductively through direct observation and collection of facts about the natural world, in an objective and unbiased manner (Snape & Spencer, 2003). Similarly, Comte postulated that this same method can be applied to the social world; we can derive laws or truths about the social world in the same inductive manner (Snape & Spencer, 2003). Inherent to what is known today as the positivist school of thought, is the assumption that the world has meaning that exists independently of any human consciousness of it (Crotty, 2003), and that through the application of the empirical scientific method, we can come to discover these meanings as absolute truths or laws of nature (Snape & Spencer, 2003). The disagreement with these positivists beliefs, if any, do not lie in the power or utility of positivist science, but rather in the belief that scientific knowledge is only valid if acquired through these methods (Crotty, 2003).

Some philosophers have questioned the existence of a "neutral, culture-independent, set of categories within the population—whether of objects or of actions-..." (Kuhn, 1991, p.21) that can be described or observed, and some question whether detached, value-free observation (Crotty, 2003) is even possible. Contrary to the demands of positivist science, many strongly defend the necessity for an "interpretivist account of the human sciences" (Rouse, 1991,

p.55) where meaning and understanding of human actions and experiences are gained through an interpretation of these actions and experiences that is “culturally derived and historically situated... [within a] social life-world” (Crotty, 2003, p.67). These arguments are rooted in a historical movement sparked by key thinkers arguing for interpretivism as a science.

Wilhelm Dilthey is cited as a major contributor to the development of the interpretivist epistemological position within the qualitative research tradition (Snape & Spencer, 2003). Dilthey wrote about the importance of ‘verstehen’, or understanding, in research when studying the ‘lived experience’ and social phenomenon (Snape & Spencer, 2003). This was contrary to the dominant positivist view at the time within the natural sciences, concerned with ‘erklären’, or explaining, and causality (Crotty, 2003). Dilthey also extended the idea of interpretive understanding to human behaviour (Prus, 1996) within the human sciences and this laid the foundation for what is known today as interpretivism within qualitative research methodology (Ponterotto, 2005).

Dilthey’s contrast of ‘explaining’ and ‘understanding’ stemmed from his belief that “natural reality and social reality are in themselves, different kinds of reality and their investigation therefore requires different methods” (Crotty, 2003, p. 67). Dilthey argued for a pure interpretivist approach to research within the human sciences concerned primarily with understanding social phenomena (Ponterotto, 2005). Snape and Spencer (2003) explain that he believed that social research should explore ‘lived experiences’ in order to reveal the

connections between the social, cultural and historical aspects of people's lives and to see the context in which particular actions take place".

Another major contributor to the philosophical movement positioning interpretivism within the human and natural sciences is Max Weber. Like Dilthey, Weber also wrote about the necessity of 'understanding' in human science research (Crotty, 2003; Snape & Spencer 2003). Where Weber differs from Dilthey is the belief that different research methods are required for the study of the natural and human sciences respectively (Crotty, 2003). Weber posited that "uniqueness and historicity are manifest in nature as well as humanity" (Crotty, 2003, p. 68) and as such, both the sciences may require methods to uncover 'laws' or 'truths' that explain behaviour, both human and/or natural (Crotty, 2003). In addition, both the natural and human sciences also require methods to 'understand' the unique aspects of a natural and/or human phenomena (Crotty, 2003). As such, Weber believes that there is less of a need for two distinct sciences and that one scientific method should meet the needs of these two forms of inquiry; nomothetic (law seeking) and ideographic (individualizing) (Crotty, 2003). Historically, there has not been any consensus among philosophers regarding a clear distinction between the natural and human sciences (Bohman, Hiley & Shusterman, 1991). The debate regarding where the distinction lies between the two, if any, involves articulating the ontological, epistemological and methodological assumptions underpinning them (Bohman et al., 1991). Regardless of where the distinction may lie, if any, philosophers have argued for centuries for the importance and necessity of 'understanding' within

the human sciences as it is only through an interpretive scientific method that the meanings underlying actions and experiences can be understood.

### **Constructivism/Interpretivism**

Constructivism aligns philosophically with interpretivism and the terms have been used interchangeably as research paradigms; with both being viewed as an alternative paradigm to the prevailing positivist notions (Ponterotto, 2005). Ontologically, constructivism aligns with a relativist position, assuming multiple context specific constructed realities versus one common shared reality (Guba & Lincoln, 1994; Ponterotto, 2005). What does this mean? Constructivist assumptions reject the notion that research is aimed at uncovering dimensions of one shared, objective discoverable truth. Rather, the products of constructivist research are assumed to be context specific interpretations of researcher and subject interactions and reflect one of many possible interpretations. Epistemologically, constructivism is subjective and transactional in that the findings are created through the interactions of the researcher and participant. In this sense, the researcher and participant are assumed to be interactively linked (Guba & Lincoln, 1994) and “interpretation thus depends pivotally on making sense of the other by reference to the community context in which the actions of others are embedded” (Prus, 1996, p.35).

### **Reflections on the Paradigmatic Spectrum**

Positivism, although unaware of alternative research paradigms at the time, would best describe my experiences as a clinician and researcher, up to and including my master’s work. My colleagues in the intensive care unit, along



with my undergraduate and master's education were formative in the way that I approached practice, research and placed value on sources of knowledge. As a clinician, I endeavored to implement best practice guidelines and as a researcher I hoped to one day contribute to their development. As previously stated, this became a great source of frustration in my practice motivating my pursuit of doctoral studies. My admittedly fragmented and protracted course of doctoral studies was fraught with tensions of reconciling the ingrained positivist notions of research with something I didn't quite understand in me at the time. What I started questioning one year into my second attempt at completing a doctoral degree was, if I could better understand the unique needs and experiences of patients with critical illness, could that help inform more holistic care thereby improving long-term patient outcomes? Up to this point, I had had very limited experience with a qualitative approach to research and quite honestly, one question that continued to echo in my mind was 'is this science'? Flash forward two attempts and six years later, and here I am completing this constructivist grounded theory.

What I came to realize over this journey called 'doctoral studies' is that I am an interpretivist at heart. I am thankful that my experience with doctoral studies allowed for the exploration of alternative research paradigms and the opportunity to appreciate the historical conversations that started a philosophical movement for interpretivism as a science. I eventually came to appreciate that by engaging with and talking to individuals recovering from critical illness, I can attempt to 'make sense' of their stories within the context of our interactions and

the environment, in order to better understand the phenomenon that is recovering from critical illness. My next challenge came in trying to find an appropriate methodology that would appropriately address my research question, as well as align with the emerging philosophical assumptions underpinning my research.

### **Grounded Theory**

Grounded theory methods were first founded and articulated in the work of Glaser and Strauss (1967) where they explicitly set out strategies for social research aimed at developing theories grounded in qualitative data. This work was revolutionary in that it challenged the dominant quantitative school of inquiry at the time, which espoused the scientific method aimed at disproving a null hypothesis (Charmaz, 2006). Glaser and Strauss illustrated an alternative qualitative school of inquiry grounded in the same positivist paradigm, but the methods were centered on conceptualization and theory generation grounded in qualitative data (Glaser and Strauss, 1967; Glaser, 2004).

Glaser's grounded theory, later rejected by Strauss for a post-positivist version (Mills, Bonner and Francis, 2006), was one underpinned with objectivity and concerned with uncovering universal 'truths' articulated in theory and or hypotheses that could be 'verified' through establishing reproducibility (Glaser & Strauss, 1967). As noted above, Strauss strayed from the positivist paradigm in later work, rejecting the positivist notion of a discoverable, objective, pre-existing reality (Strauss & Corbin, 1994). There exists much tension in the literature as to the ontological positions of Strauss' later work where theorists waver between

post-positivist and post-positivist with constructivist leanings as his work is still laden with terms such as objectivity and bias when examining the role of the researcher (Mills et al., 2006). Charmaz continued to reshape grounded theory and later championed a school of inquiry firmly grounded in the constructivist theoretical perspective aimed at finding meaning and understanding in actions, not 'truths' (Charmaz, 2003). Charmaz redefined the strategies of grounded theory set forth by Glaser and Strauss (1967) to allow for the notion of 'researcher as author' (Mills et al., 2006. p. 6).

Grounded theory is a qualitative research process that employs a set of flexible strategies (Glaser & Strauss, 1967) that allows a researcher to work inductively from the ground up by collecting and interpreting meaning in 'words' collected through observations and interviews. The basic methods of conducting grounded theory include concurrent data collection and analysis, coding, theoretical sampling where subsequent sampling is driven by the emerging theory, the use of the constant comparative method at all stages of data collection and analysis and memo-writing (Glaser & Strauss, 1967; Glaser 2004; Stanley, 2006). These methods are used to help gain understanding of and form theoretical propositions on a particular social phenomena. What is demonstrated in the evolution of Glaser and Strauss' grounded theory to that of Charmaz, is that the process of conducting grounded theory can be rooted in either the positivist or constructivist/interpretivist research paradigm.

**The development of the Constructivist Grounded Theory.** Charmaz (2006) proposed that the 'tools' to accomplish theory construction themselves, as originally articulated by Glaser and Strauss, can be viewed as neutral. What cannot be viewed as neutral is how a researcher uses the 'tools' and the underlying philosophical assumptions they bring to the research process (Charmaz, 2006). This can be seen in the subsequent transformations of grounded theory spanning the spectrum of research paradigms from positivist to postpositivist and finally constructivist grounded theory championed by Glaser, Strauss and Charmaz respectively (Mills, et al., 2006).

Charmaz accepted Glaser & Strauss' invitation for researchers to use their flexible strategies in a manner to meet their needs and demonstrated a grounded theory still rooted in examining process and studying action but added the dimension of interpretative understanding to the process (Charmaz, 2006). Charmaz offered an alternative to Glaser's positivist paradigm where researcher and participant together frame the interaction and the researcher is not separate from what is viewed but actually interactively 'linked' to the participant and generation of outcomes; offering dimensions of explanation and understanding to theory construction when studying social phenomena (Charmaz, 2003). Table 2 provides an overview of the divergent fundamental assumptions and approaches between Glaserian and Constructivist Grounded Theory methodologies and their associated methods (Charmaz, 2003; Charmaz, 2006; Glaser, 2004; Glaser & Strauss, 1967; Heath & Crowley, 2004; Mills et al., 2006).

**Table 2****An Overview of the divergent fundamental assumptions and approaches underlying Glaserian and Constructivist Grounded Theory\***

Underlying Assumptions & Approaches	Glaserian Grounded Theory	Constructivist Grounded Theory (Charmaz)
Ontological and epistemological underpinnings	Positivist; objectivist	Relativist; subjectivist
Underlying assumption	Objective external reality that can be 'discovered'	Multiple social realities and aims for interpretive understanding of subjective meanings. The emerging theory is one among many possible interpretations.
Nature of relationship between researcher and participant	Neutral and detached observer, role is one of 'discovery'	Interactively linked, researcher is the author of a co-construction created through interaction of researcher and participant
Research methods	Experimental methods aimed at verification or rejection of hypothesis. Product is a 'law' or a 'truth'	Requires researcher interaction with participants (e.g. semi-structured or free flowing interviews) that is then interpreted for meaning, informing a theory explaining social phenomena

Theoretical sensitivity	Research is entered into with as few preconceived ideas as possible including a priori hypotheses	Includes level of familiarity, experiences and insight with research area. Researchers may use this as a tool for theory construction however they must engage in reflexivity during and be open about their involvement in the research process.
Literature reviews	Discouraged for fear of constraining or contaminating the emerging theory; may be used in later stages after theory is constructed	Literature review and theoretical framework should be drafted in relation to the grounded theory. May be used to demonstrate an understanding of the research area, demonstrate connections to previous work, identify gaps in areas demonstrating how grounded theory can help answer them and provides assistance in making claims about the theory and its contribution.
Theory generation and verification	Theory is generated through comparative analysis with ongoing verification of the emerging theory with the intent of discovering 'truths'	Findings created by the researcher through their interactions with the participants and are interpreted within the temporal, social and cultural contexts in which they were created. The theory offers explanation and understanding.
Quality criteria	The generated theory must fit the data, demonstrate utility, have explanatory power, allow for empirical generalizations to increase its explanatory power, be validated through replication, be modifiable and demonstrate durability over time	The grounded theory should demonstrate credibility, originality, resonance and usefulness.

## Reflexivity

Unnecessary as researchers enter into data collection and analysis completely open and with few preconceived notions so as to prevent bias, contamination or restriction of the emerging theory

Essential to constructivist grounded theory. A thoughtful examination on how the researcher conducts research, and how their experiences and interpretations shaped the process and how the data is represented.

*\*Adapted from Charmaz, 2003; Charmaz, 2006; Glaser, 2004; Glaser & Strauss, 1967; Heath & Crowley, 2004; Mills et al., 2006.*

## **The 'Tools' of Constructivist Grounded Theory**

The tools of grounded theory can be adopted or adapted to suit a wide range of research (Charmaz, 2006) efforts and, therefore, in a sense may be viewed as neutral. However, the manner in which these tools are used in conducting the research and the assumptions that accompany their implementation are not neutral (Charmaz, 2006). Below is a description of the 'tools' of grounded theory; a detailed description of how these tools were used in the present study follows in Chapter 3.

**Theoretical sensitivity and sensitizing concepts.** Theoretical sensitivity (see Table 2) refers to the researcher's ability to form connections and concepts grounded in the data that come together to form a theory, model or hypothesis (Glaser, 2004). Glaser (2004) maintains that theoretical sensitivity can only be achieved through maintaining analytic distance and entering the process of theory construction with as few preconceived notions as possible; precluding a literature review prior to commencement of study. Contrary to Glaserian grounded theory, Constructivist grounded theory holds that the theory itself is a co-construction of both author and subject, rendering the notion of distance and objectivity inconsequential (Mills et al., 2006).

Constructivist grounded theory contends that theoretical sensitivity may be achieved through a process that acknowledges and embraces prior experiences and knowledge of the research area and draws on these 'sensitizing concepts and disciplinary perspectives' as starting points for analysis and theory construction (Charmaz, 2003). Literature reviews become part of the



researcher's theoretical sensitivity informing connections throughout theory construction. Similarly, prior knowledge and experiences may also be embraced as a tool for researchers to draw upon throughout the process (Mills et al., 2006) while still examining the data from multiple vantage points where connections are made by reflecting, asking questions, following leads and building on new ideas (Charmaz, 2006).

**Reflexivity.** Reflexivity, although unnecessary in objectivist grounded theory because of its detached unbiased position, is essential to constructivist grounded theory. The product of constructivist grounded theory (i.e., the theory) does not represent one objective, generalizable account of the patient experience, but rather, a subjective theoretical interpretation grounded in temporal and context specific researcher and subject interactions (Charmaz, 2003). The product represents the researcher's construction or interpretation of their interactions and is only one of many possible interpretations (Charmaz, 2003). This necessitates self-awareness on the part of the researcher to acknowledge what experiences, assumptions, interpretations and decisions influenced the inquiry; the examination of these factors and their influence on the process and product constitutes a reflective stance (Charmaz, 2006).

**Constant-comparative method.** The constant comparative method involves a systematic approach to coding and analyzing data that enables the generation of theory (Glaser, 2004). During this process, the researcher must continuously move back and forth between data collection and data analysis. During data analysis at each stage of theory development, the researcher is

required to make comparisons at each level of analytic work, comparing data with data, data with categories, categories with categories and categories with concepts (Charmaz, 2006). The need for further data collection and sampling procedures are then subsequently driven by the emerging theory. This process allows for the best possible fit of the many concepts that come together to form well-grounded categories and eventually theory (Glaser, 2004).

**Theoretical sampling.** Theoretical sampling is central to grounded theory (Charmaz, 2003). Theoretical sampling involves a process of simultaneous data collection and analysis where the emerging theory drives subsequent data collection (Glaser, 2004) and involves a process of sampling with the intent to seek out relevant data to help elaborate and refine categories and concepts that help illuminate the emerging theory (Charmaz, 2003; Charmaz, 2006). Constructivist grounded theory is not concerned with sampling to reflect broad population distributions to increase generalizability but rather it is the deliberate sampling of people, cases, situations and settings to help refine ideas and build theory (Charmaz, 2006). Charmaz (2006) recommends implementing theoretical sampling later on in the process: “Initial sampling in grounded theory is where you start, whereas theoretical sampling directs you where to go” (p. 100). This process involves initial rounds of sampling used as points of departures to address the initial research question, then invoking theoretical sampling to make emerging categories and concepts more definitive (Charmaz 2003; 2006).

**Theoretical sufficiency.** Theoretical sufficiency is an evolution of the original term theoretical saturation. Theoretical saturation is the term that has been used to describe a concept that marks the 'endpoint' of data collection. Theoretical saturation occurs when categories and concepts that have emerged to form a grounded theory are thought to be 'sufficiently' dense in that continued data collection offers few to little additional new insights and concepts (Glaser & Strauss, 1967; Charmaz, 2006). Charmaz does caution that this term not simply be interpreted to imply the observation of repeated patterns and stories in the data but rather espouses a more comprehensive analytic approach where researchers ask themselves pointed questions to try to determine if the data (as is) sufficiently supports the grounded theory and resonates 'intimately' with the world they have been studying (Charmaz 2003, 2006). Interestingly, both Glaser and Strauss (1967) and Charmaz (2003) acknowledge that this term does not imply a definitive point where the 'all is known'. Moreover, Charmaz (2003) insofar acknowledges that some researchers may take the position that data may never be considered 'saturated'. In this sense, the terms theoretical sufficiency may be adopted to indicate a decision point in the grounded theory research process where 'sufficient' data exists to support the claims of the current research.

**Memoing.** Both Glaser (2004) and Charmaz (2003, 2006) acknowledge 'memoing' as an integral process in data analysis and theory construction. Charmaz (2003, 2006) describes memoing as a pivotal intermediate step between data collection and analysis where the researcher stops and thinks

about the data collected; this act, at this point in the process prompts early analysis of the data, contributing to the constant comparative method and subsequent theoretical sampling. Moreover, memoing, occurring in parallel to data collection, analysis and theory construction, is a tool researchers' use to develop categories and explore connections among these categories which then inform theoretical concepts contributing to the grounded theory (Glaser, 2004). The process of memoing keeps the researcher engaged in the grounded theory research process and encourages reflection on how the researcher makes connections in the data about the studied phenomenon by examining any underlying assumptions and actions that helped form the codes, categories and theoretical concepts (Charmaz 2006).

### **Reflections on Exploring Methodologies for my Research**

It is becoming increasingly understood that the process of recovery from critical illness is a personal journey where seemingly ordinary everyday patient interactions and encounters in critical care have the potential to influence long term physical, and most certainly psychological outcomes and subsequent quality of life (Herridge & Cox, 2012). Understanding the unique experiences of patients recovering from critical illness is essential to understanding the perceived influence of these daily encounters and interactions within the context of recovery from critical illness. Understanding is central to the interpretivist and constructivist theoretical perspective and therefore an appropriate theoretical perspective from which to approach my research question.

As a clinician, the idea of trying to ‘understand’ instead of ‘fix’ or ‘change’ what I was seeing in practice was very appealing. Understanding is essential in developing meaningful, effective interactions with patients which have the potential to ultimately lead to improved care and outcomes. For instance: understanding becomes extremely valuable in dealing with situations where patients refuse to participate in treatment; it becomes extremely useful in situations where patients are agitated, restless and acting out; and it becomes extremely useful in providing a context in which those behaviours can be explained and addressed appropriately thus facilitating both positive and constructive health care professional-patient interactions, experiences and perhaps outcomes. As such, constructivist grounded theory is an appropriate methodology to understand the process from the perspective of patients recovering from critical illness and allows for the development of theoretical frameworks to inform holistic patient care with the hope to improve long-term patient outcomes.

### **Contributions of Grounded Theory to Understanding the Process of Recovery from Critical Illness**

Two grounded theory studies have explored the process of weaning from mechanical ventilation (MV), a task considered central to the process of recovery from critical illness, from both the patient and health care provider perspective (Jenny & Logan, 1994; Logan & Jenny, 1997). Logan and Jenny (1997) found that despite finding weaning from MV frightening and stressful, patients considered themselves active participants in the process engaging in work such

as sense-making, enduring, preserving self and controlling responses that facilitate the process. Jenny and Logan (1994) found that helping manage patients through the process of weaning from MV revolved around knowing the patient, the work of weaning and managing patient energy; with 'knowing the patient' as central to their clinical reasoning and judgement process when determining a successful therapeutic approach for their patient. Knowing the patient included personal identity, their physical and emotional status as well as their perception of the current situation (Jenny & Logan, 1994).

Chaing (2011) explored how patients perceive the role of informal support from family members during their stay in the ICU and thereafter. This grounded theory study illustrated that patients and family members perceive 'being together' through the process of recovery offers support and facilitates the essential acts of coping and regaining independence; (Chaing, 2011); highlighting a perceived mutual benefit to patients and families during the process of recovery from critical illness. Lastly, a constructivist grounded theory study exploring 'survivorship' following critical illness found that patients perceive surviving critical illness to include a critical period post illness centered on 'moving on' where patients have to redefine themselves within the context of their ICU acquired morbidities and regain control of their life (Kean, et al., 2016). Kean and colleagues (2016) identify that this time period varies among individuals and highlight the absence of health care pathways and policies to help patients and their families negotiate this process.

## **Synthesis and Summary**

Thus far, I have provided an account of the evolution of critical care medicine, tracing its journey from acknowledging the multi-dimensional long term morbidity associated with surviving critical illness, to a paradigm shift within critical care itself where the discipline is being challenged to redefine the concept of outcomes of care to include meaningful longer term patient centered outcomes. I have argued that increased 'understanding' of the process of surviving critical illness is essential to facilitating holistic patient centered care. I have discussed my experiences as a clinician and have provided an examination of its contribution to the philosophical assumptions underpinning my research and have situated them within the context of the historical conversations positioning them within the constructivist research paradigm. Lastly, I have articulated a rationale for using Constructivist Grounded Theory as a methodology to help make my contribution to a larger body of literature informing holistic patient-centered strategies to optimize longer term outcomes in patients recovering from critical illness.

## Chapter 3

### Methods

The purpose of this study was to employ a constructivist grounded theory approach to better understand the process of recovery from critical illness from the patient's perspective. This broad purpose served as a starting point for this research. As this research evolved, a more focussed research question emerged from the data and from elements of theoretical sensitivity; my research question eventually became "how do patients' perceive personal and environmental contextual factors influence the process of their recovery from critical illness?" Grounded theory works inductively to try to make sense of what people say about their experiences, and uses their stories to help form theoretical propositions on a social phenomenon (Stanley, 2006). In this study, individual, semi-structured interviews were completed with a cohort of patients with the end goal to develop theoretical propositions on factors that patients perceive as influential during the process of their recovery, both positively and negatively. This chapter clearly articulates the methodology and methods used in this study; constructivist grounded theory as described by Charmaz (Charmaz 2003, 2004, 2006).

### Ethics Approval

Ethics approval was obtained from Western University's Health Sciences Research Ethics Board (REB# 18857). See Appendix A.



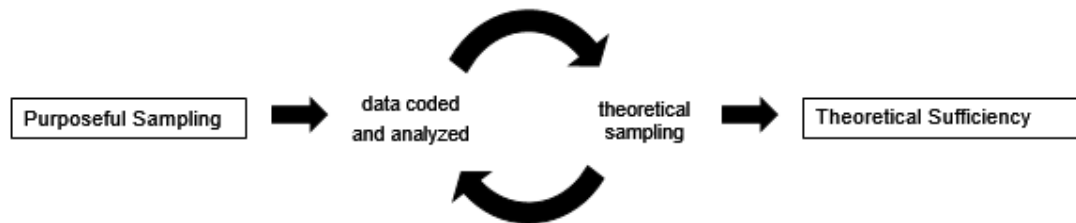
## **Recruitment of Study Participants and Sampling Process**

**Participant recruitment.** Participants were recruited from the medical-surgical ICU (MSICU) and Cardiac Surgery Recovery Unit (CSRU) at London Health Sciences Centre (LHSC), University Hospital in London, Ontario. Participants were also recruited from the Critical Care Trauma Centre (CCTC) at LHSC Victoria Hospital in London, Ontario. A physiotherapist involved in patient care from each respective ICU initially approached patients who met the study inclusion criteria and provided them with a letter of information (Appendix B). Patients who chose to participate contacted me through their nurses or a family members and I visited the patient in their hospital rooms at their requests in order to obtain informed consent and enroll them in the study.

Participants were included in the study if they satisfied the following criteria: 1) medically stable, 2) free of cognitive impairment precluding participation, 3) in the ICU for > 72 hours, 4) able to effectively communicate through verbal or written means, 5) able to understand and communicate in English and 6) be able to provide informed consent to participate in the study.

**Sampling process.** The first round of participant recruitment was conducted via purposeful sampling and potential participants were identified as per the inclusion criteria. After an initial round of purposeful sampling, the data were coded and analyzed. As some preliminary categories began to emerge from the data, theoretical sampling was used to inform subsequent rounds of sampling. This occurred until theoretical sufficiency was achieved (see Figure 1). The later rounds of theoretical sampling focused on recruiting patients who

experienced more complex courses of recovery including prolonged ICU stays, difficulty weaning from mechanical ventilation and had multiple medical complications and 'set-backs' occurring throughout their course of recovery.



**Figure 1. Participant sampling process**

**Participant characteristics.** Seventeen participants were recruited in total. Nine participants were women and their ages ranged from 57 to 84 years old. Diagnosis upon admission to the ICU varied across participants with 5 being admitted with an acute exacerbation of chronic obstructive pulmonary disease (AECOPD), 6 for postoperative complications, 3 with pneumonia and 1 participant each with congestive heart failure, amyotrophic lateral sclerosis (ALS) and multiple trauma following a motor vehicle collision (MVC). At enrolment, participants varied in their stages of recovery from acute to prolonged critical illness, shorter to longer ICU stays and patients just recently discharged from the ICU to the hospital ward. Participants also varied in their experiences of weaning from mechanical ventilation with patients who weaned with less difficulty and those experiencing prolonged mechanical ventilation, having failed extubation at least once. Length of stay in hospital up to time of interview ranged from 6 to 99 days. Table 3 provides information for each participant with respect to age, admitting diagnosis, and LOS in ICU preceding enrolment in this study.

**Table 3****Participant characteristics**

#	Age (years)	Gender	Admitting Diagnosis and Significant Co-morbidities	Days in Hospital preceding interview
1	62	Male	Pneumonia, schizophrenia, Parkinson's disease	6
2	68	Male	AECOPD, prolonged weaning from MV, delirium, depression, previous admission	39
3	62	Male	Post-operative complications, phrenic nerve injury, prolonged weaning from MV	99
4	80	Female	AECOPD, anxiety, delirium	40
5	57	Male	ALS, chronic ventilator dependence, depression, bipolar disorder	73
6	61	Female	Post-operative complications, prolonged weaning from MV	41
7	84	Female	Post-operative complications, prolonged weaning from MV	48
8	61	Female	Pneumonia, previous admission, depression	15
9	80	Male	Pneumonia, acute kidney injury, delirium, prolonged weaning from MV	76
10	66	Female	Post-operative complications, phrenic nerve injury, prolonged weaning from MV	59
11	84	Male	Post-operative complications, prolonged weaning from MV	27

12	67	Female	AECOPD, previous stroke, prolonged weaning from MV	44
13	67	Female	AECOPD, anxiety, prolonged weaning from MV, previous admission	64
14	81	Male	Congestive heart failure, delirium, prolonged weaning from MV	82
15	69	Female	Post-operative complications, prolonged weaning from MV	30
16	68	Female	AECPOD, ventilator associated pneumonia, previous admission	21
17	69	Male	MVC, chest trauma, prolonged weaning from MV	40

## Data Collection Procedures

**One-on-one semi-structured interviews.** I conducted one semi-structured free-flowing one-on-one interview with each participant in their hospital room. Interviews were scheduled in collaboration with the patient's nurse to ensure it did not interfere with patient care. A sample list of open ended questions was used to initiate conversation and guide the early stages of each interview. As the interview progressed, questions were adapted and improvised based on patient responses and the evolving conversation.

A list of sample questions is provided in Appendices C and D; with Appendix C representing the earliest version of the interview guide and Appendix D the revised interview guide. An early assumption based on theoretical sensitivity was that weaning from mechanical ventilation was central to recovery from critical illness, as such, the initial interview guide (Appendix C) focused on aspects of being mechanically ventilated and the process of weaning. It became apparent in the interviews that patients did not consider weaning from MV as distinct or separate from their overall process of recovery. True to the iterative nature of grounded theory, the interview guide was then modified (Appendix D) to better understand the significant milestones of recovery (e.g. showering, eating, drinking, leaving their hospital room) and key activities (e.g. visiting with family, mobilization, exercise) participants identified as central to their process of recovery.

All sessions were audio-recorded with prior informed consent from participants. Interview length varied from 15 minutes to one hour depending on

patient tolerance as determined by myself or their nurse with consideration given to the length of time they could safely and effectively participate in a free flowing conversation, signs of fatigue and stability of vital signs. Rest breaks were provided as needed. Patients were also instructed they were able to stop the interview at any time.

**Field notes.** During the interview process I actively engaged in recording thorough written field notes before and after the interviews, as well as during session breaks. Particular attention was given to the participant's environment and their actions and demeanor during the session (Charmaz, 2004). These field notes were grouped with individual transcripts and consulted while coding, analyzing and interpreting the data.

### **Ethical Considerations**

Patients and families where appropriate were provided detailed information about the purpose and scope of the study. Informed consent was obtained for participation from all participants prior to commencing the audio-recorded interviews. In consideration of the vulnerability of this patient population, ample time was provided for patients to consider participation in this study and it was also made explicitly clear that a decision not to participate would in no way impact their subsequent medical care. Participants were also informed that they could choose to end the interview and subsequent participation at any point during the process.

For patients choosing to participate, the interview was scheduled around the patient's daily medical and rehabilitation routine and was held at a time that

was convenient for both the patient and the medical staff so as not to interfere with any necessary daily care. All patient's were reassured that any data transcribed from the interview would be completely de-identified to protect patient privacy and confidentiality.

Patient tolerance was assessed throughout the interview and interviews were stopped at the discretion of the patient's nurse or by me to avoid fatigue or extreme stress and emotional upset appearing to affect patient well-being. As a result, several interviews were shorter than is typical of this type of research. Moreover, it was decided that in consideration of the extreme cognitive and emotional demand this interview placed on most participants, we would conduct only one interview per patient with the caveat that participants could request a follow-up interview if they felt they had something more to add to the discussion after the first interview; no patients requested follow-up interviews. For these reasons, a decision was made to increase the number of participants enrolled in the study in order to ensure a sufficient amount of data versus conducting multiple follow-up interviews.

### **Data Management**

Each audio-recorded interview was transcribed verbatim by me using word processing software. Each transcript was saved as a Word (Microsoft, Redmond, WA) document for storage and preparation for coding and analysis. Field notes from each interview were also transcribed and embedded as comments throughout the transcripts and saved for easy access and reference during the data analysis process.



## **Data Analysis**

**Constant comparative method.** Grounded theory methods are iterative and non-linear. As such sequencing the methods in a chronological order is difficult. The constant-comparative method involves continuously moving back and forth between data collection and data analysis. Throughout this process, comparisons are made at each level of analytic work, comparing data with data, data with categories, categories with categories and categories with concepts (Charmaz, 2006) in order to spark new questions, insights and perspectives that drive subsequent data collection and analysis. An interwoven cycle of theoretical sampling, data collection, data analysis, memoing, sorting and diagramming continued until a robust theory could be constructed from the successively more abstract categories and concepts emerging from the data.

**Theoretical sampling.** Theoretical sampling is a method of seeking out relevant data to help build and substantiate an emerging theory (Charmaz, 2006). Charmaz (2006) describes initial sampling as a starting point, and theoretical sampling as a technique to direct where to go from there. We conducted 2 rounds of initial sampling based on our inclusion criteria, after initial coding and analysis, the emerging categories drove subsequent rounds of data collection and participant sampling.

An example of the use of theoretical sampling in this research project is illustrated both in the evolution of the type of patients selected for later rounds of data collection. As data emerged reflecting the importance of both 'the person' and 'the environment' in the process of recovery, participants were selected

based on their perceived ability to further expand these theoretical dimensions. This led to the theoretical sampling of patients with more prolonged and complicated courses of recovery, experiences with delirium, anxiety or depression, and individuals with previous ICU admissions.

**Reflexivity.** Reflexivity involves the act of examining one's experiences, knowledge and preconceived assumptions which inherently and inevitably shape inquiry and the outcomes of a study (Charmaz, 2006). Throughout this process, I engaged in reflexivity throughout the data collection, data analysis and theory construction process. I was able to articulate and examine my preconceived notions through memoing and diagramming the connections I was beginning to make. I also regularly consulted my thesis supervisor throughout this process to explore additional external resources that may enrich and enlighten my views during data analysis and theory construction. I have also disclosed my experiences, assumptions and worldviews throughout this paper, which will help the reader further determine how I may have shaped the outcomes of this inquiry.

**Coding.** Once transcribed, all data were initially analyzed via line-by-line coding. Each line of text was examined and assigned a code that defined the action or event in the line (Charmaz, 2004). Line-by-line coding can help you think about the data in new and different ways and can help keep the researcher close to the data, allowing the building of an analysis "from the ground up" (Charmaz, 2004).

The next major phase of coding was focused coding. This involved identifying and selecting the most significant codes assigned in line-by-line coding and then using these codes to sift through larger sections of data (Charmaz, 2003). Decisions were made about what codes made the most sense to most adequately and succinctly categorize the data (Charmaz, 2006). This involved merging and collapsing codes based on what made most analytic sense.

Theoretical coding was then used to explore the relationships between focused codes and facilitated conceptualization of the data into theoretical categories and concepts that told our participants' stories and helped shape the grounded theory (Charmaz, 2006). Theoretical sensitivity helped guide theoretical coding; my theoretical sensitivity was informed by the literature review, as well as my disciplinary perspectives and philosophical assumptions disclosed in earlier chapters.

**Sorting and diagramming codes, categories and concepts.** Once theoretical categories emerged, the constant comparative method, concurrent with ongoing sorting, memoing and diagramming, was used to create a conceptual framework to organize the theoretical codes and categories under three major theoretical concepts. Appendices E, F and G illustrate three separate points in time during the process of analyzing, sorting and diagramming the theoretical codes and categories into theoretical concepts. Time point one (Appendix E) illustrates the initial groupings after focused coding, time point two (Appendix F) illustrates sorting and regrouping during theoretical coding, and

time point three represents the emergent theoretical concepts contributing to theory construction. Appendix H illustrates an example of data sorting for one data set, the isolation theoretical codes organized with respect to the associated theoretical category and concept.

**Memo writing.** According to Charmaz (2006), memos are written analytic notes that capture thoughts, connections and comparisons sparking ideas to guide theoretical sampling and theory construction. It is an essential step between data collection and theory construction that prompts early analysis of data leading to an increased abstraction of ideas (Charmaz, 2006). I used memos to help organize codes and categories into theoretical concepts that formed the basis of my grounded theory. Sample analytic memos are provided in Appendix I.

**Theoretical sufficiency.** Theoretical saturation, in grounded theory, is the criterion that signals the end of data collection (Chramaz, 2006). This criterion involves achieving a point in data collection where collecting additional data no longer gives rise to new categories or theoretical insights (Charmaz, 2006). Grounded theory is an iterative and ever evolving process. Moreover, recovery from critical illness itself is a complex phenomenon. In consideration of this, theoretical 'sufficiency' was deliberately chosen as our end point, acknowledging that additional insights likely exist; however, for the purpose of this study, sufficient data to support theory claims was collected. Our final two interviews both reiterated and reinforced our theoretical concepts, so this served as confirmation that additional recruitment would not provide any additional

connections between our established theoretical categories and concepts. This signaled the end of the theoretical sampling and data collection and our efforts were then refocused on theory construction and refinement.

### **Quality Considerations**

Quality considerations of: 1) credibility, 2) originality, 3) resonance and 4) usefulness in keeping with grounded theory as described by Charmaz (2006) were addressed to provide evidence of this study's rigor and quality.

**Credibility.** Credibility speaks to the extent to which there are enough data to substantiate our study's claims and the extent to which we are able to satisfy the reader that we have achieved an intimate level of familiarity with this patient population and practice setting. Credibility was ensured by gathering multiple perspectives and sufficient thick rich descriptions to support our theoretical concepts. Our theoretical concepts are supported by exemplar quotes in Chapter 4 and this allows the reader the opportunity to independently assess the connections among the categories and concepts that informed our grounded theory.

**Originality.** Charmaz (2006) defines originality as the extent to which the categories and concepts offer new insights and challenge current practices. The impact of personal and environmental factors on the process of recovery from critical illness is not well appreciated or understood. The development of a theory in support of the perceived influence of these factors on the process of recovery makes an original contribution to the existing body of literature.

**Resonance.** Resonance reflects the degree to which our inquiry and study outcomes have portrayed the fullness of the experience of recovery from critical illness and the extent to which it makes sense and provides deeper insights within the context of what is already known about this experience (Charmaz, 2006). Resonance was achieved by assessing the degree to which our theory both fits and perhaps even challenges the predominate theories in the current literature and explores how our contribution offers a more comprehensive understanding of this phenomena. Member checking was deliberately not done because we felt that the cognitive demands and the attention required to complete this task were not appropriate for the majority of our participants.

**Usefulness.** Usefulness suggests that the theory contributes dimensions of increased understanding to an existing body of knowledge, in turn sparking further questions and research in the area (Charmaz, 2006). The insights from this study can be used to facilitate better understanding of the process of recovery from critical illness, thereby fostering development of more comprehensive, patient-centered management strategies leading to improved long term patient outcomes.

## **Summary**

This chapter has provided a detailed account of the methods used in this study as a means of demonstrating rigor in this research. In the following chapter, the data collected from interviews with the 17 participants is presented in groupings according to their respective theoretical codes, categories, and

concepts. These theoretical categories and concepts form the foundation of the grounded theory that emerged.

## Chapter 4

### **Constructing our Grounded Theory**

The major theoretical concepts emerged from data analysis were critical illness and the care environment, the person and human connections, most notably in the form of family connection. These three theoretical codes served as a starting point for theory construction. In this chapter, I have presented exemplar quotes representing each theoretical category and code ultimately contributing to our final theoretical constructs, allowing readers to draw their own conclusions on the extent to which our data supports our theory. Each theoretical category is further indicated as either a barrier to or facilitator of recovery, as perceived from the patient perspective.



## Critical Illness and the Care Environment

Critical illness and the care environment emerged as one of three main theoretical concepts in the data. The theoretical categories comprising this construct were isolation, disempowerment, emotions and mental functions with each having several contributing theoretical codes. With the exception of 'progress inspiring hope', all theoretical codes and categories appeared to be barriers to recovery.

**Isolation.** Experiences of physical and social isolation as a product of the participants' immediate environment were evident in this data set. Several participants described experiences of isolation negatively impacting their process of recovery.

### ***Physical isolation*** [barrier to recovery].

Participant #5: ...*I am just stuck in a room all day, and I am stuck in this chair*

Participant #10: ... *[I want someone] to just understand how I feel ... I'm stuck...*

Participant #4: ...*[I] just lie in here [referring to her hospital room] quiet [all day], and that's hard to do*

### ***Social isolation.*** [barrier to recovery]

Participant #11: *I have one visitor a day for 20 minutes. [It's] frustrating [and it makes the day] very long. To talk to someone, just to talk [for] 5*

*minutes is sometimes like 5 years to someone. [Talking] to someone give[s] me that bridge and the mood change...*

Participant #13: *[describing their day] ...sitting all the time by yourself, [makes me] think too much...*

Participant #10: *Company... that's always a big help. Enough? Well not nearly enough... you always want more.*

**Disempowerment.** Critical illness and the care environment contributed to negative experiences of disempowerment, specifically in patients' perceived loss of control and loss of voice throughout recovery.

**Loss of control.** *[barrier to recovery]*

Participant #10: *...you are very restless...when you are coming to from the sedation, so you...are moving [and] trying to pull on things, so they have to tie your arms down and that's very hard. It's very hard to be in one position all the time. ...you know when you're lying in bed, how many times do you turn and move? It's a lot, but when you're on these equipments, you can't move until somebody comes along and moves you.*

Participant #15: *I kept pulling on my [restraints] and I kept looking at them and looking at my arm and looking at them. ... That was a hell of an experience I went through... I wouldn't want that for anybody.*

Participant #9: *They [the health care team] come around and prod you and poke you, take blood and stuff... walk in and out. I don't have any*

*control over it. I mean, it's not pushed on me...they got to do what they got to do... just gotta do it.*

*Participant #7: Some mornings, like this morning, I woke up at 3 o'clock...and they wouldn't let me get up cause it's too early and [fidgeting, trying to catch their breath] I've lost my train of thought.*

**Loss of voice.** *[barrier to recovery]*

*Participant #8: I've had six or seven surgeries at least, it's just a feeling of alienation when you can't talk...you feel like screaming.*

*Participant #16: I was trying [to talk], trying to make them understand what I was saying and it was hard. I was trying to ask them questions and they was asking me questions and I was trying but I couldn't get it out.*

*Participant #15: ...I can't talk... [a nurse] was [asking] "can you feel this, can you feel this"? ...she didn't give me a chance to answer [implying asking too quickly] because I couldn't answer because I didn't have a voice.*

*Participant #10: You can't talk so if you [have to] ask anybody anything, you have to write it down. At the very beginning you almost feel like you just want somebody sitting there doing your every move. You have to write it down unless they can lip read, ...[writing] is hard because your hands are not coordinated enough to write, so your writing is terrible and sometimes you couldn't read it.*

**Emotions.** Participants experienced a variety of emotions during the process of recovery; largely negative emotions perceived as barriers to recovery. Overwhelming accounts of negative emotions including frustration, anxiety, fear, hopelessness, loneliness, sadness and boredom were experienced by participants contributing to significant emotional distress. Participants also described the emotional toll of the ‘progress and set-backs rollercoaster’ of recovery, reporting an exponentially devastating emotional impact buoyed to a small extent by periods of perceived progress which inspired hope thus facilitating recovery.

***Frustration.*** [barrier]

Participant #11: *...you are dying [and] you cannot talk...you write. My handwriting, I no Shakespeare but you know, you're sick. "What's that, what's this"? [referring to nurses asking what he has written]. It is so simple, instead of 'I' I put 'e' [referring to an error in writing a message to his nurses]. Anyways, I call them a really bad name inside me, very frustrating.*

***Anxiety.*** [barrier]

Participant #7: *[speaking about trying to breathe independent of the mechanical ventilator] I want to but I know that mentally, that's my big problem. I feel that I can't breathe without it and I know that I have to get off of it in order to recuperate, but it doesn't help.*

**Fear.** [barrier]

Participant #7: *I debated about having [this] operation but the doctor said eventually I wouldn't be able to breathe because my aortic valve was shrunk so; it's about the size of a pencil and it's supposed to be the size of a loonie. I figured, I don't think I'd like to die not being able to breathe and now I feel like I am in that position, that I am going to stop breathing.*

Participant #17: *Well nighttime [is tough]. I just go to bed and go to sleep and just hope [I] wake up in the morning.*

**Hopelessness.** [barrier]

Participant #12: *The feelings and the thoughts are [are] overwhelming, very overwhelming... that [I] can't do it, that [I] won't be able to do it, that [I] won't get through it.*

**Loneliness.** [barrier]

Participant #11: *I don't have a visitor. ... I have one visitor a day for 20 minutes. Frustrating. Very long. It was only loneliness.*

**Sadness.** [barrier]

Participant #6: *I have no interest in doing anything right now, I just don't. Like when I've been in the hospital before, I've done colouring, I've brought my books in, but I just have no desire...Like last week, I was crying a lot in front of my husband.*

Participant #16: *I was a little sad. I'm on pills, they got me on pills now. Being away from home, away from my hubby, away from the cats.*

**Boredom.** [barrier]

Participant #2: *[describing a day in the ICU] There wasn't a whole lot that you did. [You] just basically laid in bed until you were well enough to get up and start going on walks and what not.*

Participant #11: *I have my Ipad, I use it from time to time. Email to my daughter or something, keep me busy, and then I like those puzzles... but it is a long long long day waiting until 10 o'clock so they can give me a needle and go to sleep. That the best part of the day. Yup.*

**Progress and set-back rollercoaster.** [barrier]

Participant #10: *Well I was making progress, but I have ups and downs and right now seeing that I have been here so long, when I get the downs, they are devastating. The downs meaning that when they tell you, you might go back on the vent... the whole process [of weaning] has to start again. And they will tell you it's one small step backwards but it feels like one giant step backwards*

**Progress inspiring hope.** *[facilitator]*

Participant #2: *[speaking about weaning from mechanical ventilator] It felt pretty good. You know you're getting there, your advancing to getting better. Making progress.*

Participant #8: *[speaking about extubation] You just feel a sense of empowerment.*

**Mental functions.** Patients consistently reported experiences of impaired mental function throughout the process of recovery. The theoretical categories included experiences of delirium, fragmented memory, distorted perception of time and an inability to concentrate; all negatively influencing the process of recovery.

**Delirium.** *[barrier]*

Participant #17: *Yesterday I got up at 1 o'clock...I have a demon problem. I don't know why, I never did before. I get hallucinating being in the war fighting. The nurses are short staffed here, I get it, but I'm in here to get better and get looked after and they get a little peeved with me. Can't blame them.*

Participant #16: *[speaking about an early memory in the ICU] I didn't know where I was and I was fighting with somebody. I don't know if I hurt somebody [or] what I said to them. ...They had my arms strapped down and they was holding me back and I'm fighting. They were scared I'm going to hurt myself. I felt bad.*

**Fragmented memory.** *[barrier to recovery]*

Participant #2: *Well, when you get that sick, you don't remember a whole lot you know, that's the problem*

Participant #12: *There [are] a lot of things I don't remember ...people say I've come so far, but I don't remember. See because, I don't remember coming into the hospital. I remember going into the ambulance but that's all I remember until I got to where I am now.*

**Disorientation to time.** *[barrier to recovery]*

Participant #13: *[speaking about passage of time] I didn't know it was 2 months, well it didn't seem like 2 months. I was surprised, [it seemed] shorter to me. But then I look at the clock I'll say 'it's only that hour, it [seems] longer...'*

Participant #8: *Time goes so slow, and well actually when your first here, time goes really haphazardly.*

**Inability to concentrate.** *[barrier to recovery]*

Participant #10: *...the problem I have is because I am sick, I can't concentrate on reading a book or doing puzzles or actually entertaining myself.*

Participant #11: *...they have [a] TV, 1930 press the button [laughing, describing the television]. No I couldn't [watch tv], I couldn't concentrate on things.*



Participant #17: *I tried to do crossword puzzles but it didn't work.*

## **The Person**

The second major theoretical concept that emerged from the data was 'the person'; the individual experiencing their own distinct and unique process of recovery. The theoretical categories contributing to this construct included mental health and personal traits. Mental health encompassed the patient's pre-existing mental health status, while personal traits referred to patients' individual coping styles, determination and life experiences, all helping to positively shape the process of recovery from the patient perspective.

**Mental health.** A pre-existing past medical history of anxiety was the lone contributing theoretical category. It was perceived to have a negative influence on the process of recovery limiting participation and engagement in the process.

***Anxiety. [barrier to recovery]***

Participant #7: *I am prone to panic attacks. I was on medication that they took me off of when I came in here and I'm back on it now, but its taking a while for it to take effect and they are waiting for that level to hit, I think.*

Participant #13: *Only thing I can say is do your best... you know, like try to walk, do whatever the nurses and the doctors tell you... If you're not a nervous person that helps too, but I've got that problem.*

**Personal traits.** Coping strategies, determination and life experiences comprised the personal traits that participants attributed to helping them through

the process of recovery. Patient's engaged in a variety of strategies to help them through stressful periods including practices of mindfulness, asking questions to promote reassurance and breaking their 'work' up into manageable pieces all to facilitate the end goal of getting home. Possessing self-determination was perceived as an attribute to getting through difficult periods, as was having previous experience with critical illness or the medical system.

***Coping strategies.*** [facilitator]

Participant #11: *[speaking about getting through difficult periods] I'm a big fighter. I close my eyes and find something in my background and that [becomes] the thing in my mind. Not the physical things like cutting the grass, but sitting in the sunshine, something beautiful like that, [and] definitely remember[ing] the good ole days in my life. I pick things in my mind, close my eyes and I see it. Could be 10 seconds or 2 minutes, but that relax me.*

Participant #2: *You know I am not bashful about asking questions. I like to know what I am dealing with. I was a bit petrified.*

Participant #5: *You set goals for yourself, one goal for each day, not the big goal though [going home]*

***Determination.*** [facilitator]

Participant #8: *[speaking about working through set-backs] If at first it doesn't work, don't give up, try again... It's somewhere in you to do it*

Participant #11: *[speaking about working through set-backs] I didn't want to give up. I don't want to die. I promise my granddaughter I don't die unless she finish and she bring me [her] doctor diploma. I hang it in my room, and then after that I leave.*

**Life experiences.** *[facilitator]*

Participant #2: *[talking about waking up in the ICU on a ventilator] Other than not being able to talk, it was kind of different, but I had went through the experience before eh, so I knew the drill kind of. You went through kind of steps.*

Participant #8: *I think with everybody [this process] is different. I used to do this type of work... so I kind of know the whole system, changes your outlook on everything, you know.*

## **Human Connection**

The desire for human connections during recovery emerged as a reoccurring theme throughout the data and formed the final theoretical concept. Specifically, connections to family, the health care team, home and the outside world were perceived as essential to recovery.

**Family** *[facilitator]*. Patients perceived family as central to recovery.

Family was observed to fill multiple roles in the patient's recovery; most notably family was perceived as a source of comfort, encouragement, reassurance and acted as caregivers when needed. The importance of continuous family

interaction and their positive influence on the process of recovery are illustrated below.

Participant #5: *They told [my wife] when I first came into the hospital that they wouldn't be able to get me off of the ventilator but she was there to help me through it.*

Participant #15: *Untie me [asking the nurse to untie her arms]. Put them around my family, they held my hand. The closeness of [my] family helped me realize I wasn't in hell and that I could go on.*

Participant #16: *Once my husband or my daughter or my son comes up, I'm alright. As soon as they go, I'm off into no-man's land. [my family] helped me a lot, made me feel better, gets me laughing and gets me going. I enjoyed it.*

Participant #2: *I have family and support, really wonderful support. ...they took turns coming up and I had people here everyday. They took turns, one was here at lunch and another at night, everyday!. And it's that kind of support that really helps, it really does. Especially mentally, just being there, their presence.*

**Relationship with the health care team** [facilitator]. Developing a relationship with the health care team was also perceived as positively influencing the process of recovery. Participants reported relying on and trusting their team to guide them through the process. Participants also sought comfort, encouragement and reassurance from the health care team in absence of family.

Participant #10: *You just have to know that [the health care team is] doing the right thing for you. They are not going to put you back on [the ventilator] if you don't need to be and they help you through by explaining, "it's not 10 steps backwards it's just a quarter of a step backwards"*

Participant #10: *Empathy helps, sympathy doesn't help. Sympathy, I don't need anybody going, ah you okay? What's wrong? I'd rather have somebody working...with you to build up the hope.*

Participant #7: *A couple of times I've asked nurses to hold my hand while I try to go to sleep and that helps some times.*

Participant #4: *Taking baby steps... that's what they [the health care team] tell me*

Participant #6: *[speaking about what helped during weaning from mechanical ventilation] I think just the nurses and the doctors and my husband talking to me... 'this is the next step to get you off this floor'. The nurses would have to tell me ...'calm down, take your breaths'. I need someone like that.*

**Connections to home and outside world.** Connections to home and the outside world emerged as the final theoretical category. Patients drew strength and motivation from connections to home through photos, texts and video messages. Patients also reported windows as helpful in the process of recovery in that they also served as a source of motivation and provided a connection to the outside world they were hoping to once again become part of.

Participant #15: *I look at my pictures and hold them in my arms and say prayers. [pointing at a photo of home] My husband built the thing, that's my dog, there's not anything you can't do with that dog, he's very well behaved. My husband [pointing at another photo] This is what I get to go home to.*

Participant # 6: *[My husband] would send them emails, [my grandchildren] just sent a video that said 'hi grandma'. I mean that's why I want to get home, they're my life.*

Participant #15: *I look out the window and think of home. I look out the window, I see people walking...I'm going to be out there soon, yup.*

### **Summary and Synthesis of Results**

Patients perceived themselves, their environment and human connections, most notably in the form of family however individually defined, as central to the process of recovery from critical illness. As such, critical illness and the care environment, the person and human connection were the three main theoretical concepts used to incisively organize and group the data. True to the iterative nature of grounded theory, and although used a starting point for theory construction, these concepts continued to evolve throughout the process into slightly more abstract constructs ultimately used as building blocks for theory construction. These theoretical constructs and our grounded theory are revealed in Chapter 5.

## Chapter 5

### The FaCeT Grounded Theory of Recovery from Critical Illness

Participants perceive **F**amily, the **C**are **e**nvironment and aspects of **T**he person (**FaCeT**) as central to the process of recovery from critical illness. These essential theoretical constructs provide key insights into factors that are perceived to influence recovery, both positive and negative, thereby helping to inform the development of more comprehensive management strategies aimed at improving long-term patient-centered outcomes following critical illness. The FaCeTs of recovery identified as integral to the process of recovery from the patient perspective are outlined in Figure 2. The complex interplay of these theoretical constructs during recovery is illustrated in Figure 3.

Family	The Person	Critical Illness & Care Environment
<ul style="list-style-type: none"> <li>• connection to people, home, outside world</li> <li>• roles</li> </ul>	<ul style="list-style-type: none"> <li>• mental health</li> <li>• personal traits</li> </ul>	<ul style="list-style-type: none"> <li>• isolation</li> <li>• disempowerment</li> <li>• emotions</li> <li>• mental functions</li> <li>• health care team</li> </ul>

**Figure 2. The major theoretical constructs in recovery**

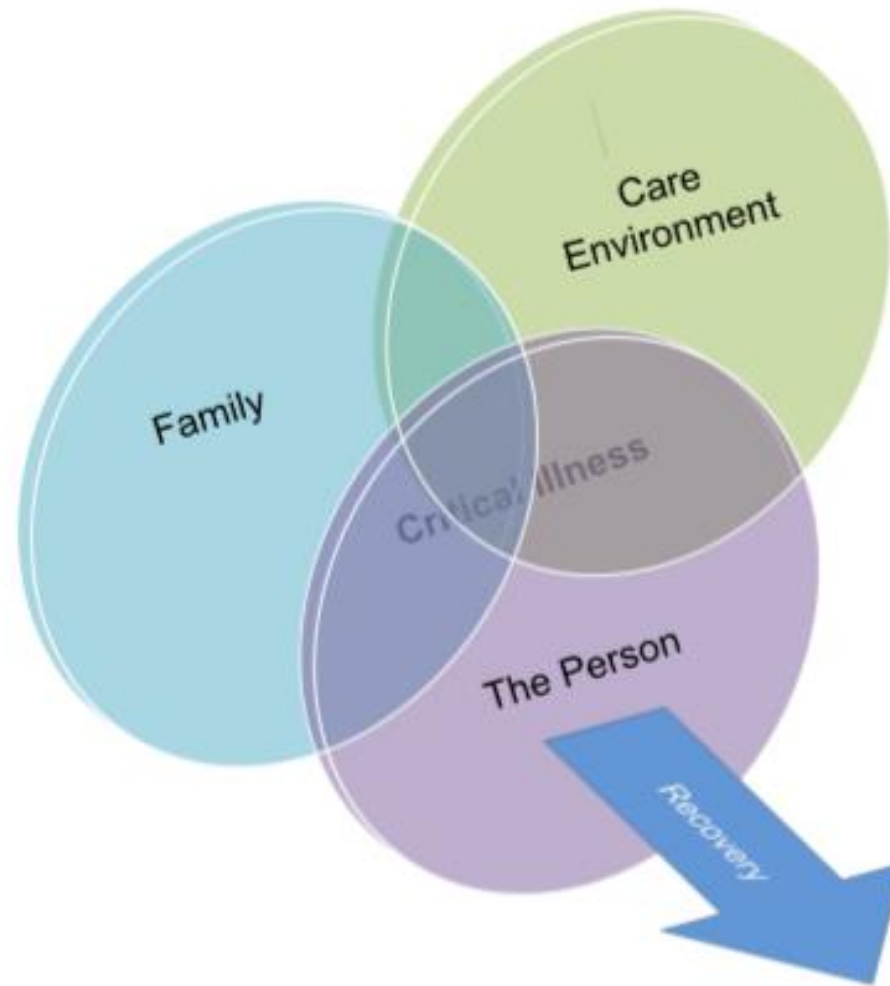


Figure 3. The FaCeT grounded theory of recovery from critical illness



### **FaCeTs of Family during Recovery**

Participant's yearned for a human connection throughout the process of their recovery. This was realized through interactions with people in their immediate environment and most notably in interactions with family. Participants perceived family, however individually defined, as central to the process of recovery. In addition to providing comfort and a reassuring presence, family also filled multiple roles integral to the process of recovery including acting as care givers, motivators and conduits facilitating connections to home and the outside world. In the absence of family presence, patients looked to their health care team to help facilitate these essential connections.

### **FaCeTs of the Care Environment during Recovery**

The critical care environment, comprised of the patient's immediate physical environment including their health care team, played a pivotal role in shaping the process of recovery from critical illness. Critical illness and the physical care environment were perceived to contribute to negative experiences of isolation, disempowerment, and contributed to significant emotional and psychological distress.

One positive and essential component of the environment was the health care team. Participants inherently trusted them as their guide through the process of recovery and sought them out for comfort and reassurance when needed. Another positive aspect of recovery was the experience of making progress and perceived gains in recovery; this inspired hope for continued

recovery and patients reported drawing on this as a source of strength and motivation.

### **FaCeTs of The Person During Recovery**

Dimensions of the person also influenced recovery; the person included dimensions of their personal attributes and life experiences, both positive and negative, as well as their pre-existing mental health. Anxiety emerged as a barrier to recovery while coping strategies, previous experience with critical illness and self-determination appeared to be facilitators throughout the process. Participants perceived themselves as active participants of the process engaging in activities reflective of their individual experiences and coping styles as a means of facilitating recovery.

### **FaCeTs of Recovery: Resonance and Discourse on the Role of Family**

Daily connections and interactions with family emerged as essential to facilitating the process of recovery from critical illness from the participant's perspective. It is becoming increasingly understood that family members, like patients who are critically ill, also emerge changed from the experience of critical illness, exhibiting similar symptoms of psychological and psychosocial morbidity following recovery. This newly appreciated phenomenon has been called PICS-F (Elliott et al., 2014; Needham et al., 2012) and has prompted increased family involvement during the process of recovery from critical illness with the hope of improving outcomes for both patients and their families. Despite lack of consensus on the effect of increased family participation as an adjunct therapy on the family members themselves, there is evidence to suggest that increasing

family support and participation during the process of recovery is beneficial for patients (Deja et al., 2006; McAdam et al., 2008).

Deja and colleagues (2006) evaluated the effect of social support from family and caregivers, in combination with professional psychosocial counseling, on overall patient mental health and quality of life following recovery from critical illness. The results of that study concluded that increasing both formal and informal social support during recovery improved longer term outcomes for patients (Deja et al., 2006). McAdam and colleagues (2008) expanded on the perceived contribution of family during the process of recovery, concluding that family is essential to making patient's feel safe, comfortable and protected. Family was also perceived to provide encouragement and play the role of advocate and communicator, enhancing communication between the patient and their health care team; all perceived to facilitate recovery (McAdam, 2008). Chaing (2011) further expanded on the perceived influence of family support during the process of recovery by demonstrating that both patients and family attributed survival as being a product of their mutually 'being together' during the process of recovery.

Participants in our study were seen to echo similar perceptions on the influence of family during the process of recovery. Family served as an essential connection to people, home and the outside world providing patients a source of comfort and reassurance in difficult times during recovery. Family was also similarly perceived to fill multiple essential roles during recovery including acting as informal caregivers, sources of strength, and acting as coaches providing the

necessary encouragement and motivation for patients to keep fighting. These findings highlight the importance of family interaction during the process of recovery and provide important insight into the utility of family as a therapeutic intervention during the process of recovery from critical illness.

### **FaCeTs of Recovery: Resonance and Discourse on the Perceived Influence of the Environment**

**Emotions, isolation and disempowerment.** Participants of this study reported overwhelming accounts of significant emotional distress including frustration, anxiety, fear, hopelessness, loneliness, sadness and boredom. Moreover, participants described feeling isolated and disempowered as a result of the critical care environment. Our findings are consistent with the qualitative accounts of ICU experiences reported in several previous studies.

Cook et al (2001), conducted a qualitative review of studies examining experiences of patients weaning from MV, a key component in recovery from critical illness, and found that experiences of frustration, uncertainty, hopelessness, fear and lack of mastery were reported during the process of weaning. Experiences of frustration, fear, isolation, anxiety and symptoms of depression in our study appeared to be a product of the environment and critical illness itself. Participants' inability to effectively communicate as a result of being mechanically ventilated, having a tracheostomy or lacking the coordination, cognition or concentration to be able to communicate effectively in written form contributed to these feelings of frustration, isolation and emotional distress. Feelings of isolation and disempowerment also appeared to be brought on by

patients' dependency on health care staff for mobility and self-care as well as their perceived lack of control over daily activities and were further exacerbated by the use of physical restraints for patient safety.

Anxiety appeared to be provoked by activities inherent to the process of recovery such as daily mobilization and spontaneous breathing trials, while many symptoms of fear and depression surfaced when patients became impatient with perceived lack of progress in achieving these milestones. Moreover, participants were significantly distressed when they experienced set-backs in their recovery; eliciting fears that they may never get better. The cumulative tolls of these set-backs were reported to have exponential detrimental effects on emotional status; buoyed to some extent by periods of significant progress and achievements in their recovery, such as breathing independently of the ventilator for significant periods of time and walking in the halls with assistance. These periods of progress served to inspire hope and provide motivation to continue, however their influence was perceived as disproportionate to the effect of set-backs in recovery.

The extent to which these ICU experiences explain outcomes of recovery is not clearly established. There is however, a growing consensus that these experiences, in particular anxiety, symptoms of depression, frustration and alienation due to the inability to communicate, are not only associated with but are likely contributors of long term morbidity following recovery from critical illness (Desai et al., 2008; Gosselink et al., 2008; Lindgren & Ames, 2005; Needham et al., 2012; Nelson et al., 2010; Nelson et al., 2000). These

experiences, all occurring largely as a product of the patient's environment, provide valuable insight into the influence of emotional well-being on the process of recovery and can be used to foster more holistic patient-centered practices that optimize long term patient outcomes.

**The health care team.** The health care team emerged as the lone aspect of the critical care environment perceived to facilitate recovery from the patient's perspective. Patients described a need for human connections during the process of recovery, and daily interactions with their health care team offered one possible opportunity for such connections and interactions. Participants in our study reported inherently trusting and relying on their health care team successfully guide them step by step through the process of recovery and in the absence of family, sought them out for comfort during times of emotional distress.

These findings are consistent with two qualitative studies exploring the role of care givers in the critical care environment. Hupcey (2000) concluded that patients in the ICU experience an overwhelming need to feel safe in their environment and patients look to their health care team to foster those feelings of safety. Specifically, patients looked to the ICU staff help them feel safe by helping them understand what was happening to them, regaining control over their situation, inspiring hope and trust, and to watch over them throughout the process of recovery. Additionally, Logan and Jenny (1994) found that nurses, through knowing the patient and the work of weaning from MV, were able to assist patients through the process of weaning specifically by helping to manage

patient energy expenditure and anxiety. Our study, in combination with the results of these previously published studies, support the notion that both patients and health care providers perceive the therapeutic relationship as essential to the process of recovery, underscoring the importance of these daily patient interactions in facilitating optimal recovery.

**Mental functions.** The term PICS is used to describe a constellation of physical, cognitive and mental health related impairments occurring as a result of critical illness and persisting well beyond hospital discharge (Elliott et al., 2014; Needham et al, 2012). These impairments include: 1) mental health symptoms of PTSD, anxiety and depression; 2) cognitive impairments including memory, attention, visual-spatial deficits, impairments in executive function and processing speed, and 3) pulmonary, neuromuscular and physical impairments contributing to impaired physical function (Davidson et al., 2013; Desai et al., 2011; Elliott et al., 2014; Mikkelsen et al., 2012; Needham et al, 2012).

Despite very few descriptions of physical disability, participants in our study described vivid images of emotional, cognitive and psychological impairments consistent with PICS occurring during their process of recovery from critical illness. Participants reported distressing accounts of hallucinations and paranoia related to episodes of delirium. They also reported fragmented memory and disorientation to time further contributing to experiences of psychological distress. Lastly participants reported a limited capacity for concentrating on tasks, precluding participation in many daily activities to help pass time and also

impairing their ability to effectively communicate through verbal and written means; all contributing to heightened experiences of frustration.

The prevalence of ICU related PTSD and its increasingly understood contribution to poor long-term patient-centered outcomes such as marital instability, inability return to work and social function and decreased quality of life has inspired a 'call to action' for researchers to better understand how to prevent and treat this phenomena. The female gender, experiences of delirium, traumatic memories, use of sedation, pre-existing mental health issues and prolonged ICU stays have all been associated with an increased risk of developing ICU related PTSD following recovery from critical illness (Hatch et al., 2011). Understanding risk factors allows for the early identifications of individuals susceptible to PTSD and early targeted interventions to mitigate their effect.

Several studies have explored novel interventions such as the use of ICU diaries (Jones et al., 2010), the addition of clinical psychologists to the ICU team allowing for early psychological intervention during recovery (Peris et al., 2011) and telephone-based follow-up interventions after discharge (Cox et al., 2012); all shown to positively influence longer term patient outcomes. The findings from our study further contribute to this body of research by identifying aspects of the environment also perceived to contribute to the emotional and psychological distress associated with critical illness and recovery; potentially informing future research aimed at mitigating their influence on outcomes.



## **FaCeTs of Recovery: Resonance and Discourse on The Person Shaping Recovery**

Patients perceived themselves as active participants during the process of recovery. Logan and Jenny (1997) found that during the process of weaning from MV, patients engaged in a variety of cognitive, emotional and physical activities they perceived influential to the success of weaning. Similarly, participants in our study actively engaged in a variety of activities as a means of facilitating recovery. These activities were reflective of their individual experiences and coping styles and included active practices of mindfulness, breaking up the 'work' of recovery into manageable pieces, drawing on previous life experiences as a means to help them through and lastly actively deciding to remain determined throughout the process.

Similarly, the process of active engagement may extend beyond discharge. Kean and colleagues (2016) theorized that survival also incorporates the process of 'moving on' and that patients need to engage in practices of redefining themselves in terms of life after critical illness in order to successfully do so. This involves patients negotiating multiple transitions after survival and discharge home, all occurring on individual timelines. These findings suggest that active patient engagement is likely a significant contributor to positive outcomes of recovery, both short and long term, and can be used to inform individualized patient-centered management strategies aimed at facilitating recovery from critical illness.

Only one aspect of the person emerged as a barrier to recovery; this was the presence of pre-existing mental illness, in particular anxiety. Interestingly, the perceived influence of anxiety is consistent with previous findings in the literature. Hatch and colleagues (2011) cited pre-existing mental health issues as a risk factor for PICS and long term ICU-acquired morbidity, underscoring the importance of the person and their inherent individual impact on the outcomes of recovery.

### **FaCeTs of Recovery: Reinforcing the Multi-Dimensionality of Recovery**

Recognition of the ICU acquired morbidity associated with surviving critical illness has brought about a shift when considering factors that influence patient outcomes. It is becoming increasingly appreciated that determinants of recovery and outcomes critical illness are likely multi-factorial, extending beyond physiological factors associated with recovery to include aspects of the person and their environment. The ICF (WHO, 2001) model of health and disability is a theoretical framework that acknowledges the importance contextual factors such as personal and environmental factors in determining health status and outcomes. The ICF also provides a framework for examining the complex interactions among these factors, fostering continued meaningful exploration of the influence of these contextual factors on recovery from critical illness.

The FaCeTs grounded theory of recovery suggests that patients perceive factors inherent in themselves and within their environment as influential to the process of recovery. Our theory, grounded in the individual narratives of our participants, identifies several contextual factors perceived to influence recovery

from critical illness, but this study is simply a starting point. These findings, framed within the context of a biopsychosocial model of care, can serve to inform future research aimed at better understanding the perceived influence of personal, psychological and environmental factors on recovery from critical illness.

### **FaCeTs Informing Care to Improve Long-Term Patient Outcomes**

Recognition of the ICU-acquired morbidity associated with surviving critical illness has also brought about a shift when considering meaningful, patient-centered outcomes of care. 'Survivorship', the next big challenge in the evolution of critical care medicine, speaks to long term outcomes of critical illness. It is no longer acceptable to define 'survivorship' within the context of mortality and ICU LOS, but rather by meaningful long-term outcomes of care such as return to work and social function and quality of life after discharge.

The FaCeTs grounded theory of recovery suggests that optimizing long-term patient-centered outcomes requires careful consideration of individual aspects of the person and their environment and their potential influence on the process of recovery. Moreover, our theory again only serves as a starting point in identifying potential factors perceived to influence recovery, opening a dialogue on ways to mitigate or optimize perceived barriers and facilitators of recovery respectively. A greater understanding of the influence of these contextual factors on recovery can foster the development of innovative holistic treatment strategies aimed at optimizing more meaningful long-term patient-centered outcomes.

## **Quality Assessment**

Study rigor and quality is demonstrated in part by an assessment of the quality criteria described by Charmaz (2006): 1) credibility, 2) originality, 3) resonance and, 4) usefulness. Each of these criteria will be discussed in the subsequent sections.

**Credibility.** Credibility reflects the degree to which our data substantiates the claims of our theory. Chapter 4 illustrates exemplar quotes used to support each theoretical code, category and concept informing our FaCeTs grounded theory of recovery. The quotes presented were selected to represent the collective experience of each individual facet of recovery. Chapter 4 allows the reader to decide for him or herself the degree to which our theory is supported in the words of our participants.

**Originality.** Originality deals with the extent to which our study provides new theoretical insights into current practice. As previously discussed, critical care medicine is primed for a paradigm shift as a result of the long term ICU acquired morbidity associated with surviving critical illness; a shift towards consideration of longer term meaningful patient outcomes. Our theory provides new theoretical insights on factors perceived to be influential to the process of recovery and can be used to inform holistic patient centered practices aimed at optimizing long- term outcomes of recovery.

**Resonance.** Resonance in our study was achieved through examining the degree to which other studies have echoed similar interpretations and results on factors influencing recovery from critical illness. A thorough examination of

our theories resonance in current critical care literature is outlined earlier in this chapter (Chapter 5.2).

**Usefulness.** Utility speaks to the usefulness of the study; in our case application to practice in critical care medicine. As discussed in Chapter 5.3, the results of our study reinforce the notion that determinants of recovery are likely multi-factorial, extending to include both aspects of the person experiencing critical illness and their environment. These theoretical insights can be utilized to inform further future research that seeks to examine the impact of aspects of the person and the environment on outcomes of recovery, ultimately informing comprehensive patient-centered management strategies to optimize longer term patient outcomes.

### **Strengths of the Study**

The primary strengths of this study are realized in the rigorous and systematic application of constructivist grounded theory methods throughout the course of this study. A thorough description of our methods is outlined in Chapter 3 complete with appendices to demonstrate the series of decisions made while constructing our theory.

Moreover, demonstrations of rigor can be seen in the multiple disclosures of my disciplinary perspectives, experiences and philosophical positions underpinning this research; allowing the reader to examine for themselves the extent to which my theoretical perspectives shaped our theory.

Lastly, an additional strength is seen in both the richness of the data, as well as the heterogeneity of participants studied. Our 17 participants provided a

variety of individual experiences, allowing for significant breadth and richness of data to inform our theory.

### **Limitations of the Study**

An early concern of this study was the potential for limited capacity of our participants to engage in in-depth dialogue. Although at times, the interviews did elicit symptoms of fatigue or emotional distress in some participants, and rest breaks or prematurely ending the interview was occasionally necessary, our participants were still able to effectively communicate their stories, allowing for sufficient data to construct a theory. Moreover, conducting only a single interview with each patient may have prevented more in-depth exploration of some concepts and member-checking was not conducted because of the cognitive and memory deficits associated with critical illness.

Lastly, inherent to the methodology of constructivist grounded theory, the results of this study represent one interpretation of the data; one interpretation of what patients perceive as influential to the process of recovery with the possibility of there being several other additional valid interpretations. This is not so much a limitation, but rather an acknowledgement of the nature of this study and an invitation to other researchers to contribute their own interpretations to this evolving body of literature.

### **Reflections on my Journey and Concluding Thoughts**

My doctoral studies, not unlike the process of recovery, was a journey filled with struggle, uncertainty and periods of set-backs and progress; but much like patients and family engaged in the process of recovery, I too have emerged

changed from this process. My interpretation of the patient experiences I have been fortunate enough to be a part of along this journey has profoundly changed me as a person, a clinician and hopefully an academic.

As a clinician, this experience has helped me see the value in seemingly mundane daily interactions with patients and the potential value and impact those interactions can have on their process of recovery. As a researcher, the FaCeTs grounded theory of recovery opens the possibility of an abundance of meaningful research aimed at fostering more holistic patient-centered care through understanding aspects of the person and their environment and their impact on recovery. And lastly, as a person engaging in daily interactions with people immersed in significant daily struggle, I have seen the power of determination and the value of family connection in helping patients navigate through struggles. Within the context of a constructivist grounded theory, my interpretations contribute to a greater ongoing discourse on potentially modifiable factors influencing recovery from critical illness and their application to holistic patient centered practices aimed at optimizing long term patient outcomes.

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## Appendix A: Ethics Approval Certificates



### Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Deborah Lucy  
 File Number: 102433  
 Review Level: Full Board  
 Approved Local Adult Participants: 16  
 Approved Local Minor Participants: 0  
 Protocol Title: Understanding the Process of Weaning from Mechanical Ventilation: A Grounded Theory Study (REB#18857)  
 Department & Institution: Health Sciences/Physical Therapy, Western University  
 Sponsor: Lung Association

Ethics Approval Date: May 28, 2012  
 Ethics Expiry Date: December 31, 2013

#### Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		
Letter of Information & Consent		2012/04/19
Other	Appendix: Sample Interview Questions	

This is to notify you that the University of Western Ontario Health Sciences Research Ethics Board (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this HSREB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request form.

Member of the HSREB that are named as investigators in research studies, or declare a conflict of interest, do not participate in discussions related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Signature

#### Ethics Officer to Contact for Further Information

Janice Sutherland (jsuther@uwo.ca)	Grace Kelly (grace.kelly@uwo.ca)	Shantal Walkott (shantal@uwo.ca)
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This is an official document. Please retain the original in your files.

The University of Western Ontario  
 Research Development & Services  
 Support Services Building, Suite 5150 • London, Ontario • CANADA - N6A 3K7  
 PH: 519-661-2161 • F: 519-661-3907 • www.uwo.ca/research





## Use of Human Participants - Revision Ethics Approval Notice

Principal Investigator: Dr. Deborah Lucy  
 File Number:102433  
 Review Level:Delegated  
 Protocol Title:Understanding the Process of Weaning from Mechanical Ventilation: A Grounded Theory Study (REB#18857)  
 Department & Institution:Health Sciences/Physical Therapy,Western University  
 Sponsor:Lung Association

Ethics Approval Date:December 13, 2013 Expiry Date:December 31, 2014  
 Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised Study End Date		

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.





The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

  
 Signature

## Ethics Officer to Contact for Further Information

 Enka Besile (ebesile@uwo.ca)	 Grace Kelly (grace.kelly@uwo.ca)	 Miss Melchill (mmelchill@uwo.ca)	 Viki Tran (viki.tran@uwo.ca)
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## Appendix B: Letter of Information Provided to Participants



Physical Therapy

### LETTER OF INFORMATION

#### Understanding the Process of Weaning from Mechanical Ventilation: A Grounded Theory Study

##### Study Principal Investigator

S Deborah Lucy PhD BScMR(PT) Associate Professor  
Western University, School of Physical Therapy

##### Study Co-Investigators

Tania Larsen BScPT PhD (candidate)  
Western University, Health & Rehabilitation Sciences Graduate Program  
Karen Koo MD FRCPC Assistant Professor  
Western University Department of Medicine & Division of Critical Care Medicine  
Critical Care Trauma Centre, London Health Sciences Centre

#### Background

You are being invited to voluntarily participate in a research study exploring what it is like to undergo the process of being removed (weaned) from a mechanical ventilator and resume independent breathing from both the perspective of the patient and their family. We are asking you and a family member to take part in the study because you have recently undergone the process of weaning from mechanical ventilation.

This letter contains important information to help you decide whether or not to participate in this study. It describes the purpose of the study, explains what you will be asked to do, and outlines the risks and benefits of participation. Please take the time to read this carefully. After you have finished reading, please feel free to ask any questions you have about the study, and your participation, or if there are any words or phrases you do not understand.

#### Purpose

Evidence from past studies suggests that psychological factors such as feelings of uncertainty, anxiousness, and 'not being in control' may affect the process of being weaned from a mechanical ventilator. Currently however these factors are not used when trying to decide whether a person is ready to start being weaned from the ventilator. The purpose of this study is to help us understand better how psychological factors impact the process and success of weaning by interviewing people and asking questions about their experiences.

Initials \_\_\_\_\_

Page 1 of 4

LOI 15/01/13

This letter is going to be given to patients both successful and unsuccessful in attempts at weaning. We are looking to recruit 16 volunteer patients and their families to participate in this study from the medical-surgical intensive care (MSICU) and cardiac surgery recovery (CSRU) units at London Health Sciences Centre University Hospital and Critical Care Trauma Centre (CCTC) at Victoria Hospital.

If you agree to participate in this study, Tania Larsen, one of the study investigators will arrange an appropriate time to come to the hospital to interview you. Please tell the investigator about any other study that you are presently in, so that we can determine if there is any reason why you should not participate in this study.

### **Procedures**

You are being asked to participate in a joint interview with yourself and a family member (e.g. spouse). During the interview you and your family member will be asked questions about your recent experience of trying to wean from the ventilator. You will be asked questions such as how it feels to breathe with a ventilator, how it feels to be taken off of the ventilator, and what it feels like if you are not tolerating removal of the ventilator. The interview will be done directly in your hospital room. You will be able to take breaks and rests as needed. You may also indicate that you wish to stop the interview at any time if you do not wish to continue or are feeling too tired. It will take approximately 30 to 45 minutes to complete an interview. You and your family member may be asked to participate in additional one-on-one interviews if we are unable to get all of the information needed in the first interview.

All interviews will be audio recorded. The interviews will then be typed out into a written document called a transcript that will contain the conversation word for word as it happened. You will have a chance to read the document to ensure we have written and recorded it accurately. You may also request that anything said during the interview(s) which you do not wish included be removed from the document.

### **Risk/Harm**

There are no known risks to participation in this study. However, you may become more tired than usual during or after the interview if this is more activity than you are currently used to. Also, if you have had a difficult time weaning from the ventilator, there is the possibility that retelling your experience may be emotional or upsetting for you or your family member. If this occurs, there are hospital social workers available for counselling and support.

### **Benefits**

You will not benefit directly from participation in this research but your participation may help improve the process of weaning for future patients.

Initials \_\_\_\_\_

**Confidentiality**

Your research records will be kept confidential by assigning you a study identification number. The audiotapes will be listened to only by members of the researcher team and they will be destroyed after 2 years. Interview transcripts will be saved on a password protected computer and written records locked in a filing cabinet to which only the investigators will have access. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published.

**Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your present or future health care at London Health Sciences. You do not waive any legal rights by signing the consent form.

**Compensation**

You will not be compensated for your participation in this research study.

**Contact Persons**

This letter is for you to keep. If you have any questions about your rights as a research participant or the conduct of the study you may contact Dr David Hill, Scientific Director, Lawson Health Research Institute (519) 667-6649. Representatives of Lawson Quality Assurance (QA) Education Program may look at study data for QA purposes.

If you have any questions or if you would like further information before deciding to participate in this study, please contact us at these numbers:

Dr S Deborah Lucy PhD PT



Tania Larsen BScPT PhD (candidate)



Initials \_\_\_\_\_

**CONSENT FORM**

**Understanding the Process of Weaning from Mechanical Ventilation:  
A Grounded Theory Study**

**Study Principal Investigator**  
S Deborah Lucy PhD BScMR(PT) Associate Professor  
Western University, School of Physical Therapy

I have read the accompanying Letter of Information, I have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

Participants Name (printed) \_\_\_\_\_

Participants Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name of Person Obtaining Informed Consent  
\_\_\_\_\_

Signature of Person Obtaining Informed Consent  
\_\_\_\_\_ Date \_\_\_\_\_

**The consent form will be retained by the research team.**

Initials \_\_\_\_\_

### **Appendix C: Initial Interview Guide**

Preamble: Thank you for choosing to participate. I am interesting in understanding what helps people wean from the mechanical ventilator (MV) and start breathing on their own as this is a very important part of getting better. I am here to learn from your thoughts and experiences on this topic.

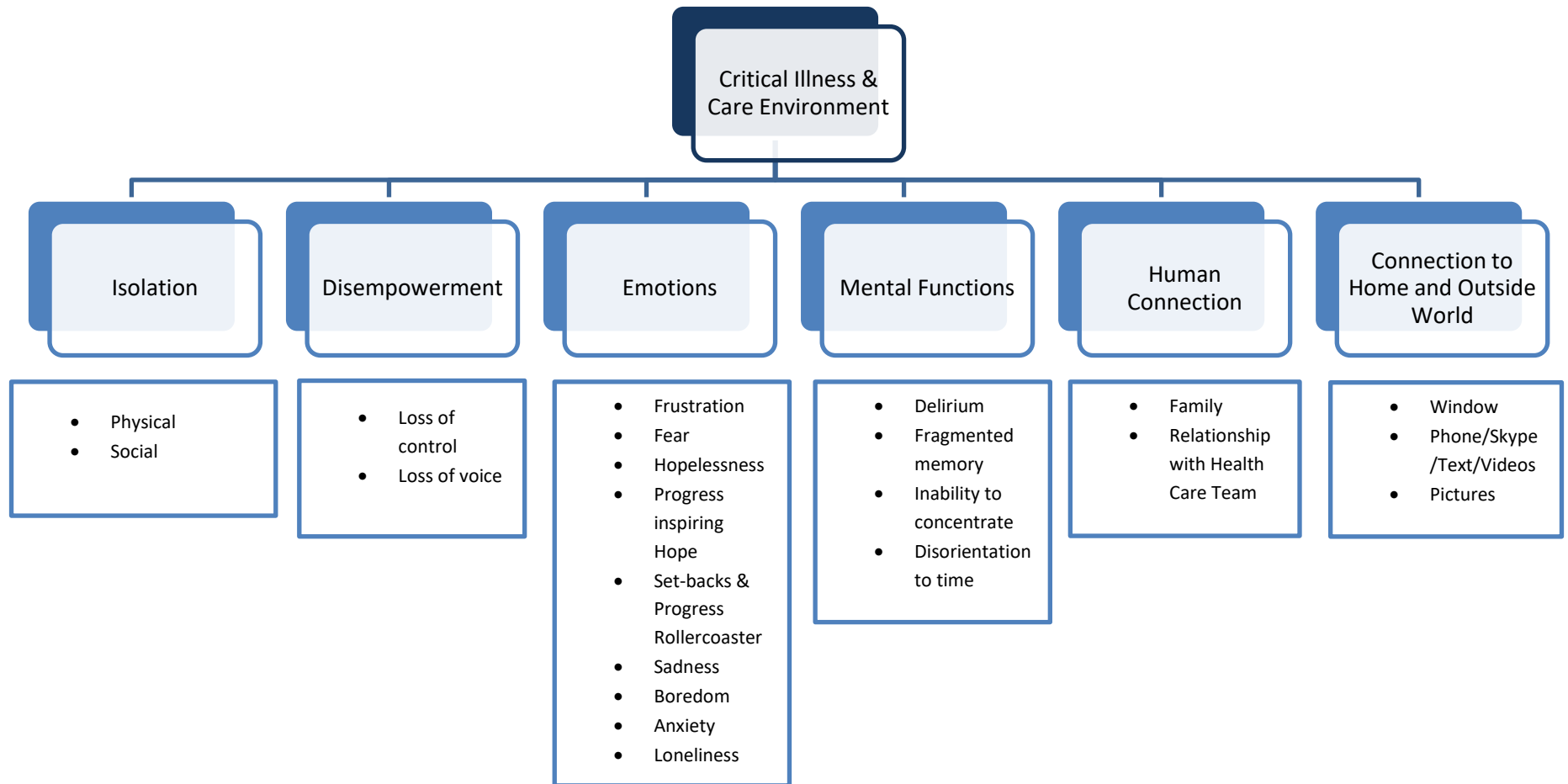
1. What is/was it like to breathe on a MV?
2. What is/was it like to try to breathe independent of the MV?
3. Who, if anyone, influences/influenced your ability to tolerate being off the ventilator? Tell me how they influence(d) you?
4. Have you ever failed an attempt at weaning from MV? If so, could you describe the events that led up to you requiring re-intubation or being re-connected to the MV again? What contributed to your needing to be put back on the MV?
5. Can you describe a typical day on a MV?
6. What helps/helped you manage your symptoms while off the ventilator?
7. After having had these experiences, what do you think your medical team should know about weaning from MV?

## Appendix D: Revised Interview Guide

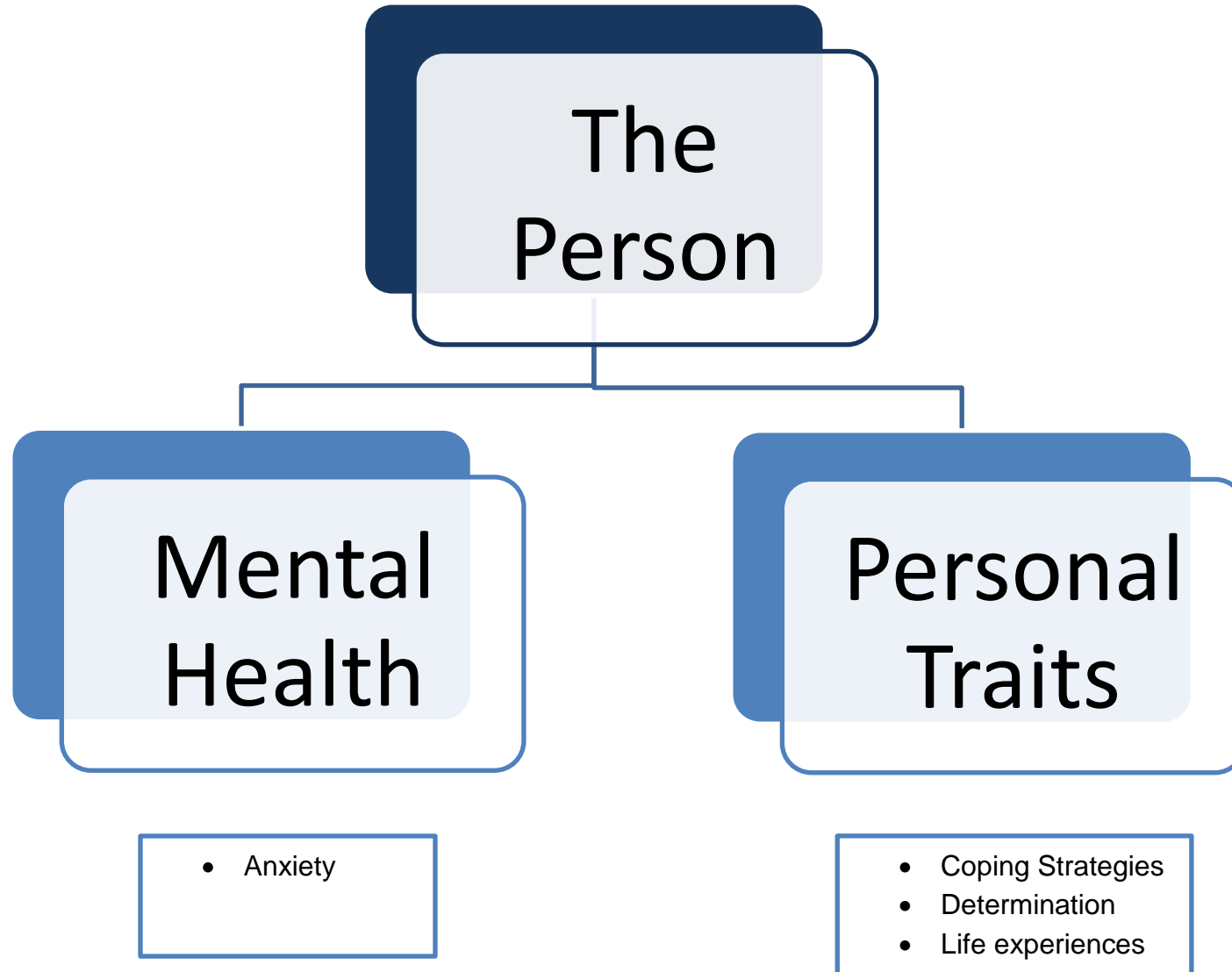
Preamble: Thank you for choosing to participate. I am interested in understanding your thoughts on how people recovery from critical from critical illness, specifically what you find is helpful during this process. I am here to ask you questions about your recovery and learn from your thoughts and experiences on this topic.

1. What is the first thing you remember about being in the ICU? Did you know where you were or why you were here?
2. What is a typical day in the ICU like? What sorts of things help you pass the time during the day? What do you enjoy doing or look forward to most in your day?
3. What is the hardest part of your day? What are some things you find hard or frustrating during this process?
4. Where do you draw strength from for each day? What has helped you get this far in your process of recovery?
5. What should your health care team know about you? What should your health care team know about what it's like to be critically ill?
6. What advice would you give to someone who is just starting their journey to recovery?

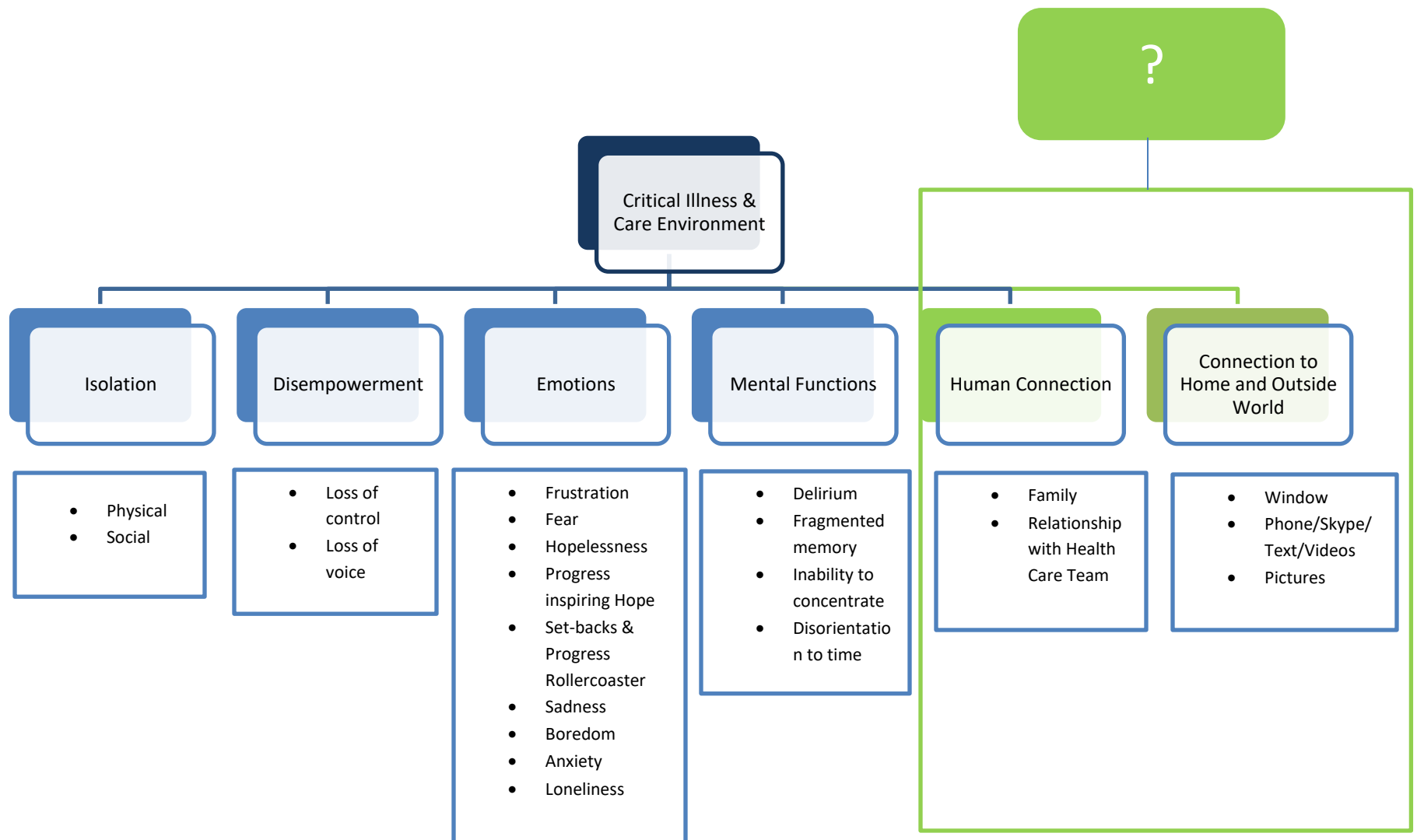
## Appendix E: Time Point Number One: Codes and categories after focused coding

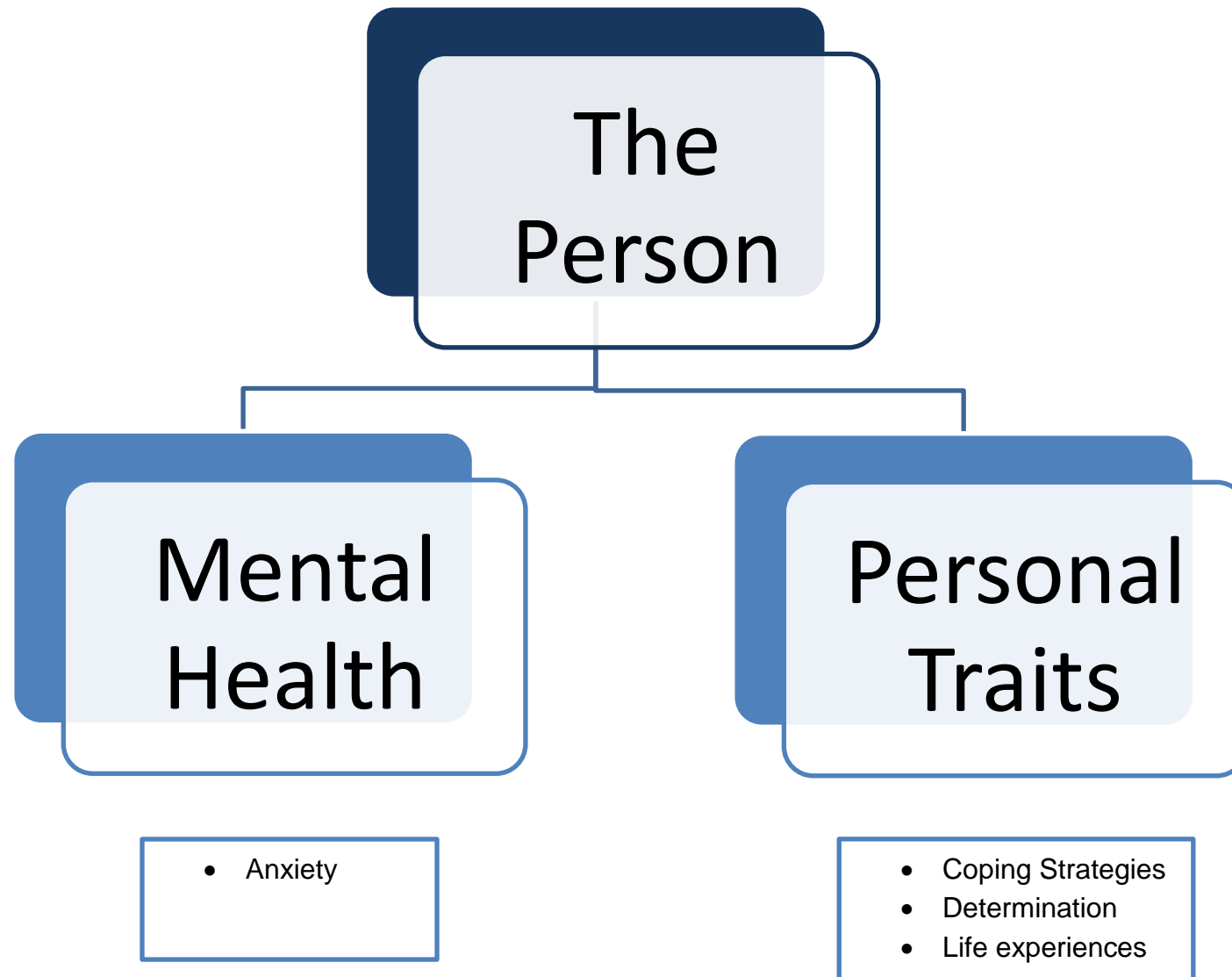




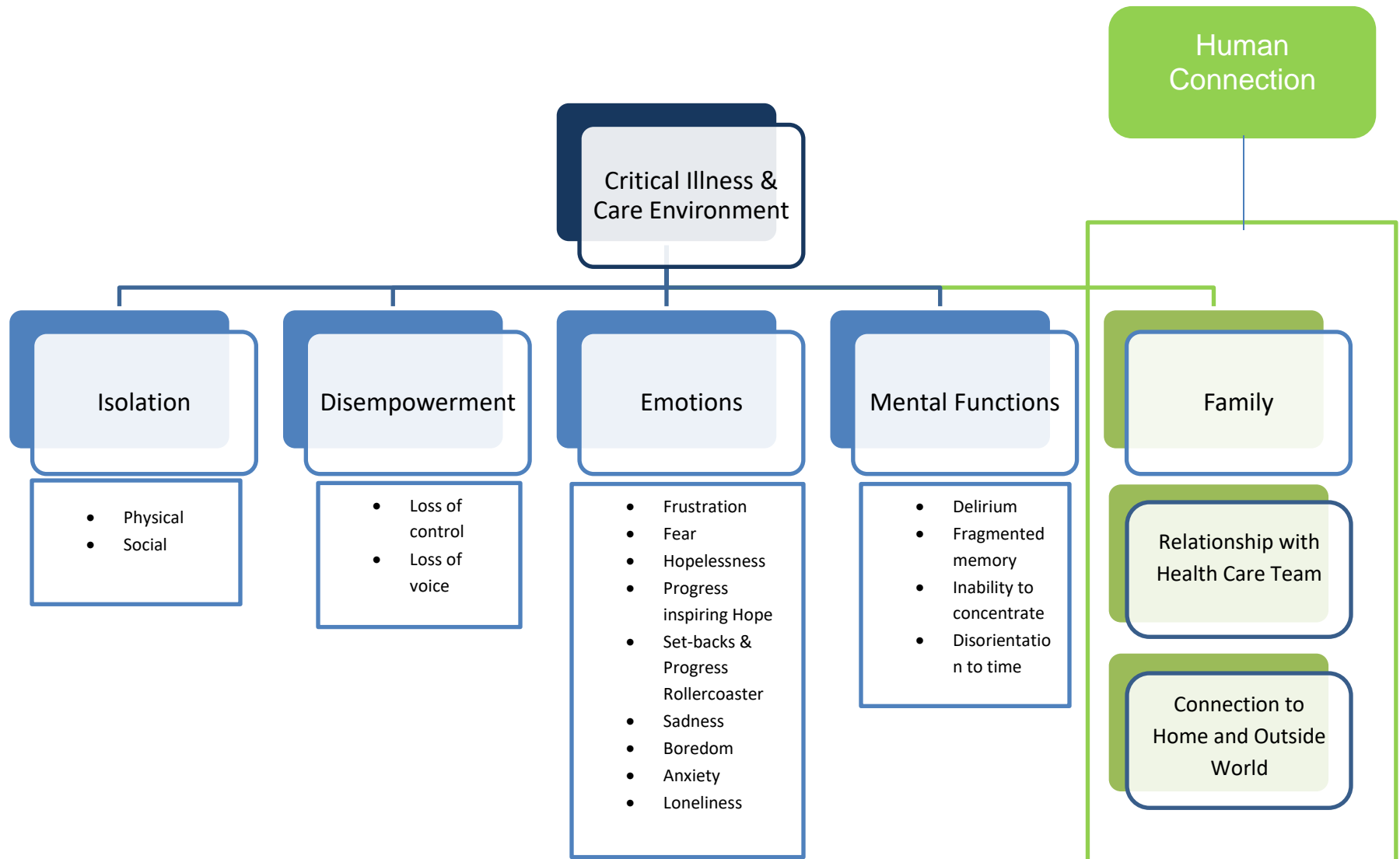


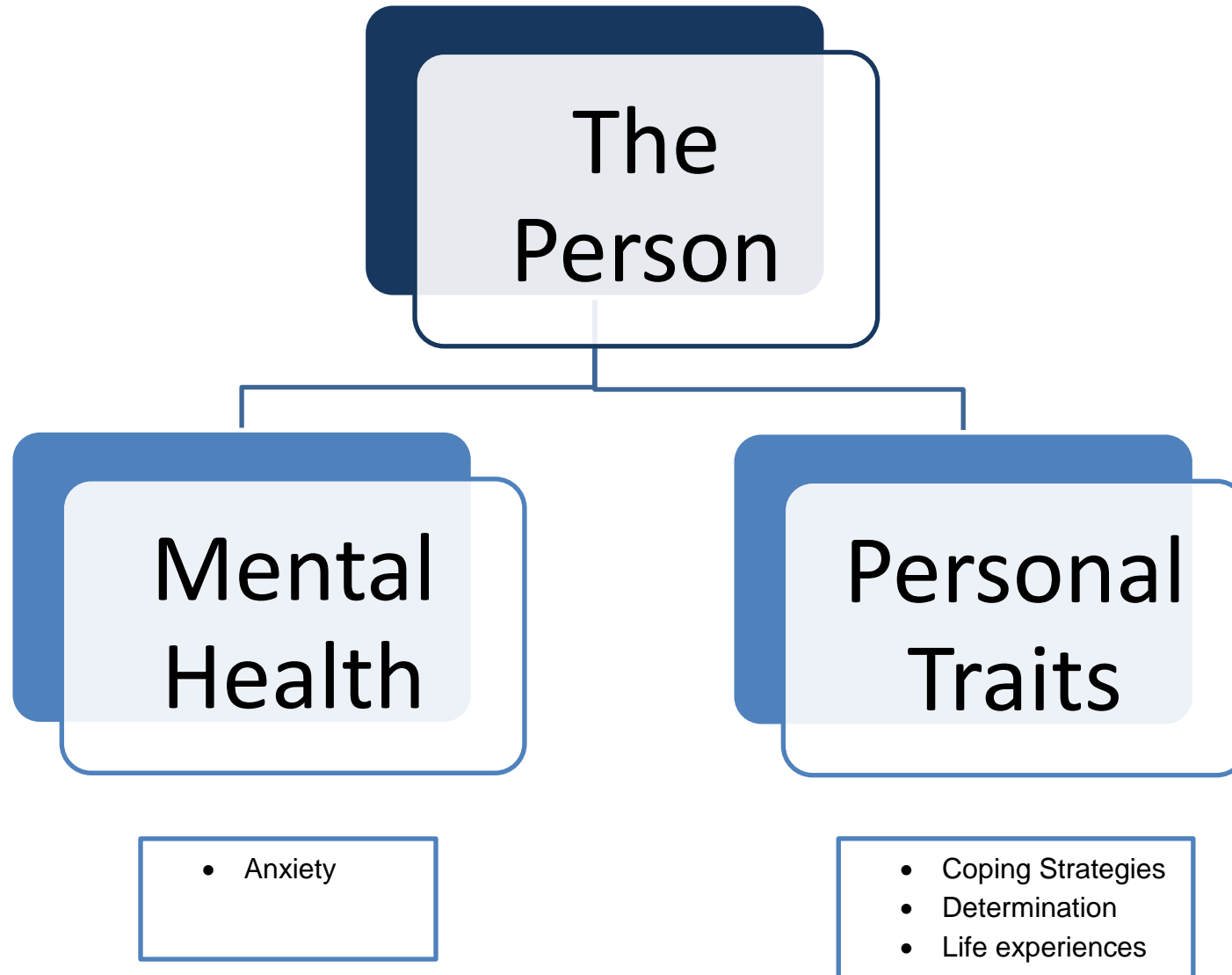
## Appendix F: Time Point Number Two: Sorting and regrouping after theoretical coding





**Appendix G: Time Point Number 3: The final theoretical concepts prior to theory construction.**





## Appendix H: An example of the sorting process for the isolation data set.

### Critical Illness and Care Environment

- **Isolation**

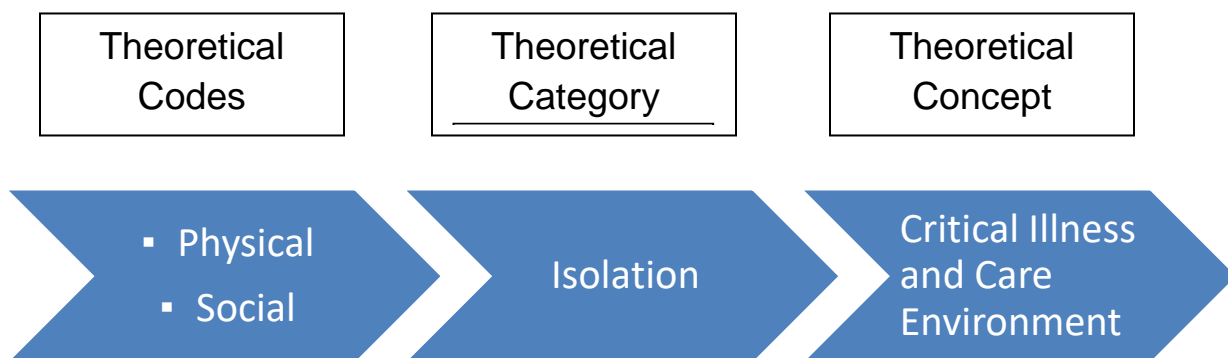
- **Physical**

- just lie in here quiet, and that's hard to do (#4)
    - I am just stuck in a room all day, and I am stuck in this chair (#5) [describing his day]
    - no, lied in bed, no energy to do anything else (#5)
    - um, [laughing], I just wanted them to stay a lot longer you know... just give a little more pampering, or just even to just understand how I felt ... I'm stuck.... And most of them do (#10)
    - Just layin there watching the hall. Until they moved me down to that room with the view... they called it... ya it did [help], it was brighter and I could see things... you know things going on. The only interaction I had was with the nurses. That was it. (#12)

- **Social**

- I don't have a visitor, I have only 1 son and my daughter in law, they're both working. ...That's what I have... I have 1 visitor a day for 20 minutes. Frustrating. Very long [without family visits – greater feeling of social isolation] (#11)
    - I told you to talk to someone, just to talk, 5 minutes is sometimes like 5 years to someone, to talk to someone, give me that bridge and the mood change, and then everything else (#11)
    - sitting, sitting all the time by yourself... you know, I think too much, so I'll put the TV on and I find that helps (#13) [did not have a lot of visitors]

- my kids ...I just like seeing their face. No because I have some activity, then I sleep, I watch tv... I have nothing else to do. ... Maybe when I go to next place I can do more? See some people I never see before and make some new friends or maybe see somebody I know from before? (#14)
- Company, you know that's always a big help. Enough... well not nearly enough... you know, you always want more. Like when my daughters come in, they will come in at noon and then stay until 9 o'clock at night. You know... so that's nice. Mostly social, they'd bring something to do and they would help if you needed help. Relieve the nurses of the little things. It helps just to know that there's people there that care (#10)



Appendix I: Sample analytic memos from data analysis process

Activity limited by  
 - concentration  
 - glasses  
 - equipment  
 - pt dependency

Fragmented memory  
 - disorienting

Health Care team  
 - facilitator  
 - provide skills to ease anxiety  
 - emotional support  
 - need to trust

look to the team for this as well in absence of family

EMPATHY

Mobility feels good to move

Sensory deprivation  
 Anxiety  
 Dependency  
 Loss of control  
 Delirium  
 Agitation  
 Depression  
 long days  
 boredom  
 loss of identity  
 Fatigue  
 Sleep = escape  
 Disorientation  
 Initially

Ability to concentrate

Accountable to environment

Isolation

Altered perception of time

at daytime

limited by  
 - fatigue  
 - equipment  
 - fear of becoming SOB  
 HARD

Want participating.  
 Finding internal strength.  
 Maintaining connection to outside world (hope)  
 Distractions - TV, company, books  
 Activity  
 Wants connections to others

windows

Sense of Isolation  
 Inability to communicate  
 loss of voice  
 Fear  
 limits participation



previous experience & illness helps orient to environment.  
 previous experience & ICU

orienting  
 temp loss of control vs seeing/knowing how this will go?  
 - trust in process

if its slow = discouraging.  
 setbacks = very discouraging.  
 = dash hope

↑  
 progress - feels good  
 Motivating  
 - sense of improving  
 - encouraging  
 - provides hope  
 - empowering

ups + downs psychological toll of setbacks

Recovery process

- baby steps
- one step at a time
- stepping stones
- Small Steps.
- day by day
- chunking out work
- small chunks of time = More manageable

Family = motivator, advocate  
 - eases psychological burden  
 - fill in blanks of memory  
 - maintain connection to home (hope)  
 - touch  
 - reassurance, support.



Facilitators → TRUST IN MEDICAL TEAM  
 PERCEIVING EMPATHY  
 - PRE-EXISTING Experience in ICU  
 - INTIMATE KNOWLEDGE OF PROCESS

Helps pt's orient + acclimatize to environment.

Exacerbators - Pre-existing anxiety

BS + F

Inability to Concentrate  
 Loss or Fragmentation of Memory  
 Delirium  
 Agitation  
 Fatigue  
 ↓ activity tolerance

ACTIVITY

Mobility  
 - walking  
 - up to chair  
 - up to commode  
 Pastimes  
 - TV, books, puzzles  
 Sleep.

PARTICIPATION

Inability to communicate  
 Social Isolation.

PERSONAL FACTORS

psychological burden  
 - pre-existing anxiety  
 - pre-existing experience  
 - depression  
 - pre-existing loss  
 - emotions produced of ICU  
 - anxiety  
 - loss of identity  
 - fear  
 - depression  
 - psychological burden of set-backs.

Coping Strategies

baby steps - find internal strength  
 chunking out "work of recovery" in manageable chunks.

Individual Progress

Motivating, encouraging ...

ENVIRONMENT

Reciprocal Interaction  
 Social Interaction  
 Human Health Care Team  
 Family  
 roles - motivator, advocate, ease psychological burden, connection to home/self, reassurance, support  
 "fill in gaps"  
 physical environment  
 Sensory deprivation - loss of identity  
 Isolation  
 Altered perception of time + day/night creates.  
 "Humanizing" a person  
 "being seen as roles"  
 facilitator: counting & trusting  
 barrier: occupying  
 facilitator of basic needs  
 - eye glasses  
 - TV, books, puzzles

②

chunking out  
 coping strategy

missed

critical illness  
 coping strategy

## Curriculum Vitae

<b>Name:</b>	Tania Larsen
<b>Post-secondary Education and Degrees:</b>	<p>The University of Western Ontario London, Ontario, Canada</p> <p>2011-2018 Ph.D. Health and Rehabilitation Sciences, Rehabilitation Sciences</p> <p>2004-2006 Master's of Science, Physical Therapy</p> <p>2000-2003 Bachelor of Science, Physical Therapy</p> <p>1997-2000 Bachelor of Arts, Kinesiology</p>
<b>Significant Graduate Research Awards:</b>	<p>Ontario Respiratory Care Society Fellowship Award 2005, 2012, 2015</p> <p>Canadian Respiratory Health Professionals Fellowship Award, 2006, 2007 (declined), 2014</p> <p>Queen Elizabeth II Graduate Scholarship in Science and Technology, 2013</p> <p>Ontario Graduate Scholarship 2007, 2012</p> <p>Dean's Entrance Scholarship, Faculty of Health Sciences, 2011</p>
<b>Related Work Experience:</b>	<p>Physiotherapist, London Health Sciences Centre, 2003-Present</p> <p>Lecturer, School of Physical Therapy, Faculty of Health Sciences, The University of Western Ontario 2013-Present: Applied Cardiorespiratory Physiology 2007-Present: Acute Care Settings II 2007-Present: Acute Care Settings I</p>

## **Publications:**

**Larsen T**, Lee A, Brooks D, Michieli S, Robson M, Veens J, Vokes O, Lucy D. The effect of early mobility as a physiotherapy treatment for pneumonia: A systematic review and meta-analysis. Accepted with minor revisions May 2018, *Physiotherapy Canada*.

## **Selected Presentations**

Larsen, T; Lucy SD. "Understanding the process of recovery from critical illness: The patient's perspective". Abstract and poster accepted for presentation at the 2017 Canadian Critical Care Conference, March 1-3, 2017, Whistler, BC.

Larsen, T; Lucy, SD. "Understanding the process of recovery from critical illness: The patient's perspective". Abstract and poster accepted for presentation at the 2017 Canadian Respiratory Conference, April 27 – 29, 2017, Montreal, Quebec.

Larsen, T; Lucy SD. "Moving Beyond Survival: The International Classification of Functioning, Disability and Health (ICF) as a framework to improve Long-Term Outcomes in People Recovering from critical illness". Abstract and podium presentation accepted for 2017 APTA Combined Sections Meeting, San Antonio Texas. February 15-18, 2017.

Larsen T; Lucy D; Lee A, Michieli S; Robson M; Veens J; Vokes O; Brooks D. "A systematic review of the effect of early mobility as a treatment for pneumonia". Abstract and poster presented at the 2016 Canadian Respiratory Conference, Halifax, NA. April 14-17, 2016.

Larsen T, Lucy D, Choong K, Koo K. "A Retrospective Study of Acute Rehabilitation of Patients who experience Prolonged Weaning from Mechanical Ventilation in a Canadian Critical Care Trauma Centre". Abstract and poster accepted for presentation at the Canadian Respiratory Conference. April 11-13, 2013. Quebec City, Quebec.

Larsen T, Kao R, Lucy D. "Exploring a Role for Respiratory Muscle Training in Facilitating Weaning from Chronic Mechanical Ventilator Dependency: A Preliminary Study". *Intensive care Medicine*. 2011;37(Suppl 1): S273.(Abstract). Poster presented at the European Society of Intensive Care Medicine Annual Congress October 1-5, 2011. Berlin Germany.