THE RELATIONSHIPS AMONG EMOTION REGULATION, ROLE STRESS, AND PSYCHOLOGICAL DISTRESS IN SURROGATE DECISION MAKERS OF THE CHRONICALLY CRITICALLY ILL PATIENTS

by

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Submitted in partial fulfillment of the requirements for

the degree of Doctor of Philosophy

Frances Payne Bolton School of Nursing

CASE WESTERN RESERVE UNIVERSITY

May, 2019

CASE WESTERN RESERVE UNIVERSITY

SCHOOL OF GRADUATE STUDIES

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Dedication

This dissertation is dedicated to my family.

Behind this accomplishment stand the two strong pillars of my life,

Variath Njalian (late) and Thressiamma Njalian, my parents.

They taught me many important life lessons, instilled the values of hard work and sacrifice,

showered unconditional love, and shared their passionate desire for education; all of which inspired me to accomplish this milestone.

To Anice Sebastian, Lissy Jose, and Varghese Njalian, my siblings,

whose encouragement, love, and support

boosted my wavering confidence

during this prolonged endeavor.

And to my husband,

whose love, constant support, and encouragement

helped me to get through the obstacles of this journey.

My deepest gratitude and love

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Acknowledgment

First of all, I thank God for this opportunity and the ability to accomplish this milestone.

I gratefully acknowledge the generosity, assistance, and guidance of Dr. Hickman, my advisor and Dissertation Committee Chairperson. I express my deepest gratitude to you for sharing your data so that my study could be completed in a timely manner. I am thankful for your unwavering support throughout this entire journey. I thank you Dr. Zauszniewski, my former advisor and committee member, for guiding me to the correct sources and for your continued support. I thank the rest of my committee members: Dr. Plow, for your time and support with statistics, and Dr. Connell for sharing your expertise.

I express my deepest gratitude to you Dr. Nosek for spending much of your time and energy to assist me in refining my writing and shaping it according to APA writing style. Even amidst your health and technological issues, you made yourself available with your best resources and found time to help and support me; I can never thank you enough. Special thanks to you my friend Sora Okumura for being readily available for any immediate assistance and for patiently reviewing my first drafts; I know it was not a simple task. Among others, both of you were special blessings during this journey.

I thank the myriad of well-wishers and supporters who assisted me in so many ways along this journey and genuinely looked forward to my accomplishments. Among them are my American family in Pittsburgh. Your encouragement and support followed

me all along the way. Special thanks and remembrance to Renzie Viggiano, my American mom (late), who was my inspiration to earn a PhD and who also proofread my papers during the course work. I thank my friends Eydith Hall, Cookie Viggiano, and Marilyn Okumura, through your friendship, encouragement, and the great deal of energy that was poured upon me throughout this journey.

Special thanks to my former mentor and friend Dr. Edwards for your genuine friendship and encouragements that made me believe in myself and pursue this endeavor relentlessly. A word of thanks to Samira Hussney for your words of encouragement that gave me hope. I thank my PhD friends for your invaluable resourcefulness, support, friendship, and the times you spent for group studies, which were great sources of energy and support.

Finally, I thank my family. Appan, it is you who taught my first lessons at home and always wanted me to advance my education; I started this study on account of you. Today you are not physically present to see my accomplishment, but I know you are proud of me and present with me in spirit. Thank you Amma, Annie, Lissy, Varghese, and Jose, my husband, for rejoicing and taking so much pride in my accomplishment. Thank you for being always there for me in spirit, with your tireless extension of love and support all along this journey: this is for you.

The Relationships Among Emotion Regulation, Role Stress, and Psychological Distress in Surrogate Decision Makers of the Chronically Critically Ill Patients

Abstract

by

MARY NJALIAN VARIATH

Background: Advancement in technologies has contributed to patients surviving critical illness, but continuing to live with chronically critically ill conditions. A majority of such patients experience transient or persistent states of decisional impairment requiring family members or authorized surrogate decision makers to render treatment decisions. Abrupt transition to the surrogate decision maker role often evokes heightened stress. Research shows that emotion regulation can help manage situational stress. **Purpose:** To examine the associations among emotion regulation, role stress, and psychological distress in surrogate decision makers of chronically critically ill patients in intensive care units. **Methods:** A descriptive, secondary analysis of 120 surrogate decision makers of chronically critically ill patients from various intensive care units within an academic medical center in Northeast Ohio. Parent investigation data were used to address the following questions: (1) what are the associations among emotion regulation (cognitive reappraisal & expressive suppression), role stress, psychological distress, and demographic variables of age, gender, ethnicity, kinship, advance directives, and living will of surrogate decision makers of chronically critically ill patients? (2) what is the relationship between emotion regulation and psychological distress while controlling for surrogate decision makers' demographic variables? (3) does role stress mediate the

relationship between emotion regulation and psychological distress while controlling for demographic variables of surrogate decision makers of chronically critically ill patients? Pearson *r* and Spearman *rho* correlations and Multiple Regression tests were conducted to answer these questions. **Findings:** Statistically significant associations included: role stress and psychological distress ($r = .29$, $p < .01$), gender and role stress (($r = .22$, $p < .05$), gender and psychological distress ($r = .27$, $p < .01$), kinship and role stress ($r = .29$, $p < .01$), race and psychological distress ($r = .18$, $p < .05$), and suppression and advance directives ($r = .21$, $p < .05$). Emotion regulation was not significantly associated with psychological distress and role stress did not mediate the relationship between emotion regulation and psychological distress. **Implications:** Surrogate decision makers require psychological support while making decisions. Gender specific support and increased emphasis on advance directives are also required. Innovative support programs for surrogate decision makers need further research.

CHAPTER I

Statement of the Problem

The surrogate decision makers of chronically critically ill (CCI) patients suffer from heightened psychological stress. With the integration of mechanical ventilation, most critically ill patients survive their initial acute stage of illness and progress to a CCI state. More than 250,000 acutely ill patients are expected to transition to a CCI state (Zilberberg, Wit, Pirone, & Shorr, 2008), and it is estimated that by 2020 nearly 600,000 patients will meet the criteria for CCI state (Zilberberg, Luippold, Sulsky, and Shorr, 2008). The increasing number of CCI patients and their complex care requirements impose a tremendous burden on the healthcare system. Annual in-hospital healthcare cost rose from $15.6 billion in 2004 to $26 billion in 2009, increasing even further in 2011, with reports of a $35 billion expenditure (Kahn et al., 2015). While increased ICU survival rate is a positive outcome of treatment advancement, it has created more CCI patients who are dependent on life-sustaining care. These patients are unlikely to have the capacity to participate in crucial conversations about their care in the ICU and thereafter (Hickman, Daly, Douglas, & Clochesy, 2010).

The transient or persistent state of cognitive impairment (Ehlenback et al., 2010), due to the acuity of illness, sedation and medically induced comas, often cause the CCI patients to rely on surrogate decision makers (SDMs) for medical decisions, including making potentially life altering choices (Hickman, Daly, & Lee, 2012). SDMs can be classified as formal, legally deemed as the durable power of attorney for healthcare decision making, or informal, where the proxy is the next of kin (Long et al., 2011). The

current study focused on formal and informal SDMs who may be family members or legally authorized proxies.

The burden of being an SDM for a CCI patient is profound and complex. Faced with their loved one's precarious situation, SDMs face an emotionally turbulent journey of their own. Their elevated state of psychological stress can impact the quality of care-related decisions, including those that would potentially prolong or end life (Hickman & Douglas, 2010). This could result in detrimental consequences for SDMs. Further, the highly stressful ICU environment, coupled with SDMs' time sensitive critical decisional requirements, may influence the regulatory stages of emotion regulation and result in psychological distress. Psychological distress is generally defined as a state of emotional suffering characterized by symptoms of depression and anxiety (Mirowsky & Ross, 2002). Emotion regulation is a coordinated set of behavioral and physiological responses that influence how humans respond to perceived challenges and opportunities. Maintaining healthy regulatory stages of emotion is required to respond effectively to such challenges and opportunities. Contrarily, unhealthy regulatory stages of emotion may influence the decision-making functions (Gross & John, 2003).

Using the Roy Adaptation Model, this descriptive study will explore the relationships among emotion regulation, role stress, and psychological distress in SDM's of CCI patients in the ICU. The goal was to generate new evidence regarding the relationships among these concepts, so that future scientists could develop cost-effective interventional strategies to provide support to SDMs as they make critical decisions. Current SDM support interventions for CCI patients in the ICU reveal inconsistent results. Also, the use of emotion regulation as a possible strategy to reduce psychological

stress is yet to be explored. This proposal provided a logical, empirical, and theoretical examination of possible relationships among emotion regulation, role stress, and psychological distress; the result of which would guide future clinicians to integrate efficient supporting interventions. This chapter addressed the background and significance, conceptual framework, research questions, and nursing implications.

Background and Significance

The Chronically Critically Ill

Chronic critical illness is a serious problem with high costs of care (Kahn et al., 2015; Zilberberg et al., 2008), increased readmission rates, reduced quality of life, poor treatment outcomes, and high mortality (Bodet-Contentin et al., 2018; Daly et al., 2005; Griffith et al., 2018; Kahn et al., 2015; Nelson et al., 2007). Patients are categorized as CCI if they experienced: (a) an initial episode of critical illness but survived to remain dependent on intensive care, (b) respiratory failure requiring prolonged dependence on mechanical ventilation, ranging from two days to four weeks, (c) one or more organ failure, for example, respiratory, renal, cardiovascular, or brain injury with intracranial hemorrhage, and (d) severe infections (Camhi & Nelson, 2007; Nelson, et al., 2010). The chronic critical illness is defined as those patients who depend on mechanical ventilation for a prolonged period, experience distinctive derangements of metabolism, organ physiologic traits, endocrine and immunologic dysfunction, and cognitive impairment limiting decision making ability (Nelson et al., 2006).

Chronic critical illness has tremendous impact on patients, the nation at large, and the family members, especially the decision makers. It is a devastating condition for patients who may suffer from multiple symptoms including profound weakness from

myopathy, neuropathy, and brain dysfunction; the latter of which can result in coma or delirium (Carson, 2012; Nelson, et al., 2010; Pisani et al., 2009). Also, patients experience significant distress from symptom burden, including pain, depression, anxiety, and inability to communicate due to endotracheal intubation (Nelson et al., 2005). Due to the presence of multiple illness conditions, chronic critical illness is considered a syndrome. Most CCI patients leave ICU with profound physical and cognitive functional impairment; and about 40% are reported to have hospital readmissions (Nelson, et al., 2005; Engoren, Arslanian-Engoren, & Fenn-Buderer, 2004).

Chronic critical illness has a tremendous impact on US healthcare systems and thus is a serious national health problem. The present estimated cost of care for the CCI patient population is about $35 billion annually, which is anticipated to increase further, consistent with continued CCI patient population growth rate (Kahn et al., 2015). A population-based study projected that the number of patients needing mechanical ventilation for at least seven days in the United States will double from 250,000 in 2000, to more than 600,000 by 2020, with a projected cost of about $60 billion (Zilberberg, Wit, Pirrone, & Shorr, 2008). Prolonged dependence on mechanical ventilation is considered the hallmark of chronic critical illness syndrome (Nelson et al., 2006), as it consumes abundance of ICU resources and contributes to the rising cost of care (Hickman & Douglas, 2010).

Moreover, the CCI state of a loved one imposes substantial burdens on family members (Douglas & Daly, 2003). In addition to ventilator dependency, the CCI patients may be cognitively impaired and decisionally incapacitated, requiring family members assume the SDM role regarding all medical decisions, especially those regarding end-of-

life care. These critical and time sensitive decision making responsibilities contribute primarily to SDMs' psychological stress and reduce their ability to make quality treatment decisions (Hickman, Daly, Douglas, & Clochesy, 2010). The family member who shoulders the surrogacy responsibility must consider certain important factors, such as patients' values, medical facts and probabilities, the possibility of poor quality of life for the patient, and the limitations of their own emotional and financial resources (Tilden, Tolle, Nelson, & Fields, 2001). These situations contribute to high levels of psychological stress, which may impact the regulatory stages of emotion. The findings are explained in chapters four and five.

Emotion Regulation

Emotion regulation is the ability of individuals to recognize and regulate their emotions. It includes those behaviors, skills, and strategies, that serve to modulate, inhibit, and enhance emotional experiences and expressions (Gross, 2014). Emotion regulation can be a potent mediator of both interpersonal relationships and socio-emotional adjustments across the lifespan (Gross & Thompson, 2007). Emotions arise when something important is at stake. Sometimes emotions come about automatically while other times they occur after careful consideration of the situation (Gross & John, 2003). Thus, humans can and need to, exert some measure of control over their emotions for a better outcome (Gross, 1998). Ryle (2009) states that emotions need "severe corrections" otherwise they could lead one to troublesome deviations from proper functioning.

The emotion theorists refer emotion regulation to a *process model* which begins with an emotion-generative process in the form of specific cues that unfold over time and

can be modulated in various ways (Gross, 2003; Ryle, 2009). Emotion regulation occurs when an emotional response is subject to valuation as good or bad. This valuation leads to the activation of a goal to change that particular emotion response (Gross, 2014). Gross (1998) discusses emotion regulation response tendencies that are relatively short lived and involved a change in the behavioral, experiential, autonomic, and neuroendocrine systems can be modulated. It is this modulation that determines the final emotional response outcome. According to Gross and John (2003), high levels of distress activate and trigger emotion regulation processes that may begin with specific cues like frustration and anger, however, the implementation of regulatory stages may also help control these emotions before they produce undesirable behaviors such as psychological distress.

There are five stages to the emotion regulatory processes: situation selection, situation modification, attention deployment, cognitive change, and response modulation. *Situation selection* refers to tailoring a situation to modify its impact. *Situation modification* implies modifying a situation so that one can manage it for a better outcome. *Attention deployment* can be used to select which aspect of a situation a person wants to focus on. *The* c*ognitive change* allows the person to attach meanings to a situation that gives rise to emotional response tendencies. The fifth emotion regulatory process, *response modulation,* enables the individual to influence the response tendencies once they have been elicited (Gross, 1998; Sheppes, Suri, & Gross, 2015). The outcome of emotion regulation varies depending on at what point of this regulatory process the individual employs deliberate effort.

Sheppes, Suri, & Gross (2015) extended this linear regulatory process model to a cyclical process model. According to their extended study, there are different types of taxonomies of valuation systems including the aspect of the *World, Valuation, Perception*, and *Action*. The World is the situation, Valuation represents the current desired goal, Perception is how one views the situation, and Action is based on what one does to manage the situation. This process can be active for an extended period manifesting in a series of World-Perception-Valuation-Action cycles. The first cycle triggers the valuation system with an event in the situation. The target of the Action process is the World, and its change or lack of change sets a second cycle and the process goes on until the Action results in either the individual get exhausted of all resources or achieves the goal meaningfully. Emotion generation and emotion regulation can be understood based on this cyclical valuation process. Starting with emotion generation, the cognitive reappraisal perspective places a strong emphasis on the emotion regulation for a meaningful outcome (Frijda & Parrott, 2011).

Cognitive reappraisal is an antecedent-focused emotion regulation, which occurs in the early phase of behavioral output. Once an emotion has been generated, for example, activation of a control process as a result of SDMs' psychological stress, it follows the path as described under the five sets of regulatory processes. Employing any type of emotion modulation at any stage as required will have some impact on the outcome. If the individual uses deliberate, effortful modulation at the early stage, it could produce the best behavioral outcome, such as decreased psychological distress.

There is an emerging body of research describing strong connections between emotion regulation and decision making process (Lerner, Li, Valdesolo, & Kassam,

2015). Decision making process requires stable cognition because decision making is an executive function just as learning and attention are executive functions and requires stable cognitive ability (Starcke & Brand, 2012). The association between emotion regulation and decision making was demonstrated by Sanfey et al. (2003) using a functional magnetic resonance imaging experiment. The activation of the anterior insula correlated with rejection of inequitable financial offers made by an opponent in an economic task known as the Ultimatum Game (a game in an economic experiment). This is because the insula activation results in ineffective emotion regulation in response to an unacceptable offer (Gross, 2014). Other researchers have examined influence of emotion regulation on making choices and suggests that difficult tasks that impact one's mood may bias decision making (Harle & Sanfey, 2007; Harle, Chang, Van't Wout, & Sanfey, 2012). Gross and John (2003) state that heightened psychological stress activate and trigger the regulatory stages of emotion in humans. Thus, it may be possible that a triggered regulatory stages of emotion amidst increased psychological stress influences the decisional quality and contribute to SDM role stress.

Surrogate Decision Making Role Stress

The high noxious levels of psychological stressors from the ICU together with the ineffective regulatory stages of emotion may result in SDM role stress. More than half of the family members who assume SDM role have no prior experience functioning in that role (Hickman, Daly, & Lee, 2012). Additionally, other situations exacerbate psychological distress such as the uncertainty of the prognosis, making time sensitive critical decisions, and multiple external factors including practical and financial problems. Among these the most distressing ones may be the time sensitive critical

decisional requirements, potential undesirable decisional outcomes from possibly not comprehending medical information, and decision making per the patient's preferences (Hickman, Daly, Douglas, & Clochesy, 2010).

Wendler and Rid (2011) in their review of 2800 SDMs to examine the surrogate decision making impact reported that one third of SDMs experienced surrogate role stress associated with the appropriateness, guilt, and doubt over the decisions made. Even when patient preferences are known, because of the uncertainty of the outcome, the decision making process in the ICU can be highly stressful. Compounding the psychological stress of uncertain outcomes, the SDMs are called upon to make critical, time sensitive, and highly technologically related decisions (Iverson et al., 2014). These stressful situations not only constrain the effectiveness of decisions but take a significant psychological toll on SDMs. The SDMs' critical decision making, the uncertainty of best role performance and concordance with the patients' preferences regarding medical treatments impose SDM role stress (Hickman, 2008).

The highly stressful ICU environment and the complex chronic critical illness conditions may have a direct impact on SDMs' psychological health, making purposeful emotion regulation difficult. As a result, SDMs may experience even higher levels of psychological stress that may progress to psychological distress. As is often the case, the family members are thrust into the SDM role unexpectedly in unprepared situations leading to the experience of high levels of role stress.

Psychological distress. The complexity of CCI patients' multiple health conditions and the transient or chronic state of cognitive impairment necessitates SDMs to make critical decisions for the patients resulting in high levels of psychological stress. The strain of being an SDM, in most situations unexpectedly and without sufficient prior experiences, result in high levels of psychological stress. If measures are not taken to reduce psychological stress, it can advance to psychological distress, which is characterized by the symptoms of depression and anxiety (Mirowsky & Ross, 2002). Horwitz (2007) argue that psychological distress will disappear when individuals adapt effectively with situational psychological stress. Scientists discuss that psychological distress is an emotional disturbance that may impact on the social functioning and other activities of daily living (Mirowsky & Ross, 2002; Wheaton, 2007). Thus, the proposed research focuses on distress which is a transient emotional disturbance resulting from an increased psychological stress. Supporting the SDMs from such experience of psychological distress is important.

Azoulay, Chaize, and Kentish-Barnes (2014) found that increased number of SDMs suffer from the symptoms of anxiety and depression, indication for the presence of psychological distress, during and after ICU admissions. Such situation is expected to persist as the number of CCI patients and the resulting ICU admissions continue to grow (Rose et al., 2008). Together with the symptoms of depression, anxiety and other problems such as practical and financial difficulties, SDMs experience high levels of role stress (Hickman, Daly, Douglas, & Clochesy, 2010; Iverson et al., 2014). It is documented in previous studies that the SDMs of CCI patients experience higher levels of distress compared to SDMs of patients with other health conditions such as

Alzheimer's disease or spinal cord injury (Douglas & Daly, 2003; Vreeburg et al., 2010) possibly due to the uncertainty of the prognosis. This is an indication that chronic critical illness conditions greatly impact SDMs.

Other situations contributing to high levels of psychological stress include the complex and potentially distressing decisions related to the implementation of important medical forms such as DNAR (do not attempt to resuscitate), CPR (cardio-pulmonary resuscitation), intubation, blood transfusion, laboratory investigations, and decisions on life-support. These procedures either save or prolong life. Sometimes saving life may mean allowing CCI patients to continue to live and suffer. Conversely, decisions on allowing a loved one to die may be the most distressing situation (Azoulay, Chaize, & Kentish-Barnes, 2014). Regardless of the stress-intensity of the decisions, most decisions in the ICUs are fraught with emotional and cognitive difficulties for SDMs (Ernecoff et al., 2016; Majesko et al., 2012).

Several researchers have examined the complexity of CCI patients' conditions and their impact on SDMs' psychological health (Hickman, Daly, Douglas, & Clochesy, 2010; Iverson et al., 2014; Iverson et al., 2013). Iverson et al. (2014) examined the SDM role challenges, characteristics, demographic factors, and the impact of these on SDMs' psychological stress. They learned that stress is a real factor influencing SDMs' confidence and comfort making quality decisions. The importance of communication between the healthcare team and SDMs has been studied extensively by many scientists who report that appropriate communication and dissemination of accurate information are crucial for SDMs to make critical and timely decisions with confidence (Daly et al., 2010; Hickman, Daly, Douglas, & Clochesy, 2010; Hickman & Douglas, 2010; Hughes,

Bryan, & Robbins, 2005; Nelson et al., 2005; Nelson et al., 2007). The impact of having advance directives (ADs) and living will on SDM stress has also been examined and showed that these documents reduce SDM stress considerably (Hickman & Pinto, 2013; Silveira, Kim, & Langa, 2010).

It is important to help SDMs of CCI patients in the ICU manage their psychological stress so that they can effectively regulate their emotions and achieve improved decision making processes. Ability to make meaningful decisions may result in better outcomes for CCI patients and decreased psychological stress for SDMs.

Conceptual Framework

Roy Adaptation Model (RAM)**:** The model that guided this study was RAM, first developed in 1970, re-defined last in 1988, as a framework for nursing by Sister Callista Roy (Roy, 2009). It is a middle range theory; currently one of the widely used frameworks in nursing practice with concepts based on general systems theory and Helson's adaptation level theory. In all, four basic concepts are presented in RAM (person, environment, nursing, and health) in which the person is described as a holistic and adaptive system with human behavior as the output of the adaptive system. In this model of the person as an adaptive system, Roy describes four major concepts: *Input, Control process, Effectors, and Output*.

Drawn from the concepts of this model, the constructs, concepts, variables, and measures were selected as shown in Figure 1. This substruct was formulated to explore the relationships among covariates emotion regulation, role stress, and psychological distress, and to learn how SDMs' situational stimuli (CCI patient conditions, the ICU environment, and the SDM's psychological stress) impact the emotion regulation control

process. Thus, RAM guided a theoretical and logical exploration for a possible relationship between emotion regulation and psychological distress and whether role stress mediated this relationship between emotion regulation and psychological distress.

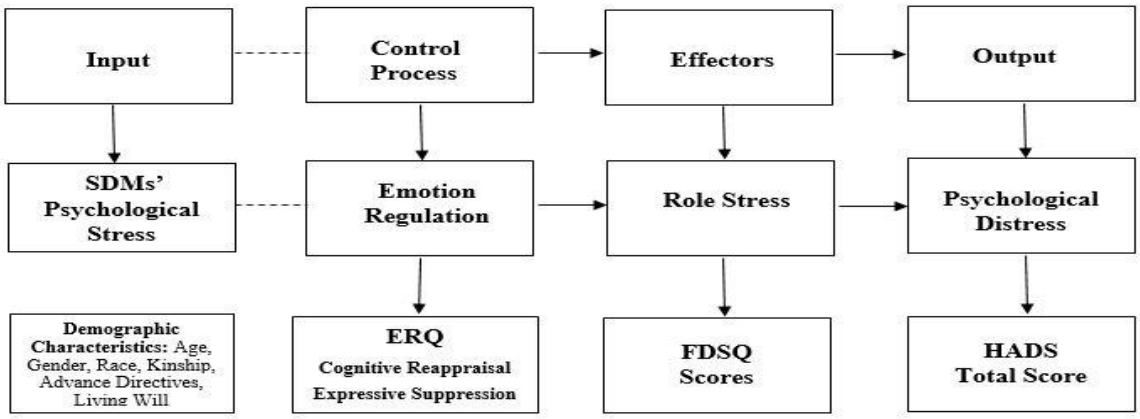

Figure 1. Theoretical constructs, concepts, and measures. The input is SDMs' situational stress, which triggers emotion regulation resulting in psychological distress. SDM's role stress may be mediating this relationship. The demographic variables also may influence these relationships.

The ***Input***, the internal and external stimuli, is comprised of three types of stimuli: *focal, contextual, and residual*. The *focal stimulus* becomes focal when it requires one's immediate response. Focal stimuli are the situational stimuli that draw one's immediate attention, requiring extra energy. For example, the significant psychological stress acquired from critical illnesses of a family member, uncertain prognosis, and time sensitive decision-making requirements, that require SDMs' immediate attention resulting in extra energy usage and becomes the focal stimulus. If this stimulus is greater than the person's available energy the responses may be ineffective and vice versa.

The *contextual stimuli* include all other stimuli present in the situation that contribute to the effect of the focal stimulus but do not directly draws one's attention as with the focal stimulus. For example, when SDMs' critical and time sensitive decision

making requirement is the focal stimulus, insufficient information and lack of decision support that contribute to the stressfulness of the decision create contextual stimuli.

The *residual stimuli* are other factors within or without the person such as previous similar experiences that may be forgotten yet reside in the memory. These buried memories may have unknown effects in the way one deals with the given situation. If SDMs have confronted stressful decision making experiences in the past, they can influence the current decision making process unknowingly. Awareness of residual stimuli may assist healthcare professionals to understand the individual background and the complexity of SDMs' decision making processes (Roy, 2009).

Roy (2009) argues that with the constantly changing environment the focal, contextual, and residual stimuli are interchangeable. The focal stimuli can become residual after a while, and contextual stimuli can become focal. Together the focal, contextual, and residual stimuli make up the person's adaptation capability level. As Roy (2009) describes, the *adaptation level* is the changing point that represents the person's ability to respond positively in a situation. This adaptation level comes from the demands of the situation and the person's current internal conditions, both of which greatly affect the way one deals with the given demand, SDMs' psychological stress. If the demands of the situation are less than the person's available energy the responses can be ineffective and vice versa. If the decision making process is extremely stressful with insufficient support and lack of pertinent information, the decisional quality can be considerably poorer, resulting in detrimental consequences to the patient and the SDM.

The ***control processes*** are comprised of both the stimuli and adaptation levels that serve as input to the person as an adaptive system and then are processed through a

mechanism that Roy (2009) calls the *control processes* of the person. The *control processes* are either automatic responses to the environment or responses based on the individual's previous experiences. In the current study the control processes was emotion regulation. According to Roy there are two control processes: the *regulator subsystem* and the *cognator subsystem*, and perception links the *regulator subsystem* to the *cognator subsystem* because inputs to the *regulator subsystem* are transformed into conscious perceptions in the brain. This occurs by changing the stimuli through chemical or neural processes, acting as inputs to the central nervous system, and by some unknown process transforming into conscious perceptions and becoming psychomotor choices of responses that become human responses (Roy, 2009).

The *cognator subsystem* involves psychological, social, and physiological factors of the person and are processed through the various cognitive and emotive pathways that trigger four types of processes: perceptual information processing, learning, judgment, and emotion. These are subjective experiences and function as neural, chemical and endocrine and later function through perception, processing, judgment, learning, and emotion (Roy, 2009). Emotion regulation, the subjective experience of the SDMs was the control process in this study. Based on SDMs' control process mechanisms, they can regulate emotions effectively to produce the best outcome of reduced psychological stress. As Roy describes, the regulator and cognator subsystems are interchangeable, and the functioning of these systems can be observed through behavioral outcomes. In this study, if SDMs were capable of healthy emotion regulation process and they used cognitive reappraisal as opposed to expressive suppression, reduced psychological stress would be the observed behavioral outcome.

The ***Effectors*** are observable behavioral outcomes described in four categories: *physiological, self-concept, role function, and interdependence modes* (Roy, 2009). The *physiological mode* is related to the way individuals respond as physical beings to stimuli from the environment, called physiological integrity; for example, the adaptive or non-adaptive behaviors to oxygenation, rest, and protection. The *self-concept mode* focuses on the psychological and spiritual aspects of the person for which psychological integrity has been identified as the outcome. Psychological integrity is the need to know who one is so that one can exist with a sense of unity. It is fundamental to health and adaptation problems in this area may interfere with the person's ability to maintain other aspects of health. The *interdependence mode* focuses on interactions related to the giving and receiving of love, respect, and value, the basic needs of which is termed as affectional adequacy (Roy, 2009).

The *role function mode* focuses on the roles individuals play in the society. A *role* is a set of expectations about how a person functions in the community, the basic need of which is identified as social integrity – the need to know who one is in relation to others based on which one can function (Roy, 2009). Threat to any such integrity can influence an individual's adaptation level. High levels of situational stress operate as a threat and interfere with the integrity of SDMs' role function. The family members' critical illness, unpredictable prognosis, SDMs' unpreparedness, and frequent decision making requirements amidst uncertainty, contribute to the greater threat to the integrity of their function as SDMs. Ineffective performance affects their identity in the society, and heightened emotional distress could be the results. Because *role function mode* was more applicable for the current study that aligned with SDMs' role stress, this study examined

whether SDM's role stress mediated the relationship between emotion regulation and psychological distress.

The ***Output***. The individual's behavior or state is viewed as outcome measures that are indicative of effective or ineffective adaptation. As described earlier, stimuli and adaptation level serve as input to the person. After processing this *input* through control processes, the individual makes a response. This response can be an *adaptive* or an *ineffective response* (Roy, 2009). Adaptive responses are those that promote integrity, while ineffective responses are those that neither promote integrity nor contribute to the goals of adaptation. In the current study the decreased psychological distress level indicated effective control processes and adaptation.

Contrarily, high levels of psychological stress that result in psychological distress would indicate ineffective adaptation. RAM helps to understand how SDMs' psychological stress may function as a threat to control processes and result in psychological distress. Similarly, improving control process strategies may prevent psychological stress from advancing it into psychological distress as well.

Constructs and Operational Definitions of Study Model

Emotion Regulation. Emotion regulation refers to regulating and shaping one's emotions, controlling as to when one should have them and how one should experience or express these emotions (Gross, 1998). Any threat to physiological, psychic, or social integrity becomes a focal stimulus requiring extra energy usage and possibly resulting in ineffective emotion regulation and individuals who function from limited energy resources experience poor emotion regulation abilities (Vohs et al., 2008). High levels of psychological stress may render as psychological threat resulting in activation of control

processes. Based on how the individuals perceive such threat and regulate their emotions, a positive or negative outcome may be the result. Additionally, emotion modulation may serve individuals to achieve resilient personality functioning because expression of positive affect is a core element of resilient personality functioning (Gross & John, 1998). High levels of psychological stress may impede the regulatory stages of emotion resulting in poor emotion regulation and quality decision making.

In the current study, these control processes involved two emotion regulation strategies of cognitive reappraisal and expressive suppression which was examined to learn how each strategy was related to psychological distress. Gross (1998) calls these strategies positive and negative affect. As described above, while the expression of positive affect renders better functioning, the expression of negative affect neither compromises nor aids for adaptive functioning. Based on the strategy one assumes, the intensity of psychological distress may vary. According to Gross and John (2003), the habitual use of cognitive reappraisal has a positive outcome, whereas the suppressors experience negative outcome. Cognitive reappraisal is a form of cognitive change that involves re-analyzing a potentially emotion-eliciting situation in a way that changes its emotional impact (Gross, 2014; Gross & John, 2003; Lazarus & Alfert, 1964). Expressive suppression is a form of response modulation or response disguise that involves inhibiting ongoing emotion-expressive behavior (Gross, 1998), possibly resulting in negative outcome.

SDM Role Stress. The term *role* consists of three elements: norm, position, and role behavior. According to Ivey and Robin (1966) norm is defined as an expectation of a behavior rooted in general social agreement. The position is considered as a social

position and role behavior defined as what an individual taking on a position performs. The SDMs, by assuming that role, acquire a social position that places an expectation from society to execute a specific social function, the best decision making role for the critically ill. Role stress is associated with the cognitive evaluation of role conflict, and role ambiguity wherein the role conflict occurs in a situation in which there is systematic difficulty involved in assuming or maintaining a role (Ivey & Robin, 1966).

Role ambiguity is inconsistent internal or external expectations of a specific role (Hickman, 2008). "The aggregation of role conflict and role ambiguity generates role specific psychological stress termed role stress" (Hickman, 2008, p.15). In other words, the concept "role stress" is the perceived psychological stress experienced by the SDMs while being in the role of a medical decision maker.

Psychological Distress. In the current study, psychological distress was considered as SDMs' experience of high levels of psychological stress characterized as symptoms of anxiety and depression that interfered with the ability to participate in valued activities and interests (Rose, 2017). Various factors lead to such high levels of psychological stress including complex patient conditions, neurocognitive and psychological sequelae that require substantial assistance, arduous, lengthy, and unpredictable recovery period. High levels of psychological stress affect their decision making ability resulting in the quality of the decisions made (Hickman & Douglas, 2010). Thus psychological distress can be generally defined as a state of transient emotional disturbance that interferes with one's social functioning and activities of daily living, manifested by the symptoms of depression and anxiety (Mirowsky & Ross, 2002; Ross, 2017).

Gross (2007) states that stress and emotion regulation may be linked in more important and fundamental ways to other dimensions of emotion regulation that may be helpful in managing psychological stress such as more basic physiological and attentional processes and have consequences on more sophisticated cognitive functions. In the current study symptoms of depression and anxiety, the two characteristics of psychological distress that are widely studied and frequently documented in the literature were addressed (Jansen et al, 2015; Llanque et al., 2016; Snaith, 2003).

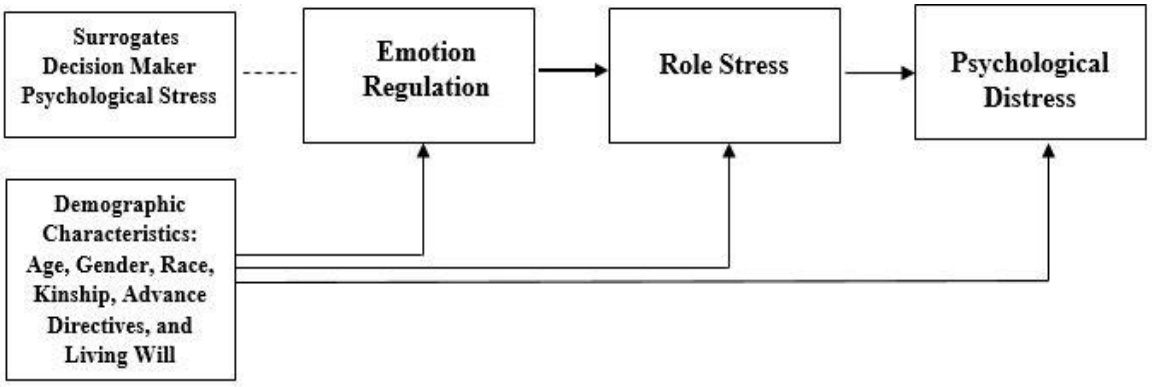

Figure 2. Research model. The situational stressors trigger emotion regulation processes, which may impact psychological distress, role stress mediating the relationship between emotion regulation and psychological distress. The demographic characteristics are potentially influencing emotion regulation, role stress, and psychological distress.

Research Questions

The purpose of this study was to examine the relationships among emotion regulation, role stress, and psychological distress, in the SDMs of CCI patients admitted in the ICU. The research questions were:

RQ1: What are the associations among the subscales of emotion regulation (cognitive reappraisal & expressive suppression), role stress, psychological distress, and demographic characteristics (age, gender, ethnicity, kinship, AD, and living will) of SDMs of CCI patients?

RQ 2: What is the relationship between the subscales of emotion regulation and psychological distress while controlling for surrogate decision makers' demographic characteristics?

RQ 3: Does role stress mediate the relationship between the subscales of emotion regulation and psychological distress while controlling for demographic characteristics of SDMs of CCI patients?

Implications

Assessment of the relationships among emotion regulation, role stress, and psychological distress among SDMs' of CCI patient populations is a unique contribution to nursing science. The conceptual framework of the current study integrated a widely utilized middle range theory of RAM (Roy, 2009) developed for nursing practice. RAM provides a meaningful explanation and theoretical guidance when examining the possible relationships among these concepts.

The two well studied emotion regulation strategies, cognitive reappraisal and expressive suppression, were examined in this study to learn how SDMs processed psychological stress and how it impacted on the development of psychological distress. Gross and John (2003) described the positive impact on cognitive reappraisers and negative impact on suppressors. Knowledge about the relationship among these study variables would be highly beneficial to clinicians in acute care settings for promoting innovative interventions to support SDMs in their critical decision making role in the ICU.

Based on the empirical knowledge on SDMs' tremendous psychological stress experiences, family support in the ICU has been heavily emphasized in the recent literature (IOM Report, 2015; Reinhard et al., 2015; Torke, Petronio, Sachs, Helft, & Purnell, 2012; White, 2011). The healthcare team has a moral responsibility to provide the much-required decision support to SDMs. Moreover, nurses are to contribute to the coherence of the person and the world (McCurry, Revel, & Roy, 2010). Maritain (1966) stated that nurses create the society that supports the dignity of the person. Apart from the responsibility to care for the CCI patients and SDMs, the expectation to contribute to the equilibrium of the society exist. By supporting the SDMs nurses contribute to the societal equilibrium. In addition, nurses who are at the forefront in helping, supporting, and educating patients and families assist SDMs to adopt healthy emotion regulation processes that can help reduce decision-making stress and the resulting residual psychological effects.

Implications for Clinical Practice: Knowledge generated through this study about how SDMs process psychological stress may help facilitate such events efficiently. Moreover, given the close proximity of the nurse to the patient and family interactions in the ICU, nurses stand in a crucial position to influence the quality and effectiveness of SDMs' care of CCI patients. Nurses hold a professional responsibility to provide a conducive environment for SDMs to mentally relax amidst highly stressful situations and important decision making events, helping to improve quality decisions.

Based on previous study results, SDMs require assistance with clear, honest communication of treatment information heard in a compassionate and respectful way, being sensitive, and responsive to their needs (Lemiale et al., 2010). Additionally, such

help needs to be provided from an early time point of the onset of chronic critical illness conditions (Hickman & Douglas, 2010) and knowledge and understanding of those from diverse cultures (Choi et al., 2016) has been recognized. The knowledge generated through this study is hoped to be of great value while assisting the SDMs as described above.

Implications for Research. Given the high vulnerability of the SDMs of CCI patients in the ICU, findings from this study may guide future scientists to a wide range of possibilities for future research regarding the development of innovative SDM assistance programs. Choi et al. (2016) state that more research is required to identify ICU caregivers who are at greatest risk for distress, time points to target interventions with maximal efficacy, needs of those from diverse cultures, and test interventions to mitigate family caregivers' burden. This study addressed some of these current research requirements. Research results of two emotion regulation strategies, demographic variables, and the relationships among these variables would provide information to future researchers to develop adequate and cost-effective decision support programs to enhance the overall decision-making experience while maintaining SDMs' stable mental health in the ICU.

Implications for Education. The results of this study would be valuable information regarding the impact of emotion regulation processes on adaptation mechanisms and the important roles these play on SDMs and their decision making role. Academic institutions could consider integration of these concepts, as well as the knowledge about the possible impact of emotion regulation on role stress and psychological distress into the curriculum of acute care educational programs.

Implications for Policy Changes. Finally, it is hoped that the knowledge generated from this study will bring awareness to the policy-makers about the impact of stressful decision making and the possible detrimental consequences to the patients. As a result, policy changes for practice guidelines in ICUs during and after ICU admissions of CCI patients, with equal importance to post admission follow up programs can be formulated. Thereby, the administration at the institutional level could support a much required policy change for SDMs in the ICU with timely, appropriate assistance from an early stage of ICU admissions. Because emotional support and decision making assistance are crucial from the time of ICU admission, it is hoped that such a need will be acknowledged by the policy makers to develop SDM support policies.

It is important that the policy makers realize that many other countries do hold ICU follow-up programs for family members. For example, follow-up clinics for families are available in about 30% of the United Kingdom (Griffiths, et al., 2006) and about 40% of the Netherlands (van der Schaaf et al., 2015). Thus, it is imperative for the United States to have similar facilities for SDMs of CCI patients in the ICUs. It is also essential that insurance companies realize this need and make insurance available for important services such as these for SDMs.

In conclusion, the SDMs of CCI patients experience high levels of psychological stress from being in that role while experiencing the stress of the patients' illnesses and an unknown outcome. Most SDMs experience psychological distress even several months after the discharge. The acuity of illness, the uncertainty of patient outcomes, SDM role stress, all contribute to the development of high levels of psychological stress leading to poor emotion regulation processes that result in high levels of psychological distress. Helping SDMs from an

early stage of ICU admission is important to maintain SDMs' psychological health to improve their role function and help optimize patient outcomes. This will also help SDMs and CCI patients to have less traumatic ICU experience. With this goal, this study intended to investigate the relationships among emotion regulation, SDM role stress, and psychological distress. The background and significance, theoretical and conceptual framework based on the RAM, research questions, and implications to nursing practice, including education, research and policy are discussed.

CHAPTER II

Literature Review

This chapter reviewed the relevant literature and described findings, identified gap in the current evidence base, and examined the existing relationships among the domains of emotion regulation, surrogate decision makers' (SDMs) role stress, psychological distress, and the demographic variables of age, gender, ethnicity, kinship, advance directives, and living will.

Chronic Critical Illness

Chronic critical illness began to receive attention when Girard and Raffin (1985) published their article *The Chronically Critically Ill: To Save or Let Die*. Since then the discussion of chronically critically ill (CCI) patients has continued with a significant focus on the impact of the extended length of intensive care unit (ICU) stay, prolonged mechanical ventilation, increased number of tracheostomy, and the resultant cost of such intensive care. Advances in intensive care technologies have enabled these patients to survive the acute phase of illness (Nelson, Cox, Hope, & Carson, 2010) creating a rise in the number of CCI patients (Nelson et al., 2007). Scientists report that more than five million Americans are admitted to an ICU annually (Choi et al., 2016; Khan et al., 2015). The cost of treating CCI patients in the US exceeds $20 billion, and it continues to rise with the latest available report showing $35 billion expenditure in 2011 (Khan et al., 2015).

The CCI patient population has been studied extensively during the past three decades, with a significant focus on defining chronic critical illness, the short and long term outcomes of CCI patients, cost and resource utilization, and its impact on the family, especially SDMs (Carson, 2012; Carson & Back, 2002; Daly, Rudy, Thompson, & Happ,

1991; Kappes & Carson, 2012; Nelson, Cox, Hope, & Carson, 2010). Camhi and Nelson (2007) discuss chronic critical illness in relation to its definition, scope, symptoms, outcomes, and interdisciplinary approach to care management. Kahn et al. (2015) examined the prevalence, outcomes, and associated costs of caring for CCI patients. A number of other scientists have investigated the impact of chronic critical illness on the patients, especially the SDMs (Ehlenback et al., 2010; Hickman & Douglas, 2010; Hickman, Daly, Douglas, & Clochesy, 2010; Nelson et al., 2010; Wiencek & Winkelman, 2010; Zilberberg et al., 2008). These accounts highlight the influence of chronic critical illness on the healthcare systems, patients themselves, the family, but more importantly the SDMs. However, it is important first to understand what chronic critical illness entails.

Defining Chronic Critical Illness

As mentioned previously, it was Girard and Raffin (1985) who first focused on CCI patient population, selecting critically ill patients who failed to improve despite intensive treatment in the acute phase. The patients required long-term, skilled-level care such as mechanical ventilation. These patients were then designated the title of CCI. In the past 30 years, there have been continuous efforts to gain insight into chronic critical illness syndrome and its impact.

Daly, Rudy, Thompson, and Happ (1991), in the effort to develop a special care unit, defined CCI patients as those whose ICU stays are incredibly prolonged with underlying chronic health conditions that are exacerbated by critical illnesses. Nelson, Cox, Hope, and Carson (2010) stated that the hallmark of chronic critical illness is respiratory failure requiring tracheostomy and prolonged mechanical ventilation.

Numerous other syndromes such as cognitive dysfunction, general functional debility, recurrence of nosocomial infection, and extended ICU stay are considered characteristics of chronic critical illness (Wiencek & Winkelman, 2010). In addition, profound weakness from myopathy and neuropathy, alterations in body composition such as decreased lean body mass, increased adiposity, distinctive neuroendocrine changes (Hollander & Mechanick, 2006), and low hormone levels resulting in altered physical functions are frequently observed syndrome in CCI patients (Van den Berghe et al., 1997).

Significant distress levels from pain, dyspnea, depression, anxiety, and inability to communicate due to endotracheal intubation (Nelson et al., 2004); poor quality of life; poor treatment outcomes; and high mortality (Daly et al., 2005; Nelson et al., 2007) are all symptoms characterizing chronic critical illness conditions identified through these studies. The current literature defines chronic critical illness conditions as those who are hospitalized with long term ICU care requirements which need lengthy periods of ICU care (Coomer et al., 2017). Mira et al. (2017) define chronic critical illnesses as "a persistent inflammation-immunosuppression and catabolism syndrome" (p.1).

From its first reference to the present, chronic critical illness has been extensively studied and clearly defined by various researchers with little variation. Summarizing all the important known symptoms for administrative and clinical purposes, Diagnosis-Related Group has categorized patients with CCI if they experienced one or more of the following: (a) survived an initial episode of critical illness but remained dependent on ICU treatment; (b) suffered respiratory failure requiring dependence on mechanical ventilation ranging from two days to four weeks; (c) succumbed to one or more organ

failure (for example: respiratory, renal, cardiovascular, or brain injury with intracranial hemorrhage); or (d) became vulnerable to severe infections (Camhi & Nelson, 2007; Coomer et al., 2017; Mira et al., 2017; Kalb & Lorin, 2002; Nelson et al., 2006; Nelson, et al., 2010).

Impact of Chronic Critical Illness

Morbidity and mortality. ICU care of CCI patients is associated with significant morbidity and mortality. The rate of morbidity and death continues to be higher during the post-ICU period because these patients suffer from multiple comorbidities, including cognitive dysfunction, in addition to the existing health conditions (Pandharipande et al., 2013). The development of comorbidities occurs due to the worsening of preexisting conditions and their advanced age; delirium is one of them. It is a strong predictor of increased length of mechanical ventilation and a form of acute brain dysfunction common during critical illness. It has consistently shown to be associated with long-term cognitive impairment and sometimes death (Pisani et al., 2009). An account by Pandharipande et al. (2013) reports that 74% of 821 cognitively impaired patients from medical and surgical ICUs developed delirium during the hospital stay and majority of them did not survive past one year.

Quality of life (QoL). The QoL of CCI patients after ICU is greatly influenced by the number of comorbidities, the age of the patient, and the severity of illnesses. Although there is conflicting evidence regarding the impact of age on the QOL of CCI patients, most research reports that multiple comorbidities in old age decrease the QoL dramatically (Bodet-Contentin et al., 2018; Griffith et al., 2018; Kahn et al., 2015; Rose et al., 2017). One report indicated that patients under 65 years of age have poor pre-

morbid physical scores when compared with their healthy cohorts, whereas older patients appeared to have higher mental scores than their younger counterparts (Cuthbertson et al., 2010).

In a current multivariate analysis by Griffith et al. (2018) pre-existing comorbidities emerged as the most important predictor of long-term QoL, whereas critical illness severity was not found to be influencing the QoL outcome. This is an indication that pre-ICU health condition is a crucial determinant of ICU outcome. Overall, multiple conditions decrease QoL of post-ICU patients such as organ dysfunction, profound weakness, extreme symptom burden, and ongoing physical and cognitive deficits (Rose et al., 2017).

Across settings of care. Most CCI patients survive the acute stage and are liberated from mechanical ventilation. However, nearly all of them leave the hospital with profound physical and/or cognitive impairments (Nelson et al., 2010). These patients, like ventilator dependent patients, are not ensured of long term survival due to underlying comorbid conditions, residual organ dysfunction, and other multiple complications. Many survivors lack sufficient cognitive functionalities requiring assistance for activities of daily life, especially decision making. About 40% of CCI patients who are discharged from the hospitals eventually require readmission and fewer than 12% survive past one year (Nelson et al., 2010).

Thus, most patients require continued medical assistance and are transferred to skilled care rehabilitation facilities or home. Caring for these patients in rehabilitation facilities pose more significant challenges as they require healthcare team with specialized skills. The provision of home care pose an additional challenge for SDMs,

cause considerable changes to the family structure, and cause financial, physical, and psychological strain.

Cost of care. The ICU care of the CCI patients is an expensive component of healthcare. Through a recent research scientists reported that it comprises about 4% of the national healthcare expenditures and 0.5% of the national gross domestic product in the US alone (Halpern & Pastores, 2010). These investigators examined critical care medicine cost against the national cost indexes and noticed that from 2000 to 2005, critical care medicine cost per day has increased by 30.4%. In 2005, critical care medicine costs represented 13.4% of hospital costs, 4.1% of national health expenditures, and 0.66% of the gross domestic product.

The ICU care cost has increased due to various reasons such as care delivery by an interdisciplinary team and life-saving equipment. Although only 5-10 % of patients transition from acute to the chronic stage, these patients generate 13% of all hospital costs, a figure that exceeds $20 billion annually (Cox & Carson, 2012). A few other accrued cost include hospital readmissions, inter-facility transportation, rehabilitation, and outpatient care. Other indirect costs of caring for CCI patients include unpaid work of family members as well as their lost days of work. In short, the ICU and post-ICU care of CCI patients result in higher healthcare cost.

Impact of CCI on SDMs. The scope of CCI patients, once solely focused on survival, is now expanded to include recovery with increased involvement of SDMs for most treatment-related decision making (Choi, Donahoe, & Hoffman, 2016). Greater participation by SDMs is required, mostly for end-of-life decision making because CCI patients may be cognitively incompetent. The concept *end-of-life decision making* can be

traced back to the late 1950s with the emergence of mechanical ventilation as a life sustaining treatment option for these patients (Truog, 2008). Since then, decision making was added to SDM's responsibility. However, such decision making has profound psychological impacts as SDMs experience significant uncertainty, stress, fear, anxiety, and distress since admission time.

Thus, family member's CCI conditions impose substantial burdens on SDMs. Research on CCI patients extensively describes the numerous challenges faced by SDMs (Choi, Donahoe, & Hoffman, 2016; Hickman, Daly, Douglas, & Clochesy, 2010; Hickman & Douglas, 2010; Hughes, Bryan, & Robbins, 2005; Iverson et al., 2014). Family member's CCI condition put SDMs at considerably high risk for depression and anxiety (Davidson, Jones, & Bienvenu, 2012; Hickman & Douglas, 2010). Choi, Donahoe, and Hoffman (2016) state that family caregivers of CCI patients in the ICU are at high risk for adverse psychological outcomes because recovery from CCI conditions can be a prolonged process, arduous, complicated, and unpredictable.

Auerback et al. (2005) examined family representatives of 40 CCI patients to learn about SDMs' experience while a family member was in the ICU. The participants responded to a brief version of the Critical Care Family Needs Inventory, the Acute Stress Disorder Scale, the Brief Symptom Inventory, the Impact Message Inventory, and the Life Orientation Test shortly after ICU admission as well as upon discharge. The results indicated that the levels of dissociative symptoms related to acute stress disorder were elevated from the time of admission. Van Pelt et al. (2007) conducted a one year longitudinal study on caregivers of CCI patients who survived the ICU period to compare depression risk, lifestyle disruption, and employment reduction between caregivers of

patients with and without pre-intensive care unit functional dependency. Prevalence of lifestyle disruption and unemployment were persistent among the caregivers of CCI patients, but depression risk was higher compared to their non-caregiver cohorts.

Hickman, Daly, Douglas, and Clochesy (2010) examined informational coping styles of SDMs, differences in informational satisfaction, role stress, and depressive symptoms. Additionally, they examined the predictive associations between these variables and SDMs. The outcome was that those who sought information projected less depressive symptoms compared to the ones who did not request information. Zier et al. (2012) investigated how SDMs interpret prognostic statements to determine the use of life support for patients with advanced illness in the ICU. In their mixed method study of eighty participants, they noticed that, when patients' values and goals are unknown, and SDMs are told of a slim survival rate, SDMs used their own judgement to make a decision. This suggests that SDMs stand in the face of uncertainty when the lives of their loved ones depend on their absolute decision making outcome.

Douglas and Daly (2003) examined the physical and psychological effects of caring on caregivers of CCI patients residing in their own homes and caregivers of CCI patients living in institutional settings receiving long-term mechanical ventilation. These caregivers were compared with their cohorts of patients with multiple sclerosis or cancer. High levels of depression were observed in the caregivers of CCI patients compared to the caregivers of multiple sclerosis and cancer patients. Pochard et al. (2005) conducted a study on 544 family members from 78 ICUs to examine the determinants of symptoms of anxiety and depression during the first few days of hospitalization. They utilized the Hospital Anxiety and Depression Scale (HADS) to gage symptoms. The results were

significant with 73.4% of family members reporting signs and symptoms of anxiety and 35.3% with depression.

Wendler and Rid (2011) reviewed 40 studies of 2854 SDMs to examine the impact of CCI conditions on the decision makers. The review comprised of quantitative and qualitative studies of SDMs who made mostly end-of-life decisions. The reports of these studies provide a strong indication that making treatment and end-of-life decisions has a negative emotional impact on SDMs which lasts for months to years.

Researchers have examined how SDMs cope with psychological stress during and after decision making experiences. Petrinec, Mazanec, Burant, Hoffer, and Daly (2015) conducted a prospective cohort study to evaluate the association between coping strategies of SDMs of ICU patients during and after their ICU experience as a possible precursor for psychological distress. They noticed that symptoms of psychological distress prevailed in many SDMs long after the ICU experience. The overall result indicated that the caregivers experienced a significant level of psychological distress even 60 days after the hospitalization. These accounts indicate that SDMs of CCI patients are exposed to intense psychological stress leading to long term health impacts such as psychological distress and other forms of psychiatric morbidity (Azoulay et al., 2005).

In short, the CCI patient population has been studied extensively during the past three decades with a significant focus on defining chronic critical illness, cost and resource utilization, and its impact on the patient and family, especially SDMs. It is clear that when SDMs were involved in treatment-related decision making roles, the experience heightened their psychological stress. Various research outcomes including clinical observations and other empirical research results indicate that the caregiver role

entails all the features of psychological stress. The widely investigated areas of chronic critical illness include family members' experience of having someone with chronic critical illness in the ICU, SDMs' psychological stress, the importance of information/communication between the healthcare providers and the family, communication-related challenges, and the psychological impacts of caring for persons with CCI conditions.

Emotion Regulation

Emotions are biologically based reactions that organize an individual's responses to significant events that unfold over a brief period (Gross, 2014). They have components in the domains of physiological response, subjective experience, and expressive behavior (Gross & Levenson, 1993). According to Barlow (2000), emotions are innate patterns of reactions and ways of responding that have evolved in many life forms because of their functional significance. Emotions are present at birth and are modifiable by learning and maturation. The study of emotions has recently expanded from psychology into other fields including psychiatry, history, and neuroscience.

Emotions involve a series of internal changes that result in external actions which begin with emotion generation (Sheppes, Suri, & Gross, 2015). According to Sheppes, Suri, & Gross, emotion generation occurs in a series of patterns, such as attending to a situation, giving it meaning, and producing a loosely coupled set of experiential, behavioral, and physiological responses. Emotions are generated when an attended situation is interpreted as being central to one's goals. Emotion generation involves multisystem changes that can be described by intensity, the magnitude of the response, the duration of the time the response is active, and the type of response requirement.

Defining emotion regulation. According to Gross (1998), emotion regulation shapes one's emotions by controlling as to when one should have them and how one should experience or express these emotions. Gross et al. (2011) define emotion regulation as an activation of a goal that recruits one or more regulatory stages to influence emotion regulation, the target of which can be to induce a change in oneself called intrinsic, or in the other called extrinsic, and may result in a change in the perception.

Emotion regulation is a vital component of everyday life, and its primary function is to prepare individuals for action and survival (Barlow, 2000). It is relevant to effective social functioning, successful cognitive performance, and in the management of emotionally arousing situations. Emotional competence, the ability to act efficaciously in flexible and adaptive ways, is crucial for successful management of emotionally arousing situations (Campos, Mumme, Kermoian, & Campos, 1994). Emotionally stable individuals can regulate their emotions when there is a mental task or a goal to be achieved. However, individuals experiencing challenging, stressful situations may dysregulate emotions resulting in an undesirable outcome.

Emotion regulation is a process, and it begins with emotion generative stage (Gross & John, 2003; Sheppes Suri, & Gross, 2015). Gross and John (2003) call such emotion generation stage the ‘emotion cues.' Thompson (1994) describes a three-stage ER process model for this emotion generative stage or emotion cues. These three regulatory stages constitute *identification, selection, and implementation*. The identification stage involves whether to regulate or not, while the selection stage involves

the selection of which regulatory category or strategy to use. The implementation stage is the execution of the selected regulatory tactic.

Recent investigations on emotion regulation describe an extended five-stage process model at the emotion generative stage. These include *situation selection, situation modification, attentional deployment, cognitive change, and response modulation* (Sheppes, Suri, & Gross, 2015). According to Sheppes, Suri, and Gross situation selection refers to efforts to change the course of an emotional situation at the earliest stage, such as avoiding certain situations, while situation modification attempts to change external features of a situation with the goal to shorten the time period. The attentional deployment stage tries to alter the situation by distraction and the cognitive change attempts to reappraise the emotional meaning of a situation. Finally, response modulation is modifying the situation with a new meaning, which can be positive or negative. Thus the actual emotion regulation process begins at the emotion generative stage. These processes are like a cycle being repeated when an emotion regulation is in operation. At the regulatory stage of selection, knowingly or unknowingly, one determines the path one wants to proceed, an adaptive or distractive strategy.

Individuals differ widely in employing these emotion regulation processes, which can be observed in its intensity, persistence, modulation, onset, and lability of emotional responses (Thompson, 1994). Such differences in reactions constitute significant response parameters that are influenced by the stages of emotion regulation that one assumes at the cognitive change stage that can be positive or negative. The outcome may depend on the type of emotion regulation process one follows. Through such emotion

regulation processes that one choose to follow, individuals can also adapt either to enhance or to undermine effective functioning (Gross, 2014).

Additionally, there are various regulatory strategies of emotion, and the outcome of one's emotional outcome depends on what strategy one assumes. Two of the best studied regulatory strategies include *cognitive reappraisal* and *expressive suppression* (Gross, 2014; Gross, 2002; Gross & John, 2003; Gross & John, 1998). Cognitive reappraisal is theoretically defined as a form of conscious, deliberate change that involves re-analyzing a potentially emotion-eliciting situation in a way that changes its emotional impact (Gross & John, 2003; Lazarus & Alfert, 1964). It can be used to down-regulate negative emotions, such as anxiety. Expressive suppression is theoretically defined as a form of response modulation or response disguise that involves inhibiting ongoing emotion-expressive behavior resulting in a negative outcome (Gross & John, 2003; Lazarus & Alfert, 1964).

Individuals tend to select cognitive reappraisal when emotional intensity is low, simple, and long-term relief is sought. Contrarily, suppression is sought when emotional intensity is high, complex, and short-term relief is preferred (Sheppes, Suri, & Gross, 2015). The selection of cognitive reappraisal may render better functioning while expressive suppression neither compromises nor aids adaptive functioning. Based on the strategy one assumes the degree of functional outcome may vary. The habitual use of cognitive reappraisal may have a long-term positive outcome, whereas the long-term use of expressive suppression may produce a negative outcome.

Additionally, a cognitive reappraisal is an antecedent-focused emotion regulation in which the individual employs deliberate effort to change emotion regulation in the

early phase of emotion generation resulting in a positive behavioral output (Gross, 2014). According to the emotion generation theory described by Gross, once an emotion has been generated, for example, activation of a control process as a result of SDMs' decision making requirement, it may follow the path as described under the five sets of regulatory processes. Selecting cognitive reappraisal strategy and employing emotion modulation process at any stage as required may produce the best outcome, such as quality decision making.

Influence of emotion regulation on SDMs. Decision making, the primary function of SDMs, requires emotional stability as decision making is an executive function just as learning and attention are examples of executive functions and requires stable cognitive ability (Starcke & Brand, 2012). Evidence exists about strong connections between emotion regulation and decision making process (Lerner, Li, Valdesolo, & Kassam, 2015). The association between emotion regulation and decision making was demonstrated by Sanfey et al. (2003) using a functional magnetic resonance imaging experiment. The activation of the anterior insula correlated with rejection of inequitable financial offers made by an opponent in an economic task known as the Ultimatum Game (a game in an economic experiment). Referring to Gross (2014), the interpretation was that insula activation reflects a negative emotional regulatory response to an unacceptable offer.

Other researchers have examined emotion regulation influence on making choices and suggest that task-irrelevant or difficult tasks that impact one's mood may bias decision making (Harle & Sanfey, 2007; Harle, Chang, Van't Wout, & Sanfey, 2012). Gross (2003) states that high levels of distress activate and trigger emotion regulation

processes in humans. It may be possible that high levels of stress impact emotion regulation negatively, influencing decisional quality, and contributing to SDM role stress.

Wout, Chang and Sanfey (2010) investigated the effect of expressive suppression and cognitive reappraisal on strategic decision making in an interactive social task using the Ultimatum Game. The participants in each group were instructed to use either reappraisal or suppression. The reappraisers were asked to interpret potentially emotion relevant stimuli in unemotional terms whereas the suppressors were asked to inhibit emotion-expressive behavior while emotionally aroused. At the end of the game, the participants in the reappraisal group seemed to accept unfair offers more often than participants in the suppression group. Additionally, the effect of emotional reappraisal appeared to influence the amount of money participants proposed during the second interaction with partners who had mistreated them in a prior interaction. This tends to confirm that the cognitive reappraisal strategies are more beneficial compared to expressive suppression.

Regardless of the strategy, one assumes, emotion regulation in general impacts decision making. Harle, Chang, Van't Wout, & Sanfey, (2012) conducted another study to explore how emotional status impact the decision making process. Nineteen adults were instructed to watch a short video that aimed at inducing either a sad or neutral emotional state. Participants who watched sad video rejected unfair offers more often than those in the neutral condition. Neuroimaging analysis of these participants revealed that receiving unfair offers while in a sad mood elicited activity in brain areas related to aversive emotional states, somatosensory integration, and cognitive conflict. Participants

who watched the sad video also showed a diminished sensitivity in neural regions associated with reward processing.

Based on Sheppes, Suri, and Gross (2015), study results such as these indicate that the emotion regulation processes are "inherently probabilistic and contextually defined" (p.381). This means that emotion regulation processes are influenced by both the internal as well as the external environmental conditions. For example, externally any threat to physiological or social integrity may result in ineffective emotion regulation, while heightened psychological stress and low energy are examples for an internal condition that may render emotion regulation ineffective. Individuals experiencing high levels of psychological stress usually function from limited energy resource resulting in ineffective emotion regulation (Vohs et al., 2008). The heightened psychological stress in the ICU environment renders severe consequences on SDMs, may impede emotion regulation processes resulting in assuming an ineffective emotion regulation strategy and the end result may be SDM role stress and psychological distress.

Operational definition of emotion regulation. Emotion regulation can be theoretically defined as the functional processes that influence the intensity, duration, and the type of emotion experienced, which permits flexibility in emotional responding according to one's short and long term goals (Gross, 2014). Emotion regulation occurs along a spectrum from conscious, effortful, and controlled regulation to the unconscious, and possibly effortless, or automatic regulation. Two theoretically and empirically supported regulatory strategies are cognitive reappraisal and expressive suppression. Cognitive reappraisal, a generally adaptive strategy involves altering the interpretation of the emotion-eliciting event at the generative emotion stage in order to change the

emotional experience. Contrarily, the expressive suppression, a generally maladaptive strategy refers to the act of inhibiting external emotion displays (Gross & John,2003). Emotion regulation was measured and operationalized using the scores from the Emotion Regulation Questionnaire (Gross & John, 2003).

SDM Role Stress

Stress has always been a part of human existence. Stress in humans was first referenced by Selye in 1936 who examined the physiology of stress and labeled the processes the *General Adaptation Syndrome* (Maguire, 2012). Selye described stress as a nonspecific response of the body to any demand from the environment. Lazarus and Folkman (1984) added by stating that stress has a psychological aspect as well. Lazarus, Cohen, Folkman, and Schaefer (1980) enhanced this understanding that stress is not only a stimulus or a response but a function of individual appraisal of the situation. Other scientists have strengthened the evidence that an event does not create stress unless an individual appraises that event as a threat (Chang, 1998; Lazarus & Folkman, 1984).

Stress is a complex multi-dimensional phenomenon focusing on a particular dynamic relationship between a person and that person's environment (Lazarus and Folkman, 1984). Stress is dependent on the individual appraisal of what is at stake and what resources are available to meet the expected demands. Additionally, personal beliefs, values, and roles, which develop from individual's unique life history shape the appraisal of stress and can have a profound impact on social functioning (Lazarus & DeLongis, 1983). Role stress is one such type of stressors that affect social functioning.

The role specific responsibilities of SDMs, including critical decision making can induce heightened psychological stress referred to as SDM role stress. Role stress has its underpinnings in psychology and sociology (Siegall, 2000). The term *role* consists of

three elements: norm, position, and role behavior. Norm is defined as an expectation of behavior rooted in general social agreement; position is considered as a social position; and role behavior is defined as a person's performance in a particular role (Ivey & Robin, 1966).

The concept of role stress was first introduced by Kahn et al. (1964) who attributed it to problems encountered in performing one's role. Since the first introduction of role stress, many scientists have invested in understanding it and developed several frameworks for the measurement of role stress. Kahn et al. described three dimensions of role stress: role conflict, role ambiguity, and role overload. Role conflict refers to the stress involved when trying to fulfill responsibilities of more than one role simultaneously. Role ambiguity involves a lack of clarity related to what is expected in the assumed role, while role overload is the degree to which individuals are overtaxed with numerous responsibilities.

According to Ivey and Robin (1966), role stress is associated with the cognitive evaluation of role conflict and role ambiguity. It arises from a role conflict in which there is a systematic difficulty involved in assuming or maintaining the role, whereas role ambiguity is inconsistent internal or external expectations of a specific role. "The aggregation of role conflict and role ambiguity generates role specific psychological stress, termed role stress" (Ivey & Robin, 1966, p.15). The feelings of uncertainty, incompatibility, or clarity within oneself about the assumed or imposed role creates role stress.

Pareek (1982) significantly expanded this conceptual framework to eight role stressors, including, among others, role distance, role stagnation, and role erosion.

Various measurement tools can be used to measure these concepts. The role conflict scale comprising eight items by Kahn et al. (1964), a six-item tool by Rizzo, House, and Lirtzman (1970), and a hassles-based measure by Zohar (1997) are a few of them being used initially.

Scientists have investigated the impact of role stress in various fields and population. The more widely researched areas include role stress in informal caregivers, nurses and nurse managers, business associates and managers, and organizational role stress. Lambert and Lambert (2001) in their research on nurses' role stress found that various situations such as high job demands, low supportive relationships, work overload, dealing with critical illnesses, and death and dying led to role stress. A literature review to examine factors related to nurses' role stress by Chang et al. (2005) identified that work overload was the top indicator of nurses' role stress. Admi and Moshe-Eilon (2010) conducted a study to explore nurse managers' role stress and reported that their role stress was positively related to role specific responsibilities. The Tarrant and Sabo (2010) investigated nurse executives' views on role conflict, role ambiguity, job satisfaction, and depression. They identified a positive relationship between role conflict and depression.

Sharma and Devi (2011) explored the factors causing role stress among bank professionals and learned that a different set of concepts such as role divergence, role fortification, resource shortage, and role invasiveness led to role stress. The level of role stress of women workers in various other organizations was examined by Khetarpal and Kochar (2006) who learned that most women experienced moderate to high levels of role stress. Sen (2012) carried out a literature review to investigate organizational role stress

and reported numerous other factors such as poor fit between work requirements and one's abilities, competitive and dynamic organizational environments, and hazardous and insecure working conditions to be active contributors to organizational role stress.

All who encounter problems in role performance experience role stress. It is present at the organizational, managerial, and other formal and informal levels of responsibilities. Role stress measures used at the organizational level include *Role Overload Scale* comprising three items: role conflict, role ambiguity, and role overload (Beehr, Walsh & Taber, 1976). Pareek (1982) significantly expanded this identifying eight role stressors by developing the *Your Feelings About Your Role* (YFAYR) Scale comprising 40 items to measure inter role distance, role stagnation, role ambiguity, role erosion, role overload, role isolation, role inadequacy, self-role distance, resource inadequacy, and personal inadequacy are a few of them. This was later known as *the Organizational Role Stress Scale* and beneficial in organizational settings.

Personal role stress variables examined include age, hierarchical position, education, and functional background. Job satisfaction is reported to be related to role stress; similarly, job satisfaction is related to personal variables; thus role stress may be related to personal variables (Asadi et al., 2008). Job satisfaction/dissatisfaction or role ambiguity among caregivers may result in role stress among caregivers of CCI patients.

Additionally, formal and informal caregivers may experience different levels of role stress. Formal caregivers are reported to be experiencing higher levels of role stress (DePasquale et al., 2017). This may be due to legal responsibilities for the lives of the patients. However, formal caregivers' professional knowledge should serve as great support in providing competent care. Contrarily informal caregivers may experience

heightened role stress at an emotional level due to their relationship with the patient as well as lack of professional knowledge may add to high levels of role stress.

Role Stress in SDMs of CCI Patients

Critical decision making is a known cause for role stress among SDMs (Hartley & Phelps, 2012; Majesko, Hong, Weissfeld, & White, 2012; Miller, Morris, Files, Gower, & Young, 2016; Wendler & Rid, 2011). Anxiety, fear, and uncertainty about the decisional outcome may result in heightened psychological stress affecting decisional quality. This might impair SDMs' ability to protect incapacitated patients and would also represent harm to SDMs. Wendler and Rid (2011) conducted a literature review based research to assess the effect of making treatment decisions on SDMs. They included 29 qualitative and 11 quantitative studies, and the participants included 2854 SDMs who had made decisions any time from the recent past to several years previously. The result indicated that one third of the SDMs experienced negative emotional impact due to role stress.

The decision making challenges of SDMs of CCI patients were investigated by Iverson et al. (2014) who focused on SDM stress characteristics and the personal, social, and care-related factors that led to role stress. The participants included 34 female SDMs who had a long-term relationship with the patients. These participants described how the strain of uncertain outcomes and decision making experience without clear and consistent information from providers contributed to their role stress.

Majesko et al. (2012) examined factors associated with SDMs' role stress while communicating with healthcare professionals and whether the quality of clinician-family communication was associated with the timing of decisions to forego life support. The

results indicated that difficulty in communicating and insufficient information contributed to heightened role stress. The most common adverse effects reported included stress, guilt over the decisions made, and doubt regarding whether they had made the right decisions.

The findings from these studies indicate that one third of SDMs experienced heightened psychological stress. Similar findings are consistent across various study locations, methodologies, types of treatment decisions, whether recent or in the distant past, and whether the patient survived or passed away. Such heightened psychological stress may affect emotion regulation processes resulting in poor decision making experiences. Hindmarch, Hotopf, and Owen (2013) state that depression affects reasoning thereby distorts or blinds perception. Based on this knowledge, heightened psychological stress may distort reasoning when making decisions resulting in the quality of decisions.

Neural pathway, role stress, and decision making. The neural circuitry path may also help explain how heightened psychological stress induces SDM role stress. Frank, Cohen, and Sanfey (2017) examined how the brain chooses among several possible options in the face of uncertainty using an emotional versus a cognitive path. Starcke and Brand (2012) state that stress and decision making are intricately connected, and that stress influences the quality of decisions by altering the decision making process. The brain regions associated with intact decision making are sensitive to stress-induced changes and, through a neural path, stress alters the quality of the decision making process (Starcke & Brand, 2012).

Neuropsychiatric studies show that anxiety alters decision-making (Greifeneder, Bless, & Pham, 2011; Starcke & Brand, 2012) and that both cognitive and affective

regulatory processes may be impaired when experiencing anxiety. However, the neurocircuitry path affecting anxiety and its impact on decision making ability is not well understood. Anxiety is an individual trait that has a neurocircuitry path that causes behavioral variation in a variety of domains including the decision making process discussed by Starcke and Brand showing that anxious individuals tend to unrealistically judge adverse outcomes to be more likely than positive outcomes. Decision making may be affected by such unrealistic judgment. It is known that anxiety has a profound impact on the ability to function adaptively because individuals use increased brain resources to reduce negative emotional experiences (Starcke & Brand).

Role stress is a widely investigated concept in the disciplines of sociology, psychology, business, including nursing. Since its introduction in 1964 by Kahn et al., role stress has gained much importance, and various measurement tools have been developed to test it, especially in psychology and business arenas. However, the mediating effect of SDM role stress in the relationship between emotion regulation and psychological distress in CCI patients remains under-investigated.

Operational definition of SDM role stress. The concept *role stress* is the perceived psychological stress experienced by SDMs while fulfilling the role of a critical decision maker. The SDMs play specific cognitive roles that may generate role-specific psychological stress known as role stress. The role conflict occurs when there is an internal and/or external role disagreement and role ambiguity contributing to the generation of role stress. Thus, role stress was conceptualized as the consequence of a disparity between what was perceived to be the role expectations and what the individual

could accomplish (Lambert & Lambert, 2001). The SDM role stress was operationalized and measured using the Family Decision Maker Stress Questionnaire (FDSQ).

Psychological Distress

Psychological distress is viewed as an emotional disturbance that can impact activities of daily living and social functioning of individuals. While distress pertains to physical or mental ill health, psychological distress denotes individuals' mental health, especially emotional health (Ross, 2017). Individuals may experience symptoms of anxiety and depression when they reach a stage of psychological distress. Evidence indicates that emotion regulation abilities tend to deteriorate during the periods of psychological distress resulting in failure to achieve goals (Tice et al., 2001).

Theories that may explain the relationship between emotion regulation abilities and psychological distress include *Capacity, Motivation, and Priority Shift*. Capacity theory predicts that psychological distress prevents rational thought and therefore undermines the capacity to regulate oneself effectively and fails to function as rational and goal-oriented beings (Leith & Baumeister, 1996; Tice et al., 2001). Motivation theory states that the person who experiences emotion regulation disturbances cease to care about pursuing positive and constructive behavior. The theory of Priority Shift refers to shifting one's attention to making one feel good first than attending to the important task at hand (Tice et al., 2001). Thus psychological distress works against the usual pattern of emotion regulation because distress promotes a short-term goal, whereas attending to long-term goals requires healthy emotion regulation. These theories help to understand the principles of how SDMs' heightened psychological stress could impact their role functions resulting in negative outcomes for themselves and for the people they care.

The high levels of psychological stress result in psychological distress in SDMs. Psychological distress is characterized by depression and/or anxiety and is the result of strain associated with being an SDM (Hickman & Pinto, 2013). As Priority Shift theory explains, psychological distress deteriorates emotion regulation abilities resulting in the failure of their efforts to achieve goals (Tice et al., 2001). Azoulay, Chaize, and Kentish-Barnes (2014) found that about 70% of SDMs suffer anxiety while about 35% suffer depression (symptoms of psychological distress) during and after ICU admissions. Additionally, SDMs experience high levels of role stress which may alter the intensity of psychological distress (Hickman, Daly, Douglas, & Clochesy, 2010; Iverson, Celious, & Kennedy, 2013). Evidence shows that the SDMs of CCI patients experience heightened psychological distress levels compared to their cohorts of other patient population, such as Alzheimer's disease (Douglas & Daly, 2003; Van Pelt et al., 2010).

Garland et al. (2010) examined depression and anxiety, the characteristics of psychological distress, in the light of Fredrickson's (1998) *Broaden-and-Build* theory to explain the pathogenic processes and to illustrate positive emotion-based therapies. According to Broaden-and-Build theory positive emotions build durable personal resources, increase a wide range of personal resources, and broaden individuals' thought-action performances. Several researchers examined this fact that positive emotions can have a long-lasting impact on functional outcomes and result in enhanced well-being and social connectedness (Cohn et al., 2009; Fredrickson & Branigan, 2005; Rowe, Hirsh, & Anderson, 2007; Schmitz et al., 2009). A longitudinal field experiment by Diener, Lucas, and Scollon (2006) on participants in their midlife resulted in a threefold increase in the dose-response relationship between time spent meditating and its positive emotional

outcome. The results of all these investigations indicate that positive emotions account for resilient people's greater ability to rebound from psychological conditions, such as depression and anxiety.

Several researchers have examined the complexity of CCI patients' conditions and its impact on SDM stress (Hickman, Daly, Douglas, & Clochesy, 2010; Iverson et al., 2014; Iverson, Celious, & Kennedy, 2013). Iverson et al. examined the SDM role challenges, characteristics, demographic factors, and the impact of these on SDMs' psychological stress and learned that stress is a real factor influencing SDMs' confidence and comfort in making quality decisions. The importance of communication between the healthcare team and SDMs has been studied extensively by many researchers who report that appropriate communication and dissemination of accurate information are crucial for SDMs to make critical and timely decisions with confidence (Daly et al., 2010; Hickman, Daly, Douglas, & Clochesy, 2010; Hickman & Douglas, 2010; Hughes, Bryan, & Robbins, 2005; Nelson et al., 2005; Nelson et al., 2007). The impact of advance directives (ADs) on SDMs' stress has also been investigated and the results indicate that having ADs reduce SDM stress considerably (Hickman & Pinto, 2013; Silveira, Kim, & Langa, 2010).

The impact of caregiving on caregivers has been investigated by more scientists. Pochard et al. (2001) conducted a study in multiple ICUs in France three to five days after the patients' ICU admission to assess symptoms of depression and anxiety. The result indicated that, among 920 participants, the overall prevalence of anxiety was 69%, and depressive symptoms were evident among 34%. Shaffer, Riklin, Jacobs, Rosand, and Vranceanu (2016) conducted a cross-sectional research to examine the associations

of patients' and their informal caregivers' psychosocial resiliency factor with their own and their partners' distress, anxiety, depression, and anger. The outcome indicated that there were no differences between patients' and caregivers' levels of psychosocial resiliency, distress, or anxiety. This finding indicates that both patients and their informal caregivers suffer similar levels of anxiety and depression in the ICU. Zanten et al. (2016) examined the experience of symptoms of depression, and anxiety among family members of ICU patients to assess caregiver strain three months after discharge. A total of 94 informal caregivers of patients who were ventilated more than 48 hours, completed the Trauma Screening Questionnaire and the Caregiver Strain Index and the result indicated that about 21% of family members suffered these symptoms even after three months.

Shaffer et al. (2016) examined the associations of patients' and their informal caregivers' psychosocial resiliency factors while in the ICU. In their descriptive cross-sectional study, they learned that nearly half of the caregivers of patients admitted to neurological ICU experienced psychological distress that tended to last months or even years. In addition, the findings show that the psychological distress of SDMs of ICU patients is rarely acknowledged but needs to be addressed from an early period of ICU admission. Cameron, Franche, Cheung, and Stewart (2002) examined the impact of providing care on lifestyle and emotional well-being in a sample of caregivers to patients with advanced cancer. The investigators examined whether lifestyle interference mediated between the amount of care provided and psychological distress. The outcome indicated that lifestyle interference significantly contributed to heightened psychological distress.

An extensive literature describes the challenges faced by the SDMs of CCI patients, but few of the studies investigated the prevalence of psychological distress. Some of the causes of psychological distress among the SDMs include insufficient communication and dissemination of accurate information on patient condition and treatment choices, and absence of ADs and living will. Studies on SDMs of CCI patients in the ICU were remarkably fewer, especially about how ineffective ER process influenced psychological distress.

Operational definition of psychological distress. Psychological distress would be a medical concern only when accompanied by other symptoms that, together satisfy the diagnosis for a psychiatric disorder. In the current study psychological distress was considered as a transient phenomenon with decreased intensity compared to a psychiatric disorder. Therefore, psychological distress was theoretically defined as caregivers' experience of any form of emotional disturbance that impacted social functioning and activities of daily living (Horwitz, 2007; Wheaton, 2007). It interferes with family care givers', especially decision makers' ability to participate in valued activities and interests, especially decision making. Psychological distress was operationalized by the total score of depression and anxiety using the scores from the Hospital Anxiety and Depression Scale (HADS) (Snaith, 2003).

Relationship Among the Variables

Emotion regulation and role stress. Emotion regulation serves many functions such as an evolutionary function (Tooby & Cosmides, 1990), a social and a communicative function (Ekman, 1993), and a decision making function (Oatley & Johnson-Laird, 1987) to name a few. Because decision making is the primary function of

SDMs the role of emotion regulation in decision making was focused in this study. The influence of emotion regulation on decision making was examined in the light of one of the cognitive theories of emotions called *action-readiness*. According to Frijda and Parrott (2011), action-readiness theory of emotion refers to the motive state that underlies feelings of emotional urge or action tendencies. "The state of action readiness form the *core* [italics added] of emotions because the functional significance of emotions is to initiate or modify tendencies to establish, disrupt, or maintain relationships with the environment or an object of thought" (p.406). The fundamental goal of emotions according to this theory is to establish, disrupt, or maintain an object of thought. However, emotions in an energy depleted state may not facilitate towards a positive emotion regulation and effective decision making.

Evidence shows that making many choices impairs subsequent self-control resulting in poor decision making (Vohs et al., 2008). Vohs et al. (2008) carried out four laboratory studies to examine how decision making depletes the same resource used for self-regulation and active responding. Some participants in the study were instructed to make choices among consumer goods or college course options, whereas others were to think about the same options without making choices. Participants who had to make choices resulted in reduced self-control.

The SDMs' priority function, the decision making role, involves making many choices. Together with SDMs' heightened psychological stress the inability to regulate emotions may negatively influence the decision making capability. In a state of depleted energy and when mental resources are lacking the person has to use self-control or willpower from the limited pool of mental resources and energy (Baumeister, 2002;

Baumeister, Bratslavsky, Muraven, & Tice, 1998). Heightened psychological stress may result in a depleted energy state through stressful life-sustaining or life-limiting decisions in the ICU resulting in SDMs' role stress.

ER and psychological distress. Emotion regulation and psychological distress may be intricately interlinked. Studies show that depressive life events contribute to the onset of depression and when depressed, individuals exhibit use of mal-adaptive emotion regulation strategies (Gross & John, 2003; Michl, McLaughlin, Shepherd, & Nolen-Hoeksema, 2013). This may occur because psychological distress deteriorates emotion regulation (Tice et al. 2001). Tice et al. present a few theories to show the possibilities of such interlink between emotion regulation and psychological distress.

Intentional Self-destruction is one theory that is based on P*sychodynamic Theory* and holds that some forms of psychological distress give rise to self-destructive tendencies. For example, a person who feels distressed may abandon the positive pursuit of desirable goals and normal healthy behaviors because the aversive state generates self-defeating motivations. Another theory called *Capacity Theory* predicts that psychological distress prevents rational thought and therefore undermines the capacity to regulate oneself effectively. Based on this theory, people who are emotionally upset cease to function rationally, resulting in inability to uphold goal-oriented behaviors.

Accordingly, psychological distress impairs the capacity to self-regulate due to limited regulatory resources. Individuals who experience psychological distress expend their energy resources struggling with their feelings, which causes further resource depletion and leave them incapable of regulating their behavior for a beneficial outcome. Yet another line of theory called *Motivation*, suggests that psychological distress may

impair the motivation to regulate oneself in the normal, optimal fashion. Individuals experiencing psychological distress may cease to care about pursuing positive and desirable options. These theories point to the possibilities of a link between emotion regulation and psychological distress.

Evidence also shows neural correlations of emotion regulation to depression. Ochsner and Gross (2008) show the involvement of the limbic system, including the amygdala and ventral striatum in the generation of emotion regulation. For example, depressive states show hyperactivity in the amygdala, while the prefrontal regions become hypoactive. Moreover, the depressed individuals exhibit amygdala hyperactivity at the presence or even at the anticipation of such events of sad stimuli (Arnone et al., 2012; Hamilton et al., 2012). This shows an interlink between emotion regulation and depression.

To examine individual differences in anxiety and depressive symptoms affecting positive emotion regulation processes in real-life contexts Carl et al. (2014) conducted a daily diary study on a sample of 164 nonclinical undergraduates. Results indicated that higher baseline anxiety and the severity of depressive symptoms were associated with decreased positive emotion reactivity and increased down-regulation of positive emotions. This shows that people who chronically suppress their emotions are at high risk for depression and anxiety disorders, such as panic disorder (Wenzlaff and Wegner, 2000; Lissek et al., 2009).

Role stress and psychological distress. SDMs experience heightened psychological stress due to various reasons such as an uncertain prognosis for the ill family member, time sensitive and life changing decision making, and uncertainty or

guilt over whether the decisions they made were the best for the ill family member. According to Baumeister (2002) heightened stress may result in a depleted energy state leaving one even less capable of making quality decisions which can lead to psychological distress. Amidst heightened psychological stress SDMs may be unable to perform their decision making roles effectively. Iverson et al. (2014) state that the cumulative effect of sustained, intense decision making of SDMs ratchets up their already elevated anxiety levels and leaves them less capable of making effective decisions. It is like a vicious cycle. Heightened stress makes SDMs make poor decisions; poor decisions result in poor patient outcomes; and poor patient outcomes result in more psychological distress.

Heightened stress level has been identified as a legitimate factor influencing SDMs' confidence resulting in psychological distress (Iverson et al., 2014; Wendler & Rid, 2011). Iverson et al. (2014) conducted a study using semi-structured interviews to examine challenges related decision making among 34 SDMs making care decision for the CCI patients in the ICU. Most of the SDMs were female and had a long-term relationship with the patient. The results highlighted stress as a concrete factor that impacted their capacity to make quality decisions. The SDMs described the strain of uncertain outcomes and decision making without clear, consistent information from healthcare providers. Given these situations, a high association between role stress and psychological distress can be expected.

Selection of Demographic Variables

Age

Age and emotion regulation. The age of the person may be associated with the emotion regulation strategies used. Gross and Levenson (1993) state that older and younger adults employ different emotion regulation strategies to cope with emotionally arousing situations. There appears to have a shift from the response-focused to antecedent-focused emotion regulation as people grow older.

Yeung, Wong, and Lok (2011) examined whether older people used more reappraisal and less suppression strategies. The sample consisted of 654 younger and older adults aged between 18 and 64. The result indicated that age was significantly associated with reappraisal. Compared with younger individuals, older adults showed higher emotion regulation maturity in regulating their emotions, and when engaged in stressful events, older adults were found to be using reappraisal strategies. As individuals grow older, they tend to regulate their emotions successfully by using more reappraisal strategies as opposed to suppression strategies.

Ali and Alea (2017) conducted research to investigate the gender differences in emotion regulation. The sample included 191 men and women from young, middle, and late adulthood. They used autobiographical memories of past events that were meaningful, yet comparatively usual life events. Participants were instructed to reappraise, suppress, or were given no instructions about what to do while recalling a negative memory about their romantic relationship. Engaging in suppression resulted in higher relationship satisfaction (particularly for women) but engaging in reappraisal reduced negative affect for middle-ages versus younger adults. Regardless of

instructions, older adults experienced higher relationship satisfaction and higher positive and lower negative affect than younger aged adults. Although this study was carried out to examine gender differences in emotion regulation, the investigators noticed emotion regulation strategy variation among various age groups as well.

Etxeberria et al. (2016) investigated emotion regulation strategy use among the older adults who are 65-74 years old and the oldest old at 75-84 years of age. Evidence derived from this study showed that the oldest old group used fewer proactive strategies (strategies that involve directly confronting negative emotions) and more passive strategies (acceptance of the situation) compared to their younger counterparts when regulating anger and sadness. The conclusion may be that as people age individualized coping strategies are adapted as their way of emotion regulation and that older individuals use positive emotion regulation strategies.

Age and role stress. The age of the SDM may have an influence on the intensity of the role stress experienced. The researcher was unable to identify empirical evidence to state that there is a relationship between age and role stress, however logically one could argue that older adults may experience less role stress because of their increased knowledge and life experience. Contrarily, younger SDMs may have insufficient knowledge and experience to perform the newly assumed SDM role of caring for a CCI family member. Older SDMs may also be better at distinguishing between what is better for patient' conditions. Additionally, with the aging process the emotion regulation strategies change for better; thus age may impact role stress as well.

Age and psychological distress. Emotional competence, the ability to act efficaciously in emotionally arousing situations, is a crucial factor for everyone (Saarni,

1999). Young adults may lack such emotional competence when assuming SDM roles; as a result, they may experience comparatively lessor psychological distress levels. Suveg and Zeman (2004) examined emotion management skill, emotional intensity, and emotion regulation in 26 children ages 8-12 with anxiety disorders and their counterparts without any psychopathology. The results indicated that children with anxiety disorders had difficulty managing worry, sadness, and anger experiences. This indicates that a positive emotion regulation may be difficult for people with anxiety disorder.

The middle aged and employed SDMs may be at a higher risk for experiencing increased psychological distress level for different reasons, such as job loss, disturbed family life, and financial problems. However, the older SDMs may be capable of managing their psychological stress better than younger ones. Laatsch and Shahani (1996) carried out a study to examine the relationship of age with psychological distress of rehabilitation patients and the statistical analysis revealed that there was a significant inverse relationship between age and psychological distress. Thus, the older SDMs may experience low levels of psychological distress.

Gender

Gender and emotion regulation. Though empirical evidence is conflicting, gender differences appear to be significantly noticeable in the use of emotion regulation strategies. Evidence indicate that men and women respond differently to emotionally stressful events and that women report using more emotion regulation skills than do men (Gross, 2014; Nolen-Hoeksema, 2012; McRae et al., 2008). In some instances, men are reported to use positive emotion regulation strategies, while some other accounts report that women are significantly more likely to use positive emotion regulation strategies.

However, study outcomes consistently report that men are more likely to use suppression than women, whereas no differences reported in the use of reappraisal between men and women (Gross & John, 2003; McRae et al., 2008). Another report shows that women experience more negative emotion than men (Mroczek, 2004). Nolen-Hoeksema (2012) examined prevalence of gender differences in emotion regulation related to psychopathology in men and women, and the result showed that women used almost all types of emotion regulation strategies compared to men, including rumination, reappraisal, problem solving, acceptance, distraction, and seeking social support.

Gender and role-stress. Insufficient empirical evidence exists on how gender is related to role stress, however, based on the following summary it can be assumed that role stress affects women more compared to men. Because women are viewed widely as emotional beings, who experience, express, and dwell on their emotions more deeply than men (Barrett & Bliss-Moreau, 2009). Contrarily, men are viewed as tending to suppression or avoid both the experience and expression of emotions. The gender role theories state that women use more internally focused, passive responses to their emotions, such as rumination, as opposed to men who are likely to engage in suppression or avoidance (Tamres et al., 2002).

Gender and psychological distress. Butler and Nolen-Hoeksema (1994) tested whether women use coping strategies more effectively than men when experiencing heightened psychological stress. They induced a sad or neutral mood in a sample of female and male college students, then gave them a choice of a task that required them to focus on and analyze their current emotional states or a task that was not emotion-focused. A majority of women chose the superior emotion-focusing task whether they

were in a sad or a neutral mood, while only half the men chose the emotion-focusing task in either mood. This shows that women tend to choose a better emotion regulation even in sad moods. This is an indication that women are better at coping when experiencing psychological distress.

Race

Race and emotion regulation. Race may account for cultural influences on emotion regulation, role-stress, and psychological distress of SDMs. Culture facilitates the development of values related to all aspects of life, especially values related to interpersonal relationships and emotion regulation (Matsumoto et al., 2008). Matsumoto et al. reported differences across 23 countries on two emotion regulation processes: reappraisal and suppression. They observed that cultural dimensions such as high social order, value embeddedness and hierarchy, and reappraisal and suppression showed a positive correlation. Contrarily, cultures that minimized the maintenance of social order valued individual autonomy, and egalitarianism, showed lower scores on suppression. Additionally, suppression may be a cultural norm for certain cultures so that emotions do not disrupt interpersonal relationships and social order. These indicate that value differences of cultures influence the selection of emotion regulation strategies.

Race and role-stress. Race appears to have some relationship with role stress. Braun et al. (2008) investigated the self-reported experience of African-American, Caucasian, and Hispanic SDMs of CCI patients to examine the influence of race, ethnicity, and culture in surrogate decision making. The experience of the burden of decision making in its medical, personal, and familial dimension was similar in all three groups. The racial-ethnicity variations of responses to this burden were related to the

physician-family relationship, religion and faith, and past experiences with race-ethnicity concordance versus non-concordant physicians. This may be an indication that regardless of ethnic background, the experience of role stress may be similar to all SDMs. Rubin, Dhar, and Diringer (2014) examined racial differences in the withdrawal of mechanical ventilation (MV) in patients with brain death. The result indicated that, compared to whites, non-whites were less likely to withdraw MV. Thus ethnic differences may impact role stress to some degree.

Race and psychological distress. Value-based cultures may contribute to a better mental disposition to cope well with psychological distress while certain other ethnic background may find it harder to manage psychological distress. Brown, Meadows, and Elder (2007) conducted a study on the impact of three racial background on psychological distress: Blacks, Whites, and Asians and learned that the experience of psychological distress were similar among Blacks and Whites. However, the Asians experienced comparatively lessor levels of psychological distress. The use of increased social support and closer family ties were attributed to such difference among the Asians. This shows a possible association between racial background and psychological distress.

Kinship

Kinship and emotion regulation. Kinship may have a stronger association with the level of psychological distress among SDMs. The *Attachment* theory by Bowlby (1982) state that humans have an innate psychobiological system that motivates them to seek proximity to significant other when they are in need of protection. The SDMs' supportive and caring response to the family member who suffers from chronic critical illness enables the person to develop a sense of attachment security. This attachment security

feeling may promote an attachment between the SDMs and the patients. Contrarily, the SDMs' unavailability or unreliable response to the patient's needs may promote the development of an insecure pattern of attachment.

Ben-Naim et al. (2013) conducted a study to examine the influence of emotion regulation among couples engaged in a relationship. The sample consisted of 127 romantic couples, who were assigned randomly to either an interventional, or to a control condition. In the affective suppression condition, one partner was instructed to refrain from expressing emotions, while in the favorable mindset condition one partner was instructed to think about the positive aspects of the relationship. The results showed that emotion regulation interventions did influence the physiology, emotional behavior, and emotional experience of both the manipulated participant and the cohort, who was oblivious to regulation of manipulations. This may be indicating that kindship influences emotion regulation.

According to the Attachment theory, when couples are engaged in a relationship, they communicate with one another using a multitude of channels, some of which may be conscious and explicit while others may be unconscious and implicit (Bowlby, 1982). Thus, when one partner reveals or conceals certain feelings, the other one detects not only those feelings but the lack thereof. In the light of this findings, it can be assumed that the SDMs' relationship may influence their family member who may be depending on them for their support and care.

Kinship and psychological distress. Based on the *Attachment Theory* it can be hypothesized that stronger the relationship between the care recipient and the SDMs, higher may be the psychological distress. Consistent with these assumptions is a review

by Pinquart and Sorensen (2011) who examined the level of psychological distress between spouse and children SDMs and reported a similar account that the stronger the relationship, the higher the psychological distress. They explain that this might be because of the spousal attachment, possible more extended periods of caregiving without respite, and possibly older age of both.

Advance Directives and Living Will

Advance directives (ADs) are legal documents that allow patients to plan their own end-of-life treatment wishes and a living will is an AD that guides the family and healthcare team to make medical decisions in the event that patients become unable to participate in such decisions (Goede & Wheeler, 2015). The Patient Self-Determination Act passed in 1990 allows patients to decide their medical care, make ADs, and have a living will. Through these processes of having ADs and living will, patients can plan in advance to let their caregivers know how intensive they would like their end-of-life care to be (Abele & Morley, 2016). Having ADs and living will have been reported to improve the quality of death, reduce aggressive medical care in the terminal phase, reduce unnecessary transfers to emergency departments, and result in earlier referral to hospice (Garrido et al., 2015; Morley, Cao, & Shum, 2016).

Since the passing of The Patient Self-Determination Act in 1990, there is increasing awareness, not only of the need of the importance of ADs but also of their benefits on SDMs, such as reduced stress. Scientists have examined the benefits of ADs and living wills on the outcomes of SDMs across patient populations. For example, Song et al. (2015) examined the benefit of ADs on SDMs of dialysis patients and learned that having ADs lowered anxiety and depression in SDMs during the end of life decision

making processes. Hickman, Daly, and Lee (2012) reported that having an AD may reduce the decisional uncertainty and alleviate the decisional burden of SDMs. Having an AD and living will significantly benefit SDMs because these documents guide SDMs to make patient-centered decisions when time-sensitive, end-of-life decisions are expected and when SDMs are unaware of patients' wishes. Therefore, examining the relationship of ADs and living will with emotion regulation, role stress, and psychological distress in the proposed study was considered meaningful.

This chapter provided definitions of chronic critical illness, challenges of CCI patients, and the stress experienced by SDMs of CCI patients while in ICUs and following discharge home or to other healthcare facilities. An extensive literature review was carried out to identify existing evidence pertaining to CCI conditions, effect of CCI on SDMs, emotion regulation processes and its impact on role stress and psychological distress. Associations among emotion regulation, role stress, psychological distress, and demographic variables of age, gender, ethnicity, kinship, and ADs and living will that may be possibly related to emotion regulation, role stress, and psychological distress were also examined and discussed.

CHAPTER III

METHODOLOGY

The purpose of this proposed secondary data analysis was to examine the relationships among emotion regulation, SDM role stress, and psychological distress in surrogate decision makers of (SDMs) of the chronically critically ill (CCI) patients. This chapter described the research methodology of parent investigation, including instruments, data collection procedures, and data management. Specific to the proposed secondary data analysis, this chapter discussed the statistical approach, human subject protection, and threats to the validity.

Overview of the Parent Investigation

The purpose of the parent investigation, *Validation of a Dual-Process Model for Surrogate Decision Making* (Hickman, 2017) was to investigate the biobehavioral mechanisms that influence the quality of decision making among SDMs, who made a decision for a cognitively impaired patient in the intensive care unit (ICU). The selection of the primary constructs was guided by a dual process model of decision making under uncertainty, for which the constructs were emotional vulnerability (genetic predisposition, dispositional cognitive appraisal, and role stress), information processing (emotional and cognitive processing), and decision making outcomes (psychopathogenic state and decision quality).

The specific aims of the parent investigation were to examine the influence of emotional vulnerability on information processing, the direct effects of emotional vulnerability on decision making outcomes, to determine if information processing mediated the relationship between emotional vulnerability and decision making

outcomes, and to identify whether contextual covariates (e.g., gender, race, kinship, and knowledge of the patients' preferences) moderated the relationship between information processing and decision making outcomes among SDMs. In order to achieve these specific aims, the investigators of the parent research chose to use a cross-sectional design with causal modeling. Data collection occurred at two times: (1) 24-48 hours following the presentation of a healthcare decision by the critical care team to a patient's SDM, and (2) two months after baseline interview. This temporal interval for data collection was selected with a goal to capture the immediate and intermediate emotional cognitive burdens associated with the act of surrogate decision making and to respect the SDM's need to process the experience. The investigators of the parent investigation recruited 120 subjects who met the eligibility criteria.

Methodology for the Proposed Secondary Data Analysis

Research Design

This present study was a secondary data analysis of cross-sectional data, generated from a parent investigation of SDMs of CCI patients. Prior to the screening or recruitment of the eligible SDMs, the investigators of the parent research received institutional review board (IRB) approval from the study site, University Hospitals Cleveland Medical Center. This secondary data analysis used de-identified data generated from the conduct of the parent investigation and did not require additional review from the study site's IRB.

A secondary data analysis is an important research method to examine health phenomena, which utilizes an existing data to answer new research questions (Glass, 1976). According to Glass, the secondary data analysis is a scientific process that is

driven by the design, methods, and procedures of data collection of the parent investigation. The secondary data analysis allows scientists to select variables in a data base to generate new knowledge that may differ from the parent investigation.

Strengths and Limitations of a Secondary Data Analysis

Strengths. Castle (2003) noted that a secondary data analysis has the potential for resource savings, reduced time burden, and cost-effectiveness for the investigator, all of which enhance efficiency in conducting the research. As the data is already available, it eliminates the need for the investigator to hire and pay personnel to collect data. The secondary data analysis also lessens data collection challenges, such as finding sufficient and appropriate participants for the research, which results in saved time. Further, having a data set is economically beneficial in that there is no participant cost in the form of incentives, no payment necessary for the research assistants, no technology related costs for data storage, and more importantly, less burden for the participants. All these factors allow the investigator to work efficiently, and use the remaining time to explore new questions, test different theoretical frameworks, and refine or assess psychometrics of instruments. In addition, a secondary data set can also be used to retest the primary research, using different statistical instruments, test theories, and validate research instruments within the primary research.

Limitations. Important limitations of using a secondary data analysis include the investigator is being constrained to the variables, measures, and procedures, and being unable to consider other variables of interest. The researcher has no control over the research design, inclusion, and exclusion criteria. In addition, the researcher cannot control for the threats to the internal validity as well as control the external

generalizability. These methodological restraints may influence the theoretical integrity of a secondary data analysis (Castle, 2003). However, the research design selected for the proposed research was a reasonable one, as cross-sectional descriptive studies examine and describe the existing relationships between the variables of interest at one-time point. Therefore, the limitations were not expected to negatively influence the current study outcome.

Setting

Since this present study was a secondary data analysis, there was no physical setting specific to this study. However, the parent investigation was conducted in the surgical, medical, cardiac, and neurosciences ICUs of an academic medical center in Northeast Ohio. In total, the study site has 74 beds designated for the care of critically ill adults and admits more than 3,000 critically ill patients each year. All of the ICUs at the study site operate under a *semi-closed* or *closed* model of management, where admission to an ICU and subsequent care in the ICU, is directed by critical care intensivists (a board-certified critical care physician) or acute care nurse practitioners with critical care experience.

Sample

For the parent investigation, the target population was SDMs who made a healthcare decision for a decisionally impaired patient in an ICU. Participants were recruited over 24 months. In all, 120 subjects met the inclusion criteria for the parent study.

Inclusion criteria. The inclusion criteria for SDMs consisted of: (1) >18 years of age, (2) next-of-kin or legal representative for healthcare decision making for a

cognitively impaired (Glasgow Coma Scale motor response score < 6 and eye response score < 3) patient who required mechanical ventilation for ≥ 3 continuous days, (3) approached by the critical care team for a healthcare decision (e.g., resuscitation status, tracheostomy, gastrostomy, or any major surgical intervention) within the previous 48 hours, and (4) able to understand and speak English. Considering the small number of potential non-English speaking participants, including them was not deemed beneficial.

Exclusion criteria. SDMs were excluded from this study if they had (1) a preexisting psychiatric disorder with current medication and/or psychotherapy, (2) a preexisting neurocognitive impairment, or (3) profound vision and/or hearing loss that would have precluded variable measurements. Participants with these conditions were excluded only if their conditions impaired them from providing the required information.

Sample Size Estimation

To determine the adequacy of the sample size to achieve statistical power for the research questions, a sample size estimation calculation was determined for each research question. The calculation of sample size included the following statistical parameters: (1) effect size, (2) Type I error, (3) Type II error, (4) power (1-beta), and (5) specification of statistical test. A brief review of the influential parameters for sample size estimation: Type I error, Type II error, and power are discussed and the sample size estimation for the proposed research questions presented thereafter.

Effect size determination. Effect size (ES) estimation provides the magnitude of the differences between study variables and is the main finding of a quantitative study (Sullivan & Feinn, 2012). ES shows the substantive significance, in relation to the population, while statistical significance reflects the improbability of findings pertaining

to the sample. The G*Power 3:1 Software program indicated effect sizes of .10, .30, and .50 as small, medium and large ESs respectively for correlation statistical analysis (Faul et al., 2009). Accordingly, for Pearson *r*, Spearman *rho*, and Multiple Regression correlation statistic tests used for the research questions of the current study, a small to medium ES (.30) was considered meaningful. In order to assess the required sample size to obtain a small to medium ES the following studies were examined.

Campbell-Sills et al. (2011) examined how anxiety-prone individuals experienced excessive negative emotions that might lead to the potential dysfunction of other systems, resulting in down-regulation of negative emotions. The researchers trained 26 participants: 13 with high anxiety (HA) scores and 13 with normal anxiety (NA) levels. They were trained to use cognitive reappraisal to reduce, as well as to maintain, negative emotions. Blood oxygenation level dependent tests were used to monitor prefrontal modulation of the amygdala and the related limbic structures, which are the underlying neural substrate of effortful emotion regulation. The researchers obtained a medium effect size ($r = .59$, $p < .05$) between the HA and NA groups.

Salters-Pedneault et al. (2006) examined the association between emotion regulation deficits and generalized anxiety disorder. They obtained a small to medium effect size (for Zero order *r*, Difficulties in Emotion Regulation Scale $r = .51$, Impulse $r = .41$, and Awareness $r = .09$) with a sample size of 87. Goldin and Gross (2010) found a medium effect size in their examination of mindfulness-based stress reduction on emotion regulation in social anxiety disorder in a study of 14 samples, $t(14) = 3.25$, $p < .01$. Furthermore, Lee and Orsillo, (2014) examined the relationship among cognitive

flexibility and anxiety disorder in a sample of 66 participants and obtained a small effect size (r = -.21).

Type I error. Type 1 error refers to the probability of rejecting the null hypothesis when it is in fact true (Polit and Beck, 2006). This means falsely rejecting the null hypothesis when there is no treatment effect. The conclusion of Type 1 or Type II error relies on a comparison between the p value and α level. By doing so, the researcher can control the probability level of errors. Thus, selection of an appropriate α level is important.

The commonly used α levels are .05 and .01, which refers to a 5% or a 1% likelihood that the observed result occurred by chance, and that the investigator will incorrectly reject the null hypothesis. This means that there is a true effect, or difference, within the population. In relation to null hypothesis, these values are informative, which would help to explain that if the researcher accepts the risk that out of 100 samples, a true null hypothesis would wrongly be rejected five times. In other words, in 95 out of 100 cases, a true null hypothesis would be correctly accepted.

Although, with a significance level of .01, the chance of Type I is lower, the investigator considered a significance level of $p < .05$ for the current study meaningful because of its exploratory nature. In addition, there was no pharmacological substances nor any intervention involved that posed a threat to life should there be an increased chance of Type II error. For example, wrongly accepting the false relationship of a pharmacological substance can be a threat to life, in which case the investigator would want to choose a stringent significance level of $p < .01$.

Type II error. Type II error refers to the probability of falsely rejecting a null hypothesis when in fact there is a relationship. The probability of Type II error occurrence is referred to beta (β), which can be estimated through power analysis. Power refers to the ability of a statistical test to detect true relationship between the study variables, thus power = $1 - \beta$. The standard acceptable risk for Type II error is .20, and the researchers use a sample size that would provide a minimum power of .80 (Polit & Beck, 2006). One can seek to reduce both types of errors, however reducing Type I error increases the risk of Type II error. According to Polit and Beck (2006), the stricter the criterion for rejecting a null hypothesis, the higher the risk of accepting a false null hypothesis. Increasing the sample size may help avoid Type II error.

In addition, the hypothesis testing can be directional or non-directional; in other words, one-tailed or two-tailed (Polit & Beck, 2006). This provides information on the direction of a relationship. A one-tailed test is chosen only when the researcher is able to theoretically trace and predict a directional hypothesis in one direction. The current study utilized a two-tailed null hypothesis test with a significance level of $p < .05$.

Power. After determining the significance level, the next step is to determine the statistical power. According to Polit and Beck (2006), statistical power refers to the probability of correctly rejecting the null hypothesis and it is directly related to the probability of making a Type II error. Establishing appropriate criteria to obtain high power in research is important because research outcomes with low power can lead to erroneous conclusions (Murphy & Myors, 2004). Murphy and Myors describe three criteria to obtain high power. These include statistical significance (α level), effect size, and power. Smaller α level increases the chance of making a Type II error, leading to

decreased power to detect effect size. The generally accepted level of power is .80, thus, β = .20 (Cohen, 1992). This means there is an 80% chance of detecting a true relationship and a 20% chance of falsely accepting the null hypothesis. Decreasing the probability of Type II error (low β) increases the power. Increased sample size may decrease Type II error and increase power. Therefore, determining the required sample size is important. An α level of .05, small to medium effect size .10 to .30, and power of .80 were established for the current study.

Determination of the Sample Size Adequacy

Research question 1. In order to determine the required sample size for research question one that examined the associations among the subscales of emotion regulation, role stress, psychological distress, and demographic variables of SDMs of CCI patients, the Pearson *r* correlation statistical test was utilized. Thus, a power analysis was carried out using G*Power 3.1, by entering the criteria: correlation, medium effect size, and power .80, which prompted a sample size of 82. Due to the exploratory nature of this study and the lack of previous studies analyzing the relationship among the exact variables of interest, a small to medium effect size was considered adequate.

Research question 2. For research question two that explored the relationships among the subscales of emotion regulation and psychological distress, while controlling for the demographic variables, the Multiple Regression test statistics was used. The G*Power 3.1 software was used to examine the required sample size by entering the criteria as Multiple Regression, two tail test, power of .80, the number of independent variables seven, a moderate effect size of .30, and the G*Power 3.1 prompted a sample size of 103.

Research question 3. For research question three that explored whether role stress mediated the relationship among the subscales of emotion regulation and psychological distress as shown in figure 1, the Multiple Regression was used as the test statistics. As in research questions one and two a power analysis was conducted using G*Power 3.1 by entering the information as: linear multiple regression, medium effect size of .30, power of .80, seven predictor variables, which prompted a sample size of 114. From these three estimations, 114 was the highest required sample size prompted, however, the investigators in the parent study obtained a sample size of 120 that was available for the current study.

Operational Definitions and Instruments

This section describes the operational definitions of key terms and variables along with the instruments that measure each variable of interest. The psychometric properties of each instrument, including the validity and reliability that operationalize the three major study variables: emotion regulation, role stress, and psychological distress are presented below.

Emotion Regulation Questionnaire (ERQ). Emotion regulation refers to the processes by which individuals control which emotions they have, when they have them, and how they experience and express their emotions (Gross, 1998). According to Gross (2014), emotion regulation encompasses various emotion regulation processes that unfold over time and involve changes in its dynamics, for example, emotion regulation latency period, generating time, magnitude, duration, and offset of responses in behavioral or physiological domains. Accordingly, emotion regulation was discussed based on two main domains: cognitive reappraisal and expressive suppression.

Cognitive reappraisal is antecedent-focused emotion regulation, that occurs before the emotion is generated, and expressive suppression is response-focused, that occurs after the emotion is generated (Gross, 2014; Gross, 1998). This fundamental difference between cognitive reappraisal and expressive suppression enables multiple domains of psychological functioning. For example, experimental findings show that cognitive reappraisal results in decreases in both behavioral and subjective signs of negative emotion, with no adverse consequences. Contrarily, expressive suppression results in decreased behavioral responses, and other side effects such as impaired verbal memory and diminished responsiveness to social activities. Taken together, these findings suggest that cognitive reappraisal has more favorable consequences than expressive suppression (Gross, 1998; Gross, 2001). In order to understand individual differences in cognitive reappraisal and expressive suppression both of these aspects were measured as two subscales of one variable by ERQ measure (Gross & John, 2003).

The ERQ measure is a 10-item scale designed to measure individual differences in the use of two emotion regulation strategies and how individuals use emotion regulation processes. Respondents answer each item on a 7-point Likert-type scale ranging from 1 (strongly disagree) to 7 (strongly agree). Items 1, 3, 5, 7, 8, and 10 measure cognitive reappraisals, and items 2, 4, 6, and 9 measure expressive suppression. According to Gross and John (2003), among the different models tested, confirmatory factor analysis resulted in ERQ measure as being the best fit to measure these two concepts. While calculating the scores, the item numbers cannot be altered or changed as the first and third items define "positive emotion" and "negative emotion," respectively. There is no reverse coding required in calculation of the score. The confirmatory factor

analysis tests have identified that this two-factorial structure is a regulatory strategy and independent of each other (Balzarotti, Gross, & John, 2010; Gross & John, 2003).

Gross and John (2003) conducted five studies of samples taken from undergraduate students to examine reliability and validity of ERQ measure and reported good internal consistency for ERQ measure: the alpha reliability = .79 for cognitive reappraisal and .73 for expressive suppression. A Test-retest reliability across three months was .69 for both items. The psychometric properties of ERQ measure confirms the reliability and validity of the measures of cognitive reappraisal and expressive suppression. According to Balzarotti, John and Gross (2010) ERQ measure holds good Cronbach's alpha reliability coefficients; .84 for the cognitive reappraisal scale and .72 for the expressive suppression scale. Item analysis confirmed internal reliability consistency for both scales. When summing items 1, 3, 5, 7, 8, and 10, the total correlations ranged between .48 and .68 for cognitive reappraisal. When summing items 2, 4, 6, and 9 for expressive suppression the correlation ranged between .42 and .63. Finally, between item analysis for both, cognitive reappraisal and expressive suppression showed no correlation (r = .08). In short, cognitive reappraisal and expressive suppression are two independent strategies of emotion regulation and that when one uses one strategy the other strategy is not in use at the same time. However, individuals use both of them at different times (John & Gross, 2003).

Family Decision Maker Stress Questionnaire (FDSQ). The family decision maker role stress refers to the perceived psychological stress experienced by the family member while assuming the role of a medical decision maker. Role conflict occurs when there is systematic difficulty involved in assuming or maintaining an assumed role (Ivey

& Robin, 1966) due to overwhelming decision making requirement. Role stress will be measured using Family Decision Maker Stress Question (FDSQ).

The FDSQ is a single-item measure that captures the SDM's perception of the psychological stress associated with the SDM role by asking, "How stressful has it been making medical decision for your loved one?" (Hickman & Pinto, 2013). This instrument is a visual analogue scale by two anchors, "not at all stressful" and "very stressful". The parent investigators asked participants to denote their stress level by making an "X" on a 10-millimetre line to reflect the magnitude of their perceived stress. The researcher then finds the center of the "X" mark, draw a perpendicular line through the center of the mark and intersect it with the horizontal line containing the three anchors. Once the perpendicular line intersects the horizontal line, the distance from zero to the perpendicular line drawn through the center of the "X" mark can be calculated. This distance was then divided by the total length of the scale in millimeters, and multiplied by 100. This was done to transform the raw score into a percentage. Higher scores indicated higher levels of role stress (Hickman & Pinto, 2013).

The family decision maker role stress is a concept that is not multi-dimensional and a single-item measure and may be an appropriate method for capturing role stress. Additionally, the FDSQ is the only known measurement method available that has been established as a valid method to measure SDM role stress (Hickman, Daly, Douglas, & Clochesy, 2010). Because FDSQ is a single item scale, internal validity testing was not applicable. However, it has been evaluated as a considerably strong scale to measure role specific stress.

Psychological distress. Psychological distress is defined as caregivers' experience of any form of emotional disturbance that impacts social functioning and activities of daily living (Horwitz, 2007; Wheaton, 2007). Ross (2017) explains it as caregivers' experience of symptoms of anxiety and depression that interferes with the ability to participate in valued activities and interests. Psychological distress was operationalized for the current study using the total score of anxiety and depression from Hospital Anxiety and Depression Scale (HADS).

The HADS was developed by Zigmond and Snaith in 1983 to provide the healthcare professionals and scientists with a reliable, valid, and practical tool for identifying and quantifying the two psychological distress symptoms (Herrmann, 1997). Though there are other symptoms related to psychological distress, for simplicity purposes only the most common symptoms (anxiety and depression) were considered while developing HADS (Snaith, 2003). This is a 14- item scale, easy to administer and well accepted by participants. In order to improve acceptability and to make the scale more sensitive to mild forms of psychiatric disorders, severe psychopathological symptoms are avoided from this scale (Herrmann, 1997). All items are scored on a four-point scale and ranges from 0 to 3. The possible total score ranged from 0 to 21 for anxiety and 0 to 21 for depression. A score of 0 to 7 for either subscale is regarded as being in the normal range, a score of 8 to 10 is considered borderline, and 11 or higher indicating significant psychological morbidity (Snaith, 2003). The total score from both subscales was used to measure psychological distress.

The HADS is well accepted by patients and its formal characteristics are reliable and good. The two-dimensional structure has been confirmed by factor analysis to ensure

that HADS has good validity. Factorial validity assessment using English and German HADS versions resulted in almost identical solutions with one depression and one anxiety factor, showing that these subscales remain stable subgroups with a correlation of $r > .90$ (Moorey et al., 1991). A report by Morrey et al. confirms that the discriminant and concurrent validity of HADS are good; that anxiety and depression are measured as two different concepts in HADS, and that these are highly correlated concepts of psychological distress. HADS also has good reliability: Cronbach alphas ranges from .80 to .93 for anxiety and .81 to .90 for depression subscales. Retest for reliability after two weeks showed a high correlation of $r > .80$, indicating the stability of HADS to withstand situational influences (Herrmann, 1997).

Table 1

Demographic Variables

SDM Demographics	**Method of Measurement**	**Level of Measurement**
Age	In Years	Ratio
Gender	Male, female	Nominal
Ethnicity	White, Non-white	Nominal
Kinship	Spouse/Partner, Child, Relative/Friend,	Nominal
Advance Directives	Legal Representative, Other No, Yes, Unknown/Unsure, N/A, Choose Not to Answer	Nominal
Living Will	No, Yes, Unknown/Unsure, N/A, Choose Not to Answer	Nominal

Table 2

Substruction of Theoretical Concepts within Study Model

Concepts	Empirical Indicators	Variables	Total Items	Cronbach's Alpha
Emotion Regulation	Emotion Regulation Questionnaire	Emotion Regulation: Cognitive Reappraisal Expressive Suppression	10: (6) (4)	 .86 .74
Role Stress	Family Decision Maker Stress Question	Role Stress	Single Item	N/A
Psychological Distress	Hospital Anxiety and Depression Scale	Psychological Distress	14	.89

Procedures

Recruitment procedures for the parent study. Each weekday, a research assistant (RA) visited the ICUs to identify eligible patients. When the eligible patient was identified, the RA approached the attending physician or nurse practitioner (NP) providing care to the patient to verify the patient's cognitive status, confirm that the patient had an available SDM, and determined if the critical care team planned to discuss a healthcare decision with the SDM. Once eligibility status of the SDM was confirmed, the attending physician or NP introduced the RA to the SDM. The RA then conducted further eligibility screening of the SDM, and when the SDM remained eligible to participate, the RA proceeded to obtain informed consent.

Data collection for the parent study. The research team for the parent investigation carried out data collection at baseline and 2 months following the presentation of a healthcare decision by the critical care team to a patient's SDM. This temporal interval for data collection was chosen because it captures the immediate emotional and cognitive burdens associated with the act of surrogate decision making.

The proposed timeframe also respects the SDM's need to process the experience, which will enhance the feasibility of participant recruitment and data collection without introducing significant threats to external validity. Data collection occurred when the subject provided informed consent and all study procedures were completed using a structured interview format (e.g., face-to-face and telephone). Subjects completed a battery of electronic surveys, interacted with computer programs on tablet PC, and had their cheeks swabbed for genetic material. The baseline interview took 60 minutes to complete and the follow-up telephone interview approximately 30-40 minutes. Data were collected at two time points for the parent investigation, from which, only the baseline data will be used for the proposed research.

Data Management

Procedures for Missing Data. Missing data is a common problem, and can be caused by various events, including relocation of study participants, omission of a response, or equipment malfunction (Musil, 2002). Two major categories of missing data are documented: missing at random (MAR), and systematic nonignorable missing data. MAR may have some randomness to the pattern of data omission and may bias the study result to some extent. Nonignorable missing data have systematic, nonrandom underlying reasons for missing values and can be the most problematic situations. They affect generalizability of study findings, and may potentially bias parameter estimates, such as means, standard deviations, correlation coefficients, or regression coefficients (Musil, 2002).

According to Musil (2002), missing data can be managed by either deleting the data or replacing the missing value with an imputed value. Deletion is either done

listwise or pairwise. In listwise deletion, all cases with missing values on any variables are discarded. This method reduces the analytic sample size, which can be problematic if missing observations occur for many subjects. In pairwise deletion data are excluded only if they have missing data on the variables included in a specific computation. This method will show different sample sizes for different calculations. These methods are applicable only for MAR. For non-ignorable missing data both methods may produce non-representative results (Musil, 2002), for which, imputing the mean value can be done. For the current study mean imputation and pairwise deletion were used.

Data Analysis

Research question one. The first research question was: What are the associations among the subscales of emotion regulation, role stress, psychological distress, and demographic characteristics of age, gender, ethnicity, kinship, ADs, and living will of the SDMs of CCI patients? To answer this question, two statistical tests, the Pearson *r* correlation and Spearman *rho* were conducted. In order to achieve a significant correlation between the variables, it was prudent to establish all assumptions (Field, 2009). In addition, testing assumptions ensures generalizability of the results (Polit & Beck, 2012).

Assumptions for Pearson correlation. The assumptions for Pearson *r* correlation include:

1. Absence of outliers
2. Linearity.

Evaluating assumptions. Testing for outliers was performed using scatterplot and depending on the amount of skewness, a decision be made either to retain or remove the

outlier. According to Osborne and Waters, (2002) testing for linearity is an important assumption in order to accurately assess the relationship between dependent and independent variables if the relationships are linear in nature. Linearity can be tested through scatterplots of residuals by standardized predicted values and heteroscedasticity. Violation of this assumption would underestimate the true relationship.

Research question two. The second research question was: "What are the relationships among the subscales of emotion regulation and psychological distress while controlling for surrogate decision makers' demographic variables?" For this research question that explored the relationship between emotion regulation and psychological distress, the Multiple Regression test statistics was used (Polit, & Beck, 2012). The assumptions are explained under research question one.

Research question three. The third research question was: Does role stress mediate the relationships among the subscales of emotion regulation and psychological distress while controlling for demographic variables of SDMs of CCI patients? For this research question that explored mediation effects, a regression analysis using PROCESS Macro Model 4 was the test statistic.

Assumptions of Multiple Regression: Important statistical assumptions for regression analysis included:

1. Test for normality
2. Linearity
3. Homogeneity of variance
4. Statistical independence of residual errors.

Evaluating assumptions. The normality assumption can be tested using box plots, Q-Q plots, visual inspection of histograms, frequency distributions, or by calculating skewness and kurtosis, and Mahalanobis distance. These tests help to look for outliers, which can be removed (if desired) by square root, log, or inverse transformation (Osborne & Waters, 2002; Polit & Beck, 2012). According to Osborne and Waters, non-normally distributed variables distorts relationships and significance of the results. Correcting the non-normal distributions depends on the causes, such as outliers, extreme values, measurement errors, or data-entry errors (Polit & Beck, 2012), which can be assessed and then either removed or transformed. If the data is positively skewed, data transformation will be performed in order to make parametric tests appropriate. A logarithmic transformation will be performed to normalize positively skewed distributions (Polit, & Beck, 2012).

Homoscedasticity assumption involves testing for variance of errors through the use of Levene's test. When the variance of errors differ at different values of the independent variable, it is an indication of the presence of heteroscedasticity, which can weaken the analysis seriously. The last assumption, statistical independence of residual errors assesses random pattern by using a plot of residuals (Polit & Beck, 2012). The statistical independence test helps examine if the occurrence of one event is independent of the other, which is carried out by finding the probability of each event occurring separately, and then the probabilities are multiplied.

Testing for mediation. Mediation analysis is a statistical method to help answer the question as to how certain causal agent, for example, an independent variable transmits its effect on a dependent variable through the influence of another variable

(Hayes, 2013). According to Hayes, there are simple and multiple mediator models. In a simple mediator model there will be only one potential mediator variable, whereas, multiple mediator models will have more than one potential mediator variables. In the current study the investigator utilized a simple mediator model, which contained two consequent variables (role stress and psychological distress) and two antecedent variables (cognitive reappraisal/expressive suppression and role stress). The analyses involved examining whether the predictor variable influenced dependent and mediator variables and whether mediator variable causally influenced the dependent variable. This simple mediator model analysis was conducted using PROCESS Macro Model 4 (Hayes, 2013).

Additionally, there are two distinct pathways, called direct and indirect effects by which the independent variable is proposed as influencing the dependent variable. Thus, mediation effect is assessed through these direct and indirect effects. The direct effect is assessed by examining a causal sequence of independent variable (IV) cognitive reappraisal and expressive suppression on dependent variable (DV) psychological distress. The indirect effect is assessed by examining a causal effect of IV on DV through the potentially mediating variable role stress. In a simple mediation the IV is postulated to affect the potentially mediating variable and this effect then is expected to reflect on the DV (Hayes, 2013). Thus the mediation analyses involved analysis of an equation Path A that is IV to mediator variable, the equation Path B that is mediator variable to DV, and an equation Path AB that is IV to DV while controlling for the mediator variable (see Figure 3). According to Hayes, such analyses would provide detailed information related to the size of mediating effect. For example, if a 95% Confidence Interval (CI) value (the value between the upper and lower range) contains 0

that would indicate the absence of mediation, for example a 0.002 would indicate a small mediating effect.

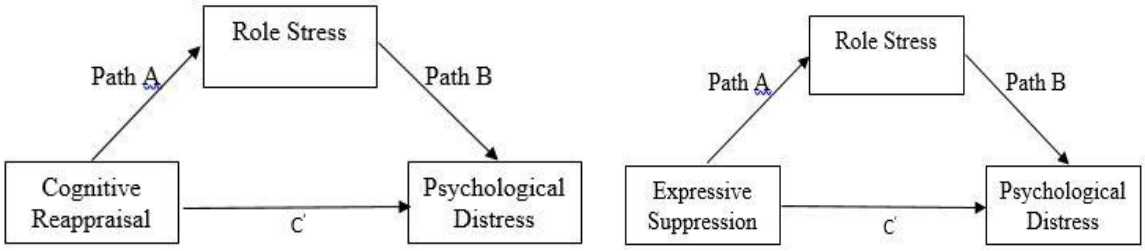

Figure 3. Test of Mediation for Research Question 3.

In PROCESS Macro Model 4 the IVs, cognitive reappraisal/expressive suppression, the mediator variable role stress, the DV that is psychological distress, and the demographic variables AD and gender were entered. Then the Regression analysis was run and the PROCESS Macro Model 4 produced the output indicating the size of mediating effect as well as if there was a mediating effect as described in chapter four under research question three. The indirect effect represents how DV was influenced by IV through a causal sequence in which IV influenced mediator variable, which in turn influenced the DV. The presence/absence of mediation was determined looking at the indirect effect of 95% CI values of Path AB. There would be no mediation effect if CI values contained zero (Hayes, 2013).

Human Subjects Protection

It is crucial for the investigator to prioritize the protection of the study participants. The Belmont Report states that the study participants need to be treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being (Belmont Report, 1979). Experimental and/or interventional studies may involve more harmful effects if human subject

protection is not practiced ethically. The current study involved no intervention or experiment for the subjects because the investigator utilized a secondary data analysis.

Confidentiality and Privacy Issues.

The investigator of the current study received de-identified data from the parent investigator. The parent investigator submitted study protocols to the Internal Review Board (IRB) and obtained IRB approval and no additional IRB was required from the study site.

Limitations

Validity

Validity refers to the degree to which an instrument measures what it is expected to measure (DeVon et al., 2007; Higgins & Straub, 2006; Polit & Beck, 2006). According to Higgins and Straub (2006), "validity is essential to a research proposal's theoretical framework, design, and methodology, including how well specific tools or instruments measure what they are intended to measure" (p 24). Validity has multiple domains: construct validity, which comprises of translational and criterion validity. Translational validity is evaluated by examining face validity and content validity. Criterion validity includes concurrent, predictive, convergent, and discriminant validity. In addition, there is design validity, which includes, internal, external, and statistical conclusion validity. In order to improve scientific rigor, it is important for investigators to examine these domains of validity and try to minimize validity threats (DeVon et al., 2007).

*Threats to internal validity***.** Internal validity is concerned with the congruence between the theoretical assertions and the relationship between two variables **(**Higgins &

Straub, 2006). In science, regardless of the measures taken, there are several recognized threats to validity related to procedures and treatments. The more abstract a construct is, the more difficult it is to assess the construct validity resulting in validity threats (Polit and Beck, 2006). The possible threats to internal validity include threats due to maturation, regression to the mean, selection bias, selection maturation interaction, mortality, instrumentation, testing and history. Maturation effect can be a validity threat for longitudinal studies when physiological or psychological changes influence test responses rather than any treatment effects. Maturation effect was not an expected validity threat for the current study because of its cross-sectional design.

Selection bias, the next validity threat occurs when the sample is selected from only one location. Participants from the same location may possess similar characteristics. This may be a threat for the current study because all participants were SDMs of CCI patients recruited from various ICUs of one large medical center. Therefore, the study outcome would be generalizable only to acute care settings. The use of randomization, that is selecting the sample from different locations, different age groups, and different cultures, can minimize the effect of this threat. Selection maturation interaction, yet another validity threat, occurs when the treatment and control groups, although similar at pretest, tend to grow apart and produce different scores during posttest even without treatment. Because there was no intervention, the current study was not challenged with this threat.

Temporal ambiguity, the direction of causal relationships among variables is a potential validity threat in cross-sectional designs. In the current study the investigator

was interested in examining the relationships among emotion regulation, role stress, and psychological distress and this threat was not expected to influence the outcome.

Instrumentation threat, the next validity threat, occurs due to the inaccuracy of the observed effects of the dependent variable as a result of the method of data capture. One of the ways instrumentation threat occurs is when participants memorize the answers and repeat them in post-test. Collection of data by multiple RAs, improper use of instruments, and lack of knowledge of the use of instruments are other ways. If memorization is a concern, the investigator can implement Solomon's four group design to minimize the threat. In addition, confirming rigor for data collection can minimize the problem. The cross-sectional nature of the current study eliminated this problem.

In summary, the content of this chapter described the research methodology of parent investigations and outlined the methods and procedures for the secondary data analysis of the current study. Specific to the current study of secondary data analysis, this chapter discussed the statistical approach, instruments, human subject protection, and threats to validity.

Chapter IV

Results

The purpose of this descriptive, correlational, cross-sectional study was to determine the associations among emotion regulation, role stress, and psychological distress in a sample of surrogate decision makers (SDMs) of chronically critically ill (CCI) patients hospitalized in intensive care units (ICUs). This chapter summarizes the statistical findings of relationships among the three main variables and the six demographic variables. The study results indicated several significant associations such as statistically significant associations between role stress and psychological distress, expressive suppression and advance directives, psychological distress and ethnicity, psychological distress and gender, role stress and gender, and role stress and kinship. The overall analyses showed no association between emotion regulation and psychological distress and that role stress did not mediate the relationship between emotion regulation and psychological distress.

Sample Characteristics

The participants in this secondary data analysis consisted of a convenience sample of SDMs of hospitalized CCI patients who were enrolled in the parent investigation entitled **Validation of a Dual-Process Model for Surrogate Decision Making** carried out from September, 2014 to August, 2017 (Hickman, Application I.D.: 26690). A total of 120 participants who met the inclusion criteria for the parent investigation also met the inclusion criteria for the current study.

Summary of Demographic Variables

The demographic characteristics of the sample are presented in Table 3. The sample consisted of twice as many females as males. The age of participants ranged from

21 to 86 years with a mean age of 54.73 (*SD* = 13.8). Concerning racial identity, the majority of participants were White and the rest were non-White. In relation to kinship, most of the participants were either the spouse or partner of the patient or self-identified themselves as a child of the patient. A very small number of participants reported themselves as legal guardians to the patient. The remaining participants identified themselves as having some *other relationship*, which included siblings, friends or relatives who did not identify themselves under any of the groups as described in Table 3. With reference to advance directive (AD) and living will, it is notable that the majority of the patients did not have an AD and living will, whereas, less than one third of samples reported that their patients had either an AD and/or living will. A few participants reported they were unsure, which may have meant that the SDM was simply not certain whether the patient had or had not made an AD and/or living will.

Table 3

Demographic Characteristics of Sample (N = 120)

Variable	Description	Frequency	%
Gender	Male	40	33.3
	Female	80	66.7
Race/Ethnicity	White	85	70.8
	Non-white	35	29.2
Kinship	Spouse/Partner	46	38.4
	Child	40	33.3
	Legal Guardian/POA	6	5.0
	Other	28	23.3
Advance Directive[a]	Yes	24	24.0
	No	68	68.0
Living will	Yes	44	36.7
	No	70	58.3
	Unknown/Unsure	6	5.0
Prior Caregiving Experience	Yes	61	51.0
	No	59	49.0
Employment	Employed	71	59.0
	Unemployed	49	41.0
Education	High school or less	36	30.0
	Bachelorette	71	59.0
	Post-Graduation	13	11.0

Notes. All participants, $N = 120$, [a]$n = 100$

Descriptive Summary of Scores and Internal Consistency Reliability Estimates

Table 4 presents the descriptive statistics of the main variables of the study: emotion regulation (cognitive reappraisal & expressive suppression), role stress, and psychological distress. The summary of main variables and subscales, including the mean, standard deviation, minimum - maximum possible and obtained minimum - maximum scores, skewness, kurtosis, and Cronbach's alpha are presented in Table 4. The skewness and kurtosis for all variables were within normal distribution. The Cronbach's alpha coefficient for cognitive reappraisal was .86, for expressive suppression .74, and for the HADS total was .89. Role stress was measured using a single item questionnaire and examining Cronbach's alpha was not applicable. Although a Cronbach's alpha coefficient greater than .80 is considered good, according to Polit and Beck (2012) a Cronbach's alpha coefficient greater than .70 is acceptable. Hence, the Cronbach's alphas for cognitive reappraisal, expressive suppression, and HADS total were within acceptable range and therefore, the reliability of the measures used in the current research was good.

In regards to cognitive reappraisal, 75% (n = 90) of participants reported cognitive reappraisal use above neutral point, which is >24. Contrarily, for expressive suppression, 75% (n = 90) of participants reported expressive suppression use below neutral point, which is <16. With respect to role stress, 69.16% (n = 83) of participants considered that making a healthcare decision was stressful for them. This was above the midpoint on a 0-100 score scale. Regarding psychological distress, 29.17% (n = 35) of participants reported normal range of psychological distress (0-7), 15% (n = 18) of

participants reported borderline psychological distress (8-10), and 55.83% (*n* = 67) of participants reported higher levels of psychological distress (11- 21) (see Table 4).

Table 4

Descriptive Statistics for Main Study Variables (N=120)

Variable/ Measure	Mean	SD	Min-Max Possible Scores	Min-Max Obtained Scores	Skewness	Kurtosis	Cronbach's Alpha
Emotion Regulation							
• Cognitive Reappraisal	30.06	8.40	6-42	6-42	-.537	-.109	.86
• Expressive Suppression	12.83	5.76	4-28	4-28	.289	-.535	.74
Surrogate Decision Maker Role Stress	60.76	31.52	0-100	0-100	-.319	-.800	(N/A)
Psychological Distress	12.75	7.67	0-42	0-32	.391	-.677	.89

Note. *N* =120. For Emotion Regulation, higher scores indicate better use of cognitive reappraisal and/or expressive suppression. Higher score for Surrogate Decision Maker Role Stress indicates higher levels of perceived role stress. Score range for Psychological Distress includes 0-42 with 0-7 normal, 8-10 borderline, and 11-21 indicating higher levels of psychological distress. (see Appendix A for more instrument details).

Assessment of Missing Data

Missing data were examined at case and variable levels, identifying one missing datum for emotion regulation, which was replaced by mean imputation technique. Additionally, there were twenty missing data for ADs, which was removed by pairwise deletion using the Statistical Package for Social Sciences (SPSS). Therefore, the sample size for AD was 100 in all analysis while all the other variables had a sample size of 120 for research question one and two. Whereas, the mediation analysis in research question three utilized a sample size of 100 for all the variables.

Findings Related to Research Questions

Research Question One

What are the relationships among the subscales of emotion regulation (cognitive reappraisal and expressive suppression), role stress, psychological distress, and demographic variables of age, gender, ethnicity, kinship, and, AD and living will of the patients of SDMs of CCI patients?

Data were analyzed using Pearson's *r* and Spearman *rho* correlations statistical tests. These tests were run simultaneously to examine associations among all the variables. Prior to conducting the statistical analysis for research question one, the statistical assumptions were examined.

Results of Testing for Assumptions

The statistical assumptions for Pearson's *r* correlation included level of measurement, influential outliers, linearity, normality, and homogeneity of variance. Data were screened and the results indicated that the measures for all main variables were continuous and all demographic variables were categorical, except for age. The influential cases were examined using Cook's distance (Cook's D) and the values for all

models were less than 1.0 and ranged from .031 to .061. A Cook's D value greater than 1 indicates presence of outliers and would be a cause for concern (Polit & Beck, 2012). The Cook's D for Pearson *r* correlation was < 1 and confirmed the absence of influential data outliers.

The linearity assumption was explored using P-P Plots by examining the differences between the values of cubic, quadratic, and linear lines in SPSS. According to Polit and Beck (2012) a value less than 0.02 difference between cubic, quadratic, and linear would indicate non-violation of linearity assumption. The results of the assessment indicated that the differences between these lines were < .02 confirming the presence of linearity. The normality assumption was assessed using skewness and kurtosis. According to Polit and Beck (2012), values that fall within -3 and + 3 for skewness and -8 to +8 for kurtosis are considered normal. The values for the data ranged between -0.319 and 2.23 for skewness and -0.109 and 5.0 for kurtosis confirming that the assumption for normality was not violated. Homogeneity of variance was examined by using scatter plots, in which a 3:1 ratio between the highest to lowest error variance were assessed. According to Polit and Beck (2012), violating this assumption could result in estimates that do not reflect the reality. The data screening resulted in a ratio between the highest and lowest error variance of 1.78:1, which was < 3:1 and indicated that the homogeneity of variance assumption was not violated.

After the evaluation of the assumptions, a Pearson *r* correlation statistical test was computed to examine the relationships among emotion regulation (cognitive reappraisal and expressive suppression), role stress, psychological distress, and the demographic

variables. As shown in Table 5, the results indicated that there was a small statistically significant association between role stress and psychological distress ($r = .29$, $p < .01$).

The Spearman *rho* statistical test was conducted to examine the associations among the main variables and the demographic variables, except for age. Prior to conducting the analyses, the statistical assumptions for Spearman *rho* were examined. Data were screened for level of measurement and monotonic relationship using scatter dot graphs. The level of measurement for all demographic variables were categorical and the scatter dot graphs presented monotonic relationships between the variables. The results indicated that the statistical assumptions for Spearman *rho* test were not violated.

The results of Spearman *rho* test statistic indicated that there were small statistically significant correlations between AD and expressive suppression (*rho* = .21, $p < .05$), gender and role stress (*rho* = .22, $p < .05$), ethnicity and psychological distress (*rho* = .20, $p < .05$), gender and psychological distress (*rho* = .27, $p < .01$) and, kinship and role stress (*rho* = .33, $p < .01$) (see Table 5).

Table 5

Correlations Between Demographic and Main Variables

		1	2	3	4	5	6	7	8	9
1	Age									
2	Gender	-.152								
3	Ethnicity	-.222*	.181*							
4	Kinship	-.174	.219*	.150						
5	Advance Directive[a]	.238*	-.145	-.131	-.200*					
6	Living Will	.281*	-.093	-.240*	-.272**	.782**				
7	Reappraisal	-.135	.118	.106	.121	-.126	-.072			
8	Suppression	.162	-.140	.091	-.110	.210*	.155	.141		
9	Role Stress	-.081	.217*	.033	.330**	-.090	-.154	.005	-.078	
10	HADS Total	-.153	.265**	.181*	.003	.149	-.006	-.165	.022	.293**

Note. $N = 120$. [a]$n = 100$. *$p < .05$ level (2-tailed). **$p < .01$ level (2-tailed).

Research Question Two

What are the relationships among the subscales of emotion regulation (cognitive reappraisal and expressive suppression) and psychological distress while controlling for surrogate decision makers' demographic variables?

This research question was analyzed using multiple regression statistical test to examine the associations among the subscales of emotion regulation and psychological distress and to evaluate the part *r* correlation coefficient. The statistical assumptions of Pearson *r* correlation that include linearity, normality, and homogeneity of variance were previously explored under research question one and confirmed that these assumptions were not violated. Data were also screened for influential data outliers using Cook's D, which ranged between 0.037 and 0.130, confirming that there were no influential data outliers.

The analysis was conducted by entering cognitive reappraisal, expressive suppression, and psychological distress into the multiple regression equation model and psychological distress was regressed on both subscales of emotion regulation simultaneously with demographic variables. The results indicated that the subscales of emotion regulation together with the demographic variables were not significantly associated with psychological distress. However, the regression coefficients indicated that there were two significant correlations between demographic variables and psychological distress; AD (Part $r = .19$, $p = .04$) and gender (Part $r = .24$, $p = .01$) (Table 6).

Table 6

(RQ2): Psychological Distress Regressed on Cognitive Reappraisal, Expressive Suppression, and Demographic Variables

Variables	*β*	*SE*	Part *r*
Cognitive Reappraisal	-0.18	0.09	-0.18
Expressive Suppression	0.00	0.14	0.00
Age	-0.13	0.06	-0.12
Gender	0.26*	1.79	0.24
Ethnicity	0.13	1.74	0.12
Kinship	-0.02	0.64	-0.02
Advance Directives[a]	0.32*	1.91	0.19
Living Will	-0.12	2.07	-0.07

Note. $N = 120$. [a]$n = 100$. DV = HADS Total. $p < .05$*

In order to determine whether the experiences of psychological distress and role stress in this sample of SDMs differed by gender, an Independent Sample *t*-test was conducted to compare the mean differences. The result revealed that women experienced slightly higher levels of psychological distress than men and the difference was statistically significant, women, ($M = 14.22$, $SD = 7.99$) and men ($M = 9.80$, $SD = 6.03$), $t(99.75) = -3.39$, $p < .01$). Conversely, women experienced slightly higher levels of role stress than men, however, the difference was not statistically significant; women ($M = 53.18$, $SD = 29.01$), men ($M = 64.55$, $SD = 32.21$), ($t(118) = -1.88$, $p = .06$).

Research Question Three

Does role stress mediate the relationship between the subscales of emotion regulation and psychological distress, while controlling for demographic characteristics of SDMs of CCI patients?

In order to explore the mediation effect of role stress in the association among the subscales of emotion regulation and psychological distress two separate simple mediator path analyses were conducted for each subscale of emotion regulation. These included the effect of role stress in the association between cognitive reappraisal and psychological distress and, expressive suppression and psychological distress. Of note, among the demographic variables, only gender and AD were included in the mediation analyses as these were consistently significantly associated with psychological distress in research questions one and two. These analyses were conducted using the PROCESS Macro Model 4 (Hayes, 2013).

The PROCESS Macro Model 4 examined direct, indirect, and total effects in relation to the hypothesized mediator. According to Hayes (2013), "The direct effect quantifies the estimated difference in Y between two cases that differ by one unit on X independent of M's influence on Y" (Hayes, 2013, p. 101). "The indirect effect quantifies how much two cases that differ by a unit on X are estimated to differ on Y as a result of X's influence on M, which in turn influences Y" (Hayes, 2013, p. 101). Finally, the total effect is the effect of X on Y, dependent on the potential mediator variable M.

This equation was translated into the current study in order to explore the beta coefficients for (i) the effect of reappraisal on role stress, Pathway A, (ii) the effect of role stress on psychological distress, Pathway B, (iii), and indirect effect, Pathway AB.

Mediation would be identified when the 95% confidence intervals (CI) for the indirect effect did not include zero.

Prior to conducting the Process Model 4 analyses the assumptions of statistical testing of normality, linearity, and homogeneity of variance, which were previously established, were re-examined. The results indicated that these assumptions were not violated and are described under research question two. Additionally, Cook's D was examined and the values ranged between .031 and .061 indicating absence of outliers. According to Field (2009), values < 1 indicate absence of outliers. Thus, absence of outliers was confirmed for the current analyses.

Path Analyses for Cognitive Reappraisal on Psychological Distress

In this model the mediating effect of role stress in the relationship between cognitive reappraisal and psychological distress was examined and the results are presented in Table 7. In Path A, the association between cognitive reappraisal and role stress was assessed while controlling for gender and AD. Based on the results, emotion regulation and role stress were not significantly associated in Path A. Whereas, in Path B role stress and psychological distress were significantly associated (β = .0637; 95% CI = .0175, .1099). Additionally, gender (β = 4.1103; 95% CI = .7628, 7.4578), and AD (β =2.6831; 95% CI = .3241, 5.0421) were significantly associated with psychological distress (see Appendix B to view detailed results of research question three). In Path AB, the indirect effect of cognitive reappraisal on psychological distress, while controlling for cognitive reappraisal, role stress, gender, and AD were examined. The results indicated that these were not significantly associated, indicating that role stress *did not mediate* the

relationship between emotion regulation and psychological distress. The direct effect of cognitive reappraisal on psychological distress was not significantly associated (β = -0257, 95% CI = .2329, -.0033) (Path AB). The indirect effect was also not statistically significant (β = -.0079, 95% CI = -.1067, .0678). In order for a mediation effect to be present the CI should not include zero. The CI of indirect effect included zero, therefore, it was concluded that role stress *did not mediate* the relationship between cognitive reappraisal and psychological distress in this sample.

Path analysis for Expressive Suppression on Psychological Distress

In this model the mediating effect of role stress in the relationship between expressive suppression and psychological distress was examined. In Path A, the association between expressive suppression and role stress was assessed while controlling for gender and AD. Based on the results, expressive suppression and role stress were not significantly associated in Path A. Similar to the findings in previous model, in Path B role stress and psychological distress were significantly associated (β = .0637; 95% CI = .0175, .1099). Additionally, gender (β = 4.1103; 95% CI = .7628, 7.4578), and AD (β =2.6831; 95% CI = .3241, 5.0421) were significantly associated with psychological distress.

In Path AB the indirect effect of expressive suppression on psychological distress while controlling for role stress was examined, which indicated that role stress did not mediate the relationship between expressive suppression and psychological distress (β = -.0079; 95% CI = -.1067, .0678). Similar to the previous model, the direct effect showed that expressive suppression was not significantly associated with psychological distress (β = -.0257, 95% CI = -.2329, -.0033). In order for a mediation effect to be present the CI

should not include zero. The CI of indirect effect included zero, therefore, it can be concluded that role stress *did not mediate* the relationship between expressive suppression and psychological distress in this sample. In conclusion, the overall results of both sets of Process Model 4 analyses indicated *role stress did not mediate* the relationship between emotion regulation and psychological distress.

Table 7

Results of the Mediation Analysis: Direct and Indirect Paths

	Hypothesized Mediator	Independent Variable	Path AB (SE) [95% CI]	Path A (SE)	Path B (SE)	Path c' (SE)
Model 1	Role Stress				0.063 (0.023)**	
		Reappraisal	-.170 (0.090)	-.008 (.389)		-0.170 (.090)
			[-0.349, 0.008]			
	Direct Effect					-0.343, -.003*
Model 2	Role Stress				0.064 (0.023)**	
		Suppression	-0.033 (.135)	-.124 (.571)		-.026 (0.130)
			[-0.300, .234]			
	Direct Effect					-.284, .233

Note. N = 100. *p < .05 level (2-tailed). **p <.01 level (2-tailed). Covariates: Gender and Advance Directives

In conclusion, the purpose of this study was to examine the relationships among the subscales of emotion regulation, role stress, psychological distress, and demographic variables of age, gender, ethnicity, kinship, AD, and living will in SDMs of CCI patients admitted to the ICU. This relationship was determined through four statistical analyses; the Pearson *r and* Spearman *rho* correlation statistical tests, Multiple Regression, and mediation analysis using PROCESS Macro Model 4.

The results indicated that, among main variables, role stress and psychological distress were statistically significantly associated. Among main variables and demographic variables the following were significantly associated: expressive suppression and AD, psychological distress and ethnicity, psychological distress and gender, role stress and gender, and role stress and kinship were significantly associated. All four analyses showed that gender and AD were significantly associated with psychological distress. This was a consistent finding in all analyses including mediation analysis. The overall mediation analysis indicated that role stress did not mediate the relationship between emotion regulation and psychological distress.

CHAPTER V

DISCUSSION

The purpose of this study was to determine the relationships among the subscales of emotion regulation (cognitive reappraisal & expressive suppression), role stress, and psychological distress in surrogate decision makers (SDMs) of chronically critically ill (CCI) patients admitted to the intensive care units (ICUs). This chapter provides an interpretation of the study findings, study limitations, and study implications for science, practice, and policy. Recommendations for future research are also discussed.

With advancement in treatment options, patients with critical illnesses survive the critical illness stage and move on to live with CCI conditions. Chronic critical illnesses affect not only the patients but also the SDMs of CCI patients in complex ways. The complexity of the CCI conditions impairs patients' cognitive abilities requiring increased involvement of SDMs for important treatment decisions, which can be very stressful. Scientists have reported that decision making role as one of the most stressful responsibilities for SDMs (Azoulay et al., 2005; Handy et al., 2008).

Surrogate decision making, amongst the multiple other responsibilities involved in caring for CCI patients, can be highly stressful and emotionally taxing (Buckey & Molina, 2012; Cameron et al., 2016). This situation renders the proxy decision makers, who may be either family members or legally appointed decision makers, high levels of psychological distress. Prolonged periods of such psychological distress can impact the quality of decisions made for the patients, resulting in long-term consequences. Shaffer et al., (2016) stated that nearly half of SDMs of patients admitted to neurological ICU had a tendency toward prolonged periods of anxiety and/or depression related to patients' CCI conditions. Investigators have demonstrated that although SDMs' symptoms of

anxiety and/or depression dissipated over time, they continue to suffer from moderate to high levels of psychological distress even after the discharge from the ICU or the patient's death (Hickman & Douglas, 2010; Zanten et al., 2016; Shaffer, 2016).

The benefits of emotion regulation on behavioral outcome has been scientifically tested and established (Gross, 2014; Gross & John, 2003; Sheppes, Suri, & Gross, 2015). The behavioral outcome can be manipulated and modified by regulating one's emotion regulation processes. If one employs cognitive reappraisal, one of the two widely studied emotion regulation strategies, the behavioral outcome could be positive while using the other emotion regulation strategy, expressive suppression, could result in negative outcomes (Cutuli, 2014; de Veld, 2012; Gross & John, 2003). Thus, behavioral outcome varies depending on which emotion regulation strategy one employs when faced with emotionally taxing situations (Gross, 2014). Therefore, the current study was conducted to learn the correlation among the subscales of emotion regulation (cognitive reappraisal & expressive suppression), role stress, psychological distress, and the demographic variables.

Discussion of the Research Questions

Research Question One

Research question one led to an examination of the associations among the subscales of emotion regulation (cognitive reappraisal & expressive suppression), role stress, psychological distress, and demographic variables of age, gender, ethnicity, kinship, AD, and living will. The Pearson *r* and Spearman *rho* correlation statistical tests were conducted to explore these associations. The following section explains the findings of that examination.

In this sample of SDMs, role stress was significantly associated with psychological distress as expected. This finding is consistent with the previous study outcomes (Iverson et al., 2014; Wendler & Rid, 2011). In these studies high association between role stress and psychological distress have been described due to the highly stressful life changing decisions SDMs are expected to make resulting in heightened stress levels. Although it is understudied, the cumulative effect of such sustained, intense decision making on SDMs seems to compound anxiety (Iverson et al., 2014, p.9). Other commonly identified impacts include guilt over the decisions made and uncertainty about whether those were the best decisions for those impacted (Wendler & Rid, 2011). This renders the high association between role stress and psychological distress a logical expectation.

Having an AD and a living will are reported to reduce the role stress intensity because having an AD to guide end-of-life healthcare decisions reduced the SDMs' decision making stress significantly (Majesko et al., 2012; Rolland, Emmanuel, & Torke, 2017; Song et al., 2015). Hickman, Daly, & Lee (2012) reported that having an AD reduces the uncertainty of decisions and thereby eases the burden of the SDMs. In the current study, about 57% of patients did not have an AD and about 58% did not have a living will. As one might expect, there was a significant correlation between role stress and psychological distress ($r = .29$, $p < .01$) in the absence of ADs and living wills.

In addition to an association with role stress ADs had a significant positive correlation with expressive suppression for the same reasons. Expressive suppression is inhibition of one's emotional expressive behavior in order to change the emotional impact of a situation (Gross & Levenson, 1993). This inhibition can result in detrimental

outcome such as decreased positive or increased negative emotions (Brans Keyes, & Bates, 2013; Gross, 2014). While not having an AD to guide end-of-life decisions can result in high levels of psychological distress, a significant positive association between expressive suppression and an AD is desirable.

Among demographic variables, gender also had a significant positive association with role stress and psychological distress. This finding is consistent with existing scientific evidence (DePasquale et al. 2017; Matud, 2004). Scientists have demonstrated that generally women report higher levels of stress compared to men for a similar stress inducing situation. For example, DePasquale et al. (2017) examined gender differences in role stress among care givers and found that women reported higher levels of role stress compared to men caregivers. Similarly, Matud (2004) examined gender differences in stress and coping in a large sample and learned that women scored significantly higher than men on psychological distress. Thus, positive association between gender and stress in general and that women's experience of higher levels of stress than men for the same stress inducing situations has been established.

Racial identity also was positively associated with psychological distress, which is consistent with previous study findings (Barnes, Keyes, Bates, 2013; Rivas-Drake et al., 2014; Song et al. 2016). Culture facilitates the development of values related to all aspects of life, especially values related to interpersonal relationships and emotion regulation (Matsumoto et al., 2008). Value-based cultures may contribute to an improved mental disposition to cope well while other ethnic groups may find it harder to manage psychological distress. There is inconsistencies on the existing evidence, that a few scientists have demonstrated that Whites are more susceptible to psychological distress

than non-whites (Gonzalez et al., 2010; Lincoln, Chatters, & Taylor, 2003; Williams et al., 2007). Douglas et al., (2010) state that Whites are better at coping strategies. According to Barnes, Keyes, and Bates (2013) and Brown, Meadows, and Eldor, (2007) the coping abilities of non-Whites may be due to non-Whites' increased social support and close family ties that drive them to cope better with stressful situations. These study findings support the evidence that racial identity impacts psychological distress and therefore the finding of the current study is not surprising.

Additionally, kinship and role stress were significantly positively associated. The knowledge of Attachment Theory help explain such significant association. According to Attachment Theory the stronger the relationship between the care giver and care recipient, the higher the level of role stress (Bowlby, 1991). This is reported to be due to fear of potential loss. It may also be harder and more stressful to make decisions for the same reasons. Consistent with these posits is a review by Pinquart & Sorensen (2011) who examined stress level between spouse and child SDMs and reported that the stronger the relationship, the higher the role stress.

The SDMs in Pinquart & Sorensen's study (2011) reported spending longer time with patient providing more care and increased number of caregiving tasks without respite. They also reported financial burden, and social and relationship strain due to such situation, showing how these can impact SDMs' role stress. Based on these findings it is not surprising that kinship and role stress were significantly correlated in the current study.

In order to gain a deeper understanding regarding who among the kinship categories suffered higher levels of role stress the mean difference was examined by

categorizing kinship as *relatives* and *non-relatives*. The result indicated that there was a slight increase in the amount of perceived role stress among non-relatives. However, the difference was not statistically significant; relatives (M = 58.42, SD = 30.93) and non-relatives (M = 71.18, SD = 32.74), t(-1.73), p = .09.

Kinship was further examined as *spouse* versus *non-spouse* to examine if spouse experienced higher levels of role stress. Based on Attachment Theory, assuming that spouse had a stronger relationship with the patient, the spouse SDM would report higher levels of role stress. However, the comparison of Mean Difference Analysis indicated that there was a slight increase in the amount of perceived role stress among non-spouses and the difference was statistically significant; spouse (M = 48.89, SD = 29.16) and non-spouse (M = 68.14, SD = 30.85), t(-3.39), $p < .01$.

Based on these two findings of relative versus non-relative and spouse versus non-spouse, the SDMs who were not related to the patients who experienced higher levels of perceived role stress as opposed to relatives or spouses. This finding is inconsistent with the Attachment Theory. It is unknown whether non-relatives and non-spouses had a stronger relationship with patients or whether non-relatives and non-spouses generally experience higher levels of role stress. Several possibilities may have contributed to such significant correlations of non-relative and non-spouses. First, as non-relative or non-spouse, they do not spend longer caring times with the patient. Second, they may not be aware of the patients' values and wishes. And third, the fear of any adverse impact of the decisions made without knowing the wishes and desires of the patients. More research is required to reach an informed conclusion on what led to such difference between relative versus non-relative and spouse versus non-spouse SDMs.

Finally, in the present study, emotion regulation was posited to have relationships with role stress and psychological distress. However, no statistically significant associations were noted in this sample of SDMs. There are several potential explanations that may account for the lack of statistically significant relationships among emotion regulation and the measures of role stress and psychological distress.

The first explanation for the lack of association between emotion regulation and the measures of role stress and psychological distress is related to the theoretical definition of emotion regulation and its operationalization in this study. The Emotion Regulation Questionnaire (ERQ) used in the present study has been conceptualized to measure cognitive reappraisal or expressive suppression accurately. Balzarotti, John, and Gross (2010) examined the internal consistency of both aspects of ERQ scale and found good internal consistency. Additionally, the ERQ was performed adequately in the sample as evident by sufficient Cronbach's alpha coefficients for each subscale (cognitive reappraisal α =.86 and expressive suppression α =.74). Therefore, measurement error is an unlikely contributor to the lack of relationships among emotion regulation and the other main study variables.

The second explanation is related to an argument related to the conceptual consistency of the ERQ measure. The ERQ measure has been conceptualized to measure the components of both trait and state phenomenon, although scientists have argued about the capability of ERQ measure to capture both trait and state related components of emotion regulation (Katzs et al., 2017; Sheppes et al., 2014). There is some evidence that the trait- emotion regulation is related to cross-situational, largely stable and enduring patterns of awareness and control and the state- emotion regulation includes situation-

bound, goal-directed awareness and control processes of emotion regulation (Gross, 2014; Maxwell, Lynn, & Strauss, 2018). Through various studies scientists have demonstrated that the ERQ measure has the ability to capture these habitual regulatory strategies and the momentary emotional changes (Aldao & Nolen-Hoeksema, 2013; Gross, 2014; McRae et al., 2012).

Maxwell, Lynn, and Strauss (2018) investigated whether trait measures predicted actual implementation of both components of emotion regulation; cognitive reappraisal and expressive suppression. They argued that if these two components predicted emotion regulation, then the ERQ measure would predict individual differences in both momentary and habitual use of emotion regulation strategies. Various emotion regulation components were examined by integrating several emotion regulation measures in the study including ERQ measure such as cognitive reappraisal, expressive suppression, emotional acceptance, emotional awareness, emotional clarities, and cold-heartedness. The results revealed that there were several significant correlations among these habitual and momentary components of emotion regulation. This indicates that the trait- emotion regulation measure is capable of capturing the components of both habitual emotion regulation tendencies and the state- emotion regulation tendencies.

Finally, Maxwell, Lynn, and Strauss (2018) and Gross and John (2002) in their investigations of conceptual relatedness demonstrated that greater habitual use of cognitive reappraisal resulted in positive outcome and greater habitual use of expressive suppression resulted in higher levels of psychological distress. According to Gross (2014), individuals who frequently use cognitive reappraisal are less likely to use expressive suppression at the same time. Consistent with this evidence is the result of the

present study that showed higher scores for cognitive reappraisal (M = 30.06, SD = 8.40) and lower scores for expressive suppression (M =12.83, SD = 5.76). This means when the cognitive reappraisal score was high the expressive suppression score was low, indicating that the constructs are conceptually related and the direction of the correlation was as hypothesized. This further establishes the validity of the instrument and renders a measurement error unlikely. Putting together, the possibility of conceptual mismatch between the trait versus state measures of emotion regulation and between the subscales of emotion regulation is unlikely. This establishes the reliability of the ERQ measure used in the present study.

Another possible explanation to be considered is whether the SDMs were aware of the complexity and seriousness of the decisions they were making. Emotional activation is based on the intensity of the given situations (Gross, 2014). Prior decision making experiences, or the lack of it, are known to contribute to the intensity and the stress level of the situation. In the present study the SDMs may have either been unaware of the complexity and seriousness of the situation or they were habituated and were in-sensitized from the ongoing stressful decision making experiences. Both situations were likely in the current study since only about half of the SDMs (51%) reported having prior experiences. Therefore, it cannot be concluded whether SDMs' awareness of the complexity and seriousness of the situation has contributed to the non-significant results obtained in the current study.

After considering all the above possibilities, the only explanation that remains for not finding a significant correlation is that the study may be statistically underpowered. The investigator used 120 subjects in this study, which was more than the sample size of

114 that the G*Power prompted. However, for constructs such as emotion regulation and psychological distress and a high levels of stressful situations such as an ICU, where subjects could be considerably distracted, a larger sample size may be required to obtain a significant correlation.

Research Question Two

Research question two examined the associations between the subscales of emotion regulation and psychological distress while controlling for the demographic variables of age, gender, ethnicity, kinship, advance directives, and living will.

For research question two that examined relationships between the subscales of emotion regulation and psychological distress, while controlling for the demographic variables, the results of both emotion regulation subscales (cognitive reappraisal & expressive suppression) indicated that emotion regulation was not significantly associated with psychological distress. In addition to the explanations provided under research question one, another possible explanation is that the adaptive strategies are context-dependent (Aldao et al., 2010). For example, individuals employ cognitive reappraisal when the situation is hopeful and that whether one is facing a solvable problem. In the current study, if the prognosis of the CCI patient in the ICU was uncertain and the chance for patient's survival was unclear, cognitive reappraisal may not have been the best adaptable strategy for the SDM. In such a situation the SDM may have, knowingly or unknowingly, begun the grieving process and the use of expressive suppression may have become a situational choice. This is because individuals experiencing stressful situations are less able to implement cognitive reappraisal and have lower self-efficacy to actually

apply cognitive reappraisal (Brozovich et al., 2015). Individuals who already experience high levels of psychological distress may be exhausted of their ability to employ cognitive reappraisal.

Additionally, high levels of psychological distress is shown to impact normal brain functions (Campbell-Sills, 2011). According to Koenigsberg and colleagues (2010) higher levels of stress downregulate the brain functions during cognitive reappraisal. Starcke and Brand (2012) state that individuals who experience anxiety may have a profound impact on their ability to function adaptively because they use increased brain resources to reduce negative emotions through cognitive reappraisal. Therefore, participants in this sample who were experiencing high levels of stress naturally may have avoided using cognitive reappraisal.

Although emotion regulation and psychological distress were not significantly correlated, another important pattern emerged in all three models of regression equation analyses; that gender and AD were significantly associated with psychological distress. This finding was consistent with previous study results that gender and AD impact SDMs' psychological distress (Bowie, 2010; Nolen-Hoeksema, 2013). The rational for the association between gender and psychological distress is described under research question one.

An AD is a legal document through which patients plan their own end-of-life treatment wishes that guide the family and healthcare team to make medical decisions in the event patients become unable to participate in such decisions (Meghani, & Hinds, 2015). The purpose of this document is to make patients' wishes known to the family and healthcare team. Having an AD is expected to reduce SDMs decision making stress.

On the contrary, the absence of an AD appears to intensify the severity of SDMs' depressive symptoms (Hickman et al., 2012).

Despite its establishment in 1990, the practice of making an AD a mandatory procedure for all patients is not established. Most patients do not have such a document and for those who have it, the implementation of such plans is said to be impractical due to the lack of situational and procedural specificity (Goede & Wheeler, 2015). In the current study most patients did not have an AD (68%) and one can well argue that the lack of an AD had an impact on the significant correlation between role stress and psychological distress ($r = .29$, $p < .01$). Therefore, it would be beneficial for future scientists to examine the reasons for the lack of emphasis of ADs in the clinical settings, revise the particulars in current document to make its application practical, and then learn its impact on the association with psychological distress.

A few of the socio-economic factors such as prior caregiving experience, employment, and education were randomly examined to learn whether these were associated with role stress and psychological distress. The result indicated that these were not significantly associated with role stress and psychological distress in the sample of SDMs.

Research Question Three

For research question three the mediating effect of role stress in the relationship between the subscales of emotion regulation and psychological distress while controlling for the demographic variables of gender and AD was examined. The rest of demographic

variables were excluded from this analysis as these were not significantly correlated with main variables in research questions one and two.

The findings of research question three indicated that role stress did not mediate the relationship between emotion regulation and psychological distress in this sample of SDMs. The lack of mediating effect could be illustrated by several methodological and other sources.

The first methodological source applicable for the present study include timing of measurement and measurement error. Regarding the timing of measurement, the participants were interviewed at one time-point, 24 – 48 hours after being presented with a decisional requirement. This may be a short time for some SDMs to reach a self-actualization of their role, especially for the child SDMs and for those with no prior experience (Hickman, 2008).

The second possible source is the measurement error. Role stress was measured using a single item indicator, which may not have captured other aspects of role stress, such as satisfaction (Hickman, 2008). Although this single-item measure has demonstrated sufficient reliability and validity in unidimensional constructs (Littman et al., 2006; Postmes, et al. 2013), it may not capture multidimensional constructs if role stress is a multidimensional construct. Additionally, this single item measure is a visual analog scale by which SDM's responses were estimated. The chance of overestimation and underestimation were highly possible (Hickman, 2008). This may have resulted in inaccurate results and accounted for the lack of a mediating effect by role stress.

Other possible sources that may have contributed to the lack of mediating effect of role stress may include prior caregiving experience, perception of the situation,

perception of the complexity of the role, and SDM's relationship with patient. The SDMs with no prior caring and decision making experiences may not have been aware of the seriousness of the situation and the complexity of the critical decisions they were making, which may have had no impact on role stress and resulted in a non-significant association.

SDM's relationship with patient also may have contributed to the situation. A legally appointed SDM who was not related to the patient may have had less emotional involvement and resulted in less role stress. It may be also possible that younger child SDMs with insufficient prior caring experiences to have less emotional involvement. About 28.3% of SDMs were either legal guardians, siblings or friends and about 33% of SDMs were child to the patient who may have been experiencing lessor role stress intensity. These conditions may have contributed to a non-mediating effect of role stress.

Although, the overall result indicated that role stress did not mediate the relationship between emotion regulation and psychological distress, two individual paths showed significant associations. As described under research question one, statistically significant association was found between role stress and psychological distress in Path B. Among demographic variables, gender and AD, were significantly correlated in Path B and Path AB for both models of cognitive reappraisal and expressive suppression. This finding was consistent with the results of research question two.

Thus, one can argue that psychological distress levels can be higher in the absence of an AD significantly. In this sample of SDMs 68% of patients did not have an AD and 66.7% of SDMs were women. Thus, it can be inferred that the chance of experiencing

higher levels of psychological distress is magnified when the SDM is a woman and does not have an AD for the patient.

Study Limitations

Several factors may have impacted the study findings or influenced the interpretation of the findings. The first is the use of a secondary data analysis. A secondary data analysis limits the researcher's ability to alter variables, instruments, or procedures to examine the phenomena of interest.

The second factor is related to temporal ambiguity. A cross-sectional design limits the ability to examine the causal relationships between the study variables across multiple points in time. Examining the impact of emotion regulation on psychological distress across multiple points in time could have produced different outcomes, such as finding a stronger, i.e. significant, association among some variables. A longitudinal study design could help control for any confounding factors that may have influenced SDM's responses at the time of interview.

The third limiting factor is related to selection bias and is two – pronged. First, the study was conducted in various ICUs at a large tertiary health science center in North East Ohio, so the present study result may not be generalizable to smaller centers in alternate settings or locations. The participants were SDMs of CCI patients admitted to the ICU within 24-48 hours of being presented with a healthcare decision. The study findings are not generalizable to other populations bound by other time frame. Besides, the study was conducted in various ICUs at a large tertiary medical center in Northeast Ohio. Therefore, the present study results may not be generalizable to smaller healthcare

centers nor to rural healthcare settings. The majority of subjects were white and female which further limits its generalizability.

The fourth limiting factor is related to sample size. This study could be underpowered because the sample size for research question three used a sample size of 100 rather than the 114 called for by G*Power because AD had only a sample size of 100 and therefore the entire mediation analysis was carried out with a sample size of 100. Future researchers should consider re-testing these phenomena with a larger sample size for better results.

Study Implications

Science. The knowledge generated through this study could be used to advance healthcare science regarding the association of emotion regulation, SDM role stress, and psychological distress among SDMs' of CCI patient populations. It is the only study found that considered emotion regulation as an independent variable to examine the associations among the selected variables in this population. Given the high vulnerability of the SDMs of CCI patients in the ICU the impact of emotion regulation on psychological distress in this population is an important area that needs to be investigated further with a goal to develop support programs for SDMs. SDMs could greatly benefit from professional support because the burden of making treatment decisions and the consequences seem to have profound and lasting impact on the SDMs (Wendler & Rid, 2011).

Understanding more about emotion regulation and its impact on psychological distress would be valuable in determining strategies to reduce SDM's decision making burden. Such knowledge would help healthcare providers in the ICU develop innovative

SDM support programs. Choi et al. (2016) state that more research is required to identify SDMs who are at greatest risk for distress, time points that target interventions with maximal efficacy, and test interventions that mitigate family caregivers' burdens. Current research has addressed some of these research requirements by examining the two widely used emotion regulation strategies, important demographic variables, and the relationships among these study variables with psychological distress. Future researchers could build on the findings generated in this study to develop adequate and cost-effective decision support programs to assist SDMs.

In scientific investigations cognitive reappraisal has shown to produce favorable outcomes, such as fewer depressive symptoms (Gross & John, 2003). However, according to Gross (2014), SDMs who are already experiencing high levels of stress are unable to use cognitive reappraisal as a beneficial self-resource to reduce psychological distress. Emotion regulation training has shown to produce better outcomes, though further research is required to solidify this finding. Given the high correlation between an AD and psychological distress in the current study, more research that examine the effect of an AD on SDMs of CCI patient populations would be beneficial.

Practice. The most valuable contributions of this study are related to the significant association between role stress and psychological distress and to higher correlations of AD and gender with psychological distress in this population. The inverse correlation between cognitive reappraisal and psychological distress, and the significant positive association between role stress and psychological distress may serve as baseline information to develop innovative training programs. Developing innovative emotion

regulation training programs to support SDMs is important because such programs have shown to be effective in lowering psychological distress levels (Gross, 2014).

Policy. The knowledge generated from this research regarding the detrimental consequences that stressful decision-making can have on patients and SDMs, and the impact of emotion regulation on role stress and psychological distress may provide policy makers with strong evidence that SDM assistance is a necessity. Policy changes to practice guidelines could be considered in the ICUs during and after ICU admissions of CCI patients as having equal importance to post-admission follow-up support programs. Administration could support a much needed policy change for SDMs in the ICU with timely assistance from an early stage of ICU admissions. Because emotional support and decision making assistance are crucial from an early stage of ICU admission, it is hoped that such a need will be acknowledged by policy makers to develop SDM support policies.

Recommendations for future research. Based on the findings of this study there are two recommendations for future research. The first recommendation reinforces the requirement for longitudinal research in order to capture the impact of emotion regulation processes on psychological distress at multiple time points. The current study did not have the capacity to account for this, however, a longitudinal research study could verify such impact.

The second recommendation proposes further investigation regarding the impact of ADs in this patient population and the resulting association between AD and psychological distress. Use of ADs in this patient population is crucial to reduce SDM's stress levels. Given that most patients in this study did not have an AD, more research

would be beneficial to identify the reasons most subjects did not have an AD, highlight strategies to increase the wider use of existing ADs, and whether any revision is required to make the current AD document more useful.

Conclusion

In summary, an in-depth search of the literature across multiple fields suggest that this is the first study that examined the associations among emotion regulation, role stress, and psychological distress of SDMs of CCI patients using emotion regulation as an independent variable. This research evaluated how emotion regulation and demographic variables were associated with psychological distress and whether role stress mediated the relationship between emotion regulation and psychological distress. The findings from this study provide preliminary evidence describing how cognitive reappraisal and expressive suppression are associated differently with psychological distress and that role stress, gender, and an AD are significantly correlated with psychological distress. The findings also indicated that kinship and race/ethnicity are significantly associated with psychological distress. Role stress, gender, and an AD were consistently significantly correlated with psychological distress in all three research question analyses. This result provides important information regarding the kind of professional assistance to offer the SDMs of CCI patients in their critical time-sensitive decision making role. Such findings are an important contribution to nursing science and are expected to help improve nursing practice, develop policy, and provide insight to advance research on the same issues. Based on the findings of this study it is possible that SDMs can be better assisted to make crucial time-sensitive life changing decisions for the CCI patients whose welfare is entrusted to them.

Appendix A

List of Study Instruments

Hospital Anxiety and Depression Scale (HADS)

This questionnaire will help us know how you are feeling. Read every sentence. Please place an "x" by the answer that best describes how you have been feeling currently. You do not have to think too much to about the answer. In this questionnaire, spontaneous answers are more important.

1. I feel tense or wound up:
   ( ) Most of the time
   ( ) A lot of the time
   ( ) From time to time
   ( ) Not at all
2. I still enjoy the things I used to enjoy:
   ( ) Definitely as much
   ( ) Not quite so much
   ( ) Only a little
   ( ) Hardly at all
3. I get a sort of frightened feeling as if something awful is about to happen:
   ( ) Very definitely and quite badly
   ( ) Yes, but not too badly
   ( ) A little, but it doesn't worry me
   ( ) Not at all
4. I can laugh and see the funny side of things**:**
   ( ) As much as I always could
   ( ) Not quite so much now
   ( ) Definitely not so much now
   ( ) Not at all
5. Worrying thought goes through my mind:
   ( ) A great deal of the time
   ( ) A lot of the time
   ( ) From time to time, but not too often
   ( ) Only occasionally
6. I feel cheerful:
   ( ) Not at all
   ( ) Not often
   ( ) Sometimes
   ( ) Most of the time
8. I feel as if I am slowed down:
   ( ) Nearly all the time
   ( ) Very often
   ( ) Sometimes
   ( ) Not at all
9. I get a sort of frightened feeling like 'butterflies' in the stomach:
   ( ) Not at all
   ( ) Occasionally
   ( ) Quite often
   ( ) Very often
10. I have lost interest in my appearance:
    ( ) Definitely
    ( ) I don't take as much care as I should
    ( ) I may not take quite as much care
    ( ) I take just as much care as ever
11. I feel restless as if I have to be on the move:
    ( ) Very much indeed
    ( ) Quite a lot
    ( ) Not very much
    ( ) Not at all
12. I look forward with enjoyment to things:
    ( ) As much as I ever did
    ( ) Rather less than I used to
    ( ) Definitely less than I used to
    ( ) Hardly at all
13. I get sudden feelings of panic:
    ( ) Very often indeed
    ( ) Quite often
    ( ) Not very often
    ( ) Not at all

7. I can sit at ease and feel relaxed:

( ) Definitely
( ) Usually
( ) Not often
( ) Not at all

14. I can enjoy a good book, radio or TV program:

( ) Often
( ) Sometimes
( ) Not often
( ) Very seldom

Appendix A (continued)

Emotion Regulation Questionnaire (ERQ)

Instructions and Items

We would like to ask you some questions about your emotional life, in particular, how you control (that is, regulate and manage) your emotions. The questions below involve two distinct aspects of your emotional life. One is your emotional experience, or what you feel like inside. The other is your emotional expression, or how you show your emotions in the way you talk, gesture, or behave. Although some of the following questions may seem similar to one another, they differ in important ways. For each item, please answer using the following scale:

1----------2----------3----------4----------5----------6----------7

strongly disagree **neutral** **Strongly Agree**

1. When I want to feel more *positive* emotion (such as joy or amusement), I *change what I'm thinking about*.

2. I keep my emotions to myself.

3. When I want to feel less *negative* emotion (such as sadness or anger), I *change what I'm thinking about*.

4. When I am feeling *positive* emotions, I am careful not to express them.

5. When I'm faced with a stressful situation, I make myself *think about it* in a way that helps me stay calm.

6. I control my emotions by *not expressing them*.

7. When I want to feel more *positive* emotion, I *change the way I'm thinking* about the situation.

8. I control my emotions by *changing the way I think* about the situation I'm in.

9. When I am feeling *negative* emotions, I make sure not to express them.

10. When I want to feel less *negative* emotion, I *change the way I'm thinking* about the situation.

Appendix A (continued)

FAMILY DECISION MAKER STRESS QUESTIONNAIRE (FDSQ)

☐ Face-to-Face Interview
☐ Self Report

ID_____

Date_____

FDSQ

Part I.

Since your family member or loved one has been in the ICU; how would you rate your overall stress?

Place an "X" on the line below that best reflects how you feel.

Not Stressed	Somewhat Stressed	Very Stressed

Since your family member has been in the hospital; have you had to make medical decisions for him or for her?

Please mark "YES" or "No".

☐ Yes (Please answer **Part II.**) ☐ NO

Part II.

In terms of making decisions for your family member:

a. How stressful has it been making medical decisions for your family member?

Not at all Stressful	Somewhat Stressful	Very Stressful

b. How comfortable have you been with being the decision-maker for your family member?

Not at all Comfortable	Somewhat Comfortable	Very Comfortable

c. How much more stressful is being the decision-maker for your family member compared to making decisions for yourself?

Not More Stressful	Somewhat More Stressful	Very Stressful

References

Abele, P., & Morley, J. E. (2016). Advance directives: The key to a good death?. *Journal of the American Medical Directors Association*, *17*(4), 279-283.

Adhikari, N. K., Fowler, R. A., Bhagwanjee, S., & Rubenfeld, G. D. (2010). Critical care and the global burden of critical illness in adults. *The Lancet*, *376*(9749), 1339-1346.

Admi, H., & Moshe-Eilon, Y. (2010). Stress among charge nurses: tool development and stress measurement. *Nursing Economics*, *28*(3), 151.

Aldao, A., & Nolen-Hoeksema, S. (2013). One versus many: capturing the use of multiple emotion regulation strategies in response to an emotion-eliciting stimulus. *Cognition & emotion*, *27*(4), 753-760.

Aldao, A., Nolen-Hoeksema, S., & Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical psychology review*, *30*(2), 217-237.

Ali, S., & Alea, N. (2017). Does Who I Am or How I Regulate Matter? Consequences of Manipulation of Emotion Regulation Strategies. *The International Journal of Aging and Human Development*, *85*(2), 135-163.

Arnone, D., McKie, S., Elliott, R., Thomas, E. J., Downey, D., Juhasz, G., ... & Anderson, I. M. (2012). Increased amygdala responses to sad but not fearful faces in major depression: relation to mood state and pharmacological treatment. *American Journal of Psychiatry*, *169*(8), 841-850.

Asadi, A., Fadakar, F., Khoshnodifar, Z., Hashemi, S. M., & Hosseininia, G. (2008). Personal characteristics affecting agricultural extension workers' job satisfaction

level. *Journal of social sciences*, *4*(4), 246-250.

Auerbach, S. M., Kiesler, D. J., Wartella, J., Rausch, S., Ward, K. R., & Ivatury, R. (2005). Optimism, satisfaction with needs met, interpersonal perceptions of the healthcare team, and emotional distress in patients' family members during critical care hospitalization. *American journal of critical care*, *14*(3), 202-210.

Azoulay, E., Chaize, M., & Kentish-Barnes, N. (2014). Involvement of ICU families in decisions: fine-tuning the partnership. *Annals of intensive care*, *4*(1), 37.

Azoulay, E., Pochard, F., Kentish-Barnes, N., Chevret, S., Aboab, J., Adrie, C., ... & Fassier, T.(2005). Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American journal of respiratory and critical care medicine*, *171*(9), 987-994.

Baeza-Velasco, C., Carton, S., Almohsen, C., Blotman, F., & Gély-Nargeot, M. C. (2012). Alexithymia and emotional awareness in females with Painful Rheumatic Conditions. *Journal of psychosomatic research*, *73*(5), 398-400.

Balzarotti, S., John, O. P., & Gross, J. J. (2010). An Italian adaptation of the emotion regulation questionnaire. *European Journal of Psychological Assessment*.

Barlow, D. H. (2000). Unraveling the mysteries of anxiety and its disorders from the perspective of emotion theory. *American Psychologist*, *55*(11), 1247.

Barnes, D. M., Keyes, K. M., & Bates, L. M. (2013). Racial differences in depression in the United States: how do subgroup analyses inform a paradox?. *Social psychiatry and psychiatric epidemiology*, *48*(12), 1941-1949.

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in

social psychological research: Conceptual, strategic, and statistical considerations. *Journal of personality and social psychology*, *51*(6), 1173.

Barrett, L. F., Gross, J., Christensen, T. C., & Benvenuto, M. (2001). Knowing what you're feeling and knowing what to do about it: Mapping the relation between emotion differentiation and emotion regulation. *Cognition & Emotion*, *15*(6), 713-724.

Baumeister, R. F. (2002). Yielding to temptation: Self-control failure, impulsive purchasing, and consumer behavior. *Journal of consumer Research*, *28*(4), 670-676.

Baumeister, R. F., Bratslavsky, E., Muraven, M., & Tice, D. M. (1998). Ego depletion: Is the active self a limited resource?. *Journal of personality and social psychology*, *74*(5), 1252.

Baumeister, R. F., Vohs, K. D., & Tice, D. M. (2007). The strength model of self-control. *Current directions in psychological science*, *16*(6), 351-355.

Barnes, D. M., Keyes, K. M., & Bates, L. M. (2013). Racial differences in depression in the United States: how do subgroup analyses inform a paradox?. *Social psychiatry and psychiatric epidemiology*, *48*(12), 1941-1949.

Barrett, L. F., Bliss-Moreau, E., Duncan, S. L., Rauch, S. L., & Wright, C. I. (2007). The amygdala and the experience of affect. *Social cognitive and affective neuroscience*, *2*(2), 73-83.

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—the pinnacle of patient-centered care. *New England Journal of Medicine*, *366*(9), 780-781.

Beauregard, M., Paquette, V., & Le, J. (2006). Dysfunction in the neural circuitry of

emotional self-regulation in major depressive disorder. *Neuroreport*, *17*(8), 843-846.

Beehr, T. A., Walsh, J. T., & Taber, T. D. (1976). Relationships of stress to individually And organizationally valued states: Higher order needs as a moderator. *Journal of applied psychology*, *61*(1), 41.

Bellani, G., Laffey, J. G., Pham, T., Fan, E., Brochard, L., Esteban, A., ... & Ranieri, M. (2016). Epidemiology, patterns of care, and mortality for patients with acute respiratory distress syndrome in intensive care units in 50 countries. *Jama*, *315*(8), 788-800.

Ben-Naim, S., Hirschberger, G., Ein-Dor, T., & Mikulincer, M. (2013). An experimental study of emotion regulation during relationship conflict interactions: The moderating role of attachment orientations. *Emotion*, *13*(3), 506.

Bermeitinger, C. (2016). The emotional Stroop as an emotion regulation task. *Experimental aging research*, *42*(2), 161-194.

Bodet-Contentin, L., Frasca, D., Tavernier, E., Feuillet, F., Foucher, Y., & Giraudeau, B. (2018). Ventilator-Free Day Outcomes Can Be Misleading. *Critical care medicine*, *46*(3), 425-429.

Bouadma, L., Sonneville, R., Garrouste-Orgeas, M., Darmon, M., Souweine, B., Voiriot, G., ... & Argaud, L. (2015). Ventilator-associated events: prevalence, outcome, and relationship with ventilator-associated pneumonia. *Critical care medicine*, *43*(9), 1798-1806.

Bowie, B. H. (2010). Understanding the gender differences in pathways to social

deviancy: Relational aggression and emotion regulation. *Archives of Psychiatric Nursing*, *24*(1), 27-37.

Bowlby, J. (1969). Attachment and loss: Attachment (vol. 1).

Bowlby, J. (1982). Attachment and loss: Retrospect and prospect. *American journal of Orthopsychiatry*, *52*(4), 664.

Brans, K., Koval, P., Verduyn, P., Lim, Y. L., & Kuppens, P. (2013). The regulation of negative and positive affect in daily life. *Emotion*, *13*(5), 926.

Braun, U. K., Beyth, R. J., Ford, M. E., & McCullough, L. B. (2008). Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *Journal of general internal medicine*, *23*(3), 267-274.

Brown, J. S., Meadows, S. O., & Elder Jr, G. H. (2007). Race-ethnic inequality and psychological distress: Depressive symptoms from adolescence to young adulthood. *Developmental psychology*, *43*(6), 1295.

Brozovich, F. A., Goldin, P., Lee, I., Jazaieri, H., Heimberg, R. G., & Gross, J. J. (2015). The effect of rumination and reappraisal on social anxiety symptoms during cognitive-behavioral therapy for social anxiety disorder. *Journal of Clinical Psychology*, *71*(3), 208-218.

Buckey, J. W., & Molina, O. (2012). Honoring patient care preferences: Surrogates speak. *OMEGA-Journal of Death and Dying*, *65*(4), 257-280.

Butler, L. D., & Nolen-Hoeksema, S. (1994). Gender differences in responses to depressed mood in a college sample. *Sex roles*, *30*(5-6), 331-346.

Cameron, J. I., Franche, R. L., Cheung, A. M., & Stewart, D. E. (2002). Lifestyle

interference and emotional distress in family caregivers of advanced cancer patients. *Cancer*, *94*(2), 521-527.

Camhi, S. L., & Nelson, J. E. (2007). Chronic critical illness. In *Intensive Care Medicine* (pp. 908-917). Springer, New York, NY.

Campbell-Sills, L., Simmons, A. N., Lovero, K. L., Rochlin, A. A., Paulus, M. P., & Stein, M. B. (2011). Functioning of neural systems supporting emotion regulation in anxiety-prone individuals. *Neuroimage*, *54*(1), 689-696.

Campos, J. J., Mumme, D., Kermoian, R., & Campos, R. G. (1994). A functionalist perspective on the nature of emotion. *Japanese Journal of Research on Emotions*, *2*(1), 1-20.

CaringInfo (2016). Understanding advance directives. Retrieved from http://www.caringinfo.org/files/public/brochures/Understanding_Advance_Directives.pdf

Carl, J. R., Fairholme, C. P., Gallagher, M. W., Thompson-Hollands, J., & Barlow, D. H. (2014). The effects of anxiety and depressive symptoms on daily positive emotion regulation. *Journal of Psychopathology and Behavioral Assessment*, *36*(2), 224-236.

Carson, S. S. (2012). Definitions and epidemiology of the chronically critically ill. *Respiratory Care*, *57*(6), 848-858.

Carson, S. S., & Bach, P. B. (2002). The epidemiology and costs of chronic critical illness. *Critical care clinics*, *18*(3), 461-476.

Castle, J. E. (2003). Maximizing research opportunities: Secondary data analysis.

Journal of Neuroscience Nursing, *35*(5), 287.

Chang, E. C. (1998). Dispositional optimism and primary and secondary appraisal of a stressor: Controlling for confounding influences and relations to coping and psychological and physical adjustment. *Journal of Personality and Social Psychology*, *74*(4), 1109.

Chang, E. M., Hancock, K. M., Johnson, A., Daly, J., & Jackson, D. (2005). Role stress in nurses: review of related factors and strategies for moving forward. *Nursing & health sciences*, *7*(1), 57-65.

Choi, J., Donahoe, M. P., & Hoffman, L. A. (2016). Psychological and Physical Health in Family Caregivers of Intensive Care Unit Survivors: Current Knowledge and Future Research Strategies. *Journal of Korean Academy of Nursing*, *46*(2), 159-167.

Cohen, J. (1992). A power primer. *Psychological bulletin*, *112*(1), 155.

Cohn, M. A., Fredrickson, B. L., Brown, S. L., Mikels, J. A., & Conway, A. M. (2009). Happiness unpacked: positive emotions increase life satisfaction by building resilience. *Emotion*, *9*(3), 361.

Consedine, N. S., Magai, C., & Bonanno, G. A. (2002). Moderators of the emotion inhibition-health relationship: A review and research agenda. *Review of General Psychology*, *6*(2), 204.

Coomer, N. M., Morley, M., Ingber, M. J., Briggs, A., & Gage, B. (2017). A preliminary look at readmission and mortality among chronically critically ill and other medically complex Medicare patients. *Applied Economics Letters*, *24*(20), 1435-1438.

Curtis, J. R., & White, D. B. (2008). Practical guidance for evidence-based ICU family conferences. *Chest*, *134*(4), 835-843.

Cuthbertson, B. H., Roughton, S., Jenkinson, D., MacLennan, G., & Vale, L. (2010). Quality of life in the five years after intensive care: a cohort study. *Critical care*, *14*(1), R6.

Cutuli, D. (2014). Cognitive reappraisal and expressive suppression strategies role in the emotion regulation: an overview on their modulatory effects and neural correlates. *Frontiers in systems neuroscience*, *8*, 175.

Dahling, J. J., & Perez, L. A. (2010). Older worker, different actor? Linking age and emotional labor strategies. *Personality and Individual Differences*, *48*(5), 574-578.

Daly, B. J., Douglas, S. L., Kelley, C. G., O'toole, E., & Montenegro, H. (2005). Trial of a disease management program to reduce hospital readmissions of the chronically critically ill. *CHEST Journal*, *128*(2), 507-517.

Daly, B. J., Douglas, S. L., O'toole, E., Gordon, N. H., Hejal, R., Peerless, J., ... & Hickman, R. (2010). Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. *Chest*, *138*(6), 1340-1348.

Daly, B. J., Rudy, E. B., Thompson, K. S., & Happ, M. B. (1991). Development of a special care unit for chronically critically ill patients. *Heart & lung: the journal of critical care*, *20*(1), 45-51.

Davidson, J. E., Jones, C., & Bienvenu, O. J. (2012). Family response to critical illness: Postintensive care syndrome–family. *Critical care medicine*, *40*(2), 618-624.

Davis, M., Walker, D. L., Miles, L., & Grillon, C. (2010). Phasic vs sustained fear

in rats and humans: role of the extended amygdala in fear vs anxiety. *Neuropsychopharmacology*, *35*(1), 105-135.

Denno, M. S., Gillard, P. J., Graham, G. D., DiBonaventura, M. D., Goren, A., Varon, S. F., & Zorowitz, R. (2013). Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Archives of physical medicine and rehabilitation*, *94*(9), 1731-1736.

DePasquale, N., Davis, K. D., Zarit, S. H., Moen, P., Hammer, L. B., & Almeida, D. M. (2014). Combining formal and informal caregiving roles: The psychosocial implications of double-and triple-duty care. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *71*(2), 201-211.

DePasquale, N., Polenick, C. A., Davis, K. D., Moen, P., Hammer, L. B., & Almeida, D. M. (2017). The psychosocial implications of managing work and family caregiving roles: Gender differences among information technology professionals. *Journal of family issues*, *38*(11), 1495-1519.

Detsky, M. E., Harhay, M. O., Bayard, D. F., Delman, A. M., Buehler, A. E., Kent, S. A., ... & Mikkelsen, M. E. (2017). Discriminative accuracy of physician and nurse predictions for survival and functional outcomes 6 months after an ICU admission. *Jama*, *317*(21), 2187-2195.

de Veld, D. M., Riksen-Walraven, J. M., & de Weerth, C. (2012). The relation between emotion regulation strategies and physiological stress responses in middle childhood. *Psychoneuroendocrinology*, *37*(8), 1309-1319.

DeVon, H. A., Block, M. E., Moyle-Wright, P., Ernst, D. M., Hayden, S. J., Lazzara, D. J., ... & Kostas-Polston, E. (2007). A psychometric toolbox for testing validity and reliability. *Journal of Nursing scholarship*, *39*(2), 155-164.

Diener, E., Lucas, R. E., & Scollon, C. N. (2006). Beyond the hedonic treadmill: revising the adaptation theory of well-being. *American psychologist*, *61*(4), 305.

Douglas, S. L., & Daly, B. J. (2003). Caregivers of long-term ventilator patients: physical and psychological outcomes. *Chest*, *123*(4), 1073-1081.

Douglas, S. L., Daly, B. J., Brennan, P. F., Gordon, N. H., & Uthis, P. (2001). Hospital readmission among long-term ventilator patients. *Chest journal*, *120*(4), 1278-1286.

Douglas, S. L., Daly, B. J., O'toole, E., & Hickman, R. L. (2010). Depression among white and nonwhite caregivers of the chronically critically ill. *Journal of critical care*, *25*(2), 364-e11.

Douglas, S. L., Daly, B. J., & Lipson, A. R. (2017). Differences in Predictions for Survival and Expectations for Goals of Care between Physicians and Family Surrogate Decision Makers of Chronically Critically Ill Adults. *Research & reviews. Journal of nursing and health sciences*, *3*(3), 74.

Drapeau, A., Marchand, A., & Beaulieu-Prévost, D. (2012). Epidemiology of Psychological distress. In *Mental illnesses-understanding, prediction and control*. IntechOpen.

InTech. Ehlenbach, W. J., Hough, C. L., Crane, P. K., Haneuse, S. J., Carson, S. S., Curtis, J. R., & Larson, E. B. (2010). Association between acute care and

critical illness hospitalization and cognitive function in older adults. *Jama*, *303*(8), 763-770.

Ekman, P. (1993). Facial expression and emotion. *American psychologist*, *48*(4), 384.

Engoren, M., Arslanian-Engoren, C., & Fenn-Buderer, N. (2004). Hospital and long-term outcome after tracheostomy for respiratory failure. *CHEST Journal*, *125*(1), 220-227.

Ernecoff, N. C., Witteman, H. O., Chon, K., Buddadhumaruk, P., Chiarchiaro, J., Shotsberger, K. J., ... & Lo, B. (2016). Key stakeholders' perceptions of the acceptability and usefulness of a tablet-based tool to improve communication and shared decision making in ICUs. *Journal of critical care*, *33*, 19-25.

Etxeberria, I., Etxebarria, I., Urdaneta, E., & Yanguas, J. J. (2016). Age differences among older adults in the use of emotion regulation strategies. What happens among over 85s and centenarians?. *Aging & mental health*, *20*(9), 974-980.

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). G* Power Version 3.1. 7 [computer software]. Uiversität Kiel, Germany.

Field, A. (2009). *Discovering statistics using SPSS*. Sage publications.

Fredrickson, B. L. (1998). What good are positive emotions?. *Review of general psychology*, *2*(3), 300.

Fredrickson, B. L., & Branigan, C. (2005). Positive emotions broaden the scope of attention and thought-action repertoires. *Cognition & emotion*, *19*(3), 313-332.

Frijda, N. H., & Parrott, W. G. (2011). Basic emotions or ur-emotions?. *Emotion Review*, *3*(4), 406-415.

Garland, E. L., Fredrickson, B., Kring, A. M., Johnson, D. P., Meyer, P. S., & Penn,

D. L. (2010). Upward spirals of positive emotions counter downward spirals of negativity: Insights from the broaden-and-build theory and affective neuroscience on the treatment of emotion dysfunctions and deficits in psychopathology. *Clinical psychology review*, *30*(7), 849-864.

Garnefski, N., & Kraaij, V. (2006). Relationships between cognitive emotion Regulation strategies and depressive symptoms: A comparative study of five specific samples. *Personality and Individual differences*, *40*(8), 1659-1669.

Garrido, M. M., Balboni, T. A., Maciejewski, P. K., Bao, Y., & Prigerson, H. G. (2015). Quality of life and cost of care at the end of life: the role of advance directives. *Journal of pain and symptom management*, *49*(5), 828-835.

Gianini, L. M., White, M. A., & Masheb, R. M. (2013). Eating pathology, emotion regulation, and emotional overeating in obese adults with binge eating disorder. *Eating behaviors*, *14*(3), 309-313.

Girard, K., & Raffin, T. A. (1985). The chronically critically ill: to save or let die?. *Respiratory care*, *30*(5), 339-347.

Glass, G. V. (1976). Primary, secondary, and meta-analysis of research. *Educational researcher*, *5*(10), 3-8.

Goede, M., & Wheeler, M. (2015). Advance directives, living wills, and futility in perioperative care. *Surgical Clinics*, *95*(2), 443-451.

Goldin, P. R., & Gross, J. J. (2010). Effects of mindfulness-based stress reduction (MBSR) on emotion regulation in social anxiety disorder. *Emotion*, *10*(1), 83.

Goldin, P. R., Manber-Ball, T., Werner, K., Heimberg, R., & Gross, J. J. (2009). Neural mechanisms of cognitive reappraisal of negative self-beliefs in social

anxiety disorder. *Biological psychiatry*, *66*(12), 1091-1099.

González, H. M., Tarraf, W., Whitfield, K. E., & Vega, W. A. (2010). The epidemiology of major depression and ethnicity in the United States. *Journal of psychiatric research*, *44*(15), 1043-1051.

Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of psychopathology and behavioral assessment*, *26*(1), 41-54.

Greifeneder, R., Bless, H., & Pham, M. T. (2011). When do people rely on affective and cognitive feelings in judgment? A review. *Personality and Social Psychology Review*, *15*(2), 107-141.

Griffiths, J. A., Barber, V. S., Cuthbertson, B. H., & Young, J. D. (2006). A national survey of intensive care follow-up clinics. *Anaesthesia*, *61*(10), 950-955

Griffith, D. M., Salisbury, L. G., Lee, R. J., Lone, N., Merriweather, J. L., Walsh, T. S., & RECOVER Investigators. (2018). Determinants of Health-Related Quality of Life After ICU: Importance of Patient Demographics, Previous Comorbidity, and Severity of Illness. *Critical care medicine*, *46*(4), 594-601.

Gross, J.J. (2014). *Handbook of Emotion Regulation*. The Guilford Press, NY.

Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of general psychology*, *2*(3), 271.

Gross, J. J. (1998). Antecedent-and response-focused emotion regulation: divergent consequences for experience, expression, and physiology. *Journal of*

personality and social psychology, *74*(1), 224.

Gross, J. J. (2002). Emotion regulation: Affective, cognitive, and social consequences. *Psychophysiology*, *39*(3), 281-291.

Gross, J. J., & Feldman Barrett, L. (2011). Emotion generation and emotion regulation: One or two depends on your point of view. *Emotion review*, *3*(1), 8-16.

Gross, J. J., & Jazaieri, H. (2014). Emotion, emotion regulation, and psychopathology: An affective science perspective. *Clinical Psychological Science*, *2*(4), 387-401.

Gross, J. J., & John, O. P. (2003). Individual differences in two emotion regulation processes: implications for affect, relationships, and well-being. *Journal of personality and social psychology*, *85*(2), 348.

Gross, J. J., & John, O. P. (1998). Mapping the domain of expressivity: multimethod evidence for a hierarchical model. *Journal of personality and social psychology*, *74*(1), 170.

Gross, J. J., & Levenson, R. W. (1993). Emotional suppression: physiology, self-report, and expressive behavior. *Journal of Personality and social Psychology*, *64*(6), 970.

Gross, J. J., & Thompson, R. A. (2006). Emotion regulation: Conceptual foundations.

Gross, J. J., & Levenson, R. W. (1993). Emotional suppression: physiology, self-report, and expressive behavior. *Journal of Personality and social Psychology*, *64*(6), 970.

Haines, K. J., Denehy, L., Skinner, E. H., Warrillow, S., & Berney, S. (2015). Psychosocial outcomes in informal caregivers of the critically ill: a systematic review. *Critical care medicine*, *43*(5), 1112-1120.

Halpern, N. A., & Pastores, S. M. (2010). Critical care medicine in the United States 2000– 2005: an analysis of bed numbers, occupancy rates, payer mix, and costs. *Critical care medicine*, *38*(1), 65-71.

Hamilton, J. P., Etkin, A., Furman, D. J., Lemus, M. G., Johnson, R. F., & Gotlib, I. H. (2012). Functional neuroimaging of major depressive disorder: a meta-analysis and new integration of baseline activation and neural response data. *American Journal of Psychiatry*, *169*(7), 693-703.

Handy, C. M., Sulmasy, D. P., Merkel, C. K., & Ury, W. A. (2008). The surrogate's experience in authorizing a do not resuscitate order. *Palliative & supportive care*, *6*(1), 13-19.

Hayes, A. F. (2013). Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York, NY: The Guilford Press.

Hayes, A. F., & Preacher, K. J. (2013). Statistical mediation analysis with a multicategorical independent variable. *British Journal of Mathematical and Statistical Psychology*, *67*(3), 451-470.

Harlé, K. M., & Sanfey, A. G. (2007). Incidental sadness biases social economic decisions in the Ultimatum Game. *Emotion*, *7*(4), 876.

Harlé, K. M., Chang, L. J., van't Wout, M., & Sanfey, A. G. (2012). The neural mechanisms of affect infusion in social economic decision-making: a mediating role of the anterior insula. *Neuroimage*, *61*(1), 32-40.

Hartley, C. A., & Phelps, E. A. (2012). Anxiety and decision-making. *Biological psychiatry*, *72*(2), 113-118.

HealthyPeople.gov.2017; Healthy People 2020 website. Retrieved from

https://www.healthypeople.gov/2020/About-Healthy-People

Herrmann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale- a review of validation data and clinical results. *Journal of psychosomatic research*, *42*(1), 17-41.

Hickman, R. L. (2008). *Predictors of the psychological well-being of family medical decision makers of the chronically critically ill*. Case Western Reserve University.

Hickman, R. L., Daly, B. J., Douglas, S. L., & Clochesy, J. M. (2010). Informational coping style and depressive symptoms in family decision makers. *American Journal of Critical Care*, *19*(5), 410-420.

Hickman, R. L., & Douglas, S. L. (2010). Impact of chronic critical illness on the psychological outcomes of family members. *AACN advanced critical care*, *21*(1), 80.

Hickman, R. L., Daly, B. J., & Lee, E. (2012). Decisional conflict and regret: consequences of surrogate decision making for the chronically critically ill. *Applied Nursing Research*, *25*(4), 271-275.

Hickman, R. L., & Pinto, M. D. (2014). Advance directives lessen the decisional burden of surrogate decision-making for the chronically critically ill. *Journal of clinical nursing*, *23*(5-6), 756-765.

Higgins, P. A., & Straub, A. J. (2006). Understanding the error of our ways: Mapping the concepts of validity and reliability. *Nursing outlook*, *54*(1), 23-29.

Hindmarch, T., Hotopf, M., & Owen, G. S. (2013). Depression and decision-making capacity for treatment or research: a systematic review. *BMC medical*

ethics, *14*(1), 54.

Hollander, J. M., & Mechanick, J. I. (2006). Nutrition support and the chronic critical illness syndrome. *Nutrition in Clinical Practice*, *21*(6), 587-604.

Horwitz, A. V. (2007). Distinguishing distress from disorder as psychological outcomes of stressful social arrangements. *Health:*, *11*(3), 273-289.

Hughes, F., Bryan, K., & Robbins, I. (2005). Relatives' experiences of critical care. *Nursing in critical care*, *10*(1), 23-30.

Hwang, D. Y., Yagoda, D., Perrey, H. M., Currier, P. F., Tehan, T. M., Guanci, M., ... & Rosand, J. (2014). Anxiety and depression symptoms among families of adult intensive care unit survivors immediately following brief length of stay. *Journal of critical care*, *29*(2), 278-282.

Institute of Medicine. Dying in America: Improving Quality and Honoring Individual references Near the End of Life. Washington, DC: National Academy of Sciences; 2015. Retrieved from *https://www.nap.edu/download/18748*. Accessed January 28, 2019.

Iverson, E., Celious, A., Kennedy, C. R., Shehane, E., Eastman, A., Warren, V., & Freeman, B. D. (2014). Factors affecting stress experienced by surrogate decision makers for critically ill patients: Implications for nursing practice. *Intensive and Critical Care Nursing*, *30*(2), 77-85.

Iverson, E., Celious, A., Kennedy, C. R., Shehane, E., Eastman, A., Warren, V., & Freeman, B. D. (2013). Perspectives of surrogate decision makers for critically ill patients regarding gene variation research. *Genetics in Medicine*, *15*(5), 368.

Ivey, A. E., & Robin, S. S. (1966). Role theory, role conflict, and counseling: A conceptual framework. *Journal of Counseling Psychology*, *13*(1), 29.

Iwashyna, T. J., Ely, E. W., Smith, D. M., & Langa, K. M. (2010). Long-term cognitive impairment and functional disability among survivors of severe sepsis. *Jama*, *304*(16), 1787-1794.

Jansen, J. E., Gleeson, J., & Cotton, S. (2015). Towards a better understanding of caregiver distress in early psychosis: a systematic review of the psychological factors involved. *Clinical psychology review*, *35*, 56-66.

Kahn, R. L., Wolfe, D. M., Quinn, R. P., Snoek, J. D., & Rosenthal, R. A. (1964). Organizational stress: Studies in role conflict and ambiguity. Oxford, England: John Wiley.

Kahn, J. M., Le, T., Angus, D. C., Cox, C. E., Hough, C. L., White, D. B., ... & ProVent Study Group Investigators. (2015). The epidemiology of chronic critical illness in the United States. *Critical care medicine*, *43*(2), 282-287.

Kalb, T. H., & Lorin, S. (2002). Infection in the chronically critically ill: unique risk profile in a newly defined population. *Critical care clinics*, *18*(3), 529-552.

Kappes, C., & Carson, S. S. (2012). Definitions and epidemiology of the chronically critically ill. *Respiratory Care*, *57*(6), 848-858.

Katz, B. A., Lustig, N., Assis, Y., & Yovel, I. (2017). Measuring regulation in the here and now: The development and validation of the State Emotion Regulation Inventory (SERI). *Psychological assessment*, *29*(10), 1235.

Khetarpal, A., & Kochar, G. K. (2006). Role Stress And Preventive Management. *Internet Journal of World Health & Societal Politics*, *3*(1), 2-2.

Koenigsberg, Harold W., Jin Fan, Kevin N. Ochsner, Xun Liu, Kevin Guise, Scott Pizzarello, Christine Dorantes et al. "Neural correlates of using distancing to regulate emotional responses to social situations." *Neuropsychologia* 48, no. 6 (2010): 1813-1822.

Laatsch, L., & Shahani, B. T. (1996). The relationship between age, gender and psychological distress in rehabilitation inpatients. *Disability and rehabilitation*, *18*(12), 604-608.

Lafrance Robinson, A., Kosmerly, S., Mansfield-Green, S., & Lafrance, G. (2014). Disordered eating behaviours in an undergraduate sample: Associations among gender, body mass index, and difficulties in emotion regulation. *Canadian Journal of Behavioural Science/Revue canadienne des sciences du comportement*, *46*(3), 320.

Lambert, V. A., & Lambert, C. E. (2001). Literature review of role stress/strain on nurses: an international perspective. *Nursing & health sciences*, *3*(3), 161-172.

Lavender, J. M., Tull, M. T., DiLillo, D., Messman-Moore, T., & Gratz, K. L. (2017). Development and validation of a state-based measure of emotion dysregulation: The State Difficulties in Emotion Regulation Scale (S-DERS). *Assessment*, *24*(2), 197-209.

Lazarus, R. S., & Alfert, E. (1964). Short-circuiting of threat by experimentally altering cognitive appraisal. *The Journal of Abnormal and Social Psychology*, *69*(2), 195.

Lazarus, R. S., Cohen, J. B., Folkman, S., Kanner, A., & Schaefer, C. (1980). Psychological stress and adaptation: Some unresolved issues. *Selye's guide to stress research*, *1*, 90-117.

Lazarus, R. S., & Folkman, S. (1984). Coping and adaptation. *The handbook of behavioral medicine*, 282-325.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York. Springer.

Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American psychologist*, *38*(3), 245.

Lee, J. K., & Orsillo, S. M. (2014). Investigating cognitive flexibility as a potential mechanism of mindfulness in generalized anxiety disorder. *Journal of Behavior Therapy and Experimental Psychiatry*, *45*(1), 208-216.

Leith, K. P., & Baumeister, R. F. (1996). Why do bad moods increase self-defeating behavior? Emotion, risk tasking, and self-regulation. *Journal of personality and social psychology*, *71*(6), 1250.

Lemiale, V., Kentish-Barnes, N., Chaize, M., Aboab, J., Adrie, C., Annane, D., ... & Jourdain, M. (2010). Health-related quality of life in family members of intensive care unit patients. *Journal of palliative medicine*, *13*(9), 1131-1137..

Lerner, J. S., Li, Y., Valdesolo, P., & Kassam, K. S. (2015). Emotion and decision making. *Annual Review of Psychology*, *66*.

Lincoln, K. D., Chatters, L. M., & Taylor, R. J. (2003). Psychological distress among Black and White Americans: Differential effects of social support, negative interaction and personal control. *Journal of Health and Social Behavior*, *44*(3), 390.

Lissek, S., Rabin, S., Heller, R. E., Lukenbaugh, D., Geraci, M., Pine, D. S., & Grillon,

C. (2009). Overgeneralization of conditioned fear as a pathogenic marker of panic disorder. *American Journal of Psychiatry*, *167*(1), 47-55.

Littman, A. J., White, E., Satia, J. A., Bowen, D. J., & Kristal, A. R. (2006). Reliability and validity of 2 single-item measures of psychosocial stress. *Epidemiology*, 398-403.

Llanque, S., Savage, L., Rosenburg, N., & Caserta, M. (2016, January). Concept analysis: Alzheimer's caregiver stress. In *Nursing forum* (Vol. 51, No. 1, pp. 21-31).

Long, B., Clark, L., & Cook, P. (2011). Surrogate decision making for patients with severe traumatic brain injury. *Journal of Trauma Nursing*, *18*(4), 204-212.

Maguire, K. C. (2012). *Stress and coping in families*. Great Britain, Polity press.

Majesko, A., Hong, S. Y., Weissfeld, L., & White, D. B. (2012). Identifying family members who may struggle in the role of surrogate decision maker. *Critical care medicine*, *40*(8), 2281.

Maritain, J. (1966). *God and the Permission of Evil*. Milwaukee, Bruce Publishing Company.

Matsumoto, D., Yoo, S. H., & Nakagawa, S. (2008). Culture, emotion regulation, and adjustment. *Journal of personality and social psychology*, *94*(6), 925.

Matud, M. P. (2004). Gender differences in stress and coping styles. *Personality and individual differences*, *37*(7), 1401-1415.

Maxwell, R., Lynn, S. J., & Strauss, G. P. (2018). Trait Emotion Regulation Predicts Individual Differences in Momentary Emotion and Experience. *Imagination, Cognition and Personality*, 0276236618781775.

Meghani, S. H., & Hinds, P. S. (2015). Policy brief: The Institute of Medicine report

Dying in America: Improving quality and honoring individual preferences near the end of life. *Nursing outlook*, *63*(1), 51-59.

McCurry, M. K., Revell, S. M. H., & Roy Sr, C. (2010). Knowledge for the good of the individual and society: linking philosophy, disciplinary goals, theory, and practice. *Nursing Philosophy*, *11*(1), 42-52.

McRae, K., Ochsner, K. N., Mauss, I. B., Gabrieli, J. J., & Gross, J. J. (2008). Gender differences in emotion regulation: An fMRI study of cognitive reappraisal. *Group processes & intergroup relations*, *11*(2), 143-162.

Merriam-Webster's online dictionary. Retrieved from https://www.merriam-webster.com/dictionary/distress?src=search-dict-hed

Messerli-Bürgy, N., Barth, J., von Känel, R., Schmid, J. P., Saner, H., & Znoj, H. (2012). Maladaptive emotion regulation is related to distressed personalities in cardiac patients. *Stress and health*, *28*(4), 347-352.

Michl, L. C., McLaughlin, K. A., Shepherd, K., & Nolen-Hoeksema, S. (2013). Rumination as a mechanism linking stressful life events to symptoms of depression and anxiety: Longitudinal evidence in early adolescents and adults. *Journal of abnormal psychology*, *122*(2), 339.

Miller, J. J., Morris, P., Files, D. C., Gower, E., & Young, M. (2016). Decision conflict and regret among surrogate decision makers in the medical intensive care unit. *Journal of critical care*, *32*, 79-84.

Mira, J. C., Gentile, L. F., Mathias, B. J., Efron, P. A., Brakenridge, S. C., Mohr, A. M., ... & Moldawer, L. L. (2017). Sepsis pathophysiology, chronic critical illness,

and persistent inflammation-immunosuppression and catabolism syndrome. *Critical care medicine*, *45*(2), 253-262.

Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., ... & Bliss, J. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *The British Journal of Psychiatry*, *158*(2), 255-259.

Morley, J. E., Cao, L., & Shum, C. K. (2016). Improving the quality of end-of-life care. *Journal of the American Medical Directors Association*, *17*(2), 93-95.

Mroczek, D. K. (2004). Positive and negative affect at midlife. *How healthy are we*, 205-226.

Murphy, G. (2004). *The big book of concepts*. MIT press.

Murphy, K. R., Cleveland, J. N., Skattebo, A. L., & Kinney, T. B. (2004). Raters who pursue different goals give different ratings. *Journal of Applied Psychology*, *89*(1), 158.

Musil, C. M., Warner, C. B., Yobas, P. K., & Jones, S. L. (2002). A comparison of imputation techniques for handling missing data. *Western Journal of Nursing Research*, *24*(7), 815-829.

Nelson, J. E., Meier, D. E., Litke, A., Natale, D. A., Siegel, R. E., & Morrison, R. S. (2004). The symptom burden of chronic critical illness. *Critical care medicine*, *32*(7), 1527-1534.

Nelson, J. E., Cox, C. E., Hope, A. A., & Carson, S. S. (2010). Chronic critical illness. *American Journal of Respiratory and critical care medicine*, *182*(4), 446-454.

Nelson, J. E., Tandon, N., Mercado, A. F., Camhi, S. L., Ely, E. W., & Morrison, R. S. (2006). Brain dysfunction: another burden for the chronically critically ill. *Archives of internal medicine, 166*(18), 1993-1999.

Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: informational needs of patients and families. *Journal of critical care, 20*(1), 79-89.

Nelson, J. E., Mercado, A. F., Camhi, S. L., Tandon, N., Wallenstein, S., August, G. I., & Morrison, R. S. (2007). Communication about chronic critical illness. *Archives of internal medicine, 167*(22), 2509-2515.

Nelson, B. D., Fitzgerald, D. A., Klumpp, H., Shankman, S. A., & Phan, K. L. (2015). Prefrontal engagement by cognitive reappraisal of negative faces. *Behavioural brain research*, *279*, 218-225.

Nierman, D. M. (2002). A structure of care for the chronically critically ill. *Critical care clinics, 18*(3), 477-491.

Nunez, E. R., Schenker, Y., Joel, I. D., Reynolds III, C. F., Dew, M. A., Arnold, R. M., & Barnato, A. E. (2015). Acutely-bereaved Surrogates' Stories about the Decision to Limit Life Support in the ICU. *Critical care medicine*, *43*(11), 2387.

Nolen-Hoeksema, S. (1991). Responses to depression and their effects on the duration of depressive episodes. *Journal of abnormal psychology*, *100*(4), 569.

Nolen-Hoeksema, S. (2012). Emotion regulation and psychopathology: The role of gender. *Annual review of clinical psychology*, *8*, 161-187.

Nolen-Hoeksema, S., & Girgus, J. S. (1994). The emergence of gender differences in depression during adolescence. *Psychological bulletin*, *115*(3), 424.

Oatley, K., & Johnson-Laird, P. N. (1987). Towards a cognitive theory of emotions. *Cognition and emotion*, *1*(1), 29-50.

Oatley, K., & Johnson-Laird, P. N. (2014). Cognitive approaches to emotions. *Trends in cognitive sciences*, *18*(3), 134-140.

Ochsner, K. N., & Gross, J. J. (2008). Cognitive emotion regulation: Insights from social cognitive and affective neuroscience. *Current directions in psychological science*, *17*(2), 153-158.

Ochsner, K. N., Bunge, S. A., Gross, J. J., & Gabrieli, J. D. (2002). Rethinking feelings: an FMRI study of the cognitive regulation of emotion. *Journal of cognitive neuroscience*, *14*(8), 1215-1229.

Ochsner, K. N., Ray, R. D., Cooper, J. C., Robertson, E. R., Chopra, S., Gabrieli, J. D., & Gross, J. J. (2004). For better or for worse: neural systems supporting the cognitive down-and up-regulation of negative emotion. *Neuroimage*, *23*(2), 483-499.

Organisation for Economic Co-operation and Development. (2011). *Health at a glance 2011: OECD indicators*. OECD Publishing.

Osborne, J. W., & Waters, E. (2002). Multiple Regression Assumptions. ERIC Digest.

Pandharipande, P. P., Girard, T. D., Jackson, J. C., Morandi, A., Thompson, J. L., Pun, B. T., ... & Moons, K. G. (2013). Long-term cognitive impairment after critical illness. *New England Journal of Medicine*, *369*(14), 1306-1316.

Pareek, U. (1982). A Survey of Research in Psychology, 1971-76, Part-2.

Parker, A. M., & Bienvenu, O. J. (2015). Posttraumatic stress disorder symptoms among family decision makers and the potential relevance of study attrition. *Critical*

care medicine, *43*(6), 1334.

Petrinec, A. B., Mazanec, P. M., Burant, C. J., Hoffer, A., & Daly, B. J. (2015). Coping strategies and posttraumatic stress symptoms in post-ICU family decision makers. *Critical care medicine*, *43*(6), 1205.

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), P126-P137.

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as Caregivers of older adults: a meta-analytic comparison. *Psychology and aging*, *26*(1), 1.

Pisani, M. A., Kong, S. Y. J., Kasl, S. V., Murphy, T. E., Araujo, K. L., & Van Ness, P. H. (2009). Days of delirium are associated with 1-year mortality in an older intensive care unit population. *American journal of respiratory and critical care medicine*, *180*(11), 1092-1097.

Pochard F, Azoulay E, Chevret S, Lemaire F, Hubert P, Canoui P, et al., (2001). Symptoms of anxiety and depression in family members of intensive care unit patients: Ethical hypothesis regarding decision making capacity. Critical Care Medicine. 2001;29(10):1893-1897.

Pochard, F., Darmon, M., Fassier, T., Bollaert, P. E., Cheval, C., Coloigner, M., ... & Zahar, J. R. (2005). Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death. A prospective multicenter study. *Journal of critical care*, *20*(1), 90-96.

Polit, D. F., Beck, C. T., & Hungler, B. P. (2006). Essentials of nursing research. Methods, appraisal, and utilization, 6.

Polit, D.F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice.* Wolters Kluwer Health/Lippincott Williams & Wilkins.

Postmes, T., Haslam, S. A., & Jans, L. (2013). A single-item measure of social identification: Reliability, validity, and utility. *British journal of social psychology*, *52*(4), 597-617.

Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior research methods, instruments, & computers*, *36*(4), 717-731.

Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). Valuing the invaluable: 2015 update. *Insight on the Issues*, *104*, 89-98.

Rivas-Drake, D., Syed, M., Umaña-Taylor, A., Markstrom, C., French, S., Schwartz, S. J., ... & Ethnic and Racial Identity in the 21st Century Study Group. (2014). Feeling good, happy, and proud: A meta-analysis of positive ethnic–racial affect and adjustment. *Child development*, *85*(1), 77-102.

Rizzo, J. R., House, R. J., & Lirtzman, S. I. (1970). Role conflict and ambiguity in complex organizations. *Administrative science quarterly*, 150-163.

Rolland, J. S., Emanuel, L. L., & Torke, A. M. (2017). Applying a family systems lens to proxy decision making in clinical practice and research. *Families, Systems, & Health*, *35*(1), 7.

Rose, M. A., Arenson, C., Harrod, P., Salkey, R., Santana, A., & Diamond, J. (2008).

Evaluation of the Chronic Disease Self-Management Program with low-income, urban, African American older adults. *Journal of community health nursing*, *25*(4), 193-202.

Rose, L., Istanboulian, L., Allum, L., Burry, L., Dale, C., Hart, N., ... & Connolly, B. (2017). Patient-and family-centered performance measures focused on actionable processes of care for persistent and chronic critical illness: protocol for a systematic review. *Systematic reviews*, *6*(1), 84.

Ross, C. E., & Mirowsky, J. (2002). Age and the gender gap in the sense of personal control. *Social psychology quarterly*, *65*(2), 125.

Ross, C. E. (2017). *Social causes of psychological distress*. Routledge.

Rowe, G., Hirsh, J. B., & Anderson, A. K. (2007). Positive affect increases the breadth of attentional selection. *Proceedings of the National Academy of Sciences*, *104*(1), 383-388.

Roy, S. C. (1984). *Introduction to Nursing: An Adaptation Model* (Vol. 84, No. 10, p. 1331). LWW.

Roy, S. C. & Andrews, H. A. (1991). *The Roy Adaptation Model*. Appleton, Norwalk.

Roy, S. C. (2009). *The Roy Adaptation Model* (3rd ed.). Upper Saddle River, New Jersey, Pearson.

Ryle, G. (2009). *The Concept of Mind* (60th Anniversary ed). Madison Ave, New York, Routledge.

Rubin, M. A., Dhar, R., & Diringer, M. N. (2014). Racial differences in withdrawal of mechanical ventilation do not alter mortality in neurologically injured patients. *Journal of critical care*, *29*(1), 49-53.

Russell, J. A. (2003). Core affect and the psychological construction of emotion. *Psychological review*, *110*(1), 145.

Saarni, C. (1999). *The development of emotional competence*. Guilford Press.

Salters-Pedneault, K., Roemer, L., Tull, M. T., Rucker, L., & Mennin, D. S. (2006). Evidence of broad deficits in emotion regulation associated with chronic worry and generalized anxiety disorder. *Cognitive Therapy and Research*, *30*(4), 469-480.

Sanfey, A. G., Rilling, J. K., Aronson, J. A., Nystrom, L. E., & Cohen, J. D. (2003). The neural basis of economic decision-making in the ultimatum game. *Science*, *300*(5626), 1755-1758.

Sanfey, A. G., & Chang, L. J. (2008). Multiple systems in decision making. *Annals of the New York Academy of Sciences*, *1128*(1), 53-62.

Schmidt, M., & Azoulay, E. (2012). Having a loved one in the ICU: the forgotten family. *Current opinion in critical care*, *18*(5), 540-547.

Schmitz, T. W., De Rosa, E., & Anderson, A. K. (2009). Opposing influences of affective state valence on visual cortical encoding. *Journal of Neuroscience*, *29*(22), 7199-7207.

Schwabe, L., & Wolf, O. T. (2010). Learning under stress impairs memory formation. *Neurobiology of learning and memory*, *93*(2), 183-188.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, *44*(sup3), 105-113.

Selye, H. (1936). A syndrome produced by diverse nocuous agents. *Nature*, *138*(3479), 32.

Sen, K. (2012). Occupational role stress-An Exploratory Study in the Indian Public Sector Banks. *Journal of Services Research*, *12*(2), 173.

Shaffer, K. M., Riklin, E., Jacobs, J. M., Rosand, J., & Vranceanu, A. M. (2016). Psychosocial resiliency is associated with lower emotional distress among dyads of patients and their informal caregivers in the neuroscience intensive care unit. *Journal of critical care*, *36*, 154-159.

Sharma, J., & Devi, A. (2011). Role stress among employees: An empirical study of commercial banks. *gurukul business review*, *7*(1), 53-61.

Sharma, R. K., Hughes, M. T., Nolan, M. T., Tudor, C., Kub, J., Terry, P. B., & Sulmasy, D. P. (2011). Family understanding of seriously-ill patient preferences for family involvement in healthcare decision making. *Journal of general internal medicine*, *26*(8), 881-886.

Sheppes, G., Suri, G., & Gross, J. J. (2015). Emotion regulation and psychopathology. *Annual Review of Clinical Psychology*, *11*, 379-405.

Siegall, M. (2000). Putting the stress back into role stress: Improving the measurement of role conflict and role ambiguity. *Journal of Managerial Psychology*, *15*(5), 427-435.

Silveira, M. J., Kim, S. Y., & Langa, K. M. (2010). Advance directives and outcomes of surrogate decision making before death. *New England Journal of Medicine*, *362*(13), 1211-1218.

Snaith, R. P. (2003). The hospital anxiety and depression scale. *Health and quality of life outcomes*, *1*(1), 29.

Song, M. K., Ward, S. E., Fine, J. P., Hanson, L. C., Lin, F. C., Hladik, G. A., ... &

Bridgman, J. C. (2015). Advance care planning and end-of-life decision making in dialysis: a randomized controlled trial targeting patients and their surrogates. *American Journal of Kidney Diseases*, *66*(5), 813-822.

Srivastav, A. K. (2010). Heterogeneity of role stress. *Research and Practice in Human Resource Management*, *18*(1), 16-27.

Starcke, K., & Brand, M. (2012). Decision making under stress: a selective review. *Neuroscience & Biobehavioral Reviews*, *36*(4), 1228-1248.

Sullivan, G. M., & Feinn, R. (2012). Using effect size—or why the P value is not enough. *Journal of graduate medical education*, *4*(3), 279-282.

Suveg, C., & Zeman, J. (2004). Emotion regulation in children with anxiety disorders. *Journal of Clinical Child and Adolescent Psychology*, *33*(4), 750-759.

Tamres, L. K., Janicki, D., & Helgeson, V. S. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and social psychology review*, *6*(1), 2-30.

Tarrant, T., & Sabo, C. E. (2010). Role conflict, role ambiguity, and job satisfaction in nurse executives. *Nursing Administration Quarterly*, *34*(1), 72-82.

Teschendorf, B., Schwartz, C., Ferrans, C. E., O'mara, A., Novotny, P., & Sloan, J. (2007). Caregiver role stress: when families become providers. *Cancer Control*, *14*(2), 183-189.

The Belmont Report, (1979). Ethical principles and guidelines for the protection of human subjects of research, retrieved from: https://www.fda.gov/ohrms/dockets/ac/05/briefing/2005-4178b_09_02_Belmont%20Report.pdf

The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute are proud to present *Caregiving in the U.S. 2015.*

Thompson, R. A. (1994). Emotion regulation: A theme in search of definition. *Monographs of the society for research in child development*, *59*(2-3), 25-52.

Tice, D. M., Bratslavsky, E., & Baumeister, R. F. (2001). Emotional distress regulation takes precedence over impulse control: If you feel bad, do it!. *Journal of personality and social psychology*, *80*(1), 53.

Tilden, V. P., Tolle, S. W., Nelson, C. A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing research*, *50*(2), 105-115.

Tooby, J., & Cosmides, L. (1990). The past explains the present: Emotional adaptations and the structure of ancestral environments. *Ethology and sociobiology*, *11*(4-5), 375-424.

Toplak, M. E., Sorge, G. B., Benoit, A., West, R. F., & Stanovich, K. E. (2010). Decision- making and cognitive abilities: A review of associations between Iowa Gambling Task performance, executive functions, and intelligence. *Clinical psychology review*, *30*(5), 562-581.

Torke, A. M., Petronio, S., Sachs, G. A., Helft, P. R., & Purnell, C. (2012). A conceptual model of the role of communication in surrogate decision making for hospitalized adults. *Patient education and counseling*, *87*(1), 54-61.

Tourtier, J. P., Moullec, D. L., & Auroy, Y. (2010). How surrogate decision makers can provide an accurate point of view to discuss limitation of treatment. *American journal of respiratory and critical care medicine*, *182*(11), 1455-1456.

Truog, R. D. (2008). End-of-life decision-making in the United States. *European Journal of Anaesthesiology*, *25*(S42), 43-50.

Turan, B., Goldstein, M. K., Garber, A. M., & Carstensen, L. L. (2011). Knowing loved ones' end-of-life health care wishes: Attachment security predicts caregivers' accuracy. *Health Psychology*, *30*(6), 814.

US Department of Health and Human Services. (1979). The Belmont Report. Retrieved from: https://scholar.google.com/scholar?hl=en&as_sdt=0%2C36&q=Belmont+Report%2C+%281979%29&btnG=#d=gs_cit&u=%2Fscholar%3Fq%3Dinfo%3Ad5bQAiLJvbgJ%3Ascholar.google.com%2F%26output%3Dcite%26scirp%3D0%26hl%3Den

Van den Berghe, G., De Zegher, F., Veldhuis, J. D., Wouters, P., Awouters, M., Verbruggen, W., ... & Bowers, C. Y. (1997). The somatotropic axis in critical illness: effect of continuous growth hormone (GH)-releasing hormone and GH-releasing peptide-2 infusion. *The Journal of Clinical Endocrinology & Metabolism*, *82*(2), 590-599.

Van den Berghe, G., De Zegher, F., Veldhuis, J. D., Wouters, P., Gouwy, S., Stockman, W., ... & Bowers, C. Y. (1997). Thyrotrophin and prolactin release in prolonged critical illness: dynamics of spontaneous secretion and effects of growth hormone-secretagogues. *Clinical endocrinology*, *47*(5), 599-612.

Van Der Schaaf, M., Bakhshi-Raiez, F., Van Der Steen, M., Dongelmans, D. A., & De Keizer, N. F. (2015). Recommendations for intensive care follow-up clinics; report from a survey and conference of Dutch intensive cares. *Minerva anestesiol*, *81*(2), 135-144.

van't Wout, M., Chang, L. J., & Sanfey, A. G. (2010). The influence of emotion regulation on social interactive decision-making. *Emotion, 10*(6), 815.

Van Pelt, D. C., Milbrandt, E. B., Qin, L., Weissfeld, L. A., Rotondi, A. J., Schulz, R., ... & Pinsky, M. R. (2007). Informal caregiver burden among survivors of prolonged mechanical ventilation. *American journal of respiratory and critical care medicine*, *175*(2), 167-173.

Vig, E. K., Starks, H., Taylor, J. S., Hopley, E. K., & Fryer-Edwards, K. (2007). Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *Journal of general internal medicine*, *22*(9), 1274-1279.

Vohs, K. D., Baumeister, R. F., Twenge, J. M., Schmeichel, B. J., Tice, D. M., & Crocker, J. (2005). Decision fatigue exhausts self-regulatory resources—But so does accommodating to unchosen alternatives. Manuscript submitted for publication.

Vohs, K. D., Mead, N. L., & Goode, M. R. (2008). Merely activating the concept of money changes personal and interpersonal behavior. *Current Directions in Psychological Science*, *17*(3), 208-212.

Vohs, K. D., Baumeister, R. F., Schmeichel, B. J., Twenge, J. M., Nelson, N. M., & Tice, D. M. (2014). Making choices impairs subsequent self-control: a limited-resource account of decision making, self-regulation, and active initiative.

Vreeburg, S. A., Zitman, F. G., van Pelt, J., DeRijk, R. H., Verhagen, J. C., van Dyck, R., ... & Penninx, B. W. (2010). Salivary cortisol levels in persons with and without different anxiety disorders. *Psychosomatic medicine*, *72*(4), 340-347.

Wendler, D., & Rid, A. (2011). Systematic review: the effect on surrogates of making Treatment decisions for others. *Annals of Internal Medicine, 154*(5), 336-346.

Wenzlaff, R. M., & Wegner, D. M. (2000). Thought suppression. *Annual review of psychology*, *51*(1), 59-91.

Werner, K., & Gross, J. J. (2010). Emotion regulation and psychopathology: A conceptual framework. Retrieved from http://sf-act.com/docs/werner_models_emotreg_09.pdf

Wheaton, B. (2007). The twain meet: distress, disorder and the continuing conundrum of categories (comment on Horwitz). *Health:, 11*(3), 303-319.

White, D. B. (2011). Rethinking interventions to improve surrogate decision making in intensive care units. *American Journal of Critical Care*, *20*(3), 252-257.

Wiencek, C., & Winkelman, C. (2010). Chronic Critical Illness Prevalence, Profile, and Pathophysiology. *AACN Advanced Critical Care*, *21*(1), 44-61.

Wierenga, K. L., Lehto, R. H., & Given, B. (2017). Emotion Regulation in Chronic Disease Populations: An Integrative Review. *Research and theory for nursing practice, 31*(3), 247-271.

Williams, D. R., Gonzalez, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., & Jackson, J. S. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean blacks, and non-Hispanic whites: results from the National Survey of American Life. *Archives of general psychiatry*, *64*(3), 305-315.

Yeung, D. Y., Wong, C. K., & Lok, D. P. (2011). Emotion regulation mediates age differences in emotions. *Aging & Mental Health*, *15*(3), 414-418.

Zanten, S., Dongelmans, D. A., Dettling-Ihnenfeldt, D., Vink, R., & van der Schaaf, M. (2016). Caregiver strain and posttraumatic stress symptoms of informal caregivers of intensive care unit survivors. *Rehabilitation psychology*, *61*(2), 173.

Zier, L. S., Sottile, P. D., Hong, S. Y., Weissfield, L. A., & White, D. B. (2012). Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. *Annals of internal medicine*, *156*(5), 360-366.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta psychiatrica scandinavica*, *67*(6), 361-370.

Zilberberg, M. D., Luippold, R. S., Sulsky, S., & Shorr, A. F. (2008). Prolonged acute mechanical ventilation, hospital resource utilization, and mortality in the United States. *Critical care medicine*, *36*(3), 724-730.

Zilberberg, M. D., de Wit, M., Pirone, J. R., & Shorr, A. F. (2008). Growth in adult prolonged acute mechanical ventilation: implications for healthcare delivery. *Critical care medicine*, *36*(5), 1451-1455.

Zilberberg, M. D., de Wit, M., & Shorr, A. F. (2012). Accuracy of previous estimates for adult prolonged acute mechanical ventilation volume in 2020: update using 2000–2008 data. *Critical care medicine*, *40*(1), 18-20.

Zohar, D. (1997). Predicting burnout with a hassle-based measure of role emands. *Journal of organizational Behavior*, 101-115.