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FAMILY NEEDS FOR WITNESSING VENTILATOR WITHDRAWAL IN INTENSIVE CARE UNITS

by

AZZAH MOUBARAKI

DISSERTATION

Submitted to the Graduate School of

Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2021

MAJOR: NURSING

Approved By:

Advisor Date

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DEDICATION

Out of gratitude for the help and guidance I have received, I dedicate this dissertation

to Allah;

to my mother for her endless love, sacrifice, advice, and prayers;

to the memory of my father, whom I will always love and remember and whose loss in the ICU without us present to say goodbye prompted me to choose this topic;

to my sisters and brothers for their support and encouragement at all times; and

to all my friends for their kindness and support.

I offer special thanks to my brother Abdulhamid , without whom none of my success would be possible.

ACKNOWLEDGMENTS

I extend my deepest thanks to my advisor and mentor, Dr. Margaret L. Campbell, for sharing her knowledge and experience as well as for her encouragement, support, guidance, and faith in me at every stage of my research. I also thank my committee members, Dr. Debra Schutte, Dr. Hossein Yarandi, and Dr. Faith Hopp, for their support, feedback, and helpful suggestions throughout this journey. I am deeply grateful to everyone who helped me pursue my PhD degree, especially Jazan University in Saudi Arabia for supporting me and sponsoring my education.

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CHAPTER 1: BACKGROUND AND SIGNIFICANCE

Background of the Study

Every year, more than 5 million patients are admitted to intensive care units (ICU) in the USA, where mechanical ventilation is required by around 20%- 40% of adult patients (Society of Critical Care Medicine, n.d). Depending on different factors such as age, severity of illness and comorbidities, 10%-29% of adult patients die in critical care settings (Society of Critical Care Medicine, n.d). Withdrawal of life support refers to the process of terminating medical intervention or therapy, including use of a mechanical ventilator, so as to allow a natural death (Vincent, 2005). End-of-life care (EOLC) refers to care that is directed toward patients and their families during and after the decision to terminate treatment; such care includes management of symptoms as well as provision of emotional and spiritual support (Noome, et al., 2016). As expected there is a high rate of patients' mortality after withdrawal of life-sustaining therapies (LST) in critical cases. Nearly all (90%) of the patients died in ICU or 24 hours after ICU discharge following the removal of LST (Gerstel et al., 2008). Owing to the high incidence of death in critical care settings after the decision to withdraw life support, family members and patient caregivers may experience severe physical, emotional, and psychological distress in ways that resemble the classical symptoms and stages of grief (Courtright et al., 2017).

Depression, and Anxiety in Relatives of Critically Ill Patients

Anxiety and depression are psychological conditions that are significant in the family members of critically ill patients in the ICU setting. Pochard and colleagues (2005) investigated the symptoms of anxiety and depression in family members of ICU patients before discharge or death and found that 76% experienced depression or anxiety symptoms. The prevalence of the symptoms of depression or anxiety was high among family members of nonsurvivable patients

(84%) (Pochard et al., 2005). Several factors were associated with depression and anxiety in relatives of ICU patients, including patient condition, family relationship with the patient, female sex, patient age, family members' level of education, family members' perception of the quality of their communication with health care providers, cultural background, and emotional background (Andresen & Andresen-Vasquez, 2016; Pochard et al., 2005).

Patient death in the ICU is traumatic for family members and caregivers and thus requires a caring and supportive environment in which their needs are addressed. It is vital that healthcare providers be prepared to recognize grieving families and be able to prepare them for the dying process, helping them cope so that their quality of life can be maintained after patient death.

Many studies have explained the importance of, need for, and quality of EOLC from the perspectives of health care providers and patients' family members. In addition, studies of families' perceptions of the decision-making process involved in terminating life-sustaining therapy (LST), as well as of families' bereavement after the death of their family member, are increasing in number (Wiegand, 2016). Such studies are intended to identify interventions to decrease the burden and stress of patient death on family members and to eventually improve the quality of the provided EOLC. However, most studies of the needs, experiences, and perceptions of families during, the withdrawal of a life-sustaining therapy and the following the dying process have been conducted retrospectively, with information about the experience and its impact measured weeks to months after patient death. Information obtained retrospectively is susceptible to recall bias, altering research findings and compromising their generalizability (El-Masri, 2013). In addition, most of these studies do not discuss how sociodemographic variables and family members' previous experiences witnessing death may influence their needs. Accordingly, a prospective study designed to determine family members' needs before they witness ventilator withdrawal is important because it can help health care providers identify and understand family members' needs when witnessing ventilator withdrawal, as well as the role of different sociodemographic variables in determining family members' needs, without tainting the findings with recall bias.

Gaps of Knowledge

Despite the existence of studies emphasizing the importance of preparing family members for LST and ventilator withdrawal and some of the factors significant to them at this critical time, little is known about which needs should be met to equip family members to witness and cope with ventilator withdrawal and the subsequent dying process or to strategically prepare them for ventilator withdrawal. Furthermore, no tools were used to measure the overall role of family members in ventilator withdrawal or the needs of family members who made the decision to witness ventilator withdrawal.

Purpose Statement

During and after ventilator withdrawal, the family members of a dying patient have needs different from those of any other families in the ICU setting. The family needs become related to the process of the ventilator withdrawal and factors that decrease the burden of witnessing the dying process, including information, communication, reassurance, closeness, comfort, and support, as defined in the critical care family needs inventory (Molter, 1979). However, family members' needs at end of life are different from their needs when visiting the hospitalized patient in the ICU, so that care providers must consider needs from the perspective of the family members of a dying patient if they are to tend to those needs effectively while promoting high-quality care for families during this critical time. The aim of this study is to prospectively determine the needs of family members who will witness their family member undergoing the process of ventilator withdrawal in the ICU setting.

Research Questions

1. What needs are identified by family members who will be witnessing mechanical ventilator withdrawal?
2. Which needs are most important for these family members?
3. What are the effects of sociodemographic status (age, gender, race, religion, and level of education) on family members' needs?
4. What is the effect of having had prior experience of witnessing death or witnessing ventilator withdrawal on family members' needs?

Assumptions

1. The patient is on a mechanical ventilator and is expected to die after withdrawal.
2. The family members understand that the patient is responding poorly to curative treatment measures and that every known treatment having the potential to benefit the patient has already been tried.
3. The family members understand that the outcome of their decision to withdraw the ventilator will be the patient's death.
4. The family members have needs that are related to their witnessing withdrawal of ventilation such as needs for medical information regarding patient care and having support at the patient's end of life.

Summary

Improving the quality of family care at EOL, especially for family members who witness their family member's death after removal of a mechanical ventilator, is essential to enhancing family health and ensuring a healthy grieving period. Health care providers, and especially critical care nurses, should prepare the family for the dying process while seeking to maintain the patient's and the family's dignity at this critical time. However, gaps in knowledge remain concerning the needs of family members who will witness and subsequently cope with ventilator withdrawal in the critical care setting and what factors influence those needs. Such needs must be addressed from the time the patient is admitted until the time of his or her discharge or death. According to many researchers, such care typically consists of informational and emotional support provided mainly by nurses based on their knowledge and experience and on the questions that family members ask. This situation leads to differences in the effectiveness of care and thus in family experiences in the critical care setting. Prospectively ascertaining family members' needs and the impact of sociodemographic status on those needs will play an important foundation for developing a structured program in which all family-specific needs are addressed.

CHAPTER 2: LITERATURE REVIEW

A literature review was conducted using CINAHL, PsycINFO, and Medline databases by searching for the terms ((*life support or life sustaining or mechanical ventilation or ventilator) AND (withdrawal or removal or stope or cease) AND (death or dying or end of life) AND (icu or intensive care unit or critical care) AND (relatives or family or families or loved one or next of kin)) NOT (pediatric or child or children or infant or adolescent or nicu or neonatal)*. The search results were limited to English language articles published from 2008 to 2020 that involved adult participants. Inclusion criteria included studies that explored family members of hospitalized adult patients on LST experience, perceptions, needs or the satisfaction in a critical care setting (ICU) at end of life (EOL). Exclusion criteria included articles about decision making to withdraw life sustaining treatments, ethics or process of LST withdrawal, health care providers' perception, education or training, organ donation at end of life, and EOL care for patients with brain injury or other health conditions. The search produced 139 articles from Medline, 34 from PsycINFO, and 97 from CINAHL. After screening of article titles, abstracts or thorough reading of the entire paper and removal of duplicate articles, 10 articles remained that met the inclusion criteria. In addition, 6 articles that found in the reference's lists were included in the review. Therefore, 16 articles that met the foregoing inclusion criteria were reviewed.

This review synthesizes extant data relating to preparation of family members to witness the withdrawal of a mechanical ventilator. The review, which yielded studies that examined family members' perceptions of the dying process after withdrawal of a mechanical ventilator or of life-sustaining therapy in general, explored the factors that are important to family members during the dying process, as well as methods of care that could decrease the burden of this experience and improve the quality of care that families receive during this critical time.

The following four themes emerged from the identified articles relating to a family's needs and experience with and perception of the withdrawal process at EOL: communication and information, emotional and spiritual support, clinical setting and the dying environment, and quality of care.

Communication and Information

Both communication between health care providers and family members and provision of information about patient condition and prognosis are important during EOLC. Most of the retrieved studies emphasized nurses' roles as information providers who can answer family members' questions and keep them up to date and otherwise informed (Kisorio & Langley, 2016; Noome et al., 2016; Williams et al., 2012). Both communication and provision of information are important before withdrawal of LST, and discussion of any such decision with family members is essential. Clear communication and detailed information about the patient's medical condition and the futility of other treatment were main aspects for family members readiness to make decision at EOL as highlighted by Wiegand (2008) describing family experience during life sustain therapy withdrawal. Prior to withdrawing treatment, nurses must assess the family's level of information and understanding and select the type of information, as well as the method of communication, that best suits the family (Coombs, Parker et al., 2017; Stacy, 2012). The information most frequently discussed with families included explanations of the nature of the procedure, the physical changes that would occur during treatment withdrawal, and details of equipment alarm settings (Coombs, Parker et al., 2017; Stacy, 2012).

Providing information to and continuously communicating with family members reduces the ambiguity and uncertainty of the situation, and helping them make decisions and take action (Stacy, 2012; Wiegand, 2008). Family members' satisfaction at this time has been noted to strongly correlate with the clarity of such communication as well as with information and explanations provided about the process of withdrawing life support and the proceeding of procedure of the withdrawal as expected. Kisorio and Langley (2016) explored families' experiences at EOL in the ICU in South Africa and found that most participants were dissatisfied with the communication they had received and felt as if they were in "darkness" most of the time (p.61). Conversely, Wiegand (2016) investigated the experiences of families during the dying process after LST withdrawal and found that, based on nurses' suggestions and other input, family members began making arrangements and taking steps to prepare for the patient's death, such as by calling a member of the clergy after the decision was made for withdrawal.

Another valuable piece of information that can be given to families is a time frame for duration of survival after LST withdrawal; however, nurses often have difficulty providing this information (Coombs, Parker et al., 2017), which leads to increased family distress. Providing a timeframe for death helps the family members and friends to be at the bedside at the moment of death. Family members consider a good death is being with their loved one at the moment of death and not having left their loved one dying alone. Missing this moment increased the family members and friend's emotional distress (Chartrand, 2020). The perception of having a good death may be distorted if there was uncertainty about the survival time following the withdrawal or if the loved one survived longer than expected. Family members and friend's emotional distress increased as they became more concerned about one another's comfort (Chartrand, 2020). Wiegand (2016) reported that some families reported dissatisfaction because they did not receive prior information about the dying process, such as how long after LST withdrawal a patient might take to die or other particulars of the dying process.

In addition to knowing the duration of survival, families should be aware of the physical changes and symptoms that accompany the dying process. Noome et al. (2016) assessed families' experiences of nursing care at EOL after the decision to terminate LST and found that many family members acknowledged and appreciated the information they received from the nurses regarding the changes to be expected during the dying period and having to do with patient care after death. However, despite its importance, information about the physical changes that occur during dying is often the least likely to be given by nurses to family members. A cross-sectional survey conducted in Australia and New Zealand revealed that gastrointestinal, genitourinary, musculoskeletal, and neurological changes, were those least mentioned by critical care nurses to family members (Ranse et al., 2016). However, Information about physical changes in the patient's senses, such as hearing, as well as breathing changes, were most frequently addressed (Ranse et al., 2016). Coombs, Parker et al. (2017) stated that information about physical changes was that most frequently provided to family members in preparation for ventilator withdrawal, noting that color and breathing changes, specifically, were the most frequently communicated information. Steinhauser et al. (2015) as well as Stacy (2012) supported the importance of communicating information about physical changes and ensuring that family members know what to expect during the dying process. Family members, as observers, are aware of the physiological changes in the patient's condition, such as responsiveness, skin colors, and death rattle; they use these cues, together with the information provided by health care providers, to prepare for the death of their family member (Coombs, Tang et al, 2016).

Virdun et al. (2017), in their meta-synthesis study, highlighted the importance of preparing a family to experience healthy grief at the patient's death; however, their study did not describe how to prepare a family. Wiegand (2016) supported the importance of preparing the family and indicated that insufficient preparation of family members for the dying process made the death vigil a painful experience for them. In an experimental study, Kirchhoff et al. (2008) provided an intervention for a family who had made the decision to withdraw a mechanical ventilator. The researchers provided the family members with information about their family member 's care plan, the process of withdrawal, ways that the family members could be involved in care, an estimate of the time of death, and the description of the environment. Although this intervention did not significantly change the family's mood state score, the participants in the intervention group reported high levels of satisfaction with the information they received to prepare them for the dying process. The insignificant differences in the mood scores is probably related to the fact that measurement of the family members' mood at the time of withdrawal was in fact collected 2-4 weeks after the patient death. This lapse of time and the impact of grief on the family members may limit the accuracy of the data due to recall bias. In addition, their mood during withdrawal may have been affected by other factors such as presence/or not of social support, or their mood and emotional status before the withdrawal. Furthermore, some items in the subscale were not accurate to be measured at the time of withdrawal. For example, in the subscale, fatigue, the family were asked how (fatigued, worn out and exhausted) would describe them at the time of the withdrawal. They may have felt exhausted from other factors such as traveling and transportation; this subscale doesn't relate to the effect of the intervention on the preparedness.

Kirchhoff et al. (2008), Ranse et al. (2016), and Wiegand (2016) concluded that nurses should prepare family members for the dying process after LST withdrawal by communicating with them to provide adequate information about what they can expect, thereby improving the quality of care given to a patient's family members. Moreover, in a literature review by Salins et al. (2016), the authors pointed out the need for the provider to communicate the patient's condition with the family at EOL in a clear, empathetic way while being an active listener and giving honest and accurate information so as to increase family satisfaction and avoid distress.

Emotional and Spiritual Support

All the included studies discussed the importance of providing emotional and spiritual support to family members, noting families' appreciation for this support. Nurses must gain an understanding of the lasting effects that emotional support and spiritual care can bring for family members at the time of death (Coombs, Parker et al., 2017; DeSanto-Madeya & Safizadeh, 2017; Wiegand, 2016). Nurses play a significant role in providing support to families by showing compassion and empathy during and after LST and ventilator withdrawal. Indeed, nurses' provision of emotional support and presence with family members has been identified as the most prevalent form of care they provide—and the one that family members appreciate most (Coombs, Parker et al., 2017; Kisorio & Langley, 2016; Ranse et al., 2016; Williams et al., 2012). In addition, family members appreciated when nurses and other health care providers showed respect for the patient—for example, by using the patient's name and talking to the patient regardless of the patient's unconsciousness and maintain the deceased body dignity (Williams et al., 2012). Accordingly, nurses must provide emotional support to family members during the dying process.

Family members also need emotional support from other family members and friends. Families responded positively to open visitation hours and decreases in restrictions on access to a patient's room during and after LST withdrawal—changes that allowed friends and family members to come together to support one another at the time of a family member's death (Kisorio & Langley, 2016; Noome et al., 2016; Salins et al., 2016; Steinhauser et al., 2015; Wiegand, 2016).

Many cultures are marked by specific spiritual beliefs and practices that are particularly relevant at the time of death, and family members of a dying patient may be particularly concerned about the possibility of observing these customs in a critical care setting at the patient's bedside.

Spiritual care helps a family make meaning of their loss. Rajamani and colleague (2015) noted that 40% of the family members did not receive spiritual support. Several studies have noted that at such a critical time, family members are preoccupied with the patient's condition; accordingly, nurses should make family members aware of the possibility of performing important rituals at the time of death and should also apprise them of the various spiritual resources available (DeSanto-Madeya & Safizadeh, 2017; Noome et al., 2016; Salins et al., 2016; Virdun et al., 2017).

Clinical Setting and the Dying Environment

The clinical setting, such as that of the ICU, affects family members' perspectives of EOLC and colors their experience at the time of a patient's death. Studies have revealed that family members respond negatively to the ICU atmosphere, whether to room size, lack of privacy, noise level, or room lighting (DeSanto-Madeya & Safizadeh, 2017; Coombs, Parker et al., 2017; Salins et al., 2016; Virdun et al., 2017). Other studies found that family members appreciate nurses' efforts to maintain their privacy, including by dimming lights, closing curtains, silencing machines, and removing non-essential equipment (Noome et al., 2016; Wiegand, 2016). In addition, family members were dissatisfied with the small sizes of rooms and expressed a need for a more comfortable environment, such as could be created by adding a chair to the room to make it more like home for the patient during the dying process (Wiegand, 2016).

Quality of Care

Family members are affected deeply by the care that their family member receives at EOL in the critical care setting. They construe the quality of EOL care from nurses' actions, which can be perceived positively or negatively by family members. For example, showing respect for the patient, minimizing distractions and noises, decreasing pain and suffering by administering pain medication, giving family members opportunities to assist in providing care, and reassuring family members of the patient’s comfort affected family members’ psychosocial care positively and were considered important for meeting the family’ needs at EOL (Coombs, Tang et al., 2016; Coombs, Parker et al., 2017; Kisorio & Langley, 2016; Noome et al., 2016; Stacy, 2012; Wiegand, 2016). Because of the patient’s inability to communicate, family members’ main concern was making sure that their family member was comfortable and not suffering; family members who perceived that their family member was not suffering felt relief and satisfaction, but families became distressed and helpless when worried about the patient’s suffering (Steinhauser et al., 2015).

It is also important to encourage family members to stay with the patient, sharing stories and saying their goodbyes, even if the patient is not responsive, and to maintain patient dignity and provide thoughtful care for the body after death (Coombs, Parker et al., 2017; Kisorio & Langley, 2016; Noome et al., 2016; Stacy, 2012; Wiegand, 2016; Williams et al., 2012). Virdun et al. (2017) concluded that family members often feel as if they are observers and should instead be involved with the care. Another aspect of care perceived as important by the family is preparing the patient in a way that can create positive memories and making the patient look normal before withdrawing; examples of such care include bathing the patient, covering any wound or burn, encouraging the family to bring patient bedding and night clothes from home, applying the patient’s favorite moisturizer, and allowing family members to take photos or hold hands (Coombs, Parker et al., 2017). Furthermore, Steinhauser et al. (2015) described the provision of supportive services for family members, such as by providing food and a place to park the car, as an important aspect of family care at EOL.

Providing follow-up care and sending condolence letters was describing as enhancing a family’s feeling of connection with the providers and as supporting family members during their time of grief (Noome et al., 2016; Steinhauser et al., 2015; Virdun et al., 2017).

Strengths and Limitations

The consistency of findings among the various synthesized studies increases the robustness of the evidence. The qualitative approach of most of the included studies provided a useful way of describing a topic as sensitive as family members’ experience witnessing withdrawal of life-sustaining therapy and mechanical ventilation. Studies of a sensitive nature, such as those concerning rape, drug use, death, and grief, require particularly careful consideration before choice of an appropriate research design (Dempsey et al., 2016). Qualitative studies enrich our understanding of participants’ experiences and their interpretations of them (Dempsey et al., 2016). By focusing on family members’ experiences with and perspectives on witnessing the withdrawal and subsequent dying process, the included studies provided a starting point for developing future studies that could investigate other aspects of the phenomenon, such as how to prepare family members for ventilator withdrawal.

Although the included studies present key findings that offer information vital for further research, they are not without their limitations. Most studies had a low sample size, which limited their representation of the population studied. What’s more, most family members who participated were non-Hispanic Caucasians. This lack of diversity limits the generalizability of these findings, particularly those related to similarities or differences in perspective on witnessing the withdrawal process for a dying relative among other races, cultures, and ethnicities. Notably, only two studies were conducted in countries other than the United States: Noome et al. (2016), in the Netherlands, and Kisorio and Langley (2016), in South Africa. Although participants’ race and culture were different, family members’ experiences were similar to those reported in U.S. studies—but definitive conclusions about other groups cannot be drawn without a comprehensive investigation.

Additionally, most studies were retrospective, with family members interviewed to assess their satisfaction with or their experience witnessing the withdrawal process weeks after the patient's death. Such a time frame could limit our understanding of family members' experience with and perspective on the death of a family member after withdrawal of life-sustaining therapy and ventilation—as well as of their needs at this critical time. Preparing a family to witness the withdrawal process and the death of a family member is important and having information about family members' experiences and needs before the withdrawal process would help in developing a preparatory intervention. Because only one small pilot cited study (Kirchhoff et al., 2008) assessed the effect of preparatory interventions for withdrawal of life support, more preparatory intervention studies of ventilator withdrawal and the subsequent dying process are needed.

CHAPTER 3: THEORETICAL FRAMEWORK

Self-Regulation Theory Of Coping With Stressful Experiences

Self-regulation theory of coping with stressful experience (SRT) is a middle-range theory proposed by Johnson (1999) that is used to prepare a patient to cope with illness-associated events. This theory is derived from psychological information-processing theories that describe the ways in which individuals control their responses and behaviors using schema that they have learned from their past experiences and their surroundings (Johnson, 1999).

In SRT, the patient forms a mental representation, or a “schema,” of an event based on the information and experience that he or she has about that event and copes with or regulates his or her response through two parallel pathways: cognitive and emotional (see figure 1). The cognitive pathway includes concrete objective features of the event, including physical sensations and symptoms, temporal features, environmental features, and causes of sensations, symptoms, or experience. The second pathway focuses on regulation of emotional responses and achieving emotional goals. This pathway includes subjective features of the event, such as having emotional and spiritual support (Johnson, 1999).

Self-regulation theory proposes that providing concrete information for an individual about what to expect to see, hear, and feel during a stressful experience helps that person develop a coping mechanism for the experience. However, it is important to understand and know the type of information that is crucial for someone to match his or her expectations with what he or she sees before developing an intervention (Johnson 1999).

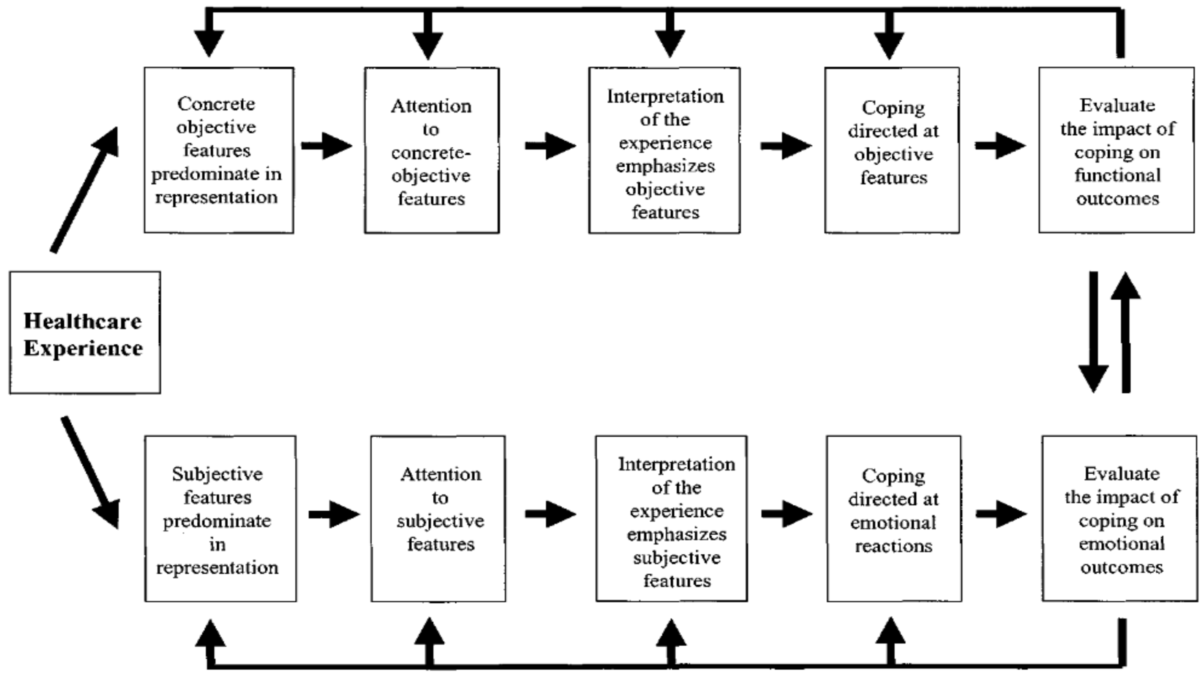
Chartrand (2020), examined the families’ perception of death following ventilator withdrawal by comparing the dying process of family member as shown in television (TV) series with the experience of death in the ICU in reality. There were similar aspects between TV series and the reality which are maintaining privacy, emotional control and encouraging memorializing. However, two of major differences between the TV series and the reality is the timing of death and the physical changes. Unlike in reality, death of the patient following the withdrawal in the TV occurred rapidly and peacefully without portraying of physical changes especially the agonal breathing and physical changes as urinary and bowel incontinence (Chartrand, 2020). This unrealistic portrayal of what patient's look like, smell, sound and how long it takes to die in the TV did not match the family members expectations in reality. This increased the participants' distress and traumatized their experience as they felt that their love one was suffering (Chartrand, 2020).

Self-regulation theory was selected as a framework to guide this proposed study owing to its assertion that determining family members' needs before they encounter a threatening situation—in this case, witnessing ventilator withdrawal and subsequent patient death—is essential for developing an effective intervention that helps family members regulate their actions, thoughts, and feelings as they deal with stressors. However, as a framework for guiding this study, SRT does not explain why certain concrete objective features might be important to some family members but not to others. What factors influence this difference, if any?

Cumulative experience, including social and cultural background, is as important in developing a cognitive scheme as is the information provided by health care providers, a fact that underscores the importance of sociodemographic characteristics for the emotional and psychological health and well-being of family members of a critically ill patient in the intensive care unit (ICU) setting. Accordingly, studying sociodemographic characteristics and the family members' prior experience with death can help in determining which concrete-objective and subjective needs are important for the family.

Figure 1

Model of Self-Regulation Theory of Coping With Stressful Experiences



Note. Reprinted from Self-regulation theory and coping with physical illness by J. Johnson, 1999, *Research in Nursing & Health, 22*(6), 435–448.

Concept of Self- Regulation Theory for Family Needs to Witness Ventilator Withdraw

Concrete Objective Features

Provision of concrete objective information, including thorough descriptions of the physical sensations of an expected experience, the causes of those sensations, and the environmental and temporal characteristics of that experience, before encountering a stressful experience is a central concept in SRT (Johnson, 1999). Then the person approaches the experience looking for these concrete features. If representations of the experience's features are lacking, then persons use feedback mechanisms to add or remove features, interpreting and regulating their response and coping with the concrete features of the experience (Johnson, 1999). In SRT, provision of such information reduces uncertainty throughout the experience, allowing people to have a mental representation of what to expect and giving them the opportunity to plan a response to the experience (Johnson, 1999; Kirchhoff et al., 2003). Finally, patients appraise their coping mechanism in relation to the experience, assessing how it affects their daily function and activities.

The current study focuses on assessing the concrete-objective features of witnessing ventilator withdrawal and patient death that are needed by family members beforehand, including the following:

1. The physical sensations and symptoms expected to be seen, heard, or otherwise recognized by family members after withdrawal, affecting the respiratory, skin, neurologic, and musculoskeletal systems.
2. Temporal characteristics, including those related to the timing and planning or organization of the withdrawal, as well as the duration of the patient’s survival after withdrawal.
3. Environmental features include the locations involved in the stressful experience (Reuille, 2002). In this study, the environmental features include, ventilator withdrawal location and characteristics of the patient’s room, the ICU setting, and the hospital. These needs include removing unnecessary equipment from the patient’s room, maintaining privacy, and making available resources such as transportation after the death and parking space for family members. In addition, the environmental features include the people involved in the experience (Reuille, 2002). In ventilator withdrawal this include the availability of health care providers, spiritual leader, a social worker, family members, and friends as well as a bereavement service.
4. Causes of sensations and symptoms, which include the causes of changes in breathing,

heart rate, and blood pressure, as well as the ways in which medication can alleviate discomfort.

Relational Proposition

A relational proposition is the link between the concepts of interest in a theory (Fawcett & DeSanto-Madeya, 2013). The following proposition will guide my dissertation topic: family members construct their needs for witnessing ventilator withdrawal and the subsequent dying process according to the concrete objective information available to them.

The concept map in figure 2 illustrates the concepts of family needs for witnessing ventilator withdrawal and their relation. The substruction model of SRT proposed for assessing family needs during ventilator withdrawal (Figure 3) is adapted from the use of SRT to cope with stressful experiences (Figure 1).

Empirical Indicators

1. A representation of the experience to be constructed using data from the developed family needs survey, including concrete objective representations, such as items addressing the need for information related to physical symptoms, causes of these symptoms, and temporal and environmental needs.
2. Sociodemographic characteristics and prior experience with the death of a family member.

Summary

Application of SRT to assess family members' needs related to witnessing ventilator withdrawal is illustrated in the substruction model of SRT seen in Figure 3. The substruction illustrates the relationship among determining concrete-objective variables and sociodemographic variables when identifying family members' needs relating to witnessing a threatening situation—

in this case, ventilator withdrawal. In addition, it shows the measures that will be used in this study to assess the selected variables.

Figure 2

Concept Map for Family Members' Needs Relating to Ventilator Withdrawal

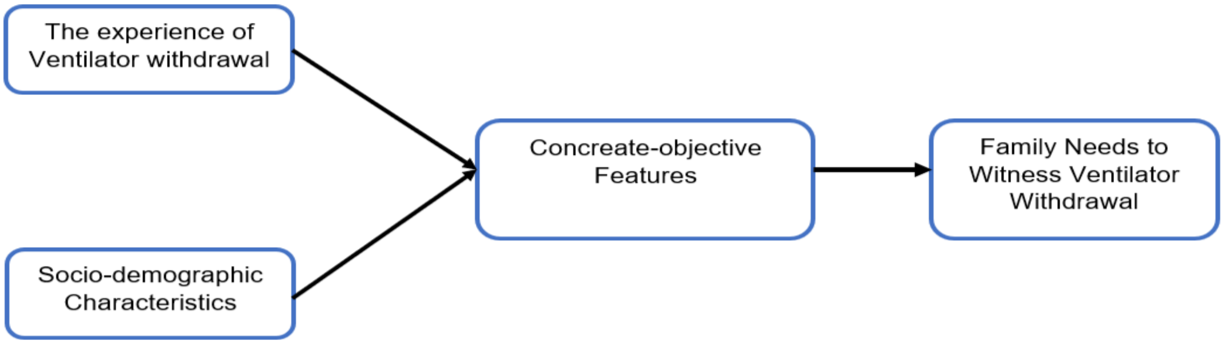
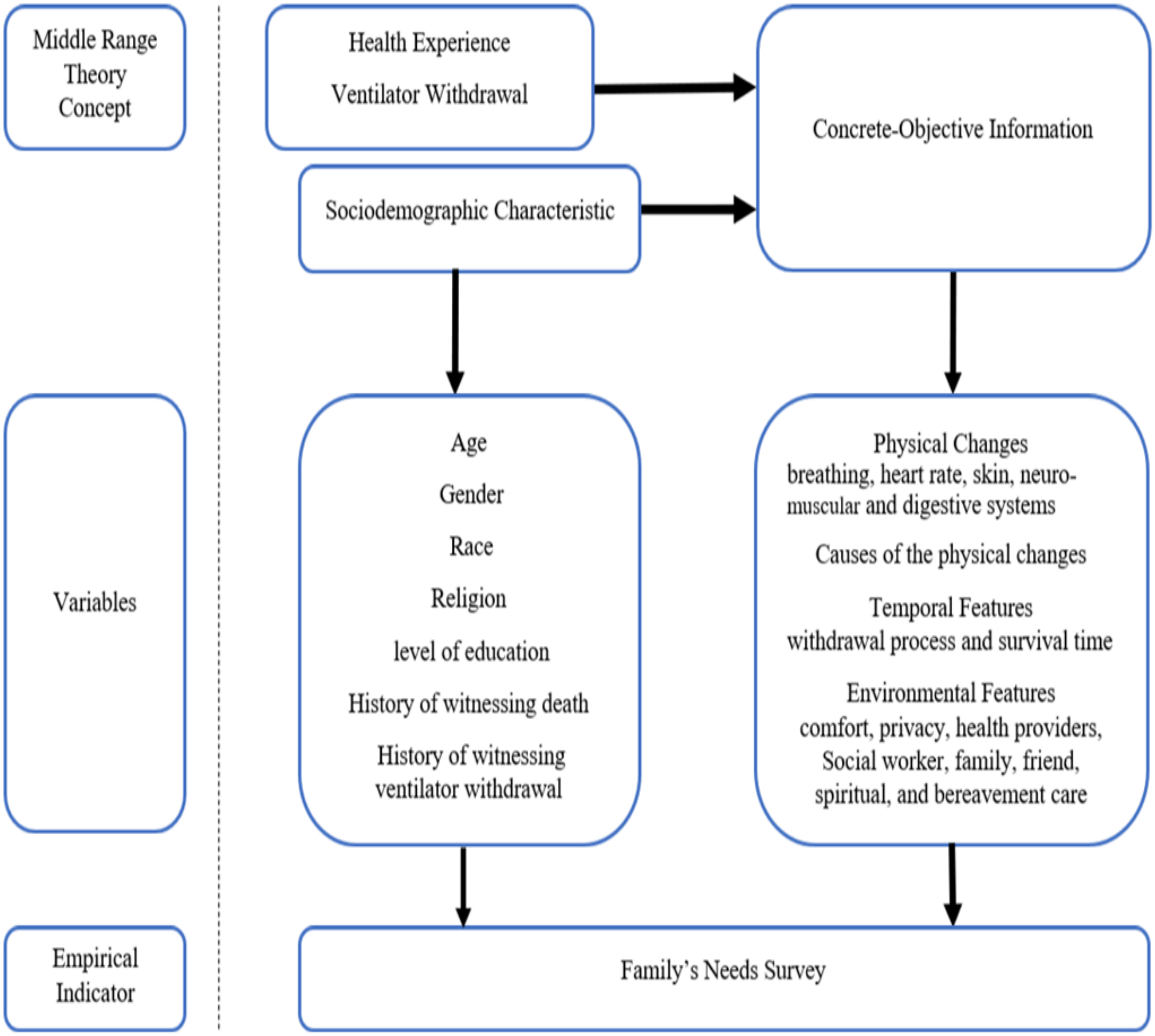


Figure 3

Substruction Model of Self-Regulation Theory to Assess Family Members' Needs Relating to Ventilator Withdrawal



CHAPTER 4: RESEARCH DESIGN AND METHOD

The aim of this chapter was to discuss the research design of a study (1) exploring family needs when witnessing ventilator withdrawal, (2) identify the most important needs for such a family, and (3) exploring the effects of having had prior experience of ventilator withdrawal in the ICU setting as well as sociodemographic characteristics such as age, gender, race, religion, and level of education on participants' needs.

Research Questions

1. What needs were identified by family members who would witness mechanical ventilator withdrawal?
2. Which needs were most important for these family members?
3. What were the effects of sociodemographic status (age, gender, race, religion, and level of education) on family members' needs?
4. What was the effect of having had prior experience of witnessing death or witnessing ventilator withdrawal on family members' needs?

Research Design and Method

To achieve the study's aims, a prospective, non-experimental, descriptive research design was implemented. A hypothetical scenario of family members who are willing to witness their family member undergoing ventilator withdraw at ICU was used to investigate the family needs. This research design would help to describe the studied phenomenon as well as the characteristics of the sample and the association among the variables, thus providing quantifiable information that can be analyzed statistically to produce findings that may be generalized from the representative sample to the target population (Omair, 2015). The use of a prospective design allowed exploration of family members' needs when witnessing ventilator withdrawal and indicated whether family members' needs were related to their sociodemographic characteristics.

Setting

The survey was conducted online via Qualtrics within the Wayne State University (WSU) community at Detroit Michigan. Wayne State University is a diverse public research university that had around 27,000 students and 7,500 faculty and staff (WSU, 2019). The racial/ethnic classification of the students compared to the faculty and staff population within WSU is as follows: White (58% vs 59%), Black or African American (15% vs 22%), Asian (9% vs 14%), Hispanics of any race (5 % vs 3%), and others (13% vs 3%). The gender of WSU students compared to faculty and staff is as follows: Male (42% vs 44%) and female (58% vs 56%) (WSU, 2019).

Sample Size and Power

The target sample was 109 of WSU students, staff and faculty. Inclusion criteria were being able to read in English, aged 18 or older who had access to the Wayne state University website (Academica). The sample size was calculated using the G*Power software, a free-to-use power and sample size calculation program. This sample size provided a sufficient power (80% at alpha level = 0.05, effect size f^2 = 0.15 and 8 predictors).

Procedures for Subject Recruitment

Web based recruitment procedure through Wayne state University website (Academica) was used to invite eligible participants to complete an online survey through Qualtrics. An online flyer was posted on (Academica) that include an information about the study (see Appendix A for flyer). This information included the purpose of the study, description for eligibility, the PI's contact information ,and the link to the online survey. The online flyer was advertised as "Wayne State University students, faculty or staff are invited to participate in a research study to address the family members’ needs to witness removal of life support in the ICU.” Before beginning the study, a concurrence of exemption research application had been submitted and permission to conduct the study was obtained from the Institutional Review Board of Wayne State University (see Appendix B for IRB approval letter).

Data Collection and Management

A self-administered survey was used to determine families’ needs associated with witnessing ventilator withdrawal and the subsequent dying process, as well as the effects of sociodemographic status (age, gender, race, religion, and level of education) and participants’ history of witnessing ventilator withdrawal or death, on such needs. The survey was developed by the investigator through a review of the literature with readability level at 9th grade. The survey contained a hypothetical scenario which was “ Imagine your family member/ friend is a patient in an ICU on mechanical ventilator (breathing machine). Your loved one’s condition is very critical, and the treatment is futile and ineffective. Your loved one will undergo removal of mechanical ventilator to allow a natural death. You have talked with the doctor about your decision and your willingness to watch and to stay at your loved one’s bedside during and after the ventilator withdrawal process. Please take a moment to respond to this survey and indicate what you need to watch/witness the withdrawal process.” The questions in the survey following the hypothetical scenario categrized into three main sections. The first section (Part A) contained questions about the participants’ sociodemographic data as well as their previous experience witnessing ventilator withdrawal and death. The second section (Part B) contained a list of items that represent need statements, presented as 5-point Likert-type items whose responses ranged from not important (1) to very important (5). The third section (Part C) included open questions asking participants about their needs that were not included in the items. Part A featured 10 items, Part B had 35 items and

Part C featured one open question (see Appendix C for family needs when witnessing ventilator withdrawal survey).

The survey was developed and uploaded in Qualtrics, an online survey tool that allowed users to design, distribute, and analyze data. Wayne State students and staff had free access to Qualtrics. The participants completed the survey only once. We predicted approximately 10-15 minutes would be needed for completion of the survey. The survey was introduced through an information sheet outlining the purpose, method, and implications of the study (see Appendix D for information sheet). Participants had to answer one question requested for their agreement to participate before proceeding. Participants' responses were saved automatically once the survey was completed and stored in a secure database.

Variables

Dependent variable was family members' needs during the processes of ventilator withdrawal and subsequent dying while in the ICU.

Independent variables were previous history witnessing death, previous history witnessing ventilator withdrawal, and sociodemographic data—statistical data conveying classifiable characteristics of population such as age, gender, race, religion, and level of education.

Reliability and Validity of the Questionnaire

To assess the questionnaire's reliability, internal consistency via Cronbach's coefficient α was computed for the entire survey. Dr. Margaret Campbell, a professor and a researcher who had clinical experience with ventilator withdrawal, reviewed the questionnaire for content face validity.

Research Questions

1. What needs were identified by family members who would be witnessing mechanical

ventilator withdrawal?

2. Which needs were most important for these family members?
3. What were the effects of sociodemographic status (age, gender, race, religion, and level of education) on family members’ needs?
4. What was the effect of having had prior experience of witnessing death or witnessing ventilator withdrawal on family members’ needs?

Quantitative Data Analysis

The first phase of the analysis was computing the frequency distributions (absolute frequency and percent) for demographic variables. Significance level was set at a *p*-value equal to or less than 0.05. All statistical analyses were carried out using SPSS 25. In addressing research questions 1 and 2, analysis of frequency was used to report the needs of family members related to witnessing withdrawal of a mechanical ventilator and the importance of these needs to the family members. In addressing research questions 3 and 4, multiple regression was used to evaluate the potential effects of previous experience witnessing death, previous experience witnessing ventilator withdrawal, and sociodemographic status on family needs. In predicting family needs, step-type regression analysis was used to obtain the optimal model.

Qualitative Data Analysis

At the end of the survey, participants were asked to report any important needs that had not been included in the survey. This open-ended question was analyzed using deductive or directed content analysis, in which prior defined categories are used to guide the interpretation of the collected data. Such categories are generally derived from existing studies, theories, models, or mind mapping (Elo & Kyngäs, 2008). Deductive content analysis is used to test existing works, such as theories, in new contexts or situations. This approach also provides evidence that may support existing theory (Elo & Kyngäs, 2008). In this study, the responses were reviewed for content in which keywords or phrases were coded into several subcategories, which were then coded to four prior defined major categories. The major categories were based on the four aspects of concrete-objective features of self-regulation theory: physical sensation and symptoms, causes of the physical sensation, environmental features, and temporal features. All responses were transcribed to Word documents, with a table created to guide the analysis, as shown in the examples given in Table 1. The final categories and subcategories were transferred to SPSS25 for analysis of frequency and percentage.

Table 1

Example of Categorization Table for Analyzing Qualitative Responses

Participant Response	Keywords or Phrases	Subcategories	Categories
"The issue of what to do after my family member dies related to funeral arrangements. A simple handout would be helpful. The cost of a funeral is overwhelming when you are trying to process an unexpected death. Starting these conversations early is important. So, simply know what needs to be done in a simple format would be helpful. So, once you get home you can process all that has happened and know what the next steps are for funeral arrangements."	What to do . . . related to funeral arrangements. A simple handout would be helpful. Cost of a funeral. Know what needs to be done. Know what the next steps are for funeral arrangements.	Hospital's resources and services/cost of care	Environmental features
"I need to have time for family members to say goodbyes before [the] patient is removed from [the] ventilator."	Time to say goodbyes before removal of patient from ventilator	Time to say goodbyes and find meaning	Temporal features

Human Subject Protection

Characteristics of Human Subjects

The study sample included Wayne State students, staff, and employees who were invited to participate in the study. Inclusion criteria for the participants were being 18 years old or older, able to read English and had access to WSU web site (Academica). The recruitment strategy of eligible participants was indirect, and recruitment was through a flyer that had been posted at Academica.

Sources of Materials

Data from participants were collected through a hypothetical scenario survey of family members relating to their needs and included their demographic data and a statement of their needs after ventilator withdrawal.

Potential Risks and Benefits of Research to the Subjects and Others

Participants' identifiable information was not required to maintain their confidentiality and protect them against any harm that might otherwise arise from a breach of confidentiality. The potential risks associated with participation in the study were minimal. Participants were notified of their rights to stop at any time and to drop out of the study if they feel uncomfortable.

There were no direct benefits of this study for participants, but the findings may improve future family care at end of life in critical care settings if an intervention based on the results is developed.

Data and Safety Monitoring Plan

To ensure participants' safety, the principal investigator was responsible for monitoring the study regularly and adhering to the ethics of human-subjects research in accordance with institutional policies and IRB regulations. The participants' information sheet and survey were retained and saved automatically by Qualtrics, with access limited to the PI.

CHAPTER 5: RESULTS

The aim of this prospective, non-experimental, descriptive study was to explore the needs of family members witnessing ventilator withdrawal and identify their most important needs. Furthermore, the study examined the effects of prior experience related to ventilator withdrawal in the ICU setting and the impact of sociodemographic characteristics such as age, gender, race, religion, and level of education on participants' needs. A survey with a hypothetical scenario involving family members willing to witness their family member undergoing ventilator withdrawal in the ICU was used to investigate these family needs.

Participants were recruited from June 30, 2020, to October 26, 2020, from WSU students, staff, and faculty, with a total sample size of 109 participants. All 109 surveys were included in the final data analysis with no missing data. The results of data analyses include (a) a description of the sample characteristics, (b) the reliability of the survey, (c) frequency and percentage analysis of the 35 needs statements, (d) regression analysis to examine the relationship between the family needs and sociodemographic characteristics, and previous history of witnessing ventilator withdrawal or death, and (e) report of the participants' comments and feedback**.**

Sample Characteristics

Table 2 displays the frequency and percentage of the sample characteristics. Most of the participants were female (*n* = 97, 89%). Most participants were aged between 18–25 years (*n* = 35, 32%), followed by those who were 25–34 years old (*n* = 25, 23%). More than half of the participants were students (*n* = 75, 69%) or had a bachelor's degree (*n* = 40, 37%) or master's degree (28, 26%). Most participants reported their race as White/Caucasian (*n* = 81, 74%) versus Black or African American (*n* = 10, 9%) or other minorities (*n* = 18, 17%). More than half of the participants indicated Christianity as their religion (*n* = 57, 52%).

Table 2

Sociodemographic Characteristics of the Sample (N = 109)

Variable	Frequency	Percent (%)
Gender		
Female	97	89
Male	12	11
Age		
18-24	35	32.1
25-34	25	22.9
35-44	18	16.5
45-54	11	10.1
55-64	16	14.7
65 or above	4	3.7
Level of Education		
High school or less	21	19.3
Bachelor's Degree	40	36.7
Master's Degree	28	25.7

Ph.D. or higher	20	18.3
I am --- at WSU		
Student	75	68.8
Faculty	18	16.5
Staff	16	14.7
Race		
White/Caucasian	81	74.3
Black/African American	10	9.2
American Indian	1	.9
Asian	5	4.6
Hispanic	4	3.7
Other	8	7.3
Religion		
Christian	57	52.3
Hindu	1	.9
Jewish	1	.9
Muslim	14	12.8

Other	36	33.0

The participants were also asked about any previous experience with witnessing ventilator withdrawal or death. Among the participants, 35% had witnessed ventilator withdrawal (*n* = 38, 35%), where the majority (*n* = 24, 63%) reported having had this experience more than 1 year ago. More than half had previously witnessed the dying/death of a family member (*n* = 63, 58%); most of these indicated that more than 1 year had passed since they had witnessed the death of a family member (*n* = 46, 73%).

Table 3

The Sample's Previous Experiences with Witnessing Death or Ventilator Withdrawal (N = 109)

Variable	Frequency	Percent (%)
Previously witnessing ventilator withdrawal		
No	71	65.1
Yes	38	34.9
Period since witnessing ventilator withdrawal (n=38)		
< 3 months	7	18.4
3-6 months	4	10.5
7 months – 1 year	3	7.9
> 1 year	24	63.2
previously witnessing the death of a family member		
No	46	42.2
Yes	63	57.8
Period since witnessing the death of a family member (n=63)		
<3 months	4	6.3
3-6 months	6	9.5

7 months – 1 year	7	11.1
>1 year	46	73.0

Analysis of Family Members’ Needs

Research Questions 1 and 2

The first two research questions this study sought to answer are as follows:

1. What needs were identified by family members who would be witnessing mechanical ventilator withdrawal?
2. Which needs were most important for these family members?

The purpose of this part of the analysis was to identify the needs of family members who anticipated witnessing mechanical ventilator withdrawal and determine which needs they perceived as most important. The participants were asked to rank 35 need statements from 1 (not important) to 5 (most important). Analysis of the scale’s reliability (Cronbach’s alpha) indicated that the scale had good internal consistency ($\alpha = 0.91$).

Table 4 displays the frequency and percentage of the need statements, ranked from the highest percent on the “very important” category to the lowest percent. More than half the participants gave a “very important” rating for 11 need statements, including the need to “know if I can touch, or talk with my family member” and to “know if my family member will receive medication to ensure comfort during and following the removal of the ventilator as needed.” Twenty-three needs were rated as very important by 20% to 45% of the participants. Meanwhile, only 6% of the participants ranked one need, “contact with the healthcare team after my family member’s death,” as very important. Overall, except for the last item, the remaining items were rated important or very important by most of the participants (Table 4). The 11 very important need statements related to information addressing three aspects of the concrete-objective information of self-regulation theory, including information about physical sensation, the temporal feature, and the environmental features (Table 5).

Table 4

Frequency and Percentage of The Needs: Ranking from Higher to Lower Percentage

Family Need	Not Important	Less Important	Neutral	Important	Very Important
	n (%)	n (%)	n (%)	n (%)	n (%)
Know if I can touch, or talk with my family member	0 (0.0)	1 (0.9)	0 (0.0)	18 (16.5)	90 (82.6)
Know if my family member will receive medication to ensure comfort during and following the removal of the ventilator as needed	0 (0.0)	0 (0.0)	1 (0.9)	21 (19.3)	87 (79.8)
Know what to do if my family member is awake or alert	2 (1.8)	1(0.9)	3 (2.8)	28 (25.7)	75 (68.8)
Know if my family member will be awake and aware	2 (1.8)	3 (2.8)	2 (1.8)	30 (27.5)	72 (66.1)
Know how long following removal of the ventilator my family member may live	1 (0.9)	3 (2.8)	6 (5.5)	28 (25.7)	71 (65.1)
Respect my family privacy	0 (0.0)	1 (0.9)	5 (4.6)	35 (32.1)	68 (62.4)
Know whom, I should ask about my family member's condition all the time	1 (0.9)	2 (1.8)	5 (4.6)	35 (32.1)	66 (60.6)
Know what changes in my family member's breathing that I might see and hear	1 (0.9)	0(0.0)	7 (6.4)	36 (33)	65 (59.6)
Be involved in my family member's care	0(0.0)	1 (0.9)	12 (11.0)	32 (29.4)	64 (58.7)
Have regular updated information about my family member's	0 (0.0)	3 (2.8)	5 (4.6)	37 (33.9)	64 (58.7)

condition.					
Know what involuntary movements of muscles might occur	2 (1.8)	2(1.8)	4 (3.7)	41 (37.6)	60(55.0)
Know whom, I share my fears and worries about my family member's condition	2 (1.8)	1(0.9)	19 (17.4)	37 (33.9)	50 (45.9)
Know what to do if my family member is sedated or unconscious	4 (3.7)	8 (7.3)	9 (8.3)	40 (36.7)	48 (44.0)
Have my questions answered all the time	0 (0.0)	5 (4.6)	15 (13.8)	41 (37.6)	48 (44.0)
Have a quiet environment	2 (1.8)	4 (3.7)	17 (15.6)	38 (34.9)	48 (44.0)
Know what physical changes to expect in my family member's appearance	4 (3.7)	5 (4.6)	6 (5.5)	47 (43.1)	47 (43.1)
Know if my family member will feel thirst or hunger	6 (5.5)	11 (10.1)	7(6.4)	39 (35.8)	46 (42.2)
Have my spiritual and cultural beliefs taken into consideration	10 (9.2)	9 (8.3)	19 (17.4)	28 (25.7)	43 (39.4)
Have time for family rituals at the time of death before moving my family member from the ICU	15 (13.8)	10 (9.2)	23 (21.1)	18 (16.5)	43 (39.4)
Contact/ communicate with the same health care team all the time	0 (0.0)	6 (5.5)	17 (15.6)	45 (41.3)	41 (37.6)
Understand the causes of physical changes in my family member's appearance	5 (4.6)	13 (11.9)	21 (19.3)	29 (26.6)	41 (37.6)
Have my family and friends in the room	2 (1.8)	12 (11.0)	17 (15.6)	37 (33.9)	41 (37.6)
Understand the causes of breathing changes	4 (3.7)	12 (11.0)	20 (18.3)	35 (32.1)	38 (34.9)
Have or to know religious or spiritual clergy are available if	15 (13.8)	9 (8.3)	17 (15.6)	31 (28.4)	37 (33.9)

needed					
Know about the social and spiritual resources in the hospital	9 (8.3)	18 (16.5)	15 (13.8)	33 (30.3)	34 (31.2)
Have a free place to park	12 (11.0)	14 (12.8)	15 (13.8)	34 (31.2)	34 (31.2)
Know what changes in my family member's heart rate and blood pressure	4 (3.7)	12 (11.0)	20 (18.3)	41 (37.6)	32 (29.4)
Understand the causes of involuntary movements of muscle	8 (7.3)	12 (11.0)	22 (20.2)	37 (33.9)	30 (27.5)
Have my family member cared for by the same physician/ nurses	3 (2.8)	10 (9.2)	28 (25.7)	39 (35.8)	29 (26.6)
Have a place to sleep	6 (5.5)	14 (12.8)	30 (27.5)	30 (27.5)	29 (26.6)
Have help with beginning funeral arrangements	5 (4.6)	22 (20.2)	21 (19.3)	33 (30.3)	28 (25.7)
Receive follow-up care, supportive and bereavement service	11 (10.1)	16 (14.7)	21 (19.3)	33 (30.3)	28 (25.7)
Understand the causes of heart rate and blood pressure changes	8 (7.3)	16 (14.7)	20 (18.3)	38 (34.9)	27 (24.8)
Have food	9 (8.3)	11 (10.1)	28 (25.7)	35 (32.1)	26 (23.9)
Contact with the healthcare team after my family member's death.	28 (25.7)	34 (31.2)	28 (25.7)	13 (11.9)	6 (5.5)

Table 5

The Frequency and Percentage of the Very Important Need Statements (N=11)

Family Need	Very Important	
	n	%
Know if I can touch, or talk with my family member	90	82.6
Know if my family member will receive medication to ensure comfort during and following the removal of the ventilator as needed	87	79.8
Know what to do if my family member is awake or alert	75	68.8
Know if my family member will be awake and aware	72	66.1
Know how long following removal of the ventilator my family member may live	71	65.1
Respect my family privacy	68	62.4
Know whom, I should ask about my family member's condition all the time	66	60.6
Know what changes in my family member's breathing that I might see and hear	65	59.6
Be involved in my family member's care	64	58.7
Have regular updated information about my family member's condition.	64	58.7
Know what involuntary movements of muscles might occur	60	55.0

Analysis of Sociodemographic Characteristics Effects on Family Members' Needs

Research Questions 3 and 4

The next two research questions that the study sought to answer are as follows:

1. What are the effects of sociodemographic status (age, gender, race, religion, and level of education) on family members' needs?

2. What is the effect of having had previous experience of witnessing death or witnessing ventilator withdrawal on family members' needs?

A multiple regression analysis was conducted to examine the effect on family needs of gender, age, level of education, religion, race, history of having a prior experience with witnessing ventilator withdrawal, and having a prior experience with witnessing death. As indicated in Table 6, no significant relationship emerged between family needs and the predictor variables.

Table 6

Regression Analysis Predicting Family Needs (N = 109)

Variable	B	SE B	Beta	*t*	*p*-value
Gender	-4.382	5.660	-.076	-.774	.441
Age	-4.345	5.119	-0.112	-0.849	0.398
Level of education	1.560	5.978	.034	.261	.795
Religion	-3.110	3.595	-.086	-.865	.389
Race	-7.987	4.128	-.193	-1.935	.056
Witnessing ventilator withdrawal	3.526	4.051	.093	.870	.386
Witnessing death	-.740	3.609	-.020	-.205	.838

$R^2 = .072$, $F = 1.127$, $p < .352$

Note. B: Unstandardized regression coefficient
SEB: Standard error
Beta: Standardized regression coefficient

Stepwise regression was also conducted to determine the optimal regression model of sociodemographic characteristics on family needs. As Table 7 indicates, race was the only significant predictor in the regression equation ($t = 2.13$, $p = .035$). Only 4.1% of the variance of the family needs was explained by race ($R^2 = .041$). Those who identified their race as White/Caucasian had an 8.3 lower needs score compared to other races, including African

American/Black, American Indian, Asian, Hispanic, and others.

Table 7

Stepwise Regression Analysis Predicting Family Needs (N = 109)

Variable	B	SE B	Beta	*t*	*p*-value
Race	-8.336	3.913	-.202	-2.131	.035
$R^2 = .041$, $F = 4.540$, $p = .035$					

Note. B: Unstandardized Regression Coefficient
SEB: Standard Error
Beta: Standardized Regression Coefficient

Comments and Feedback

The participants were asked to list any needs that were important to them but not included in the survey. Comments that were not related to the research purpose, such as responses regarding decision-making and medical power of attorney, were excluded. Furthermore, comments concerning subjective needs, such as the need for empathetic and compassionate care, were excluded since this study was focused on concrete-objective needs. A total of 23 comments were analyzed using deductive content analysis for categories and subcategories. Table 8 illustrates the subcategories and categories that emerged during the analysis. Only three categories of concrete-objective features of the self-regulation theory emerged in the final analysis: physical sensation, environmental features, and temporal features. Notably, most of the needs presented in the participants' responses were already mentioned in the survey.

Table 8

Categories and Subcategories of Family Needs Using Self-Regulation Theory's Concept (N = 23)

Category	*n*	%
Physical sensation		
Expected physiological changes	3	30
Patient's physical comfort and medication	5	50
Communication	2	20
Temporal features		
Withdrawal process/expected survival period	3	75
Time to say goodbye	1	25
Environmental features		
Hospital's resources and services	1	7
Cost of care	3	20
Hospital's rules	1	7
Presence of health-care personnel with the patient	2	13
ICU/patient's room characteristics	3	20
Grief, bereavement, and follow-up care	3	20
Objects or practices for finding meanings	2	13

Note. Some responses were coded into more than one category.

Physical Sensation

The self-regulation theory generally identifies physical sensations as as preparing the family for physiological changes and symptoms expected to be seen, heard, or otherwise recognized in the patient following the withdrawal process. Some participants' comments emphasized knowing what physical changes to expect (*n* = 3), such as the following examples: "understanding how the body will likely shut down so not surprised, for example, by liquid leaking from mouth" and "I need to know if there is any possibility the family member/friend can hear and see what is happening around them." Moreover, some participants (*n* = 2) highlighted regular communication and choosing the proper term when communicating with the family and describing the patient's condition. For instance, one of the participants commented, "Please stop calling it 'the death rattle!' It's a very unsettling term for the family to hear repeatedly." Some of the participants (*n* = 5) also stated concern regarding their family member's struggling to breathe and wanted to know about the medications that ensure comfort.

Temporal Features

The second category was temporal features, meaning any characteristics related to the timing and planning or organization of a traumatic experience, such as the ventilator withdrawal process. The need to have time to say goodbye before withdrawing the ventilator machine (*n* = 1) and information that would increase the family's awareness of the survival period following the removal of the mechanical ventilator were highlighted in some of the participants' comments (*n* = 1 and *n* = 3, respectively). For example, one participant commented, "The family needs to be more made aware that death isn't going to always be instant once mechanical ventilation is removed. We had no idea what to expect, and it wasn't explained well enough to us. We weren't sure if there was still hope if our family member was struggling to breath[e] after the ventilator was removed. I wish that this was explained better for my family's experience." Another participant wrote, "Info on how long it is expected my loved one will live once ventilator is withdrawn."

Environmental Features

The environmental features were highlighted as an essential need by most participants. This category concerns characteristics related to the place where the experience happens and the people involved in the experience. Several subcategories were classified under environmental features, as indicated in Table 8. Comments with needs that related to the patient's room, ICU unit, or the hospital resources and rules were categorized as environmental features. For example, one participant pointed out that privacy and having a place to sleep were vital needs, while another participant mentioned the need to find a place to plug in their cell phone to update other family members who could not be present. The need to find meanings by having memorialized objects such as photos or prints or the ability to play music or read for their loved ones were also crucial needs for some participants (*n* = 2).

Some participants' responses pointed to the presence of health-care providers with the patient in the absence of the family members (*n* = 2) and the need to provide bereavement and follow-up care (*n* = 3). On this topic, one participant asked, "Can staff come to the funeral?" Another participant requested "to not be made feel guilty about the choices I and my family may make regarding the patient."

Furthermore, three participants required information regarding the cost of care, phrased as "transparency in costs and billing." Another participant addressed the need for an informational handout that would help the family with funeral arrangements and their cost, specifying, "The issue of what to do after my family member dies related to funeral arrangements. A simple handout would be helpful. The cost of a funeral is overwhelming. … You can process all that has happened and know what the next steps are for funeral arrangements." Finally, one participant highlighted the need for knowing the policy covering the period after the patient's death, such as information regarding performing an autopsy for the deceased family member.

Summary

In this study, more than half of the participants considered 11 out of 35 need statements high priority or very important. These needs were related to communication, information regarding the medications that ensured their family member's comfort, and information about physical changes in breathing, muscle movement, and alertness. The participants also prioritized having information about what they could do at their relatives' bedsides, information regarding the survival time of their relative after the withdrawal of the ventilator, and respecting their privacy. The analysis showed that race was the only factor that demonstrated a statistically significant relationship with the participants' needs. Analyzing the participants' comments highlighted many of the need statements that were listed in the survey and were related to the need for transparent information regarding the patient's physical changes, the ventilator withdrawal process, the patient's survival time, and medication that would ensure the comfort of a participant's relative. Lastly, the participants' comments emphasized needing to maintain their privacy, providing objectives or ways to make meaning, and having time to say their goodbyes.

CHAPTER 6: DISCUSSION

The purpose of this study was to determine family members' needs to witness the ventilator withdrawal process and the subsequent imminent death of a family member in the ICU. This study was also intended to assess the ways in which sociodemographic factors and previous experience witnessing a family member's death or withdrawal of a mechanical ventilator affected family members' needs.

In this study, the most important needs were related to communication with health providers; information of the family member's comfort, information about possible physical symptoms, especially breathing and muscle movement; and knowledge of what family members could do at the family member's beside. The need to respect the family members' privacy and the need for information about survival time after withdrawal were also very important. The least important need related to continued contact with health care providers after the patient's death. Findings about family priority needs in this study are consistent with existing studies assessing family members' needs and experience retrospectively (Coombs, Parker et al., 2017; Kisorio & Langley, 2016; Ranse et al., 2016; Williams et al., 2012). Only two intervention studies examined the ways in which having preparatory information about the dying process affected family members' psychological status (Kirchhoff et al., 2008; Scharf et al., 2020). Kirchoff et al. (2008) provided preparatory information verbally and in print, including information about the family member's care plan, the process of ventilator withdrawal, ways in which family members could be involved in care, an estimation of survival time, and a description of the environmental features for the ICU and patient's room. In addition to the usual ICU care, Scharf et al. (2020) provided a verbal explanation and a printed preparatory information booklet for participants in the control and intervention groups. The intervention group also received a psychological intervention in the form of comfort cart items. The booklet was arranged in several subheadings followed by bullet points at a third- to fourth-grade reading level, discussing things the family might need to arrange, such as presence of clergy; things family members could do at the patient's bedside; and things that would happen as a result of the withdrawal process. The booklet also provided information about changes that family members might notice in the patient's appearance and breathing, alertness, and movement. Finally, it offered assurances of the health care team's support, encouraged family members to ask questions and seek help, and assured family members of the loved one's comfort. Scharf et al. (2020) reported that the information in the booklet was described as helpful and was well received by participants, with 82% recall rate of the information. Families' priority needs for information were well received in both experimental studies, but the ability of information to improve their psychological well-being (depression, mood state score, anxiety, stress, and PTSD symptoms) was not significant (Kirchhoff et al., 2008; Scharf et al., 2020), perhaps owing to the impact of the grief process or to the impact of other factors, such as family members' predeath psychological status; prior ICU experience; prior experience with death; and social, demographic, and economic characteristics. Family preparation does not correspond to the intensity of the information provided or the length of time that family members are in the ICU; it is a very personalized process that is tailored to the family's needs, and perception of their preparedness (Hebert et al., 2006).

No studies empirically investigated the impact of sociodemographic characteristics on family needs preparatory to witnessing the ventilator withdrawal process and the inevitable death of a family member in the ICU. Disparities that affected the preparation process arose from several factors, including level of education, family culture and ethnicity, religion and beliefs regarding EOL and death, presence of social support and family relationships, availability of a support system, and family members’ financial and economic status (Hebert et al., 2006). Family members’ demographic characteristics might influence their ability and their coping mechanism and thus must be identified and taken into consideration by ICU health care providers as they communicate and make contact with family members (Kentish-Barnes et al., 2016). The current study examined the ways in which participants’ personal characteristics (e.g., age, gender, race, level of education, religion, history of witnessing family members’ death and/or ventilator withdrawal) affected their preparedness needs.

In this study, participants’ race was the only factor significantly related with family members’ preparatory needs. Whites/Caucasians had less need than African Americans/Blacks and other minorities to witness ventilator withdrawal, a difference in family needs that may be related to racial preferences for withdrawing aggressive treatments such as mechanical ventilation at the end of life. As reported by Rubin et al. (2014), surrogates of non-White patients who had severe neurological injuries were less likely to withdraw mechanical ventilation in the ICU. Termination of ventilator support was 44% less likely in non-White patients than in White patients (Rubin et al., 2014). Racial differences in family members’ needs to witness the ventilator withdrawal process and subsequent death in the current study were also significant. Accordingly, health care providers must recognize such differences when caring for families who decide to withdraw a ventilator. Effective communication and attention to family members’ needs is essential to help them through this critical time.

The findings of this study also showed that other sociodemographic characteristics, including age, gender, level of education, religion, and previous history of witnessing a family member’s death or ventilator withdrawal, were not significant determinants of a family’s needs. This finding could indicate participants’ lack of a lived experience in which they were a family member and an anticipatory griever at an ICU. The association between sociodemographic characteristics and symptoms of anxiety and depression among family members who anticipated the death of their loved one in the ICU is significant. Previous studies have found that several factors were associated with depression and anxiety in relatives of ICU patients, including patient condition, female sex, patient age, and family members' relationship with the patient, level of education, perceptions of the quality of their communication with health care providers, cultural background, and emotional background (Andresen & Andresen-Vasquez, 2016; Pochard et al., 2005).

The current study also showed no association between prior experience with death or ventilator withdrawal and family needs, perhaps related to participants' lack of a lived experience of anticipating death in the ICU. A study has shown that prior experience in the ICU as a patient or as a family member is significantly associated with acute anxiety, depression, and acute stress disorder (Lewis & Taylor, 2017). Health care providers should consider family members' prior history in the ICU when communicating and providing care, especially at the end of life.

Verification of the Study Findings With the Theory

The findings of this study support the self-regulation theory's definition and its concrete-objective features to cope with a traumatic experience. This theory emphasizes that beyond individual cumulative experiences, providing information about what is expected to occur during a traumatic experience such as witnessing ventilator withdrawal helps people cope. The current study focuses on (1) understanding what aspects of concrete–objective information is important for the family members and (2) how family members' cumulative experiences, in the form of their sociodemographic characteristics and prior experience witnessing death, influence their needs. All the very important need statements were emerged from 3 aspects of concrete-objective features of self-regulation theory. The 3 aspects were physical sensations in the patient after the ventilator withdraw, environmental features of the hospital, ICU or patient's room, and the temporal features of the ventilator withdrawal experience. Information about the causes of physical changes or symptoms, such as causes of the breathing changes, were not considered to be very important by the participants. The current study's findings supported the general principle of the theory that coping with a traumatic experience requires that individuals be provided with information that is important to them. Finally, the impact of race on family members' needs in this study is consistent with the theory's principle that people's prior knowledge and experiences play a role in their coping mechanisms.

Strengths of the Study

The current study is the first to examine family members' anticipated needs related to witnessing ventilator withdrawal in a family member. In only two previous studies did researchers deliver an intervention message based on the SRT's concrete–objective features. The current study is also the first to address the impact of racial differences on family members' needs to witness ventilator withdrawal. What's more, this study is unique in emphasizing the importance of understanding what needs are most important to family members and what factors may influence their needs with a view to developing an intervention that targets their needs.

Limitations of the Study

The COVID-19 outbreak hindered research at hospitals, especially during its early stages. Non-essential personnel were restricted from entering ICUs, which—together with uncertainty about when this restriction would be lifted—limited the researcher's ability to recruit family members in the ICU as participants in the study. To overcome this struggle, the study sample selection was changed to the WSU community, with participants asked about their needs using a hypothetical scenario. Accordingly, their needs and preferences might not be what they would be in a real situation in an ICU. Additionally, because there was little diversity in the sample, especially in gender, race, and religion, the generalizability of the current study's findings might be limited by the study's selection bias.

Clinical Implications

Although the study population did not comprise family members of ICU patients, the findings of this study related to determining such family members' most important needs might help novice nurses in the ICU. Novice nurses could use the survey items as guidance when communicating and providing care for family members who have decided to withdraw mechanical ventilation. Moreover, the study's findings could help decrease disparities in care and improve family center care at the end of life. Health care providers, especially nurses in the ICU, should observe the impact of racial differences on family members' decision-making process as well as their need for information.

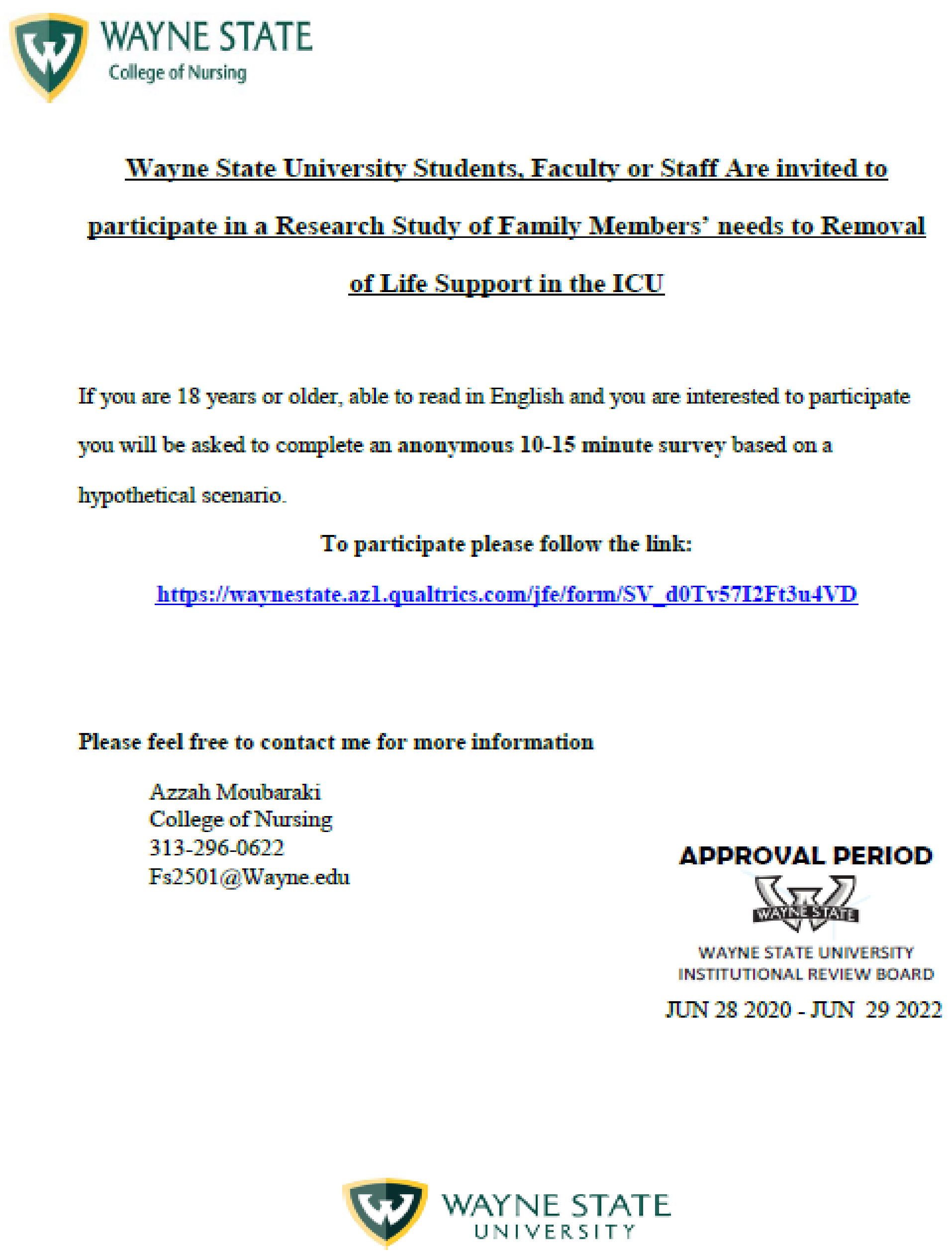
Research Implications

Replicating this study with family members who anticipate the death of a loved one in the ICU would offer more insights into what needs are the top priorities for family members before they witness the withdrawal process. Because understanding how social and demographic characteristics might influence family members' priority needs would represent a major step toward decreasing gaps in care, replication of this study could help decrease health disparities and improve family members' psychological and emotional status and their quality of life. Addition of survey items relating to the needs for time to say goodbye, for participation in activities or objects that facilitate memory making, and for help covering the costs of care is recommended. Futures research is needed into ways of designing an intervention that uses a culturally tailored approach to meet the needs of family members who witness ventilator withdrawal.

Summary

The purpose of this study was to determine the most important needs of family members who witness ventilator withdrawal and subsequent death. It was also intended to determine which factors, such as sociodemographic and prior experience witnessing death or ventilator withdrawal, influence such needs. Provision of information regarding patient status and things that family members might experience at the bedside after withdrawal is crucial. Health care providers must be aware of the importance of meeting such needs when approaching family members who made the decision to withdraw ventilator support from their relative in the ICU. Furthermore, health care providers should be aware of how sociodemographic characteristic affect family members' needs, remembering that family members' personal characteristics play an important part in decreasing gaps in health care and disparities as well as in improving family members' psychological health status and their use of coping mechanisms at the end of life.

APPENDIX A
STUDY FLYER



WAYNE STATE
College of Nursing

Wayne State University Students, Faculty or Staff Are invited to participate in a Research Study of Family Members' needs to Removal of Life Support in the ICU

If you are 18 years or older, able to read in English and you are interested to participate you will be asked to complete an **anonymous 10-15 minute survey** based on a hypothetical scenario.

To participate please follow the link:

https://waynestate.az1.qualtrics.com/jfe/form/SV_d0Tv57I2Ft3u4VD

Please feel free to contact me for more information

Azzah Moubaraki
College of Nursing
313-296-0622
Fs2501@Wayne.edu

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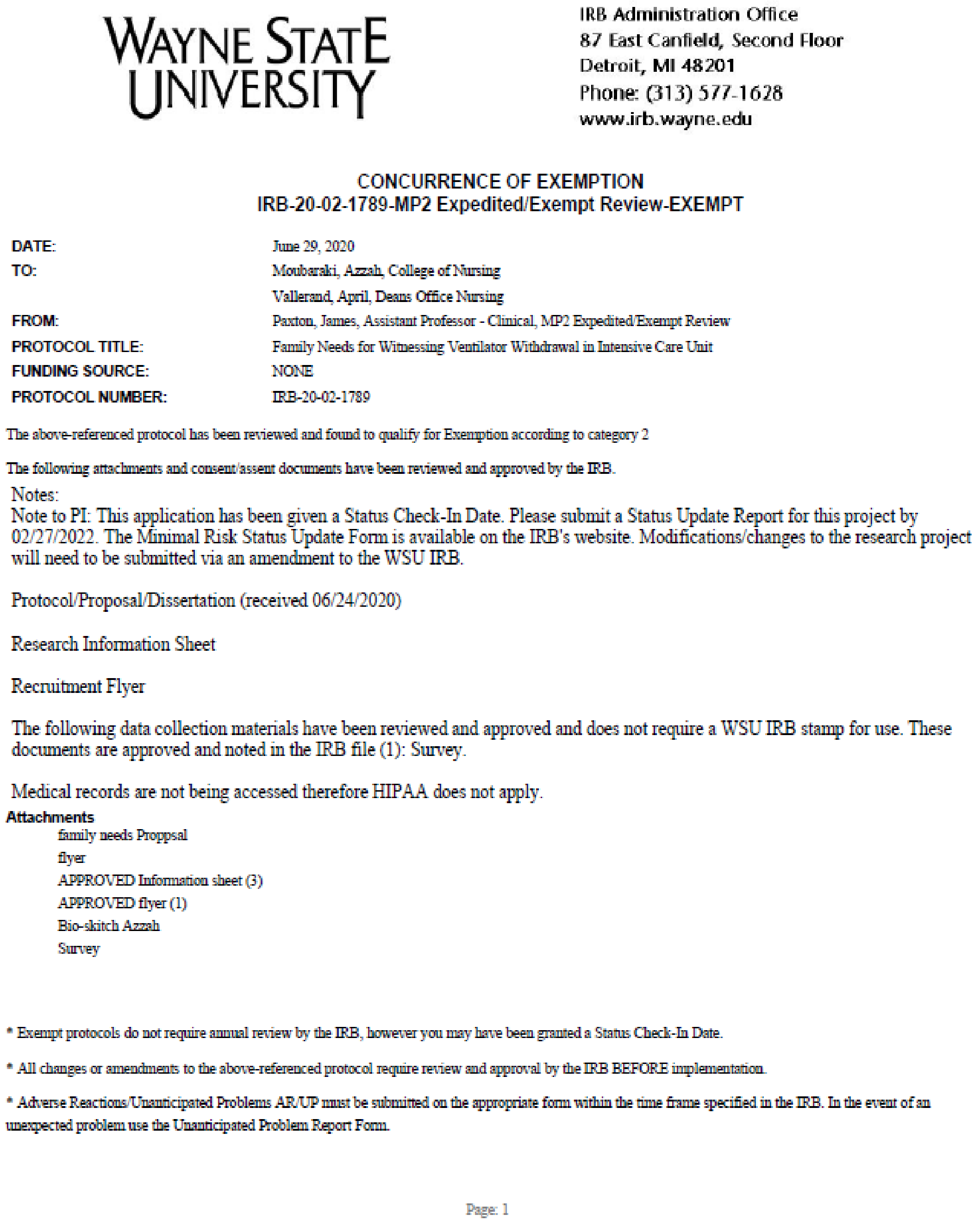
APPENDIX B
IRB APRROVAL LETTER



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IRB Administration Office
87 East Canfield, Second Floor
Detroit, MI 48201
Phone: (313) 577-1628
www.irb.wayne.edu

CONCURRENCE OF EXEMPTION
IRB-20-02-1789-MP2 Expedited/Exempt Review-EXEMPT

DATE:	June 29, 2020
TO:	Moubaraki, Azzah, College of Nursing Vallerand, April, Deans Office Nursing
FROM:	Paxton, James, Assistant Professor - Clinical, MP2 Expedited/Exempt Review
PROTOCOL TITLE:	Family Needs for Witnessing Ventilator Withdrawal in Intensive Care Unit
FUNDING SOURCE:	NONE
PROTOCOL NUMBER:	IRB-20-02-1789

The above-referenced protocol has been reviewed and found to qualify for Exemption according to category 2

The following attachments and consent/assent documents have been reviewed and approved by the IRB.

Notes:
Note to PI: This application has been given a Status Check-In Date. Please submit a Status Update Report for this project by 02/27/2022. The Minimal Risk Status Update Form is available on the IRB's website. Modifications/changes to the research project will need to be submitted via an amendment to the WSU IRB.

Protocol/Proposal/Dissertation (received 06/24/2020)

Research Information Sheet

Recruitment Flyer

The following data collection materials have been reviewed and approved and does not require a WSU IRB stamp for use. These documents are approved and noted in the IRB file (1): Survey.

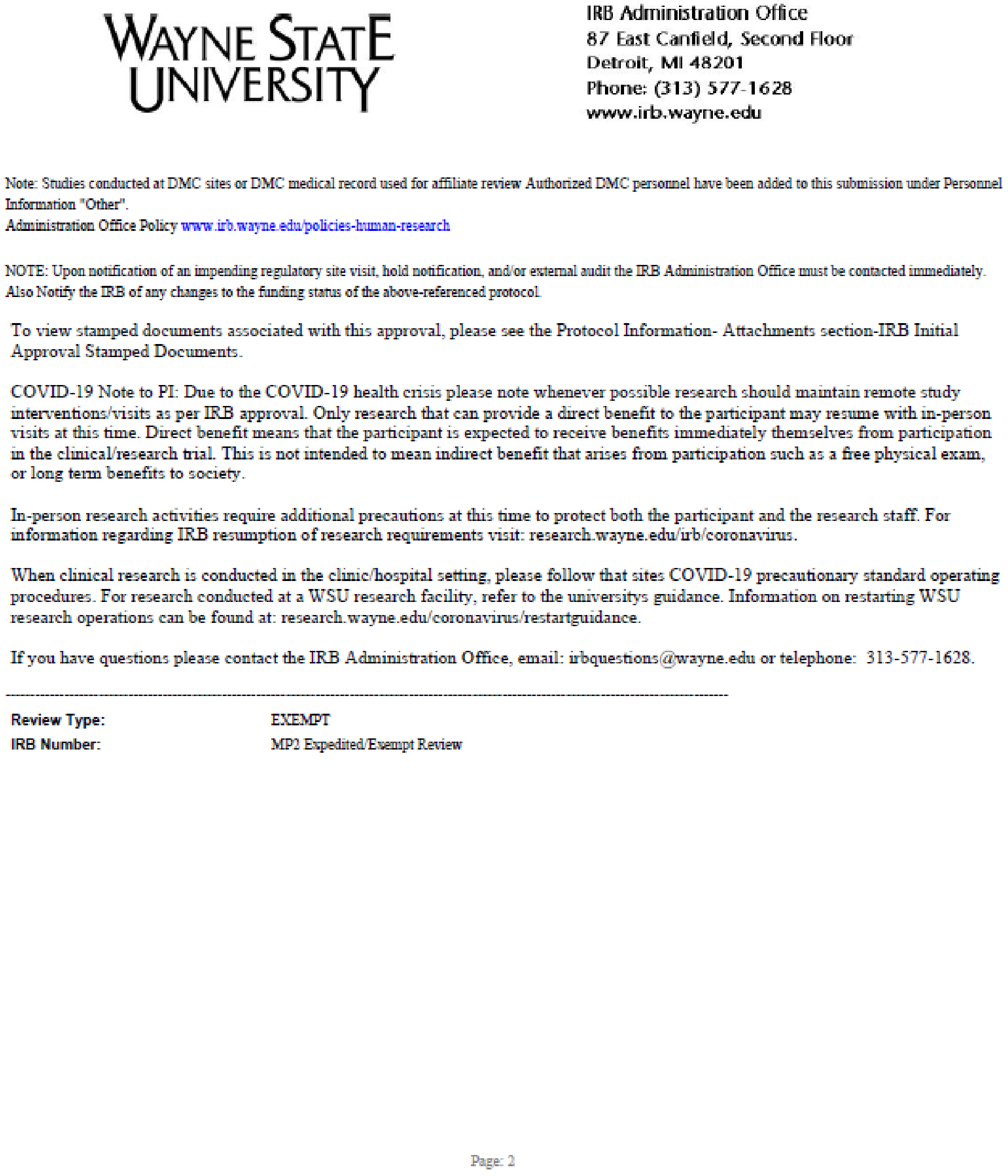
Medical records are not being accessed therefore HIPAA does not apply.

Attachments
- family needs Proppsal
- flyer
- APPROVED Information sheet (3)
- APPROVED flyer (1)
- Bio-skitch Azzah
- Survey

* Exempt protocols do not require annual review by the IRB, however you may have been granted a Status Check-In Date.

* All changes or amendments to the above-referenced protocol require review and approval by the IRB BEFORE implementation.

* Adverse Reactions/Unanticipated Problems AR/UP must be submitted on the appropriate form within the time frame specified in the IRB. In the event of an unexpected problem use the Unanticipated Problem Report Form.



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Note: Studies conducted at DMC sites or DMC medical record used for affiliate review Authorized DMC personnel have been added to this submission under Personnel Information "Other".
Administration Office Policy www.irb.wayne.edu/policies-human-research

NOTE: Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately. Also Notify the IRB of any changes to the funding status of the above-referenced protocol.

To view stamped documents associated with this approval, please see the Protocol Information- Attachments section-IRB Initial Approval Stamped Documents.

COVID-19 Note to PI: Due to the COVID-19 health crisis please note whenever possible research should maintain remote study interventions/visits as per IRB approval. Only research that can provide a direct benefit to the participant may resume with in-person visits at this time. Direct benefit means that the participant is expected to receive benefits immediately themselves from participation in the clinical/research trial. This is not intended to mean indirect benefit that arises from participation such as a free physical exam, or long term benefits to society.

In-person research activities require additional precautions at this time to protect both the participant and the research staff. For information regarding IRB resumption of research requirements visit: research.wayne.edu/irb/coronavirus.

When clinical research is conducted in the clinic/hospital setting, please follow that sites COVID-19 precautionary standard operating procedures. For research conducted at a WSU research facility, refer to the universitys guidance. Information on restarting WSU research operations can be found at: research.wayne.edu/coronavirus/restartguidance.

If you have questions please contact the IRB Administration Office, email: irbquestions@wayne.edu or telephone: 313-577-1628.

Review Type:	EXEMPT
IRB Number:	MP2 Expedited/Exempt Review

APPENDIX C
Family Needs When Witnessing Ventilator Withdrawal Survey

Imagine your family member/ friend is a patient in an ICU on a mechanical ventilator (breathing machine). Your loved one's condition is very critical, and the treatment is futile and ineffective. Your loved one will undergo removal of the mechanical ventilator to allow a natural death. You have talked with the doctor about your decision and your willingness to watch and to stay at your loved one bedside during and after the ventilator withdrawal process. Please take a moment to respond to this survey and indicate what you need to watch/witness the withdrawal process.

A. Demographic status

1. Gender
    - Male
    - Female
2. Age
    - 18-24
    - 25-34
    - 35-44
    - 45-54
    - 55-64
    - 65 or above
3. Level of education
    - High school or less
    - Bachelor's Degree
    - Master's Degree

  - Ph.D. or higher

4. I am------- at WSU
   - Student
   - Faculty
   - Staff
5. Race
   - White/Caucasian
   - Black/African American
   - American Indian
   - Asian
   - Hispanic
   - Other
6. Religion
   - Christian (Catholic protestant or any other Christian denominations)
   - Hindu
   - Jewish
   - Muslim
   - Other (please specify)
7. Have you previously witnessed ventilator withdrawal?
   - Yes
   - No
8. Have you previously witnessed dying / death of a family member?
   - Yes

- No

9. How many months or years since you witnessed ventilator withdrawal?

    - Less than 3 months
    - 3-6 months
    - 7 months – one year
    - More than one year

10. How many months or years since you witnessed the death of a family member?

    - Less than 3 months
    - 3-6 months
    - 7 months – one year
    - More than one year

B. Family needs Following ventilator withdrawal

Please consider how the statements below are important for you:

1= Not important

2= Less Important

3= Neutral

4= Important

5= Very important

I need	1	2	3	4	5
To know what physical changes to expect in my family member's appearance					
To understand the causes of physical changes in my family member's appearance					
To know what changes in my family member's breathing that I might see and hear					
To understand the causes of breathing changes					
To know what changes in my family member's heart rate and blood pressure					
To understand the causes of heart rate and blood pressure changes					
To know what involuntary movements of muscles might occur					
To understand the causes of involuntary movements of muscle					

To know if my family member will feel thirst or hunger					
To know if my family member will be awake and aware.					
To know what to do if my family member is awake or alert					
To know what to do if my family member is sedated or unconscious					
To be involved in my family member's care					
To know if I can touch, or talk with my family member					
To contact/ communicate with the same health care team all the time					
To know how long following removal of the ventilator my family member may live					
To know if my family member will receive medication to ensure comfort during and following the removal of the ventilator as needed					
To have or to know religious or spiritual clergy are available if needed					
To know whom, I should ask about my family member's condition all the time					

To know whom, I share my fears and worries about my family member's condition					
To have my questions answered all the time					
To have regular updated information about my family member's condition.					
To have my family member cared for by the same physician/ nurses					
To have my family and friends in the room					
To have my spiritual and cultural beliefs taken into consideration					
To know about the social and spiritual resources in the hospital.					
To have a quiet environment					
To respect my family privacy					
To have a place to sleep					
To have food					
To have a free place to park					
To have time for family rituals at the time of death before moving my family member from the ICU					
To have help with beginning funeral arrangements					
To receive follow-up care, supportive and bereavement service					

To stay in contact with the healthcare team after my family member’s death.					

C. What other needs are important to you, but they were not listed in the survey?

APPENDIX D
INFORMATION SHEET

Family Needs When Witnessing Ventilator Withdrawal Survey

Research Information Sheet

Title of Study: *Family Needs for Witnessing Ventilator Withdrawal in Intensive Care Unit*

Principal Investigator (PI):	*Azzah Moubaraki*
	Wayne State University/ College of Nursing
	313-296-0622

Purpose:

You are being asked to be in a research study of determining the needs of family members of patients undergoing the process of life support removal in the ICU setting because you are a Wayne State University student, staff or faculty, who is willing to respond to a hypothetical scenario in which you will stay at a family member's bedside during and after removal of life support, able to read English and aged 18 or older. This study is being conducted at Wayne State University community.

Study Procedures

If you take part in the study, you will be asked to complete a 10-15 minute survey about your needs to witnessing ventilator withdrawal and to stay at your family members bedside following the withdrawal process.

Benefits

As a participant in this research study, there *may* be no direct benefit for you; however, information from this study may benefit other people now or in the future

Risks

There are no known risks at this time to participation in this study.

Costs

There will be no costs to you for participation in this research study.

Confidentiality:

All information collected about you during the course of this study will be kept without any identifiers.

Voluntary Participation /Withdrawal:

Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time.

Questions

If you have any questions about this study now or in the future, you may contact Azzah Moubaraki at the following phone number 313-296-0622. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call the Wayne State Research Subject Advocate at (313) 577-1628 to discuss problems, obtain information, or offer input.

Participation

By completing the questionnaire, you are agreeing to participate in this study.

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JUN 28 2020 - JUN 27 2022

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ABSTRACT

FAMILY NEEDS FOR WITNESSING VENTILATOR WITHDRAWAL IN INTENSIVE CARE UNITS

by

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May 2021

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Major: Nursing

Degree: Doctor of Philosophy

Background: Witnessing ventilator withdrawal and the subsequent death of a loved one in the ICU is a traumatic experience for family members, whose needs thus differ from those of other families in the ICU. Although various studies have noted the importance of preparing family members for ventilator withdrawal, based on retrospective interviews, little is known about which needs should be met, prospectively, to equip family members to witness and cope with ventilator withdrawal or about how sociodemographic characteristics affect those needs. **Purpose:** To prospectively determine the needs of family members who will witness a loved one undergo the process of ventilator withdrawal in the ICU, determining the effects of sociodemographic status (age, gender, race, religion, education, and previous history of witnessing death and/or ventilator withdrawal) on those needs. **Theoretical framework:** Self-regulation theory and its concrete–objective features were used to develop a survey with which to identify family members' needs in response to a hypothetical scenario. **Method:** Using a prospective, descriptive study, data were collected using self-administered survey uploaded at Qualtrics from a sample of the university's students, staff, and faculty. Frequency and percentage analysis were used to compute demographic data and report the important needs of family members. Multiple regression and stepwise regression were used to evaluate the potential effects of sociodemographic status on family needs. **Results:** sample of 109 participants were completed the survey. In analyzing participants' needs, 11 needs statements were considered to be very important for family members. Those needs related to have regular communication with the health care team. The needs for information about expected physiological changes and the medications provided for the patient after the withdrawal process were very important. The needs for privacy, for information regarding survival time after ventilator withdrawal, and for time to say goodbyes to the dying loved one were also very important. Regression analysis indicated that White/Caucasian family members having fewer needs than other minorities. **Conclusions:** Determining family members' needs prospectively will lay the foundation for developing a structured program that can guide critical care nurses in communicating with family members and addressing their needs at the end of a patient's life.

AUTOBIOGRAPHICAL STATEMENT

Azzah Moubaraki's research focuses on family care at the end of life. She earned her Bachelor of Science in Nursing from King Abdul-Aziz University, Saudi Arabia, and her Master of Science in Nursing/Adult–Gerontology Acute Care Nurse Practitioner from the University of Michigan–Ann Arbor, USA. Her doctoral dissertation focuses on family members' needs for witnessing ventilator withdrawal. Azzah works as a lecturer at the Jazan University College of Nursing, Saudi Arabia. She has also worked as a clinical instructor for undergraduate nursing students at Jazan University.