# Critical Illness and Rurality: Interfacility Transfers to Urban Centres and the Impact on Rural Families

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# Abstract

A relative's critical illness is an intensely stressful time for family members. In the past, it was generally assumed that family members were relatively unaffected by a relative's admission to an intensive care unit. However, there has been increasing understanding and concern in the healthcare community that family members experience negative, long-term psychological, emotional, physical and financial consequences from this experience. In addition to these noted negative consequences, it has been suggested that the unique context of rural family members of critically ill patients may result in additional burdens. In rural areas, a critically ill patient's healthcare needs at times exceed the service capacity of the local hospital, thereby necessitating an interfacility transfer of the patient to a distant urban centre for advanced critical care services. To date, the rural family member's experience of this phenomenon is poorly understood, specifically within the context of North America. The purpose of this study was to gain an increased understanding of the meaning of the lived experiences for rural family members whose relative undergoes an interfacility transfer to an urban tertiary centre for advanced critical care services. Munhall's method of interpretive phenomenology was used to guide this study. Purposive sampling strategies resulted in the recruitment of 11 participants who experienced this phenomenon. Data analysis revealed the common themes of a longing for home, a sacrifice of self, and a persistent need to be close to the critically ill patient. Unique, context-specific meanings were also revealed by analyzing data through the lenses of the four life-worlds: corporeality, relationality, spatiality, and temporality. These meanings included a sense of vulnerability in the urban centre, a reluctance to communicate with urban healthcare providers, a loss of connection to both the critically ill relative and other family members, and a need to maintain responsibilities at home while in the urban centre. Through this study, nurses may better understand the multiple possible, context-specific meanings of this experience for rural family members thereby enhancing the individualized nursing care of these family members. Specifically, rural nurses may advocate for family members to be provided telephone contact details of the transport team or be permitted to accompany their relative during transfer to maintain a sense of closeness during transport. Urban nurses may appreciate the uniqueness of both rurality as culture and the loss of supports experienced by family members during this event and, thus, offer additional supports to rural family members. This improved understanding is specifically important for urban and rural critical care nurses who are in a key position to implement interventions to mitigate additive burdens experienced by rural family members.

*Keywords:* critical illness, interfacility transfer, interpretive phenomenology, family nursing, rural nursing, rurality

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# Dedication

This work is dedicated to my husband Eugene and our children Isabel and Edward. I am so grateful for our family and proud of the individuals our children are growing into.

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## List of Abbreviations

Healthcare Provider (HCP)

Intensive Care Unit (ICU)

Interfacility Transfer (IFT)

Postintensive care syndrome (PICS)

Postintensive care syndrome – family (PICS-F)

Roy Adaptation Model (RAM)

# CHAPTER 1

## 1.1 Background

A patient's critical illness event affects the entire family in significant and potentially negative ways (Svenningsen et al., 2017). These negative consequences on family members can be physical, psychological, financial, and/or social and can include worsening pre-existing health problems, the development of depression or post-traumatic stress disorder (PTSD), loss of income from taking time off work to care for their recovering relative, and disrupted family dynamics (Davidson et al., 2012; Harvey & Davidson, 2016; Needham et al., 2012). Increasing awareness of the consequences of a patient's critical illness for both the patient and the family has led to increasing concern in the healthcare community (Harvey & Davidson, 2016). Indeed, the Society of Critical Care Medicine hosted a conference focusing on this concern; during this conference, in recognition of the multiple dimensions of health status within which negative consequences of critical illness manifest, it was determined that a syndrome-based approach would be most appropriate to raising awareness in the healthcare community (Needham et al., 2012). Hence, the terms postintensive care syndrome (PICS) and postintensive care syndrome – family (PICS-F) were established to describe the variety and often simultaneous symptoms experienced by recovering patients and their family members respectively (Needham et al., 2012).

It is noted in the literature that several elements of a relative's critical illness influence the family member's experience of this event. The highly technical critical care environment is noted to be anxiety provoking for family members and despite being prepared by staff before first entering the critical care unit, they describe it as worse than they could ever have imagined (Christensen & Probst, 2014; DiSabatino Smith & Custard, 2014). The persistent uncertainty inherent in critical illness combined with not knowing what the future will hold is intensely stressful and demanding for family members (Ågård & Harder, 2007; Al-Mutair et al., 2014; DiSabatino Smith & Custard, 2014). Family members often seek information in an attempt to alleviate these feelings of uncertainty and stress, however the information they receive about the patient's vital signs, test results, diagnosis, or prognosis may in fact not provide the sustained reassurances they need (Ågård & Harder, 2007; Al-Mutair et al., 2014; DiSabatino Smith & Custard, 2014).

Family members also fear that their critically ill relative may be frightened and suffering; in an effort to help their relative, they often self-sacrifice and hide their needs and fears from nursing staff so as not to detract the nurse's focus from their relative (Ågård & Harder, 2007; DiSabatino Smith & Custard, 2014). Feelings of hopelessness and helplessness are pervasive feelings described by family members and they note that being close to their critically ill relative is important and they have a strong desire to help them but often do not know how (Ågård & Harder, 2007; Christensen & Probst, 2014). Again, family members often sacrifice themselves in these moments and do not ask nursing staff for direction in how they can help their relative; however, in situations where the nurse invites the family member to participate in patient care, the family member feels closer to their relative and thus reassured (Ågård & Harder, 2007; Al-Mutair et al., 2013). While the need to be close to their critically ill relative is important for family members, this need may lead to further stress for family members who are often trying to maintain rival responsibilities at home (McKiernan & McCarthy, 2010). Receiving support helps to sustain family members and while they acknowledge the important role critical care nurses play in providing support during this stressful time, the most important source of support for these individuals was their family as a unit, together with the critically ill patient (Frivold et al., 2015).

It is suggested by Harvey and Davidson (2016) that PICS-F may be mitigated by reducing the family members' levels of stress and anxiety during a relative's critical illness event. However, according to Myers et al. (2016), phenomena related to critical illness must first be better understood before interventions to prevent or mitigate adverse consequences can be developed. Although PICS and PICS-F have received attention in the health-related literature, it is less clear what the unique experiences are for rural family members of patients who undergo an interfacility transfer (IFT) for advanced critical care services.

The context of critical illness in rural settings differs from the urban context. In rural centres, the regional hospital may not be equipped with the appropriate personnel or equipment to meet the needs of a critically ill patient (Johnson, 1999). In these situations, critically ill rural patients undergo an IFT to an urban centre for advanced critical care services (Johnson, 1999). However, it is suggested in the literature that rural family members of these patients experience psychological, social, financial, and physical burdens that may exacerbate the negative experiences inherent in a relative's critical illness event (Burns et al., 2018). Mackie et al. (2014) note that an IFT for advanced critical care services uniquely affects the rural family members' experience; subsequently, these individuals have distinct needs that require support from nurses and other health care providers. It is important that a better understanding of this phenomenon is gained; doing so will expand nursing knowledge in this area, thereby resulting in improved nursing care of these individuals.

## 1.2 Purpose

The purpose of this study was to enhance the understanding of the meaning of the rural family member's experiences of a relative's IFT for advanced critical care services.

## 1.3 Research Question

The research question that guided this inquiry was: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?*

## 1.4 Relevance to Nursing

Critical care nurses care for both the critically ill patient and their family members (Ågård & Harder, 2007). A relative's critical illness has been described by family members as an incredibly difficult time (Engström & Söderberg, 2004). Family members describe their fear and horror at seeing their critically ill relative in intensive care for the first time (Engström & Söderberg, 2004). The uncertainty of their relative's future leads to feelings of vulnerability and sorrow for family members who often are unable to eat or sleep during this time (Engström & Söderberg, 2004). Indeed, Ågård and Harder (2007) describe a patient's critical illness as a time when family members constantly have to adapt to new and changing realities. It has been suggested that levels of stress experienced by family members is directly proportional to the development of PICS-F (Davidson et al., 2012) and reducing the degree of stress and anxiety that family members endure during a relative's critical illness may mitigate the development of PICS-F (Harvey & Davidson, 2016). Kinrade et al. (2009) suggest that the degree of support family members receive from critical care staff may directly influence their health and well-being.

In addition to these stressors experienced by family members during a relative's critical illness, rural family members of patients who undergo an IFT for advanced critical care services likely have additional unique needs (Mackie et al., 2014). A rural critically ill patient's transfer from a less specialized hospital to an urban tertiary care centre for advanced critical care services is not a recent phenomenon (Blackwell, 2002). However, understanding of the potential negative consequences of this experience for rural family members is only beginning. As noted in previous work (Burns et al., 2018), the emotional, psychological, physical, and financial burden of an IFT is additive to the stress experienced by family members during a relative's critical illness. Furthermore, health inequities between urban and rural individuals may place rural family members at a disadvantage to their urban counterparts. Death from cardiovascular disease, chronic obstructive pulmonary disease (COPD), motor vehicle collisions, injuries, and poisoning are more prevalent in rural areas that in urban areas (Eberhardt & Pamuk, 2004; Pong et al., 2009). Of note, these are patient conditions that frequently require critical care admission for management (Canadian Institute for Health Information [CIHI], 2016). This suggests that rural populations bear a higher burden of critical illness events than individuals who live in urban centres.

These factors combined with the rural geography of Canada and the anticipated rise in ICU admissions and subsequent IFTs (CIHI, 2016) makes this phenomenon of importance to nursing, Canadians, the Canadian Healthcare system, and beyond to the global context. A better understanding of the unique situation of rural individuals especially within the context of a relative's IFT for advanced critical care services is needed in order to minimize health disparities and better inform the nursing care of these individuals (Eberhardt & Pamuk, 2004; Johnson, 1999; Mackie et al., 2014; Pong et al., 2009). To my knowledge, there has not been any research conducted within the Canadian context that aims to understand rural family members' experiences of a relative's IFT for advanced critical care services. Critical care nurses are in a position to positively influence the unique rural family member's experiences of a relative's IFT (Mackie et al., 2014). Indeed, according to Harvey and Davidson (2016), interventions that reduce the family member's experiences of stress and anxiety during a relative's critical illness experience may be key to reducing the negative consequences of PICS-F. However, this experience is complex and to support these individuals, critical care nurses must first gain an awareness and understanding of this phenomenon as experienced by rural family members (Johnson, 1999).

To address the gap in understanding of rural family members' experiences of a relative's IFT for advanced critical care services, I proposed an interpretive phenomenological approach to inquiry. As both a philosophy and a research methodology, interpretive phenomenology considers human experiences within context and from this, seeks to understand the hidden structures of meaning that are "taken for granted" and thus overlooked and unacknowledged by those individuals in experience (Frede, 2006; Leonard, 1989, p. 52; Mackey, 2005). An interpretive phenomenological methodology was appropriate to address this problem because it enabled a penetrating exploration of rural family members' experiences of an IFT to reveal that which lies within (Mackie et al., 2014). The enhanced understanding of human experience, a goal of nursing that is gained through interpretive phenomenological inquiry, has the potential to inform nursing practice when caring for individuals during significant life events (Annells, 1996; Leonard, 1994; Matua & Van Der Wal, 2015; Starks & Brown Trinidad, 2007). Exploring this experience using interpretive phenomenology has the potential to inform critical care nursing practice (Johnson, 1999), specifically within the Canadian context that had yet to be understood.

With the knowledge gained through this work, critical care nurses can appreciate the unique experiences of rural family members in this context and also the breadth of possibilities of this experience. This knowledge can inform the nursing care of these individuals with the aim of mitigating or preventing the negative consequences family members may experience. Furthermore, a better understanding of the family member's experiences will guide future research efforts in this area in order to continue to expand and develop nursing knowledge.

## 1.5 Nursing Philosophical Perspective

As noted previously, family members are in a situation of constant adaptation to a fluctuating reality when a relative is critically ill (Ågård & Harder, 2007). In order to deepen the understanding of the family member's experiences during a relative's critical illness event, the Roy Adaptation Model [RAM] (Roy, 2009) was proposed as a philosophical lens during this study. Below, the philosophical assumptions and key tenets of this conceptual framework are discussed.

### 1.5.1 Assumptions of the Roy Adaptation Model

Since the initial publication of the RAM in 1974 (Roy, as cited in Cipriano Silva & Rothbart, 1984), this conceptual model has undergone developments and revisions to expand the philosophical, scientific, and cultural assumptions underpinning it (Roy, 2009). Roy (2009) identifies humanism as a key philosophical assumption underpinning the RAM. Humanism views subjective human experience as fundamental to knowing and "humans, as individuals and in groups, share in creative power; behave purposefully, not in a sequence of cause and effect; possess intrinsic holism; and strive to maintain integrity and to realize the need for relationships" (Roy, 2009, p. 28). Contemporary empiricism and postmodern philosophies have influenced Roy's work and caused her to question previous assumptions of *truth* in the context of postmodernism where meaning is sought in multiple realities (Roy, 2009). This tension resulted in Roy developing a philosophic view of reality that she termed *cosmic unity* (Roy, 2009). Cosmic unity as described by Roy (2009; 2011) views the individual as being unique and independently diverse, yet inextricably connected to and a vital part in contributing to community, society, and the universe. Individuals are viewed as socially and physically interconnected within a purposeful universe and through these connections with each other and the world, meanings are revealed (Roy, 2009; 2011).

Scientific assumptions of the RAM are based on systems theory and adaptation-level theory (Roy, 2009). From these theories, individuals in the RAM are described as adaptive systems with interrelated components functioning together to respond to stimuli with behaviour (Roy, 2009). However, Roy (2009) cautions us that this process is not linear; indeed, as complex, living systems, the process should not be perceived as a single stimulus eliciting a single response. Rather, individuals as adaptive systems are extremely complex and multifaceted and as such, adaptive processes are comprised of complex processes (Roy, 2009). Adaptation-level theory is foundational to Roy's conceptual framework and contributed to her understanding of individuals' capacity to adapt to changes in the environment. Roy conceives this adaptation level to be a function of the burden of the situation and the resources available to the individual to support adaptation. Roy identified three levels of adaptation: integrated, compensatory, and compromised. Additional scientific assumptions of the RAM include: (a) the understanding that consciousness and meaning are necessary elements for the integration of the individual with their environment; (b) individual thinking and feeling is constitutive of the individual's awareness of self, their environment, and also mediates individual's actions; and (c) human consciousness is the domain where transformations in the individual and environment occur (Roy, 2009).

Recently, nurses in countries with differing cultures raised concerns that explicit concepts within the RAM did not fit within their context (Roy, 2009). As such, Roy (2009) integrated cultural assumptions into the RAM to increase its cultural relevancy around the world. These cultural assumptions include: unique cultural contexts will exert a unique influence on how each element of the RAM is expressed, some concepts in the RAM will be influenced to a greater or lesser degree dependent on the degree of importance placed on that concept by the culture, and nursing practices related to the RAM are culturally dependent (Roy, 2009).

### 1.5.2 Key Tenets of the Framework

According to Roy (2009; 2011), in a general sense, the goal of nursing is to promote the health of both individual people and society as a whole. Specifically, the role of the nurse is to support adaptation by individuals and groups with their environment in each of the four modes described in the RAM; in doing so, nurses aim to enhance health and quality of life, or provide support for those who are dying to die with dignity (Roy, 2009). Although the RAM as a conceptual framework was applied to both individuals and groups from its inception, it is in recent years that Roy (2009; 2011) has formally incorporated groups into the adaptive modes. Enhanced relationships between individual human systems and the environment is supported by the concepts of acceptance, protection, fostering of interdependence, and promotion of personal and environmental transformations (Roy, 2009). By supporting adaptation to illness, health is enhanced (Roy, 2009).

As described by Roy (2009), it is through the four modes of physiologic-physical, self-concept or group identity, role function, and interdependence that interactions between individuals or groups and the environment occur and degree of adaptation can be observed. These modes are overlapping and interrelated and cannot be considered in isolation from the others (Roy, 2009). The physiologic-physical mode refers to the interaction between individuals or groups as physical beings with the environment (Roy, 2009). In response to stimuli, observed human responses or behaviours in this mode are related to the physical functioning of the individual human body, such as that related to the respiratory or cardiovascular system (Roy, 2009). For groups of individuals, this mode considers the group response to external resources such as fiscal or physical resources (Roy, 2009).

The self-concept or group identity mode is concerned on an individual level about the identity of self, and who they are as situated in the world; it encompasses the physical self, the ideal self, and moral self (Roy, 2009). In the group context, this mode is concerned with interpersonal relationships, group image, culture, and shared responsibilities of the group (Roy, 2009). The group has shared values and relies on one another (Roy, 2009). Ineffective adaptation can be observed on both the individual level and the group level of this mode (Roy, 2009).

The role function mode as related to the individual level refers to an individual's understanding of their position within society and how to interact with individuals in other social positions within society (Roy, 2009). In the group context, this mode refers to groups of individuals working together through reciprocal and integrative roles to achieve, as a group, the requirements expected by society (Roy, 2009). It is in this mode where individuals work as a group to perform tasks expected and required by society such as maintaining law and order and the distribution of public information (Roy, 2009).

The fourth and final mode described by Roy (2009), the interdependence mode, refers on the individual level to the relational activities of love, respect, nurturing, and security with significant others, support systems, and other individuals. On the group level, this mode refers to a group such as a family or a community and their interactions and relationships on the social level to meet the group’s needs for relationships, development, and other resources (Roy, 2009). Examples of relationship needs that may exist for groups include connections with the healthcare system or government agencies (Roy, 2009). The group’s need for development relates to the progressive maturation of a group such as that of nursing students, or a new group of employees (Roy, 2009). Finally, the need for resources that is sought to be fulfilled through the interdependence mode refers to the need for physical space, security, and funding for the group (Roy, 2009). According to Roy, it is through this mode of interdependence that the group’s need for resources are met; without which, groups will certainly struggle.

Nursing knowledge to inform practice arises from work with each adaptive mode (Roy, 2011). Individuals and groups are considered as whole and adaptive systems (Roy, 2009). Stimuli from both internal environments such as pain or fatigue and external environments such as financial instability or family role adoption are assessed as to how they influence both within and across adaptive modes (Roy, 2009; 2011). Changes in stimuli may result in stress for individuals and groups and thus negatively impact coping and subsequently adaptation (Roy, 2009). The first step for nursing is to collaborate with the individual or group and determine if exhibited behaviours according to the four described modes indicate if coping is effective or ineffective (Roy, 2009). If coping is ineffective and adaptation is negatively impacted, the nurse aims to work with the individual or group to determine the stimuli that is motivating these behaviours of ineffective coping (Roy, 2009). Together, with the goal of promoting adaptation to the change in stimuli, the nurse and individual or group work together to change the stimuli if possible, or enhance coping skills (Roy, 2009). Thus, from knowledge gained through this process, nursing practice interventions are developed to promote adaptation (Roy, 2009; 2011).

Conceptual frameworks must be dynamic and responsive to the changing contexts within which individuals exist; if they remain static, and do not evolve, they will become irrelevant and defunct (Reed, 1995). Roy (2011) acknowledges the challenges experienced by nurses trying to practice according to the values and goals of nursing within the current context. In response to this, Roy states that ongoing development of nursing theories can support nursing practice in present, challenging contexts. In her recent work, Roy explicitly elaborates on the family as a group and the application of the RAM as a conceptual model within this context. When considering the family using the physical adaptive mode of the RAM, Roy (2011) describes the family's need to maintain "operating integrity, that is, wholeness achieved by adapting to changes in resources to function as a group" (p. 347). Changes in resources may include changes to accommodation, child care, transportation, emotional and social support, employment and healthcare (Roy, 2011). As described previously, the goal of nursing care, according to the RAM, is to support individual and group compensatory activities that facilitate adaptation in response to changes in stimuli, and also identify behaviours indicative of compromised adaptation (Roy, 2009; 2011). Thus, in the situation of a family experiencing ineffective adaptation in response to stressors or stimuli, the nurse involved in their care may determine, in collaboration with the family, that nursing interventions such as seeking emergency shelter or child care options, alternative transportation options, and enabling access to government supportive services may be beneficial to promote adaptation to the family's change in circumstance (Roy, 2009; 2011).

Utilizing a conceptual framework such as the RAM (Roy, 2009) as a philosophical lens through which to view phenomena aids in highlighting problems and issues that are important to nursing (Risjord, 2010). The RAM explicitly focuses on both the individual and the family unit as adaptive entities; thus, as a philosophical framework, the RAM fits well with the context of the family members' experiences of a relative's critical illness event and the inherent constant state of adaptation required of family members (Ågård & Harder, 2007). Therefore, the RAM was used as a philosophical lens through which to view the phenomena of this study. In addition to the influence the RAM had on my approach to this study, my personal ontological, epistemological, and worldviews also impacted this study (Denzin & Lincoln, 2018). Below, I explore my presuppositions in relation to the individual, society, nursing, and nursing research.

## 1.6 Researcher Presuppositions

The researcher's ontological and epistemological beliefs shape their perspective of the world and thus influence both what research questions are asked and how research findings are interpreted (Denzin & Lincoln, 2018). Being that these beliefs are so instrumental in guiding the research process, it is important that the researcher engages in a critical reflection of these beliefs to gain an appreciation of how they shape the nursing knowledge generated through research (Crowther et al., 2017; Reimer-Kirkham & Anderson, 2010). Therefore, I explored my ontological, epistemological and overall worldview beliefs related to the individual, society, nursing and research to gain an increased reflexivity of how these assumptions influenced and shaped the nursing knowledge I developed through my doctoral research.

### 1.6.1 The Individual

I value the dignity, individuality, and autonomy that is inherent within each individual. Informed by the work of scholars such as Alvesson and Sköldberg (2018), Cheek and Rudge (1994), Mill et al. (2001) and Munhall (2012), I understand that influences from both intrinsic and extrinsic factors impact the perceptions, experiences and, in fact, social positions of individuals within society. Influential intrinsic factors may include those related to genetics and health status. Extrinsic factors include those related to geographic location, socio-economic status, employment status, family relationships, and educational experiences. These extrinsic factors, I believe, are directly impacted by visible and invisible power relations that have occurred in the past and persist into the present and the future. I highly value the autonomy of the individual; thus, as a nurse, I often find myself searching for underlying influences of power that impact the individuals I see in my practice and in my community and beyond. The value I place on individual autonomy at times causes tension for me. I also believe that all individuals have a responsibility to each other and society as a whole. Tension manifests at times when individual autonomy and social responsibility are in opposition.

I believe that each individual has a unique reality that can only be fully known to them, thus situating me within the ontology of the constructivist paradigm (Lincoln et al., 2018). I understand this reality is formed from the individual's interactions with the world and is influenced by historical factors. Therefore, I don't believe that there is one *truth*, rather, I believe that there are multiple individual realities. Because I believe that reality is individual and arises from the factors described above, I believe that a researcher seeking *truth* will in fact produce a *shared truth* with participants of studies (Lincoln et al., 2018; Munhall, 2012); however, the individual truths of participants can only ever be truly known by the participant themselves.

### 1.6.2 Society

Informed by critical theory, feminism, and the philosophy of phenomenology (Alvesson & Sköldberg, 2018; Frede, 2006; Guignon, 2006; Taylor, 2006; Munhall, 2012), I believe that historical factors such as socio-political, economic, and cultural influences frame present-day societal structure and thus impact individuals. These historical elements combined with present day factors influence and change society and will continue to do so into the future. As a result, I believe that individuals within society may perceive their roles and relationships as *normal* and, thus, accept their position as natural and as it should be.

All individuals who live within society play a role in influencing and shaping the functioning of society. I believe that some individuals and groups exert more of an influence than others and I believe this is a result of power relations, akin to a Foucauldian perspective explicated in the work of Cheek and Rudge (1994). Individuals and groups who are perceived to hold more power (e.g., white males of higher socio-economic status) exert more influence to either directly or indirectly shape society compared to those with less perceived power. I believe that individuals and groups with less perceived power have the ability to initiate societal changes; these changes occur when these individuals and groups mobilize the power of media to exert pressure on individuals and groups who hold positions of power. Furthermore, I believe that the majority of people within society seek the good for society as a whole. However, the perception of good is subjective and thus, what one individual or group perceives as *good*, may in fact be perceived a *bad* for another individual or group. Herein lies tension when I reflect on my philosophical assumptions: What I perceive to be good for individuals and society may, in fact, be perceived by others as negative or even oppressive.

### 1.6.3 Nursing

Nursing is concerned with optimizing the holistic well-being of individuals (Mill et al., 2001; Risjord, 2014). Using the unique disciplinary knowledge of nursing, nurses engage with individuals in a collaborative way to determine what *is* well-being for that individual and then working together to meet their goals (Mill et al., 2001; Risjord, 2014; Villarruel et al., 2001). I believe that nurses cannot know what the correct path to well-being is for individuals; rather, it is through collaboration and facilitation that this becomes known to both the nurse and the individual. However, nursing’s mandate is broader than simply the health needs of individuals; rather, it sees the health of individuals as directly linked to the contexts within which individuals and communities have existed in the past, through to the present, and on into the future. I believe that it is the responsibility of nursing to address the inequities that exist within society. The social determinants of health provide an important framework to guide nurses when assessing and addressing these inequities (Phillips et al., 2020). By revealing these inequities, nursing can then work with individuals and groups to improve their socio-economic status and thus their health status.

### 1.6.4 Nursing Research

I view research as an important activity to reveal that which is hidden. In other words, as informed by the work of Alvesson and Sköldberg (2018), research is an important endeavour in society to highlight situations that are problematic, but perhaps are not recognized or are perceived as *normal* and, thus, no change is necessary. Within the public arena, I believe that nursing research is generally perceived to be subordinate to medical research, an idea articulated by Yeo (2014). Informed by the writings of scholars such as Alvesson and Sköldberg, (2018), Denzin and Lincoln (2018), Hoeck and Delmar (2018), Latimer (2014), Risjord (2010) and Yeo (2014), I perceive this scientific domination to result from both the outcome-based culture that prevails in current society, and also from the position of privilege held by medicine and its association with the postpositivist approach to science. Furthermore, during my academic journey, I have come to appreciate that postpositivism has held a position of privilege as the most respected way to generate knowledge or means to reveal *the truth*. However, the concerns of nursing do not necessarily align solely with this paradigm (Clark, 1998); hence, the generation of nursing knowledge that arises from other paradigms occurs at the expense perhaps of rigour, as perceived by postpositivism and society as a whole. However, within the last decade, I have seen increasing public interest in addressing inequities and problems that are best addressed by research approaches outside the postpositivist paradigm. Because these other paradigms (e.g., critical theory, constructivism) are frequently used by nursing in the conduct of nursing research, I believe that change in societal research priorities is on the horizon, if indeed this change has not already begun.

In conducting nursing research, and based upon my position within the constructivist paradigm (Lincoln et al., 2018), I do not believe that the researcher can approach the inquiry from a state of complete objectivity. Researchers, as are all individuals, are unique products of their historical experiences and perceive a reality that is unique to them. I believe that the researcher arrives at the inquiry with presuppositions and beliefs that both interact with and subsequently influence the research process and resultant findings. It is through this influence that I see the researcher and participant as co-creating research findings. Furthermore, I do not believe that the researcher can be unaffected by the research process; rather, the researcher is changed during the course of the inquiry through the development of new understandings of the phenomenon of interest (Munhall, 2012).

My ontological, epistemological, and overall worldview beliefs shape and influence how I see the world and, thus, influence the research I conduct. Therefore, it is important to me that I reflect upon and acknowledge my philosophical assumptions and appreciate the influence they have had and will continue to exert on my research endeavours in both my doctoral and future studies.

## 1.7 Dissertation Organization

This dissertation is presented in a manuscript-style format and describes the progression of my research. The included manuscripts that have been published in peer-reviewed journals (i.e., chapters 2 and 3) have been formatted from their published version for inclusion in this dissertation. Following this introductory chapter, in chapter two I present an integrative review manuscript (Burns & Petrucka, 2020) that I completed as the primary author in order to more clearly understand the current state of knowledge related to the rural family member's experiences of a relative's IFT for advanced critical care services. In chapter three, as lead author of this manuscript, I explore the evolution and philosophical foundations of interpretive phenomenology and then compare three prominent phenomenologists in nursing (Burns & Peacock, 2019) in order to determine the most appropriate methodologist to guide my study. From this work, Munhall (1994; 2012) was chosen as the most appropriate phenomenologist to guide this study and justification for this decision is offered. Chapter three continues with descriptions of specific methodological design decisions, ethical considerations, and dissemination plans. In chapter four, demographic data of the present study are presented followed by a manuscript style overarching narrative of study findings that "tells many different stories of meaning" (Munhall, 2012, p. 145). In chapter five, a discussion of the findings of the present study are described in the format of a publishable manuscript. Lastly, chapter six offers a review of the contributions of each manuscript contained within this dissertation and links each of these works to the overarching goal of this dissertation.

## 1.8 Chapter Summary

A relative's critical illness is a challenging time for family members and has the potential to negatively impact the health and well-being of family members. While there has been an increasing appreciation of the impact of critical illness on family members, the rural family member's experiences of a critically ill relative's IFT to a distant urban centre for advanced critical care services remains poorly understood. This gap in knowledge is significant to nursing; critical care nurses care for both the patient and their family and are in a key position to support family members. This study aimed to address this gap in knowledge to improve the understanding of this event and, thus, enhance the care nurses provide to these family members. The RAM (Roy, 2009) was presented as a philosophical lens for this study and my personal ontological, epistemological and world views were explicated to make clear the influence that my researcher presuppositions had on this work.

# CHAPTER 2

## 2.1 Review of Literature

Although research suggests that a patient's IFT to a distant tertiary care centre for advanced critical care services results in additional psychological, emotional, physical, and financial burdens on family members, this area has received little attention in the literature (Burns et al., 2018; Burns & Petrucka, 2020; Mackie et al., 2014). To set the foundation for future research in this field, an integrative review of the extant literature was completed. As this area of critical care is perceived to be new and emerging, an integrative review format was considered to be the most appropriate format of literature review because it results in a preliminary "holistic conceptualization and synthesis of the literature to date" (Torraco, 2005, p. 357). The resultant conceptual framework generated during an integrative review may reveal new relationships between concepts not previously appreciated; thus, an integrative review may inspire future research efforts in the area (Torraco, 2005). What follows is an integrative review by Burns and Petrucka (2020) published in a peer-reviewed critical care nursing journal.

## 2.2 Manuscript 1

Burns, M., & Petrucka, P. (2020). Interfacility transfers for advanced critical care services: Impacts on rural families. *Nursing in Critical Care, 25*(3), 179-191. https://doi.org/10.1111/nicc.12487

I collaborated with Dr. Petrucka, course facilitator, and contributed 75% of the work to complete this manuscript that was a result of a course titled *Integrative Review: Critical Appraisals of Health Evidence*. My contributions included: conceptualizing the structure of the review and subsequent manuscript, completing the electronic and manual searches and critical appraisals, data analysis, generation of the conceptual map of themes, writing the initial draft and incorporating feedback from Dr. Petrucka on subsequent drafts, preparing and formatting the manuscript to meet journal guidelines, addressing revisions and subsequently managing post-acceptance duties. This manuscript aligns with and supports the dissertation by presenting the existing conceptual understanding of the phenomenon of interest. This manuscript also identifies gaps in nursing knowledge from which the research question that guided this dissertation was developed.

## 2.3 Abstract

The aim of this article is to provide an integrative review of rural family members' experiences of a relative's interfacility transfer to an urban tertiary care centre for advanced critical care services. Although there is an increasing awareness of the negative consequences of a relative's critical illness for family members, there has been limited research conducted on the impacts of this experience for families of patients in rural settings who require an interfacility transfer for advanced services. The search strategy for this review was framed by the study purpose, research question, and a conceptual structure of key constructs. Databases and reference lists were electronically and hand searched. Articles were included if they were research articles, available in English, and focused on family members' experiences of interfacility transfer during critical illness. Articles focusing on critical care transfers within a single urban setting, elective transfers undertaken for patient or family preference, transfers not associated with critical illness, and systematic or scoping reviews were excluded. Stress and anxiety are central to the rural family members' experience of this phenomenon. These constructs are influenced by modifiable factors including the actions of healthcare providers, the financial burden associated with the transfer, the family members' physical proximity to the patient, and their access to information and support networks. Further research is required to explore potential short- and long-term consequences of this experience, the experience of family who are left behind, and to develop and test interventions to support families. This review highlights the concern that healthcare providers frequently misunderstand the needs of family members who are experiencing this phenomenon. Through a better understanding of this phenomenon, healthcare providers will be better positioned to effectively support these individuals during this unique experience.

## 2.4 Interfacility transfers for advanced critical care services: Impacts on rural families

A critically ill patient's admission to an ICU puts family members at a high risk of developing severe, negative consequences, such as anxiety, depression, complicated grief, and post-traumatic stress disorder (Davidson et al., 2012). In rural areas, the critically ill patients' healthcare needs may exceed the expertise or resources of the local, less specialized hospital; these rural patients may require transfer to urban, tertiary care hospitals for advanced critical care services (Blackwell, 2002; Johnson, 1999).

Rurality as a concept has proven challenging, yet essential, for researchers and health policy analysts to define (Hart et al., 2005). In response to this inconsistency in the literature, Hart et al. (2005) suggest that the unique aspects of rurality as related to the phenomenon of interest be first identified and then used to develop a relevant definition of rurality. Thus, within the context of an IFT for advanced critical care services, the definition of rurality must reflect on local access or lack of access to such services. Definitions of rural and remote as well as other definitions relevant to this review are outlined in Table 1.

Table 2.1

*Conceptual and Operational Definitions of Variables*

| Variable | Conceptual Definition | Operational Definition |
|---|---|---|
| Family member | Close relative of the critically ill patient | Spouse, parent, child, sibling, grandchild, or someone with whom the patient has a similar relationship |
| Critical illness | Admission to a critical care environment for a life-threatening illness | Attendance to an Emergency Department or admission to an ICU for a life-threatening illness |

| | | |
|---|---|---|
| Interfacility transfer | Transfer of a critically ill patient from a critical care unit in one hospital to a critical care unit in another hospital | Transfer of a critically ill patient from their home or local hospital to a critical care unit in a hospital more than one-hour drive away |
| Rural and remote | A geographic location that has limited critical care resources | The family's geographic location that necessitates, at times, transfer to an urban centre for advanced critical care services |

In countries with rural and remote geography and demography, the realities of IFT and resultant impacts are significant to patients, family members, health care practitioners (HCP), and health systems as a whole. For those living in rural and remote settings, the unexpected, urgent IFT of a critically ill patient to a distant hospital potentiates the emotional, psychological, social, and financial burden experienced by family members (Burns et al., 2018). Hence, family members of rural critically ill patients experiencing an IFT have unique needs requiring specific nursing interventions (Mackie et al., 2014).

## 2.5 Background: Justification for Review

There has been an increased recognition and interest in the negative consequences that patients and family members experience during a critical illness episode. Historically, HCPs inaccurately assumed that survivors of critical illness and their family members seamlessly re-enter their lives after a critical illness experience, whereas more recently there is an increased awareness of the negative and sustained physical, emotional, and psychological consequences related to the critical illness experience (Iwashyna, 2010). Accompanying this emerging trend, significant evidence has addressed post-intensive care syndrome and post-intensive care syndrome-family (Davidson et al., 2012; Harvey & Davidson, 2016; Marra et al., 2018). Research efforts in prevention and interventions to mitigate the negative consequences experienced by patients and family members after a critical illness experience have included exploration of the utility of follow-up programs (Svenningsen et al., 2017), specific family support interventions delivered within the ICU (White et al., 2018), and theoretical development related to this emerging area (Ågård et al., 2015).

Despite the work conducted to support patients and family members experiencing a critical illness, the phenomenon of IFT during critical illness has received little attention. Since the intra-hospital transfer of a recovering critically ill patient from an ICU to a medical floor can be a traumatic and stressful experience for family members (Chaboyer, 2006; Cypress, 2013), the experience of an IFT to a tertiary care hospital for advanced critical care services may result in an additional stressor for family members as suggested by Burns et al. (2018). Despite this initial work regarding IFTs in the context of critical illness, our understanding of this phenomenon remains incomplete.

## 2.6 Aims and Objectives

Although the evidence shows that a critical care admission has a negative effect on family members (Davidson et al., 2012), there is a limited understanding of the family members' experiences of an IFT for advanced critical care services. Therefore, the purpose of this paper is to present an integrative review that analyses and critiques the extant research literature related to the family members' experience(s) of an IFT during critical illness. Through this integrative review process, we aimed to consolidate what is currently known about this topic, conceptualize new perspectives, and identify gaps in understanding (Torraco, 2005). The research question that guided this integrative review was: *What is the family members' experience(s) of a relative's IFT for advanced critical care services?*

## 2.7 Design and Methods

### 2.7.1 Type of Review

An integrative review strategy was chosen to guide this literature review as it inclusively analyses and synthesizes research findings across a range of research methodologies thereby potentiating a new conceptualization of the phenomenon of interest (Whittemore & Knafl, 2005). As such, this type of review may exponentially increase our understanding of this complex phenomenon, thereby informing nursing practice and research efforts in this area (Whittemore & Knafl, 2005).

### 2.7.2 Search Strategy

The stated purpose and associated research question form the boundaries for this review (Whittemore & Knafl, 2005). According to Torraco (2005), authors of an integrative review must first develop a “conceptual structure” of the topic to be reviewed (p. 359). This review was conceptually structured around the following constructs: family members’ experiences of critical illness, family coping during critical illness, family members’ experiences of IFT during critical illness, and critical illness with associated IFT in rural and remote areas. When conducting an integrative review, it is important that the variables are both conceptually and operationally defined (Russell, 2005). The conceptual and operational definitions of the key variables within the constructs under study are provided in Table 1.

The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE were searched using combinations of the following medical subject headings (MeSH), subheadings, and keyword terms: family, family coping, family relations, family functioning, family psychosocial factors, acute disease, catastrophic illness, critical illness, emergencies, critically ill patients, patient transfer, transportation of patients, inter-facility transfer, transfer anxiety, transfer discharge, inter-hospital transfer, advanced critical care services, rural hospitals, rural health, and rural health services. Throughout all stages of the review, all methodological decisions were documented in a journal (Coughlan & Cronin, 2017).

### 2.7.3 Inclusion and Exclusion Criteria

To be included in this review, articles were required to be research articles, available in English, focused on the family members' experiences of IFT during critical illness, and used a quantitative, qualitative, or mixed method methodology. Studies that focused on critical care transfers within a single urban setting, elective transfers undertaken because of patient or family preference, and transfers not associated with critical illness were excluded from the review. Because the purpose of this integrative review was to analyse and critique the research literature related to the family members' experience of an IFT during critical illness, theoretical and conceptual articles were excluded. An IFT for critically ill patients who require advanced critical care services is not a new or recent phenomenon; according to Blackwell (2002), patients have been transferred between institutions since the 1970s. Because IFTs have been occurring for nearly 50 years, no limits were placed on publication year to ensure that both older and recent published literature were included (Torraco, 2005).

The electronic database search resulted in 24 articles. The titles and abstracts of these articles were reviewed to determine eligibility for inclusion into the integrative review. References of articles eligible for inclusion in this integrative review were hand searched for additional references that may meet the inclusion criteria. If review articles were discovered, the original research articles within the review were assessed for inclusion (Watson et al., 2018). Hand searches of reference lists resulted in 16 potential articles of which two met the inclusion criteria for this review.

### 2.7.4 Critical Appraisal

Assessing the quality of included articles is an important component of the data analysis phase of reviews (Whittemore & Knafl, 2005). Critical appraisal of the articles proceeded initially with the data reduction technique of extracting and coding data so that the data were structured into the manageable format of summary tables (see Appendix A) (Pinch, 1995; Whittemore & Knafl, 2005). Following this, methodologically appropriate critical appraisal tools created by the Joanna Briggs Institute (JBI) (2020) were used to assess study quality. Two of the included articles were assessed to be of lower methodological quality. In the study by Fulbrook et al. (1999) an explicit identification of the methodological approach that guided the study was absent, and a small sample size and associated lack of measurement tool development and validation limited the strength of the findings in the study by Brown et al. (1998). Because of the low number of retrieved articles, these articles were not excluded; however, less weight was placed in these findings during the conceptualization phase of this integrative review.

### 2.7.5 Data Analysis

This integrative review was developed to inform future research by looking at the knowns and unknowns within the extant evidence. A grounded theory approach to analysis (constant comparative method) was deemed appropriate as it aligns with Milliken and Schreiber's (2001) vision that the aim of a ground theory study is to gain knowledge about socially-shared meaning that forms the behaviors and the realities of the participants of interest. Therefore, the next step of data analysis involved constant comparison whereby data in summary tables were compared and categorized according to similarities (Whittemore & Knafl, 2005). Data displays, where data from individual studies are grouped around specific variables or concepts in a visual display, were used to further enhance data comparison and seek “patterns, themes, or relationships” across studies (Whittemore & Knafl, 2005, p. 551). For example, from the summary tables (see Appendix A), the individual data elements of increased worry experienced from loss of family support networks, increasing panic and anxiety from a perceived lack of information, and feeling overwhelmed and depersonalized in the tertiary care centre were grouped around the concept of anxiety and stress in the data display. As patterns began to emerge, related concepts were grouped and relationships depicted between variables or themes (Whittemore & Knafl, 2005). Through this strategic, analytical, and organizational process, a concept map emerged whereby the conceptual understanding of the phenomenon was enhanced (Kemppainen et al., 2013; Whittemore & Knafl, 2005). From this phase, we synthesized key elements and findings into a “comprehensive portrayal of the topic of concern” (Whittemore & Knafl, 2005, p. 551). During this process of data integration and innovative thinking, a new conceptualization of the phenomenon emerged and gaps in knowledge were identified (Pinch, 1995; Torraco, 2005).

## 2.8 Results

### 2.8.1 Description and Appraisal of Selected Studies

The six included articles were evenly divided between qualitative and quantitative methods. Of the qualitative studies, two used a hermeneutic phenomenological methodology to explore the rural family member’s experience of a relatives IFT to an urban centre for advanced critical care services (Johnson, 1999; Mackie et al., 2014) and one used a case study approach to explore a family member’s experience of a spouse’s critical illness, of which an IFT was a part of the care (Fulbrook et al., 1999). The phenomenological studies by Johnson (1999) and Mackie et al. (2014) used an explicit study design and thus were critically appraised to be the articles with the highest degree of methodological quality in this integrative review. These studies were set within the Australian context, had small sample sizes (10 and 7 respectively), and utilized a study design underpinned by the philosophical assumptions of Heidegger and Gadamer (Johnson, 1999; Mackie et al., 2014). Both studies collected data through participant interviews; however, Mackie et al. (2014) reported maintaining a researcher journal of personal experiences in alignment with Heideggerian assumptions. The study by Johnson (1999) deviates from Heideggerian phenomenological assumptions by employing thematic analysis to analyse data; a limitation in this study. Mackie et al. (2014), however, clearly follow a Heideggerian approach to data analysis thereby further strengthening the findings of this study. Set within the United Kingdom, the third qualitative study by Fulbrook et al. (1999) does not explicitly describe the research methodology utilised; however, it appears to follow a form of case study approach whereby a family member describes their critical care experience and includes an associated commentary from a variety of HCPs. The phenomena discussed by Fulbrook et al. (1999) are similar to those described by Johnson (1999) and Mackie et al. (2014); therefore, despite being appraised at a lower quality because of the absence of methodological description and guidance, this study was used to support the generation of this integrative review.

The quantitative studies all used a cross-sectional descriptive design and were conducted in the United States (Brown et al., 1998; Menon et al., 2015; Perez et al., 2003). As part of a quality improvement initiative, Brown et al. (1998) used a closed-ended survey styled questionnaire to evaluate the family members' perceptions of accompanying a critically ill relative during air transport to an urban tertiary care centre. While the questions in this survey aimed to elicit the family member's perspective of this experience and an open-ended question allowed the participants to identify key areas of the experience not captured in the preceding questions, the development of this tool and its validation were not detailed in the article. This, along with the small sample size weakens the methodological quality of this study. However, because the findings by Brown et al. (1998) align with previously described methodologically sound studies, this study was included in the development of this integrative review. Menon et al. (2015) completed a small retrospective chart review to determine the feasibility of using telemedicine family conferences to support rural family members during a relative's IFT. Although this study is methodologically sound in addressing the study aim, data from family participants were not collected. As such, this study revealed limited information about the family members' experiences of an IFT, and thus contributed minimally to this integrative review. The final quantitative study by Perez et al. (2003) used a modified family needs assessment tool to rank family members' needs during a critically ill relative's IFT from the perspectives of both medical transport personnel and the family members. Although this modified tool was not validated and the sample sizes of family members and medical transport team participants were small, this study highlighted important information related to family needs during IFT and the potential that medical teams misinterpret the needs of family members.

A central theme in the majority of the literature was the anxiety and stress that a family member experienced during an IFT. Subthemes that either increased or decreased the family member's experience of anxiety and stress during an IFT were (a) information available to the family member, (b) the family member's proximity to the patient, (c) the support network of family and home, (d) the financial burden of the IFT, and (e) the role of the healthcare provider (HCP). A concept map of these themes and their relationships is provided in Figure 1. These inter-related themes form the basis of the discussion of family members' experience(s) of a relative's IFT for advanced critical care services as described in the research literature.

### 2.8.2 Anxiety and Stress

Anxiety and stress were predominant themes in all of the qualitative articles reviewed (Fulbrook et al., 1999; Johnson, 1999; Mackie et al., 2014). Family members were found to experience constant anxiety when separated from their critically ill loved one both during and after an IFT (Fulbrook et al., 1999; Johnson, 1999). Indeed, Johnson (1999) and Fulbrook et al. (1999) noted that the anxiety experienced by family members during an IFT to an urban centre is additive to the anxiety experienced by a non-IFT ICU admission. Because the future is unknown, it is important for family members to say goodbye to the critically ill patient prior to the IFT (Mackie et al., 2014). Upon arrival to the urban ICU, rural families feel overwhelmed and depersonalized in this new environment; while they acknowledged the need of the IFT for advanced care, they worried about the quality of care their family member was receiving (Fulbrook et al., 1999; Johnson, 1999). Although family members feel they are able to understand and cope with the situation of their family member's critical illness in their home hospital, this feeling is lost when the IFT occurs (Mackie et al., 2014). The anxiety and stress that family members experience during an IFT can be so profound as to worsen pre-existing health status or increase their physical risk such as becoming involved in motor vehicle accidents while travelling to the urban centre (Fulbrook et al., 1999; Mackie et al., 2014). The constructs of anxiety and stress were found to be influenced by the following subthemes.

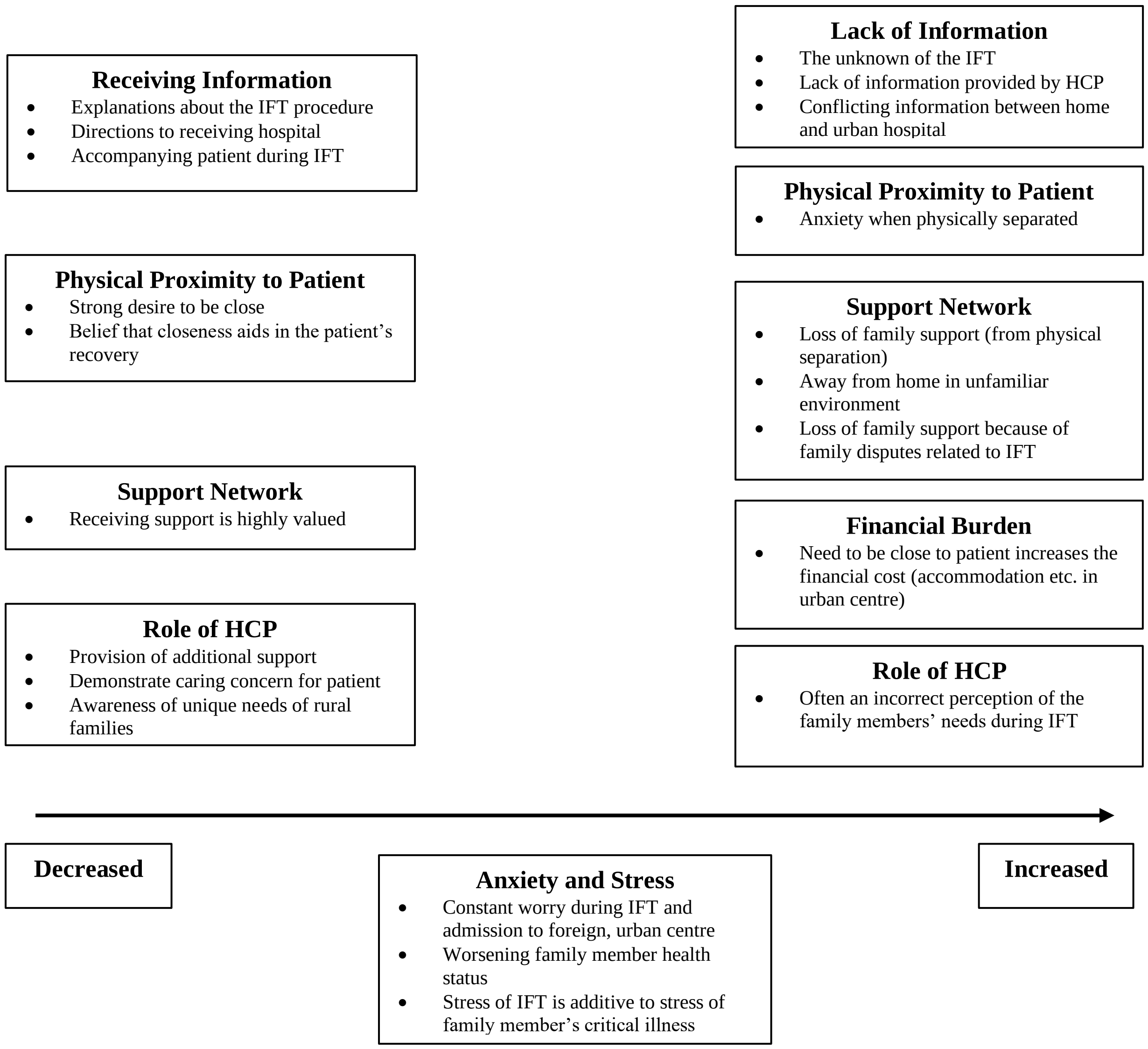

*Figure 2.1.* Conceptual map of themes revealed during data analysis. The central theme of 'Anxiety and Stress' was noted to be increased or decreased by the subthemes noted on the right and left.

#### *2.8.2.1 Need for Information*

Confusion or a perceived lack of information within the context of an IFT and urban centre hospitalization is associated with increased anxiety (Johnson, 1999; Mackie et al., 2014). Navigating to the urban receiving hospital is also challenging and stressful for family members (Fulbrook et al., 1999); family members have identified the importance of receiving directions to the urban hospital prior to IFT (Perez et al., 2003). Providing family members with information about the process of IFT may reduce the anxiety and stress they experience during transfer (Johnson, 1999). Family members may experience confusion related to contradictory information they receive from the rural and urban hospital; differing opinions of the patient's level of acuity and subsequent discharge instructions often fails to meet the family member's need for information thus adding to the experience of stress (Johnson, 1999).

#### *2.8.2.2 Remaining Close to the Patient*

The need to be close to the critically ill family member is a recurring theme in the research literature (Brown et al., 1998; Johnson, 1999; Mackie et al., 2014). In some situations, the need results in the family member sacrificing self as described by both Brown et al. (1998) and Johnson (1999) when family members accompanied the patient in an air ambulance despite a fear of flying. Family members experience anxiety if they are separated from the patient either during or after the IFT (Johnson, 1999) with families perceiving a benefit to themselves, the healthcare team, and the patient's recovery if they are allowed to remain close to the patient during the IFT (Brown et al., 1998; Mackie et al., 2014). Furthermore, the desire to remain close to their family member results in a financial burden related to the cost of accommodation and other necessities in the urban centre (Mackie et al., 2014).

#### *2.8.2.3 Support Network of Home and Family*

The context of home and family support networks are described as valuable and important to family members who are experiencing a patient's IFT (Brown et al., 1998; Mackie et al., 2014); however, because home and family support networks are often several hundred miles away, this loss of support is acutely felt and worsens the feelings of anxiety (Fulbrook et al., 1999; Johnson, 1999; Mackie et al., 2014). The unfamiliar urban environment is depersonalizing for these family members and feelings of isolation have been described

(Fulbrook et al., 1999; Johnson, 1999). Additionally, families who travel to the urban centre to be close to their critically ill family members often share accommodation which, given the circumstances  may contribute to family disputes (Mackie et al., 2014). According to Johnson (1999), these features contribute to the uniqueness of the experience for family members of critically ill rural patients who require IFT.

#### *2.8.2.4 Financial Burden of IFT*

Families described a need to be close to their critically ill family member when undergoing an IFT (Brown et al., 1998; Mackie et al., 2014). However, the associated cost of transport, accommodation, and other necessities to sustain the family, while in the urban centre, creates a financial burden (Johnson, 1999; Mackie et al., 2014). This financial strain, added to the anxiety experienced by family members, may further impact family relations (Johnson, 1999; Mackie et al., 2014).

#### *2.8.2.5 Role of the Healthcare Provider*

Healthcare providers involved in the IFT of a critically ill patient often incorrectly identify what family members' needs are during this experience (Perez et al., 2003). For example, HCPs may not be cognizant that rural family members suffer a loss in family support while in the urban centre; this may result in the HCP not providing necessary additional support to these families, thereby creating a missed opportunity for support and quality care (Mackie et al., 2014). Family members felt that HCPs should allow them to accompany the patient during an IFT; however, family members are often not allowed to accompany patients because of the transport team's personal judgements (Brown et al., 1998). Through the provision of information and explanations about the process of IFT to rural family members, HCPs can reduce their levels of anxiety and stress (Johnson, 1999; Mackie et al., 2014). It is important for family members to know that the transfer team cares about their family member and that the patient will receive the best possible care during transfer (Perez et al., 2003). Furthermore, encouraging the family member to say goodbye before the IFT, involving family members in the patient's care, and employing flexible visiting policies are strategies that the HCP may use to meet the family members' needs to be close to the patient (Johnson, 1999; Mackie et al., 2014).

## 2.9 Discussion

Although anxiety and stress were central themes in the qualitative studies, these constructs were not clearly investigated or discussed in the retrieved quantitative studies. The data collection strategies for these studies involved structured, closed-ended survey style questions; therefore, family members were not invited to or able to describe their experiences outside of the questions asked. As such, the methods used in these quantitative studies may explain the absence of the constructs of anxiety and stress among family members during an IFT.

The identified subthemes are inter-related and together influenced the central themes of anxiety and stress experienced by rural family members of a patient undergoing an IFT for advanced critical care services. The experience of anxiety and constant worry associated with the shift from a non-IFT critical care admission to an IFT may lead to worsening health outcomes and increased physical risk to the involved family members (Fulbrook et al., 1999; Johnson, 1999; Mackie et al., 2014). Through this integrative review of the literature, it appears that a lack of information increases the family members' experience of anxiety during an IFT, whereas receiving information reduces the levels of anxiety these individuals experience. A persistent need to be close to the patient carries with it a financial burden which may further exacerbate the feelings of anxiety and lead to family disputes (Mackie et al., 2014). This may subsequently negatively impact the family support available to these family members further impacting the precarious support already reduced by geography (Johnson, 1999; Mackie et al., 2014). The HCP is an active agent in increasing or mitigating the family members' experiences of the additive anxiety of an IFT. With an increased awareness of the unique experiences and needs of rural family members who undergo an IFT to an urban centre, HCPs are in a position to provide information, demonstrate a caring concern for the critically ill patient, and provide additional support in the context of a disarrayed family network with the aim of reducing the levels of anxiety experienced by these individuals.

Although this review provides an overview of the rural family members' experience of a relative's IFT for advanced critical care services, the research conducted in this area is limited and many gaps in understanding of this phenomenon were revealed. For example, there is a noted need and benefit for family members to be close to their critically ill relative. However, this begs the question: what is the impact of an IFT for those family members left behind at home to manage family responsibilities or who are otherwise unable to travel to the urban receiving hospital? Further exploration is also required into potential short-term and/ or long-term consequences of an experience of an IFT. It is noted that the literature reviewed has primarily come from Australia, but the gap in understanding of this phenomenon also exists outside of this context. To the best of our knowledge, there have been no studies conducted to date in other cultural contexts, aside from a case study in the United Kingdom (Fulbrook et al., 1999). Finally, although this review suggests interventions that HCPs can implement to better care for these family members, there is a need for improved concept clarity to inform subsequent interventions and to assess the impacts on care improvement and family-centred care.

## 2.10 Limitations

This integrative review has several limitations. First, a limited number of recent research articles were available to inform the conceptualization of this topic. Although the search strategy was thorough and inclusive, some research articles may have been missed. Of the six retrieved articles, only two were methodologically very strong which highlights the need for more rigorous research in this area to improve our understanding of this unique phenomenon. The diversity in research methodologies and quality of studies made it challenging to synthesize this evidence into a conceptual structure. To reduce this limitation, a journal was maintained to document all methodological decisions undertaken during this review.

## 2.11 Implications and Recommendations for Practice

This integrative review offers a new conceptualization of the rural family members' experience of a relative's IFT to an urban centre for advanced critical care services. Central to this new conceptualization are the family member's experience of stress and anxiety that are either increased or mitigated by a number of factors. These factors are modifiable and include the family member's physical proximity to the patient, the amount and type of information provided to the family member by HCPs, access to support networks, actions of HCPs, and the degree of financial burden resulting from the IFT. In addition to highlighting the uniqueness of this experience for rural and remote families, this review also reveals the current under appreciation of the unique needs of this population by HCPs.

The results of this review have several implications for nursing practice. Critical care nurses must be cognizant that rural family members of patients undergoing an IFT for advanced critical care services have unique needs distinct from other family members. Recognizing this, critical care nurses can use the findings of this review to guide their care of these individuals and implement interventions designed to reduce the rural family members' experiences of stress and anxiety. Interventions may include ensuring that family members receive detailed information about the IFT process, supporting the family member's desire to be in close proximity to their critically ill relative, and providing additional individual support to family members in the context of reduced family support while in the urban centre.

While this review provides a new conceptualization of this phenomenon based upon the extant research, gaps in knowledge have also been highlighted. Further research is required in other cultural contexts, to explore short-term and long-term consequences, and to examine the impacts on family members accompanying or left behind during an IFT.

## 2.12 Conclusion

Family members of critically ill patients are at high risk of developing severe, negative consequences such as anxiety, depression, complicated grief, and post-traumatic stress disorder (Davidson et al., 2012). Furthermore, an IFT of a critically ill patient for advanced critical care services adds an additional emotional, psychological, social, and financial burden to family members (Burns et al., 2018). Family members exhibit a strong desire to be close to their critically ill family members and separations exacerbate the feelings of anxiety and worry. While it is known that a patient's intra-facility transfer from an ICU to a medical floor can be a traumatic and stressful experience for family members (Chaboyer, 2006; Cypress, 2013), our understanding of the experiences of an IFT for advanced critical care services is incomplete. The aim of this review was to understand what is currently known about this experience, develop a new conceptualization of this phenomenon, and identify gaps in knowledge that require further research. By articulating and building an understanding of the rural and remote family members' experience of an IFT for advanced critical care services, HCPs will be better prepared to care for them with the aim of preventing or reducing the development of negative physical, emotional, and psychological consequences related to the critical illness experience.

## 2.13 Chapter Summary

As outlined in the preceding integrative review, there has been limited research completed that explores rural family members' experiences of a relative's IFT to an urban centre for advanced critical care services. This integrative review provides a conceptualization of an emergent area of critical care nursing and consequently highlights what is known and what gaps exist in our understanding of this phenomenon. In response, the aim of this study was to utilize an interpretive phenomenological methodology to enhance our understanding of the meaning of the lived experiences for family members of a relative's IFT to a distant tertiary care centre for advanced critical care services.

# CHAPTER 3

## 3.1 Method

Phenomenology as both a philosophy and methodology values human experience as foundational to knowledge; thus, this methodology aligns closely with the ideology of nursing and is especially useful to address concerns of the discipline (Mackey, 2005; Munhall, 2012). Prior to successfully undertaking a phenomenological inquiry, the researcher must first develop an in-depth understanding of the philosophical underpinnings of this methodology (Munhall, 2102). Further complicating this undertaking is the difficulty the researcher may have in choosing an appropriate phenomenological methodologist from the available multitude to guide their inquiry (Green, 2014). Prior to undertaking this study, I completed extensive reading and writing on phenomenology as both philosophy and methodology and selected three prominent phenomenological methodologists in nursing to compare and analyse. In completing this work, I aimed to develop an in-depth knowledge of this methodology and also select a specific method appropriate to address the following research question: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* Below, a published, peer-reviewed manuscript by Burns and Peacock (2019) described this exploration of phenomenology.

## 3.2 Manuscript 2

Burns, M., & Peacock, S. (2019). Interpretive phenomenological methodologists in nursing: A critical analysis and comparison. *Nursing Inquiry*, *26*(2), 1-10 https://doi.org/10.1111/nin.12280

I collaborated with Dr. Peacock, co-supervisor and course facilitator, and contributed 75% of the work to complete this manuscript that was a result of an independent reading course on phenomenology. My contributions included: conceptualizing the structure of the manuscript, writing the initial draft and incorporating feedback from Dr. Peacock on subsequent drafts, preparing and formatting the manuscript to meet journal guidelines, addressing revisions and subsequently managing post-acceptance duties. This manuscript aligns with and supports the dissertation by presenting the justification and detailed discussion of differing forms of interpretive phenomenology and shares the in-depth reflection and consideration undertaken to determine the best approach to be used to study IFT for rural family members.

## 3.3 Abstract

Phenomenology is one of the most popular qualitative research methodologies used in nursing research. Although interpretive phenomenology is often a logical choice to address the concerns of nursing, the vast number of methods of phenomenology means choosing an appropriate method can be daunting, especially for novice researchers. It is critical that nurse researchers select a phenomenological method that fits the research problem and the skill and world view of the researcher; doing so will result in a research experience that resonates with and excites the researcher. The interpretive phenomenological methodologies of Benner, Munhall, and Conroy each offer unique methods of phenomenological inquiry. However, to date, we are not aware of any literature that explores and compares the methodological approaches of these nurses. In this paper, the origins and influence of phenomenology as both a philosophy and methodology on nurse researchers will be explored, followed by a critical analysis and comparison of these three nurses. By highlighting the distinctive differences and attributes of each method, this paper provides an analysis and comparison of the approaches of these prominent nurses. In doing so, we aim to aid the researcher in their methodological selection, thereby resulting in a successful and rewarding research endeavor.

Keywords: Phenomenological Research, Phenomenology, Nursing Research, Nurse Researchers, Qualitative Studies, Benner, Munhall, Conroy

## 3.4 Interpretive phenomenological methodologists in nursing: A critical analysis and comparison

According to Heidegger (1953/2010), phenomenology aims to reveal the essential theme that is concealed within that which shows itself: The "truth of being…*Ontology is possible only as phenomenology*" (p. 33). Heideggerian or interpretive phenomenology and its ontological form of questioning aim to uncover fundamental dimensions of phenomena that are rarely accounted for, thereby providing an opportunity to understand the lived experience of being-in-the-world (Crowther et al., 2017; Orbanic, 1999). Indeed, according to Crowther et al. (2017), the interpretive phenomenological approach underscores the importance of connecting with the individual on numerous levels and to thoughtfully consider the shared human experience. Because the philosophy of phenomenology aligns with the ideology of nursing (Munhall, 2012), nurse researchers are often drawn to interpretive phenomenology as a logical choice to address the concerns of nursing. In fact, phenomenology is second only to grounded theory as the most popular nursing research methodology (Petrovskaya, 2014).

Although internationally nurses frequently use interpretive phenomenology in their research endeavors, choosing a method of phenomenology can be daunting for the novice researcher; according to Spiegelberg (1982), methods of phenomenological inquiries are as numerous as phenomenologists themselves (cited in Dowling, 2007). Indeed, as we embarked upon our journey into the realm of interpretive phenomenology as novice researchers, we were at once confronted with the perceived elusiveness and complexities of the philosophical underpinnings of this methodology. To add further complexity for the novice phenomenological researcher, there is a tangle of linguistic confusion surrounding phenomenology. According to van Manen (2017a), while there have been efforts made by authors to make practical distinctions between different phenomenological philosophies and methodologies, this may have increased misunderstandings about phenomenology. Subtle differences in the spelling of *interpretive* phenomenology and *interpretative* phenomenology should not be dismissed simply as cultural preferences in spelling. Indeed, there are significant differences between interpretive phenomenology and interpretative phenomenological analysis, so much so that in fact van Manen states that interpretative phenomenological analysis “is really interpretive psychological analysis” (van Manen, 2017a, p. 778).

With intensive study and contemplation of the philosophical principles of Heideggerian phenomenology and an increasing appreciation of the confusion of language related to phenomenology, our initial murkiness of understanding gradually gave way to a clarity of understanding. However, confusion and hesitation returned as we searched through a multitude of interpretive methods for an appropriate method to guide our phenomenological inquiries. As stated by Green (2014), choosing the right phenomenological method is important because a method that is commensurable to both the researcher and the proposed study topic will resonate with and excite the researcher. However, phenomenological methodologists in nursing are infrequently discussed in the literature; as such, it can be very challenging for novice nurse researchers to find the *match* they seek with a particular interpretive phenomenological methodologist.

To the best of our knowledge, there has been no paper published to date that describes and compares interpretive phenomenological methods developed by nurses. Therefore, it is the purpose of this paper to explore the origins and influence of interpretive phenomenology upon nursing researchers. Furthermore, an exploration and comparison of three nurse interpretive phenomenological methodologists (namely Benner, Munhall, and Conroy) will be offered with the aim of supporting nursing researchers in selecting a method of interpretive phenomenology that fits well with them and the aims of their study. Although other interpretive phenomenological methodologists in nursing are noted within the literature, we have decided to limit our discussion to these three nurse methodologists because they are frequently referenced internationally, and also because their methods are germane to the context of clinical nursing practice.

## 3.5 Background

### 3.5.1 Origins of Interpretive Phenomenology

Heidegger is considered to be the founding father of philosophical hermeneutic phenomenology; however, the work of Heidegger is built upon the work of Husserl, an early twentieth century phenomenologist who mentored Heidegger during his studies in Germany prior to the First World War (Annells, 1996). Prior to Heidegger’s work, Husserl developed the philosophy of phenomenology in response to the prevailing views of the time about the nature of truth (Dowling, 2007). Husserl objected that philosophy had ceased to value experience itself as phenomena that could and should be studied in a scientific manner; instead the philosophical treatment of experiences was to consider them as nothing more than an irrelevant illusion to be objectively explained and consequently dismissed (Carman, 2006). This progressive creep of naturalism into the philosophical thinking of the time resulted in primacy being given to the objective world, with subjective meanings or realities being dismissed (Carman, 2006). Husserl considered experience to be the ultimate source of knowledge, and consequently rejected this empiricist position (Racher & Robinson, 2002). Hence, phenomenology is the study of subjectivity, distinct thereby from prevailing empiricist positions (Carman, 2006).

Although Husserl and Heidegger agreed that phenomenology is descriptive in nature, there are several differences inherent within their philosophies (Carman, 2006). Husserl conceived of phenomenology "as a science of the cognition of essences", thus transcendental in nature whereby an untainted description of consciousness is sought through phenomenological reduction (Annells, 1996, p. 706; Carman, 2006). Through reduction, the phenomenologist sets aside or brackets preconceived understandings and biases so that phenomenon can be seen as purely as possible, without prejudice (Dowling, 2007; Koch, 1995); phenomenological reduction makes possible the description of pure consciousness (Carman, 2006). Husserl's phenomenology is founded upon the Cartesian duality, or the mind body split and is objective in nature whereby the researcher is removed from the context of study; these elements thus place this philosophy within the post-positivist paradigm (Koch, 1995; Lincoln et al., 2018). Heidegger however, considered it impossible to achieve this pure description through observation as it were, and instead articulated that phenomenology is an interpretation of *Daesin* or "human existence" (Carman, 2006; Guignon, 2006, p. 3). Heidegger objected to both Husserl's assumption of a Cartesian duality, as well as the objective intent of Husserl's phenomenology to uncover essences of phenomena that remain unaffected or unchanged by the researcher (Koch, 1995). These differences led to the development of an alternative phenomenological philosophy: Heideggerian or interpretive phenomenology.

### 3.5.2 Interpretive Phenomenology

Husserl's phenomenology is epistemological in its approach whereby the researcher seeks "what can be known" about the world (Annells, 1996; Koch, 1995; Mackey, 2005, p. 181). However Heidegger reacted to the epistemological and purely descriptive focus of Husserl's phenomenology and extended it to be more ontological in nature whereby the researcher seeks to understand “the meaning of Being” (Annells, 1996; Koch, 1995; Mackey, 2005, p. 181). Heidegger developed Husserl’s work to be more interpretive than descriptive because Heidegger asserted that all knowledge is an interpretation (Amos, 2016). Indeed, according to Heidegger, it is through *being-in-the-world* that understanding occurs (Annells, 1996); as such, researchers who are guided by Heidegger’s philosophy will aim to understand the nature of being rather than searching for what can be known (Mackey, 2005). Dasein, a term used by Heidegger, represents the notion of human existence within context, or what it is to be human in the world (Annells, 1996; Koch, 1995). According to Heidegger, “being-in-the-world is an *a priori* necessary constitution of Dasein” (Heidegger, 1953/2010, p. 54). Humans are situated within their world and cannot be separated from their culture, relationships, or history; thus, individuals arrive at a situation with pre-understandings or fore-structures that cannot be held in abeyance or bracketed as was suggested by Husserl (Amos, 2016; Koch, 1995; Mackey, 2005).

To understand human existence, Heideggerian phenomenology requires one to consider *Being* in relation to the philosophical concepts of space, time, embodiment, and care (Mackey, 2005; Taylor, 2006). These concepts along with the hermeneutic circle have significantly influenced nursing phenomenological approaches and will be described in more detail below.

#### ***3.5.2.1 Spatiality, Temporality, Embodiment, and Care (Sorge)***

It would be an error on the part of the researcher to proceed with an interpretive phenomenological study without first becoming immersed in and understanding the ontological thrust of Heidegger’s philosophy: “what it means to *be* a person and how the world is intelligible to us at all” (Leonard, 1994, p. 45). According to Heidegger (1953/ 2010), *Dasein,* does not travel through measured space, rather distance disappears through de-distancing or “bringing near” (p. 102). Being-in-the-world encompasses human existence that is situated within space;

from their location, individuals pull elements of importance or concern closer to them while holding other elements that are perceived to be less important at a distance (Mackey, 2005). Thus, when conducting an interpretive phenomenological inquiry, it is essential that the nurse researcher positions the participants' descriptions of their experience within space and note what the individual brings close to their being-in-the-world, and what is subsequently held at a distance, and may be meaningful, yet beyond the realm of awareness (Mackey, 2005; Orbanic, 1999).

Human experience is situated in time, and according to Heideggerian phenomenology, interpretation of human experience cannot occur without consideration given to time as a foundational element of human existence (Mackey, 2005). *Dasein* is at once the past, present, and future (Heidegger, 1953/2010). Temporality provides context and through being-in-the-world, the past, present, and future simultaneously shapes the *lived experience* as described by the individual (Orbanic, 1999). To situate the individual's experience within time, particular attention must be paid to events that stand out within the individual's descriptions of being-in-the-world; doing so enhances understanding of the temporality of the experience, and thus "the nature of Being" (Mackey, 2005, p. 184).

Heidegger has been criticized for not acknowledging the role of the body with regard to being-in-the-world (Aho, 2005). It is thought by some that Heidegger's omission of the body was deliberate in an effort to dismantle the prevailing philosophical view that "humans are essentially free 'individuals,' as self-contained subjects with no roots to a shared, historical lifeworld" (Aho, 2009, p. 9); this Cartesian philosophy asserts that people *have* a body rather than are embodied (Leonard, 1994). This perceived omission by Heidegger was addressed by the phenomenologist Merleau-Ponty who, building upon the work of Heidegger, described the relationship between the human body and existence (Aho, 2005; Taylor, 2006). As such, scholars note the Heideggerian phenomenological assumption that the consciousness and body are closely and inextricably linked; thus, by being embodied, physical sensations, feelings, and thoughts are connected and concurrently experienced, thereby shaping our being-in-the-world (Orbanic, 1999; Taylor, 2006). Through being cognizant of embodied experiences, individuals can recognize and explore connections between the mind and body, and subsequently gain interpretations into the meaning of the lived experience (Orbanic, 1999).

Care or *sorge* is a form of being that "is a *being toward* [*Sein zu*] beings encountered in the world" (Heidegger, 19953/2010, p. 118). *Sorge* represents the notion that it is through the individual's caring, concern for people, or meaningful experiences that connects people in a relational way (Koch, 1995; Mackey, 2005; Orbanic, 1999). In describing Heidegger's notion of care, Zimmerman (2006) states "To be human means to be concerned about things and to be solicitous toward other people" (p. 300). Meaningfulness and caring are inextricably linked, and in gaining an understanding of one, the other also becomes understood (Orbanic, 1999). This understanding of space, time, body and caring is essential to the work nurses carry out with individuals at the bedside or in the community.

#### *3.5.2.2 Hermeneutic Circle*

Understanding the "meaning of being" is not a logical, rational process (Heidegger, 1953/ 2010, p. 7). Rather, understanding involves a "'relatedness backward or forward' of what is being asked about (being) [Sein] to asking as a mode of being a being" (Heidegger, 1953/2010, p. 7). Heidegger (1953/2010) refers to the "circle" of understanding where meaning is influenced by and inextricably linked to "fore-structures" or pre-understandings of being (p. 147-148). Hence, understanding happens through being-in-the-world and arises through the process referred to as the hermeneutic circle (Mackey, 2005). The hermeneutic circle is the back and forth process between pre-understandings and a more complete understanding; an individual's pre-understandings influence the act of understanding and then are subsequently modified during the process of the hermeneutic circle (Koch, 1995; Mackey, 2005). The interpretive phenomenological approach assumes a co-creation of data between the interpreter and the participant; this co-creation occurs because of the hermeneutic circle (Koch, 1995).

## 3.6 Data Sources

This paper is based on our own experiences and is supported by scholarly phenomenological literature. The original works of Heidegger (1953/2010), Benner (1994a), Munhall (1994), and Conroy (2003) were consulted and supplemented by peer-reviewed journals and companion texts.

## 3.7 Discussion

### 3.7.1 The Influence of Interpretive Phenomenology on Nursing Research

Generally speaking, in social and scientific arenas, post positivists' methods of inquiry such as quantitative methodologies hold a place of privilege as the most respected way to generate knowledge. However, considering that nursing is a human science and as such is interested in understanding and interpreting meanings (Munhall, 1989), these methodologies of inquiry may have limited usefulness in answering some questions that are important to the discipline of nursing. In contrast to quantitative methodologies, nurse researchers have found phenomenology to be a meaningful methodology because it values experience as the foundation of knowledge and as such is consistent with the ideology of nursing (Mackey, 2005). However, the use of phenomenology as a research method in nursing inquiries has not been without controversy; indeed there has been much scholarly debate from the 1990's through to present.

Crotty (1997) notes that there are dichotomous interpretations of Heidegger's work in its application to nursing research endeavors. These "opposite" interpretations of Heidegger's philosophy are important considerations not only because they impact how researchers conduct research, but also because they impact how they see and react to the world (Crotty, 1997, p. 89). To address these disagreements in interpretations of Heidegger's philosophy, Crotty encourages researchers conducting an interpretive phenomenology inquiry to discern Heidegger's (1953/2010) true intent by returning to the text *Being and Time*.

Paley (1998; 2014) offers further criticism of the use of phenomenology as a research method in nursing inquiries. According to Paley (2014), nurse phenomenologists have misread the work by Heidegger and as such, the "'Heideggerian' phenomenological studies in nursing, psychology and education are based on a mistake" (p. 1521). Paley (1998) articulates that nursing studies of the *lived experience* contravene the ontology of Heidegger because they invoke Cartesian duality between what is *experience* and what is *reality*. Furthermore, Paley asserts that collecting data through the use of interviews is distinctly anti-Heideggerian and that more appropriate means of collecting data for a Heideggerian based study include observation, discourse analysis, and naturalistic experiments (Paley, 2014). Paley's assertions have not gone unnoticed by other scholars; the distinguished hermeneutic phenomenologist van Manen (2017b) published an incisive and at times scathing reply to Paley's assertions related to interpretive phenomenology to which Paley (2018) also replied in similar fashion. Despite these at times fierce scholarly debates, it must be acknowledged that interpretive phenomenology as a research methodology has been and continues to be a valuable tool for the discipline of nursing with regards to generating knowledge that aligns with the principles and practice of nursing.

Despite (or because of) these scholarly debates, phenomenology as a methodology remains popular among nursing researchers. According to Kleiman (2004), although phenomenology did not evolve from the discipline of nursing, findings of a phenomenological inquiry are legitimate for use in nursing practice when the researcher conducts the inquiry from the disciplinary perspective of nursing. Furthermore, in addition to focusing on human experience, interpretive phenomenology specifically emphasizes the importance of considering the context of human existence while at the same time recognizing that all understandings are interpretations; as such, gaining an understanding of the meaning of experiences of our patients can subsequently inform both nursing research and practice (Mackey, 2005; Matua & Van Der Wal, 2015). To illustrate the influence of interpretive phenomenology on nursing research, methods developed by the nurse phenomenologists Benner, Munhall, and Conroy will be explored.

#### *3.7.1.1 Benner*

Benner is a nurse researcher who developed an interpretive phenomenological method that aims to address problems and concerns that are important to nursing (Benner, 1994b). Benner (1994b) challenges readers of her work to "consider the power of understanding for becoming more effectively, skillfully, or humanely engaged in practice" (p. xv). To gain this understanding, one must consider both the phenomenon of interest as well as the context under which the individual experienced the phenomenon (Benner, 1994a). In doing so, the researcher gains understandings of not only the phenomenon of interest, but also of themselves, other individuals, and the world at large. Benner (1994a) asserts that personal knowledge, social contexts, and research methodologies enable and influence the understandings that are gained during an inquiry. In conducting an interpretive phenomenological inquiry, Benner asserts that a key research skill of researchers is to be reflexive in appreciating how their personal background impacts their understanding of their participants' world and experiences. Therefore, in approaching a phenomenological inquiry, Benner (1994a) identifies that researchers must clearly understand any personal assumptions they bring to their research project prior to commencing the study. Specific considerations for study designs guided by Benner's interpretive phenomenological method are outlined in Table 2.

Table 3.1

*Comparison of the Method's of Benner, Munhall, and Conroy*

| Study Considerations | Benner (1994a; 1994b) | Munhall (1994; 2012) | Conroy (2003) |
|---|---|---|---|
| Aim | To address problems important to nursing practice. | To understand meanings of experiences and to defend against generalizations and dehumanizing practices. | To interpret changes (paradigm shifts) in individual understanding of how to be in the world. |
| Study Outcome | "Consider the power of understanding for becoming more effectively, skillfully, or humanely engaged in practice" (1994a, p.xv). | Through understanding, partnership within the nurse patient relationship is enhanced. | A spiraling process whereby key people build upon each other's understandings. |
| Researcher's Approach | Reflexivity of personal background and assumptions that both shape the researcher's interpretations and are subsequently modified during the research process. | • Assumption of the perspective of *unknowing*.<br>• Through *unknowing*, different understandings are allowed to emerge during the course of the study.<br>• The researcher's worldview is changed. | • Researcher shares personal ideologies with participants as they build upon each other's interpretations of the phenomenon.<br>• The researcher must ensure that the meanings revealed are those of the participants and not the researcher's understandings of the meanings. |
| Sample Size | • Dependent upon the forms (individual and group interviews, participant observations, documents), number of researchers available to analyze data, and the amount of data collected.<br>• Large amount of data is encouraged. | • No set rules; guided by the nature of the phenomenon.<br>• Becomes known only as the study progresses. | • Inclusion of groups: individuals engaged with the phenomenon, the community that contributes to the context, and the researchers themselves. |

| | | | |
|---|---|---|---|
| Pragmatic Considerations | • Conduct interviews in a natural context.<br>• Probing to clarify.<br>• Multiple interviews to fill gaps in understanding.<br>• Second researcher present during interviews to enhance data collection.<br>• Structured approach to data analysis (paradigm case, thematic analysis, exemplars). | • Multiple interviews with each participant.<br>• The interview is a conversation with minimal interruptions from the researcher; only general prompts.<br>• Structured approach to data analysis through the four life-worlds (spatiality, corporeality, temporality, relationality).<br>• Final, overarching narrative produced.<br>• Member checking. | • Multiple interviews until sufficient repetition of understanding occurs for the participant.<br>• Researcher logbooks and second readers (five) to enhance accuracy of interpretations. |

According to Benner (1994a), data collection and analysis occur simultaneously; it is this "interpretive dialogue" that ensures the researcher can follow lines of inquiry that arise from the interviews and are related to the phenomenon under study (p. 107). During data collection, Benner (1994a) advocates the researcher to first identify a *paradigm case*; a paradigm case is a strong example of a particular way of being-in-the-world and may be selected by the researcher as the case they feel they understand the best or is the most puzzling. To develop a paradigm case, the researcher first reads the interview transcript as a whole to gain a global appreciation for the phenomenon under study, and then selects particular components of the text to analyze for further interpretation (Benner, 1994a). Once the initial paradigm case is created, additional paradigm cases are created and analyzed independently and then in comparison to the initial paradigm case for commonalities and differences between cases (Benner, 1994a). Comparing paradigm cases enhances the researcher's understanding of the participants' way of being: "Through their different concerns and eyes we more fully see the practical world of both. One naturally occurring practical world sheds light on another" (Benner, 1994a, p. 114-115).

Once paradigm cases have been established, a *thematic analysis* is conducted across these cases to reveal differences and similarities in patterns or concerns that are felt to be meaningful

(Benner, 1994a). During this analysis, the researcher moves back and forth between the parts and the whole of the data and fluctuating from dwelling within the participant’s world to observing this world from afar in an effort to understand and interpret the experience (Benner, 1994a), similar to the hermeneutic circle. Drawing on Leonard’s (1994) Heideggerian phenomenological view of the person whereby the person is viewed as “having a world” (p. 46), as “a being for whom things have significance and value” (p. 49), as “self-interpreting” (p. 51), as “embodied”, and as a “person in time” (p. 53), the researcher comes to interpret and understand the phenomenon of interest (Benner 1994a).

Finally, in preparing the study findings, the researcher provides exemplars pulled from the data that demonstrate the differences and commonalities that were revealed during data analysis (Benner, 1994a). These exemplars consist of examples of elements of the phenomenon that remain constant across differing contexts and are helpful in recognizing patterns, thereby increasing the understanding of the phenomenon (Benner, 1994a).

An example of the use of Benner’s (1994a) phenomenological approach can be found in the study completed by Massimo et al. (2013). Consistent with the aims and anticipated outcomes of Benner’s phenomenological method, the purpose of this study was to explore the experiences and responses of partners of patients diagnosed with frontotemporal degeneration; according to the authors, a better understanding of the partner’s experiences is needed so that the healthcare provider may better support these individuals (Massimo et al., 2013). Massimo et al. describe the approach used by the researchers during this inquiry whereby their personal assumptions and pre-understandings were explored and made explicit thereby allowing the meanings of the participants to be revealed. Contrary to Benner’s (1994a) suggestion, the sample size for this study was extremely small; however, the authors do acknowledge this is a limitation of their study and recommend a larger sample size for future studies of this nature (Massimo et al., 2013). Consistent with Benner's (1994a) method, data collection involved interviews with probing that were conducted in a natural setting, the participant's home. A second interviewer was not present during the interviews as recommended by Benner (1994a), however, a second researcher was involved during data analysis (Massimo et al., 2013). During data analysis, the authors identify that a structured approach was used as suggested by Benner (1994a) whereby themes and exemplars are generated from the data (Massimo et al., 2013). Although the transferability of this study is limited because of the sample size of two, we chose it as an example of Benner's method because it clearly demonstrates the application of this interpretive phenomenological method in a nursing research inquiry.

#### *3.7.1.2 Munhall*

Munhall is a nurse researcher who developed an interpretive phenomenological method to aid nurses in understanding the meanings that reside at the core of each individual's experience, thereby enhancing partnerships within the nurse-patient relationship (Munhall, 2012). Munhall's (1994) method of interpretive phenomenology focuses on understanding the meaning of being human in all of its many modes. According to Munhall, the phenomenological approach is a pillar of defense against widespread generalizations, amoral practices, and technological practice environments that are dehumanizing. As with Benner's (1994a) assumptions, Munhall asserts that being exists within both historical and unique contexts; this context is fluid and is influenced by time, space, embodiment, and relationships.

In contrast to Benner's (1994a) method, Munhall (1994; 2012) stresses the need of the researcher to assume a perspective of *unknowing* when approaching a phenomenological inquiry. Munhall (1994) acknowledges the debate in the literature related to whether or not bracketing is possible; however, she notes that unknowing may be a better term to describe the notion that a researcher must set aside their beliefs and pre-understandings so that different understandings may be allowed to emerge during the course of study. Unknowing is described by Munhall (1994) as a decentering process whereby the researcher suspends themselves, thereby allowing the participant’s unique reality to become known to the researcher. Through unknowing, Munhall (1994) states that the researcher is then enabled to understand the context of the participant’s experience and, thus, understand the meaning of their being-in-the-world.

Although Munhall (1994; 2012) identifies unknowing as an essential element of her method of phenomenological inquiry, she also alludes to the co-creation of knowledge that occurs between the participants and researcher. Because the researcher approaches an inquiry from their own subjective world, Munhall (2012) stresses the importance of the researcher documenting their subjective world as acknowledged through self-reflection. Self-reflection is a circular process whereby the researcher flows back and forth between the parts and the whole of understanding (Munhall, 2012), much like the hermeneutic circle. According to Munhall (2012), this research process will result in changes within the researcher’s worldview. Specific considerations for study designs guided by Munhall’s interpretive phenomenological method are outlined in Table 2.

Data analysis occurs with the researcher dwelling with the data collected from participant interviews in an attempt to understand the meaning of the experience that the participant was trying to express (Munhall, 2012). Additionally, Munhall (1994) notes that artistic mediums such as photographs may supplement the data and aid in understanding experiences. Whereas Benner uses paradigm cases, thematic analysis, and exemplars during data analysis, Munhall (1994; 2012) encourages consideration and analysis of the data through the lenses of the four *life-worlds* as a way to situate data within context, thereby enhancing the researcher's understanding of the phenomenon. These four life-worlds as described by Munhall (2012) include spatiality, corporeality (or embodiment), temporality, and relationality. Although these life-worlds are described as distinct, Munhall (1994) articulates that they must also be considered together, as one single life world.

In order to determine if the researcher has successfully captured an understanding of the meaning of a participant's experience, Munhall (2012) suggests returning to the participant with descriptions and interpretations of the phenomenon; if the participant agrees that their experience has been captured in these writings, then the researcher can be confident that they succeeded in interpreting the meaning of the participant's experience. Upon completion of the study, the researcher reflects on individual descriptions and interpretations and then writes an overarching interpretation (i.e., narrative) of the phenomenon, including both similarities and differences of meanings (Munhall, 2012). Once again, Munhall (2012) encourages the researcher to return to the participants to share the overarching narrative. Generating a narrative of a particular phenomenon is a powerful means to understanding the lived experience of persons in a given context. Where Benner favors exemplars or clinical examples to showcase consistent elements of the phenomenon, Munhall advocates for narratives or stories written by the researcher as a means to share a co-created understanding of the lived experience.

An example of the use of Munhall's phenomenological method can be seen in the study conducted by Peacock et al. (2014). In this study, the aim was to understand the experiences of family members who cared for relatives who had dementia and were approaching end of life (Peacock et al., 2014). Through increasing our understanding of this experience, the authors sought to enhance the supportive relationship between the healthcare provider and family member (Peacock et al., 2014). This aim aligns with the aims of Munhall's (1994; 2012) interpretive phenomenological method: To understand the meanings of experiences to enhance the partnership between the nurse and patient. In this study, Peacock et al. (2014) note that the researchers sought to attend to the "existential context of the lived experience of the participants" (p. 119) which alludes to the use of Munhall's (1994) concept of unknowing. The sampling strategy of this study was purposive in nature and guided by the nature of the phenomenon; the authors pursued a heterogeneous sample in order to obtain a diverse understanding of the phenomenon (Peacock et al., 2014). This sampling strategy resulted in 11 participants recruited to the study. During data analysis, as guided by Munhall (1994; 2012), interviews where conversational in nature and involved only sparing, general prompts to garner meanings of this experience (Peacock et al., 2014). Each participant was interviewed two or three times to enhance interpretation as guided by Munhall (1994; 2012). Data analysis involved the structured approach advocated by Munhall (1994; 2012) whereby data were analyzed through the four life-worlds. The resulting narrative generated through data analysis was then subsequently checked by participants to ensure the interpretations where resonate, accurate and credible (Peacock et al., 2014). Finally, following Munhall's method (1994; 2012), the primary researcher in this study published an overarching narrative of the family members' experience of caring for relatives with dementia at end of life in a separate publication (Peacock, 2015).

#### *3.7.1.3 Conroy*

Conroy (2003) is a nurse researcher who developed an interpretive phenomenological method in reaction to Benner's (1994a) method of interpretive phenomenology. According to Conroy, Benner's search for themes, paradigms, and exemplars mistakenly implies a consistency in an individual's reality that contravenes Heideggerian principles; instead, Conroy asserts that in an interpretive phenomenological inquiry, the researcher must explicitly search for the fluctuations that inherently occur in the human mode of thinking. Although Benner (1994a), Munhall (1994; 2012), and Conroy all identify their methods as interpretive in the tradition of Heidegger, there are key differences in Conroy's approach that will be discussed below.

Conroy (2003) asserts that Heidegger's phenomenology assumes human existence is dynamic in nature, such that change is constant and ever-present in life. When an individual experiences a disquieting awareness of the nature of their existence, a *paradigm shift* occurs in their thinking whereby the individual's way of understanding of how to be in the world changes (Conroy, 2003). Interpretation of these paradigm shifts is the focus of Conroy's interpretive phenomenological method and is represented in the *hermeneutic spiral* (rather than a circle). According to Conroy, the hermeneutic circle by nature is a closed loop of circling understandings that requires modification to include more than simply the interpretations shared between the researcher and the participant. As such, Conroy proposes a release of the circle into a hermeneutic spiral, thereby permitting the inquiry to grow through the inclusion of interpretations of others. Through the use of the hermeneutic spiral, the inquiry process is envisaged as spiraling whereby key people converge to build upon each other's understandings. This spiraling process is unique from Benner (1994a) and Munhall's (1994; 2012) methods.

As with Benner (1994a) and Munhall (1994; 2012), Conroy (2003) emphasizes that all understandings are co-created, and that while data are collected primarily from narratives, other media are also valuable sources of information. Conroy also agrees with Munhall (2012) that it is important to return to participants with interpretations to access their accuracy. There is also agreement between Benner and Conroy's methods to using exemplars during a phenomenological inquiry. However, Conroy's method of interpretive phenomenological inquiry contains elements that are unique from the previous methods. In contrast to Munhall's (1994; 2012) method where the researcher must assume a position of unknowing during a phenomenological inquiry, Conroy asserts that the researcher should share their personal ideologies with the participant as both the researcher and participant build upon their interpretations of the phenomenon during the course of the inquiry. This researcher stance is similar than that which is described by Benner (1994a). Specific considerations for study designs guided by Conroy's interpretive phenomenological method are outlined in Table 2.

To enhance the quality of an inquiry during data collection and analysis, Conroy advocates the use of researcher logbooks and second readers as methodological devices to generate accurate interpretations. Although Conroy does not explicitly define the requirements for second readers in an interpretive phenomenological inquiry, she advocates the use of five, second readers who are experienced in seeking that which is not immediately obvious. These second readers both audit the primary researcher's interpretations and also through their contributions to the project, further build upon these interpretations (Conroy, 2003). As such, Conroy's phenomenological method is similar to Benner's (1994a) method in regard to the use of multiple researchers, yet different from Munhall (1994; 2012) who describes the role of a single researcher in a phenomenological project.

An illustration of the use of Conroy's phenomenological method can be seen in the study of adolescents with chronic pain by Forgeron et al. (2013). The aim of this study was to explore peer relationships between adolescents and understand the impact of the experience of chronic pain on these relationships (Fogeron et al., 2013). As guided by Conroy's (2003) phenomenological method, the outcome of this study was the generation of understandings of the impact of chronic pain on adolescent relationship through interpretation by the principle investigator that where then expanded upon by the co-investigators (Fogeron et al., 2013). Fogeron et al. (2013) used Conroy's method to guide the researcher's approach to this inquiry whereby the researcher and participants build upon each other's understanding of the phenomenon of interest. For example, Fogeron et al. note that the hermeneutic spiral began with the adolescents' interpretation of their relationships during their individual interview with the researcher. This spiral continued as the primary researcher dwelled with the interview data, built upon these understandings using their own experiences and knowledge of the literature, and continued with discussion and debate between the primary and secondary researcher (Fogeron et al., 2013). The sampling procedure for this study involved the recruitment of 16 adolescents, however, Fogeron et al. did not include other groups that contribute to the context of the phenomenon of interest as suggested by Conroy. However, the researcher's approach described above implies the inclusion of the researchers as participants. Additionally, Fogeron et al. also deviate somewhat from Conroy's method by conducting a single interview with each participant. Fogeron et al. however did include the use of field notes and second readers (four) during data collection and analysis as described in Conroy's method.

## 3.8 Implication for Nursing Researchers

The field of qualitative research is dynamic, and at times its methodologies can be both complex and contradictory (Denzin & Lincoln, 2018). Indeed, according to Denzin and Lincoln (2018), disagreements regarding qualitative methodologies and subsequent interpretation of findings are common and in fact expected within the realm of qualitative research. An example of methodological disputes in relation to interpretive phenomenology have been noted previously. To further add to the complexity of qualitative research, each qualitative methodology often shares similar features with other qualitative methodologies, thus blurring the boundaries between methodological approaches (Moser & Korstjens, 2017). For example, although the methodologies of phenomenology, discourse analysis, and grounded theory sprouted from unique intellectual traditions, “their coevolution in the history of ideas means that the boundaries between them are porous” (Starks & Brown Trinidad, 2007, p. 1373). Examples of overlap in these methodologies include the similar approaches to sampling, data collection, and interview strategies (Starks & Brown Trinidad, 2007).

This overlapping of methodological strategies can be seen in the interpretive phenomenological methods proposed by Benner (1994a; 1994b), Munhall (1994; 2012), and Conroy (2003). For example, Benner’s method of data collection includes participant observation, which is reminiscent of ethnography. Furthermore, the findings of an inquiry guided by Benner’s method results in a paradigm case, thematic analysis, and exemplars which echoes the outcome of a grounded theory inquiry. Similarly, the methods advocated by Munhall and Conroy share commonalities with a narrative inquiry approach. Yet despite these similarities and overlap with other qualitative research methodologies, phenomenology is distinct (Kafle, 2011); the methodology of interpretive phenomenology requires the researcher to be immersed in philosophy while conducting the study in order for “the complexity and depth of human experience to be expressed” (MacKey, 2005, p. 184). It is in this way that the aim of interpretive phenomenology is achieved: To discover meaning that is concealed or taken for granted in the lived experience through the study of human behavior (Leonard, 1989). Interpretive phenomenology views human experience as the key source of knowledge and as such, this methodology closely aligns with the ideals and foundations of nursing (MacKey, 2005). As such, this methodology is valuable for the discipline of nursing to inform practice (Annells, 1996).

The complexity of interpretive phenomenology as both a philosophy and a methodology may be intimidating for the novice researcher seeking to answer a research question. Indeed, embarking upon our research journey into this realm involved extensive reading, discussion, and debate. Yet beyond the initial study required to grasp the philosophy and principles of this methodology, it is also important for the novice researcher to consider the practical aspects and academic context of his/her study before selecting a method of interpretive phenomenology. Korstjens and Moser (2017) note that available resources and time influence a study design. The novice researcher often works within limited time frames and limited resources, so these pragmatic considerations are important and will be discussed below.

Benner’s (1994a) method involves the collection of large amounts of data from numerous sources including individual interviews, group interviews, participant observations, and documents. Collecting and analyzing this large amount of data may be overwhelming and extremely time consuming for the novice researcher. However, Benner’s approach may be appealing for the novice researcher because of the structured approach to data analysis; perhaps an important support for those undertaking data analysis for the first time. Conroy’s (2003) method involves five additional researchers to participate as second readers during data analysis; novice researchers may be challenged to access this resource when conducting a study guided by Conroy. In contrast to Benner and Conroy, Munhall’s (1994; 2012) method encourages the researcher to make study decisions that are guided by the nature of the phenomenon itself; although this guidance may at first appear vague and unsettling to the novice researcher, we believe that support from an experienced supervisor is sufficient to assist the novice researcher with these decisions. Additionally, Munhall’s method is also well suited to the academic context of novice researchers because there is a structured approach to data analysis, and additional researchers are not required thereby reducing the resource requirements for this method of phenomenological inquiry.

The influence of Heidegger's phenomenology is evident in the interpretive phenomenological methods developed by the nurse phenomenologists Benner, Munhall, and Conroy. Yet, although Heidegger's work is foundational for these methods to interpretive phenomenological inquiries, each has a unique style and as such presents nurse researchers with the opportunity to select a method that fits their worldview as well as the phenomenon under study.

## 3.9 Conclusion

Interpretive phenomenology is a valuable methodology for addressing the concerns and questions of interest to nursing. However, when embarking on an interpretive phenomenological inquiry, it is essential that the method chosen to guide the study fits well with both the researcher and the study itself (Green, 2014). Novice researchers may feel overwhelmed when attempting to choose an appropriate method. This paper aimed to provide an understanding of the history of the methodology and showcase three methods of interpretive phenomenology that were developed by nurses. These interpretive phenomenological methodologists in nursing are infrequently discussed in the literature; however, their methods of phenomenological research can provide valuable guidance to nursing researchers who are generating knowledge for nursing practice.

## 3.10 Manuscript Summary

As described in the preceding manuscript, interpretive phenomenology closely aligns with the ideology and goals of nursing. As such, this methodology is particularly useful to better understand and address the concerns of nursing. Additionally, the philosophical underpinnings of interpretive phenomenology closely align with my ontological and epistemological assumptions (discussed in chapter 1). Thus, this methodology was a logical choice to address the research question that guided this study: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* In the previous manuscript, the ideas of three prominent phenomenological methodologists in nursing were analyzed and compared to determine which interpretive phenomenological method is most appropriate for this study. Through this work, it was determined that Munhall's (1994; 2012) method was most appropriate to guide this inquiry for several reasons. First, both the structured approach to data analysis described by Munhall (1994; 2012) and the absence of the need for a second researcher to be present during participant interviews made this method suitable for the context of a novice researcher who was based a significant physical distance from dissertation supervisors.

Additionally, this method was particularly appealing for me because the researcher is encouraged to make research decisions as guided by the phenomenon of interest; therefore, with the support and guidance of my co-supervisors, I was able to approach this study with a flexible and dynamic approach to gain an in-depth understanding of the meaning of this experience for participants of this study. Below, the process for participant recruitment, setting, data collection and analysis is described as guided by Munhall's (1994; 2012) interpretive phenomenological method.

## 3.11 Research Design

### 3.11.1 Participant Recruitment

Participants were recruited through a purposive and snowball sampling strategy. To be eligible, participants were required to: (a) reside in a rural area, (b) be a family member of a critically ill patient who underwent an IFT to an urban centre for advanced critical care services, (c) be 18 years of age or older, (d) speak and understand English, (e) were willing to share their experience, and (f) at least one month had passed since their relative's IFT event, but not more than 24 months. Rurality was defined within the context of access to advanced critical care services. With the regionalization of health care services whereby specialist services have been concentrated into a few "high-quality centres" with the aim of improving system efficiencies and patient outcomes (Kahn et al., 2008, p. 285), these urban, regional referral hospitals generally receive critical illness related IFTs from hospitals a median distance of 306 kilometers away (CIHI, 2010; 2016). It is within the context of the regionalization of specialist health care services and the flow of patients undergoing an IFT for advanced critical care services in Canada that rurality was defined. Thus, participants were considered to live in a rural area when their home location necessitates, at times, transfer to a more urban centre for advanced critical care services that are not available locally.

To ensure clarity related to the second inclusion criteria, operational definitions of key concepts are offered. According to Frivold et al., (2015) spouse, child, grandchild, and sibling are considered to be family members in the context of family focused research in ICU. Guided by this definition, for the purpose of this study, I defined a family member as a spouse, child, parent, sibling, grandchild or someone with whom the critically ill patient has a similar relation with. Critically ill patients are transferred to tertiary care centres for advanced critical care services related to myocardial infarctions, coronary artery bypass grafting, and percutaneous coronary interventions (CIHI, 2010). Therefore, for the purpose of this study, critical illness was conceptually defined as an urgent, life-threatening condition that results in the patient attending the emergency department and is subsequently admitted to a critical care unit for critical care services not available in a general nursing unit. Lastly, the definition of IFT was informed by the CIHI (2010) report indicating that critically ill patients who are transferred for advanced critical care services are generally a median distance of 306 kilometers away from home. As such, the operational definition of IFT for the purpose of this study was: the transfer of a critically ill patient to a tertiary care centre offering specialized advanced critical care services not available at the originating centre and was more than 150 kilometers away.

Potential participants were contacted no earlier than 1 month after their relative's critical illness IFT event. While there has been concern that interviewing participants within 6 months of a critical illness event may interfere with the family member's immediate grieving period (Bremer et al., 2009), several studies investigating family members' experiences with critical illness successfully interviewed participants within 1 to 2 months of the event (Engström & Söderberg, 2004; Frivold et al., 2015; Weslien et al., 2005). Additionally, in health research projects, many family members have expressed a willingness to being interviewed within five months of a relative's death, and many are in fact agreeable to be interviewed within weeks of the event  (Bentley & O'Connor, 2015). Indeed, Bentley and O'Connor (2015) found that participants reported no distress from being interviewed and identified a preference to being interviewed soon after their relative's death because they wanted to talk about their experiences. It has been noted that the shorter the time between the event and the interview, the easier it is for participants to recollect the event (Addington-Hall & McPherson, 2001). However, it has been found that spouses' descriptions of their partner's critical illness event up to 27 months later were so detailed, it seemed as though the event happened very recently (Ann-Britt et al., 2010). Therefore, participants were recruited for interview up to 24 months after their relative's IFT for advanced critical care services.

Ethical approval for this study was first be obtained from the University of Saskatchewan Behavioural Research Ethics Board (Application ID 1389). Subsequent approval was sought and obtained from the local health organization Research Ethics Board. Once approval from the two research ethics boards was obtained, I commenced the study. To recruit participants, I received support from the rural hospital ICU Nurse Manager and Emergency Department Nurse Manager (see Appendix B) to post advertisements to participate (see Appendix C) in these areas and assist with recruitment via telephone invitations. Although I was employed as a registered nurse (RN) within the local health authority, I had no contact with potential participants prior to their decision to participate in the study.

I provided the Emergency Department Nurse Manager with the study inclusion criteria and they delegated a member of their nursing staff to participate in recruitment for this study. This member of staff had pre-existing access to patient health information as a part of their regular employment duties and used this information to identify critically ill patients who underwent an IFT to an urban tertiary care centre for advanced critical care services at least more than 1 month ago, but not more than 24 months previous. This staff member then accessed identified health records to retrieve the contact details of the patient’s next of kin. Once the staff member obtained the contact details of these potential participants, they contacted them by telephone to inform them of the study using a script prepared by me (see Appendix D). At the end of the script, the potential participants were asked if they would be willing to be contacted by me to further discuss the study and potentially arrange a time to meet. In some situations, a follow-up telephone call was completed by the staff member if the potential participant could not be reached on the first attempted call.

For those participants who agreed to be contacted by me by telephone, during our first contact, I offered to mail the letter of invitation (see Appendix E) and consent form (see Appendix F) to them for consideration. No participants requested a copy of the letter of invitation and consent form prior to meeting with me. At the time of our first meeting, participants were provided the letter of invitation and consent form which described the purpose and procedure of the study, as well as the voluntary nature of the study and the participant's right to withdraw from the study at any time. The letter also included the researcher's office telephone number and email address for the potential participants to use to contact if they wanted to participate in the study, or if they had any questions. Snowball sampling was also utilized when participants choose to pass this letter of invitation on to other family members who then contacted me to participate in this study.

Shortly after recruitment commenced, the COVID-19 pandemic preparations began and directly impacted the local emergency department staff member who was responsible for identifying potential participants. As such, participant recruitment through this route was stalled and it was unclear when this staff member would be able to resume telephone recruitment efforts. Therefore, I sought an amendment to my recruitment strategy from the above noted research ethics boards to both complete a Canadian Broadcasting Corporation (CBC) radio interview and post the letter of invitation on social media platforms. I received approval from both research ethics boards to proceed with these recruitment strategies. Recruitment continued until a second male participant was recruited for a total of 11 participants.

I determined if participants met the inclusion criteria of the study at the time of first contact. Those who met the inclusion criteria were invited to participate in the study. If they agreed to participate, they were asked to sign a written consent form at the time of our first in-person meeting, prior to the interview commencing. These recruitment strategies follow other strategies previously used. In a study that examined the experiences of spouses who witness a partner’s cardiac arrest at home,  Ann-Britt et al. (2010) reviewed medical records of survivors and non-survivors of cardiac arrest to gain spouses’ contact details. A letter of invitation was subsequently mailed to the spouse, and the researchers followed up this invitation with a telephone call invitation one week later (Ann-Britt et al., 2010). Similar styles of recruitment were utilized by Frivold et al. (2015) and Weslien et al. (2005).

According to Munhall (1994), the required number of participants cannot be known at the beginning of a study; rather, this becomes known as the study progresses. Therefore, for this study, I initially sought to recruit between six to 10 participants but understood that this number may change as the study progressed (Munhall, 1994). Additionally, the number of interviews with each participant varied but aimed to be a minimum of two with the potential for a third meeting to discuss the overarching narrative (Munhall, 1994).

### 3.11.2 Setting

This study took place in a rural location in Atlantic Canada. In this region, the largest hospital is located in a city of approximately 36,000 people. Within this hospital, general critical care services are available to residents, however advanced critical care services related to cardiovascular services, neurological services, hematological services, and specialized orthopedics services are not available. For critically ill patients who need these services, they are required to undergo an IFT to a tertiary care centre that is located between 170 to 330 kilometres away from the originating hospital. These IFTs are not infrequent from the rural hospital and typically occur between four to eight times per week for advanced cardiovascular services and two to four times per month for other advanced critical care services. Currently, when a critically ill patient is transferred to a tertiary care centre, family members will receive notification about the planned IFT and if necessary, directions to the receiving hospital. In some situations where an immediate family member wishes to travel to the tertiary care hospital but does not have the financial means to complete the journey, the social work department at the local hospital is consulted for funds to purchase a bus pass for the family member.

Individuals who meet the inclusion criteria were interviewed at a time and location agreed upon by both me and the participant. Munhall (1994) cautions against using an office because this may imply that the researcher is in a position of power and thus change the mood of the interview. Therefore, as suggested by Munhall (1994) with the goal of enhancing conversation and the sharing of experiences, interviews occurred in settings such as the participant’s home or in a quiet room at their place of employment as was preferred by the participant.

### 3.11.3 Data Collection

In an interpretive phenomenological inquiry, the researcher seeks to understand the meaning of being in the world, thereby revealing hidden understanding (Munhall, 1994; 2012). This form of inquiry acknowledges that human experience and interpretations are situated within context and understandings are formed through two subjective perceptions: the researcher and participant interacting to form a co-constructed interpretation (Munhall, 2012). When conducting an interpretive phenomenological inquiry, the researcher must access several forms of data to enhance the understandings gained of a phenomenon (Munhall, 1994).

The researcher’s approach to data collection involves a strategy that Munhall refers to as *unknowing*; this perspective of unknowing is achieved through the researcher acknowledging preconceptions and biases and to the best of their ability, setting these aside during data collection so that they may see “the experience in whatever form it shows itself” (2012, p. 137).

To implement this process of *unknowing*, I wrote my presuppositions related to the relative's experience of a critically ill patient's IFT in my researcher journal. These presuppositions included my beliefs about what the meaning of this experience is for family members and what I expected to find during the course of the inquiry (Munhall, 2012). In documenting my presuppositions, I developed a heightened awareness of my situated context so that I could more effectively "quiet my own thoughts and absorb the story" of the participant; in doing so, I was more open to understanding the reality of the participant (Munhall, 1994, p. 67). Prior to each interview, I prepared to *unknow* by rereading and revisiting these presuppositions.

Interview data were collected through one to two, digital audio-taped, one-on-one interviews, one to two weeks apart using an open-ended interview style (see Appendix G). With every participant, a second interview was requested as suggested by Munhall (1994; 2012), however, two participants declined a second meeting stating that they felt they had shared everything they could about their experience. According to Munhall (2012), the interview is an important part of interpretive phenomenological data collection and should be a "dialogic conversation" in nature (1994, p. 66). Conducting the interview in a conversational nature may result in the participant sharing anecdotes, stories, and various examples that will deepen the researcher's understanding of the meaning of the experience (Munhall, 1994). Key to the dialogic conversation described by Munhall (1994) is initial listening of "*the whole story*" as told by the participant prior to the subsequent conversation about the phenomenon (p. 65). Therefore, the first interview commenced with the grand tour question: Can you describe your experience in as much detail as possible when *[name]* was critically ill and then needed to be transferred to a specialist ICU for advanced care? Subsequent questions were guided by the participant's responses and general disposition or *being* with the goal of understanding the meaning of the experience of the phenomenon (Munhall, 1994). If the initial grand tour question resulted in the participant sharing what was perceived to be a superficial overview of their experience, I used prompts (see Appendix G) to encourage the participant to delve deeper into their experience. Demographic data were collected at the time of the first interview (see Appendix G).

It is important that the researcher limit interruptions during the phenomenological interview; in doing so, the researcher demonstrates respect for the participant's perception of their experience and thus may result in the participant feeling more "seen and heard" (Munhall, 1994, p. 67). Additionally, the researcher should not attempt to re-direct the participant's discussion to areas perceived by the researcher to be relevant to the phenomenon of interest; while the direction of conversation may not appear to be important to the researcher, this may in fact be extremely relevant to the participant and re-direction by the researcher may re-structure the participant's experience (Munhall, 1994; 2012). During the interview, the researcher must be attentive to how the participant describes their experience as well as the context within this experience is interpreted (Munhall, 2012). Additionally, non-verbal modes of communicating such as body language and facial expressions may provide further insights into understanding the meaning of the experience (Munhall, 2012). Upon the completion of the first interview, I asked the participant to select another date for us to meet for the second interview at a location of their choosing. According to Munhall (1994), in the week following the first interview, the participant often reflects upon that which was discussed in the first interview and subsequently has a desire to meet again with the researcher to share more about their experience of the phenomenon.

In addition to the interview, Munhall (1994) notes other forms of data that should be considered to enhance the researcher's understanding of the meaning of being. Maintaining a researcher journal during the inquiry is a useful way to record elements of interpretation or experience that may otherwise be missed or forgotten (Munhall, 1994; 2012). Additionally, by using the researcher journal as a mode of data collection, the researcher is included within the study findings; a co-creator as it were (Munhall, 1994). Data collection for this study also included inviting the participants to share writings such as personal journals with me. Families are often encouraged to keep an ICU diary during a relative's critical illness to aid their relative, who often has limited memory of the event, during recovery (Harvey & Davidson, 2016); because these diaries are also be a valuable source of data for this study, I asked participants for consent to make a photocopy of any writings they made during the event.

Art as a medium has the ability to bring the researcher closer to the experience in ways that the interview cannot (Munhall, 1994). Forms of art that may be useful in a phenomenological inquiry include photographs, film, literature including both fiction and non-fiction, and music (Munhall, 1994), whatever is meaningful to participants. Therefore, data collection included inviting participants to consider examples of media such as films, music, and other literary works that represent aspects of their experience. In sharing these examples during interviews, I was better able to understand their experience and subsequently weave these examples into participant narratives generated during data analysis. Each participant was asked to check the narrative generated from both their data collected from interview(s) and other modes of interpretation to determine if the meaning of their experience had accurately been captured.

### 3.11.4 Data Analysis

Munhall's (1994; 2012) method of interpretive phenomenology was used to guide data analysis for this study. Specific steps of data analysis are outlined in Table 3. Data collection and analysis are simultaneous and occur through the researcher attentively listening to self and others (Munhall, 2012). Munhall (2012) encourages researchers to conduct two or three interviews with each participant because with reflection between interviews, additional interpretation occurs. As noted previously, two participants declined a second interview. Data collected through interviews were transcribed and checked for accuracy against the audio-recording (Munhall, 1994). The initial interview was transcribed by me. Following this, I employed an experienced transcriptionist to complete subsequent transcripts that I then cleaned. Munhall (1994) cautions against relying on computer software to aid data analysis; doing so may decontextualize the data and limit interpretations. While I did not intend to use computer software as a tool for data analysis, I did utilize a computer program, NVivo 12 (Version 12.6.0), as a means to store both the interview data and my process of analysis.

Data collected from participants, media, and myself as researcher were processed through the four *life-worlds* of corporeality, spatiality, temporality, and relationality to enhance the understanding of meaning (Munhall, 2012). This process involved dwelling with individual participant data and considering data elements to subsequently discern the context-specific meanings within as revealed through the lenses of each of the four life-worlds (Munhall, 1994; 2012). Data were organized according to identified meanings within each participant's life-world, and from these, data displays were generated. Through the use of data displays, context specific meanings unique to individual participants were revealed as well as an overlapping of meanings between life-worlds as described by Munhall (1994; 2012). During this phase of data analysis, I continued to dwell with the data and consider the four life-worlds together as a singular life-world in an effort to glean the meaning of being in the phenomenon of interest for the participant. Subsequent to this, I prepared individual participant narratives (see Appendix H) that aimed to make sense of the meaning of the experience using the participant's language (Munhall, 2012). Through using the words of the participant in the creation of narratives, this written interpretation of their experience aimed to be more accessible to the participant. Subsequent to the generation of the participant narrative, I shared the narrative with the participant to determine if I accurately captured the meaning of being for the participant. Participants were given the opportunity to make any changes to the narrative that they felt were required.

Upon completion of the study, I wrote an overarching narrative of the meaning of the experience (Munhall, 2012). During this stage of data analysis, Munhall encourages the researcher not to seek out and document similarities or differences in participant narratives; rather, the final overarching narrative "tells many different stories of meaning" (Munhall, 2012, p. 145). During this phase of data analysis, I considered the context-specific uniqueness of each of the 11 participants' life-worlds and prepared an overarching narrative using pseudonyms to convey the many possible meanings of this experience. This overarching narrative was created in a temporally sequential format, from onset of critical illness until resolution, and contained elements of each of the four life-worlds to form a unified, singular life-world of possible meanings as experienced by the participants in the present study. It is in this way that the individuality of meaning is maintained and aligns with Heideggerian philosophy.

Table 3.2

*Steps to Data Analysis (adapted from Munhall, 2012)*

| Step | Description |
|---|---|
| Step 1 | Transcribed the audio-recorded interview into a computer software program |
| Step 2 | Cleaned the transcript by listening to the audio-recording while reading the transcript to ensure accuracy |
| Step 3 | Using processes of intuitiveness, attentiveness, and constant reflection to *unknow*, I dwelled with and contemplated the data with the aim of understanding the meanings of the experience as communicated by the |

| | |
|---|---|
| | participant. This step involved sufficient time for reading and rereading the transcripts, reflecting on other media such as my researcher journal, photographs, music, film until understanding begins to emerge. Data were processed through the four life-worlds to situate meaning within context. |
| Step 4 | I commenced the writing of the narrative using the language of the participant to exemplify the meaning of the experience for the participant. |
| Step 5 | I shared the resulting narrative with the participant to determine if I had accurately captured the meaning of their experience of the phenomenon. If the participant determined that it was not yet accurate, I was prepared to seek clarification and correct the narrative. |
| Step 6 | Step 1 to 5 occurred for each participant. Step 6 involved the writing of the overarching narrative that at once shared an overarching interpretation of the experience from all participants (and myself) yet maintained unique elements of meaning from each of the participants. |
| Step 7 | I sought key, informative participants to read the overarching narrative that resulted from the study to determine the accuracy with which I had captured the meaning of this experience using the criteria of rigour described below. |

## 3.12 Ethical Considerations

Ethical approval was first be obtained from the University of Saskatchewan Behavioural Research Ethics Board, and then from the Health PEI Research Ethics Board, prior to the commencement of this study. Rural, critically ill patients who underwent an IFT to an urban tertiary centre for advanced critical care services were identified by a staff member delegated by the Emergency Department Nurse Manager as described previously. Participant confidentiality was maintained by conducting participant interviews in a private location of their choice and through the coding of the interview data. These steps aimed to safeguard the participant’s personal information and privacy when participating in the study. I maintained a confidential notebook for the study; this notebook contained a key linking interview code numbers to participant names and only I and my committee had access to this notebook. This notebook was and will continue to be kept locked in a drawer in a separate location from the digital audio-recordings, transcripts, and research notes.

Digital audio-recordings and transcriptions were only permitted to be accessed by myself as the primary investigator, my co-supervisors, and a transcriptionist hired through the University of Saskatchewan Canadian Hub for Applied and Social Research. The digital audio-recordings were stored on a Universal Serial Bus (USB) key and my laptop which is password protected. The analysed transcripts stored within NVivo 12 (Version 12.6.0) files were backed up in the researcher's online University of Saskatchewan secure *Cabinet* files to further protect against data loss. A separate researcher journal was also maintained to record my thoughts, feelings, and reactions during data collection and analysis. Upon completion of this study, the research notebook, digital audio-recordings, transcripts, and researcher journal will be secured and held for five years, by my co-supervisors at the University of Saskatchewan after which these will be destroyed. Participants' anonymity was maintained when preparing the research findings for publication; pseudonyms were used to conceal participants' identity and other identifying descriptors such as geographic location and names of family members were concealed. Actual names and demographic information of each participant were coded and stored separately.

The letter of information provided to participants prior to study participation detailed the purpose of the research, as well as the risks and benefits to the participants. The risks to participants included: the investment of time for the interviews (approximately 1 hour each), and a risk of psychological harm related to feelings raised during the interview. To reduce the risk of psychological harm, I was prepared to offer counselling support after the interview, if requested. This support would be provided by myself who has expertise as an ICU registered nurse (RN) in the care of families of critically ill patients who have undergone IFT. If further counselling services were required, I was prepared to provide the participant with the telephone number of the local Community Mental Health Centre. The benefit to participants participating in this study was to have an opportunity to reflect upon and share their experience during their relative's IFT for advanced critical care services. After reviewing their individual narratives, two participants indicated that they found the interview experience to be beneficial to them.

Once family members provided their written consent to participate in the study, I reviewed with them how the interview would proceed and then answered any questions they had. At this time, participants were asked for permission to digitally audio-record the interview. In addition to written consent, as suggested by Munhall (1994), I also utilized the concept of process consent and obtained verbal consent from participants prior to subsequent interviews.

## 3.13 Rigour

Maintaining rigour is an important part of a phenomenological inquiry (Munhall, 1994). In addressing the research question with an interpretive phenomenological approach, research decisions were made as guided by the phenomenon of interest. Therefore, to enhance the rigour of this study, I documented all research decisions in my researcher journal. For example, I documented the rationale for continued recruitment until a second male participant was recruited, the process of my evolving understanding of this phenomenon as I completed participant interviews and dwelled within their experience, and how interpretation of additional sources of information such as music and participants notes influenced my understandings.

In addition to these strategies to enhance rigour, Munhall (1994) has also suggested the following criteria as a means to evaluate the rigour of a phenomenological inquiry: (a) *the phenomenological nod* (does the resulting narrative feel familiar to the participants?), (b) *resonancy* (does the final narrative resonate with the reader?), (c) *reasonableness* (is the interpretation a reasonable account of the meaning of the experience?), (d) *representativeness* (do the results represent the full scope of the meaning of the experience?), (e) *recognizability* (do individuals who have not experienced this phenomenon recognize elements and thus develop a heightened awareness?), (f) *raised consciousness* (does the reader of the study subsequently seek to gain an increased understanding of the meaning of the experience not previously appreciated?), (g) *readability* (does the resulting narrative provide a readable and interesting representation of a conversation?), (h) *relevance* (are the results relevant to both the researcher and the reader within the realm of the people cared for?), (i) *revelations* (did the study reveal a deeper understanding of the experience?), (j) *responsibility* (was the study conducted ethically with concern for the participants?), (k) *richness* (was the study vibrant and does it enrich the reader?), and (l) *responsiveness* (are individuals who read the study results inspired to action?). For this study, I invited two key, informative participants, my committee, colleagues, and someone unrelated to the study to read the overarching narrative and assess if it is both understandable and the degree to which each of the above criteria of rigour described by Munhall were met.

### 3.14 Dissemination of Results

Interpretive phenomenological inquiries are ultimately undertaken in nursing so that what may be hidden is revealed, resulting in a narrative that may guide improvements in the care of individuals (Munhall, 2012). Therefore, it is important that the results of this study are disseminated to key stakeholders to support positive change in both direct care situations as well as in the healthcare system as a whole. Dissemination plans for the results of this study include, in addition to the manuscripts already published, the publication of findings in peer-reviewed journals (e.g., *Canadian Journal of Critical Care Nursing* and *Nursing in Critical Care*), oral and poster presentations at nursing and critical care conferences (e.g., Critical Care Canada Forum, Dynamics of Critical Care, International Family Nursing Conference), presentations at key stakeholder groups including healthcare leadership (e.g., Prince Edward Island Executive Leadership Team), nurse manager and educator groups (e.g., Nurse Manager's Council, Prince Edward Island Nursing Leadership Day), as well as in guest presentations at the local faculty of nursing (e.g., University of Prince Edward Island Nursing Research Day). Through the dissemination of findings, the results of this study have the potential to effect positive change in the care provided to family members of critically ill patients at the bedside and at the policy level.

## 3.15 Chapter Summary

In this chapter, the origins of interpretive phenomenology were explored and the ideas of three prominent interpretive phenomenologists in nursing were presented. Following this, Munhall's (1994; 2012) method of interpretive phenomenology was identified as the interpretive phenomenological method chosen to guide this study. Guided by Munhall's method of interpretive phenomenology, specific study design elements were presented including those relating to participant recruitment, study setting, data collection and data analysis. Ethical considerations designed to protect the well-being of participants were outlined and literature supporting these decisions offered. To enhance the trustworthiness of the findings of this study, specific strategies to enhance rigour, as suggested by Munhall, were presented. These strategies include returning to key participants and my committee members with the final, overarching narrative to determine the presence of important features of rigour such as the phenomenological nod and resonancy. Finally, plans for dissemination of the study findings were outlined and included publication in peer-reviewed nursing journals and conference presentations. Next, the results of the study are presented followed by a discussion of these results and implications for future nursing practice and research.

# CHAPTER 4

## 4.1 Findings: Overarching Narrative

The purpose of this study was to enhance the understanding of the meaning of the rural family member's experiences of a relative's IFT for advanced critical care services. Specifically, I sought to answer the research question: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* Munhall's (1994; 2012) method of interpretive phenomenology was used to guide this inquiry. Data collection commenced as described previously but was then suspended because of public health restrictions related to the COVID-19 pandemic. This pause in data collection lasted approximately three months until public health restrictions permitted in-person data collection. Data collection then resumed and was completed prior to the implementation of additional public health restrictions. During in-person data collection, all public health measures were followed.

I sought to interview each participant twice and nine participants agreed to two meetings. Two participants declined a second interview and indicated that they felt they had shared everything during the first interview and there was no more to discuss. Within the context of the COVID-19 pandemic, to minimize in-person contact, I provided participants with the option of receiving their individual narratives by email or hard copy delivered to their mailbox by myself. All participants who agreed to review their individual narrative chose to receive it by email. Each individual narrative was stripped of identifying information to protect the participant's privacy and maintain anonymity. One participant declined to review their narrative and one participant did not respond to queries regarding the accuracy of their narrative. For this participant, I indicated in the email that if I did not receive a response within seven days of sending the narrative, I would assume they considered it to be accurate.

Data collected from participants included 20 transcribed interviews with an average length of 45 minutes, three songs and two participant journals. These data and data from my researcher journal were processed through the four *life-worlds* of corporeality, spatiality, temporality, and relationality to enhance the understanding of the meaning of this experience (Munhall, 2012). This process involved listening to each interview recording several times, reading and re-reading interview transcripts, listening to the songs and reading the participant journals and my researcher journal while using the lenses of the four life-worlds to discern and reveal context specific meanings. Elements of data and the meanings elucidated from them were placed within associated life-worlds using a data display. This data display allowed for the recognition of the multiple, possible, context specific meanings of this experience as well as the overlapping nature of the life-worlds that together, form the life world (Munhall, 1994).

As is encouraged by Munhall (2012), who acknowledges the inevitability of the co-construction of knowledge that occurs between researcher and participant in an interpretative phenomenological inquiry, I engaged in self-reflection during data collection and analysis and documented my understandings in my researcher journal. Thus, a co-construction of understanding of meaning is manifest in the overarching narrative that follows. To enhance the rigour of this study, I invited two study participants, my student advisory committee, colleagues, and an individual unrelated to the study to read the overarching narrative to assess if it meets the criteria of rigour for phenomenological studies as described by Munhall (1994).

In this chapter, I present details of participant demographics for this study. Subsequently, an overarching narrative of meaning for rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services is presented in the format of a manuscript. The purpose of the overarching narrative is to share multiple meanings of the phenomenon yet retain the uniqueness of meanings grounded within the participants' own situated contexts (Munhall, 2012). Furthermore, Munhall (2012) asserts that the final, overarching narrative must include implications for the profession of nursing. Through the writing of the many possible meanings of this experience, what may be hidden is revealed, thus, altering current perceptions by nurses and enabling positive change in nursing practice in the care of these family members (Munhall, 2012).

## 4.2 Participant Demographics

Participant recruitment for this study was challenged by the COVID-19 pandemic declared on March 11, 2020 by the World Health Organization (2020). As previously noted, recruitment was to occur with a member of staff from the local emergency department contacting potential participants by telephone to offer the opportunity to participate in this study. With the onset of the COVID-19 pandemic and resultant preparations required in health institutions, and specifically emergency departments, recruitment in this manner was delayed. Therefore, I sought and obtained approval from the two previously noted Research Ethics Boards to utilize social media and radio interviews as additional recruitment tools. Subsequent to the implementation of these additional recruitment efforts, the staff member in the local emergency department was able to resume recruitment efforts as described.

Participant recruitment initially resulted in ten participants agreeing to participate in this study. However, because this initial sample included only one male participant, recruitment efforts continued and were successful in recruiting one additional male participant so that understandings of the situated context of male family members may be strengthened in this study. The age range of participants was between 33 to 79 years and included spouses, siblings, friend, parent, and adult child. The length of time between the IFT event and the interview was between 3 to 24 months. None of the participants travelled with their critically ill relative in the ambulance or helicopter; rather, nine participants followed in a personal car. Two participants did not travel to the urban receiving centre and one of these individuals indicated that they did not travel because of travel restrictions resulting from the COVID-19 pandemic. The length of time that the critically ill relative remained in the urban centre for critical illness care ranged between 24 hours to 1 month. Participant demographics are described in Table 4 and 5.

Table 4.1

*Participant Demographics P1-6*

| | P1 | P2 | P3 | P4 | P5 | P6 |
|---|---|---|---|---|---|---|
| Relationship to patient | Husband | Sister | Wife | Wife | Wife | Sister |
| If spouse, length of relationship | 50 years | | 57 years | 10 years | 55 years | |
| Length of time since event | 24 months | 24 months | 7 months | 5 months | 7 months | 4 months |
| Reason for IFT | Intracranial bleed | Intracranial bleed | Intracranial bleed | MVC, multi-trauma | Liver mass/ bleeding | Ischemic leg |
| Participant is male or female | Male | Female | Female | Female | Female | Female |
| Participant age | 71 | 58 | 79 | 57 | 76 | 56 |
| Participant accompanied in ambulance or helicopter? | N | N | N | N | N | N |

|  | P1 | P2 | P3 | P4 | P5 | P6 |
|---|---|---|---|---|---|---|
| Participant accompanied in personal car or public transport? | Y | Y | Y | Y | Y | N |
| If yes, which? | Personal car | Personal car | Personal car (next day) | Personal car | Personal car |  |
| Participant accompanied with additional family member(s) during IFT? | Y | Y | Y | Y | Y |  |
| If yes, what relation? | 2 sons | sister | son | mother-in-law | daughter |  |
| Length of time patient was admitted to receiving hospital | 2 weeks | 1 month | 6 days | 1 month | 2 days | <2 weeks |

Table 4.2

*Participant Demographics P7-11*

|  | P7 | P8 | P9 | P10 | P11 |
|---|---|---|---|---|---|
| Relationship to patient | Sister | Daughter | Mother | Friend | Son |
| If spouse, length of relationship |  |  |  |  |  |
| Length of time since event | 3 months | 8 months | 4 months (but 6 events prior) | 5 months | 8 months |

| | P7 | P8 | P9 | P10 | P11 |
|---|---|---|---|---|---|
| Reason for IFT | Myocardial infarction | Obstructed carotid artery and stroke | RSV | Intracranial bleed | Intracranial bleed |
| Participant is male or female | Female | Female | Female | Female | Male |
| Participant age | 63 | 54 | 33 | 54 | 49 |
| Participant accompanied in ambulance or helicopter? | N | N | N | N | N |
| Participant accompanied in personal car or public transport? | N (not allowed because of pandemic) | Y | Y | Y | Y |
| If yes, which? | | Personal car | Personal car | Personal car | Personal car |
| Participant accompanied with additional family member(s) during IFT? | | N | N | Y | Y |
| If yes, what relation? | | | | friend | mother |
| Length of time patient was admitted to receiving hospital | 24 hours | < 2 days | 3 days | 3 weeks | 6 days |

## 4.3 Manuscript 3

Burns, M. (2021a). *Far from home: Rural families in urban centres during critical illness* [Manuscript submitted for publication]. College of Nursing, University of Saskatchewan.

## 4.4 Abstract

The interfacility transfer of critically ill patients from rural areas to urban, tertiary care centres a significant distance away is not an infrequent occurrence in Canada. Critical care nurses in both urban and rural centres are familiar with this process however, it is poorly understood what this event is like for the family members of these rural, critically ill individuals. It has been suggested that rural family members suffer additional burdens during critical illness events involving interfacility transfer because of the need to leave their *home* to follow their critically ill relative to the urban centre; often a journey taking several hours. The following narrative is the result of a study guided by Munhall's (1994; 2012) method of interpretive phenomenology that explored the meaning of the lived experience of rural family members whose critically ill relative underwent an interfacility transfer to an urban centre for advanced critical care services. To conceal participant identities, pseudonyms are used when revealing the multiple meanings and realities experienced by rural family members in this study. In reading this narrative, nurses' perceptions of what this experience is like for rural family members can be altered and more open to what is possible. Thus, the care provided by both rural and urban nurses to rural families may be positively changed.

*Keywords:* rural nursing, family nursing, interfacility transfer, critical illness, interpretive phenomenology

### 4.5 Far From Home: Rural Families in Urban Centres During Critical Illness

Kate will never forget the day she came home from work to find her husband Sam collapsed on their kitchen floor. It is as though the memory is forever etched in her mind; Sam lying on his side on the floor with the remnants of broken plates around him. She ran over to him and saw that he was breathing but it was with a horrible, guttural type of sound. She immediately called 9-1-1 for help even though she could barely make her fingers work to dial the number. She knew something terrible had happened to Sam.

While she was sitting by his side on the floor, awaiting the arrival of the ambulance, Kate tried to piece together what may have happened. She called him a half an hour ago as she was leaving work to see if she should stop for milk on the way home. He seemed fine then. What could have happened? Nothing was making sense to Kate; how could things have changed so suddenly and dramatically? What was going to happen now?

Kate met the paramedics at the door and brought them through to her husband. They worked on Sam for a little while before putting him on the stretcher and then in the back of the ambulance. They said that they worried that Sam may be having a bleed in his brain. This terrified Kate because she had a sister who died from a brain hemorrhage 20 years ago when she was only 25 years old. After frantically looking for her car keys, Kate got in her car and closely followed the ambulance to the nearby hospital. After she parked in the emergency room parking lot, Kate rushed to the reception and asked to see her husband. No one knew where Sam was, but they told her to wait in the waiting room. After waiting anxiously for what felt like a really long time, she went back to the desk to try to get some more information. She was desperate to be close to Sam and wished that someone would tell her something, anything about her husband. The person at the desk gave her some vague information about how the doctor was seeing Sam now and they would come and get Kate when she could see her husband. After waiting a bit longer, she started to wonder if her husband was doing better; no news was good news, right?

Kate decided to call her husband's brother Lewis to let him know what was happening. Lewis was very close to both Kate and Sam, both a friend and a brother. She told Lewis what she knew so far, and he told her he would come to the hospital as soon as he could. After she hung up the phone, a nurse came over to Kate and asked her to come with her to her husband's room; the doctor wanted to speak with Kate. Kate asked the nurse if *her Sam* was okay, but the nurse would only say that the doctor would speak with her. Why would no one tell her what was going on? Receiving fragmented information in this way increased Kate's fear. What was really going on?

When Kate was led into her husband's room, she could not believe what she saw; Sam was unrecognizable. He had tubes everywhere and was lying so quietly on the stretcher. She could see his chest rise and fall with the ventilator breaths and could hear the beeping of the heart monitor, so she knew he was alive. It was surreal. The doctor was talking to her, but she only heard bits and pieces of what she was saying. She heard 'subarachnoid hemorrhage - a bleed in the brain', and 'we have to ship him to the city hospital in the other province so he can have brain surgery'. Kate felt like she was floating near the ceiling, looking down at Sam. She couldn't believe this was happening. Suddenly, she felt very hot and weak and she had to sit on the floor. She didn't want to be in the way of the doctors and nurses who were working on Sam, but she couldn't make it to the chair across the room to sit. She felt so embarrassed. In the back of her mind she wished someone would help her, but Sam was the one who was sick and needed help, not her. Once she felt a bit better, she stood up and moved closer to Sam and touched his face. He opened his eyes and Kate saw that he was terrified. She tried to reassure him as best she could; it upset her to think that Sam was frightened.

The staff were busy looking after Sam and while Kate wanted to stay close to Sam, she didn't want to be in their way, so she went to a waiting room across the hall. Shortly after, her brother-in-law Lewis arrived, and she told him that the doctor said Sam was having a bleed in the brain. He had to be shipped to the city in the other province immediately for brain surgery. Kate was so glad to see Lewis. Lewis told her not to worry about anything here at home. He would call their mother, Gertie, and tell her about Sam and what was happening. Kate worried about her mother-in-law because she was in her late 70's and had health conditions. Lewis reassured Kate that he would take care of all of his mother's needs and also drive her over to the city hospital to be close to her son Sam. Lewis also told Kate not to worry about her house or their pets; he would arrange for someone to look after these things while they were in the city hospital. Lastly, Lewis said "they are calling for 30 centimetres of snow tonight Kate, maybe you should wait to drive over tomorrow morning". Kate knew that Lewis was just trying to look after her too, but she couldn't bear the thought of Sam going to the distant city by himself. What if he was scared or in pain? What if something happened to him? What if he died?

While the nurses and doctors were preparing to send Sam, Kate rushed home to pack a bag to take to the city. It was important to her that she stayed as close to Sam as possible. She had asked if she could travel in the ambulance, but they told her she couldn't; she would have to take her own car. What would she need? How long would they be there? She didn't know, so she packed everything she could think of into her car. She called the emergency room before she left home and they told her that the ambulance had just left with Sam. It would take about four hours for the ambulance to get to the city hospital. Kate got in her car and started to drive. As she was driving, she remembered that she didn’t have much money. It had only been a few weeks since Christmas and her credit card was at its limit. Payday was in three days and she remembered that she only had about $70 in her bank account. She quickly realized that this will only cover her gas and possibly parking fees at the city hospital. How was she going to eat when she got to the city? Where would she stay?

About an hour into the drive, it started to snow very heavily; she could barely see the truck in front of her. Traffic was travelling at 40 kilometres per hour and the road was very slippery. Kate started to feel pain in her shoulders and into her neck and she realized that she was clenching both the steering wheel and her jaw. She was not used to driving on these big highways. She was always nervous about doing it on a good day, not to mention during a significant snowstorm. During the drive, her mind was constantly with Sam. Not having any way to contact the team who were looking after Sam for the four-hour journey was incredibly difficult. If only she could call the paramedics in the ambulance to get an update. How close were they to arriving at the city hospital? Did they get into an accident in the storm? Was Sam frightened? Was he still alive? Her only other experience of a brain bleed was when her sister died from one. This made her even more frightened for Sam. What would be waiting for her when she arrived at the city hospital?

While Kate was driving to the city hospital, Lewis was busy organizing the rest of their family and taking care of his, Kate’s and Sam’s responsibilities at home. Lewis called his mother Gertie to tell her what had happened with Sam. Of course, Gertie wanted to go to the city hospital right away, but because his mother was elderly and he knew that she doesn’t sleep well when away from home, he suggested that they wait until after the storm to go over to the city the next day. That way Gertie would be able to get a good sleep at home before driving over. Lewis then called other family members and friends to tell them what was happening. He also arranged for someone to check in on Kate and Sam's pets for the next few days. He then went home to pack and try to, unsuccessfully, get some sleep before picking up his mother and driving to the city early the next morning.

Kate arrived in the city during the storm and because she was not familiar with the city, she really struggled to find the hospital parking lot. After trying numerous streets for about 30 minutes, she finally found the hospital parking lot and parked her car. She almost ran into the main hospital entrance, feeling frantic to get to Sam and get an update; because of the ambulance transfer, there has been no way for her to contact the healthcare team, or for the paramedics to call her for over four hours. The person at the front desk told her that they couldn't share any information with her, but they directed her to the neurological intensive care unit. She tried to follow the directions they gave her, but she got lost. She found her way back to the main entrance and they gave her more directions again. She wished someone could walk her to the right nursing unit, but she tried to get to the nursing unit again on her own and eventually found her way there. Once she arrived, the nurses told her to wait in the waiting room. She was still wondering what was happening with Sam. Was he okay? Had something terrible happened? She asked the nurses again what was going on with Sam and they told her that the doctor was coming to speak with her. She knew then that he had died; why else would the nurses make her wait for the doctor to speak with her?

The doctor came to tell her that Sam was stable, but he needed to have surgery right away. The doctor was nice and answered her questions. While Kate was glad that Sam was in the city hospital because that was where he needed to be to have the specialized surgery, she felt a bit intimidated by the *city-folk* and was a bit hesitant and uncomfortable talking to them. It was so much easier talking to the staff back at her local hospital; there, they were people like her. The doctor asked Kate for consent to do the surgery and she felt the incredible burden of responsibility. Normally, she would have Lewis and Gertie with her to discuss something like this before deciding. Now, because the surgery is so urgent, she had to decide right away what to do; all alone. There was no time to call other family members. Kate consented for Sam to receive the surgery.

Once the doctor left, the nurses invited Kate in to see Sam for the first time in the new hospital. She experienced incredible relief to see Sam and know that he was still alive after the trip to the city. The nurses were so nice and friendly; they seemed to sincerely care about both Kate and Sam. They made some toast and tea for Kate and gave her some blankets to use to sleep in the waiting room. Kate didn't know how hungry she was until she smelled the toast. Because the nurses were so caring and clearly knew how to look after Sam, Kate felt comfortable to leave Sam's side while they got him ready for surgery. She tried to rest in the waiting room while Sam was in surgery, but her thoughts were constantly with Sam and she couldn't sleep. She wished she could get a coffee but she didn't want to bother the nurses and she didn't have any money to buy one. Waiting for the surgery to finish was so hard. Kate wished she had a family member or friend with her to ease her feelings of loneliness and be a shoulder for her to cry on.

Early the next morning, after a mostly sleepless night worrying about his brother, Lewis drove to his mother's house and together they set off for the city. They chatted about Sam and what all of this may mean for him and Kate. Lewis and Gertie have a very good relationship and were comfortable to talk about both the good and the bad. Lewis was conscious of his mother's health conditions and he made sure to have regular stops for food and rest during the drive. Once they arrived at the city hospital, Lewis dropped his mother off at the main entrance and then parked their car. When he returned to the main entrance, he noticed that his mother looked uneasy. Lewis asked her about it but she said that it was nothing, she was just not used to the crowds and busyness of the city and the city hospital; it was all so foreign to her. Together they got directions from the front desk and then made their way up to the nursing unit to find Kate and Sam.

They found Kate in the visitor waiting room and Lewis noticed that she looked exhausted. Kate fell into Gertie’s arms and they held each other for several moments. Kate told them that she was so glad to see them, she was so lonely and homesick. Sam had his surgery and was recovering in a four-bed patient room. They all went in to see Sam. He was drowsy, and a bit confused at times, but Lewis was so glad to see Sam was still with them. After several hours sitting at Sam’s bedside, Lewis noticed that the other patients in the room were at times agitated and using foul language. Lewis could tell that this upset his mother. He also noticed again that Kate looked pale and exhausted and he remembered Sam telling him that money was tight for them at the moment. Lewis decided to go and book a hotel room for them to rest in. He was familiar with the city, so he picked a hotel that was very close to the hospital. Lewis then asked Kate to take his mother to the hotel for some rest and gave her some money for a taxi and room service; Lewis will stay with Sam. To protect Sam from his occasionally agitated roommates and feel less fearful, Lewis organized a schedule to make sure that there was someone sitting with Sam during these days after his surgery.

Kate was so glad to see Lewis and Gertie. Seeing them felt like a little piece of *home* was with her in the city. She was grateful for the support and kindness that Lewis showed her. She was also surprised about the outpouring of support that she received from people she least expected. People she barely knew in the community at home sent her messages of support.

Surprisingly though, people she expected to receive support from were silent, including a good friend who lived in the city. Kate had hoped that this friend would come to visit them in the hospital, but she never came. This was very disappointing and it changed the way Kate thought of her friend.

Kate, Lewis and Gertie longed for the time when Sam would be discharged from the city hospital and they could all go home. Home represented *normal* for them. There was something about being around people you know and your own house and routine that was so comforting. Lewis was starting to get concerned about his mother's well-being. She had been doing her best to get sleep and he had been conscious to balance her need to be at Sam's bedside and her need to take care of her own health. She had to follow a very specific diet and it was nearly impossible for Lewis to find appropriate food in the hospital; all he could seem to find was muffins and coffee from the hospital coffee shop. The cafeteria never seemed to be open when he went to get food for them. Additionally, Lewis was the manager of a local company back home and he was conscious of his ongoing responsibilities there. When the doctor told them that Sam could be discharged, they were all relieved to be going home.

During the drive home, they had to take on the role of healthcare provider for Sam. They had to have frequent breaks during the four-hour journey, assist him to the bathroom and carefully choose food that he could eat. Once they arrived home with Sam, they felt that life may be beginning to return to normal. Now, several months later, because Sam is doing so well, the stresses of the actual events that they experienced are beginning to fade.

## 4.6 Chapter Summary

In this chapter, the process of data collection and analysis were described and subsequent results of this phase discussed. Participant demographics were presented and rationale provided for the recruitment of an additional participant beyond the initial 10 participants that were sought at the outset of the study. An overarching narrative of study results was presented and aimed to reveal the multiple possible meanings of this experience while maintaining the context specific uniqueness of meaning for each participant's experience as described by Munhall (2012). Embedded within this narrative are implications for the nursing profession. In the next chapter, the findings of this study are fully elaborated with discussion in the form of a manuscript styled research report.

# CHAPTER 5

## 5.1 Findings: Life-worlds and Discussion

The aim of this study was to address the following research question: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* The interpretive phenomenological approach as described by nurse researcher Munhall (1994; 2012) was used to address this research question. In this chapter, results of the present study are presented in a manuscript format with findings first presented in detail followed by discussion that situates the findings within the context of what is currently known of this phenomenon. Findings of the present study both support previous work and uniquely extend the understanding of the phenomenon. Following discussion of the findings, strengths and limitations of the present study are highlighted and implications for practice and research identified. While this research addressed the research question posed, more questions were raised.

## 5.2 Manuscript 4

Burns, M. (2021b). *Critically ill rural patients: Interfacility transfers to urban centres and impacts on families* [Unpublished manuscript]. College of Nursing, University of Saskatchewan.

## 5.3 Abstract

This study aimed to enhance the understanding of the meaning of the rural family member's experiences of a relative's interfacility transfer for advanced critical care services. Critically ill patients requiring advanced critical care services at times undergo an interfacility transfer to an urban tertiary referral centre a significant distance away from home. With the recognition of postintensive care syndrome- family, there is increasing attention to the burdens experienced by rural family members that are in addition to the stress experienced during a relative's critical illness. However, the understanding of this phenomenon for rural family members is only beginning and a clearer understanding is required. An interpretive phenomenological approach as described by Munhall was utilized to explore the meaning of a critically ill relative's interfacility transfer to an urban centre for rural family members. Data were collected through 20 interviews from 11 participants and analyzed according to the four life-worlds described by Munhall. Family members described a time of intense stress and worry of both the unknown present and future. These individuals experience a persistent need to be close to their critically ill relative and a need for clear and honest information from healthcare providers. Often, rural family members sacrifice self for both their critically ill relative and other family members and they hesitate to communicate concerns or questions to urban nurses out of a reluctance to interrupt or bother the healthcare team. Findings of this study shed light on the previously underappreciated, unique experiences of rural family members whose critically ill relative undergoes an interfacility transfer in Canada. With this increased understanding, both rural and urban healthcare providers may better care for these family members thereby reducing the development of negative consequences associated with this experience.

*Keywords:* rural nursing, family nursing, interfacility transfer, critical illness, interpretive

phenomenology

## 5.4 Critically Ill Rural Patients: Interfacility Transfers to Urban Centres and Impacts on Families

Family members experience intense stress and anxiety when a relative is critically ill and requires care in an intensive care unit (ICU) (DiSabatino Smith & Custard, 2014; Engström & Söderberg, 2004). This experience can result in negative, long term consequences for family members, a condition referred to as postintensive care syndrome- family (PICS-F) (Harvey & Davidson, 2016; Needham et al., 2012). In some situations of critical illness, specifically in geographically rural areas, the critically ill patient requires advanced care services not available at their local hospital and as such require an interfacility transfer (IFT) to an urban centre for advanced critical care services (Blackwell, 2002; Johnson, 1999). It has been suggested in the literature that an IFT of a critically ill patient to a distant urban centre may add additional stressors for family members (Burns et al., 2018; Kulnik et al., 2019; Mackie et al., 2014). Critical care nurses are well positioned to support family members during this experience (Frivold et al., 2015; Mackie et al., 2014); by reducing the level of stress experienced by family members, nurses may mitigate the development PICS-F (Harvey & Davidson, 2016).

## 5.5 Background: Justification for Study

Regionalization of healthcare, where speciality services are concentrated in select centres (Kahn et al., 2008), has resulted in the necessity of IFTs of critically ill patients from less specialized hospitals to more specialized hospitals for advanced critical care services (Blackwell, 2002). Within the Canadian context, specialized tertiary referral centres generally receive critically ill patients from less specialized centres a median distance of 306 kilometers away (CIHI, 2010; 2016). It is increasingly recognized that a critically ill patient’s IFT contributes additional stress to family members (Burns et al., 2018; Kulnik et al., 2019; Mackie et al., 2014).

According to Mackie et al. (2014), rural family members who experience a critically ill relative's IFT to a distant urban centre have needs that are distinct from their urban counterparts.

At present, the experience of rural family members whose critically ill relative undergoes an IFT for advanced critical care services is poorly understood (Burns & Petrucka, 2020; Karlsson et al., 2020). In addition to this limited understanding, Burns and Petrucka (2020) also found that healthcare professionals do not view the rural family member's experience as unique, thereby potentially neglecting their unique care needs. While there has been increasing interest in the needs of family members of critically ill patients who undergo an IFT to a distant urban centre in Australia (Johnson, 1999; Mackie et al., 2014) and Sweden (Karlsson et al., 2020), to date I could locate no studies exploring this phenomenon in North America.

Critical care nurses are responsible to care for the patient and their family members (Ågård & Harder, 2007). Furthermore, critical care nurses are in a position to effectively support rural family members who experience significant stress and anxiety during this phenomenon (Burns & Petrucka, 2020; Mackie et al., 2014). By reducing the stress and anxiety experienced by family members during a critical illness event, the development of PICS-F may be lessened (Harvey & Davidson, 2016). However, critical care nurses must first gain an understanding of the unique experiences of rural family members.

## 5.6 Aims and Objectives of Study

The aim of this study was to enhance the understanding of the meaning of the rural family member's experiences of a relative's IFT for advanced critical care services. The research question that guided this study was: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* By increasing the awareness and understanding of the multiple possible meanings of these context-specific experiences, nurses may better individualize the care they provide to rural family members (Munhall, 2012), thereby mitigating the development of negative outcomes for these individuals such as PICS-F.

## 5.7 Design and Methods

Central to phenomenology is the belief that knowledge arises from human experience and as such, this methodology aligns with both the philosophy and goals of nursing to inform practice (Annells, 1996; Mackey, 2005; Munhall, 2012). Specifically, this study was guided by the nurse researcher, Munhall's (1994; 2012), method of interpretive phenomenology. With an embedded focus on the context of nursing practice, this approach is useful in developing nursing knowledge and guiding practice (Burns & Peacock, 2019; Munhall, 2012). According to Munhall (2012), through gaining an increased understanding of the multiple, possible meanings of individuals' context-specific experiences, nurses can better tailor care for each unique individual perspective, thus, improving the nursing care of patients and families.

### 5.7.1 Setting and Sample

This study was set in Atlantic Canada. For clarity, key definitions of the main concepts of the research question, as informed by previous work, are offered. For the purpose of this study, *rural* was defined within the context of access to advanced critical care services, as a participant's "geographic location that necessitates, at times, transfer to an urban centre for advanced critical care services" that are not available locally (Burns & Petrucka, 2020, p. 180). *Family member* was defined as a spouse, parent, child, sibling, grandchild, or someone with whom the patient has a similar relationship" (Burns & Petrucka, 2020, p. 180). *Critical illness* was conceptually defined as an urgent, life-threatening condition that results in the patient attending the emergency department and then subsequently is admitted to a critical care unit for critical care services not available in a general nursing unit (Burns & Petrucka, 2020). Lastly, the definition of *IFT* was informed by both the work of Burns and Petrucka (2020) and a report from the Canadian Institute of Health Information [CIHI] (2010) indicating that critically ill patients who are transferred for advanced critical care services are generally a median distance of 306 kilometers away from home. As such, for the purpose of this study IFT was defined as the transfer of a critically ill patient to a tertiary care centre offering specialized advanced critical care services not available at the originating centre and is more than 150 kilometers away from the originating hospital.

Participant recruitment occurred through advertisements posted in the local, rural hospital emergency department and critical care family waiting areas. Participants were also recruited through telephone invitation. An emergency room staff member, who had pre-existing access to patient charts as a component of their duties, identified patients who were critically ill and required an IFT to an urban centre for advanced critical care services within the last 24 months, but not within the last month. This time frame for inclusion was informed by previous studies investigating family members' experiences with critical illness that successfully interviewed participants within one to two months of the event (Engström & Söderberg, 2004; Frivold et al., 2015; Weslien et al., 2005). Also, while some scholars articulate that a shorter time frame between the event and interview facilitates participants' recollection of an event (Addington-Hall & McPherson, 2001), Ann-Britt et al. (2010) found that spouses' descriptions of a partner's critical illness up to 27 months after the event were so vivid, it seemed as though the event happened very recently.

Upon identifying patients who met this criterion, the emergency room nurse then accessed the patient's chart to obtain the next of kin telephone number. The nurse then telephoned potential participants and invited them to participate using a script prepared by the researcher. If potential participants indicated their interest in participating in this study, the emergency room nurse provided their preferred mode of communication to the researcher. The researcher contacted potential participants and assessed if they met the following inclusion criteria: (a) resided in a rural area; (b) were a family member of a critically ill patient who underwent an IFT to an urban centre for advanced critical care services; (c) were 18 years of age or older; (d) spoke and understood English; (e) were willing to share their experience; and, (f) at least one month had passed since their relative's IFT event, but not more than 24 months. If the potential participant met the inclusion criteria, the researcher provided information about the study, and if the potential participant chose to participate, a time and location for the first interview was mutually decided. All participants chose to complete the interview in their home except for one participant who chose to be interviewed in a private area at their place of work.

At the time of first meeting, participants were provided with the letter of invitation and written consent form. Once participants indicated their willingness to participate by signing the written consent from, data collection commenced through audio-taped interviews. Process consent was used throughout data collection. Snowball sampling was also used if participants chose to share the letter of invitation with other potential participants.

### 5.7.2 Data Collection Tools and Methods

Participants were interviewed one to two times, one to two weeks apart using an open-ended interview style that was digitally audio-recorded. A second interview was sought because new understandings of the meaning of the experience may be revealed in the days following the initial interview (Munhall, 2012). As encouraged by Munhall (2012), these interviews were conversational in nature and occurred in a setting where the participant felt most comfortable, predominately in the participant’s home. During these interviews, participants were encouraged to share other forms of data that would shed light on the meaning of this experience; these included music that was felt to be meaningful and personal journals that participants maintained during the experience.

During data collection and analysis, the researcher approached data collection and analysis from the perspective of *unknowing*. In contrast to *knowing*, which embodies a sense of “confidence that has inherent in it a state of closure”, Munhall (1994, p. 63) encourages the researcher to adopt an approach to data collection where researcher preconceptions and assumptions are set aside thereby allowing new understandings of the phenomenon of interest to reveal themselves. However, it must be noted that while Munhall encourages the researcher to *unknow*, the researcher is more than an instrument for data collection. As an individual situated within their own lifeworld, the researcher approaches the inquiry from their unique, individual reality, and as such, unavoidably contribute to the study as a participant (Munhall, 2012). Thus, the researcher journal and personal reflections are also data to be considered when seeking to understand the meaning of the experience of the phenomenon and as such become a part of a co-created understanding of the meaning of the experience (Munhall, 2012).

### 5.7.3 Data Analysis

Data were analysed according to Munhall’s (1994; 2012) interpretive phenomenological method. According to Munhall (1994), when undertaking an interpretive phenomenological inquiry, the steps to the method become known to the researcher as the study progresses and the phenomenon becomes more and more understood. Additionally, as noted above, interpretive phenomenology places the researcher as both instrument and participant; through being-in-the-world, the researcher is situated within context and thus approaches understanding through their own unique perspective (Munhall, 2012). As such, the findings of this study include elements of the researcher's meanings of this experience.

Data collection and analysis occurred simultaneously. The researcher maintained a researcher journal to note thoughts and emerging understandings that were revealed during and after participant interviews. Oftentimes, upon completion of a participant interview, the researcher would need to pause on the return drive to document new thoughts that were emerging in relation to the phenomenon under study. Interviews were audio-recorded and initially transcribed by the researcher. Subsequent interviews were transcribed by a transcriptionist and subsequently cleaned by the researcher. Significant dwelling with the data and a going back and forth between the whole and the parts (Munhall, 2012) ensued and involved listening to recorded interviews, reading and rereading transcripts and participant journals, listening to songs submitted by participants and making notes in the researcher journal.

Researcher notes, media shared by participants including music and personal journals, and interview transcripts were all processed through the four life-worlds: corporeality, relationality, spatiality and temporality (Munhall, 1994; 2012). In processing data through the four life-worlds, meanings of the experience are situated within context and thus enhance the understandings of this experience (Munhall, 2012). It is in this way that concealed and unique multiple realities as experienced by individuals being-in-the-world are revealed, and understandings are enhanced (Munhall, 1994; 2012).

Once data were processed, a narrative of each participant's experience was produced and shared with the participant to determine if the meaning of their experience of the phenomenon was accurately captured (Munhall, 2012). In this study, 10 of the 11 participants indicated that the produced narrative was accurate; one participant declined to review their narrative. These individual narratives then in part, informed the development of an overarching narrative (Burns, 2021a) that shares the many possible unique and individual interpretations of the meaning of this experience as situated in context (Munhall, 2012). The aim of the final overarching narrative was to open the minds of nurses to understand the many possible meanings for individuals experiencing this phenomenon and subsequently critique current practices and consider implications for improving the nursing care of these individuals (Munhall 2012).

### 5.7.4 Rigour

As noted previously, when employing an interpretive phenomenological method of inquiry, methodological decisions are made as the study evolves (Munhall, 1994). To enhance the rigour of this study, the researcher documented all methodological decisions in the researcher journal. Additionally, strategies specific to evaluating the rigour of a phenomenological study were used. These strategies included the evaluation of the phenomenological nod, resonancy, reasonableness, representativeness, recognizability, raised consciousness, readability, relevance, revelations, responsibility, richness, and responsiveness Munhall (1994).

These elements of phenomenological rigour were evaluated in several ways. The final overarching narrative (Burns, 2021a) was shared with two participants who confirmed that it felt familiar to them (the phenomenological nod), resonated with them (resonancy), was a reasonable account of the meaning of the experience (reasonableness), represented the full scope of the meaning of the experience (representativeness), and revealed a deeper understanding of the meaning of the experience (revelations) (Munhall, 1994). Additionally, the overarching narrative (Burns 2021a) was also shared with the lead author’s supervisory committee and individuals unrelated to the study to assess if individuals who have not experienced this phenomenon recognize elements within it and subsequently develop a heightened awareness (recognizability), if they seek to further understand the meaning of the experience after reading the narrative (raised consciousness), if the narrative is readable and interesting (readability), if the results are relevant in relation to those that are cared for (relevance), if a deeper understanding of the experience was revealed (revelations), if the study was conducted ethically (responsibility), if the study was rich in nature thereby enriching the reader (richness), if readers of the study were inspired to action (responsiveness), in addition to the previously described resonancy, reasonableness, representativeness, and revelations (Munhall, 1994).

## 5.8 Ethical Considerations and Research Approvals

Ethical approvals were sought and obtained from both the Behavioural Research Ethics Board (REB) at the University of Saskatchewan and the REB at the local health authority where this study was conducted. The COVID-19 pandemic directly impacted the recruitment phase of this study. Shortly after recruitment commenced, pandemic preparations accelerated and recruitment by telephone invitation by the emergency department nurse was paused. Because the duration of recruitment suspension was unclear, an amendment for recruitment was sought from both REBs to recruit through radio interviews and posting of the study advertisement on social media platforms. Initially, only one male participant was recruited. Recruitment then continued until a second male participant was recruited, resulting in a total of 11 participants for this study. Confidentiality was maintained throughout the study. As a critical care nurse with extensive experience caring for both patients and families, I was prepared to offer emotional support to participants during interviews if necessary. If more support was required, I was prepared to offer individuals the contact details of the local Community Mental Health Centre.

## 5.9 Findings

The sample consisted of 11 rural family members whose critically ill relative required an IFT to an urban centre for advanced critical care services. Due to the relatively small population of the study location, specific demographic data will not be presented in order to ensure participant anonymity. General participant demographics are offered and include participant age range from 33 to 79 years and relationship to the critically ill patient: spouse, sibling, child, parent, and friend. Interviews occurred between 3 to 24 months after the event and reasons for the IFT included intracranial hemorrhage, major trauma, cardiovascular events, and respiratory failure. Nine of the participants traveled by personal car to the urban centre and two participants remained at home for the duration of the event. Initially, I aimed to recruit between six to 10 participants. However, recruitment of 10 participants resulted in only one male participant; thus, recruitment continued until a second male participant was recruited. Challenges in recruiting male participants have been described elsewhere (Markanday et al., 2013).

Munhall (2012) notes that while similarities in experiences may emerge and are useful in advancing understanding of the meaning of phenomena, it is important to situate meanings and understanding within context. In doing so, the multiple possible meanings or the "heterogenous perspectives on life events" become understood (Munhall, 2012, p. 169). Upon dwelling with the data and reviewing individual narratives generated during data analysis, it became apparent that several themes were embedded in each of the participants' experiences. According to van Manen (1990), themes provide a mode to understand the "structures of experience" (p. 79). However, corresponding to Munhall's (2012) assertion that context directly affects the meaning of experiences, van Manen (1990) notes that emerging themes offer an incomplete understanding of the meaning of experience. Below, three themes that were noted to be pervasive in some form throughout the participants' experiences of a critically ill relative's IFT to an urban centre are discussed. Then, meanings situated within context are described according to the four intertwined and overlapping life-worlds described by Munhall (1994; 2012).

### 5.9.1 Longing for Home

When a critically ill relative underwent an IFT to an urban centre for advanced critical care services, family members expressed a persistent *longing for home*. Family members noted how it was frightening being far from home. For those family members who had experienced an IFT previously, they expressed dread of living the experience again. Family members described how they felt hesitant speaking with nurses in the urban centre compared to nurses in their local hospital. When describing why they felt more comfortable speaking with critical care nurses at the local hospital, one participant, a middle-aged sister stated "I don't know, it's just different. Maybe it's just me, maybe I feel different. We all live here in <home province> so it's easier to talk here." Rural family members appreciated it when urban critical care nurses attempted to make connections with them, trying to make the family member feel more at home in the urban centre. For example, a son in middle age stated:

> I felt like the majority of the nurses that we had were very caring and were very supportive. Even in conversations, trying to make connections of some sort, seems that maybe that's a 'Maritimer' type of thing. Any nurse that came in was like, 'Oh, where are you from and what do you do?' And 'Oh, well I know somebody from there,' some of those connections stuff that you're still trying to make, and I still feel like, you know, even though you're in a different province, I still feel like people are there to support you.

An elderly husband whose wife was critically ill described:

> And the second I... ICU, the step down, there was one nurse in there for two patients. So.... And this is where we got to know one... there's one... one of the nurses there, Beth was her name. She's from... <region of Atlantic Canada>. What a great girl. Just, just she... just... it was almost... she was like, she was one of the family. You know. And that, that was so... it was so nice. You know. You know, we showed her pictures of the, of the kids and you know... and, and, she showed us her pictures, her wedding pictures, you know... it's just, she was just phenomenal.

While in the urban centre, family members spoke about how they wished they could be home. The elderly wife of a critically ill patient notes that the song Green, Green Grass of Home (Tom Jones, 1966) reminds her of her experience at the urban centre. During this time, she wished to be home because home represented *normal* for her, a beckoning, safe place. The association of home with *normality* was described not only by family members who travelled to the urban centres. Indeed, family members who were unable to travel to the neighbouring province with their critically ill relative also described their relative's return to their home province as a return to a more normal life.

For many family members, the home hospital provides a sense of comfort in sharp relief to the urban centre. An elderly wife describes the differences between the recent IFT and her husband's past hospital admission to the local hospital which she found to be easier to endure: "Oh it- you couldn't compare it. Because it was just farther away from home, where it's in <my home town> I could come home at night. So that was the difference". The *home* that was longed for was more than the physical structure of a house. The young mother of a critically ill child describes:

> When there's bad moments you want to go home to your parents and cry on someone's shoulder that you know and go home to a comfortable bed where you can have a good sleep and kind of forget things for a few hours. But over there you don't really get to do that. They try as best they can to make sure you're comfortable. The accommodation was great, but still, it's not your home. It's not your routine.

She continued to describe her efforts to get back home as soon as possible:

> So, normally when my son gets out of ICU and if he gets put in transition, I normally always ask for a transfer home right away… It's probably the very first thing I ask as soon as I know he's out of ICU, is to make sure if you can go- if your [home] hospital is equipped to deal with them [her son] that's the very first thing I ask for…. Just because I wanna' be closer to home.

Frequently, family members described how they attempted to pull *home* closer to them in the urban centre. This was manifest in participants describing how having family who lived in the urban centre was comforting to them. The daughter of a critically ill patient described:

> So, the ride was pretty stressful but once I got to the hospital I was like a big [deep sigh] and I knew I had people in [the city] 'cause my son was at his girlfriend's over there just for that weekend. They said, 'Just let us know when you're in [the city],' and my son came right over and he stayed with me… and it was really kinda' nice to have him there even though you don't think you wanna' see anybody, but so nice to see him.

She goes further to describe her efforts to pull her family and sense of *home* closer to her and her mother using technology: "Facetiming on the computer was great… It's kinda' life-changing, I think, for families. Even the night we arrived, once we arrived, I did a Facetime and they [her parents] said goodnight to each other." Another participant, a mother, describes how she considers her personal vehicle to a part of *home* that she brings with her to the city:

> It's also a part of your home too, right? You feel comfortable in your own vehicle…. And I stock it a lot, full of stuff. My van's usually pretty packed by the time I go over there. But yeah, it's that other thing. It's *your* vehicle, it's a bit of home that you have with you.

### 5.9.2 Sacrifice of Self

In sharing the meaning of a critically ill relative's IFT to an urban centre for advanced critical care services, study participants universally described elements of self-sacrifice. Family members often denied themselves basic, essential needs such as rest, sleep, food and medical assistance in order to be available for or assist with the care of their critically ill relatives. These sacrifices often led to feelings of exhaustion and physical pain such as neck and jaw pain during the event. After her husband was urgently transferred to an urban centre for immediate surgery, an elderly wife receives a post-surgery update at 5 o'clock in the morning: "By this time we'd been up- I had been up over 24 hours so we went to the hotel and we got there about 6:30 [in the morning] so we had a couple of hours sleep." As a direct result of the COVID-19 pandemic, interprovincial travel was restricted and the sister and next of kin was not able to accompany her critically ill brother to the urban centre. Despite having a strong need to frequently call the urban ICU, she self-sacrificed and denied herself these updates stating:

> I figured, [I was] bothering the nurses. They're looking after the patients, y'know?... you sit here and you go, 'Hmm, well when did I call? Well, I just called, it was only an hour. Probably shouldn't do this again. I wonder if it's their shift-change and I'll get a different nurse?' 'Cause you do, you feel like you're bothering everybody… and they gotta' look after the patients so can't be talking on the phone and looking after them at the same time.

After receiving a telephone update about her brother, she expressed relief and a brief sense of comfort: “That was quite a relief… ‘Now I can go to bed. Now I’ll go to bed and I’ll toss and turn there for a while’… And then thinking, ‘I wanna’ wake up early because I gotta’ phone.’”

Even in moments where family members themselves were experiencing significant medical distress, they described a sacrifice of self. The middle-aged wife of a critically ill patient describes a situation where she was medically unwell, but attempted to redirect the healthcare providers’ attention from herself back to her husband:

> I was talking to him and all of the sudden it was like this wave of heat hit me and I stood there for a second and I grabbed the railing on his bed, and I went ‘I’m gonna’ pass out.’ I go ‘no I’m not gonna’ pass out,’ I was embarrassed because I didn’t want them to know that I thought I was gonna’ pass out ‘cause I went ‘There’s nothing wrong with me!’ So, I kept hanging onto the bed, thinking it’ll go away, it’ll go away, it’ll go away and it didn’t go away. And all of the sudden I said, ‘I think I’m gonna’ pass out.’ … I was like ‘oh my god I’m so embarrassed’ because this wasn’t about me… [the doctor] just said ‘Just sit on the floor.’ So, I did… I kept apologizing to them I go ‘Listen, don’t worry about it, it’s okay.’ ‘Cause I said ‘I feel so embarrassed’ I said because there’s nothing wrong with me.

Sacrifice of physical self was also evident in the actions of participants during the time of the patient transfer window. Some family members risked adverse weather conditions to travel to the urban centre to be with their relative. The wife of a critically ill patient who was being airlifted to an urban centre describes how she exceeded the speed limit while driving to the urban centre, approximately 4 hours’ drive from her home: “I didn’t do the speed limit the whole time. I bet you I was 150, 160 [km/hr] the whole time. I remember that because I remember looking down and going ‘Oh my god, slow down, you’ve gotta’ slow down.’” Another participant, an elderly wife of a critically ill patient, describes how she immersed herself in a busy, crowded waiting room at the beginning of the COVID-19 pandemic despite her fears of the disease so that she could get to her husband: “It was just the beginning of being sick and coughing and all this for the virus… there were a lot of people over there and you hated to walk through all the people.”

Family members often self-sacrificed to manage household and family needs at both the urban centre and at home. This included coordinating care needs for one or more family members and also at times bearing the burden of responsibility as the primary decision maker for their critically ill relative. The sister of a critically ill patient describes the time when her sister was transferred to the urban hospital and two days later, her brother was admitted to the local hospital: “He had taken two strokes… I was at that hospital oh my God…. just run ragged eh, like just running back and forth.” In some situations, only one family member could travel to the urban centre to be with their critically ill relative. For these family members, the perceived weight of responsibility of sole decision maker was profound. A young mother of a critically ill child describes:

> You have to be the one to make the decisions, you’re the one that has to talk to all of the doctors, keep an eye on what’s going on. As much as you might have family support [at home] at the end of the day it’s still you that has to make all of the decisions… they [healthcare providers] don’t always have time for me to call my husband to make sure that we have the same plan at that exact moment… so you feel like it’s all on you, it’s all on your shoulders. If something happens you have to be the one to be quick about it and there’s no time to second-guess or to call somebody and say, ‘Hey! I need help! What do I do?’ You don’t always have those moments; you just have to breathe through it and make a decision based on what you think is okay. So, it’s very terrifying. I have panic attacks a lot.

### 5.9.3 Pulling Close

Participants described a need to be close to their critically ill relative. A wife describes her need to find her husband after a motor vehicle accident: “So she [a nurse] left, so I was there for a while by myself and then no one came back, and I actually start wandering the hall and I started kind of going toward where I thought he might be.” If they were unable to be physically close, for example when interprovincial travel was restricted because of the COVID-19 pandemic, family members describe keeping their relative close in mind. A persistent sense of an *unknown future* accompanied this need to be close to the critically ill relative. A middle-aged participant describes her journey to an urban centre where her friend was urgently transferred for advanced critical care services. Initially, her friend was texting her from the ambulance before she became too critically unwell:

> She stopped texting at that point, so then I was starting to get really worried ‘cause she was texting all along… So, I was like, ‘I don’t know what’s going on’... We didn’t stop, we just got gas and we went straight over there, found the hospital and I tried calling but nobody could tell me what happened, where she was, was she admitted? I wasn’t given any information… I go to the front desk and they just said, “she is in-” I can’t remember the department… And I said, ‘Well, what’s going on?’ They couldn’t give me any information even though my name was there to give out medical information.

Similarly, with the future unknown, a middle-aged daughter describes her need to be physically close to her mother during the IFT: “you’re worried… I understand now why people always feel the need to follow the ambulance. Because you’re always afraid that something’s gonna’ happen and you’re not gonna’ be there.”

Being present at the relative's bedside was also described as important for the flow of information between the family and healthcare providers. An elderly participant describes her encounter with a physician in the emergency room when her sister was awaiting an IFT by air ambulance: "We all went into the room… the doctor let us in, and he was unbelievable. Like he was excellent… I've never met such passionate… he explained everything, he showed us on the monitors." However, it is also important for family members to be able to provide information to the healthcare team. An elderly wife describes: "he has dementia… so he can't always express himself…. I was just scared that he would answer the questions wrong and they wouldn't understand … It's very important to have the right information when you're going to have surgery." Some participants described attaining a feeling of control and a sense of hope when present and participating at their critically ill relative's bedside:

> At the end of the day, you're gonna' be happy because you understand what's going on… I do feel like I'm in control of the situation. My opinion matters too… Just being over there and just knowing that you're not completely hopeless

### 5.9.4 Life-worlds

The context within which a phenomenon is experienced directly influences meaning (Munhall, 2012). It is within differing contexts that interpretations of experiences diverge and become alternate, individual perspectives of unique realities (Munhall, 2012). Thus, to comprehend an individual's perspective of a phenomenon, the meaning of the lived experience as it were, the researcher must consider the data within the individual's unique situated context (Munhall, 2012). By processing the data collected through the four life-worlds of corporeality, relationality, spatiality and temporality, individual experiences are placed within context, thereby extending understanding of the individual's being-in-the-world (Munhall, 1994; 2012). These life-worlds are interconnected and together form an individual's life world (Munhall, 1994; 2012). The four life-worlds make explicit the context from which meanings of experiences arise, thus enhancing the understanding of multiple possible perspectives of a lived experience (Munhall, 1994; 2012). Findings from the present study will be presented within context below, according to the four life-worlds.

#### *5.9.4.1 Corporeality*

When considering experience through the lens of corporeality, it is understood that the mind and body are not separate; rather they are one as the mind experiences the world through the body (Munhall, 1994; 2012). Therefore, to begin to understand the individual's being-in-the-world, the researcher must consider meanings that emerge from the embodiment of experience (Munhall, 2012).

**Stress Manifest.** The embodied experience of a critically ill relative's IFT to an urban centre for advanced critical care services was described in numerous ways. Participants described feeling shocked, frantic, and an urgent need to act when their relative suddenly became critically ill. For one middle-aged participant, the news that her husband had sustained life-threatening injuries in a motor vehicle collision was so shocking that she felt as though she was floating near the ceiling; an experience so surreal that she felt disconnected from reality. The phenomenon as experienced through the body was so intense as to further manifest in a vagal response where she became faint and had to sit on the floor next to her husband's stretcher in the emergency department. Other participants also described a feeling of disconnect from reality where they describe a dream-like experience and are functioning in a daze. The future was unknown, and participants described this as terrifying. Family members felt confused and unable to perform even the most basic of tasks such as using a credit card to pay for gas on the journey to the urban centre. One participant described her embodied experience of her relative's IFT as "I was just, everything I did was just at warp speed all the time… it's funny how your body just kind of takes over and you're just running completely on adrenaline, it's just crazy."

During the time when the critically ill patient was in transit by helicopter or ambulance from the local hospital to the urban centre, family members described feelings of agitation and restlessness while awaiting notification that their relative had arrived safe and alive to the urban centre. Some participants described this transfer window as the hardest time of the whole experience because they were unable to contact the paramedics who were transporting their relative for 3 to 4 hours. During this time of no communication, family members described feeling upset, stressed, and angry. These experiences are in direct contrast to a daughter who was provided with the mobile telephone number of a paramedic who was transporting her mother to the urban centre. For this participant, the regular updates she received from the transport team during a winter storm was a lifeline that helped her to cope with her own journey to the urban centre during dangerous winter storm conditions. Family members who were unable to follow their relative to the urban centre because of COVID-19 related restrictions on interprovincial travel felt upset knowing that their relative had to go alone to the urban centre. For family members who were able to travel to the city, they sometimes travelled at unintentionally, excessively high speeds.

Upon arrival to the urban centre, family members at times describe feeling agitated and overwhelmed with trying to find their way to their relative in a foreign hospital. A friend and next of kin to a critically ill patient describes how she was so focused on her friend's needs that even organizing her own mundane, basic needs was stressful. Some participants who were alone in the urban centre found that they were solely responsible to make quick, health care decisions for their relative; this caused some participants to feel terrified, panic stricken.

During the critically ill patient’s time in the urban centre, family members described feelings of emptiness within, tension, holding it together and then breaking down, and a pervasive sense of exhaustion. Some participants had numerous responsibilities to maintain at home and the constant pull between tending to these responsibilities and being with their critically ill relative contributed to this feeling of exhaustion. Other participants described feeling as though they could not “shut their mind off” and as such their nights in the urban centre were both scary and sleepless. One participant describes:

> I remember just falling on the bed, completely dressed and I’d wake up at three or four in the morning completely dressed ‘cause I’d be SO exhausted. And my face just started hurting so bad and I’m like ‘What is wrong with my face?’ But I was just clenched [visibly clenches her jaw] … And I started being cognizant of it, so I started going ‘Okay, you gotta’ relax, you gotta’ relax, you gotta’ relax.’

Some participants described ways that they tried to cope with the experience. Several participants tried to stay busy with tasks while others exercised to release tension.

**Vulnerability in the Urban Centre.** Family members describe feelings of vulnerability in the urban centre, particularly if they were alone without family support. Feelings of loneliness, fear, and homesickness were prevalent. Compared to participants who were familiar with the city, participants who were unfamiliar with the city described fear with wayfinding, driving in the city, or being outside after dark. Participants who had limited financial resources available to them described this context as “terrifying” and they wondered what they would eat because they had no money to purchase food. A mother describes her time in the sick children’s hospital in the urban centre: “The homesickness feeling that you have is miserable [crying].” For family members who are elderly, being in the urban centre also evoked feelings of vulnerability that they perceived as being unique to their age:

> Because when I’m away from home I don’t sleep properly and to be honest, it’s a simple thing but my bowels never work good… because of my age it made it hard… the whole thing because you’re older… I felt it bothered me more that I’d have been able to handle it different if I was younger.

This elderly wife goes on to describe how important it was to have her sons with her in the urban centre and without them, it would have been scary.

**Feeling of Peace.** Interspersed within the feelings of stress described above were feelings of peace. Family members travelling to the urban centre described a sense of relief when they arrived safely at the urban centre. Others describe feelings of relief when they received notification that their critically ill family member arrived safely. Seeing their relative for the first time after the IFT evoked feelings of peace, seeing that they were still alive. Family members who maintained connection with family at home using virtual audio-visual means described labile emotions that alternated between happiness and sadness.

Some family members attempted to gain control and thus a sense of peace through a variety of actions. A mother packed her van with everything she could think that her and her son may need in the urban centre prior to departing home. Two participants sought to actively perform personal care for their critically ill relatives and engage in care planning with the healthcare team. Another participant assumed the role of healthcare provider for the 4-hour drive home after his elderly father, who underwent neurological surgery two days previously, was discharged home. This element of the experience where family members assumed the role of caregiver or protector overlaps the life-world of relationality.

#### *5.9.4.2 Relationality*

The life-world of relationality refers to how an individual perceives their connection to others within experience (Munhall, 1994; 2012). When searching for the meaning of experience, Munhall (2012) urges researchers to carefully attend to the interpretations of relationships as described by participants; doing so allows the unique meanings of the individuals’ life-world to be revealed.

**Need to Protect.** Family members experienced a need to protect their critically ill relative, and at times other vulnerable members of their family, resulting in a sacrifice of their own needs. In the urban centre, in situations where other patients who were agitated or visitors who were perceived to be a risk to the well-being of a relative, family members would purposely take shifts sitting at their relative’s bedside to protect. For some family members, it was important to be present at the bedside to receive information from healthcare providers so that they could then make the best healthcare decisions for their critically ill relative. Some participants described a concern that their relative might be frightened and by being at their bedside, they could provide reassurances to them and reduce their fear. A daughter describes her need to be present as her mother was taken from her room to go to the operating room:

> And it’s funny how you feel like you have to see somebody before they go for surgery, but you just wanna’… you wanna’ say goodbye. I don’t know if that’s ‘cause- I guess you’re afraid that if something happens in the OR and they come out and they’re not able to talk to you and stuff? …I wanted my face to be the last face she saw…I wanted [her] to know that she had people there too, I didn’t want her going in scared.

This need to protect also extended to other members of the family who were perceived to be vulnerable. A son described an intrinsic need to ensure that his elderly mother had nutritious food and obtained sufficient rest while their father was critically ill. A friend of a critically ill patient described her need to provide emotional support to the patient's children who were far away from the urban centre.

Family members who were not permitted to travel to the urban centre because of COVID-19 interprovincial travel restrictions also experienced this need to protect their critically ill relatives. A sister described how important it was for her to call the urban centre frequently for updates and ask the nurses to tell her brother that she had called: "They always made a point of telling him which was nice because if you couldn't get in because, [of COVID-19 restrictions] … just so they won't be alone, know that somebody cares." For another sister, because of interprovincial travel restrictions, she was unable to be present when her brother was discharged from the urban centre; as a result, she was not a part of the discharge teaching which left her struggling, trying to meet her brother's needs such as dressing changes, medication adjustments and safely increasing mobilization.

**Maintaining Responsibilities.** Participants described numerous responsibilities that they needed to attend to and maintain during their relative's critical illness and IFT to an urban centre. Some participants described a multitude of competing demands both at home and at the urban centre. A wife described how she had to frequently commute 4-hours home to manage her rental business, her husband's construction business and care for their pets and then return to the urban centre to be with her husband. Other family members, both middle-aged and elderly, described situations where they were simultaneously providing care to ill siblings at home while also striving to be at their critically ill relative's bedside at the urban centre. Many participants indicated that they did not ask for help in managing these responsibilities; rather they perceived this to be their role within their family. This role also included managing and organizing family members, updating family members regarding their critically ill relative's status and acting as the primary decision maker. Assuming these roles often resulted in family members forgoing their own rest and sleep.

**Supportive Connections.** Family members identified numerous relationships that were perceived as supportive during their critically ill relative's IFT to an urban centre. Participants described connections with healthcare providers as important and necessary to help them cope with the situation. Being welcomed into the critical care area and receiving up-to-date information was comforting and family members identified that it was important for them to be able to provide information about their relative to the healthcare team; in doing so they were able to contribute to the care of their relative. When family members trusted the healthcare team, it was easier for them to endure separations such as during the transfer window or during surgical procedures. While family members expressed a need for information, many were hesitant to "bother" the nurses and doctors. An elderly wife of a critically ill patient describes: "a couple minutes to talk to you and tell you what's going on then you'd be, you'd be happy and they wouldn't have to feel like you're hounding them for information. Which you don't like to do."

While several family members described positive and supportive experiences where healthcare providers were "nice" and "friendly", some family members described situations where relationships with healthcare providers were negative and added to their stress during this event. The mother of a critically ill child describes:

> We were really nervous when [their son] was born to ask the doctors the questions because there is a lot of- sometimes there is a lot of intense questions or when the doctors are all

> there for their rounds you do kind of feel like they're talking above you and you don't quite understand what's going on. When they would leave, we would talk to the nurses who we were comfortable with and we would ask those questions that we thought were silly or didn't make sense to us, but we asked them, and they were very sweet and kind. They would break it down so you would understand it and they were on your side. So, I think that's what really made us feel like we could open up more toward the nurses and feel like you weren't so lonely if you found one that you could click with and talk with. Yeah, that was a big thing for us.

Communication from the team was sometimes fragmented, incomplete or condescending which was perceived as negative for some family members. An elderly wife describes her interaction with her husband's physician: "I don't like to say I was not impressed with him but… He… just seemed to talk down to a person… then when he was talking about the liver… he said, 'So you're a drunk?'… I was shocked."

Connections to family, friends, strangers, and existential entities were perceived as positive and important during a relative's IFT to an urban centre. Many participants described how it was these connections with family and friends that helped them to cope with and get through this experience. Support from family and friends included regular in-person or telephone contact, assisting with meeting basic needs such as arranging accommodation and food, providing financial support if needed to pay for essentials in the urban centre, wayfinding in the city, and for some participants, driving them to the urban centre if the family member was uncomfortable driving far from home. Family members with relatives who lived in the city described this as additionally supportive because they would come to visit them in the urban centre and in doing so, make the rural family member comfortable enough to leave their critically ill relative's bedside for a much-needed reprieve from the hospital. For family members who were alone in the city, a pervasive feeling of loneliness was described. Having family physically present with them in the city mitigated these feelings of loneliness. An elderly wife of a critically ill patient describes how important it was for her daughter to drive her to the city and be present during the experience:

> If I was by myself and had to go over, it would've been a different experience…without somebody with me to talk to… when you can't go in the ambulance and as old as we are…it's not ideal for me to be going to [city] myself driving

For some family members, family and other responsibilities were viewed as contributing burden to their experience. Some participants described feeling "let down" by family and friends that they expected to be available to support them during this experience. Relationships with family members that were perceived as challenging or difficult before their relative's critical illness event often were exacerbated during the IFT event and added additional stress to family members. Some family members described Facebook as a useful way to keep in touch with family members. However, when the wife of a critically ill patient describes the use of Facebook during her husband's stay in the urban centre: "a bad thing for mental health you know? And I think that people who rely so much on the social media side of things and they don't get those, the responses that they expect can be very detrimental mentally."

Family members also remained deeply connected to their critically ill relative during their IFT to the urban centre. Consistently, participants described a persistent need to be close to their relative, if not physically, then close in mind. It was very difficult for family members to bear witness to their relative's suffering and seeing their critically ill relative calm and at peace resulted in the family member also feeling at peace.

**Loss of Connection.** A loss of connection, and thus support, with family members and healthcare providers was at times experienced by family members. Family members who had to say goodbye to family at home in order to travel alone to the urban centre described this physical separation as an acute loss of important support. And while some family members described feeling a connection with healthcare providers, other family members described situations where there was a distinct lack of connection with the team and this was perceived as negative. This loss of connection was attributed by some to the provision of incomplete information or mixed messages from healthcare providers. Some family members sensed that the healthcare providers were unwilling to help them. A friend, and next of kin, describes her experience with nurses when she initially arrived at the urban centre and is looking for her critically ill friend:

> I go to the front desk and I ask the nurse, ‘Do you know what’s going on with [friend’s name]’ They didn’t give me any information. They said, ‘Go wait in the waiting room.’ So, an hour passed, no information. I didn’t even know if she was living, to be honest with you. And I got really upset and a little mad and I said, ‘Y’know I really want information. I haven’t had any information since she left [home province]. I don’t even know if she’s still living, to be honest.’ And I start crying, and then that’s when the nurse got somebody to talk to me.

For this participant, this part of the experience was the most prominent and upsetting time for her.

Forced separation from their critically ill relative was also noted to be particularly difficult for family members. A middle-aged sister describes the time when her brother was being transferred by ambulance to the urban centre:

> I'd say the ambulance drive was really the longest part because you have no contact with anybody, and you don't know what's going on…it's an unknown…You just wanna' know… I'd say that was the toughest part was the drive up, him going and me not being able to have some kind of control I guess… Being able to call really

Yet despite this persistent need to be close to their critically ill relative, family members often described a reluctance to interrupt or potentially obstruct the work of healthcare providers. Family members described a hesitation to telephone the urban centre for updates because they did not want to be "bothering the nurses. They're looking after the patients." Some participants described feeling a sense of a lack of privilege to be physically present in the critical care area and others noted that they did not want to "be in the way" of the doctors and nurses who were looking after their critically ill relative. The relational meaning of this loss of connection with their critically ill relative overlaps with the life-world of spatiality.

#### *5.9.4.3 Spatiality*

Experience occurs within the physical space and therefore, the environment within which individuals are situated contributes to the meaning of experience (Munhall, 2012). Mackey (2005) also notes that beyond the physical environment, spatiality refers to the metaphysical where an individual within their situated context pulls something, or someone, to them or pushes it away. Within this life-world of spatiality, there is a sense of the life-world of relationality; an inevitability given the intertwining and overlap of the life-worlds (Munhall, 2012). However, in the following section, the life-world of spatiality is distinct from relationality in the way in which participants interpreted both the physical space they found themselves within, and the metaphysical space in which they pulled closer or pushed away elements of experience.

**Pulling Patient and Family Close.** As noted previously, the meaning of the experience of a critically ill relative’s IFT to an urban centre is influenced in a relational way through family members seeking to maintain a close connection with their relative. However, despite family members’ need to be physically close to their critically ill relative, forced separations did occur and were endured by participants. In these situations, family members described how they pulled the patient close to them in mind during the transport and also while they were admitted to the urban centre. An elderly husband describes his four-hour journey out of province shortly after his critically ill wife was air-lifted to the urban centre: “now...well I thought 'where am I going to stay' that, that's, that wasn't important. 'How long I was going to be there' that wasn't important. And 'how's she going to be... when I get there’?” A middle-aged wife describes a similar experience of holding her husband close to mind during the journey to the city: “I don’t have a lot of memory of that particular, that drive over… I was just consumed with thought and what was I gonna’ find when I got to [city]? Because I wasn’t getting phone calls from [city].” For family members who were unable to travel to the urban centre, they kept their critically ill relative close in mind through telephone contact or by trying to anticipate their needs.

Family members who travelled to the urban centre also described how they pulled family members at home close to them in mind. An elderly sister describes her time in the urban centre when calling family at home to give updates about her critically ill sister: “But we would be in contact with them; always on the phone or something letting them know how- you know things are.” Being physically apart from family members influenced the meaning of delivering difficult news to others who are not present at the urban centre. A middle-aged participant describes what it was like to call her critically ill friend’s son to share news about his mother’s critical illness:

> It was really hard… both of us were crying. Because it’s different when you’re talking to him and you can’t see his face, you can’t hug him, you can’t do anything. I knew he was just devastated… he didn’t see it coming.

Despite this prevalent need to be close to their critically ill relative and other family members, some participants described an intermittent need to push away from the physical space of their relative’s bedside. In doing so, participants described gaining some much-needed space for themselves. However, in order to feel comfortable to momentarily part from their critically ill relative, family members described a need to trust that the healthcare providers would watch over their relative while they were away from the bedside. Alternatively, if other family members were present in the urban centre, their presence at the bedside also provided a sufficient level of comfort for the family member to take a break from the bedside. A young mother describes this: “you need to be able to distance yourself from the hospital and just take a breather every once in a while. That’s how I deal with being lonely… I get out in public or just go for a drive.”

**Home and Away.** Participants often perceived the IFT for their critically ill relative as a positive event where they would receive the advanced care that they required. Some family members expressed a fear for their relative’s safety during the transfer by ambulance or helicopter. This was especially experienced by family members if the transfer occurred during adverse weather conditions such as fog or blizzard conditions. When family members arrived in the city, those who were unfamiliar with the city or city driving experienced feelings of stress and vulnerability. Upon arrival at the hospital, some family members experienced difficulty finding a place to park and then when entering the hospital, were frustrated and experienced stress with their inability to locate their critically ill family member. The environment of the urban hospital and critical care unit was described as busy, foreign, shocking, and sterile.

The concept of *home* represented rest, comfort and support. Some participants described *home* as a geographic place or area that represented normality and peace. When describing why she wanted to return to her home, an elderly wife stated: “Because I wanted to be back home, back to normal.” Other family members described *home* not as a geographic place, but rather their network of family and friends that surrounded them. For these individuals, they did not express a loss of *home* during the IFT; rather, their *home* came with them to the urban centre in the form of their friends and family members. While in the urban centre, family members pulled close elements of *home*. They tried to make connections with healthcare providers, connect with family who lived in the city, and held close items that reminded them of home. Having family with them resulted in the hotel room feeling more like *home* than a hotel. Family members also described the use of technology to connect with family at home to make the urban centre feel more *home*-like. *Home* was also close in mind for some family members because they described feeling torn between responsibilities at both the urban centre and at home. This was described by participants who left work to travel to the urban centre or who had young families at home to care for. Other family members indicated that they had no concerns with responsibilities at home.

**Pushing Away Unimportant or Uncomfortable Thoughts.** Family members described moments in this experience where they pushed thoughts far from mind. Thoughts that were irrelevant or unimportant were pushed away in order for the participant to focus on more important concerns including the well-being of their critically ill relative. Upsetting memories of finding their relative collapsed and other distressing situations were also seemingly pushed to the back of mind. For example, a participant describes how painful it was to witness her sister in pain after neurological surgery: “I just went out in the waiting room. Yeah, and the sisters, there was family around, there was family around. I just had to leave.” In the context of difficult or strained family relationships, participants described pushing away these individuals in order to preserve relationship in the future. The wife of a critically ill patient describes her experience: “I found myself within the first three days completely trying to distance myself from them ‘cause I was afraid I was gonna’ say something that I was gonna’ not be able to take back.” Other participants described metaphysically pushing away family members who were perceived as to add to their burden of responsibility while in the urban centre. Finally, family members also at times described an intentional, pushing away of thoughts of the future because it was unknown and as such, distressing. This meaning of the experience overlaps with the life-world of temporality.

#### *5.9.4.4 Temporality*

Experience is embedded within time, and at once the past, present, and future intertwine and influence the meaning of experience (Mackey, 2005; Munhall, 2012). Through considering experience as situated in time, the researcher may advance the understanding of an individual’s situated context and thus the unique meaning of experience (Mackey, 2005; Munhall, 2012).

**Unknown Present and Future.** With the sudden onset of a relative’s critical illness and subsequent IFT to an urban centre for advanced critical care services, family members experienced a sudden shift in their present reality and the future became unknown. While travelling to the urban centre, participants described the phenomenon of not knowing what their present reality was for several hours and if their relative had in fact, survived the transfer to the urban centre. A middle-aged sister describes waiting at home wondering when her brother would arrive at the urban centre during a transfer that occurred in the night during dense fog conditions: “you’re wondering, ‘Did he make it over or did something happen on the way?’… It was the fog I was thinking about and that long drive. No contact whatsoever for that many hours. Oh, that was a little tough.” Again, a sense of the life-world of relationality is present here illuminating the overlapping life-worlds (Munhall, 2012), yet the temporal nature of this element of experience is revealed. The onset of the COVID-19 pandemic added additional uncertainty of the present context for many participants; family members described the backdrop of the rapidly evolving pandemic as contributing further stress and a perceived loss of control to their experience of a critically ill relative’s IFT to an urban centre.

The sense of a previously, predictable future suddenly becoming unknown influenced the meaning of this experience for family members. Participants described a “wait and see game” where the future was unknown and could not be known for some time. For example, not knowing how long they would be at the urban centre, if their relative would sustain permanent damage from the event, or if they would survive were pervasive thoughts described by participants. Some participants noted that they tried to pass this time or consciously will it to move faster. For participants who were already burdened with managing care needs of other family members, this unknown future of an unexpectedly critically ill relative was overwhelming. A daughter describes her thoughts when she hears of her mother’s acute illness:

> When I first found out, I was at work. The thing is my dad had been sick too, really quite needing a lot of care. So, when I heard about my Mom I really was just overwhelmed. I didn’t know what to do.

As noted in the life-world of spatiality, some family members pushed these thoughts and fears for the future away and attempted instead to focus on the present context. Family members who received information from healthcare providers described this as helpful for anticipating what the future may hold.

Some participants had previous personal or professional experiences of critical illnesses and they described drawing on this past knowledge to help them understand and cope with their present situation. Some participants reminisced about their relative's health before the event and this gave them comfort and hope for the future. Some family members described feelings of hope and then hopelessness that their relative would survive and return to their normal life. Other family members discussed their past experiences and pragmatically shared their feeling that the future is inevitable, and individuals are encompassed by the circle of life. For all participants in this study, the critically ill relative survived to be transferred back to their home. Within this context, several family members described how the future suddenly became known and that everything would be fine. An elderly wife describes seeing her husband the day after his neurological surgery: "he was getting along really well, as far as surgery went and he was- not able to talk to him or anything but you knew that everything was going to be okay."

Family members who were in a strong financial position indicated that they did not have financial concerns while they were spending time in the urban centre with their critically ill relative. Other participants described worrying about costs adding up over time if they would need to remain in the city for a prolonged period of time. Family members who described their financial situation as precarious expressed considerable stress with regards to the cost of travel to the urban centre and then the costs of accommodation and food that they would subsequently incur. A mother of a critically ill child describes:

> So, I remember it was a really rough morning. I paid [the travel costs] and then I got over there, I think I got over there at midnight…I went upstairs to see [her son] and he was

> doing okay, and then I went downstairs to just get a coffee and pay for my parking and that would've been my 70 bucks gone… thankfully they have the Ronald McDonald room downstairs and they do usually do suppers and stuff like that, and there's always snacks and stuff like that. So, that's the first thing I do is I go downstairs and see what the plan is for dinner for them if I know I don't have money for dinner…There's no charge for it…it's all free.

**Changing Existence as Time Passes.** For many family members, the sudden onset of a relative's critical illness and subsequent transfer to an urban centre for advanced critical care services was so abrupt that it was difficult to reconcile their present situation with the very recent past, a normal day. Participants described the experience of rushing home to pack belongings needed for a journey to an urban centre that had no known end point. For family members who had responsibilities at home, for example dependent parents or children, these urgent preparations also involved making arrangements to care for these individuals. The urgency of the moment experienced by many family members then abruptly changed to a period of waiting where the passage of time felt altered; time felt prolonged. Family members described waiting for their relative to arrive at the urban centre, waiting to be seen by the physician, waiting for their relative to go to surgery, and waiting for the surgery to end. A middle-aged son describes the urgency of his father's transfer to the urban centre for neurological surgery followed by a prolonged period of waiting:

> It was supposed to be a Tuesday afternoon around 1:00 or something like that, so there was a long stretch of waiting… the nurse came in and said, 'They're prepping him. They're gonna' prep him and take him into surgery.' And this would've been midnight, one o'clock in the morning this decision was made so we ended up all staying up… We waited in the

> waiting area and I wanna' say it was probably three o'clock in the morning, maybe, that the doctor came back and said the surgery was extremely successful

While in the urban centre, many family members described the sensation of losing track of time and the merging together of days and events. As the critically ill relative progressed in their recovery, family members describe witnessing gradual improvements in the patient's health. For some family members, the decision of the healthcare providers to send their relative back home came abruptly and unexpectedly. For these individuals, the journey home was anxiety provoking because they wondered if their relative was being discharged prematurely from the urban centre. For children of elderly parents who experienced an IFT for advanced critical care services, the meaning of the experience included an awakening understanding that their parent was aging and becoming increasing frail.

**Positive Outcome Fades Memories of Distressing Events.** Each participant in this study described an experience where their critically ill relative survived the event to return home. Several participants remarked that the positive outcome of their relative's critical illness event resulted in the blurring of distressing memories. A sister describes: "you have a crisis and then it goes and then it gets better and better and better. Then when you see… your brother and he's doing so much better… it's like oh, you kind of forget about the crisis." In contrast, a husband indicated that the experience of finding his wife collapsed at home is ever present and front-of-mind. Another participant described how her life experience has taught her to keep the past in the past: "when things are over, they're over and I don't- try not to dwell on anything that's happened… in the last few years, I've tried not to be so… worrying about everything that usually doesn't happen." These individual meanings of the experience of a critically ill relative's IFT to an urban centre highlight the importance and influence of individual context.

## 5.10 Discussion

It is recognized in the literature that a more complete understanding of the meaning of rural family members' experiences of a critically ill relative's transfer to an urban centre for advanced critical care services is required (Burns & Petrucka, 2020). To the best of my knowledge, this research is the first to explore the context-specific meanings of this experience for rural Canadians. According to Munhall (2012), through understanding individual, unique meanings of experience, nurses may better individualize the care provided to patients and families, thus reducing negative outcomes and enhancing well-being. This study aimed to increase the awareness of nurses to what meanings are possible for rural family members and then develop interventions to better care for this unique population of individuals.

Participants of this study described how shocking, confusing and anxiety provoking it felt to learn that their relative was critically ill and required an IFT to an urban centre 3 to 4 hours journey away from their home. For some participants, the stress of this time was so intense as to manifest as feelings of panic or physically with a vagal response. These findings support previous, similar findings in Australia (Johnson, 1999; Mackie et al., 2014) and Sweden (Karlsson et al., 2020). As with previous studies, family members in the present study experienced concern about managing responsibilities at home while away at the urban centre, fear and uncertainty related to travelling to an unfamiliar city and hospital, worry that something would happen to their relative while en route to the urban centre, and for some family members, concern related to how they would manage financially (Johnson, 1999; Karlsson et al., 2020; Mackie et al., 2014). As described by Karlsson et al. (2020), and Mackie et al., (2014), receiving information from healthcare providers that is honest and complete is necessary for family members and the absence of this is distressing, an experience also echoed by participants in the present study.

During this time of stress and uncertainty, family members described a pervasive need for information from healthcare providers. The provision of information from healthcare providers that was clear, understandable, complete and delivered in a respectful manner provided comfort to family members in the present study. The delivery of information that was confusing, incomplete or in some situations, omitted, resulted in increasing levels of stress for family members. Beyond receiving information, when healthcare providers gave family members the opportunity to share information about their relative with the team, family members felt more in control of the situation and able to contribute to their relative's care. While these findings have also been described in previous studies (Karlsson et al., 2020; Mackie et al., 2014) the present study extended the knowledge related to communication during the patient transfer window, by land or air ambulance.

Family members frequently referred to the time during which their critically ill relative was in transit, a time when there was no means of communication between family members and the transport team caring for the critically ill patient. This transfer window lasted between 3 to 4 hours and was described as intensely stressful, the hardest part of the event to endure. For some participants, the transfer occurred during adverse weather conditions such as blizzard conditions or dense fog; this extended the transfer time and increased the stress that family members endured. Family described this time as a time when they wondered if their relative was still alive, if they made it to the hospital, and what would they discover when they themselves arrived at the urban hospital. One participant knew a member of the transport team professionally and this paramedic provided her with their mobile phone number. During the daughter's drive to the city, the paramedics called her regularly with updates on her mother's condition. This family member indicated that this ongoing communication during the transfer was invaluable to her; she is not sure how she would have been able to cope without it. This finding is in direct contrast to findings by Nadig et al. (2019) where family members described the importance of communication with healthcare providers during transfers but expressed frustration with the lack of it. Additional study is required to explore this form of support for rural family members whose critically ill relative undergoes IFT to an urban centre.

Family members in the present study described a persistent need to be close to their critically ill relative prior to transfer, during transfer, and then in the urban receiving centre, a finding supported by previous studies (Karlsson et al., 2020; Mackie et al., 2014). For several participants, it was important to say goodbye to their relative before the transfer "in case something happened to them" on the journey, a finding also previously described by Mackie et al., (2014). For those family members that were not permitted to travel in any way to the urban centre because of COVID-19 interprovincial travel restrictions, it was particularly important for them to be present in their local emergency department in order to say goodbye to their critically ill relative. Several participants asked the transport team if they could travel with their relative but were refused this option. While it has been supported that family members may safely accompany critically ill relatives, family members are often denied this opportunity because of the personal assumptions of the transport team (Brown et al., 1998).

The context of the global COVID-19 pandemic resulted in several unique findings. At the onset of the pandemic in Canada, before travel restrictions were enacted, the increasing awareness of health concerns associated with COVID-19 caused some older family members to experience additional fears related to their critically ill relative's IFT. For these individuals, in addition to the noted stressors of a relative's critical illness and associated IFT, they experienced a heightened appreciation of personal health risks with travelling to urban centres and immersing themselves in busy, cramped emergency rooms and waiting rooms. As the pandemic evolved, public health guidelines were developed and strengthened to include a requirement to self-isolate for 14 days after return from interprovincial travel (Government of Canada, 2021a). For family members of critically ill patients undergoing IFT, a choice had to be made to either follow their critically ill relative to the urban centre and then self-isolate upon return to their home province or remaining in their home province during their relative's IFT so that they could then tend to their relative upon their return home, without the restriction of self-isolation.

As the pandemic continued to evolve, interprovincial travel restrictions tightened such that no travel was permitted beyond that which was necessary for urgent health care (Government of Canada, 2021a). In these situations, family members were not given the choice to travel with their critically ill relative to the urban centre. Subsequent to their relative's departure, these family members described the anxiety-provoking wait at home for notification by telephone that their relative arrived safely at the urban centre. The dynamic context of the pandemic and associated public health guidelines and restrictions added additional stressors to these family members and additionally contributed to the sense of the unknown present and future.

At present, the experience of rural family members who are not able to travel to an urban centre when a critically ill relative undergoes an IFT is poorly understood in the literature. Although not the initial aim of this study, the context of the COVID-19 pandemic and associated travel restrictions may provide insights into other experiences where family members are unable to travel to an urban centre (e.g., situations of limited financial resources or lack of access to transport). As noted by Mackie et al. (2014), being present and involved at a critically ill relative's bedside may assist family members in regaining a sense of control during an experience that often feels out of control; thus, denying this may negatively impact rural family members. Through the meanings experienced by family members denied the option to travel to the urban centre as revealed in the present study, an initial understanding of this experience is offered.

While in the urban centre, family members remained physically at their relative's bedside or in the waiting room of the critical care unit. When choosing accommodation, it was a priority for many family members that it be in close proximity to the hospital; thereby remaining physically close to their relative. These findings are similar to those described by Mackie et al. (2014) who also found that this unexpected need for accommodation results in a financial burden for family members. Despite this, family members in the present study often chose accommodation closest to the hospital despite accommodation farther away being considerably more inexpensive.

Family members who perceived their financial resources to be sufficient to support an IFT noted that they had no financial concerns during this event. In contrast, family members with self-described limited resources, such as a fixed income or minimal savings, described significant financial concerns that were additive to pre-existing concerns related to their relative's critical illness and IFT. The unknown of the critical illness trajectory also contributed to these concerns; family members feared mounting costs associated with an urban hospital admission with no known end. This finding supports previous studies by Mackie et al. (2014) and Johnson (1999). This experience changed the way some participants managed their finances after the event; some family members described their practice of saving money in the present in the event that their relative required an IFT again in the future.

Family support during a critically ill relative's IFT to an urban centre was described by participants as very important. When the participants of the present study were accompanied by other family members to the urban centre and were supported by these individuals during their stay in the city, these extended family members provided practical support such as arranging accommodation, organizing meals, and taking turns at the patient's bedside. When describing their experience, family members often note that they could not have coped without this level of family support, a finding echoed by Mackie et al. (2014). The present study's finding supports Mackie et al. (2014) and Johnson's (1999) finding that separation of a family member from their network of support at home is detrimental and exacerbates the degree of anxiety experienced by rural family members. However, it must be noted that some family members in the present study described negative experiences including behaviours by extended family members that were perceived as selfish or in some way burdensome to the family member who participated in this study. Family conflict was also described by Mackie et al. (2014) and may be significant enough to risk the integrity of the family.

As with findings by Karlsson et al. (2020), participants of this study experienced a persistent longing for home. *Home*, as longed for by family members encompasses more than the physical home; rather it includes both past and present family connections, routines, familiar items, memories, and a sense of normality itself. Participants described a sense of *home* present with them in the urban centre through the presence of other family members, familiar items such as books or their vehicle. Longing for home often was described as the family member pulling close a sense of *home* through telephone or video calls, reminiscing about *home*, and wishing for their critically ill relative to recover and be discharged *home*; a return to normal. While family members have described the transfer of their relative to a hospital closer to home as positive and a change toward a sense of normality (Karlsson et al., 2020), the concept of *home* as described by participants in the present study has not previously been noted. This novel finding is important because it suggests that *home* may be more mobile than previously perceived by urban critical care nurses. As such, critical care nurses are in a position to encourage and support rural family members to draw on elements of *home* beyond the physical or geographical and pull these close to provide support and comfort during their time in the urban centre.

Participants in the present study often described an aversion or reticence to communicating with healthcare providers or even being present in the critical care area for fear of "bothering" healthcare providers. This is similar to the finding by Bell at al. (2018) who found that family members chose not to voice concerns to healthcare providers because they felt that they did not have the required knowledge or understanding of their relative's healthcare situation, or they perceived the team to be too busy. In addition to this, one participant of the present study noted she was less comfortable speaking with urban nurses compared to rural nurses; with rural nurses being from and living in the same geographical location as her, it felt easier to talk to these individuals. While it has been noted in previous work that family members generally are reluctant to communicate concerns with ICU healthcare providers, thereby suffering in silence (Bell et al., 2018; Burns et al., 2018; Karlsson et al., 2020), the discomfort of rural family members specifically when communicating with urban nurses has not previously been noted. The findings of this study raise the question as to whether the variable of rurality further increases this hesitation and discomfort with communicating to ICU healthcare providers. According to Slama (2004), in a general sense, individuals living in rural areas share a culture with characteristics including a respect for perceived authority, self-sacrificing personal needs in preference for the needs of others and an intrinsic difficulty in communicating concerns with individuals unknown to them such as urban nurses.

In addition to the consideration of rurality as culture is the consideration of how health literacy, or the degree to which individuals successfully interact with health systems, may be influential in this issue. It has been noted that health literacy is an area of health concern in rural Canada (Gillis & Sears, 2012). This understanding of rurality as a distinct culture (Smally & Warren, 2012; Slama, 2004) and its resultant influence on the rural family members' meanings of experience are an important consideration. As an ICU nurse for more than 20 years, I have borne witness to numerous nurses questioning why some family members of critically ill patients do not call for updates on their relatives or do not come in to visit them. It is important to remember that each individual encountered in the healthcare environment has a unique history, experience and culture that has shaped their lifeworld and, thus, their perceptions and actions (Munhall, 2012).

## 5.11 Strengths and Limitations

This study had several strengths. In preparation for the commencement of this study, I undertook extensive reading and writing to gain an increased understanding of the philosophy of phenomenology; a critical step in completing a trustworthy phenomenological study (Annells, 1996; Koch, 1995; Munhall, 2012). Reading involved the original work of Heidegger (1953/2010), writings with Guignon's (2006) companion text, as well as articles relating to phenomenology as philosophy and methodology. My writing included a co-authored publication on interpretive phenomenology and specifically explored the work of three phenomenologists in nursing (Burns & Peacock, 2019). Through this reading and writing, I was able to develop an in-depth understanding of both the philosophy and methodology of phenomenology and consequently was successful in deliberately selecting an appropriate method of interpretive phenomenology and rigorously apply it to answer the research question posed in the present study.

Another strength of this study relates to my previous experience as a critical care nurse. With more than 20 years of critical care experience in both rural and urban centres, I have an appreciation of the process of IFT as it relates to both the transfer and receiving of critically ill patients. This knowledge of process, considered with the approach of *unknowning*, facilitated the conversational nature and search for meaning during participant interviews that is encouraged by Munhall (1994; 2012). Additionally, use of the Roy Adaptation Model (Roy, 2009) as a philosophical lens enhanced my understanding of the perceptions and responses of family members as they adapted to the context of this experience.

This study was also strengthened by the willingness of participants to meet with me to be interviewed in locations where they were most comfortable. Ten participants invited me into their home and the remaining participant invited me to their office for interview. As noted by Munhall (2012), it is of utmost importance that participants are comfortable during interview so that a conversational rapport and dialogue develops between the interviewer and interviewee, thereby enriching the sharing of experience and understanding. Data collection was also enhanced by the shared geographic location of myself and study participants; as noted by a participant in the present study, it is perceived to be easier to talk with others who live within the same cultural and geographical location.

The present study encountered several limitations. Male participant recruitment, a noted challenge in many studies (Markanday et al., 2013), was limited to two out of 11 participants in total. Another limitation in relation to data collection was noted with two participants electing not to engage in a second interview; both participants identified that they had shared all they could in the first interview and therefore they felt a second interview was not required. All individual narratives were offered to respective participants to review to ensure that the meaning of their experience was accurately captured. One participant declined to read the narrative stating that they did not want to review memories of the difficult experience of their critically ill relative's IFT to an urban centre. A second participant did not respond to an email request to review the narrative. A follow-up email was sent a week later indicating that if no response was received in 7 days, the researcher would assume the narrative was accurate; no response was received and thus, the narrative was assumed to be accurate. Of note, all other narratives were deemed acceptable by the participants, requiring no changes.

Another limitation of this study is related to the uniqueness of the context within which it was set. Canada is a geographically vast country with diversity of culture and experiences. Findings of the present study reveal meanings of this experience for family members within the Atlantic Canadian context; however, these meanings may be very different from those experienced by family members in different rural locations within Canada or farther beyond.

The context of the global COVID-19 pandemic also presented a limitation to this study. Because of pandemic preparations and public health guidelines, participant recruitment and in-person participant interviews were paused for a period of time. When pandemic preparations and public health guidelines allowed for the resumption of participant recruitment and in-person interviews, the dynamic nature of the pandemic caused me to conduct participant interviews in quick succession during the summer months with anticipation that restrictions would be re-enacted in the autumn and winter months. As such, these phases of study were more sequential in nature than originally planned, although a degree of data collection and analysis did occur simultaneously. In an effort to minimize this limitation, I was specifically methodical to fully analyse one participant's data prior to moving to the next participant's data. Of note, despite the limitations and disruptions of the COVID-19 pandemic, rich data were collected.

None of the participants in the present study experienced the death of their critically ill relative. As such, the meanings of the experience of a critically ill relative's IFT to an urban centre for advanced critical care services remains poorly understood within the context of a relative's death. As noted in this study, a positive outcome is perceived to fade the stressors and challenges faced by these family members. It is unclear what influence a negative outcome has on the experience for family members.

Finally, some may view the methodological choice of interpretive phenomenology as a limitation in this study. This methodology arises from the constructivist paradigm and as such the findings that are generated reflect individual, specific and multiple realities (Lincoln et al., 2018). In comparison, a methodology that arises from the postpositivist paradigm results in findings that are considered to reflect a singular reality (Lincoln et al., 2018); in my experience as a critical care nurse where attempts are made to standardize care, research findings of this nature are perceived to be more easily applied to practice. However, as articulated by Munhall (2012), it is through understanding the unique realities of patients that nurses can individualize care and thus enhance each unique nurse-patient relationship. In this way, rather than perceiving this methodology as a weakness, I view it as a strength in building nursing knowledge.

## 5.12 Implications and Recommendations for Practice and Research

Through an enhanced understanding of the multiple possible context-specific meanings uniquely perceived by each individual, nurses are better positioned to care for these family members (Munhall, 2012). Furthermore, as clearly articulated by Munhall (2012), the completion of a phenomenological study should lay the foundation for a “call to action” to change practice to better care for patients and families (p. 168). The findings of this study have several implications for nursing practice in both urban and rural settings.

Family members have an urgent need to remain close to their critically ill relative both during transfer and at the urban centre. Some family members describe the separation during transport as the most difficult part of the entire experience. Transport teams should make every effort to accommodate a family member accompanying their critically ill relative during transfer to the urban centre. If this is not possible, transport teams should consider providing the next-of-kin family member with a contact number that can be used to communicate during the transfer; having access to contact the transport team may mitigate the intense stress family members experience during this part of the event.

Rural nurses have an opportunity to support rural family members during this event by ensuring they feel welcomed at the critically ill patient’s bedside and advocating for the family member to accompany the patient in the land or air ambulance. Also, rural nurses can assist family members by providing clear information about the process of IFT, directions to the urban centre, and accommodation choices that are in close proximity to the receiving hospital. Rural nurses should also assess for potential financial concerns that these family members may have and collaborate with available resources to support families financially during this time.

With insights revealed in this study, urban nurses can better appreciate the unique challenges experienced by rural families including a loss of family support, need for information, a need to be close to their critically ill relative, a hesitation in voicing concerns to urban healthcare providers, and a proclivity to suffer in silence. With this knowledge, urban nurses may appreciate the additional emotional, psychological, social, and practical supports required by these family members who often remain silent in self-sacrifice.

While the present study supports previous work and extends the understanding of this phenomenon, more research is needed. One participant of the present study had the unique experience of being provided the mobile telephone number of the paramedic who was transporting her mother. This participant noted the importance of this connection to her critically ill mother during the transfer process. More work is needed to explore and evaluate this intervention, or the utility of other forms of technology, to provide a sense of closeness to the patient during the transfer window, thus, supporting rural family members. Additionally, future studies are required to understand the meaning of this experience for family members whose critically ill relative does not survive the critical illness event.

## 5.13 Conclusion

This study aimed to reveal the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services. Results of this study support previous research and extend the understanding of this phenomenon. Rural family members have unique needs and experiences that may add additional burdens to an experience that is already a time of intense stress. With this enhanced understanding and appreciation of the many possible meanings that are context-specific and unique, both rural and urban nurses can more effectively communicate with, understand, and support rural family members during this experience.

## 5.14 Chapter Summary

In this chapter, the results of this study were presented in a manuscript format. This manuscript included the identified gap in knowledge, research question and chosen method, findings, discussion, strengths and limitations, and implications and recommendations for nursing practice and research. This work has supported knowledge gained from previous studies and also extended the understandings of these experiences for rural family members. While this study sheds light on this experience within the Canadian context, further research is needed to continue to grow the understanding of this phenomenon and develop and evaluate interventions to support rural family members during this event.

# CHAPTER 6

## 6.1 Discussion and Conclusions

The purpose of this study was to enhance the understanding of the meaning of the rural family member's experiences of a relative's IFT for advanced critical care services. The research question that guided this study was: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* In this chapter, I will discuss findings of the preceding manuscripts that were prepared over the course of the present study which together, address the stated purpose and research question. Throughout this chapter, I will integrate manuscript findings into the extant literature. Following this, strengths and limitations of the present study are reviewed and areas of future research identified. At the conclusion of this chapter, concluding thoughts are offered related to my journey as a researcher and the impact of this work on myself.

## 6.2 Manuscript Findings with Linkages to Literature and Goal of Dissertation

### 6.2.1 Manuscript 1: Integrative Review and Gap in Nursing Knowledge

It has been acknowledged in the literature that a critical illness event may negatively impact family members physically, psychologically, financially, and socially (Davidson et al., 2012; Harvey & Davidson, 2016; Needham et al., 2012; Svenningsen et al., 2017). Harvey and Davidson (2016) have suggested that these negative short-term and long-term consequences may be lessened by reducing the level of stress that family members experience during a relative's critical illness. In addition to the stressors of a relative's critical illness, Burns et al. (2018) found that rural family members whose critically ill relative required an IFT to a distant urban centre for advanced critical care services may experience additional burdens. While there has been initial work completed that aimed to better understand the experiences of family members whose critically ill relative requires an IFT for advanced critical care services (Johnson, 1999; Karlsson et al., 2020; Mackie et al., 2014) understanding of this experience is incomplete. In response to this, an integrated review of existing literature was completed (Burns & Petrucka, 2020) for the purpose of informing the development of the purpose and research question that guided the present study. Through completing this integrative review, a better understanding of the current state of knowledge of this phenomenon was gained and important gaps in knowledge identified. These are described in more detail below.

The constructs of anxiety and stress were noted to be central in the experiences of family members of critically ill patients who required an IFT for advanced critical care services (Burns & Petrucka, 2020). The experience of anxiety and stress were noted to be minimized by the following subthemes: (a) receiving information about the IFT and being able to physically accompany the patient to the urban centre; (b) being close to their critically ill relative; (c) the availability of a support network; and (d) actions of health care practitioners (HCPs) that included offering support to family members, demonstrating a caring concern for the patient, and an accurate understating of the uniqueness of the rural family member's needs (Burns & Petrucka, 2020). The experience of anxiety and stress were increased by: (a) the lack of information about the IFT process or conflicting information between the rural and urban centres; (b) physical separation from the critically ill patient; (c) being away from the familiar home environment and a loss of family support; (d) the financial burden associated with the transfer; and (e) HCPs misunderstanding the needs of the family members during the IFT (Burns & Petrucka, 2020).

While this integrative review provided a new conceptualization of the rural family members' experiences of a critically ill relative's IFT to an urban centre for advanced critical care services, gaps in understanding of this phenomenon were also revealed (Burns & Petrucka, 2020). At the time of the integrative review, only the cultural contexts of Australia, the United Kingdom, and the United States were explored to varying degrees. Subsequent to the publication of this integrative review, a phenomenological inquiry into this phenomenon within the context of Sweden was published (Karlsson et al., 2020). However, the experience of this phenomenon within the cultural context of Canada remains unexplored. Thus, the following research question was developed to guide the present study: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* It was this research question that guided the research methodology chosen for the present study.

### 6.2.2 Manuscript 2: Research Method to Address the Research Question

Interpretive phenomenology is a research methodology that aims to understand lived experience (Crowther et al., 2017; Orbanic, 1999). Interpretive phenomenology is both a philosophy and a methodology; through approaching an inquiry in a philosophically phenomenological way, the application of a specific method of phenomenology can reveal hidden meanings of being-in-the-world that are “taken for granted” and thus generally unacknowledged (Frede, 2006; Leonard, 1989, p. 52; Mackey, 2005). Furthermore, Crowther et al. (2017) note interpretive phenomenology fosters connections between individuals on multiple levels thereby facilitating the sharing of experiences. Indeed, interpretive phenomenology aligns closely with the ideology of nursing (Mackey, 2005; Munhall, 2012) and also my personal presuppositions as explicated in chapter one. Thus, interpretive phenomenology was determined to be an appropriate methodology to address the research question as stated for the present study.

However, while interpretive phenomenology was determined as a logical choice of research methodology to guide the present study, selecting an appropriate method or approach within this methodology posed a challenge. As noted in the work of Spiegelberg (1982), a vast number of unique phenomenological methods are available to choose from (cited in Dowling, 2007). Thus, as a novice researcher and supported by my co-supervisor and co-author, I embarked upon an exploration of interpretive phenomenologists specifically within the field of nursing (Burns & Peacock, 2019) in order to inform the most appropriate interpretive phenomenological method to address the research question for the present study.

In this paper, the philosophy of interpretive phenomenology is explored and linkages between the philosophy and methodology illuminated (Burns & Peacock, 2019). As interpretive phenomenologists in nursing have received limited attention in the literature, an in-depth study and comparison of the unique, yet at times overlapping, interpretive phenomenological methods of Benner (1994a), Munhall (1994; 2012), and Conroy (2003) are offered (Burns & Peacock, 2019). The aims of this paper were two-fold: to determine the most appropriate interpretive phenomenological method for the present study and also to offer support to other novice researchers when choosing a research method.

Following the exploration of the philosophy of phenomenology and the comparison of three interpretive phenomenologists in nursing, I chose Munhall's (1994; 2012) method of interpretive phenomenology as the most appropriate method to guide the present study. In addition to Munhall being a nurse and therefore a distinct focus on the discipline of nursing permeates her method (Munhall, 1994;2012), several other benefits of this method were revealed (Burns & Peacock, 2019). The use of life-worlds as lenses to reveal multiple, context specific meanings, the generation of an overarching narrative at the conclusion of the study which is both powerful and perspective changing, and the pragmatic nature of this method made it an excellent fit for both myself and the research question of the present study.

With the determination of the gap in knowledge, development of the research question, and thoughtful choice of appropriate research methodology to guide the present study, I commenced data collection and analysis. At the culmination of data analysis, an overarching narrative (Burns, 2021a) was produced as a mode to assess rigour and to disseminate the findings of this study. This overarching narrative forms the third manuscript in this dissertation.

### 6.2.3 Manuscript 3: Overarching Narrative of Study Findings

According to Munhall (1994; 2012), the generation of an overarching narrative at the completion of an interpretive phenomenological inquiry is essential to revealing the multiple and complex possible meanings of being that are unique and context specific to each individual. In disseminating findings in this format, the perceptions of nurses are changed from what was previously taken for granted assumptions and opened to new, meanings of experiences of family members during this phenomenon (Munhall, 2012). Furthermore, Munhall (2012) encourages researchers to incorporate implications for nursing practice, a “call to action” (p. 168). In generating this overarching narrative, I used pseudonyms to represent three rural family members who experienced a critically relative’s IFT for advanced critical care services. The experiences of meaning portrayed in this overarching narrative arose from the multiple, context specific meanings and perspectives of both myself and study participants as were revealed in the present study. Throughout the overarching narrative, implications for nursing practice are embedded with the aim of effecting positive change in the care provided for these rural family members (Munhall, 2012). This manuscript is presently undergoing review for publication thereby contributing to the increasing understanding of this phenomenon, specifically within the Canadian context.

### 6.2.4 Manuscript 4: Findings of the Life-worlds

In the fourth and final manuscript within this dissertation, I offer an in-depth description of the processes and findings of the present study that addressed the purpose and research question posed (Burns, 2021b). In this manuscript, research decisions are described such as ethical considerations, recruitment strategies, steps for data collection and analysis, and strategies to enhance the rigour of this study. Following this, a detailed description of the findings is offered and subsequently discussed within the context of existing literature. This manuscript concludes with a discussion of strengths and limitations of the present study and implications for practice and research.

With the completion of the present study, previous findings were confirmed as well as novel and sometimes contradictory findings revealed. As with previous work (Johnson, 1999; Karlsson et al., 2020; Mackie et al.,2014), the present study confirmed the family members' experiences of a shocking, confusing, intensely stressful and anxiety provoking time when they learned that their relative was critically ill and required an IFT to a distant urban centre for advanced critical care services. These experiences were compounded by the family member's concern of travelling to an, at times, foreign city, fear for their critically ill relative during the transport window, associated financial burdens, loss of the support network of *home*, and a need to manage responsibilities at home while in the urban centre; findings supporting previous work (Johnson, 1999; Karlsson et al., 2020; Mackie et al., 2014). As with previous work (Karlsson et al., 2020; Mackie et al., 2014), open communication between HCPs and family members and an opportunity to be physically close to their critically ill relative and receiving support from family in the urban centre was found to be both sought after and beneficial.

Unique to the present study was the meaning of the experience of physical separation and absent communication that occurred during the patient transfer window; some participants described this time as the most difficult to endure part of the experience. Although previous work has suggested it is safe for family members to accompany the critically ill patient during transfer, family members historically have been denied this option (Brown et al.,1998). Unfortunately, the present study reveals that family members continue to be refused this option. Although the study by Nadig et al. (2019) did not focus specifically on the IFT experiences of rural family members, they note that family members express frustration with the lack of communication during patient transfers from less specialized ICUs to more specialized ICUs. However, the present study revealed a contradictory finding from a participant who had direct telephone contact with the transfer team during the transfer window from originating rural hospital to receiving urban centre. This participant noted the vital importance of this line of communication; a finding that is significant when considering implications for research and practice.

Novel findings were also revealed in the present study. Although the experience of *longing for home* has been described previously (Karlsson et al., 2020), participants of the present study described *home* in a novel sense including the physical presence of family members in the urban centre, recalling fond memories, telephone or video calls with family members far away, and having familiar items such as books with them. With this novel finding, urban nurses may better appreciate the mobility of *home* and provide a means or encouragement for family members to access this potential support during the experience.

The context of the COVID-19 global pandemic offered a serendipitous and novel finding. Interprovincial travel restrictions associated with the pandemic (Government of Canada, 2021a) limited or restricted the travel of family members to urban centres. For these family members, waiting at home for information such as their safe arrival at the urban centre or the changing plan of care within the urban critical care unit was anxiety-provoking. Presently, the experience of rural family members who are unable to travel a significant distance to an urban centre (e.g., because of limited finances or access to transport) is not well described; thus, the findings revealed in the present study related to the inability to travel to the urban centre offer a beginning understanding of this component of the phenomenon.

Finally, a novel finding related to rurality itself was revealed in the present study. Rural family members at times expressed a reluctance to communicate with urban nurses, noting an increased comfort level communicating with rural, critical care nurses in the originating hospital. Rurality as culture and the degree of health literacy were put forth as potential contributing factors for this reticence on the part of rural family members when communicating with urban nurses.

The purpose of the present study was to enhance the understanding of the meaning of the rural family member's experiences of a relative's IFT for advanced critical care services. Each manuscript prepared in this dissertation was foundational in addressing the stated research question: *What is the meaning of the lived experiences of rural family members whose relative undergoes an IFT to an urban tertiary centre for advanced critical care services?* In the process of addressing the research question, the present study provides support to previous work, offers a contradictory finding, and puts forth several novel findings that together, increase understanding of the rural family members' experiences of a critically ill relative's IFT to an urban centre for advanced critical care services. In the following section, I will identify the strengths and limitations of this work.

## 6.3 Strengths and Limitations

The strengths of each manuscript contained within this dissertation together strengthen the findings of the present study. In the paper by Burns and Petrucka (2020), using the existing literature to date, the structured approach of an integrative review resulted in a new conceptualization of this emergent area of critical care nursing (Torraco, 2005; Whittemore & Knafl, 2005). Furthermore, as an integrative review may identify gaps in existing knowledge (Torraco, 2005; Whittemore & Knafl, 2005), the result of this paper highlighted areas for future research and thus inspired the present study.

Following the completion of this integrative review (Burns & Petrucka, 2020) and subsequent development of the research question to guide the present study, the search for an appropriate methodology to address this question commenced. This effort culminated in the generation of the second manuscript within this dissertation: An in-depth study of the origins and philosophy of interpretive phenomenology and subsequent comparison of three methods of interpretive phenomenology (Burns & Peacock, 2019). The prolonged engagement and study of the works of Heidegger (1953/2010), Benner (1994a; 1994b), Munhall (1994; 2012), and Conroy (2003) as well as companion texts and papers in peer-reviewed journals enabled an in-depth comprehension of the philosophy and methodology of interpretive phenomenology and thus supported the accurate application of research method in this dissertation.

With the in-depth understanding of Munhall's (1994; 2012) method of interpretive phenomenology, the present study commenced and upon its completion an overarching narrative was generated (Burns, 2021a). The third manuscript within this dissertation, the overarching narrative, strengthened by its grounding within the context specific meanings of participants within this study and critiqued for rigour as described by Munhall (1994) provides an accessible mode for knowledge dissemination to practicing nurses. As noted by Munhall (2012), the overarching narrative reveals that which may be hidden and thus increase nurses' appreciation of the many possible meanings and perceptions of experience. With the aim of improving the care of rural family members during this experience, implications for nursing practice are embedded within this overarching narrative.

The final manuscript, the detailed report of the present study (Burns 2021b) has several strengths. In addition to the strengths outlined above in the work that was foundational to this study and dissertation, my experience as both a rural and an urban critical care nurse was a strength. This past experience, combined with an enhanced understanding of human adaptation explicated by the Roy Adaptation Model (Roy, 2009), facilitated a penetrating exploration of the meaning of participant experiences in the present study. This study was further strengthened by the participants' degree of comfort in sharing their experiences with me. This comfort was in part enhanced by their willingness to be interviewed by myself in their home, and potentially by their perception of me as a peer in the realm of rurality. As noted by a participant in the present study: it is easier to talk with nurses who are from the same rural geographical location.

The COVID-19 pandemic contributed a limitation to the present study. With the dynamic and evolving situation of the pandemic and associated public health restrictions (Government of Canada, 2021b), data collection was paused for a period of time. When restrictions lifted, data were collected without pause between participants with the expectation that public health restrictions would be reinstated in the fall and winter seasons thereby preventing further data collection. As such, data were primarily collected and then analysed although a degree of simultaneous data collection and analysis did occur as originally planned. Despite this, rich data were collected.

This study was also limited by the inclusion of only two male participants. Recruitment efforts continued until a second male participant was recruited thereby adding further understandings to the male family member experience of a critically ill patient requiring an IFT for advanced critical care services. Some participants declined participation in the second interview and, out of respect, a second request for the second interview was not attempted. Additionally, as this study was completed in Atlantic Canada, the findings of this study, being context-specific, may not reflect the potential meanings that family members experience in other regions of Canada or beyond.

Finally, for each participant in the present study, the critically ill relative survived the IFT and recovered from the critical illness event. As noted by some participants, a positive outcome faded or mitigated the negative experiences of the critical illness event. Limited by the absence of participants who experienced poorer outcomes (including death of their relative), this context of experience remains poorly understood.

## 6.4 Direction for Future Research

The present study provides direction for future research. Because understandings of the meanings of the experience when a critically ill relative requires an IFT but does not survive remains poorly understood, more research is required in this area. Additionally, based on the unique experience of one participant who was provided the contact information of a member of the transport team to use during the transport window, more research is required to explore and evaluate this intervention, or the utility of other forms of technology, to provide a sense of closeness to the patient. This participant indicated how incredibly comforting and positive this level of access to the transport team was during the time of the transport window. By completing additional research in this area, this intervention may be successfully applied within the context of rural to urban IFTs.

## 6.5 Conclusion

In this dissertation, each manuscript was foundational in the generation of the findings of the present study. In Burns and Petrucka (2020), a new conceptualization of the existing literature related to the phenomenon of interest was developed and gaps in knowledge identified. From this work, the research question for the present study was created. To determine the most appropriate method of interpretive phenomenology to address this research question, an in-depth exploration of interpretive phenomenology and comparison of three nurse phenomenologists was undertaken and thus produced the second manuscript (Burns & Peacock, 2019). Upon completion of data analysis, a third manuscript was produced, an overarching narrative (Burns, 2021a), as a mode to assess rigour and also as a way to disseminate findings of the study as directed by Munhall’s (2012) version of interpretive phenomenology. All preceding work informed the generation of the fourth and final manuscript, an in-depth report of the study findings (Burns, 2021b). In addition to the contributions of each manuscript to the successful completion of the present study, each manuscript added to the existing nursing knowledge regarding IFT related to critical illness in a rural context.

## 6.6 Chapter Summary

In this chapter, the findings of each manuscript were revisited and linkages drawn between manuscripts to highlight the contributions of each that culminated in the successful completion of the present study. Additionally, findings of each manuscript were situated within the extant literature related to methodology and critical care nursing knowledge. Strengths and limitations of the study were identified and directions for future research presented. In the next and final section, I offer concluding thoughts upon the completion of this dissertation.

## 6.7 Concluding Thoughts

During the course of this research journey, I have gained a new understanding for the many possible meanings that rural family members may have when undergoing an IFT experience. Further to this, and as described by Munhall (2012), this journey has caused me to increasingly *be* phenomenological and *think* phenomenologically. I find myself contemplating both my being-in-the world and that of other individuals that I encounter in both my personal life and in my work. By being and thinking phenomenologically, and now almost effortlessly *unknowing*, I find myself being more present to my experiences and the experiences of others, thereby increasing my knowledge and understanding of self and those I encounter.

I am grateful to the participants who willingly shared their experiences of an incredibly challenging and stressful time. I am also proud of the quality of the work that has resulted from their sharing of experience; findings of this study provide a foundation to inform nursing practice and improve the care of these families. While the research question that guided this study has been answered, more questions have been raised and I am excited to continue on this journey of research, discovery, and enhancement of nursing practice in critical care.

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# Appendix A

## Summary Tables of Included Studies

*Summary Table of Included Quantitative Studies*

| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Brown, Tompkins, Chaney, & Donovan (1998) | Brown, J., Tompkins, K., Chaney, E., & Donovan, R. (1998). Family member ride-alongs during interfacility transport. *Air Medical Journal*,*17*(4),169-173. https://www.airmedicaljournal.com | “ to evaluate AMT’ s ride-along program from the perspective of the FMP.” (p. 170)<br>AMT:Air Med Team<br>FMP: Family member passenger | -31 FMP<br>- age>18<br>-78% parents<br>-16% spouse<br>Of the transports surveyed, 81% involved a child aged 1 month- 14 years<br>-consecutive sampling plan | -Telephone survey (10 item questionnaire with scaled responses of agreement. Open ended question at the end: “ The transport experience would have been better if:”<br>-Descriptive design. Cross-sectional measurement | -100% thought accompanying the patient was beneficial for them<br>-97% thought FMPs should always be allowed on transports<br>-97% thought the patient benefited from the FMP being there<br>-94% thought the FMP was beneficial during transport (emotional support to patient and information to receiving doctor)<br>-100% felt well informed during the transport<br>-9% were scared of flying, however, the patient’ s critical status was such that they felt it was necessary to accompany them<br>-7% wished their spouse could have accompanied them too<br>-13% wished they could have sat in the back with the | -Family should be allowed to accompany a critically ill patient during IFT<br>-Flight programs frequently deny FMPs; personal feelings of the flight team often influence this decision<br>-Families benefit personally from staying close to the patient during IFT<br>-Family members feel useful when they can accompany the patient during IFT (emotional support, communicating information)<br>-Family members desire to be close and be there for their relative causes them to self-sacrifice (flying with fear)<br>-Family members need other family support during IFT but may not get it |

*Summary Table of Included Quantitative Studies*

| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Perez, Alexander, & Wise (2003) | Perez, L., Alexander, D., & Wise, L. (2003). Interfacility transport of patients admitted to the ICU: Perceived needs of family members. *Air Medical Journal*, *22*(5), 44-48. https://doi.org/10.1067/mmj.2003.66 | 1) " to identify the most important informational and situational needs of family members during the IFT of their critically ill adult family member" (p. 44)<br>2) " to identify the extent to which CCT team members accurately determined the importance of family members' needs during a transport" (p.44) | -Consecutive sample.<br>-42 family members (13% men, 69% women, 55% were spouses of the patient)<br>-13 air and ground CCT team members<br>CCT= Critical Care Transport | Cross-sectional, descriptive | -The family' s most important need was: " to know how the patient would be treated during transport" . Second most important need was: " to have questions answered honestly" (p. 45)<br>-Chi square analysis was used to assess for differences between CCT team members and family members on family needs importance. Significant ($p < .05$) difference between groups in 13 of the 25 items in the questionnaire. | - " CCT team members generally underestimate the importance of these needs to the family members" p. 45<br>-Family members want to know that the CCT team care for their relative and a high standard of care will be provided during transport<br>-It is important for the family to know that equipment used during the transport is comparable to that used in the hospital<br>-Family members note it is important to receive directions to the new hospital<br>-More than half of family members want to travel with the patient<br>-If CCT team members better understood the needs of family members, they could better address them at the bedside before the IFT |

*Summary Table of Included Quantitative Studies*

| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Menon, Stapleton, McVeigh, & Rabinowitz (2015) | Menon, P. R., Stapleton, R. D., McVeigh, U., & Rabinowitz, T. (2015). Telemedicine as a tool to provide family conferences and palliative care consultations in critically ill patients at rural health care institutions: A pilot study. *American Journal of Hospice & Palliative Medicine, 32*(4), 448-453. https://doi.org/10.1177/1049909114537110 | “ to investigate the feasibility and to describe patient outcomes of palliative care consultations via telemedicine in critically ill patients” p. 449. | -Patients who were transferred from a rural hospital to a tertiary care MICU<br>-12 patients who had telepalliative care consultations offered prior to transfer were included (8 were subsequently transferred to the tertiary care ICU, 4 remained at their rural hospital) | Retrospective review of telemedicine family conferences among critically ill patients requested for transfer to a tertiary care ICU<br>Descriptive design. | - 7 of the 8 patients who transferred to the tertiary ICU were subsequently transferred back to their rural hospital<br>-Did not collect data from directly from family members (chart review). Therefore, perceptions of participants were not evaluated. | -Although it is unclear why patients were transferred back to their rural hospital, the authors speculate that it was because the families and patients chose to receive the rest of their care closer to home (particularly if they perceived that death was imminent)<br>-Avoiding transfers of patients who are expected to die may reduce the psychosocial burden on family members |

*Summary Table of Included Qualitative Studies*

| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Johnson (1999) | Johnson, P. (1999). Rural people's experience of critical illness involving inter-hospital transportation: A qualitative study. *Australian Critical Care*, *12*(1), 12-16. https://www.australiancriticalcare.com | To explore the experience of rural people with critical illness that requires an IFT to an urban center for further management | 10 patients who experienced a critical illness and was admitted to a rural ICU before being air transferred to a tertiary ICU for advanced care. | Hermeneutic phenomenology | - Patients experienced anxiety both during and after an IFT when separated from family members<br>- the family network of support was so far away that anxiety was increased during the critical illness<br>- rural patients and families feel overwhelmed and depersonalized in the urban environment<br>-discharge instructions from the tertiary hospital conflicted with the directions they received when they returned to their rural environment<br>- Unique to rural patients and families is the additional anxiety and confusion experienced during an IFT | - patients and families must receive clear explanations about the transfer procedure so as to reduce anxiety and stress<br>- nurses play a key role in involving family members in the care of the patient<br>- nurses must be aware of the unique needs of rural families who experience an IFT to an urban centre in the context of critical illness<br>-It is financially challenging for rural families to travel to urban centres for an IFT |

*Summary Table of Included Qualitative Studies*

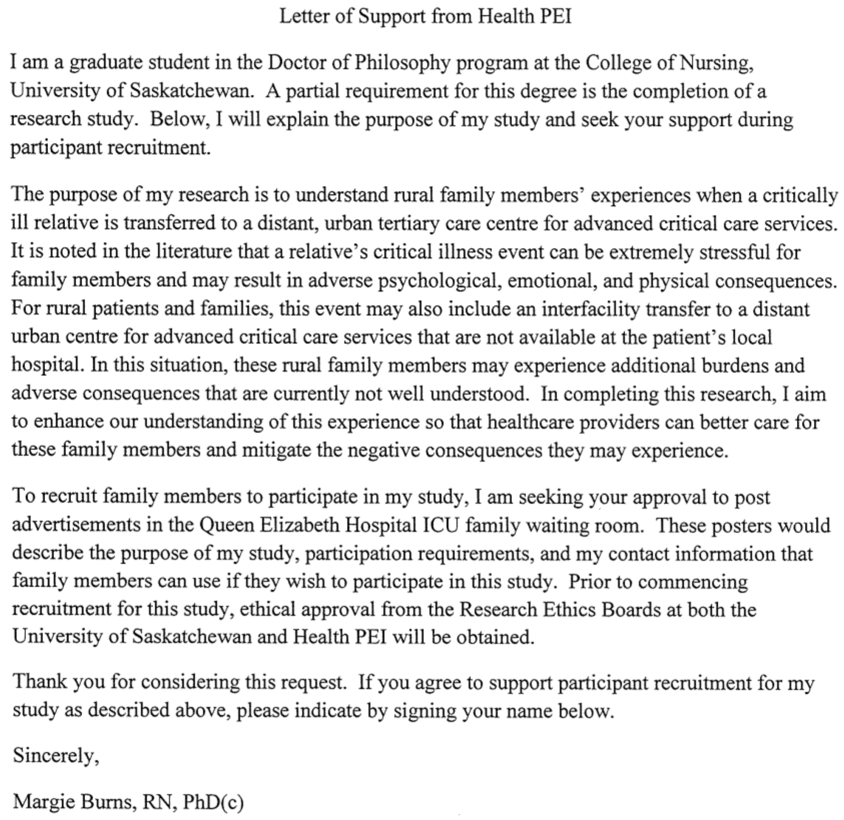
| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Fulbrook, Allan, Carroll, & Dawson (1999) | Fulbrook, P., Allan, D., Carroll, S., & Dawson, D. (1999). On the receiving end: Experiences of being a relative in critical care. Part 1. *Nursing in Critical Care*, *4*(3), 138-145. https://onlinelibrary.wiley.com/journal/14785153 | To describe a wife's (and also an ICU nurse) experience of her husband's admission to ICU so that other HCPs may learn | 1 wife of a patient who was admitted to an ICU | Case study | -Following the ambulance during an IFT is very stressful<br>-There are navigation challenges that the family member has to deal with but doesn't want to deal with because they are so focused on their relative arriving safely at the receiving hospital<br>- The family member felt positive about the IFT because she knew he needed the advanced level of care the tertiary centre could offer<br>-She felt the IFT may have had a negative effect on her husband's heath status<br>-She felt isolated at the tertiary care unit<br>-The home hospital environment is familiar, and the receiving hospital is perceived as an unfamiliar, strange environment<br>-Worry about the quality of the care in the unfamiliar, receiving hospital | - travelling during an IFT to an unfamiliar urban/ tertiary care centre adds an additional burden to family members<br>-family constantly worries for their family member during the IFT<br>-Although the IFT is perceived to be positive initially, the unfamiliarity and loss of the familiar and perhaps social support system at home leaves family members feeling isolated and even more worried about their loved one (worry about the quality of care the patient is receiving) |

*Summary Table of Included Qualitative Studies*

| Source | Full Reference | Purpose | Sample | Study Design | Results | Implications |
|---|---|---|---|---|---|---|
| Mackie, Kellet, Mitchell, & Tonge (2014) | Mackie, B., Kellet, U., Mitchell, M., & Tonge, A. (2014). The experiences of rural and remote families involved in an inter-hospital transfer to a tertiary ICU: A hermeneutic study. *Australian Critical Care*, *27*, 177-182. https://doi.org/10.1016/j.aucc.2014.04.004 | " To gain an understanding of rural and remote critical care families' experiences during an inter-hospital transfer to a tertiary ICU"<br>(p. 177) | A purposive sample of 7 rural and remote family members who had a relative admitted to a tertiary ICU via IFT from a rural or remote community.<br>Majority were female, a spouse, parent or adult child | -Hermeneutic phenomenology<br>-Two interviews 1st interview within the first two weeks of the patient being admitted to the ICU. 2nd interview 2-10 weeks later<br>-researcher' s journal<br>-fieldnotes post interview | 4 modes of being and 14 shared meanings:<br>1) being confused<br>Shared meanings:<br>-feeling unsupported<br>-need for information<br>- sense of panic<br>2) being engaged<br>Shared meanings:<br>-saying goodbye<br>-focus on the patient<br>-seeking information<br>3) being vulnerable<br>Shared meanings:<br>-sense of shock<br>-feeling the pressure<br>-old wounds<br>-financial burden<br>-threatened breakdown of family<br>4) being resilient<br>Shared meanings:<br>-holding it together<br>-sense of support<br>-life goes on | -support is removed (home) yet support from HCP is not always provided resulting in a reduced level of support for these individuals compared to local ICU families<br>-lack of information contributes to increasing anxiety and panic which may lead to physical risk for families (car accidents)<br>-families have a need to say goodbye to the patient before IFT (because of the unknown that the IFT presents)<br>-a need to be close to the patient because family members thought this is important to aid recovery<br>-perceived understanding and coping prior to IFT was lost upon arrival to the new hospital<br>-new environment combined with uncertainty in the outcome results in increased pressure on family members and worsening health status<br>-desire to be close caused financial stress because of the cost of accommodation<br>-financial burden and living in very close proximity to each other in the urban setting may lead to increased family tension and dispute<br>-IFT gave time to reflect on the support they did receive and how important it was for them<br>-a perceived need to continue with important life events during this experience (such as weddings) |

# Appendix B

## Letters of Support from Health PEI



### Letter of Support from Health PEI

I am a graduate student in the Doctor of Philosophy program at the College of Nursing, University of Saskatchewan. A partial requirement for this degree is the completion of a research study. Below, I will explain the purpose of my study and seek your support during participant recruitment.

The purpose of my research is to understand rural family members' experiences when a critically ill relative is transferred to a distant, urban tertiary care centre for advanced critical care services. It is noted in the literature that a relative's critical illness event can be extremely stressful for family members and may result in adverse psychological, emotional, and physical consequences. For rural patients and families, this event may also include an interfacility transfer to a distant urban centre for advanced critical care services that are not available at the patient's local hospital. In this situation, these rural family members may experience additional burdens and adverse consequences that are currently not well understood. In completing this research, I aim to enhance our understanding of this experience so that healthcare providers can better care for these family members and mitigate the negative consequences they may experience.

To recruit family members to participate in my study, I am seeking your approval to post advertisements in the Queen Elizabeth Hospital ICU family waiting room. These posters would describe the purpose of my study, participation requirements, and my contact information that family members can use if they wish to participate in this study. Prior to commencing recruitment for this study, ethical approval from the Research Ethics Boards at both the University of Saskatchewan and Health PEI will be obtained.

Thank you for considering this request. If you agree to support participant recruitment for my study as described above, please indicate by signing your name below.

Sincerely,

Margie Burns, RN, PhD(c)

## Letter of Support from Health PEI

I am a graduate student in the Doctor of Philosophy program at the College of Nursing, University of Saskatchewan. A partial requirement for this degree is the completion of a research study. Below, I will explain the purpose of my study and seek your support during participant recruitment.

The purpose of my research is to understand rural family members' experiences when a critically ill relative is transferred to a distant, urban tertiary care centre for advanced critical care services. It is noted in the literature that a relative's critical illness event can be extremely stressful for family members and may result in adverse psychological, emotional, and physical consequences. For rural patients and families, this event may also include an interfacility transfer to a distant urban centre for advanced critical care services that are not available at the patient's local hospital. In this situation, these rural family members may experience additional burdens and adverse consequences that are currently not well understood. In completing this research, I aim to enhance our understanding of this experience so that healthcare providers can better care for these family members and mitigate the negative consequences they may experience.

To recruit family members to participate in this study, I am seeking your approval to post advertisements in the Queen Elizabeth Hospital Emergency Department. These posters would describe the purpose of my study, participation requirements, and my contact information. Additionally, I am seeking your support to contact potential participants by telephone to invite them to participate in this study. As the primary investigator, I am unable to contact potential participants directly; therefore, I would seek your support to have a member of your staff (who normally has access to patient charts) identify potential participants and then contact them by telephone using a script. This script would describe the study details and include my contact number for them to use if they wish to participate in this study. In some situations, a follow-up telephone call to a potential participant may be requested of your staff member. Prior to commencing recruitment for this study, ethical approval from the Research Ethics Boards at both the University of Saskatchewan and Health PEI will be obtained.

Thank you for considering this request. If you agree to support participant recruitment for my study as described above, please indicate by signing your name below.

Sincerely,

Margie Burns, RN, PhD(c)

Appendix C

Advertisement to Participate

## College of Nursing
## University of Saskatchewan

# PARTICIPANTS NEEDED FOR RESEARCH IN:

## *THE IMPACT OF CRITICAL ILLNESS ON FAMILY MEMBERS*

We are looking for volunteers to take part in a study of the family member's experience when a critically ill relative is transferred to a specialized ICU in a different city for advanced ICU services.

As a participant in this study, you would be asked to share your experiences when your relative was transferred to an ICU in another city for advanced critical care services.

Your participation would involve two or three interviews with the researcher, each of which is approximately 60 minutes.

For more information about this study, or to volunteer for this study, please contact:

Margie Burns RN, MN, Graduate Student, College of Nursing
at
902-566-0754
Email: margie.burns@usask.ca

**This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.**

UNIVERSITY OF SASKATCHEWAN | usask.ca

# Appendix D

## A Script for Use by the Emergency Department Staff Member During Recruitment

The following is a script for the Emergency Department Staff Member to use when contacting potential participants by telephone to explain the proposed study and providing my contact telephone number if they wish to participate.

Margie Burns is a graduate student in the Doctor of Philosophy in Nursing program at the University of Saskatchewan. She is doing a research study into what it is like for family members when a relative is critically ill and needs to be transferred to another ICU in a large city far advanced care that is not available in the local hospital. She is interested in learning about the families' experience during this transfer to the specialized ICU in the large city, so that nurses and other health care providers can better understand what it is like for them. With a better understanding of what it is like for family members, she hopes to find ways to improve our care of families during this time.

If you agree to be a part of this study, your involvement is completely voluntary. The study involves Margie interviewing family members of patients who were critically ill and transferred to a specialized ICU in another city. If at any time during the interview you want to stop, you can do so without any consequences. If you want to withdraw partway through the study, any information that has been collected will be destroyed and will not be included in the study report. Margie will use several strategies to keep your participation in the study strictly confidential. She will interview you at a location of your choice, code the interview information so that your name is not linked to what you say during the interview, lock up and secure the information you share during the interview, and also use fake names in the study report.

If you think you might be interested in participating or would like to know more about this study, I can give your telephone number to Margie if you wish. When she calls you, she can tell you more information about the study and answer any questions you may have before you decide if you want to participate or not.

## Appendix E

## Letter of Invitation

### Critical Illness and Rurality: Interfacility Transfers to Urban Centres and the Impact on Rural Families

**You are invited** to take part in a research project that is taking place at the University of Saskatchewan, College of Nursing. We are doing this study with families of patients who are critically ill and need to be transferred to a specialized intensive care unit in another city. We want to find out what this experience is like for families, so that nurses and other health care providers can do a better job of looking after families who are going through this experience. Because we want to understand what this experience is like for all members of the family, we would ask you to share this letter with other members of your family that may be interested in taking part in the study. To be able to take part, you must be at least 18 years old, be able to speak and understand English, and be a partner, sibling, child, or parent of someone who has lived after an admission to intensive care within the last 1 to 24 months.

**Who is doing the research?** The study is being led by Margie Burns, Graduate Student at the College of Nursing, University of Saskatchewan.

**Is taking part in the study voluntary and confidential?** Yes. You can choose whether you want to take part or not. If you decide to take part, you can also choose to leave the study at any time after the study begins. If you decide not to take part, or you choose to leave the study before it finishes, you will be supported to do this. All of the information that you share will be kept confidential within the limits of the law.

**How will the study be done?** If you agree to take part, you will be asked to read and sign a consent form. At this time, you and the researcher will arrange a time and place to meet for two or three interviews. The interviews will take about 1 hour each. During the interview, the researcher will ask you to describe what it was like for you during the time around when your relative was critically ill and needed to be transferred to a specialist intensive care unit in another city. The interviews will be digitally audio recorded, and then typed out for the researcher to look at later.

**What will happen to my information?** At all times, the information that I collect during the study will be secured in a locked drawer in my personal office. Identifying information will be coded and stored in a different place from the interview information so that your interview discussion cannot be connected to your name. After your interview, and before your data is included in the final report, you will be given the opportunity to review the transcript of your interview, and to add, change, or remove information from the transcript as you see fit. After the study is over, fake names will be used in the study report. If you would like to see the results of the study when it is complete, you can call me and I will mail you a copy of the results.

**Are there risks and benefits to taking part?** There are no known risks associated with taking part in this study. But if you become upset during the interview, I will be able to talk to you about your experience further after the interview if you wish, or I can help you to find someone who can help you. The benefits are that you may help us to better understand how to help families who have a critically ill family member who is transferred to a specialized intensive care unit in another city.

**If you have questions about the study,** please contact Margie Burns at (902) 894-2143, or by email at margie.burns@usask.ca or my supervisors, Dr. Shelley Peacock at (306) 966-7375 or shelley.peacock@usask.ca or Dr. Lorraine Holtslander at (306) 966-8402 or lorraine.holtslander@usask.ca . This project was reviewed on ethical grounds by the University of Saskatchewan Behavioural Ethics Board. However, if you have any concerns about how the research was done, please contact the Research Ethics Office toll free at 1-888-966-2975 or email at ethics.office@usask.ca . Please keep this sheet in case you need to look at it later.

Flesch-Kincaid Grade Level 9.2

Appendix F

Written Consent Form

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College of Nursing
NURSING.USASK.CA

# *Participant Consent Form*

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If you have read the Letter of Information and would like to take part in this study, please read and sign this consent form.

**You are invited to participate in a research study entitled:**

Critical Illness and Rurality: Interfacility Transfers to Urban Centres and the Impact on Rural Families

**Researcher:** Margie Burns: Graduate Student at the College of Nursing, University of Saskatchewan
Phone: (w) (902) 894-2143, email: margie.burns@usask.ca

**Supervisors:**
Dr. Shelley Peacock: Co-supervisor and Associate Professor, College of Nursing at the University of Saskatchewan
Phone: (306) 966-7375 or shelley.peacock@usask.ca

Dr. Lorraine Holtslander: Co-supervisor and Professor, College of Nursing at the University of Saskatchewan
Phone: (306) 966-8402 or lorraine.holtslander@usask.ca

**Purpose of the Research:**
The purpose of this study is to find out what it is like for families when their critically ill relative is transferred to a specialized intensive care unit in another city for advanced services that are not available in their local hospital.

**Procedures:**

- It is up to you whether you take part in this study.
- You will be interviewed by the researcher two or three times. Each interview will take about 1 hour. During the interview, the researcher will ask you to describe what it was like for you during the time around when your relative was critically ill and needed to be transferred to a specialist intensive care unit in another city.
- The interviews will be digitally audio recorded, and then typed out for the researcher to look at later. You may request the recorder to be turned off at any time.

- After your interviews, and before your data is included in the final report, you will be given the opportunity to review the transcript of your interviews, and to add, change, or remove information from the transcript as you see fit.
- After the study is over, false names will be used in the study report in order to keep your information confidential.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Potential Risks:**

- There are no known risks to taking part in this study.

**Potential Benefits:**

- The benefits are that I may help families of patients who are need to be transferred to a specialized intensive care unit in another city.

**Confidentiality:**

- The information you give will be kept confidential within the limits of the law.
- To keep your participation in the study confidential, the interview will be done in a private office, information will be coded so that your name cannot be not linked to what you say during the interview, this information will be locked up and secured, and fake names will be used in the study report. Anything said during the interview may be used as a quotation in the final report.
- All of the interview information will be kept in a locked drawer at the researcher's office. Only the researcher and research team will be able to see and use this information.
- After 5 years, the information will be destroyed.

**Right to Withdraw:**

- Your participation is voluntary, and you can answer only those questions that you are comfortable with.
- You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort. If you choose to withdraw from the study, any information that has been collected will be destroyed and will not be included in the study report.
- Your right to withdraw data from the study will apply until results have been disseminated. After this date, it will not be possible to withdraw your data.
- Whether you choose to participate or not will have no effect on you or your relative's access to services or how you will be treated.

**Follow up:**

- If you would like to see the results of the study when it is complete, you can contact the researcher to receive a copy of the results.

**Questions or Concerns:**

- If I have any questions, I can contact Margie Burns at (w) 894-2143, or by email at margie.burns@usask.ca, or her supervisors, Dr. Shelley Peacock at (306) 966-7375 or shelley.peacock@usask.ca, or Dr. Lorraine Holtslander at (306) 966-8402 or lorraine.holtslander@usask.ca .

- This project was reviewed on ethical grounds by the University of Saskatchewan Behavioural Ethics Board. However, if you have any concerns about how the research was done, please contact the Research Ethics Office toll free at 1-888-966-2975 or email at ethics.office@usask.ca .

**Continued or On-going Consent:**

- After the first interview is completed, you may be asked to participate in additional interviews.
- If you agree to a second or third interview about the same topic as described previously, it will be assumed that this consent also applies to this participation in the study.

SIGNED CONSENT

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

| | | |
|---|---|---|
| ______________________________ | ______________________________ | ________________ |
| *Name of Participant* | *Signature* | *Date* |

| | |
|---|---|
| ______________________________ | ________________________ |
| *Researcher's Signature* | *Date* |

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

Flesch-Kincaid Grade Level 9.4

# Appendix G

## Interview Guide and Demographic Data

To begin interview one:

- Can you describe your experience in as much detail as possible when *name* was critically ill and then needed to be transferred to a specialist ICU for advanced care?

To begin interview two and three if appropriate (questions for subsequent interviews will emerge from the previous interview(s)):

- Sometimes in the days after talking about an experience, a person may think more about the experience and additional thoughts or ideas may come to mind. Have you thought about what we talked about the last time we met? If so, what did you think about?
- Did you talk about what this experience was like for you with another person since our last conversation? If so, would you like to share what you discussed and any thoughts you had afterward?
- Did you write any notes about your experience since we last met? If so, would you be willing to share them with me?
- Can you think of any books, music, or movies that you feel resonate with what this experience was like for you?
- Is there anything else you would like to share?

Other prompts to consider during the interviews if necessary:

a. How did you make sense of…?
b. Can you expand on…?
c. Help me understand…?

d. It was exactly what..?
e. Did you have concerns about money or finances during this time? If so, could you describe what these were and what this part of the experience was like for you?
f. If there is a period of silence: Can you tell me what you are thinking about?

## Demographic Data

1. Relationship to the patient: ___________________________
2. If spouse or partner, length of time of relationship: ______________
3. Length of time since patient's critical illness: ___________________
4. Reason for IFT/ relative's medical diagnosis:____________________________
5. Participant is: female/ male
6. Age of participant: __________
7. Participant accompanied relative during IFT in ambulance or air transport: Y / N
8. Participant accompanied relative during IFT by personal car or public transport: Y / N
    - If yes, which: ______________________
9. Participant was accompanied by additional family members during IFT experience: Y / N
    - If yes, what relation: ________________
10. Length of time relative was admitted to receiving hospital: ________________

# Appendix H

## Individual Participant Narratives

### P1

It was a very intense and stressful experience when his wife had the bleed in her brain. Finding her collapsed at home is a memory that is always there and is the most prominent memory of the entire event. This experience was felt physically as well. Fear for the future and worry about whether his wife would be okay caused muscle tension and physical stress. Receiving physical gestures of reassurance from family (pats on the back and hugs) and positive news from healthcare staff helped to relieve some of this physical stress. Often, he would choose to sacrifice his own needs (such as rest) to be near his wife during her time in Halifax.

There were times when he had to be physically apart from his wife, for example, when she was transported by helicopter to Halifax. Even when physically apart, his thoughts always kept his wife close. The transfer to Halifax was felt to be a positive thing because it meant that she would be receiving the care she needed. It was very reassuring for him to see that the nurses caring for his wife where in close proximity to her at all times. During her time in Halifax, it was important for him to remain physically close to her. He tried to spend as much time as possible at her bedside and chose to stay at a hotel directly beside the hospital despite knowing that it would be less expensive to stay at a hotel a longer distance from the hospital. Although he was physically far from home while in Halifax, having family present with him in Halifax made it feel almost like home while he was away from PEI. He did not have to worry much about responsibilities at home while he was in Halifax; he had family at home in PEI taking care of all these responsibilities so that he could focus his attention on his wife.

During his wife’s time in Halifax, he felt unsure of what the future would hold for them. Her changing health status resulted in continuous changes to what the future may hold. Not knowing what the future would hold was very stressful and receiving information about what the future may be was felt to be reassuring. In many situations, thoughts of what the future may hold would change from minute to minute. Examples of this include when his wife was waiting to go to the operating room, when she was undergoing surgery, and then when she was recovering but experienced a sudden change in her level of consciousness and required urgent treatment. At times when he had to ‘wait and see’ what would happen, to try to reduce the stress this caused, he would try to find ways to pass the time or make time move faster. During these times, he would also think back to previous, positive memories about her and this was comforting to him.

During the time that his wife was ill, he always felt an extremely close connection with her. Relationships with family and healthcare providers was very important to him during this time. Family was always present, either physically or by telephone. Family provided important support to him that helped him to cope with this experience; this included physical support, emotional support, psychological support, and financial support. This connection with family was very strong; even though there was a physical separation from family at times, the feeling of closeness was always present. At times, requirements from family added some burden for him, such as when family arrived at his wife’s bedside or called by telephone to request an update. However, this burden was perceived as only minor. Healthcare providers that shared information about themselves grew to be perceived as family by him and this was comforting. Overall, he felt that there was a force (God) greater than him that was in control of this event. This was felt by the way everything ‘lined up and was meant to be’ and this was also very reassuring and comforting for him.

## P2

Her sister’s sudden bleed in her brain was an incredibly stressful and unreal experience. This was such an urgent and stressful time that simple tasks such as using a cell phone, packing for travel and buying gas were confusing and difficult to complete. The experience of her sister’s critical illness felt unbelievable and unreal. It was very hard to reconcile her sister’s present situation with the very recent past (she seemed to be in very good health; then she was suddenly extremely ill). The future was known before this event happened, but then when this happened, so much of the future was unknown and this was very hard to cope with. A lot of time was spent waiting and waiting and wondering what the future would bring. Receiving information was helpful when anticipating what the future may hold. Past experience of a friend’s sudden death from a bleed in the brain was present in her mind and she feared her sister would die as well.

She is very connected with her sister and during this experience, she had an urgent and continuous need to be physically close to her sister (she urgently travelled to Halifax to be there with her sister and she stayed at the hotel that is closest to the hospital). Despite times when they had to be separated (for example during transport to Halifax) her sister was always close in her mind. When this event happened, she had a persistent, empty feeling inside and it was very hard for her to be physically present and see her sister suffering with headaches. When learning of the need for her sister to go to Halifax, she was glad that she was going to the specialist, but she worried that her sister would be frightened during the helicopter flight and being so far from home.  When with her sister, she always tried to protect her from feeling worry or fear. During her sister's transport by helicopter to Halifax, she had a loss of connection with her sister and she had no idea what was happening with her. During her drive with her other sister to Halifax, she wondered if her sister had arrived at the hospital yet, did she survive the transfer by helicopter, and was she still with them? When she received good news, she felt a bit more perked up.

She felt many connections with others during this event. She felt a real connection with God and felt that He had a hand in lining things up (like a waiting helicopter for her sister and also her niece in the north) so that everything worked out for the best. She felt connected to the doctors when they gave the family information and answered all of their questions. She felt connected to family members of other patients in Halifax who were also far from home and going through a similar experience. Connections to her family were of the utmost importance and she does not know how a person could get through an experience like this without the support of a (big) family. Having a family member who lived in Halifax was reassuring and perhaps felt a bit like she had a piece of home with her in the city. Even when family members were physically separated, they were held close in her mind. However, even though family were felt to be incredibly important for support, they also sometimes contributed stress or feelings of disappointment. This was present at times in the competing needs to help several family members in different locations at the same time, and when some family members were absent when they perhaps should have been present at specific times during this event. She felt worried for her sister's husband and tried to look after him too.

This experience was physically exhausting at times. She had competing responsibilities in several locations at once. Caring for her own family at home, concern for her sister in Halifax, and care needs of other family members near but separate from her home. She does feel that her sister has changed because of what happened to her. Though she finds this distressing, she is grateful that she survived and is still with them.

### P3

It was very scary hearing that her husband had a brain bleed and had to go to Moncton immediately. Her sons felt it would be best for her to go back home to rest for the night and then travel to Moncton the next day. She would have preferred to go immediately to Moncton, but she did what her sons suggested. It was scary to see her husband go to Moncton and then for her to come back home. That night at home was very scary and she didn’t get much sleep because she didn’t know much about a brain bleed, what may be happening with her husband, and what the future would be. She wondered if that night might be the end. This fear continued until they drove to Moncton the next day and she saw her husband with her own eyes and then knew that he was still alive. It was very important for her to be physically close to her husband; she feels very bad for families who cannot be close together during situations like this.

In Moncton, they had to wait three long days before her husband could have surgery. This time of waiting was extremely hard because they didn’t think he would make it through the surgery. Then during surgery, they had to wait again to see if he survived and what the results of the surgery would be. This time of waiting was the most stressful time of all. During this time, it was easy to lose track of the small things because she was so worried about her husband. She felt completely focused on her husband and did not have any concern about responsibilities at home. When she saw him the next day and saw that he was getting along really well as far as the surgery went, then she knew everything was going to be okay. In fact, with the positive outcomes of the whole event, the worries she had during the experience seem lessened.

Being far from home during her husband’s illness was very hard. She is not comfortable being away from home, especially in an unknown city and at night. She is unable to sleep well when she is not in her own bed at home and this becomes physically exhausting. She would prefer not to be as dependent on her sons as she was when they were in Moncton together. However, she was very grateful that they were there to drive her to Moncton, arrange accommodation (at a house that was more home-like than a hotel would have been), stay at her husband’s bedside in shifts, speak with the physicians, and plan the meals. She felt vulnerable in the city- she was unfamiliar with Moncton and wouldn’t be able to drive there. She wouldn’t know how to get around, where to stay, where to park, and where to get food. Also, growing expenses from accommodation, food, and parking were a concern. She doesn’t know how she would have managed going to and staying in Moncton without her sons. She feels that her age makes it more challenging to cope with events such as these compared to when she was younger.

It was important to her to received honest updates from the nurses and doctors. Also, she felt it was important that her family be available to provide information to the team; her husband may not always be able to communicate necessary information to the team. Not having information, for example about brain bleeds, was stressful. Also, there were a number of people in her husband’s hospital room that she worried about (patients and visitors). She was glad that her sons could stay with her husband to safeguard him if needed and call her with updates as needed. This made it easier for her to be physically separate from her husband at these times.

She longed for her home and ‘the normal’ while away. Home represented rest, comfort and support for her. Being away from home resulted in nervousness and sleeplessness. However, when her husband was abruptly discharged directly home from Moncton, she had several sleepless nights at home because of worry for her husband.

### P4

When her husband was injured in the snowmobile accident, her reality in both the present and future was abruptly and significantly changed; where before the future was known, now it was unknown. When she first was notified of the accident, she thought her husband had minor injuries. When she went to the ER, she had to wait in a room for a very long period of time, too long really, before she received information about her husband. During this time, she received pieces of information from several people, but not the whole story. Eventually, driven by the need to get information and find her husband to be close to him, she began to wander the halls of the ER, even though she didn’t feel she had a right to do so. She found someone who took her to her husband’s side. The team were working on her husband and she asked a lot of questions and did get some answers, but she was conscious to stay out of the way and not interrupt the team in doing their job. This was a very surreal moment and at one point, she felt as though she was going to faint, a vagal episode. This was very embarrassing for her; this situation was not about her. Staff told her to sit on the floor and eventually she found a chair to sit on.

The night her husband was airlifted to Halifax, she didn't get much sleep. She heard the helicopter overhead and knew that he was gone- he was always in her mind. During her drive to Halifax the next morning, she was consumed with thoughts of what she would find when she got there.  There was no contact from Halifax except for once when they called at 4:45 to gain consent for a procedure. She has very little memory of the drive over. Looking back at her phone records, she found that she was constantly fielding calls on her and her husband's phone. Also, she frequently and unexpectedly found herself excessively speeding in order to get to the hospital. During this experience, she felt she did everything at warp speed. When she arrived at the Halifax hospital, she was once again directed to wait in a waiting room. They waited there without any update for 10 hours. She would have liked an update from the team at some point.

She had numerous responsibilities to maintain during this time: two large business to keep running, caring for her pets, coordinating friends and family, considering her mom's needs in Halifax, and keeping family and friends updated. She felt torn between being with her husband and keeping everything else going. While being busy may have helped her to cope, she became incredibly exhausted and stressed; she had no one to help her. She was so busy that she had no time to cry or feel, eat, or sleep and she developed face pain from constantly clenching her jaw. Although she is a loner by nature and she takes pride in being independent and getting things done, she felt so alone, and she wished she had someone to help her or at least give her a hug at times. She did receive support from some family, friends, and unexpected people and she valued this. She self-sacrificed during this experience; she frequently bit her tongue when speaking with employees and family in order to preserve relationships, she gave up sleeping in a comfortable bed in order to remain close to her husband, and she gave up her time to herself (like her fitness regime). She frequently felt that she didn’t have a right to be places (like the ER) or feel certain ways (anger or irritation with family members and friends).

Disappointment and irritation with friends and family members has resulted in a change to relationships. During this event, she pushed away uncomfortable thoughts and she physically removed herself as needed from the company of irritating friends or family in order to prevent negative consequences in the future. Reflection has since provided new insights. She has found that social media can be dangerous to one’s wellbeing and she has since culled her Facebook friends to include just those who truly care for her. It felt good to remove herself from unhealthy relationships. During this time, it was important to her that she protect her husband from feelings of disappointment about his family or friends. She did this by keeping her feelings about them to herself.

When her husband came home early from the hospital because of the pandemic, she had to assume the role of caregiver. It was hard to find support to do this, but she did get some support from a physiotherapist at the hospital who helped her get the right equipment. This was an emotional time for both her and her husband; her husband has changed. This was one of the only times that she allowed herself to breakdown. She knows that the situation could have been much worse, and she is grateful that it is not, and that they are in a financial position to weather this event. It may be that the positive outcome for her husband has faded some of the stress she endured during the event. One memory persists and leaves a bad taste; what happened to her husband’s snowmobile gear? Did a healthcare provider steal it during their time of vulnerability?

## P5

When her husband woke her up at 3 am to tell her he wasn’t feeling well, she knew this was serious; he didn’t have any health issues before this. She immediately got up and called 911. When they arrived at the hospital, she found the doctors to be good; they did a lot of tests to find out what was wrong, and they answered any questions that she had. Communication was a big thing for her during this experience but was often inadequate in Halifax. Initially, she was glad he had to go to Halifax because she felt it was a good place based on her past experiences there as a patient. She didn’t expect that her daughter could come too, but her daughter wouldn’t hear of anything else. She was grateful that her daughter could drive to Halifax. Because of her age, she knew it wouldn’t be ideal for her to drive in the city. While driving, they tried not to talk much about what the future may hold, and she hoped that everything would work out okay.

Because of her previous experiences with paramedics, she didn’t worry much about her husband during the drive to Halifax; she knew they were excellent and would take care of him. When they arrived at the emergency room in Halifax, she was glad to see her husband with the same paramedics. The emergency room was incredibly busy; not like anything that she is used to at her home hospital. They had to walk past large numbers of sick people and paramedics to get into where her husband was. It was so overwhelming that she didn’t even want to go in- it was surreal, and she hated walking past all of these people at the beginning of the pandemic.

The doctors decided that her husband needed to go to surgery right away, but this was delayed because of an emergency. They had to wait a long time- they stayed awake in the waiting room until 5 am the next morning. There’s no way they would leave while her husband was having surgery. She was grateful that she had her daughter with her to talk to; she would have been out of it if she was alone while waiting. They had no idea what was happening or what the future held until the doctor came out and told them that everything went fine.

They went to a hotel about a 15 minutes' drive away. The person at the desk tried to help them by giving them a later checkout time. She like going here because it was a chance to be outside and away from the hospital. She does have family in the city, but she didn't want to bother them at that hour. They managed to get a few hours of sleep at the hotel but were awoken by their minister who was checking in. She didn't worry about responsibilities at home; there were family members at home who could take care of any issues.

When they went back to the hospital, it was very busy. They got mixed messages from staff about her husband being moved to another unit and whether he was going to see a liver specialist or not. They also found out that he had a heart arrhythmia during surgery and that a cardiologist had seen him. It was suggested to them that it may be age related, but she didn't feel that this was correct because he never had heart issues before. Because of her previous experiences with heart problems, they thought this was very serious. But the doctors and nurses didn't seem to think it was serious and they decided to move her husband to a nursing unit in another building that didn't have heart monitors because they needed his bed for another patient. She worried about whether her husband would have the care he needed in this other unit. They wished that someone had just taken the time to explain to them what the plan of care was and answer any questions that they had; then they wouldn't have to feel like they were hounding the doctors and nurses (which they really wanted to avoid). When the liver specialist came to see her husband, he was dressed unprofessionally and was very judgmental of her husband. She was offended that he asked if her husband was a ‘drunk’. While she could understand his perspective was different than hers because of where he worked, she was very unimpressed with his attitude and behaviour. Based on her past experiences in Halifax, she expected better communication; rather, the lack of communication made her feel annoyed and worked up. Because of her past experience, she knows that she wants to receive information because it helps her to anticipate and prepare for the future. She tries not to worry about things that may not happen.

When her husband was transferred back to their home hospital, life became a little more normal which was good. But then when the pandemic lockdown began, she wasn’t able to visit her husband, and this was hard. She worried about him alone at the hospital because he’s not great to ask questions. Moving forward, she doesn’t dwell on the past- it remains in the past.

### P6

Her brother had been feeling unwell but he refused to get help despite being asked to by his family. When she was notified that he was in the ER, she immediately went to see him. She was glad he was being transferred to Halifax for treatment; she knew he needed it because they have been through this before. Even though her brother wanted to go to Moncton, it didn’t matter to her where he went as long as he got the care he needed. She knew that getting him to a specialist was the priority and thus, her primary focus. She tried to anticipate what her brother may need in Halifax. She didn’t go with him because she knew he would need her more after his surgery.

Her brother waited for 6 days in Halifax for a procedure. He would call saying that he wanted to come home. He was becoming anxious and stressed with waiting. She tried her best to keep him calm so that he would stay in the hospital to get the needed procedure; she trusted that the staff in Halifax knew what they were doing. During this time, she didn't know where her brother was and she didn't want to call and bother the nurses. Because she was far from her brother and had no connection to the healthcare team, it was hard for her to understand why the wait was so long; she felt disappointed and let down by Halifax. Eventually, a nurse called her and told her that her brother wanted to come home. Although she worried about her brother's health, she agreed with him that the wait was too long and told the nurse to discharge him and they would take him home. When he came home, she was frustrated with her brother's lifestyle choices that she knew were bad for his health. While she was worried about the future for her brother, she remained hopeful and tried to live in the present, dealing with things as they came up.

Shortly after returning from Halifax, her brother went to Moncton and had his procedure very quickly. She kept in touch with him by phone. She was relieved that his surgery was complete and knew that he was going to be okay. He felt at peace, and when he felt at peace, so did she. She has since regretted the decision to go to Halifax; perhaps they should have waited a day and then get transferred to Moncton. This would have prevented the prolonged wait for the procedure. Her brother wanted his friend to take him home rather than his siblings. She thinks this may be because he sees his friend as being more physically able to help him.

It was shortly after her brother went to Moncton that the pandemic closed the provincial borders and numerous support systems. This was a strange and confusing time that felt out of her control.

She was conscious of limiting her movement off Island so as to not make other people sick. She kept herself busy with preparing for her brother's return home which was helpful. She was not able to be present when her brother was discharged home so she was unsure of any discharge instructions that he may have received. She felt a disconnect with the Moncton staff. She contacted his family doctor who was instrumental in setting up appointments for her brother. She had to guess what his other needs may be (like a medication blister pack) and get the necessary supplies (like dressings). She saw her brother gradually improving. Returning home was also a return to a more normal life. Her brother's positive outcome has faded some of the stresses and worries that she experienced during the event.

She had competing demands during the whole experience; working, supporting her brother, and caring for her own family. Although her siblings were supportive, she had to consciously care for and meet their needs too when her brother was sick. She made sure to get physical exercise and adequate sleep to ensure that she would be able to help others and deal with things as they happened.

### P7

It started when she called her brother to check up on him like she usually does. She always looks out for him. He wasn't feeling good, so she called 911. The ambulance took her brother to the QEH and she followed too, but because of COVID, she didn't know what she was allowed to do in the hospital. This was nerve wracking because her brother avoids doctors and she worried about how he would be with the doctors and nurses. She went home so that she could use the phone to call the hospital to see what was going on with her brother. But before she got to her house, the hospital called and told her husband that her brother was leaving in 15 minutes for St. John. She had to rush back to see him before he left. Because of COVID, she had to choose whether to go with him and then self-isolate when she got back or stay home so that she could take care of him when he got back. If it was her husband or child that had to go, she would have definitely travelled over too. It was hard to see him go to St. John, but he was calm about going, so this made her feel a bit better. From previous experience, she remembered the city as unpleasant and the hospital old and not very clean- while she was glad he was going, she didn't like the thought of her brother being there alone. She wished she could go too so that she could help her brother and the nurses and doctors because he can be a bit difficult to manage at times.

The hardest part was the time when her brother was being transferred by ambulance. There was no way for her to call the paramedics to see if he was okay and the driving conditions were poor because of fog. Waiting to hear that he arrived in St. John was pretty rough and she felt restless and tried to find things to do to pass time. She counted out the hours. This was a time when she had no idea what was happening or what the future would hold. When she called St. John and found out that he arrived and was comfortable, she was relieved. She tried to go to sleep but she tossed and turned and then got up early in the morning to call to check up on him. While her brother was in St. John, she had a persistent and intense need to frequently call the nurses to check in on her brother. She wanted her brother to know that she called because she didn't want him to feel alone; it's her job to look out for him and protect him. She held back from calling as often as she really wanted to because she didn't want to bother the nurses. However, the nurses in St. John seemed very busy and she assumed that she probably was bothering them.

They had to wait for her brother to have his procedure done- she didn't know why they had to wait. But it went well and then he was quickly transferred back to the QEH. This quick return was surprising but she trusted the team and she assumed it was probably because of COVID. COVID changed everything. It seemed easier and nicer to call the nurses at the QEH- they seemed to have more time to talk and weren't as rushed. They were also Islanders like her and know how things are. The doctors and nurses were nice, and this was good.

That first night her brother was home, he quickly and unexpectedly became unwell in the middle of the night and the nurses called her to come into the hospital. Because he was closer now, she was able to rush over and spent the night until they knew he was ok. She was exhausted from the previous sleepless night, but she sacrificed another night of sleep to be there for her brother. Once he was better and in the healing phase of his illness, it was better for her to be apart from him so that he would have time to deal with what happened to him. Otherwise, he may have repeatedly asked her to take him home. She would have probably relented and took him home and cared for him herself, but she wanted to avoid this. She has a big family, and she has been through things like this before. These past experiences helped her to understand what was going on and what to anticipate for the future.

### P8

She received word that her mom was sick when she was at work. This was already a very stressful time for her because she was managing her father's serious illness; she immediately felt overwhelmed when she found out her mother was also suddenly very ill. She didn't know what to do. Her work colleagues took care of her work responsibilities and took her to the ED to see her mom. At this point, her mom looked a bit better, but she knew that this could turn out to be really serious- her mind was whirling with competing demands including how she was going to manage her dad’s care if her mom was also in hospital. Because she is a nurse, her family always look to her to coordinate everything and make the healthcare decisions. This time was so overwhelming that she had to remind herself to deal with what was immediately in front of her and then the rest as it comes. While in the ED, she was surprised that they wanted to send her mom to the outpatient clinic for a neurology consult; she has a lot of experience and this seemed odd to her, but both she and her sister-in-law decided to trust the team because they must know what they are doing. Taking her mom to the outpatient clinic was very stressful; her mom was acutely unwell- why were they going to a clinic? Everything was happening so fast. She felt an incredible burden of responsibility by agreeing to take her there- what if something happened? The nurse at the clinic didn’t seem to have any understanding of the acuity of her mom’s situation and wasted a lot of time asking irrelevant questions. This was incredibly frustrating. Finally, when they got to see the neurologist, her mom suddenly became acutely unwell and although this was upsetting to see, she was glad that it happened in front of the neurologist because then the decision was made to return urgently to the ED and then on to Halifax. She was glad they were going to Halifax- she knew this is what her mom needed. Her family all wanted to help, but she made the decision to go to Halifax on her own and others look after things at home. She didn’t want to have others with her in Halifax because she would have felt the need to look after them too. This was a time when she was completely focused on her mom.

She was so glad that she knew one of the paramedics who was taking her mom to Halifax. She knew her mom was in good hands. Even more important to her was that the paramedics took her phone number and called her with regular updates during the transfer. This was especially important because it was storming, and the ambulance got stuck behind an accident. If it wasn't for the frequent updates during the transfer, she would have been beyond with worry for her mom- her mom was always on her mind. Driving in the storm was so stressful- she felt such relief when she arrived at the hospital and didn't have to drive in the storm anymore. Although she didn't think she wanted to see anyone else, her son came right to the hospital and it was so good to see him and to know she had people in the city. This was good because she is not all that familiar with the city. She felt welcomed onto the nursing unit and she discussed with the nurses the estimated time for her mother's arrival. When her mom arrived, the nurses took great care of her and made her a snack. It was very important for her to be physically close to her mom- to take care of her physical needs, to prevent her mom from feeling scared or worried, to make sure she got the rest she needed, and to be present to get information from the team and then make good decisions for her mother. While receiving information is comforting, it can also be frightening because it becomes obvious that the future is somewhat unknown, and she worried about "what if…" and knew that decisions about her mom's health would fall to her.

Once her mom was settled and she felt that the staff would take care of her mom, she went to her son and girlfriend's place to sleep. She was exhausted. She got a bit of sleep but not much. Her family tried to look after her in the morning by making her breakfast, but she was just desperate to get back to the hospital to see if her mom would be going to surgery. When she arrived at the hospital, she was surprised to find her mother was about to be pushed into the operating room. She felt disappointed that the staff didn't tell her it was that imminent, but she was glad she was able to say goodbye to her mom before she went to surgery- she wanted her face to be in her mom's mind when she went to sleep. She thought about "what if…" and feared that her mother may die or have a negative outcome from the surgery. The surgeon came to see her and she was glad to meet him. Staff came out to tell her that everything went well and when she saw her mother, she couldn't believe how well she looked. They Face Timed with their family back home and this was emotional. It's one thing to be told over the phone that people are okay, it's another to see them- seeing is believing. This technology can bring people closer together.

During this time, the support she received from her family, friends and colleagues was very important and comforting. However, there are some family relationships that are not positive, and this does anger her at times. She doesn't usually ask for help, but she is starting to realize that she can, and others can successfully take care of things- all she has to do is ask. Upon return home, it because obvious that there is a broken link between the specialists in Halifax and continuing care at home. Getting prescriptions written in Halifax filled in PEI is challenging and burdensome.

### P9

Her son has a lot of medical conditions and things can change very quickly for him. Even knowing this, when they took him to the QEH emergency department, they weren't expecting him to require air transfer to the IWK. She really hoped that they would be able to manage his care at the QEH because she hates when he has to go to the IWK. She is terrified of flying and if she has to drive, she finds leaving home and travelling by herself to be uncomfortable and scary. Even talking about leaving home makes her get choked up. She has learned from past experience that the future is unknown, and she needs to pack her van with everything they may need in

Halifax. Not knowing how long they will be in the IWK is scary. Because of the loss of contact with the air transport staff, she worried about her son during the transfer and wondered what would be waiting for her when she arrived at the IWK.

Being away from home and the homesickness she experiences while at the IWK is miserable. When money is extremely tight, the transfer to Halifax is even more terrifying. Will she have enough money to get meals? She misses her family, friends, pet, and house with the things in it that give her comfort and support. She finds she is very lonely in the city away from family and friends; she misses having people come to visit her and her son in the hospital or even to have a shoulder to cry on. She tries to seek out family who live in the city so that they can sit with her son so she can take small breaks from the hospital. She took her younger son with them once to Halifax, but this actually added more stress for her. She appreciates when her friends, family and community reach out to support her family during these times. In Halifax, she does feel vulnerable and would not venture out after dark. Once her son is out of ICU at the IWK, the first thing she asks is for a transfer back to the QEH, in order for them to be closer to home.

She sometimes has panic attacks because the future is unknown and therefore terrifying. She also feels the incredible weight of responsibility to be the main decision maker for her son’s care. His condition can change so quickly that there isn’t always time for her to call her husband to discuss the various options. She sleeps in the ICU room with her son in order to be close; she hates to think of him as bored or lonely and it’s important for her to be there when he awakens. Sleeping in this room is hard though because of all the alarms; it’s difficult to get the rest she needs. It’s important for her to take care of herself during these times so that she is able to care for her son. She takes books and art supplies with her to stay occupied and avoid going crazy.

In the past, they would not ask questions of the doctors and just agreed to whatever they suggested for their son. They relied on the nurses to later on explain what the doctor was talking about or look it up on Google. They do have some regret about this and have learned to be more assertive with the doctors and ask more questions and make suggestions for their son's care. By asking more questions and being more involved in both the plan of care and the physical care of her son while in hospital, she feels as though she has more control over the situation and does not feel as hopeless as in the past. It is important that she trusts and knows the nurses that are caring for her son; doing so allows her the ability to leave her son's bedside for short periods of time to give her the much-needed breathing room from the hospital. If she doesn't know the nurses or have an established trust in them, it is very difficult for her to leave her son's bedside. However, once she is away from her son, she often has a persistent need to quickly return to him. He is constantly on her mind and she is always wishing for him to do well.

### P10

She was at work when her friend texted her saying that she was being sent to Moncton. Knowing from their previous trip to Moncton that her friend had an aneurysm, she asked what was going on- her friend told her she was getting some tests. She offered to follow her over and when her friend agreed, she knew then that it was serious; her friend is a very independent person. She packed some supplies for her friend, said goodbye to her husband, and then headed for the bridge. Her friend was texting her with updates (one of which included the message that she was being re-routed to Halifax) but then these suddenly stopped before she got to Borden. Her other friend G happened to call her while she was driving, and she broke down in tears speaking with her because she was so worried about her friend. She didn't know what was happening. G told her that she would meet her at the bridge; she didn't want her to be alone if something happened to her friend in Halifax.

They drove straight to Halifax. During this time she had no idea what was happening. Where was her friend? Was she admitted? Was she going for tests or was it something more serious? Was she even still alive? No one would tell her any information at all. G dropped her off at the hospital entrance when they got to Halifax. There was a nice woman at the information desk who tried to help her find the nursing unit where her friend was, but she still got lost and was feeling quite frustrated. G came in after parking the car and calmed her and then helped her find the unit. At the nursing unit, the nurses wouldn't give her any information either and just directed them to wait in the waiting room. She had no idea what was happening to her friend. She feels like the nurses were putting her off because something bad had happened. Eventually after waiting for an hour, feeling agitated, frustrated, and angry, she went back to the nursing desk to ask them to tell her something, anything about her friend- she needed information. She is her friend's next-of-kin. She thinks that if she hadn't gone back to the desk, the nurses would have left her in the waiting room. The nurses went to get a doctor to speak with her and when she realized this, she was sure her friend had died. This lack of information sharing was the worst part of the whole experience. When the doctor came in, he was very nice and gave her updates about her friend who was in surgery. She then had to call her friend's son to tell him what was happening. This was very hard because he was so upset, and she was not physically present with him to comfort him. G then suggested they go check into the hotel that she had just booked and then get something to eat. She doesn’t know what she would have done without G to drive over to Halifax, find the hospital, and take care of all of the mundane but necessary things for her while she was so focused and worried about her friend. G also was a great help with managing all the calls from friends and family that they were receiving. She would have been lost without G. If only there would be someone assigned to meet families coming to the hospital from away that could help them to take care of the mundane things.

Her friend did well after surgery. She stayed in Halifax with her for several days after the surgery and her friend was constantly on her mind. She always wanted to be close to her friend in case she needed something. Her friend’s sisters arrived around the same time as her husband. When the sisters arrived, it was a relief to her because she then felt more comfortable to leave her friend’s bedside to take a break and go out for supper with her husband. However, her friend was still on her mind and she felt the need to check up on her again on the way back to the hotel. She was due to leave for Cuba in a few days and though she didn’t want to leave, her friend insisted that she go because she was doing fine. She did go to Cuba, but she continued to think about her friend during the trip.

### P11

His mom phoned him to tell him that his dad was not quite right. His father has had neurological events in the past which make it difficult to know if he should be taken to hospital or not. They decided to call 9-1-1 and go to the QEH. When they arrived, he seemed to be better and he expected his dad to be discharged home. However, he was shocked to find out that his dad had to go to Moncton immediately for brain surgery. At this point the future was unknown: how quickly would the surgery need to take place and how critical was his dad? The family had to start planning for the transfer to Moncton. Should their mom go immediately too, or would it be better for her to sleep at home and travel over the next morning? Their mom has health conditions as well, so it was important that her wellbeing was carefully looked after. This was an important consideration for the family when making plans for the trip to Moncton. In the end, it was decided that one brother would follow their dad to Moncton that evening and he would take his mom home for the night and then drive her to Moncton the following morning.

His role in the family is to take the lead in situations related to family health and illnesses. He took great care to make sure that his mom had what she needed, and her wellness was cared for during this event. After giving her an update from his brother, he picked her up and drove with her to Moncton. They are very close and can comfortably talk about the potential ‘what-ifs’ of the future. This is not something that his other brothers would be comfortable talking about. When they arrived at his dad’s bedside in Moncton, while he was concerned for his dad and wanted to be physically close to him, his mom’s wellbeing was always on his mind and he was conscious of trying to ensure that she had adequate food to eat. He was also trying to balance his mom’s need to be by his dad’s side with her need for rest. He took turns with his brothers sitting at his dad’s bedside. In several ways, he filled the role of caretaker for his dad while in hospital. The waiting was hard and there were many unknowns at this point; it was a wild time. He tried to pass the time as best as he could, and it was easy to lose track of days. While in the hospital, it was very challenging to get adequate food; it was not clear when the canteen was open and while there was a fridge available for family use on the nursing unit, they only discovered this on the last day they were there. The nurses were nice, and he felt supported when they spoke with him and tried to make connections in a Maritime sort-of-way. Based on his past education, professional experiences, and his wife’s profession as a nurse, he trusted that the nurses and doctors were doing the best they could in an imperfect health care world, and he trusted them to take good care of his dad. This was at times in contrast to what his brothers’ perspectives were, but he understood that they saw things differently than him. He did feel however, that there was fragmented communication at times from the healthcare team and this did make the situation more challenging for the family. For example, they had to wait for what felt like an excessively long time to meet with the doctor in Moncton, then for the surgery to start, but then they received very short notice about their father’s impending discharge home.

Family support was very important during this experience. His brothers had roles that they filled, and he kept in close contact with his wife and other family members at home by phone. While he thought about his family at home often, he did not worry about responsibilities there because he knew they were being looked after. When preparing for the drive home, they had to plan to provide physical care to their dad including helping him get to the bathroom if needed. While he was proud of how well his mom coped while in Moncton, he did worry about his mom taking care of his dad when he got home. However, the brothers would all take turns helping her if she needed.