“Can I See my Daddy?”

Child and Adult Family Members as Visitors in the Adult Intensive Care Unit

By

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B.Ed. (Hons), 1993, Leeds University

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We acknowledge with respect the Lekwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

Supervisory Committee

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Abstract

The purpose of this qualitative study was to supply preliminary insights into improving the support of visiting families with children who are minors during the intensive care unit stay (ICU) of an adult family member. Hospitals often restrict children from visiting in ICUs; however, a review of the literature revealed that despite the prevalence of this policy, there has been little research into whether visiting is harmful or supportive (Liu et al., 2013; Manici & Ghillani, 2018). Although family-centred care (FCC) is considered beneficial for adult family members (Davidson et al., 2012; Eggenberger & Nelms, 2007), there is little evidence that policymakers have considered the involvement of children during an ICU stay (Knutsson & Bergbom, 2007). In this study, seven families shared their experiences of the critical illness of a loved one. Using a constructionist lens, this study explored the interaction between the gathered stories and the policies and practices associated with child and adult family members visiting adult critical care contexts in British Columbia (BC), Canada. This study found that the involvement of children in a family illness event is important and that tailoring involvement to the individual preferences of the child, and their family, is crucial. While navigating an ICU stay, families may benefit from a collaborative approach between the child, their caregiver/s, and a member of the ICU team. The goal of this research is that it will resonate with its readers and move people to deeper curiosity and further study. This exploratory study led to a list of seven preliminary insights that could inform the interdisciplinary policies and practices associated with supporting child and adult family members as visitors in an ICU. Further research is needed to explore the experiences of families with children more fully, and to understand the systems that need to be in place to support them during the critical illness of a loved one.

Keywords: visitation policies, children, ICU, family-centred care, health care, critical illness

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List of Abbreviations

BC	British Columbia
CFCC	Child- and Family-Centred Care
FCC	Family-Centred Care
FHA	Fraser Health Authority
GFBI	Grant Foundation Bereavement Inventory
ICG	Inventory Complicated Grief
ICU	Intensive Care Unit
IES	Impact of Event Scale
NICU	Neonatal Intensive Care Unit
OVP	Open Visitation Policies
PICU	Pediatric Intensive Care Unit
PTSD	Post Traumatic Stress Disorder
PTSS	Post Traumatic Stress Symptoms
RVP	Restricted Visitation Policies
VCH	Vancouver Coastal Health Authority, BC.
VIHA	Vancouver Island Health Authority (Island Health), BC.

Glossary

Bereavement	Experiencing the death of a loved one.
Caregivers	The primary adult/s providing care to child/ren. Used interchangeably with parents and may refer to grandparents, aunts, uncles, or close friends.
Child/ren	The term “child” or “children” refers to all individuals under 19 years of age. This is the age of majority in the province of BC.
Critical Illness	Critical illness refers to a period of illness during which an individual’s life is threatened. Therefore, both chronic and acute illness may include a critical period.
Critical Care Unit	Provides care to critically ill adults and is used interchangeably with an intensive care unit.
Family	Family is understood in functional terms (Mirabelli, 2018). A functional definition of family stresses the relationships and ongoing support members provide to one another rather than what a family looks like. A functional definition of family embraces the diverse nature of families in Canada.
Grief	Individual response to the loss of a loved one, which may include emotional responses as well as physiological and behavioural responses to bereavement (Heath & Cole, 2012)
Intensive Care Unit	A unit within an acute care facility providing treatment to critically ill adults.
Level 1 Trauma Centre	ICUs have a designated level based on the number of beds available and the complexity of care they can offer. The most critically sick patients may require treatment in a level one trauma centre. In BC, level one trauma care is only available in the Vancouver Coastal and Fraser Health Regions.
Mourning	The outward expression of grief as influenced by an individual’s spiritual beliefs or cultural traditions.

Neonatal Intensive Care Unit	A unit within an acute care facility providing treatment to critically ill babies from birth to 28 weeks.
Open Visitation Policies	No restrictions on the presence of family at the bedside (Davidson et al., 2017). Sometimes referred to as “family presence” policies (Farmanova et al., 2015). Compare with *restricted visiting policies*.
Parent/s	The person or people in a primary caregiving role to a child. This might include parents, grandparents, aunts, uncles, or other significant adults. Used interchangeably with caregivers.
Pediatric Intensive Care Unit	A unit within an acute care facility supplying treatment to critically ill children.
Restrictive Visitation Policies	Visiting restricted based on one or more of the following criteria: time of visit, duration of visit, age of the visitor, number of visitors, and whether the visitor is a member of the immediate family (Liu et al., 2013).

Acknowledgements

This research would not have been possible without the support of many people. Firstly, I would like to thank my supervisory committee, Dr. Alison Gerlach and Dr. Sarah Wright Cardinal, for the feedback and insights they provided to this work. I would also like to thank the families who graciously shared their stories – I hope that I have treated your stories with the honour and respect they deserve. Most importantly, I would like to thank my family and friends who believed in me and supplied the encouragement I needed to complete this thesis. Joe, Ethan, and Callum—I could not have done this without you! And Taz, thank you for reminding me to get outside for a walk each day.

Dedication

I dedicate this thesis to ‘Aiden.’ Thank you for teaching me to listen to, and wrestle with, the requests of a child. I hope that this work helps children like you who want to be heard and involved in matters that are important to them.

Chapter One: Introduction

[1]the pronouncement came
gone the hope for tomorrow
time to say goodbye

Aiden[2] *was 4-years old, and his father was in a coma. Doctors told the family that they needed to prepare themselves to turn off the machines that were sustaining him. Since hospital policy did not allow children into the Intensive Care Unit (ICU), Aiden waited at home for his life to return to normal.*

my thoughts turned to the child
the future a shattered mirror
shards too sharp to hold

Unsure how to move forward, I suggested to the family that we turn our attention to Aiden and how to involve him in what was happening. Aiden asked to see his dad.

a young voice
asked a question without an answer
a road without a map

In a situation where I believed there to be no right answer, I suggested to the family that we honour the voice of a child. Aiden and I walked into the ICU. With his little hand in mine, I felt the trepidation of not knowing if this was the correct decision. Should we have listened to Aiden? Would this traumatize him? Was this too much for a 4-year-old?

As we stepped into the room, Aiden looked intently around. After what felt like forever, I asked Aiden how he was doing. He let go of my hand and walked over to his dad and said, "This tube goes from daddy's heart to God, and it is taking away fear." He went on to discuss his interpretation of each machine. Throughout his visit, Aiden was calm, peaceful, and contemplative. After a while, Aiden told me he was ready to go and play. Later that day, his dad was disconnected from life support.

silence eternal
in a room filled with sound
a goodbye whispered

While I was volunteering as a clergy member in an adult ICU,[3] a 4-year-old child, whom I shall call Aiden, requested to see his critically ill father. My role was to offer pastoral support. Licensed as an

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[1] Italic font is used to throughout this study to denote a passage of creative/poetic writing. APA formatting is not adhered to for these elements as the positioning of the words on the page is considered to carry meaning. I discuss how I came to write these poetic elements and the role they played in data analysis and representation in chapters three and four.

[2] Aiden's story is based on a true story. Written from memory, it includes enough truth to hold the weight of the dilemma while also using enough fiction to protect the privacy of the child I call Aiden.

[3] This study inquires into intensive care units providing care to critically ill adult patients and is referred to as the ICU throughout the thesis. Units providing critical care to children are referred to as the pediatric intensive care unit (PICU), and those providing care to babies are referred to as the neonatal intensive care unit (NICU).

independent minister afforded me great flexibility in shaping my support to meet the unique needs of each family in my care, which for me meant a specific type of spiritual “withness” (Anderson & Gehart, 2007); a connectedness to the family that extended beyond their spiritual needs to incorporate any dimension in which they needed help. I viewed my role as helping them navigate a time of crisis and uncertainty. Aiden’s request challenged me. I struggled to know how to advise the family and found myself wondering if the policy of restricting children[4] from visiting a family member in the ICU was best for this child. In trepidation, I suggested to the family that maybe we should let Aiden see his father, but I felt that this advice lacked the backing of substantiated knowledge. This story led me to want to conduct exploratory research into how child and adult family members experience the critical illness of an adult family member.

1.1 Context

ICUs account for 13 beds per 100,000 population in Canada (Crippen, 2012); a number set to increase given the known link between critical care capacity and lower mortality rates (Vincent, 2013; Zilberberg, 2012). In Canada, an adult is now significantly more likely to survive critical illness or injury than before the creation of ICUs (Hamilton, 2010). Furthermore, rapid technological advances have rendered ICUs as unrecognizable compared to those of even two decades ago (Manici & Ghillani, 2018). Alongside these advances, the literature indicates a growing awareness of the humanization of care and an increased focus on the non-medical needs of the patient in the ICU (Vincent, 2013; Zilberberg, 2012). Additionally, many ICUs recognize the benefits of an open visitation policy (Davidson et al., 2012; Eriksson et al., 2011; Kean, 2010) and a family-centred approach to care (FCC) (Eriksson et al., 2011; Mitchell et al., 2016). FCC recognizes family members as more than visitors and views them as part of the patient’s care team (Farmanova et al., 2015). Also, FCC recognizes that care needs to extend beyond the patient to include family members (Shields, 2010). Although endorsed by the World Health Organization as an essential element of quality healthcare (Mitchell et al., 2016),

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[4] The use of children/child throughout this thesis refers to any individual under the age of 19 years as this is the age of majority in British Columbia (BC).

discussion of FCC in the ICU has tended to exclude children (MacEachnie et al., 2018). Additionally, the majority of ICUs restrict children from visiting family members (Ihlenfeld, 2006; Kean, 2010; Liu et al., 2013). Despite the prevalence of this policy, there has been virtually no research into how families with children experience the ICU stay of an adult family member (Kean, 2010; MacEachnie et al., 2018). While reviewing ICU literature, I came to realize that discussions of ‘family’ is not always inclusive of child family members, which raises questions about the construct of family within the institutional context of adult critical care. To counter this tendency, I explicitly frame my discussion of children as integral members of a family. To reinforce this inclusive framing throughout this thesis, I refer to ‘families with children’ or ‘child and adult family members.’ I return to a discussion of family again in section 1.4.

1.2 The Rationale for the Study

In 1979, an American nurse conducted seminal research into the needs of the ICU patient’s adult family members that led to the creation of the Critical Care Family Needs Inventory (CCFNI) (Molter, 1979). The CCFNI consists of a list of 45 statements that adult family members rank according to importance during their ICU experience. The CCFNI continues to be used by researchers to provide insights into what adult family members need during the ICU stay of a loved one. Beyond Molter’s original research, the CCFNI has been used in more than 50 subsequent international studies[5] exploring the needs of adult family members during the ICU stay of a loved one (Al-Mutair et al., 2013). In addition to data gathered through the CCFNI, a literature review by Al-Mutair et al. (2013) examined 30 further studies all looking at the importance of family involvement during the ICU stay. Although still under development, the growing awareness of the needs of adult family members is reflected in the changes to policies and practices in the ICU over the last two decades (Manici & Ghillani, 2018). However, it is essential to note that the CCFNI was designed for use with adults, and a review of the literature revealed virtually no research regarding the needs of child family members.

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[5] Use of the CCFNI was noted in research conducted between 2000 and 2012 in the “USA, Canada, Britain, Sweden, Norway, Australia, Turkey, Jordan, Germany, Greece, Hong Kong, Iran, and Saudi Arabia” (Al-Mutair et al., 2013, p. 1806).

1.3 Significance of this Study

To inform this study, I spoke with an ICU manager and an ICU nurse educator within the Island Health Region. Both expressed a keen interest in research to help inform their visitation policies and practices. The ICU nurse educator described the growing frequency of questions from staff around the inclusion of children in FCC (personal communication, July 5th, 2019). The nurse educator explained that caregivers[6] are directed to discuss children visiting with the patient's nurse but stated that current ICU nurse orientation does not include training regarding visiting children. Furthermore, Island Health contracts out the specialized training of ICU nurses to the British Columbia Institute of Technology (BCIT). The program head of the Critical Care Nursing Speciality program at BCIT described children as visitors as a "hot topic." Also, although their curriculum includes a module focussed on FCC, the module does not address children as visitors (personal communication, Sept. 19th, 2019).

The ICU nurse educator explained to me that when needed they can call on a social worker to support a family but noted that social workers work across multiple units and are typically available during business hours. Therefore, caring for families can fall to nurses as they are often the most visible member of the ICU team and are present 24 hours a day. To understand additional supports available to families, I also met with a spiritual health practitioner who expressed reduced contact with the ICU due to restructuring. Additionally, I talked to a child life specialist, and a clinical resource nurse in the PICU to understand how families are supported in pediatric critical care. Furthermore, I met with a hospice counsellor who specializes in supporting children, youth, and families during the illness, death, and dying of a loved one. The hospice counsellor informed me that she can provide support to families following the loss of a loved one in the ICU but noted that it is rare for a family to be referred to her. The findings of this study will be relevant for the interdisciplinary[7] team of practitioners in the ICUs of Island Health and other health regions in BC that are interested in examining their policies on this topic.

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[6] In this study the terms 'parents' and 'caregiver/s' are used interchangeably to refer to the primary adult/s responsible for the care of a child/ren, which might include grandparents, aunts, uncles, or close family friends.

[7] I understand an interdisciplinary team as including a range of practitioners providing overlapping services and supports (Körner, 2010). In the ICU, an interdisciplinary team might include doctors, nurses, social workers, child life specialists,

1.4 Research Purpose

The overarching purpose of this exploratory study is to provide preliminary insights into supporting families with children who are minors during the ICU stay of an adult family member. The following objectives support the overall purpose of the research:

- To inquire into the experiences of child and adult family members during the ICU stay of an adult family member in order to gain a deeper understanding of what families go through when a loved one is critically ill.
- To explore the languaging and content of online resources, visiting pamphlets, and policy documents in order to understand how ICUs position child and adult family members in relationship to a loved one's treatment in an ICU.
- To consider the physical spaces associated with critical care and to consider what these spaces may communicate about the involvement of children during an ICU stay.

Understanding the experiences of child and adult family members when an adult loved one is admitted to an ICU can be used to inform how interdisciplinary members of the ICU team support and care for a patient and their family. Additionally, seeing the physical spaces, such as waiting rooms, through the eyes of the individuals who sit in them can be useful in determining what supports, or does not support, the needs of visiting families with children. Furthermore, insights regarding the support of families during the ICU stay may inform the ways that services are provided to families in child and youth care contexts more broadly. This might be particularly useful in environments that seek to provide a family centred approach to services focussed on adult family members.

Family is a complex structure to define in contemporary Canadian contexts. Understanding this complexity, the Vanier Institute of the Family offer a functional definition that focusses on the nature of the relationships that bind people together rather than what a family looks like (Mirabelli, 2018). A focus on how people experience family is seen as a way to capture the diversity of family compositions in Canada (Mirabelli, 2018). Although I embrace this broad understanding of family, I acknowledge that the dominant colonial discourse pervasive in healthcare contexts and FCC tends to privilege

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counsellors, and spiritual health practitioners working collaboratively to care for the critically sick patient and their child and adult family members.

assumptions of ‘family’ as consisting of two heterosexual, monogamous, gender normative parents and their children (Iantaffi, 2009) and may not take into consideration understandings of family across different population groups. Furthermore, to reinforce the view of children as integral members of their family, I use the framing of ‘child and adult family members’ and ‘families with children.’ The intention of this framing is to ensure the visibility of children as members of their families rather than suggesting that children should be viewed as separated or removed from adult family members. Also, I use the terms parents and caregivers to refer to those individuals in a primary caregiving role to child family members, which might include grandparents, aunts, uncles, or close family friends.

1.5 Organization of the Thesis

This research is framed by a consideration of Tracy’s (2010) quality markers of qualitative research. **Chapter One** provides an overview of child and adult family members as visitors in an ICU and establishes the topic as worthy of inquiry. **Chapter Two** reviews the literature for insights into the understandings that inform current ICU policies and practices. **Chapter Three** discusses the research design with consideration of rigour, sincerity, credibility, and resonance. Ethical considerations are named, and coherence between the nature of the inquiry and the chosen methodology and methods are discussed. **Chapter Four** identifies the key findings of the research and uses narrative and poetic elements to help readers enter into the experiences of families. **Chapter Five** discusses these findings in relationship to existing literature and leads to a list of preliminary recommendations that might inform the support of child and adult family members during the ICU stay of a loved one. In the final chapter, I also discuss the implications of this study for child and youth care practice more generally.

1.6 Chapter Summary

In this first chapter, I have established that although critical care is a rapidly growing area of healthcare, little is known about children’s experiences during an adult family member’s ICU stay. Through personal communications, healthcare providers in BC have expressed a growing need to understand the experiences of families with children, which can then inform visiting policies and practices in the ICU.

Chapter Two: A Review of the Literature

I conducted a literature review using the search terms *critical care*, *acute care*, *intensive care units, family-centred care, hospital visitation policies, children, adults, visitors, patients, critical illness, death, dying, grief, and bereavement* individually and collectively to search the online databases ERIC, PsycINFO, Google Scholar, MEDLINE, CINAHL and Social Work Abstracts. Additionally, an examination of the bibliographies of related literature reviews revealed further research related to this topic.

This chapter is organized into three sections, the first section provides an overview of healthcare in Canada and the creation of ICUs and their associated visitation policies. The second section explores conceptualizations of children and childhood from both a developmentalist and sociology of the child perspective and explores concepts such as protectionism, agency, and autonomy that are pertinent to this study. The third section discusses how children experience the critical illness of an adult family member and what might support them during the illness, death, and dying of a loved one.

2.1 A Historical Overview of Critical Care and Visitation Policies in Canada

This section examines the historical context of Canadian healthcare as a way to situate the development of ICUs and children's visitation rights.

Healthcare in Canada

The Canadian Constitution Act of 1867 assigned responsibility for establishing, maintaining, and managing hospitals to provincial governments (Government of Canada, 2011). Up until the second world war, healthcare in Canada was largely privately funded and delivered (Government of Canada, 2011), with publicly funded healthcare not taking shape until the 1950s and 60s (Lewis et al., 2001). In 1966, the Medical Care Act established universal physician services insurance plans to cover the cost of medical services received outside of hospital care (Government of Canada, 2011). The Canadian Health Act of 1984 sought to unify the provision and access to healthcare across Canada (Government of Canada, 2004). The Canadian Health Act established five national healthcare principles: public administration, comprehensiveness, universality, portability, and accessibility that continue to underpin healthcare throughout Canada (Lewis et al., 2001). However, in a Canadian report analyzing the performance of universal healthcare systems in 28 high-income countries, Canada ranked as one of the most expensive and among the worst regarding timely and accessible healthcare (Barua & Moir, 2019). Canadian geography continues to make the provision of accessible healthcare challenging in remote rural areas (Sibley & Weiner, 2011). Also, systemic racism within the healthcare system is a serious barrier to healthcare access and health outcomes for black, Indigenous, and people of colour (BIPOC) (Allan & Smylie, 2015). Therefore, access to healthcare in Canada is not universal and many individuals and population groups continue to experience barriers to accessing care.

The Evolution of Critical Care

ICUs began in Denmark in response to the polio epidemic of 1952 (Kelly et al., 2014). Dr Ibsen discovered that tracheostomies and hand ventilation could cut mortality rates in half (Kelly et al., 2014). In the name of efficiency, an area of the hospital was dedicated to patients in need of hand ventilation and led to the birth of the ICU (Kelly et al., 2014). Caring for critically sick patients in one centralized location gained rapid support through the 1960s resulting in the spread of ICUs throughout Europe and North America (Hamilton, 2010; Kelly et al., 2014). The first ICU in BC was established in 1967 in the basement of the Vancouver General Hospital (Hamilton, 2010). Positioned at the end of a tunnel, the small, dark space was distant from the rest of the hospital and described as “pitiful” (Hamilton, 2010, p. 45). The location of the ICU was distressing for visiting family members as they had to wait outside the doors of the morgue, reminding them of the possibility of death (Hamilton, 2010). Adult visits to a family member in the ICU were very limited due to the lack of space and fear of infection (Hamilton, 2010).

Initially, critical care was characterized by the individualized nature of nursing care rather than by technological advancement (Hamilton, 2010). However, by the 1990s, ICU as a speciality included a interdisciplinary team of ICU nurses, physiotherapists, pharmacists, dieticians, technicians, radiologists and microbiologists and utilized increasingly sophisticated technology in order to sustain life (Kelly et al., 2014). ICUs are now found throughout BC and are classified according to the capacity and level of care available (Jones & Evans, 2014).

As a result of technological advances, the likelihood of surviving critical illness has greatly increased (Manici & Ghillani, 2018). In the early days of critical care, the survival rate of patients in Vancouver's ICU was around 25%; a figure that increased exponentially with the expansion of knowledge and technology (Hamilton, 2010). The improved survival rates have drawn attention to the long term impacts of an ICU stay on both the patient and their adult family members (Anderson et al., 2008; Eggenberger & Nelms, 2007; Manici & Ghillani, 2018). Over the last two decades, increasing awareness of balancing advanced medical techniques with the humanization of care (Manici & Ghillani, 2018) has led to a shift from focussing solely on the medical needs of the patient to addressing the non-medical needs of the patient and their family (Eggenberger & Nelms, 2007).

Visitation Policies and Family-Centred Care

The need for patients and family members to see each other during hospitalization evolved with the ongoing evolution of Canadian hospitals. The first Canadian hospitals, established in the 1820s to serve individuals who did not have anywhere else to go for care (Martin, 2015), have been described as "full of infection" and "a place that people went to die" and as a result visitation was almost non-existent (Giganti, 1998, p. 2). It was not until 1910, with the arrival of antiseptic, anaesthesia, and trained nurses, that visiting hours were introduced (Rosenberg cited in Giganti, 1998). However, fear of infection and concerns that visitors would interfere with patient care meant that visiting hours were minimal and usually excluded children (Institute for patient- and family-centered care, n.d.).

FCC has been defined as "care that is planned around the whole family" (Shields, 2010, p. 2629), and emerged in the 1960s as pediatric healthcare providers in the United States and Europe recognized that sick children were comforted by the presence of their parents (Shields, 2010). In the 1980s, visiting rights were extended in the United States to include the siblings of sick children in recognition that the risk of infection was low and that the benefits of visiting were significant for both sick and well siblings (Giganti, 1998). A recent Canadian scoping review indicates that family members are now recognized as playing an important role in the care and recovery of sick family members; supporting a shift towards many healthcare contexts adopting FCC (Kokorelias et al., 2019).

FCC is built on a premise that when a family member is sick, everyone in the family is affected (Knutsson & Bergbom, 2016). According to Mitchell et al. (2009), FCC seeks to provide “information, reassurance, and proximity” (p. 544); understanding that the natural response of family members to illness is to want to be close to the patient and each other (Alvarez & Kirby, 2006; MacEachnie et al., 2018). In 2007, the BC Ministry of Health (2007) announced its commitment to ‘partners-in-care’, a collaborative approach to healthcare that moves patients and their families from being passive recipients of care to being actively engaged in conversations about their health and centred around the needs of the family rather than the needs of healthcare providers or facilities (Bar et al., 2018; British Columbia Ministry of Health, 2007). This collaborative approach is evidenced in the following quote from a critical care nurse in Vancouver Coastal Health: “We have a holistic approach to care here in the ICU. Yes, we have very sick patients we’re looking after, but it’s not just about the sick patients in the bed, it’s about the family and how we can support them through this difficult time.” (Vancouver Coastal Health, 2018). Despite the rhetoric of FCC, this approach has been critiqued both in terms of its conceptualization and its practical application (Smith et al., 2017). FCC policies typically allow patient’s, or their next of kin, to define who they consider to be ‘family’ (Farmanova et al., 2015). However, there is concern about how FCC addresses the needs of children, a discussion revisited in section 2.2.

ICU Visitation Policies for Children

Despite the growing recognition of FCC, children continue to be largely restricted from visiting critically sick loved ones in ICUs in many nations (Ihlenfeld, 2006; Kean, 2010; Manici & Ghillani, 2018; Vint, 2005). Restrictive visitation policies can result in children experiencing feelings of being excluded and ignored; promoting “feelings of uncertainty, sadness, and loneliness” (MacEachnie et al., 2018, p. 2930). Swedish researchers found that healthcare providers restrict children because of their fears that the experience would be too frightening or that there is a risk of infection for the child or the patient (Knutsson & Bergbom, 2007). However, a North American literature review on children visiting a family member in an ICU found no research to support concerns about an increased risk of infection, or any adverse impacts of children visiting a critically ill adult family member (Hanley & Piazza, 2012). Moreover, Swedish research found that after visiting a family member in the ICU, children expressed that they felt less guilty and had a greater sense of peace (Knutsson & Bergbom, 2016). Similarly, British research concluded that allowing children to visit adult family members in an ICU may help children to deal with a loved one's illness and the uncertainty that they may feel while a family member is hospitalized (Kean, 2010). Visiting may also benefit patients. In an Italian study, former ICU patients talked about being aware of family members visiting and feeling comfort from knowing that they were close, even when they were unconscious (Danielis et al., 2020). Similarly, in a review of critical care in the United States, a former ICU patient expressed that, while unconscious, "We do hear. I knew each and every person that visited me, and talked to me, and touched me" (Nelson et al., 2006, p. 9).

A Canadian and British review of visitation policies suggests that few address children visiting adult family members. A review of 114 Canadian hospitals revealed that few had visitation policies that accommodated the needs of families (Farmanova et al., 2015). Similarly, A British study found that of the 67 ICUs surveyed, none were found to have a written policy regarding children visiting (Vint, 2005). A lack of policy can place decision-making entirely at the discretion of whomever happens to be on duty. Dworkin (1977) likened professional discretion to the hole in a doughnut surrounded by the associated rules and regulations. In the absence of a written visitation policy, healthcare providers are operating with 'a hole but no doughnut'. Ponnert and Svensson (2016) are quick to point out that while the goal is not to eradicate professional discretion, as this is felt essential in allowing staff to respond to the individual needs of families, staff need the guidance of a policy and practice framework. Also, professional discretion must be informed by education rather than previously held assumptions, beliefs, and attitudes to children visiting (Vint, 2005). In a recent study in Sweden, an open visitation policy that welcomed children as visitors in the ICU failed to result in the children having greater access to their sick loved one (Knutsson et al., 2017). In this study, nurses expressed a lack of knowledge about how to provide children with a "caring child-focused encounter" with their family member and therefore discouraged families from bringing children to visit (Knutsson et al., 2017, p. 10). Education may be essential in opening the doors of the ICU to children during the critical illness of an adult family member.

It may therefore be concluded that allowing children to visit in the ICU is a contentious topic (Mitchell et al., 2019) and that there is a need for more research so that policies provide a coherent, consistent approach to children visiting in an adult ICU (Hanley & Piazza, 2012; Harvey & Davidson, 2018; Kean, 2010; MacEachnie et al., 2018). Although hospitals in Canada have slowly opened the doors of the ICU to adults, doing the same for visiting children continues to be viewed by some as problematic.

2.2 Conceptualizations of Children and Childhood

Social constructionism considers how the interactions and negotiations between people and social systems shape understandings of what it means to be a child (James & James, 2012); recognizing enormous variability across time, place, and diverse sociocultural contexts (Qvortrup, 2009). Conceptualizations are continually changing as diverse people interact and renegotiate social constructs. In this section, I discuss how adult conceptualizations of children continue to shape a child’s experiences of an adult family member’s ICU stay.

Euro-western, developmentalist understandings of childhood that conceptualize children as needing adult governance and protection are prevalent in mainstream institutional systems, including healthcare systems, in colonial societies such as Canada (Wall, 2015). Developmentalism derives predominately from the perspectives of white, middle-class, Western European men (Wall, 2015), and assumes a top-down understanding of childhood in which children are viewed as “human becomings” rather than as “human beings” (Holloway & Valentine, 2000, p. 763). From this perspective, the goal of childhood is to be socialized into an adult (James et al., 1998) and progress towards this goal is measured according to developmental benchmarks outlined in stage-based frameworks created primarily by Euro-western developmental psychologists (Qvortrup, 2009). In colonial societies such as Canada, this conceptualization of childhood has been extended to include Indigenous adults, who have been constructed as needing governance (Sultan, 2020) and in a state of “perpetual childhood” in which they never achieve the right to make decisions for themselves (de Leeuw, 2009, p. 123). Also, colonial interventions, such as the Indian Residential Schools, were aimed at ‘de-Indigenizing children’ so that they could be assimilated (de Leeuw, 2009). The Indian Act of 1876 expressed the control of colonial rule and, despite several amendments, the Act continues to marginalize Indigenous peoples and fails to grant full participation rights in the establishment of new and just legislation (Hanson, 2009). A current ramification in the healthcare system in Canada is that Indigenous patients can often experience healthcare providers talking down to them, dismissing what they have to say, and treating them like a child (Goodman et al., 2017). Thus, developmentalism positions children, and those conceptualized as children, as in need of governance and control and incapable to making decisions for themselves.

Children’s Agency and Autonomy

In contrast to developmentalism, an alternative conceptualization considers children as human beings possessing agency and autonomy (James & James, 2004). Agency is understood as the ability of children to express their ideas and make choices for themselves (James & James, 2012). In the 1980s and 90s, resistance to developmentalism began to emerge in the USA and Europe (Prout, 2011), which led to a wide range of disciplines calling for understandings of children as active and autonomous agents (James & James, 2012) rather than passive dependants (Tisdall & Punch, 2012). This movement led to what has become known as the ‘new’ sociology of childhood, or, in recognition of the cross-disciplinary nature of the field, ‘childhood studies’ (Tisdall & Punch, 2012). While childhood studies does not dispute the biological immaturity of children, it emphasizes that people continually negotiate and renegotiate what it means to be a child, or adult, within a social system (James & Prout, 2015). Childhood studies led to an interest in conducting research ‘with’ children rather than ‘on’ them, but children’s participation in research remains limited (Blaisdell et al., 2014).

In the context of Canadian pediatric healthcare, developmental stages and theories continue to shape children’s experiences and position them as in need of protection (Koller, 2017). The centrality of chronological age in developmentalism fails to consider variations in children’s understandings and competencies and might lead healthcare providers to “underestimate and possibly undermine the abilities of children” (Koller, 2017, p. 2658). Furthermore, viewing children and their abilities through a colonial developmental lens can fail to recognize how competency can be viewed and experienced differently across population groups (DeMichelis, 2020). However, rather than calling for total abandonment of developmental theories, childhood studies suggest that they are drawn upon alongside careful consideration of an individual child’s temperament, experience, coping style, and personal preference (Koller, 2017). In contrast to stage-based developmental theories, which only consider chronological age, childhood studies pay attention to a broader range of factors such as the child’s life experience or their support system and make it possible to ask if children have the capacity to participate in decision-making (Qvortrup et al., 2009).

The United Nations’ Convention on the Rights of the Child (UNCRC) (United Nations, 1989) is well aligned with the sociology of childhood (Tisdall & Punch, 2012). Ratified in all but one country (the United States), the UNCRC added six participation rights to the provision and protection rights of former declarations.[8] Article 12 is particularly pertinent to this study because it established the right for children to be heard on matters that are important to them and for their views to be given due weight in the decision-making process. The UNCRC further established conceptualizing children as more than an ‘adult in training’ and reinforced the understanding that children are human beings and individuals with their own rights (Unicef, n.d.). The individualized decontextualized nature of children’s participation rights in the UNCRC is questioned by some who prefer to consider children’s rights in connection to their family relationships (Wall, 2015). Similarly, Carnevale (2020) questions the extent to which children, or adults, are truly autonomous and advocates for adults to engage with what children have to say in ways that are meaningful and ethical, while also recognizing their voices as embedded in relational, social, and cultural contexts.

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[8] Provision rights – a child’s right to nutrition, healthcare, aid, and education. Protection rights – a child’s right to be protected from harm, violence, and discrimination (Wall, 2015).

Given the limited research on children's experiences in the ICU, in the following section, I draw on what is known about children's participation in the literature on pediatric healthcare. When adults consider children to be competent at decision-making, the passive, vulnerable, and immature child is replaced by the active, capable, and knowledgeable human being in their own right (Alderson, 2007). However, although the UNCRC established the right for children to participate in decision-making related to their health, research conducted in Ireland, Canada, and Sweden reveals that these rights are often unrealized (Coyne & Gallagher, 2011; Koller, 2017; Runeson et al., 2007). Contrary to parents' beliefs, research indicates that involving children in discussions about their health lowers their pain, anxiety, fear, anger, confusion, and frustration while increasing their sense of being valued, included, and in control (Becker et al., 2018; Ehrich et al., 2015; Feenstra et al., 2014; Gilljam et al., 2016; Jeremic et al., 2016; Koller, 2017). However, how and to what degree children want to be involved can vary (Coyne & Gallagher, 2011); indicating the need for a collaborative process between children, caregivers, and healthcare providers. In consideration of this research, might the same be true of inviting children into conversations about how they would like to be involved during the ICU stay of a family member?

From Family-Centred Care to Child- and Family-Centred Care

As previously mentioned, an approach to healthcare that has influenced family member's involvement during a hospital stay is the concept of FCC. FCC is "respectful of and responsive to individual families' needs and values" (Davidson et al., 2017, p. 105) and explicitly understands that because a patient is embedded in a family,[9] it is crucial to involve and care for family members during an ICU stay (Mitchell et al., 2016). An international, interdisciplinary team of 29 healthcare providers reviewed 238 studies and consulted with 27 former ICU patients and families to create 23 recommendations for FCC in ICUs (Davidson et al., 2017). The recommendations represent "the current state of international science in family-centred care and family support for family members of

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[9] In the context of FCC, family has been defined as the individuals who are in a close, supportive relationship with the patient (Davidson et al., 2017)

critically ill patients across the lifespan" (Davidson et al., 2017, p. 104). Although FCC is thought to mitigate the stressors family members often experience in connection with an ICU stay (Davidson et al., 2017), it is crucial to note that children are not mentioned in the recommendations. As highlighted in the previous chapter, the framing of a 'family' in FCC discourses and policies can result in losing sight of child family members (Coyne et al., 2016; Smith et al., 2017). The continuing exclusion of children in pediatric healthcare contexts has resulted in a push to reframe FCC as child- and family-centred care (CFCC) (Coyne et al., 2016; Gerlach & Varcoe, 2020). A shift towards CFCC emphasizes that the needs of the child may be different from those of their adult family members (Coyne et al., 2016), and recognizes children's agency and participation rights in matters that are important to them (Coyne et al., 2016). To adopt CFCC in the ICU requires asking how and where children as active agents can be reflected in the policies, practices, and associated physical spaces of adult critical care contexts.

CFCC has been criticized for its tendency to reflect Euro-western values and its usefulness across diverse sociocultural and economic contexts has yet to be examined (Gerlach & Varcoe, 2020). Therefore, some population groups may continue to experience barriers to accessing equitable healthcare (Nelson & Wilson, 2018; Shields et al., 2012).

2.3 Children and the Critical Illness of an Adult Family Member

As previously noted, rapid technological advances in critical care contexts over the last two decades have dramatically increased the likelihood of a successful ICU outcome (Ewens, 2017; Manici & Ghillani, 2018). Although families may not be faced with the death of a loved one, the invasive therapies necessary to sustain life often result in significant physiological disturbances, and the emotional stress of critical illness can have long-term impacts on the patient and family members (Ewens, 2017). Illness discourses suggest that children are affected when a family member is sick (Golsäter et al., 2019; Knutsson & Bergbom, 2016; Oja et al., 2020). Currently, little is known about how an adult family member's ICU stay can impact children.

There is, however, some research on the impacts of an ICU stay on adult family members. A French study examining the long-term impact of an ICU stay indicated that 41% of patients and 33% of adult family members experience posttraumatic stress-related symptoms following an ICU stay (Garrouste-Orgeas et al., 2012). Similar findings were reported in studies undertaken in Sweden, the United States, and Australia (see Bäckman et al., 2010; Drumright et al., 2020; and McIlroy et al., 2019). When a loved one is critically ill, adult family members have been found to put normal life on hold as they hold a vigil at the hospital (Deitrick et al., 2005; Fridh et al., 2009; Health Experiences Research Group, 2006). This research raises the question that if a child is not at the hospital, might they experience a loss of connection with both their sick and well family members?

The impact of illness on adults' normal, everyday lives has been conceptualized by Bury (1982) as 'biographical disruption' and has been applied to both patients and adult family members' experiences of critical illness (Ewens, 2017; Tembo, 2017). This concept is under-examined in the context of how children experience a family member's ICU stay. Aligned with the concept of biographical disruption is the rupturing of a family's identity and the need for support in adapting to life post-ICU (Tembo, 2017). Both adult and child family members may need to grieve the loss of their pre-ICU life (Tembo, 2017). Given the absence of research into the impacts of an ICU stay on children, in the following section I draw on grief research more generally to help examine how children process loss.

Children's Processing of Loss

Social constructionists argue that viewing child or adult grief as an individual journey creates an overly prescriptive sense of what constitutes an ordinary course of grief (Cragg, 2008; Neimeyer et al., 2014). Instead, one must consider how interactions within sociocultural contexts shape understandings of what constitutes a 'normal' response to the illness or death of a loved one (Neimeyer et al., 2014). Currently, little is known about how children's experiences of grief are shaped by and intersect with "cultural, racial and linguistic diversity, histories of immigration, poverty, Indigeneity, sexual identity, geographical region, and histories of criminal activity, or contact with the child welfare system" (Pileggi, 2019, p. 2). Grief literature tends to focus on one aspect of children's identity, rather than exploring how multiple and intersecting dimensions such as sexuality, gender, race, or religion might impact how a child experiences a loved one's illness, death, and dying (Pileggi, 2019).

It is estimated that 1 in 14 children in Canada will experience the death of a parent or sibling before they turn 18 (Children and Youth Grief Network, 2019). However, more research is needed to fully understand what might contribute to children experiencing complicated grief and how best to support a child after the loss of a parent (Pileggi, 2019). Research suggests that children's grief is different from the more stage-based process often associated with adult grief (Kübler-Ross & Kessler, 2005; Parkes, 1998; Parkes & Weiss, 1983; Worden, 1996, 2009). A review of 23 studies published across Europe, Australia, and the United States between 2000 and 2018 indicates that the grieving process in children tends to be non-linear, intermittent, and influenced by a child's cognitive and emotional development (Ridley & Frache, 2020). A significant aspect of grief in children is that they may need to revisit loss as they mature and their understandings of events change and evolve (Victoria Hospice, n.d.). North American research with parentally bereaved children indicates that most children (90%) experience adaptive[10] grief (Melhem et al., 2011). Another North American study explored the impact of the cause of death on the grief process in parentally bereaved children and found that the sudden loss of a parent did not result in higher levels of maladaptive grief than children who had experienced the loss of a parent following a prolonged illness (Kaplow et al., 2014). Although research indicates that most children do not experience prolonged grief symptoms, many adults appear to want to protect children from loss.

'Protecting' Children from Grief/Loss

Protectionism is a key concept underlying the apparent lack of participation of children during the ICU stay of a loved one and is evident in how some cultures navigate the death of a loved one. A

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[10] Feeling sad, missing someone/something, interrupted sleeping or eating patterns are considered normal after experiencing loss. In adaptive grief, these symptoms lessen over time as a child or adult incorporates the loss into their life. Grief is considered maladaptive when a person continues to find it difficult to eat, sleep, take part in their normal activities, or finds themselves continually thinking about the loss more than 33 months after the event (Kaplow et al., 2014).

British social attitudes survey revealed that 50 per cent of parents felt that children under 12 years should not attend a funeral as it would be too upsetting (Halliwell, 2018). Since Canada was colonized by England and under the Queen's Dominion until the 1960s, British views on family systems and race are foundational to Canadian legislation, policies, and mainstream social discourses. As such, in Canada, the Children and Youth Grief Network suggests that many adults try to shield children from death (Ashpole & Warnick, 2018). In contrast, research from Scandinavia and the Netherlands indicates that the dominant discourses in these contexts may be shifting towards greater inclusion of children in family death rituals. A Norwegian study concluded that involving children in the death rituals following the loss of a parent or sibling resulted in children feeling like a "full member of the family" (Søfting et al., 2016, p. 141). Similarly, a case study in Holland concluded that failure to include children in death rituals leaves them feeling set aside rather than recognizing them as grievers alongside adult family members (Faro, 2018). The findings of these two studies suggest that shielding children from the ICU experience may not be protective and that involving them may help children to cope with their loved one's illness.

Although involving children in the family process of illness and death remains a controversial topic for many families in Britain and North America, an extensive international literature review examining how to support children when a parent is dying of cancer found that allowing children to have contact with the dying parent was important in aiding their ability to grieve (Ellis et al., 2017). The implications of being allowed to visit are further evidenced in a British study into the short- and long-term impacts of restricting a child from visiting a family member who later died (Clarke & Harrison, 2001). Although somewhat dated, this research is included as it directly relates to the purpose of this study and does not appear to have been replicated in more recent research. Clarke and Harrison (2001) compared the effects of a pediatric critical care policy that allowed children to visit a dying sibling, with an adult critical care policy that restricted children from visiting an adult loved one. They concluded that allowing visitation supported the child in integrating the crisis into their life, which ultimately reduced the long-term detrimental effects of their grief. Conversely, they found that by not visiting, a child was found to suffer guilt, discomfort, and an inability to say goodbye. Despite an adult's desire to protect children, the literature suggests that being involved during the critical illness of a family member may support a child in their processing of loss.

Informing Children About the Critical Illness of Adult Family Members

A recent literature review of 32 international studies revealed that honest information may support children's wellbeing during a parent's illness (Oja et al., 2020). Although none of the studies explored the provision of information during an ICU stay, informing children about their parent's chronic illness or cancer care was found to lessen misconceptions, improve coping strategies, reduce feelings of guilt, or a sense of being unimportant (Oja et al., 2020). Conversely, failure to inform children about their parent's sickness can result in increased somatic symptoms or the child believing that they have caused the illness (Dale & Altschuler, 2006; Oja et al., 2020).

Research suggests that withholding difficult information from children can be problematic as children often have an innate awareness of the truth. Supporting the importance of providing honest information to children, Kaplow et al. (2014) found that when caregivers tried to conceal that a parent had died by homicide or suicide, the children's grief responses were comparable to those who had been told the truth, suggesting an innate awareness of what had happened. The awareness of truth is also evident in research with terminally ill children and Whitty-Rogers et al. (2009) advocate for adults telling children the truth even when they feel the news might be too difficult for a child to bear. This position is supported by Ashpole and Warnick (2018), who state that adults may be surprised by the resilience exhibited by children and young people when they are given access to accurate information. Furthermore, providing honest information about their critically ill loved one may support children's ability to story loss.

Grief Narratives

The ability to story loss is suggested as key to supporting the grief process in both children and adults (Neimeyer et al., 2014). Mnemonic objects, such as diaries, funeral photographs (see Figure 1 on p. 22), letters, poems, and drawings can help children and adults create grief narratives that link the past, present, and future (Faro, 2018). Grief narratives require the integration of event stories with back-stories: the event-story is needed to make sense of what happened; the back-story assists an individual in moving back and forth between their life before and after loss to create continuity (Neimeyer et al., 2014). Additionally, the use of diaries in supporting ICU patients and their adult family members are increasingly well documented in research from Sweden, United States, France, and Australia (Bäckman et al., 2010; Drumright et al., 2020; Garrouste-Orgeas et al., 2012; McIlroy et al., 2019). Although research exploring the use of ICU diaries with children was not located, psychologists support children's need to narrate struggle to create a coherent life story that supports mental well-being (McAdams & McLean, 2013; Reese et al., 2010). Encouraging families to create ICU diaries might be a way to both involve children during the ICU stay as well as providing a tool for processing loss.

Research shows that journaling may support children's grief process. In a North American longitudinal case study with a 19-year old who had recently lost her father, Balk and Vesta (1998) noted the importance of journaling as a way to maintain a sense of connection with her father. A similar grief process was expressed by Cragg (2008), who writes about her experiences of journaling after the loss of her father when she was 11 years old. Cragg stated that the "paper listened" (p. 123) and that her dad took care of her "through the writing" (p. 124). Given the expansion of technology, the creation of a journaling tool might support families as they record their experiences during an ICU stay. However, it should be noted that although technology has expanded writing opportunities to include weblogs and other online platforms, a study in the United States found that many children and youth prefer to utilize traditional diaries and journals to lower stress and anxiety (Murnahan, 2010).

Figure 1: Funeral Photographs as Mnemonic Objects

Photograph 2. Wytze closing the coffin. © Stilbeeld Uitvaartfotografie.

Note: (Faro, 2018, p. 9) *The mother in Faro's case study hired a funeral photographer to record her children's involvement in the family's death rituals. This photograph is of her 6-year-old joining the male members of the family in closing his father's casket. I chose to include this photograph as I was aware of the sense of pain and discomfort I experienced while looking at it. Pondering my own discomfort led me to ask: does our adult sense of pain and discomfort when looking at a child's loss prevent us from seeing what might be in the best interests of the child?*

Understanding more about how children process loss can inform the support provided to families with children during and after the ICU stay of an adult family member. Although a successful ICU outcome is more likely than two decades ago, families may experience several associated losses (Ewens, 2017). Despite the number of Canadian children who will experience the loss of a significant loved one (Children and Youth Grief Network, 2019), little is known about how children grieve or when additional supports and interventions might be beneficial, suggesting a need for more research. A review of the literature indicates that a supportive environment that invites children into the family grieving process helps children to make sense of loss (Faro, 2018; Goldman, 2004; Søfting et al., 2016). This understanding raises questions about how restricting children from visiting in the ICU might affect the ability of children to process illness, death, dying, and grief.

2.4 Chapter Summary

In chapter two I reviewed the literature related to the experiences of families with children during the critical illness of a loved one. I began with an overview of the Canadian ICU system, the development of ICUs, and the visitation policies often associated with adult critical care contexts. Next, I examined childhood as socially constructed and explored how developmentalism, and the privileging of Euro-western understandings of family, can position children as in need of protection rather than as active social agents capable of participating in their own decision-making. The concluding section explored children's experiences when a family member is ill and suggests that involving children during the ICU stay, as well as providing honest information about their loved one's medical condition, might support children when a family member is critically ill. Also, while reviewing the literature, I noted that although ICU research often talked about the needs of family members, inclusion criteria revealed that data was only collected from adult family members. Strikingly little research included children in discussions about the experiences of family members during the critical illness of an adult family member.

Chapter Three: Research Design and Implementation

The purpose of this qualitative interpretivist study was to gain insights into how child and adult family members experienced the ICU stay of a loved one. I sought descriptive data about what people saw, thought, or felt as their family members received care in the ICU. In particular, I was interested in understanding how the institutional story of the ICU shapes the experiences of visiting families with children and where their experiences might call for a renegotiation of the grand narrative. As an interpretivist study, the findings do not represent “what is” but rather “what I saw” (Newbury, 2007, p. 9). By which I mean, the research does not claim to be objective but instead acknowledges that it reflects what was seen from my perspective, and later in this chapter, I discuss more about my social location and relationship to the research.

3.1 Research During a Pandemic

The COVID-19 pandemic made conducting this study challenging. Ethics approval was granted on March 16th, 2020. On March 18th, BC entered a provincial state of emergency and all in-person research and contact with Island Health personnel were suspended indefinitely.[11] The original research proposal included interviews with families (n=3-5) and healthcare providers (n=3-5). Before the pandemic, I did not anticipate difficulty recruiting people to share their stories since support to recruit healthcare providers had been received from two Island Health ICUs, and three families, known through community connections, had already expressed interest in participating. I planned to gain additional families through in-person contact with family resource programs or health centres that I was connected to. Furthermore, I had the approval to conduct family interviews with adult family members in a place of their choosing and hoped that this might be amended to include specific child family members once participating families had been solidified. The pandemic meant that the inclusion of health authority staff was not possible and interviews with families had to be done remotely. The recruitment of storytellers was complex since everyone was living under a requirement to ‘shelter at

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[11] At the time of writing, the BC state of emergency has been renewed 18 times (34 weeks).

home.’ Other than essential services, all public spaces and programs were shutdown, which significantly impacted even remote contact with agencies. Additionally, one family who had expressed interest in participating was significantly impacted by COVID-19, and therefore my relationship with them changed to one of support rather than research. In the absence of other channels, I circulated a recruitment poster through email distribution lists at the University, which meant that I was drawing storytellers from a narrower demographic than originally intended. Furthermore, since interviews were conducted remotely, most included one family member and the inclusion of children was not possible. As such, the research was in part designed around the restrictions of life during a global pandemic.

3.2 A Storied Approach

The research is grounded in social constructionism, which views knowledge as being constructed through our interactions and relationships with others (Berger and Luckmann cited in Dodge et al., 2005) and which shift and change through time and place. Over time, these interactions can develop into taken-for-granted understandings (Gergen & Gergen, 2008) or ‘grand narratives,’ that are viewed as ever-changing rather than as finished products or truths (Esin et al., 2014). Attention to the stories people tell is seen as a useful way to gain insights into what people consider to be ‘true’ and to understand how taken-for-granted ideas shape people’s lives and position them within social systems (Dodge et al., 2005; Fraser, 2004).

In this study, I drew on narrative approaches to inquire into the experiences of families during the ICU stay of a loved one. Narrative approaches are based on the belief that we are storied beings who express how we experience the world through narratives (Clandinin & Connelly, 2000). Through the stories people tell, we can come to understand the human experience (Patterson, 2008). Narrative approaches are valued as a way to draw attention to “unexpected, hidden, or alternative interpretations” that change how we view ourselves and others (Dodge et al., 2005, p. 293). Stories are described as a window that allows us to see the topic of inquiry in human terms, which Bartel (2015) believes is essential in discussions about public policy.

My rationale for using narrative approaches is that the ‘thick descriptions’ provided through a narrative-based approach are thought particularly useful in healthcare contexts as they allow for a disruption of the healthcare provider/user hierarchy (Orsini & Scala, 2006). Stories provide a way for healthcare providers to perceive what it is like to be a patient, a perspective that may not always be within their sight (Lapum et al., 2012). Also, narrative approaches have gained recognition in North American public policy research as a useful way to reveal how a policy meets, or does not meet, the needs of different groups (Bartel, 2015; Dodge et al., 2005; Orsini & Scala, 2006; Rudman & Aldrich, 2017). Thus, stories offer a way to connect those providing care with the experiences of those receiving care.

Added to the usefulness of stories in exploring public policies, gathering data through stories is described as a “gentle” approach (Haydon et al., 2018, p. 125). An ICU stay can be a time of emotional turmoil and difficulty. I felt that inviting people to share the story they were ready to tell was less intrusive than asking probing questions that storytellers felt obligated to answer. This interview approach allowed storytellers to determine the direction of the interview (Firmin, 2008). I return to a discussion of how I engaged with storytellers in the sharing of their stories in section 3.6 on data collection. Additionally, Razfar (2012) states that stories aid in “dealing with surprising, disturbing, and unexpected events” (p.65). Stories can play a central role in our processing of sickness as “storytelling seems to be a natural reaction to illness” (Broyard cited in Haydon et al., 2018, p. 125), and stories are how people restructure their lives following an illness (Frank cited in Chase, 2018, p. 548). Furthermore, story-based methods are increasingly used in nursing research to increase understandings of patients’ experiences and viewpoints (Wang & Geale, 2015). Similarly, writing as a medical doctor, Charon (2006) states that she accompanies families through life by way of narratives. Charon speaks about “the braiding of stories” (p. 157), which inspired me to gather stories, braid them together around a question, and suggest new understandings (or further questions). Therefore, using a storied approach was a way to gather data in a manner that might feel more comfortable and natural for storytellers, as well as an approach that is already an established method in nursing and health research. Furthermore, it is argued that a storied approach is fitting for research within child and youth care since it connects relational practice with a relational approach to research (Bellefeuille & Ricks, 2010; Hoskins & White, 2013). Moreover, narrative approaches have also been used in social work research as a way of initiating social change (Fraser, 2004).

3.3 My Relationship to the Research

In this section, I consider two aspects of how I was situated within the research: (1) my ability to hear the muted channel, and (2) how my own story shapes the story gathered and re-told.

Hearing the Muted Channel

As storytellers shared their experiences, I was aware that there were valuable insights beyond the words spoken. I wanted to capture what was 'said' in the pauses, the silences, and the sighs. Therefore, as a novice researcher, I had to learn to listen to the "muted channel" running behind and around the words spoken (Anderson & Jack, 1991, p. 11). I understood the 'muted channel' as existing in the dialogical space between the storytellers and myself (Teachman, 2020) and I used journaling as a way to cultivate my reflective thinking about the stories shared and my interpretations of the meanings attached to these words. Reflective journaling is commonly used in ethnographic research to capture not only descriptions and observations but also feelings and reactions (Friedemann et al., 2011). Law (2008) speaks of "knowing as emotionality" (p. 2) and encourages the researcher to pay attention to feelings of hunger, pain, and discomfort, suggesting these as ways to hear through the physical responses of our bodies. Reflective journaling was a way for me to learn how to connect with this embodied data. St. Pierre (2018) describes data as both "always already in my mind and body" but often "fugitive" or "fleeting" (p.829) and urges researchers to capture this data through writing so that it can be incorporated into the inquiry. I viewed journaling as both a tool for data collection and reflexivity.

I began a journal as I was formulating my research proposal. Many of my early reflections became key as I progressed through the study. Also, as I looked back in my journal, I could see links between reflections on conversations with health authority staff while forming my research proposal;

journal entries before, during, and after interviews; and seemingly non-research related thoughts—all of which may have been missed if I had not recorded them in my journal.

Through my Eyes

I do not consider the writing of this study to be a mirror image of the stories told but, a reflection of the stories as experienced through my eyes. I acknowledge that I see in response to the sum of all my stories, which, from a social constructionist perspective, recognizes that how I see reflects the social discourses that have shaped my social location and world view. For instance, I recognize that my childhood experiences of growing up in a rural fishing village on the east coast of England forms one of the lenses I look through. Added to this lens are my experiences as a teacher in an inner-city school, as well as the years I spent travelling and living with families in Central America, Scandinavia, Russia, and Spain. Collectively, many of my stories are about walking alongside others, particularly during stressful or challenging times. Furthermore, I understand life as a spiritual journey and recognize that, in my walking alongside, I draw on a belief in that which is beyond the rational world that I can see, hear, and touch. I believe that my spirituality contributes to a valuing of the bonds between people, particularly those considered ‘family.’ I believe that connectedness to family is especially crucial during illness, dying, and death.

I began reflecting on the tension between adults and children navigating complex decisions during one of my graduate courses. I found myself recalling incidents in which I had observed children asking to be heard on matters that were important to them but had witnessed adults sidelining their requests. Aiden’s story is a tangible representation of this tension. The story is based on an encounter I had with a young child while volunteering as a clergy member in an ICU. Ingrained on my heart is the moment when Aiden asked to see his dying father. While I knew the policy of restricting children from visiting a family member in the ICU, I struggled with the idea of not giving Aiden’s request the consideration I felt it called for. After lengthy discussions with Aiden’s family and the healthcare providers treating his father, I took Aiden to see his father. I can still feel Aiden’s hand in mine and remember the uncertainty I felt as we walked into the ICU. I have written Aiden’s story from memory, with enough truth that it holds the weight of the dilemma while wrapping the story in enough fiction to respect the privacy of the child I call Aiden. Along with my social location as a privileged, white, middle-class, and educated woman, throughout this research, I continue to hold the hand of the 4-year-old child who asked to see his dying father. As Esin et al. (2014) caution, having entered the research from a particular position my vantage point is unlikely to change. At the beginning of the research process, I used to ask myself if it was necessary to let go of Aiden's hand before walking into this research. However, I have come to understand that his story is a part of mine, and I cannot set it aside nor obtain neutrality from it. I used journaling as a way to place my biases on a page in front of me. Fahie (2014) describes journal writing as a way for a researcher to be "both part of, and detached from, the research process at the same time" (p. 29). While I could not attain neutrality, I could see my thoughts, feelings, and reactions from a different perspective making them more transparent. Aiden's voice is one of the many I sought to capture in this study.

3.4 The Plural Voices of Many

Beuthin (2014) expresses that the story rendered from the study is "a complex representation containing the plural voices of many" (p.127). The notion of polyvocality refers not only to the many voices the research seeks to incorporate but also to the idea that one individual may have many voices (Newbury & Hoskins, 2008). St. Pierre (2008, p. 222) states that "voice in its presentness…vanishes immediately" as a reminder that our research captures a moment in time and can change as new voices are added. Adding to this idea, Esin et al. (2014) identify the audience in shaping the story told. As such I am mindful that the research story is being told for multiple audiences at the same time. First, the families who participated in the research, second, healthcare providers, and third, current and future academic audiences reading the research as part of a master's program. The ethical issues considered amid capturing the many voices, and representing their stories for different audiences, is discussed next.

3.5 Ethical Considerations

Guillem and Gillam (2004) emphasize that research begins in ethical tension because it involves asking something of people to construct knowledge. Ethical tensions were particularly apparent in this study due to the sensitive topic of inquiry. However, I felt that it was necessary to wrestle with the complexities of the study to gain a fuller understanding of the subject. Ethics approval was granted by Research Ethics BC (REBC)[12]; however, as Miller and Boulton (2007) stress, approval by REBC did not mean that all ethical considerations were accounted for. The amalgamated decision-making model I created for the study reflects the understanding that ethics required constant attention (See Appendix A). I drew on elements from a healthcare model (Health Canada, 2010), two counselling models (B.C Association of Clinical Counsellors, 2018; Lehr & Sumarah, 2004), and a policy review model (J. Newbury, personal communication, 2019) in order to be attentive to ethical considerations throughout the study.[13] I recognized that a researcher has to rely on their own ability to act ethically (Brinkman & Kvale, 2017), which highlighted the importance of self-awareness and reflexivity (Guillemin & Gillam, 2004). Ethical considerations informed *who* was included in the research, *when* they were included, and *how* they were included.

In an effort to minimize the potential risk of harm to storytellers, I felt that there needed to be a gap in time between when a family experienced the ICU stay and when they participated in the research. Initially, I had proposed a gap of five years but, on the suggestion of REBC, reduced this to one year. The REBC suggested that families would not respond to an invitation to participate unless they felt ready to do so and that my suggested time frame might overly restrict participation. The reduced gap in time also reflected a relational ethic that positions the participant as knowing what is right for them, rather than the researcher (Chapman, 2013). Additionally, I considered how to invite family members to share their story. I perceived my invitation to bring an artefact, which I described as

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[12] Research Ethics BC (REBC) approved the research design and implementation outlined in this chapter as part of a harmonized study between the University of Victoria and Vancouver Island Health Authority. REBC # H19-02885.

[13] In CYC 552 J. Newbury shared a video interview with Z. Ludski regarding an ethical decision-making framework called RUMPLE. The interview and handout outlining Ludski's model informed the one I created for this research.

photographs, letters, cards, or drawings, as a way to allow people to tell their story in a way that felt comfortable and reflected an invitation to construct the story they wished to tell (Scarletti & Hocking, 2010). Additionally, I gave family members the option to share their story alone or with other adult family members. Throughout the interviews, I checked in with storytellers and made sure that I left them with information about where they could access help if difficult emotions arose after the interview had ended. My experience was that family members were significantly affected by the ICU stay and welcomed the opportunity to share what they had experienced. Several reached out after the interview to share something they had forgotten, and thought might be of interest to me.

3.6 Research Site

As previously discussed, due to the COVID-19 pandemic participant recruitment and data collection occurred remotely. Although I was unable to have contact with Island Health employees during data collection, dialogue with healthcare providers within the region through the summer and fall of 2019 was instrumental in shaping the research. I drew on their questions and comments to generate practical and useable knowledge, which I discuss further in the section on knowledge mobilization.

3.7 Data Collection

The study incorporated three main avenues of data collection: interviews, field texts, and journaling.

Interviews

Inclusion Criteria. Storytellers represented three sub-groups: (i) caregivers of children during the critical illness of an adult family member; (ii) adults who had experienced children visiting/not visiting while they received treatment for critical illness; (iii) adults (19 or over) who had experienced the critical illness of a family member while they were a child. Inclusion criteria suggested a gap of at least a year between the ICU stay and participation in the study.

Recruitment. In addition to word of mouth, a recruitment poster (see Appendix B) was distributed electronically throughout the Greater Victoria area. In response, a total of 10 individuals expressed interest in the study, and seven agreed to take part after receiving study information and consent forms (see Appendix C). Although invited to have more adult family members join them for the interview, all but one participant chose to be interviewed alone.

Interviews. Each participant took part in a single, 60-minute interview. Interviews took place remotely at a time chosen by the storyteller. Storytellers received consent forms a minimum of a week before the interview, which allowed time to ask questions and seek clarification. All but one participant chose to be interviewed by phone rather than through Zoom. Interviews began with a review of the participant consent form. I also asked storytellers if they would like to choose their pseudonym, which often led to a casual conversation about favourite names and supported the creation of a comfortable, informal atmosphere. After a first open-ended invitation to share their story, I offered occasional prompts to draw out more of the story.

I invited storytellers to use artefacts (described as cards, letters, or drawings) in the telling of their story. One participant found her childhood diary written during her mother's hospitalization and this formed the basis of our entire conversation. Another participant shared a photograph of her family moments before her husband was admitted to the ICU and used this photograph to frame her story. One participant did not have an artefact but instead chose to write their story beforehand and read the account to me. I used a semi-structured guide (required by ethics – see Appendix D) with one participant who felt this would be useful, but partway through the interview, they remarked that they were surprised at how much they had to say and no longer needed questions. Consistent with social constructionism and the valuing of storytellers' voices in the forming of conclusions (Gergen & Gergen, 2008), storytellers formulated ideas about how their experience might inform the support of child and adult family members during an ICU stay. Storytellers' ideas were thus instrumental in forming the recommendations provided in the closing chapter.

I audio-recorded interviews using a hand-held device and acted as both the interviewer and transcriber. After I had transcribed the interview, I invited storytellers to review completed transcriptions and add or remove details. I also corresponded with storytellers through email as I worked with their stories, clarifying how I was describing events and confirming details. I viewed the interview as a shared experience and crucial to my ability to understand participant experiences. Verbatim transcription was instrumental in becoming familiar with the participant’s stories and enhanced my knowledge of not only the words used, but the tone of voice, the pauses, and the shared moments (Fraser, 2004).

Some storytellers continue to correspond with me as events have led them to remember something about their ICU experience or as they have additional insights to share. While writing my research proposal, I felt concerned about the morality of developing empathetic relationships with a stranger solely for the purpose of collecting data. I considered the power dynamic made explicit in the control the researcher holds over beginning and ending the relationship with those who contribute to the research (Fahie, 2014). In an effort to shift the power dynamic, I have chosen to let storytellers determine when they are ready to end the relationship and have aligned myself with a relational ethic (Gergen, 2015), which allows contact between storytellers and myself to be mutually determined. At the time of writing, I continue to be in relationship with several of the storytellers.

Furthermore, I considered research by Rolling (2011) who analyzed physical spaces as telling institutional stories. Storytellers were invited to share their experiences of the spaces associated with the ICU. By reflecting on these descriptions, I considered how physical spaces either welcomed families with children or excluded them.

Field Texts

Field texts are described as policy documents, memorandums, reports, and media stories and are considered necessary in contextualizing research and providing insights into institutional stories, or “grand narratives” (Clandinin & Connelly, 2000, p. 92). With the help of a BC Support Unit knowledge broker, I was able to access the Island Health Policy Stewardship Office for documentation related to visiting in Island Health facilities. Additionally, I drew on an approach outlined in “Much More Than a Visit” (Farmanova et al., 2015), which looked for evidence of a shift in the perception of families in healthcare by evaluating visiting information available on hospital websites. Farmanova et al. (2015)

assessed the availability and usefulness of information on visiting hours and visiting policies, scoring hospitals on how accommodating their policies were for family members. After surveying the websites, a researcher called the hospital to see if the information supplied online matched the information given by a switchboard operator. Adapting their approach, I surveyed healthcare websites for ICU visitation policies, practices, and associated resources. In addition to family-centred policies, I looked for any references to children as visitors. Beginning with Island Health, I surveyed the websites of the five health authorities in BC. I also looked at the other provincial acute care websites to see where variations or similarities were apparent across Canada.

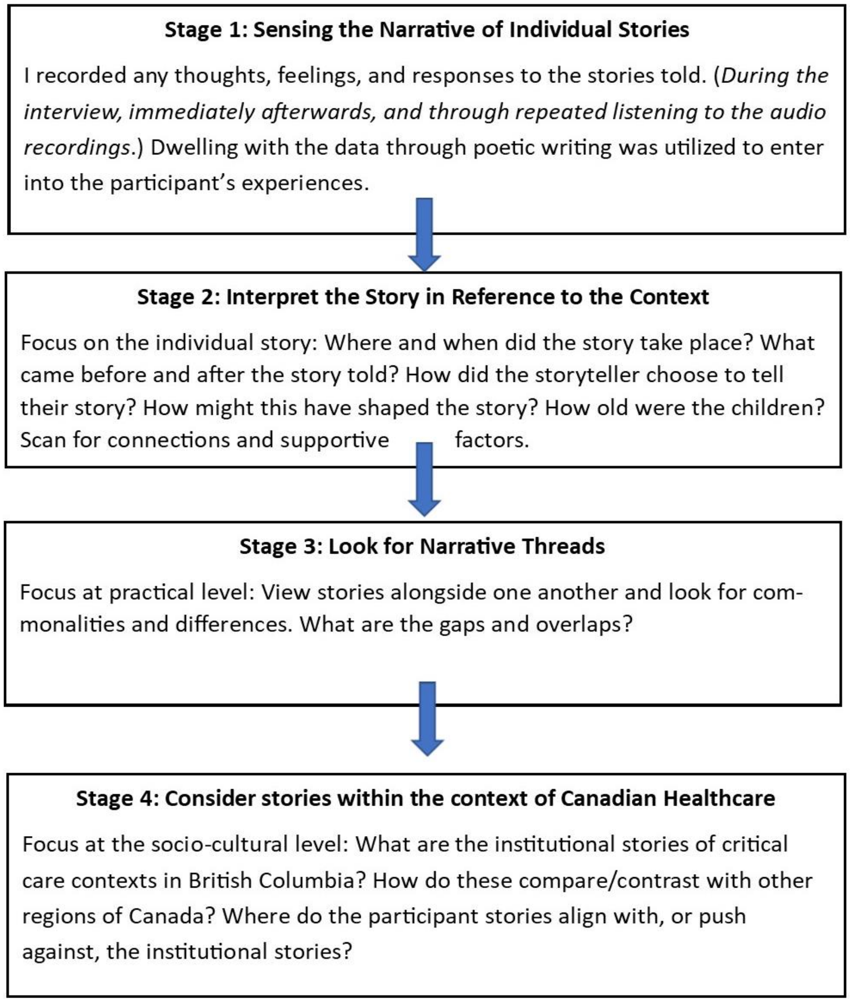
Journaling

Richardson advocates for incorporating reflexive writing throughout the research and suggests journaling to record thoughts, ideas, and reflections as they occur (Richardson & St.Pierre, 2018). In this way, journaling was both a data collection tool and a way to remain alert to how I was influencing the stories gathered. I carried my research journal with me everywhere throughout the research process beginning in July 2019. I recorded thoughts and reflections during initial points of contact with critical care contexts; before, during, and after interviews; while looking at healthcare websites; or reading associated resources. I also recorded thoughts as they occurred during unrelated research activities such as sitting on the beach, watching news broadcasts, or talking with a friend. Journaling during the unfolding pandemic also informed my thinking in connection with children, families, and illness narratives.

3.8 Data Analysis

Informed by Lindsay and Schwind (2016), my data analysis included focusing in on individual stories, a comparison across stories, and a stepping back to consider the stories within the context of healthcare in BC. From each vantage point, I drew on questions suggested by Fraser (2004) who conducts narrative research within the field of social work. I looked for where the experiences of storytellers converged and diverged as well as how they aligned with the structure of healthcare—as outlined in Figure 2. I looked for patterns of experiences as well as outliers. Viewing the data through different refractions is suggested as increasing the validity of the analysis (Lindsay & Schwind, 2016). The goal was not one singular truth, but “to open up a more complex, in-depth, but still thoroughly partial, understanding of the issue” (Tracy, 2010, p. 844).

Figure 2: Process of Analysis



Stage 1: Sensing the Narrative of Individual Stories

I recorded any thoughts, feelings, and responses to the stories told. (*During the interview, immediately afterwards, and through repeated listening to the audio recordings*.) Dwelling with the data through poetic writing was utilized to enter into the participant’s experiences.

Stage 2: Interpret the Story in Reference to the Context

Focus on the individual story: Where and when did the story take place? What came before and after the story told? How did the storyteller choose to tell their story? How might this have shaped the story? How old were the children? Scan for connections and supportive factors.

Stage 3: Look for Narrative Threads

Focus at practical level: View stories alongside one another and look for commonalities and differences. What are the gaps and overlaps?

Stage 4: Consider stories within the context of Canadian Healthcare

Focus at the socio-cultural level: What are the institutional stories of critical care contexts in British Columbia? How do these compare/contrast with other regions of Canada? Where do the participant stories align with, or push against, the institutional stories?

Note: Questions are based on those posed by Fraser (2004)

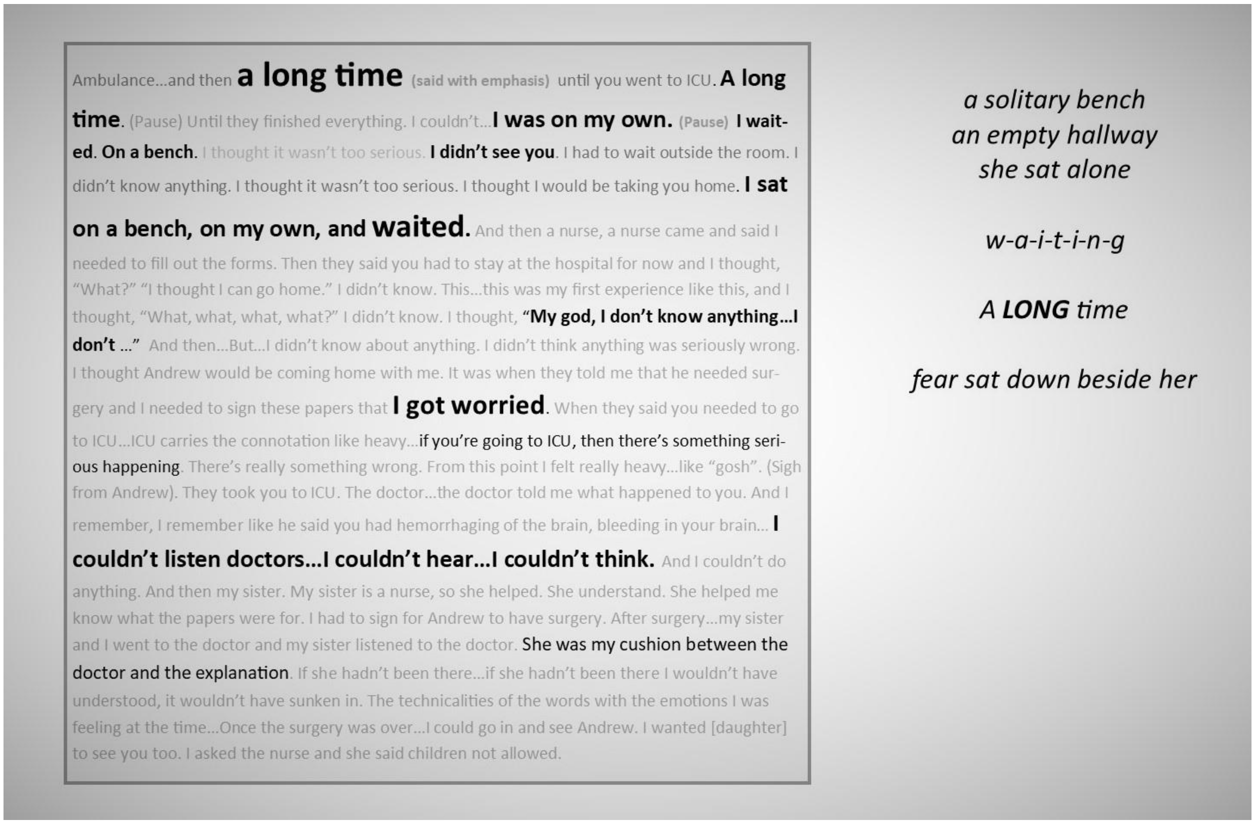
Sensing the Narrative of Individual Stories

Since six of the seven interviews took place by phone, I was able to begin journaling during the interview, which helped me to “listen in stereo” (Anderson & Jack, 1991, p. 11). I recorded not only the emotions evident as storytellers shared but also my emotional responses to them (Law, 2008). Furthermore, the initial stage of analysis included repeated listening to the story to foster what

Clandinin et al. (2016) describe as lingering in the story rather than working on it. The analysis was about “sensing” the narrative, ready for what jumped out or “glowed” (MacLure, 2013, p. 661). As I sat with the stories, I paid attention to the moments where I experienced their experience with them. I used my journal to write down the ‘glowing’ phrases, the words that stood out to me, and journaled around these phases (see Figure 3). I recorded both the emotions I heard in their voice as well as my own physical and emotional responses to them. If a family member repeated specific phrases or experiences, I noted those down. After having listened to the story repeatedly, I transcribed each interview in full trying to capture the pauses, tone, and weight of emotion, which was an additional way to become familiar with people’s stories as well as being a form of interpretation (Fraser, 2004).

Understanding writing as a method of analysis, I experimented with transforming interview transcripts into poetic representations. I used the “words, rhythms, figures of speech, breath points, pauses, and syntax” as a way to come to know the storyteller, and my relationship with the story, in a new and different way (Richardson & St.Pierre, 2008, p. 494). While listening to people’s stories I highlighted phrases or moments I felt to be of significance. I then foregrounded these portions of the transcript while allowing the rest to fade into the background. Literature refers to this approach, and the foregrounded portions, as found verse (Wiggins, 2011). As my responses mixed with the storyteller’s expression, found verse grew into free verse (Lapum et al., 2012). As a critical care nurse and researcher, Lapum suggests that poetry can capture the humanistic side of healthcare and uses poetry in both analysis and research dissemination to draw attention to “raw, emotional, and embodied” experiences (Lapum et al., 2012, p. 102). Consistent with this view, I chose to include ‘poetic elements’ in my findings.

Figure 3: Poetic Analysis



Ambulance...and then **a long time** (said with emphasis) until you went to ICU. **A long time**. (Pause) Until they finished everything. I couldn't...**I was on my own.** (Pause) **I waited**. **On a bench.** I thought it wasn't too serious. **I didn't see you**. I had to wait outside the room. I didn't know anything. I thought it wasn't too serious. I thought I would be taking you home. **I sat on a bench, on my own, and waited.** And then a nurse, a nurse came and said I needed to fill out the forms. Then they said you had to stay at the hospital for now and I thought, "What?" "I thought I can go home." I didn't know. This...this was my first experience like this, and I thought, "What, what, what, what?" I didn't know. I thought, **"My god, I don't know anything...I don't** ..." And then...But...I didn't know about anything. I didn't think anything was seriously wrong. I thought Andrew would be coming home with me. It was when they told me that he needed surgery and I needed to sign these papers that **I got worried**. When they said you needed to go to ICU...ICU carries the connotation like heavy...if you're going to ICU, then there's something serious happening. There's really something wrong. From this point I felt really heavy...like "gosh". (Sigh from Andrew). They took you to ICU. The doctor...the doctor told me what happened to you. And I remember, I remember like he said you had hemorrhaging of the brain, bleeding in your brain... **I couldn't listen doctors...I couldn't hear...I couldn't think.** And I couldn't do anything. And then my sister. My sister is a nurse, so she helped. She understand. She helped me know what the papers were for. I had to sign for Andrew to have surgery. After surgery...my sister and I went to the doctor and my sister listened to the doctor. She was my cushion between the doctor and the explanation. If she hadn't been there...if she hadn't been there I wouldn't have understood, it wouldn't have sunken in. The technicalities of the words with the emotions I was feeling at the time...Once the surgery was over...I could go in and see Andrew. I wanted [daughter] to see you too. I asked the nurse and she said children not allowed.

a solitary bench
an empty hallway
she sat alone

w-a-i-t-i-n-g

*A **LONG** time*

fear sat down beside her

Note: On the left is a segment of an interview transcript, on the right a 'poetic element' drawn both from the transcript and my response to it. The bolded phrased are the ones that 'glowed.' The phases that stood out to me, something in the way that they were said made these moments significant. I explored these glowing phrases in my journal, writing the word down and journaling around it. Phrases like 'fear sat down beside her' are free verse (Lapum et al., 2012). Like Lapum et al. (2012), the placement of the words on the page is reflective of how I heard them in the audio recordings.

Interpreting Story in Context

A criticism of narrative approaches is that they treat the story like a self-contained product rather than considering it in context (Holstein, 2018). In analyzing storied data, Riessman (2008) discusses the importance of considering what the story is hanging on: how does the storyteller situate their story in time and place? Conversely, how might time and place be shaping the story told? Where does the storyteller choose to begin and end? How do they connect events in time? Similarly, Daiute (2017) stresses that stories are not just report, they are relationally situated and are influenced by who and why they are being told. Furthermore, the stories told today are built on our experiences of yesterday; they change over time and may not be told in the same way tomorrow. As Riessman (2015) explains, storytelling simultaneously exists in the present, the past, and the future. The story is being told in a present-day setting and yet seeks to bring the past to life while considering the future.

Looking for Narrative Threads

Having lingered in the individual stories, I began to consider the experiences of families alongside one another, Esin et al. (2014) describe this as the stories dialoguing with one another. I imagined the storytellers sharing their stories over dinner and envisioned how they might respond to one another. I sought to identify where their stories overlapped and where there were tensions, conflicts, and multiple meanings (Richards, 2016). For instance, I noted that all the stories included expressions of families wanting to be together during an ICU stay. However, how, and where they gathered varied from one family to another. Next, I considered the stories of families within the broader sociocultural context of critical care in BC. Here I looked at how the institutional story, as communicated through health authority, hospital, and critical care websites, was co-constructing the stories of families (Esin et al., 2014). I was looking for what Bury (2001) describes as the narrative threads; the places where the stories tied together or pushed against one another.

3.9 Knowledge Mobilization

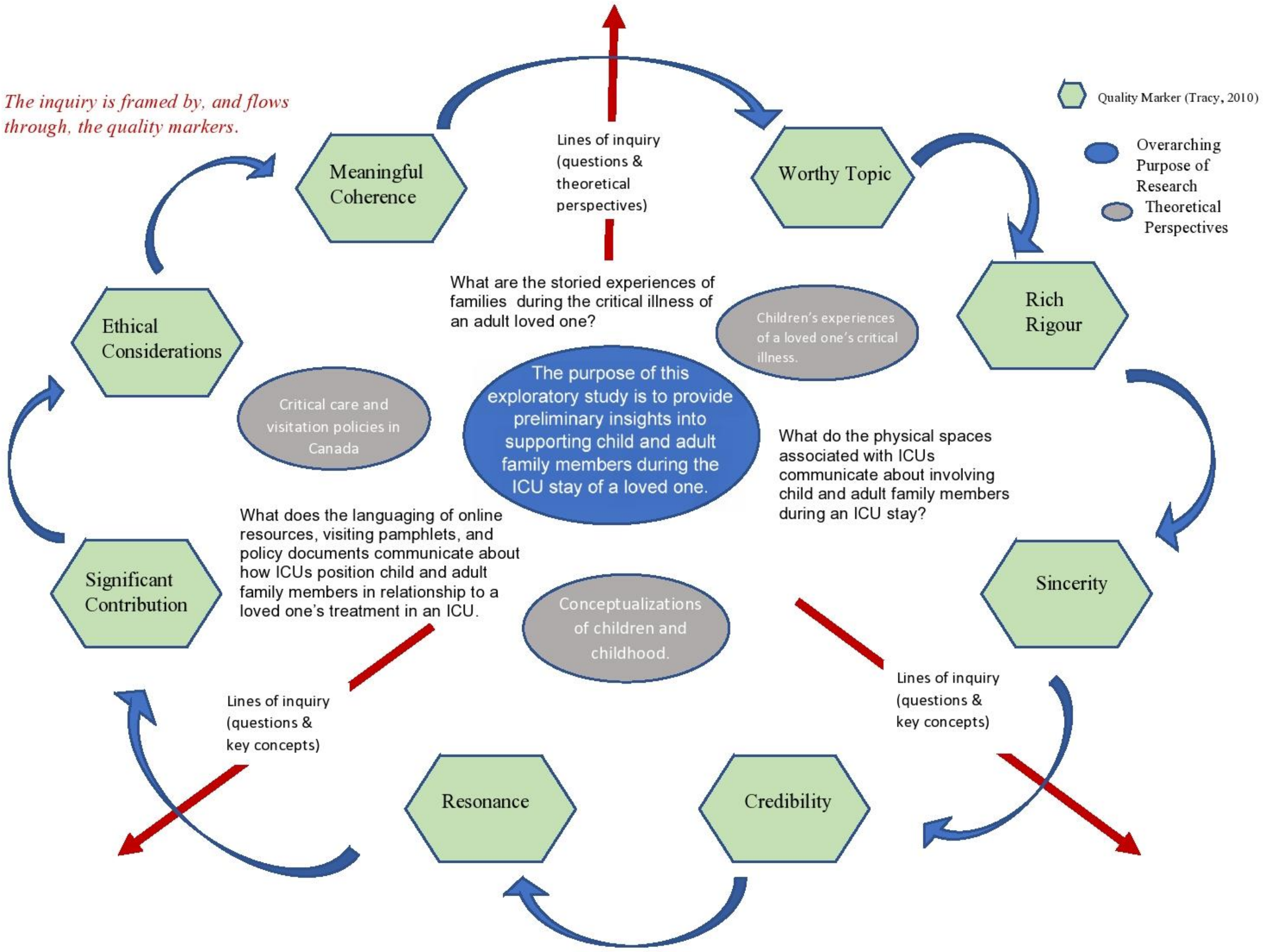
Narratives make it possible to view the familiar from a different perspective (Bresler, 2006; Dodge et al., 2005; Lapum et al., 2012; Orsini & Scala, 2006). In a push towards a more humanistic approach to healthcare, Rose et al. (2015) argue that stories are more compelling than statistics, particularly in research that seeks to capture human experience. According to Bartel (2015), the creation of policy must be based on the ability to “insert ourselves into the lives and consciousness of others” (p. 118). This approach was evident in “The 7,024th Patient” project in which a narrative approach was used to provide insights into the human experience of heart surgery (Lapum et al., 2012). As healthcare providers in the ICU, Lapum et al. (2012) suggest that “what is unfamiliar and traumatic to patients is intimately familiar and normal to them” (Lapum et al., 2012, p. 102). Viewed as a way to disrupt the clinical perspective, stories, poetry, and photographs were employed to initiate change so that “the 7,024th patient no longer feels like the 7,024 patient” (Lapum et al., 2012, p. 102).

In addition to the connection between story-based research and policy, Mosher et al. (2014) suggest that research is more likely to be acted on if there is readiness for change and the findings are actively sought. Before writing the research proposal, I talked to both an ICU nurse educator and manager within Island Health. The ICU nurse educator stated that she believed the research to be “timely” given the growing number of questions she receives from staff about supporting visiting child family members in the ICU (personal communication, July 2019). Similarly, the ICU manager stated that the research was relevant to discussions around revising their visitor’s pamphlet and informing ICU staff training and orientation (personal communication, October 2019).

3.10 Truthfulness and Credibility

I framed the research with a consideration of Tracy’s (2010) quality markers of qualitative research as illustrated in Figure 4 below. Having established the topic as worthy of inquiry, the research design was attentive to rigour, sincerity, credibility, resonance, and ethical considerations.

Figure 4: Framing the Research with Tracy's (2010) Quality Markers



3.11 Chapter Summary

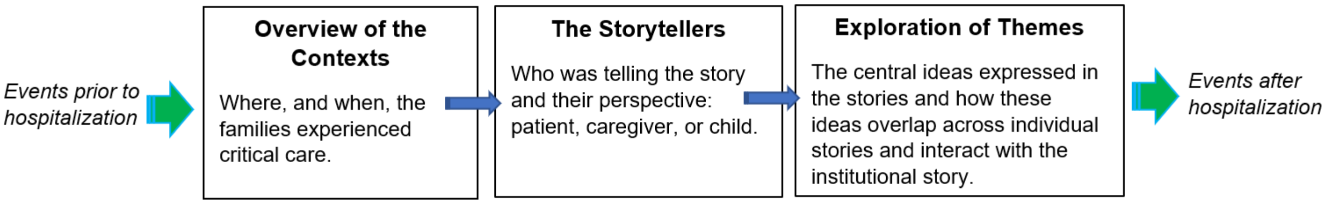
In this chapter, I outlined the design and implementation of the study. I explained that the study is framed as a qualitative interpretivist study that draws on narrative approaches. Grounded in social constructionism, I described narrative approaches as a way to gain insights into storytellers' experiences and the taken-for-granted understandings that shape them. I discussed how the COVID-19 pandemic influenced amendments to the study as well as being an illness narrative running in the background. I described the process of both data collection and analysis, which included a discussion of how I came to write the poetic elements included in chapter 4. In this chapter, I also discussed ethical considerations, my social location, connection to the research, and potential limitations to the study.

Chapter Four: The Findings

Through interviews, I gathered seven stories and analyzed them for insights into how families experienced the hospitalization of a critically ill adult family member. The insights discussed in this chapter came from viewing the stories alongside one another, as well as considering them within the institutional narrative of visiting critical care contexts. The chapter begins with an overview of the contexts in which the families experienced critical care, identifying where and when the stories took place and names any significant sociocultural factors. Next, the discussion moves onto the storytellers and considers who was telling the story and how their perspective might have shaped the story told. After contextualizing the stories, I move onto an exploration of the central themes expressed in the stories and how these intersect with the institutional narrative of healthcare in BC. Furthermore, I include events leading up to hospitalization and after coming home as essential elements of their story.

I have chosen to incorporate elements of free and found poetry into the discussion of the findings. Informed by Lahman et al. (2011), who experimented with using poetry in their representations of the experiences of graduate students, I began to think of the free and found verse as more than a mechanism for data analysis. Although I do not consider myself a poet, I chose to include what I think of as *poetic elements* in the retelling of the stories to draw readers into the emotional depth of people's experiences. Lapum et al. (2012) included poetic excerpts in the dissemination of their research arguing that it provided a way to "disrupt practitioners' ways of thinking and being in clinical environments" (p.103). Tracy (2010) argues that research that affects or resonates encourages its readers to "feel, think, interpret, react, or change" (p.845) and increases the validity of the research. The figure below summarizes the organization of the findings.

Figure 5: Outline of the Discussion of the Findings

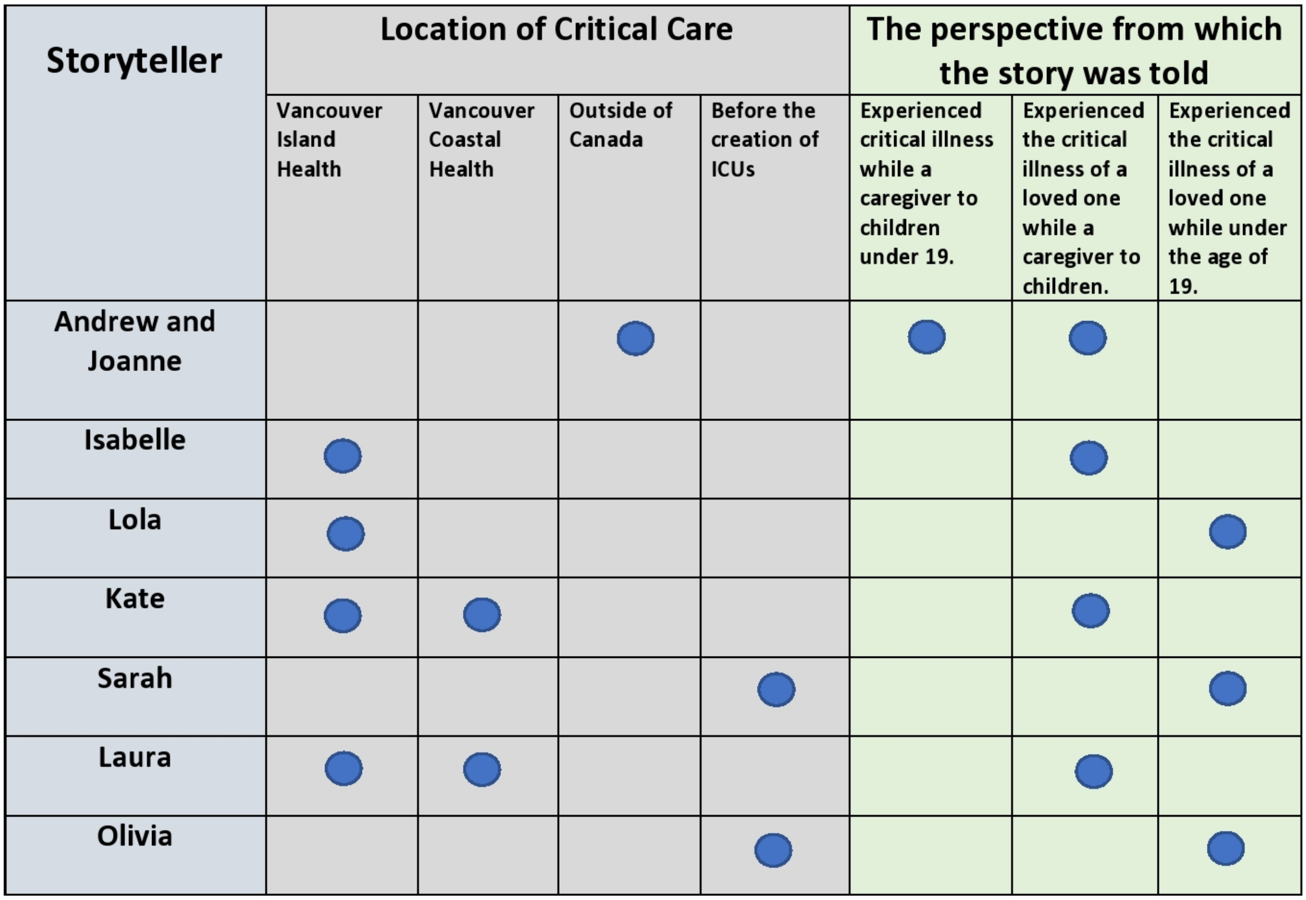


4.1 Overview of the Contexts

The storytellers in this study now live on Vancouver Island or the Lower Mainland of BC; however, their illness stories took place in a variety of contexts. Table 1 summarizes where their stories took place and the perspective from which the story was told. It is significant to note that some specialized care is not available on Vancouver Island, which can necessitate travel to Vancouver. When travel is necessary, the family must deal with several added stressors such as finding accommodation or handling an ICU stay away from home and the support of extended family and friends.

One story took place in an ICU outside of Canada as the family were living in Japan at the time of illness. Two stories pre-date the creation of ICUs and took place during the 1950/60s in a healthcare system that tended to prioritize the physical needs of patients rather than their social and emotional needs. During this era, hospitals typically had restrictive visitation policies. Adults could visit family members, but only during limited prescribed times. Usually, hospitals did not allow children to enter unless in need of treatment.

Table 1: Time and Place of Critical Illness



Storyteller	Location of Critical Care				The perspective from which the story was told		
	Vancouver Island Health	Vancouver Coastal Health	Outside of Canada	Before the creation of ICUs	Experienced critical illness while a caregiver to children under 19.	Experienced the critical illness of a loved one while a caregiver to children.	Experienced the critical illness of a loved one while under the age of 19.
Andrew and Joanne			●		●	●	
Isabelle	●					●	
Lola	●						●
Kate	●	●				●	
Sarah				●			●
Laura	●	●				●	
Olivia				●			●

4.2 The Storytellers

A diverse group of eight individuals told their stories of lived experience of critical illness, seven as visitors and one as a patient. I gathered a total of seven stories as two of the storytellers were from the same family and chose to tell their story together. The storytellers ranged in age from 20 to 70 years old, and their stories date from 1956 to 2019. All the storytellers are now residents of BC, two of the families were biracial,[14] and one caregiver was born and raised in Japan. There were no Indigenous

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[14] Adults of mixed European and Japanese ancestry.

families in this study. To protect the privacy of the families, I have used pseudonyms throughout, and have removed identifying information.[15]

Joanne and Andrew told their story of critical illness together. In 2014, Andrew became ill and spent two weeks in a coma. Joanne talked about what this experience was like for her[16] and their then 4-year-old daughter. ***Isabelle's*** husband became ill in the spring of 2019, which led to extensive surgery and an ICU stay. At the time, their children were 14 and 16 years old. ***Laura's*** husband became ill in 2019 and required treatment in a level one trauma centre away from their home on Vancouver Island. Laura spent several months at the hospital with her 12-month-old,10-year-old, and 19-year-old. ***Kate*** shared multiple stories of the ICU stays of her husband and her daughter in Island Health and Vancouver Coastal Health, dating from 2007-2019. ***Lola,*** now 20, shared her experiences during her mother's critical illness when she was 11 years old. ***Sarah,*** now in her seventies, was nine when she experienced what she remembered as the year-long hospitalization of her mother. Sarah used her childhood diary in the re-telling of her story. ***Olivia*** experienced the loss of her 17-year-old brother in 1956 when she was seven years old. Olivia shared how not being able to see her brother at the hospital, have an opportunity to say goodbye, or to grieve with her family affected her for over 40 years.

4.3 Exploration of the Themes

Table 2: Summary of the Themes and Key Findings

	Theme	**Description of Theme**	**Finding**
The Beginning	*'I called 911'*	The memoried experiences of child family members leading up to hospitalization	Recognition that children are often present when illness or injury occurs may inform how they are involved during the ICU stay.

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[15] Since communities within the Island Health region are small, I have chosen not to include the names of cities or hospitals in the accounts.

[16] Gender pronouns are based on the preferences expressed by the storytellers.

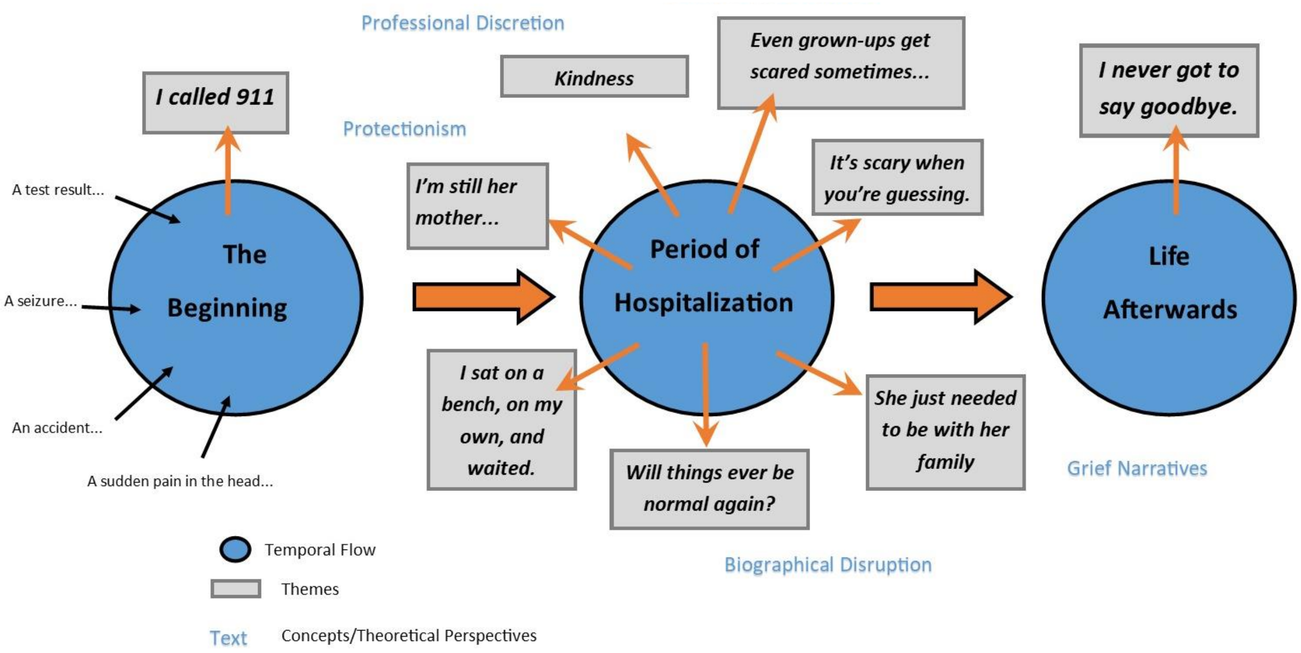
The Period of hospitalization	*‘I sat on a bench and waited’*	The specific nature of waiting when a loved one is critically ill	Children may enter a particular type of waiting when a loved one is in critical condition and they may need to gather at the hospital with adult family members.
	‘Will things ever be normal?’	The potential impact of critical illness on the everyday lives of child and adult family members.	When a loved one is critically ill, children may not be able to continue with their everyday activities.
	‘She needed to be with family’	Child and adult family members may need to gather and be close to the sick family member	Children may need to gather with family both for their comfort and reassurance and as a way of expressing comfort and strength to the sick family member.
	‘I’m her mother’	The role of caregivers as decision-makers for children.	BC Policy positions adults as initiators of children visiting in the ICU but provides little in the way of resources or guidance to help them with this role. Therefore, caregivers have to rely on ‘adult discretionary power’ when navigating an ICU stay with children.
	‘Kindness’	The interactions of child and adult family members with ICU staff	Kindness can play a significant role in helping families cope during the ICU stay. Furthermore, children’s access to the ICU is often based on the professional discretion of nurses who may have neither training nor policy to guide them.

	'Even adults get scared sometimes'	A comparison of PICU and ICU policies and practices.	Critical illness can blur the adult/child distinction and render adults as vulnerable and in need of protection, while children emerge as capable and competent.
	'It's scary when you're guessing'	The need to be informed from the child and adult perspective.	Timely, transparent, and understandable information may support children during the ICU stay. Caregivers may benefit from resources to help them answer children's questions and navigate critical illness with children.
Life Afterwards	*'I never got to say goodbye'*	The potential long-term impacts of experiences during the critical illness of a loved one	Involving children during the period of hospitalization can help children make sense of the illness event and incorporate it into their life narrative.

Note: Although presented linearly, the themes are understood as being intricately related to one another.

The themes use phrases drawn directly from the "glowing parts" of the transcripts (MacLure, 2013), a process discussed more thoroughly in chapter three. I understand the themes as complex, overlapping, and interrelated and their ordering is reflective of the temporal flow of events in the stories. Broadly speaking, the stories were thought of as having a beginning, middle, and end. While comparing the stories, I considered experiences leading up to arrival at the hospital, during hospitalization, and family life afterwards. However, as Riessman (2015) stresses "illness narratives are seldom linear" (p.1057). Storytellers interspersed experiences during hospitalization with details about the onset of illness, or reflections on family life afterwards. Figure 6 represents the relationship between the flow of events and the themes discussed in this study. The purpose of this study is to provide insights into supporting visiting child and adult family members during the ICU stay, therefore the themes focus primarily on the period of hospitalization.

Figure 6: The Experiences of Child and Adult Family Members



'I Called 911'

peace drops to the floor
fear and turmoil fill the air
911 called

> *11-year-old Lola woke in the middle of the night to discover that her mother was having a seizure. Since nobody else was home, the responsibility to get help fell to Lola. Lola called for an ambulance and ran outside to wait.*

This theme explores the experiences of child and adult family members leading up to the period of hospitalization. Lola began her story by saying, "I was 11 years old when my mom entered the hospital." Throughout, Lola reflected on her experiences as a child compared with her present-day perspective as a "20-year-old more frontally developed individual." Lola described waking up as "the traumatic part for me" and went on to say, "I was so alone and so afraid…and I was on the phone." Initially, I thought that Lola ran outside to help the paramedics find them, but Lola said, "I ran outside because my mom…I think she was trying to be consoling…trying to be motherly…but...I felt like I couldn't be… I remember running outside so I could be there, but away…"

The words, "be there, but away," conjured up the picture of a child trying to care for her parent despite feeling shocked and afraid. Juxtaposed to this image is a mother wanting to provide comfort to her daughter despite the medical emergency she was experiencing. In this scene, I saw the ability of critical illness to turn upside down what might more typically be perceived to be the role of the child and the parent. In the face of illness, Lola found herself in a position that she described as feeling unfamiliar, uncertain, and uncomfortable. I was interested to see what the other stories might contribute to how we understand the experiences of children during the onset of critical illness.

None of the other stories included accounts of children having to call 911. Nevertheless, children were often there when illness arrived and experienced worry, fear, and uncertainty alongside their adult family members. Another of the storytellers—Sarah—described the ambulance picking up her mother: “I remember the ambulance…I remember being scared. You know…people wearing suits coming in and…Mom was in such pain. And of course, you're watching the pain…it was a scary thing.” Sarah went onto explain that she did not know who "the people wearing suits" were or where they were taking her mother. Sarah was not familiar with hospitals, or ambulances and the lack of familiarity added to her concern. Similarly, Joanne and Andrew described the sudden onset of pain, which eventually became so bad that they called for an ambulance. Their 4-year-old watched her father as the pain worsened. While the paramedics were taking her husband away, Joanne recalled her daughter screaming "I'm scared! I'm scared."

The theme ***‘I called 911’*** highlights that at the onset of illness or injury, children are often present. Regardless of their age, they may feel the same mix of confusion, shock, and worry that adults experience. Recognition that children are already involved might inform how we involve them during the period of hospitalization. Lola’s story also illustrates that critical illness can blur the distinction between what it means to be an adult and what it means to be a child.

‘I Sat on a Bench, on My Own, and Waited’

a solitary bench
an empty hallway
she sat alone

w-a-i-t-i-n-g

*A **LONG** time*

fear sat down beside her

Waiting was a common and reoccurring theme in the stories. This theme explores the particularity of waiting when a family member is critically ill. Both child and adult family members expressed a need to gather at the hospital and wait. The discussion begins with an examination of ICUs as closed units and moves into a discussion of waiting areas.

‘You Have to Buzz to Get in.’ Joanne and Andrew’s storytelling took the form of a conversation between the two of them. After Andrew explained events leading up to the decision to call an ambulance, Joanne took over the storytelling, "…they took you to the emergency room. And…I couldn't go in. I didn't see you for a *long* time. I waited." The word *long* hung in the air as the three of us shared in the intensity of that moment. Children are not immune to the stress and anxiety associated with waiting. Lola described a vivid memory of sitting in “the large, dark room waiting” as her mother underwent emergency surgery. Similarly, Sarah recalled what she remembered as a year-long wait for her mother to return home. Like adult family members, children wait outside the closed doors of critical care.

In many parts of the hospital you can “come and go freely," said Isabelle, but with the ICU "you have to buzz to get in." Kate also mentioned her experiences of getting into the ICU:

> I walked over and was all the way through the hospital to the place where he was and the little doorbell you had to ring… someone would answer, and I would tell them I was here to visit my husband, and they would check and say, "Can you come back in half an hour?" And, so I'd go and come back, and they'd say, "No, not yet. Can you come back later?" And, I’d have to keep going and coming back and trying again. Not knowing when I was going to be let in and when was a good time.

I was struck by the fact that children are not authorized to ring the buzzer and ask to come in. As evident in an ICU Family Visiting Pamphlet (Island Health, n.d., see Appendix E) children are reliant on parents to initiate visiting.

‘The Sad Room.’

hours meld together
in the room filled with sadness
that knows only night

When I asked what might have helped during the ICU stay, Laura mentioned improving the waiting room:

> It was a very mentally draining atmosphere. It was very hot and very suffocating, and really sad. It was an empty room, meant only for sitting. I guess that you can’t take the sad factor out of it but making it a bit more comfortable…

Laura expressed struggling with the fact that the ICU waiting room closed at 11 pm, which she felt added to the stress of a loved one’s critical illness. Laura felt that being asked to leave the hospital, knowing that your family member may not survive the night, can make a very difficult situation unbearable. Added to closing the waiting room at 11 pm, the physicality of waiting areas was not felt to support families during the extensive waiting often associated with a critical illness.

Laura and Kate shared that the lighting, ventilation, and furnishings of waiting areas were not ideal for long hours of waiting. Waiting areas were often described as windowless, and both Laura and Kate felt that the inability to know whether it was night or day added to the disorientating nature of an ICU stay. While adding windows might not always be feasible, Laura suggested that being able to dim the lights at nighttime would have helped. Laura felt that being in the waiting room with children heightened all these factors. There was nothing “kid-centric,” and although Laura did not feel that the waiting room was a good environment to bring children into, she did not feel that she had any other option. Like Laura, Kate also had extensive experience with waiting areas and mentioned that distractions would be welcome, perhaps television or some magazines. Also, the ability to make a drink or a fridge to store some food would be beneficial. Kate noted that pediatric waiting areas are full of things to do and felt that replicating this atmosphere in adult ICU waiting rooms would benefit both adults and children. Lastly, Laura expressed that she did not feel safe and would have liked “a more secure waiting area…it would have made a difference. I know that the burn unit has a waiting area that you have to be buzzed into…like you couldn’t just walk in there.”

The theme **‘I sat on a bench and waited’** highlights that during critical illness, both child and adult family members may feel unable to do anything other than wait at the hospital (Health Experiences Research Group, 2006). The physicality of waiting areas, and the policies and practices associated with them, were not found to align with the need to be close to their sick loved one. Furthermore, descriptions of waiting areas did not suggest that the presence of children is anticipated.

‘Will Things Ever Be Normal Again?’

memories drift by
out
of
reach

waiting

alone

afraid

This theme explores how critical illness can impact the ordinary, everyday lives of families. As evident in Andrew’s story, an ICU patient is often put into a medically induced coma. When they regain consciousness, they must make sense of a period of life for which they have no memory. However, the stories in this study indicate that it is not only the patient who experiences the disruptive impact of critical illness.

the call came
before the food arrived
his face ashen

The patient’s child and adult family members may also experience the disruptive impact of an ICU stay. The intensity of disruption felt by child and adult family members was seen to ebb and flow alongside the trajectory of their loved one’s medical condition. When a patient appeared to be more stable, family members expressed going home to sleep or getting something to eat. Sadly, these everyday activities were often abruptly interrupted by critical illness. Lola shared her experience,

> … my dad took me to White Spot so that he could take me for a meal and …I think before the food even came, they gave us a call, and they told my dad something like "We’re rushing her to surgery.” My dad …he just took whatever change he had in his pocket and threw it on the table, and we left. We were driving so fast to get to the hospital that he drove on the wrong side of the road. Like…he was so scared… We finally got to the ICU, and the doctor looked at me and said, “Tell your mother goodbye and tell her that you love her.” And I didn’t know what that meant, I was 11, right? …And then…they sent us away to a room to wait while she had this emergency surgery.”

Lola talked about how she and her father “just stayed in that room” until her mother was out of surgery and she seemed stable enough that they could go home and sleep. Like Lola, Laura and her children suspended normal life during her husband’s ICU stay. They spent 12-18 hours a day, for 42 days, sitting in the ICU waiting room. Often ICU staff told Laura to “prepare herself” since they did not expect her husband to survive. It was not until his condition stabilized that Laura felt she could be anywhere other than at the hospital. Initially, Laura tried to protect her 10-year-old daughter from the disruptive impact of critical illness, “…our younger daughter...it was just really bad timing. It was her last year of elementary school and she was new to the school …so…we thought…okay, it would be better for her to stay home with family and friends.” It became evident that her daughter was not doing well, and that no matter how hard family, friends, teachers, and school counsellors tried, her daughter could not go on with her normal life while her father was in the ICU.

> The people she was with are our very dear friends and family. But…for her…it made her really anxious. She was throwing up at night and…crying…she couldn't sleep. It was just…like even going to school was really hard on her … and…she couldn't resume normal life. …it started with 3-day weekends, then 4-day weekends, and …it just got to the point where she tolerated being at the hospital a lot more than she tolerated being at home. She ended up coming and staying with us.

Even though Laura would have preferred that her daughter continued with school and her normal activities, Laura realized that her daughter's life was as disrupted by critical illness as her own. The disruptive influence of illness was also reflected in Sarah's story:

> It is a piece of my childhood that I remember. I couldn't tell you for one iota about what I learned that year in school or anything else, but I can tell you that I missed my mom. I remember it was an upsetting time for me because she wasn't there. And she left crying. She left in pain. It was adult stuff that I didn't understand. I think you just…you just cry yourself to sleep because you don't know what to think. Yeah. [Pause].

Family and friends may provide childcare or meals; however, as Sarah described, life simply does not feel normal, "…going to someone else's house for breakfast and they eat differently than you're used to. It's not your family sitting around the table. I remember being quiet and not saying anything because I felt strange." Indicative of how deeply her mother's illness impacted her, Sarah had always remembered her mother as being away for a year. It was not until Sarah was preparing to share her story in this study that she went looking for her childhood diary. Sarah was surprised to discover that her mother was in the hospital for just under two months. It was also fascinating to note that both Sarah and her father felt the need to write a diary during the period of hospitalization, but both stopped writing on the day their mother/wife came home.

Sarah's diary was full of the longing of a 9-year-old asking, **'*will things ever be normal again*.'** This theme draws on the concept of biographical disruption outlined in chapter two (Bury, 1982) and highlights how critical illness can significantly disrupt the normal, everyday lives of ICU patients and their family members. Understanding the potentially disruptive nature of critical illness might inform the supports provided to families during an ICU stay, as well as after the family have returned home. The next theme considers a family's need to be together during the ICU stay.

'She Needed to be with her Family'

A strong theme, seen in all seven stories, was the need for family members to be together when a loved one is critically ill but noted that 'together' can look different from one family to another. Gathering appears to serve two purposes: it reflects a belief that having loved ones close-by supports the healing and recovery of the patient, and it provides comfort and reassurance to both child and adult family members as they cope with the ICU stay. This section discusses each purpose in turn.

"Sorry, children are not allowed in the ICU," the nurse pronounced.

later
the quiet of nighttime
"Come," said the nurse, "Just this once."
gratitude flooded Joanne

Joanne told her daughter that they must help Daddy to find his "try-hard feelings."

The phrase "try-hard feelings" was Joanne's translation of the Japanese expression "Ganbatte." The expression was used by the Japanese as a way to survive internment camps during the second world war and means to endure or persevere (Balanger, 2018). Joanne and Andrew explained that they believed that both child and adult family members must come together in times of adversity to form a collective strength. I understood finding "his try-hard feelings" to be about family pulling together physically, emotionally, and spiritually to overcome critical illness. At a time when the patient may not feel that they have the strength to keep going, family members gather around the bedside to offer strength and support.

Similarly, Lola expressed believing that being close to your sick loved one is important for their healing. Even though Lola described seeing her mother in the ICU as "shocking and traumatic" she was emphatic about the importance of being there for her mother:

> Yeah, no definitely…it was traumatic to see her in that situation but if I had the choice now …I still would choose to see my mom versus not see her…if I didn't go into the ICU …I would have felt like…I would have had a different memory. And the memory would have been of my mom being alone. You know…that I wasn't there…I would have had the memory of her being there alone, instead of me being there for her.

The phrase "of me being there for her" once again reminded me that critical illness can reshape adult/child roles and responsibilities. Lola went onto explain that she believed being with her mother in the ICU was an essential part of her mother's recovery,

> You know it definitely helps with the recovery process…like, of the patient themselves. Just having that…and I am a little bit of a yogi; I'm into the positive aura and stuff like that …but if you have the positivity of having your family there…coming to see you when you have tubes

> down your throat and your fingers are swollen up like sausages…the comfort of having your family come and say hello. I can't think of anything worse than not having that.

As an 11-year-old, Lola felt that part of her family role was to be there for her mother. Furthermore, in describing herself as "a little bit of a yogi," I was aware that Lola was speaking of an understanding of health that is beyond the intellectual. Lola's mother was not conscious during these early visits; nevertheless, Lola felt that her mother would be aware that her family were surrounding her and that this would have a healing impact. In addition to supporting the patient, visiting the sick loved one or gathering in the waiting room appeared to provide comfort and reassurance to family members.

The idea that adult family members may need to visit a loved one, particularly after a significant surgery or medical procedure, seems to be widely accepted. Even though asked to keep their visits short, Kate, Isabelle, and Joanne all talked about being invited into the ICU. Afterwards, Isabelle noted that "I knew he was in care." Similarly, Kate expressed, "[visiting] was reassuring because I knew that someone was watching every minute…24/7—all the time." It seems that children may also experience comfort from seeing the care and attention that their loved one is receiving. After taking her 4-year-old in to see her father, Joanne noted that "she didn't seem so scared after seeing him. Because…she was there when the ambulance came to pick Andrew up, and she knew something was wrong. She was crying, and she was saying, 'I'm scared!' 'I'm scared!'"

Although her daughter did not articulate how she felt after visiting, the relative peace and calm she exhibited after seeing "her daddy sleeping" implies that knowing where he was and that he was being looked after seems to have provided some comfort. Similarly, Sarah talked about hearing adults talk about the hospital but not understanding what that meant. Having never been to a hospital, Sarah thought that it must be "a bad place because [she] wasn't allowed to go there." Visiting allowed Sarah to make sense of where her mother was and she "felt comforted that there were really nice people there."

It is significant to note that not all children will want to be at the bedside. Isabelle asked her children if they wanted to visit their father while he was in critical care, but

> …they both declined …actually my younger son just told me that he did not want to see his dad hooked up to all the machines …he was still really out of it, and he wasn't responding. And …I don't think they wanted to see him in those conditions.

Even though Isabelle's children did not wish to visit, their story suggests that coming together was still a significant part of coping with the illness experience. Throughout their father's hospitalization, Isabelle and her sons met with a close family friend with experience of critical care. The friend was able to talk Isabelle and her children through each stage of their father's treatment. Isabelle felt that being so well informed may have been the reason her sons did not feel the need to visit in the ICU. Isabelle's story suggests that not all children need or want to be at the bedside, but some form of involvement during an ICU stay may be supportive. Also, although Isabelle's children did not visit their father in critical care, once he was moved to another floor and no longer attached to all the machines, they were keen to visit. Changes in a child's need to visit were also evident in Lola and Kate's stories. This highlights that a child's need to visit may vary across the course of an ICU stay and suggests a need to regularly check-in with children to see what they need.

Laura's story also supports the understanding that involving children in the family experience of illness is important. Although Laura's daughter did not go into the ICU, her stress level appeared to be significantly lower once she joined her mother and siblings at the hospital. Similarly, Joanne's daughter only went into the ICU once. Still, she went with her mother and grandmother to the hospital each day and waited outside the ICU while they took turns going into the ICU to visit. One day, Joanne decided to go to the hospital alone, and her daughter became upset. Her sudden, and out-of-character, outburst suggests that even though she did not see her father, going to the hospital each day might have been meeting some emotional need. This finding suggests that waiting areas need to reflect the understanding that some children might need to be at the hospital. Additionally, consideration of how children are going to be cared for when they are at the hospital is necessary.

The theme **'*she needed to be with family*'** highlights the significance of being together during critical illness. Although limited, research conducted in Britain and Sweden supports the understanding that allowing children to visit a critically ill adult family member can be beneficial (Kean, 2010; Knutsson

& Bergbom, 2016). Furthermore, there is evidence that unconscious patients may feel comforted and strengthened by the presence of family members (Danielis et al., 2020; Nelson et al., 2010). The following theme explores how critical care contexts in BC construct the role of caregivers in shaping children's experiences during the ICU stay of a loved one.

'I'm her Mother and I Know What She Can Handle'

A review of visiting pamphlets, websites, and online resources in BC for this study revealed that there is little information about children visiting in the ICU. One statement occurs frequently: "parents wishing children to visit should discuss this with the patient's nurse." This statement positions caregivers as deciding whether a child should visit in the ICU and highlights the discretionary power of both caregivers and healthcare providers in determining how a child experiences the critical illness of a loved one. In this theme, I explore the resources available to help caregivers as they navigate the ICU stay with children as well as identifying other factors that may influence parental decision-making.

None of the storytellers spoke of receiving support in navigating critical illness with children. Although Kate and Laura both mentioned receiving support from a social worker, the help seemed to come late in the ICU stay, and the focus was on practicalities such as accommodation, meals, and parking. Laura talked about an ICU information packet but told me that it included nothing regarding children. Since resources did not seem to be available, the parents appear to have relied on the guidance of intuitive understandings of what was best for their children.

Laura's story was interesting because she was navigating a prolonged ICU stay away from home with a 12-month-old, a 10-year-old, and a 19-year-old. Age seems to have played a role in helping Laura determine what she felt was best for each of her children:

> My [10-year-old] didn't actually see her dad at all…he was on way too many machines, and it would have been difficult for her to see him like that. Like…with the baby…I'm just hoping that he was too young and I had him in his baby carrier … he was strapped to my chest and in there… and with my eldest…I just tried to time her visits with when he was stable enough for her to go in and sit with him.

In addition to age, Laura's position as a parent also played a part in decision making. Even though her eldest daughter was technically an adult, Laura felt responsible for protecting her. Laura said, "she might be an adult, but I'm still her mother, and I know what she is capable of and what she can handle." Laura described how she came to determine when it might be okay for her eldest daughter to visit,

> …when my husband's heart was stopping frequently—I would wait until the nurses would give him what they called a bolus dose of the medication …they would inject him with the medication just to calm him down …so I would often be in there when they did that, and so I knew that his heart was not going to stop for at least half-an-hour/ forty-five minutes. So, then I would call my daughter in and say, "okay… you can sit with him for a while." When the medication kicked in, she could stay with him for a while and then I'd call her out when I knew it was kind of wearing off so that she wouldn't have to see that part of it.

I asked if ICU staff helped Laura make these decisions, but she expressed that their job was to prioritize saving her husband's life. When her husband's condition stabilized, Laura revisited her decision around visiting in the ICU:

> Once my husband was no longer critical, and he was stable …I had to start bringing both of the kids in with me because we were the only people there …and, so he was just sitting there all day by himself. And, he couldn't talk, he couldn't eat, he couldn't move, and so…he needed us there. My daughter wasn't quite comfortable because her dad couldn't talk yet but…but we had to push her to come in …I had to make that judgement call …her dad wasn't out of the woods, but he wasn't connected to tons of tubes and wires – he had a simple tracheostomy and an IV pull so…she had to come in now and watch movies.

At each stage of her husband's hospitalization, Laura decided what she felt was appropriate for her children to experience. Decisions about visiting seem to have been based on the child's age, her awareness of each child's emotional make-up, and her parental desire to protect them from being exposed to more than she felt right for each child.

Prior experience of sickness was also seen to influence parental decision-making. Isabelle and her husband felt that it was important not to "water the situation down," a position Isabelle felt was in part informed by her husband's experience of losing his father at the age of 17*.* Isabelle's husband was not aware of how gravely ill his father was and felt that this made it difficult to process his subsequent death. Therefore, as parents, they chose to provide their children with honest updates, even if these were not always easy to hear.

Sometimes caregivers seemed to weigh up a few options and choose the one that appeared to be the least detrimental. Kate described deciding that she felt it would be less frightening to allow her 5-year-old to visit than telling her that she could not see her father:

> I told her all about what to expect. You'll probably see lots of tubes and lots of bandages and …urr…doctors are taking care of him, all that kind of stuff. I don't remember much about how she reacted. I think she was just like "okay." I don't think it scared her. I don't think she went straight up to him; I think it was a little weird… but then … then it was okay. I think it would have been weird for me to say you can't visit him right now. I think that would have been scarier for her. And…I think knowing what to expect and that it was going to look kind of strange and …that he was going to be okay. I think it was good for her.

The experience did not appear to traumatize Kate's daughter. Still, I wondered how many caregivers would feel confident in their ability to prepare a young child to visit in the ICU, especially amid their own emotional turmoil.

In the theme of ***'I'm her mother and I know what she can handle*'** I have discussed that provincial policy places the responsibility of initiating children visiting in the ICU on parents. Despite this responsibility, BC appears to offer few resources to guide and support caregivers as they navigate an ICU stay with children. In the absence of resources, decisions about how a child might be involved during an ICU stay are left to parental and nursing discretion. While not wanting to remove all decision making from caregivers, this theme suggests that the availability of materials to guide caregivers might be beneficial. An example of what these resources might look like was found on Sunnybrook's website (Sunnybrook Health Sciences Centre, 2020). Moreover, in the PICU, visiting pamphlets state: "If your child's brothers or sisters wish to visit…" This wording invites children into the conversations about whether visiting might be something that would help them cope with the illness of a loved one. Additionally, in BC, if a parent wishes to have their child visit, they are asked to discuss this with the patient's nurse. The following theme explores the role of nurses' discretionary power in shaping children's experiences in the ICU.

'Kindness'

Interactions between healthcare providers and families were prominent in the gathered stories. In this theme, I focus on the professional discretion of healthcare providers as both opening and closing opportunities for families to be together. I also consider the impact of positive and negative interactions with ICU staff.

I got a treat for my birthday
A kind nurse with a nice smile
let me see my mom

Sarah's story, dating back to 1961, reveals that healthcare providers have long held discretionary power over visitation policies. Despite a policy that did not allow children into the hospital, a nurse made it possible for Sarah to see her mother:

> My birthday was in the middle…it was the end of January. And, I was turning 10. And my dad was able to get permission from the head nurse in the evening to bring me in as a birthday gift, as a birthday treat, and I wrote that down in my diary, "*I got a special treat today…I got to go see Mommy!"*
>
> I remember we couldn't go through the front door…we had to come in through the back door. [The nurse] met my dad and me in the hospital, and I was told to keep really quiet because I wasn't supposed to be up there. I remember everything being big, huge hallways, and …well I wasn't very big… and I remember holding my dad's hand…but this nice lady was there, and she was in charge. I remember her being very kind, letting me go and see my mom.

Professional discretion was also apparent in Joanne's story, which took place in 2014 in an ICU in Japan. When Joanne asked the ICU nurse if she could bring her daughter into the ICU,

> the nurse said that's not really allowed. But…this time, this time is ok. Just for a little bit. And that was the only time she was allowed to see Andrew. I only asked that first night. That was the only time my daughter was allowed inside the ICU.

In addition to opening the doors of the ICU to children, the stories also held examples of nurses limiting visiting access. In BC, children can visit in the ICU, but healthcare providers are positioned as determining whether a visit is appropriate. Isabelle shared that a nurse "invited me to go in but recommended that the boys not come until he was moved out of critical care…" The nurse did not offer a rationale for this recommendation nor did Isabelle ask for one. When allowed to visit, nurses encouraged parents to keep children's visits short. Since children's visits were brief, the distress noted in the adults' experiences of being asked to leave during shift changes, doctor's rounds, or procedures were not apparent in the gathered stories.

Added to making it possible to see her mother, Sarah noted the significant impact of kindness. Sarah said that the nurse's smile made her feel welcome and communicated "we're here for you." Joanne also spoke about how kindness supported her during the ICU stay,

> the people who worked at ICU…they were so kind. The words they used. The way they explained. They were very kind to sleeping Andrew, taking care of him. I felt very, very thankful to them. I could talk to them about anything. I could ask them anything and the reply would always be kind. That image of them being really, really kind still remains with me. I think that image of their kindness was what helped me the most.

I noted, however, that kindness did not epitomize all interactions with healthcare providers. Joanne recalled "this one nurse" who she felt failed to recognize the emotional vulnerability of family members during an ICU stay. Similarly, Kate talked about the many acts of kindness towards both herself and her family but stated that "there's always that one nurse…like, I don't know…overtired or something?" Despite expressing gratitude to healthcare providers, Lola recalled longing for a "Greys Anatomy Moment," which she described as "someone coming to me and asking me how I was doing and what I was feeling…I think that would have helped me," but Lola went on to say "that's not their job."

Lola, Kate, Isabelle, and Laura all noted the tremendous workload healthcare providers carry. Isabelle described nurses as having "their task list and they're heads down, busy doing it." Storytellers were reluctant to add to the workload of ICU staff because, as Lola said, "you're not the patient." Similarly, Laura did not want to pull nurses attention away from saving her husband's life, which raises questions about the provision of FCC in the context of the ICU. Denying children access to the ICU may be because nurses do not have time to support and care for a visiting child and raises questions about who else might be called upon to support families.

The theme ***'kindness'*** highlights that nurses are often the most visible member of the ICU team (Vance et al., 2010) and play a significant role in shaping the experiences of families. Professional discretion continues to play a notable role in interpreting vague visitation policies. Moreover, healthcare provider workloads may impact the care extended to the patient's children and family. The next theme explores Kate's numerous experiences as a visitor to pediatric and adult critical care contexts.

'Even Adults Get Scared Sometimes'

with her

we could stay
we didn’t have to ring the bell and wait

no need to leave

we could hold her hand
until she drifted asleep

with him

leaving

that was the hardest part
you never knew when you’d be able
to get back in

This theme compares a family’s experience of receiving care in a PICU and an ICU and considers the ability of critical illness to blur the distinction between how we might conceptualize what it means to be a child and what it means to be an adult. Additionally, this theme examines how the different policies and practices in the PICU shape the experiences of patients and their visiting family members.

At the beginning of the interview, Kate seemed a little apprehensive. In response, I asked if she would prefer that I ask more direct questions and so I used the interview guide discussed in chapter three (see appendix D). Initially, Kate opted for some questions, but later she remarked that once she got talking the memories came back to her and the stories flowed. Kate and her family have experienced many hospitalizations. In 2007, Kate’s husband was in an accident that required emergency surgery and several follow-up hospitalizations. A year later, diagnosed with a serious medical condition, Kate’s 6-year-old daughter required surgery and two ICU stays.

During the interview with Kate, the conversation often circled back to the idea that in the PICU “they seem to do so much more to make the experience feel okay for the patient and their family.” Kate spoke about the personalization of care in the PICU and illustrated the point with a story from her daughter’s first surgery.

> …when she came out of surgery her favourite turtle stuffie was right there next to her. [My daughter] had what we called a brain drain, a tube coming out of the top of her head to drain brain fluid so that pressure would be relieved…and her turtle had the same thing…there was this tube stuck to the top of his head, and he was bandaged just like her. So…yeah, that was really cute, the turtle had had surgery too, and one of the nurses had done that for her [laughter]. We still have that…it's in a box. So, you know, stuff like that…they always do things to help them feel okay.

Kate mentioned nurses taking care of her, bringing blankets, and making her as comfortable as possible. Although Kate said that she had experienced some fantastic doctors and nurses in the ICU, ones who "sit down and have all the time in the world to talk to you and find out what you need," the level of care seemed less personalized than that she experienced in the PICU.

I asked Kate what she had found most challenging about the ICU, and Kate responded, "With him, I would say leaving. It's really hard to leave and just not know what was going on… and to get back in, you had to call to make sure it was a good time." Whereas, in the PICU "we were always allowed to be there…we didn't ever really have to leave." Additionally, Kate and her husband were able to stay with their daughter until she went in for surgery. They could also be in the recovery room with her again as soon as it was over:

> We've always been allowed to go in with her until she's asleep, and then we leave. We've always been brought in… we have like the gown and the things over our shoes. All wrapped up… and then we're allowed to go in as they put her to sleep and then she drifts off with us there… we lay her down, and then we go. But…with adults, they don't allow that.

I noted that the worry and stress associated with waiting were not present to the same extent in Kate's stories of her daughter's PICU stay. Furthermore, Kate mentioned that information was more accessible in the pediatric unit.

> **Emma:** And were you allowed to stay for doctors rounds when [your daughter] was in the ICU?
>
> **Kate:** Yes… they talked to us. They were giving us information about how she was doing. I remember her first surgeon coming around and telling us …I think we were allowed to stay every time.
>
> **Emma:** And, was that helpful?
>
> **Kate:** Yes! Definitely, yes. Yeah…because we always had something we were wondering about. We always had a question or something we were hoping he would tell us about.

In contrast, Kate had to leave her husband during rounds and said that nurses would give her updates "if I asked." Kate was reluctant to ask the nurses questions expressing that "they're very busy and the last thing I want to do is ask the nurse something."

Kate described the PICU as being full of distractions for both patients and visitors. Waiting areas had lots of activities, and children could watch movies during procedures and tests. Kate also mentioned a binder that outlined what children might see and experience during their hospitalization. In contrast, Kate said that there was nothing in the ICU to distract yourself with and that "to have nothing in a situation where you're already stressed, it makes it harder." As Kate pointed out, in critical care units, the sick family member is "often sleeping or out of it," and therefore having something to do would be supportive. Kate went onto to say that distractions become even more essential if you are visiting with a child. Kate described visiting her husband in the ICU with her 5-year-old:

> "I couldn't sit there very long because eventually, she'd get bored. Sitting there on the end of the bed or the chair beside it. Just hanging out and that doesn't go well for too long with a kid. My daughter discovered a couple of things that we had to push her away from. There was this thing that was attached to the ceiling that moved. So, that looked like a really fun thing to ride on but… you start looking around as a kid and all the things on the wall…"

Kate's story indicates that providing activities at the bedside might help to keep children away from all the buttons and pieces of equipment that would not be safe for a child to explore. The issue of safety came up in discussions with the ICU manager and raises questions about the supervision of visiting children.

Despite her familiarity with hospitals, Kate described the ICU stays as "one of the most stressful things I've gone through…people get scared." Overall, Kate felt that there was more support available to them as a family in pediatric critical care. Kate attributed the differences in policy and practice in an ICU to an assumption that "adults are fine with it, that they don't get scared because they're a grown-up," but Kate asserted that "even adults get scared sometimes." Here we find discussion circling back to age and the ability of critical illness to blur the distinction between adult and child. In Lola's story, we saw how critical illness revealed a child's competence to act, while Kate's story emphasizes that adults can feel vulnerable and in need of protection. As Kate and I pondered the things done in the PICU to comfort children and their visiting family members, we wondered what it would be like to replicate them in the world of adult critical care.

The theme **‘even adults get scared sometimes’** examined the differences in policy and practice between ICUs and PICUs. Kate’s descriptions of being able to stay with her daughter and ask questions during doctor’s rounds closely align with family presence policies, which Farmanova et al. (2015) suggest are necessary for FCC. Understanding that adults get scared too suggests that adopting some of the policies and practices of PICUs in ICUs might improve the support of ICU patients, children, and families. The next theme continues to examine the supportive role of information.

‘It’s Scary When You’re Guessing’

Piecing together
the information adults drop
longing to tell someone how my day was

I do my homework
walk the dog
If I’m good, can Mom come home?

In this study, the need to feel informed was equally apparent from both the adult and child perspective. This theme begins by establishing that information is an important aspect of supporting children during an ICU stay. Next, the discussion considers who is going to inform children and how they are going to keep children informed.

Lola expressed the idea that information was comforting,

> it would have been nice if throughout and in-between someone had talked to me. I understand that I was young and that it was a delicate situation, but I would have liked to have been more informed. I would have felt consoled if I was more informed. I guess it’s hard to know how much to inform a child, but for me, …it was all a guessing game, and I think that made it worse. It is scary when you are guessing, and you have no clue what is going on. I’m sure I must have asked my dad or could have asked my dad, but it would have been nice if people told me things without having to ask, you know. I think that would have made me feel better. I think it would have been good for someone to come and tell me, “Your mom had this kind of surgery and…”

Sarah echoed the feeling that providing direct and continual information would have supported her during her mother’s hospitalization:

> I would just pick up what people had dropped in terms of information. Urm…and sometimes that's worse than just asking the questions because you…you just get pieces of information rather than a real conversation. Yeah…I would say, it would have been helpful… but…to have it done ongoing…because…the situation was ongoing…not just about one time.

Both Sarah and Lola indicated that providing regular updates to children is an important part of supporting them during an ICU stay. They both note that if the information is not forthcoming, children may piece together what they do know into something that might be more worrying than an honest explanation about what is happening. Moreover, an ICU stay is an emotionally difficult time and caregivers may struggle to respond to children's questions or may not know the answers. The availability of a support person for a parent to consult with or ask to support them as they talk to their child/ren might be beneficial.

Although Lola was clear about the significance of visiting, I wondered what might have lessened the shock she experienced when she first saw her mother. I asked Lola if anyone prepared her before she visited. Lola replied,

> God no! Not even my dad, you know because when we recall that story, we remember being so shocked. I think the major point was that she was okay, that she was alive…but no, nobody talked to us. Maybe it's because it's not their mom. Maybe they don't notice it that much? As a doctor, I guess you know that she's going to unswell, right. I don't remember anyone telling me, "She going to look different because…" or anything. I went in…and she had the tubes, and she was very swollen.

Amid his turmoil, Lola's dad may not have known how to prepare Lola to see her mother or that she needed to be prepared. While some generic materials could be created to support caregivers and children, such as a video outlining the typical sights and sounds in the ICU, it seems that an additional support person, such as a child life specialist, spiritual health practitioner, or social worker might also be beneficial.

The doctor spoke
"Tell your mom goodbye."
I didn't understand

In many of the stories, I noted the presence of a support person. Isabelle had a friend with experience of critical care supporting both her and her children. Similarly, Joanne talked about how her sister, a nurse, supported her:

> After surgery…my sister and I went to the doctor, and my sister listened to the doctor. She was my cushion between the doctor and the explanation. If she hadn't been there… I wouldn't have understood, and it wouldn't have sunken in. The technicalities of the words with the emotions I was feeling at the time…

If possible, support from a member of the ICU team might be ideal, especially for families who are away from home or lack the support of extended family members or friends. A support person can help by translating information into language that children and family members can understand. Additionally, since the stress of the situation might make it difficult for people to grasp what they are being told, a support person can repeat the information until the details can be retained. Despite difficulty absorbing the information, family members were clear that they did not want healthcare providers to withhold hard truths from them.

Although Laura agreed that regular updates and information were helpful, she stressed that the information must be transparent and honest: "You know there was this one doctor… and… what I appreciated about him was that he was so direct and that he didn't try to sugar coat anything." Laura warns that healthcare providers sometimes try to shield families from harsh realities but that this can make the experience harder:

> There was one doctor … he kind of gave us this false sense of hope. I had asked how long my husband would be on the waitlist if he needed a transplant 'cause you know – you see on TV that people can be on the list for years…and he said, "Oh…don't worry about that…he'll be on the top of the list; he'll be in and out in two weeks…" When we got to the ICU, the doctor said, "No, no, no, no! —I've worked at the ICU for twenty years, and the reality is that now that we've intubated your husband, they will probably not even look at him.

Laura's comment about shielding people from hard truth led me to consider how an adult's desire to protect children may influence the information they provide. Lola, Sarah, and Olivia's stories suggest that in trying to protect children, adults may inadvertently make the experience more challenging.

The theme **'it's scary when you're guessing'** suggests that timely, transparent, and understandable information may support children during the ICU stay of a loved one. Information was also found to support children facing a parent's cancer diagnosis or mental illness (Ellis et al., 2017; Oja et al., 2020). Research suggests that children have an innate awareness of what is happening and that trying to conceal hard truths could make a difficult situation more challenging (Kaplow et al., 2014; Whitty-Rogers et al., 2009). Conversely, providing children with regular updates about their parent's illness can help them to feel supported as an individual as well as acknowledged as part of the family (Gullbrå et al., 2016). The final theme touches on the impact of critical illness beyond the period of hospitalization.

'I Never Got to Say Goodbye'

The storytellers were able to reflect on the impact of critical illness from a variety of viewpoints ranging from one to 60 years since the period of hospitalization. Collectively, the stories reveal that the effects of an ICU stay can stretch beyond the doors of the hospital. This theme explores the potential impact of critical illness and how families integrate any losses associated with an ICU stay into life after the period of hospitalization.

even now
I see myself in that moment
never to be forgotten.

sixty years ago
but remembered like it happened yesterday
shaping all that came afterwards.

seven
standing in the hallway
the phone rings

I take the message
"Tell your mother he has passed."
made no sense to me

colour drained
tears fell
he died alone.

Olivia shared "I had no knowledge that my brother was sick…I did not have any inkling whatsoever that there was anything wrong with him." Unable to support Olivia in her grief, her family sent her away for two weeks following her brother’s death. Finding herself separated from her family and all that was familiar, Olivia felt that “I had done something terribly wrong and was being punished.” For 40 years, Olivia’s struggle remained unresolved. One day, during a role play in a group therapy session, Olivia had an opportunity to return to the hospital room to say goodbye. Of the seven stories gathered, all but Olivia’s had a good outcome, and the sick family member was able to return home. Even so, critical illness can have a lasting impact on families.

I asked Lola if her family talked about her mother’s hospitalization, Lola laughed and responded, “we’re not exactly that sort of family.” Nevertheless, Lola went on to say that periodically someone would mention her mother’s illness,

> …it comes up…mostly in passing. For a while, my dad would say things like, “This time last year Mom was in ICU.” Or, the next year, “This time two years ago, Mom was in ICU” [*imitating dad’s voice*].

Even though Lola’s family did not discuss what they experienced, this story suggests that something of the ICU stay remained with her family for some time after her mother came home. Similarly, Isabelle shared, “I’m not sure that [the children] think much about what they went through a year ago you know, but …I do [pause].” In addition to indicating that thoughts of her husband’s hospitalization remain with her, Isabelle’s pause seemed to carry with it a weight of emotion. Later, Isabelle spoke of having a family event to mark the anniversary of her husband’s hospitalization. A moment to express gratitude for her husband’s recovery and recognition that events could have ended very differently. As Isabelle shared, I contemplated the role that storying events might play in supporting child and adult family members after an ICU stay. The ability to come together, to remember, and to reflect may be a significant element in helping families recover from an ICU stay. In her reflecting forwards and backwards, Isabelle’s story illustrates the temporal nature of story (Clandinin and Connelly, 2000).

Olivia’s account illustrates the use of story in a counselling session to enable her to go back to events that happened when she was seven and find resolution. Story can also reach forwards as shown by Joanne who shared how thoughts of the future intruded into coping with the ICU stay:

> The doctor said I would have to start thinking about how to make the residence barrier-free. That there was no guarantee that Andrew would be able to return to work, or that he would be able to talk properly…or things like that and so these thoughts…the thoughts kept circulated through my mind. While this whole experience was going on…I would go home and notice sort of…get back to the house and think these stairs will need to go…we will need to build a ramp…. Having this constantly on my mind made it more difficult to cope emotionally.

Additionally, Joanne's story acts as a reminder that many patients come home from the hospital with several health challenges (Bäckman et al., 2010; Drumright et al., 2020). Although a family may not be grieving the loss of a loved one, they may be grieving for the way family life used to be. These losses may affect children as much as they do adult family members.

The theme ***'I never got to say goodbye'*** highlights that an ICU stay can have a lasting impact on patients and their family members. How a child is involved during a loved one's illness may affect their ability to integrate events into their life afterwards. Tembo (2017) advocates for post-ICU support groups to help families after coming home from the ICU. In agreement with this proposal, research has shown that the children of parents in cancer care benefit from support groups (Oja et al., 2020).

4.4 Chapter Summary

In many instances, critical illness arrives suddenly, without warning, and children are close by. It may not be possible or beneficial to try to shield children from a family event in which they are already involved. Whether at home, in the waiting room, or at the bedside, children might feel a need to join adult family members in a vigil for their sick loved one. Both caregivers and healthcare providers may benefit from resources to guide them as they support children during the ICU stay. This study suggests that information, proximity, and reassurance may be equally as important for child family members but questions whether nurses can meet this need given their current workloads. The inclusion of a child life specialist as part of the ICU team might be beneficial. Child life specialists generally work in pediatric health care contexts and have undergone extensive training in supporting children and their families during illness (Bruce & McCue, 2018). This study suggests that involving children during hospitalization may reduce the long-term impacts of an ICU stay. However, this study stresses that tailoring involvement to the individual needs of the child and their family is crucial and might require a collaborative approach between the child, their caregiver/s, and a member of the ICU team. The following chapter discusses the implications of these findings in supporting visiting child family members during the ICU stay of an adult family member.

One, two, three… years ago
Mom was in the ICU
No one forgets

Chapter Five: Discussion

In March 2020, surging numbers of COVID-19 cases prompted Canadian hospitals to restrict family members from entering the hospital with their loved ones. Since the beginning of the pandemic nine months ago, people have had to receive life-changing news or endure hospitalizations without the love and support of family members. Although acknowledging the necessity to limit the spread of infection, Sas and Rendely (2020) call attention to the impact of these policies on human dignity and patient recovery. As ICU doctors, Wakam et al. (2020) state that “the fear of dying alone is nearly universal” (p. 88) and wonder if more can be done to give family members a moment together to say goodbye. The recent approval of a COVID-19 vaccine offers hope that the end of the pandemic is in sight, but I wonder what effect our experiences might have on hospital visitation policies in the future. Will we have a greater appreciation of how important visiting is for both the patient and their family members? Will the impact of separating family members during illness change how we think about including child family members during the ICU stay of a loved one?

In chapter four, I discussed seven stories that described families’ experiences during the critical illness of a family member, highlighting the pertinent points of visitation policies and practices in critical care contexts. The purpose of this chapter is to discuss how these findings contribute to existing knowledge and inform preliminary recommendations to support the inclusion of both child and adult family members during the ICU stay of an adult loved one. This chapter is organized into three core areas: (1) critical illness as complicating understandings of ‘family’ in a Canadian context; (2) the concept of protectionism, and (3) systems-level transformation to support the inclusion of child family members in adult ICUs. Following a discussion of the findings, I outline seven preliminary recommendations for improving the support of visiting child and adult family members in the ICU. The implications of this study to child and youth care praxis are also considered. This chapter closes with suggestions for future research, which are integrated into a discussion of the limitations of this thesis study.

5.1 Complicating Understandings of ‘Family’ in a Canadian Adult ICU

The gathered stories illustrate the complexity of understanding what it means to be a child and a member of a family during the ICU stay of an adult family member, and challenges taken-for-granted understandings of the roles and responsibilities of children and their caregivers. I suggest that it is the recognition of this complexity that is key to supporting children and their families during an ICU stay. In this section, I discuss three areas of complexity: children as present when illness or injury occurs and therefore already involved, the recognition that critical illness can disrupt the everyday lives of child and adult family members, and that child and adult family members may need to be together during an ICU stay.

Children as Present and Already Involved

This study highlights that children are often present when a loved one is injured or becomes ill and that It may not be possible, or desirable, to keep children separated from a family member’s critical illness. Children may know that their family member is seriously ill regardless of what they are told or not told. Research has shown that critically sick children have an innate awareness of how sick they are (Whitty-Rogers et al., 2009), might this same awareness apply when a loved one is critically ill? Children can suffer when a family member is sick and allowing them to be involved may alleviate their suffering (Knutsson & Bergbom, 2016).

As previously discussed, healthcare in BC and Canada is frequently framed as being family-centred (BC Ministry of Health, 2020; Farmanova et al., 2015). However, the findings of this thesis suggest that framing services as FCC does not ensure that the needs of child family members are taken into consideration in ICU policies, resources, or waiting areas. This finding is consistent with the work of early years scholars who have examined children’s participation in pediatric contexts (Koller, 2017) and have raised concerns about the inclusion of children in pediatric healthcare and called for a reframing of FCC as CFCC (Coyne et al., 2016; Gerlach & Varcoe, 2020). A reframing of CFCC emphasizes that a child is both a part of a family while also possessing distinct rights and a need to participate in events impacting themselves and/or their family members (Coyne et al., 2016; Gerlach &

Varcoe, 2020; Smith et al., 2017). A similar reconceptualizing may be useful in the context of adult critical care to ensure that the needs of child family members are reflected in ICU policies, practices, and physical spaces.

While the intention of reconceptualizing FCC as CFCC is to highlight the agency, needs, and preferences of children as integral members of their family, there is also the danger that this conceptualization might inadvertently lead to thinking of children apart from their families. Wall (2015) discusses the complexities of children's rights as existing within the tensions between dependence and independence, receiving and contributing, and being active and passive. The findings of this study support an understanding that children are important members of the family and as such their participation rights may best be considered in connection to their unique family system. As discussed in the introduction, what it means to be 'family' in the Canadian context is complex. Therefore, whether conceptualized as FCC or CFCC, the approach must consider the "cultural values, beliefs, and practices pertinent to each family" (Al-Motlaq & Shields, 2017, p. 344) and how these might influence how a family responds to the critical illness of a loved one.

The Disruptive Impacts of Critical Illness for Child Family Members

This study highlights that children are not immune to the disruptive impact of a family member's ICU stay. The impact of critical illness on patients and their adult family members is well documented in studies in France, Sweden, the USA, and Australia (Bäckman et al., 2010; Drumright et al., 2020; Garrouste-Orgeas et al., 2012; Tembo, 2017). Although research into how an ICU stay might impact children's health was not located, the findings of this exploratory study suggest that children's lives may also be significantly disrupted both during and after an ICU stay and that children may be unable to continue with their normal activities during the period of hospitalization. The storytellers spoke about an inability to do anything other than wait at the hospital when a family member was in critical condition. Similarly, Swedish research by Fridh, Forsberg, and Bergbom (2009) noted that the more uncertain the situation became, the more adult family members expressed a need to gather at the hospital and hold a vigil. What is less evident in literature is that children may experience the same inability to continue with their normal activities. Recognizing that children may not be able to continue with their everyday lives might inform how they are involved in the hospitalization of a critically ill family member.

It is important to note, however, that the needs of each child are unique. The findings suggest that embracing complexity means accepting that each child and adult family member will have unique needs and that these may change throughout an ICU stay. Both the findings of this study and the literature support an understanding that when a family member is sick, *everyone* in the family is affected (Knutsson & Bergbom, 2016; Shields, 2010) and may need to find their own way of being included.

The Need to Be Together

Restricting children from entering the ICU is common across Europe and the US (Kean, 2010; Liu et al., 2013; Manici & Ghillani, 2018), yet little is known about how children experience the ICU stay of a family member (MacEachnie et al., 2018). The findings in this study suggest that being close to a sick family member may provide comfort and reassurance to visitors as well as reflect a belief that gathering around a sick loved one supports their recovery. Like adults, children may be comforted by seeing their loved one in the ICU and feel reassured by the care and attention they are receiving (Kean, 2010; Knutsson & Bergbom, 2016).

The findings also suggest that visiting may be about more than a child's need for comfort and reassurance and that being close to a sick loved one supports a sick family member's healing and recovery. This study emphasizes that children may wish to be included during the ICU stay as part of their need to express love and care to their family member. Moreover, excluding child family members may have a long-term detrimental impact on their health and wellbeing. Furthermore, restricting a child from visiting a family who later dies may lead to a child suffering from guilt, discomfort, and an inability to say goodbye (Clarke & Harrison, 2001).

Research also supports the understanding that adult patients may benefit from children and family gathering at their bedside. Since ICU patients are often unconscious, research capturing the experiences of the critically ill are scarce (Rier, 2000). However, there is some evidence to support the idea that unconscious patients may be aware that their loved ones are present. Danielis et al. (2020) found that ICU patients recalled being able to smell their family members close by, and one patient said that they could recall feeling their son's hand. In another study, an ICU patient declared that, despite being unconscious, "We do hear. I knew each and every person that visited me, and talked to me, and touched me" (Nelson et al., 2010, p. 9). Even if children do not physically go into the ICU, it may be beneficial for children and sick family members to remain connected during the ICU stay. Rier (2000) recalled a moment during his ICU stay where he knew that he was dying. When he looked across the room, Rier saw a wall covered with drawings and cards from his children. He said, "I instantly snapped out of it: 'Hey! I've got five kids! I've got a wife! We've got a newborn baby! I'm not allowed to die.' I resolved to pull myself together" (p.79). Drawings, cards, video messages, or audio recordings might all be ways that children can connect with their loved one and extend comfort and care.

5.2 The Concept of Protectionism

The concept of protectionism was evident throughout this study. In this section, I examine age as a factor in shaping decisions about a child's involvement during the ICU stay. Next, I consider the ability of critical illness to blur, or even reverse, the distinction between adult and child. Lastly, I examine whether restricting children's access to a family member in the ICU is protective.

Age as a Factor Shaping Children's Involvement in the Critical Illness of an Adult Family Member

A strong relationship between age and access to a loved one in the ICU was noted both in the literature and the gathered stories. Storyteller's narratives often began with their age or their child/ren's ages at the time of hospitalization. Perhaps the reluctance to involve children in the illness event is founded on the understanding that critical illness is what one storyteller described as "adult stuff" rather than a family event. Even though children are often present at the onset of illness or injury, their involvement during the period of hospitalization was found to vary.

As previously discussed, developmentalism and the Euro-western emphasis on chronological age positions children as not-yet-adults and therefore in need of protection (Holloway & Valentine, 2000; Wall, 2015). This thesis study suggests that caregivers may believe that children, particularly those old enough to be aware of what is going on around them, should be kept separated and protected from the challenges associated with the critical illness of a family member. While there is no research to support that children are at risk of infection or that visiting in the ICU would be emotionally detrimental (Hanley & Piazza, 2012), research indicates adults are concerned that entering the ICU might be too frightening for a child (Knutsson & Bergbom, 2007).

As seen in this study, even where a policy might allow children to visit in an adult ICU, healthcare providers may recommend that a caregiver not bring child family member to visit. If the sights, sounds, and smells of entering the ICU are viewed as not belonging in childhood, then perhaps inviting a child into the ICU is thought of as asking them to prematurely enter the world of an adult. However, reconceptualizing children as active, autonomous beings (James & James, 2004) might offer alternative understandings by which adults can navigate an ICU stay with children.

Additionally, this study found that protectionism not only influenced whether children entered the ICU, but also the extent to which they were informed about their family member’s illness. Being informed and having the opportunity to ask questions is thought to be crucial to a child’s health and wellbeing when a loved one is sick (Golsäter et al., 2019). This study suggests that timely, transparent, and understandable updates throughout the ICU stay might ease the stress and anxiety some children experience when a loved one is critically sick. Research indicates that when children are not informed about a parent’s sickness they may blame themselves for what is happening (Oja et al., 2020) or form misconceptions (Ellis et al., 2017). Conversely, when children are informed about their parent’s sickness, they may experience less anxiety, fear, anger, and confusion, while increasing their sense of being valued, included, and in control (Dale & Altschuler, 2006; Ellis et al., 2017; Oja et al., 2020). Caregivers may not know how to talk to their children amid their own turmoil and might benefit from resources or personnel to support them.

Blurring the Adult/Child Distinction

Developmentalism distinguishes the roles and responsibilities of children from adults (Wall, 2015). Despite this distinction, the storyteller's narratives seem to call for a renegotiation of what it means to be a child or an adult and suggest that critical illness can blur the distinction of a child from an adult. This study suggests that "even adults get scared sometimes" and that critically ill adults can feel as vulnerable and afraid as children. As stated in the Regional Networks for Major Trauma report, "coming into contact with the [ICU] as a result of trauma renders the patient vulnerable and disorientated; they can feel extremely powerless" (NHS Clinical Advisory Groups Report, 2010, p. 48). In describing his own experiences of critical illness, Rier (2000) says he was aware that he was dying and could only focus on taking his next breath. In contrast to children wanting to be recognized as partners in care (Coyne & Gallagher, 2011; Gilljam et al., 2016), Rier attributes his survival in the ICU to accepting his position as a passive recipient of care and to "the selective disclosure of information" (2000, p. 81). Therefore, when a loved one is critically sick, the preferences and needs of child and adult family members may not be so easily distinguished from one another.

It seems that if we focus only on the biological development of children, we might not see their competence and capacity to be involved (James et al., 1998). Moreover, relying on age as the only determining factor may mean that the vulnerability of patients and adult family members is not recognized. Therefore, when navigating an ICU stay with families, care is required in determining how each family member would like to be included in the ICU stay. The age of an individual might not be the best or only way to determine how to provide support during the ICU stay.

How Protective is Restricting Children's Access to Adult ICUs?

In addition to raising questions about using a child's age to determine their access to adult ICUs, this study asks whether separating children from their family during a time of crisis might do more harm than good. The findings of this study suggest that excluding children from their family's process of dealing with illness, death, and grief can have a long-term detrimental impact. Similarly, MacEachnie et al. (2018) found that excluding children during the ICU stay may "promote feelings of uncertainty, sadness, and loneliness” (p. 2930). Given the lack of research into the risks and benefits of involving children during the ICU stay, I draw on research into the grieving process of children for further insights.

As with an ICU stay, involving children in the family grief process remains a controversial topic. According to Halliwell (2018), a social attitudes survey revealed that half of British parents feel that children under 12 years should not attend a funeral as it would be too upsetting. In contrast, research in Norway and Holland suggests involving children in family death rituals makes them feel like a “full member of the family” (Søfting et al., 2016, p. 141) while excluding them leaves them feeling set aside (Faro, 2018). The involvement of children in family death rituals in Norway (Søfting et al., 2016) and Holland (Faro, 2018) highlight the role of culture in navigating illness and death with children. Furthermore, they indicate that involving children in death rituals may be beneficial, suggesting that children might also benefit from inclusion during the ICU stay.

Critical illness can result in multiple losses for families. Not all patients survive the ICU stay, and many may never return to their former lives (Ewens, 2017). Therefore, children may have to adjust to how their family once was and how it is now. To make sense of these losses, Niemeyer et al. (2014) believe that an individual must be able to construct a coherent grief narrative. A grief narrative requires both a back-story and an event-story: the event-story is needed to make sense of what happened; the back-story assists an individual in moving back and forth between their life before and after a loss to create continuity. As noted in this study, if children are excluded from the event story, their ability to create a grief narrative may be impaired, which can make it difficult for them to comprehend the ICU stay and any associated losses.

The supportive nature of diary writing was also noted in this study, and one way to construct a grief narrative can be the use of mnemonic objects such as diaries, photographs, letters, or cards (Faro, 2018). One storyteller expressed that she wrote a diary because she “needed someone to know how my day was” and remarked that even reading the diary now, 60 years later, helped her gain new insights into her childhood experiences. The use of mnemonic objects may be especially important for children as they might need to revisit the ICU stay to makes sense of the associated losses at various developmental stages (Victoria Hospice, n.d.). Diary writing, in particular, is strongly supported as a way to help patients and adult family members regain their grounding in life following critical illness (Bäckman et al., 2010; Drumright et al., 2020; Ewens, 2017; Garrouste-Orgeas et al., 2012; McIlroy et al., 2019). Although research exploring the use of ICU diaries with children was not found, there is evidence from narrative psychologists that diary writing helps children integrate difficult events into their life story and leads to improved mental well-being (Baerger & McAdams, 1999; McAdams & McLean, 2013). Writing about journaling as a child following the sudden loss of their father, Cragg (2008) stated that the “paper listened” (p.123).

This study suggests that whether it is writing an ICU diary, drawing pictures for the sick family member, or sitting with family in the waiting room, finding ways to include children may be more protective than excluding them. This section stresses that a personalized approach to involving children in the ICU stay is crucial. A collaborative approach between the child, their caregiver/s, and a member of the ICU team might help determine how each family member is coping and their preferences in terms of support and involvement. The following section examines the need for systems-level transformation to support visiting families with children in the ICU.

5.3 Systems-Level Transformation

Whether conceptualized as FCC or CFCC, the findings of this study indicate that supporting families with children during the ICU stay requires attention to systems-level transformation, including adequate staffing and the right resources, guidelines, and tools (Al-Motlaq et al., 2019; Al-Motlaq & Shields, 2017). In this section, I discuss how structural changes can support the inclusion of child family members during the ICU stay of an adult family member, including an interdisciplinary team approach, supportive policies and resources, and modifications to waiting areas.

Resourcing an Interdisciplinary Approach to Caring for Families with Children in an ICU

Throughout BC, ICU visiting pamphlets, guidebooks, and websites often include the phrase: “parents wishing children to visit should discuss this with the patient’s nurse,” who are often the most visible members of the ICU team (Vance et al., 2010). Storytellers expressed deep gratitude for the life-saving work of nurses, but they also acknowledged a reluctance to add their preferences, concerns, and needs to a nurse's workload. Embracing the inclusion of children in the ICU therefore necessitates asking how and who is going to support families in determining what involvement might look like and supporting children if they choose to be at the hospital. A report on improving the provision of critical care in Britain suggests that there be a named person responsible for caring for the patient's family and providing them with reassurance and information; the report indicated that family members may need as much attention and care as the patient (NHS Clinical Advisory Groups Report, 2010). Furthermore, Jordan (2018) argues that while a medical team performs a patient assessment, there also needs to be an assessment of the needs of the patient's family, which I argue includes child family members. Consistent with this research, the findings of this thesis study suggest that this kind of personalized care and support be extended to include child family members. Families might receive support from social workers, spiritual health practitioners, or child life specialists if adequate resources were made available to fund this work. Child life work is now gaining recognition in supporting the children of adult patients (Bruce & McCue, 2018), therefore, the named person supporting families with children in the ICU might be a child life specialist as an additional member of the ICU interdisciplinary team.

Specific ICU Policies and Resources on Child Family Members

A review of written ICU policy documents, family visiting guides, and online information and resources revealed that there is little written about the inclusion of children during an ICU stay in BC. Policy 9.5.1 (see Appendix F) is the only written visiting policy I was able to locate for all acute care settings in the Vancouver Island Health Region.[17] This policy document is less than a page long and consists of three statements that, while reflecting the provincial commitment to FCC, positions Island Health staff as determining the appropriateness of visiting. Moreover, despite a stated commitment to FCC, the visiting policy makes no specific mention of children visiting or being involved in the hospitalization of a loved one. A similar lack of clarity and failure to address the needs of child family

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[17] A Knowledge Broker for the BC Support Unit contacted the Policy Stewardship Office on my behalf as access is not available to members of the public. Other documents discussing visiting within Island Health were not located.

members was evident in BC’s healthcare websites and online resources. A five-page, online introduction to the ICU did not discuss children visiting (Vancouver Coastal Health, 2013). Similarly, a 20-page patient and family handbook talked about every imaginable aspect of a hospital stay except for the inclusion of children as visitors (Vancouver Coastal Health, 2015).

An absence of policies can result in caregivers and healthcare providers using their discretionary power to guide them as they navigate an ICU stay with children. Discretion is understood as operating in the space between policy and the interpretation of policy in meeting the needs of a child, adult, or family (Ponnert & Svensson, 2016). As evident in several of the stories in this study, discretionary power may play a significant role in shaping how child family members experience the ICU stay of a loved one. Ponnert and Svensson (2016) argue that policy should not seek to eliminate discretionary power. The issue, however, is that few ICUs have been found to have any written policy regarding children visiting a loved one (Vint, 2005). Therefore, rather than policy and discretionary power working together, whether a child gets to visit in the ICU is often left entirely to discretionary decision-making. Eradicating discretion is not the goal but cultivating written policies and practice frameworks is seen as a way to inform discretionary decision-making and demonstrate that the inclusion of children has been considered and planned for.

In addition to detailed policy documents, caregivers may welcome materials that help them navigate critical illness with child family members (Bruce & McCue, 2018). In this study, storytellers spoke of receiving information packets but noted that they did not include information related to children. BC hospital websites also lacked materials offering caregivers information, recommendations, or support in navigating the illness of an adult family member with children. Resources such as picture books addressing illness to share with children or perhaps resources that help caregivers navigate issues such as visiting/not visiting might be useful. As an example, in Ontario, Sunnybrook’s ICU website (Sunnybrook Health Sciences Centre, 2020) includes resources to help caregivers determine whether visiting is advisable, deciding what is best for your child, involving children in the decision, as well as suggesting alternatives to visiting. Having resources available either online or in waiting areas might help caregivers as they care for their children during a loved one’s ICU stay.

Modifying Adult-centric Waiting Areas

The experiences of families during an ICU stay are shaped not only by the people, policies, and resources they interact with but also by the care and comfort that they feel when in the associated physical spaces. This study asked what the physical spaces associated with the ICU communicated about the inclusion of child and adult family members. The long hours of waiting often connected with a loved one’s critical illness are reflected both in the literature (Deitrick et al., 2005; Fridh et al., 2009; Karlsson et al., 2011) and in this study. Despite this understanding, both the literature and the storyteller’s descriptions suggest that ICU waiting areas offer little in the way of comfort, support, or privacy for visiting families (Deitrick et al., 2005; Karlsson et al., 2011). Policies described by storytellers, such as closing a waiting room down at 11 pm, were not felt to reflect an understanding that when a loved one’s life hangs in the balance, family members may struggle to leave the area even for a moment. Rather than supporting families during a difficult time, waiting areas were found to add to their stress.

The storytellers in this study identified several ways to improve waiting areas and make the ICU stay less challenging for families. Suggestions included having access to a fridge and kettle, more comfortable furniture, better lighting, and ventilation. The findings of this study also suggest a need for waiting areas that feel safe, secure, and are available 24 hours a day and highlight the importance of including child-friendly elements in waiting rooms, such as information, things to do, and distractions, suggesting that these might support both child and adult family members.

Also, the literature indicates that the addition of a receptionist may help family members to feel welcomed and supported (Karlsson et al., 2011). It should be noted, however, that the need for activity and noise is not welcomed by all (Deitrick et al., 2005). It may be necessary for ICUs to consider how to welcome children into a space that is occupied by multiple families who may be experiencing extreme stress and emotional turmoil. An additional quiet, private space may be beneficial for those facing difficult decisions or receiving upsetting news.

5.4 Recommendations

Drawing on both existing research and the findings of this exploratory study, the following preliminary recommendations are suggested as ways to improve the support of families with children during the ICU stay of an adult family member. As an exploratory study, the findings barely touched the surface of a complex and under-researched area. Therefore, each of the following recommendations warrants additional research and inquiry. Furthermore, as previously discussed, implementing changes in how child and adult family members are supported is dependent on careful consideration of the structural level reorganization necessary to ensure adequate staffing and resources.

1. On arrival at the ICU, an **initial family needs assessment** can help inform the nature of supports offered to the family both during and after the ICU stay. The assessment might ideally be completed by a social worker or child life specialist, however, given that families may find themselves in the ICU at any time of day, an initial assessment might be performed by a nurse to ensure that any immediate need for support is accounted for. This speaks to the necessity of an interdisciplinary approach wherein practitioners support families through an overlapping of their disciplinary-specific skillsets. Considerations in the assessment may include the experiences of both child and adult family members during the onset of critical illness or injury, the availability of extended family and friends to provide support and comfort to both child and adult family members, as well as any practical needs such as accommodation or parking. The assessment might inform the nature of supports offered to the family both during and after the ICU stay.
2. Building on the initial family needs assessment, a named member of the ICU team might offer **ongoing support** throughout the ICU stay. This support might be particularly important for families experiencing lengthy ICU stays or where the initial assessment highlighted areas where

a family might welcome additional support. For instance, a family who has travelled a considerable distance to be with a loved one receiving care in a level one trauma centre might need additional help finding accommodation. Families might also welcome support navigating illness with child family members. A collaborative approach that includes children, caregivers, and a trained member of the ICU team can determine the personalized involvement of each child and adult family member at every stage of the ICU stay. Ongoing collaboration is necessary in recognition that the nature of involvement might change throughout the ICU stay as the sick loved one's medical condition improves or declines. Consideration of the following is suggested:

  - The ideal choice for the ICU team member offering support to a family throughout the ICU stay might be a child life specialist. Child life specialists undergo extensive training in helping families cope with the stress of illness (Association of Child Life Professionals, 2020).
  - Integrate children into the family's illness experience by providing children with a variety of options and allowing them to choose how they wish to participate during the ICU stay.

3. Provide all ICU team members with **training and policies** to guide them as they interact with families visiting a critically sick loved one. Ensure that policies allow enough space for practice to be tailored to the specific needs and circumstances of a given patient, child, or family.
4. Support caregivers by providing **family resources** to help them navigate decisions and conversations with children during the ICU stay. The resources might provide suggested ways to respond to children's questions, guidance on visiting/not visiting, or alternative ways for children to feel connected to their sick loved one. Additionally, provide resources for direct use by children. These might include picture books describing the sights and sounds of the ICU or art materials that encourage children to create something for their sick family member.
5. Incorporate the use of an **ICU diary** into care options to minimize the short- and long-term impact of an ICU stay on the health of patients, children, and families. A record of the ICU

experience can be used to fill in memory gaps for the patient as well as allow children to revisit the experience as their understanding of events change with maturity.

6. Modify **ICU waiting areas** to reflect the lengthy waiting often associated with the critical illness of a family member. Furthermore, include child-friendly materials in waiting areas to communicate that children are welcome and considered an important part of the family. Preparing for children's presence in waiting areas acknowledges that children may not be able to continue with their normal activities during the ICU stay of a loved one and as a result may be at the hospital with adult family members. Provide additional quiet spaces for families who need to talk in private or hold difficult conversations.
7. Offer ongoing support to patients and their child and adult family members after the ICU stay. Support groups, like those available to families with experience of cancer or stroke, might be beneficial in helping patients and their families re-establish their way of being following an ICU stay. Family members may also benefit from counselling as they process their ICU experiences. If a loved one does not survive the ICU stay, connecting families to grief support services such as those offered through hospice might be beneficial.

5:5 Implications for Child and Youth Care Practice

Child and youth care (CYC), which includes a broad range of professions providing support and care to children, youth, families and communities (Newbury & Pacini-Ketchabaw, 2015) is complex, continually changing, and requires "ongoing interrogation, critical reflexivity, and a high tolerance for uncertainty and contradiction" (White, 2015, p. 506). The findings of this study are also relevant beyond the context of ICUs for CYC practitioners who are working in agencies that frame their services as being 'family-centred' and yet may fail to advance children's agency and participation. Insights from this study on how child and adult family members can experience a loved one's critical illness, highlight how children's rights, agency and participation in key events that impact them, and their family, can be implicitly constrained by adults' concerns underpinned by protectionism, and/or the absence of supportive policies. Creating space for children's participation requires that CYC practitioners talk directly to child family members and learn how to listen and hear what children are saying (Lundy, 2007). The findings support the need for CYC practitioners to question how they are engaging with child and adult family members in ways that meaningfully involve children in decision-making processes about key events in their families' lives. Making space for children's agency might involve working with children separately from adult family members, or learning how to facilitate family meetings that maintain the visibility of children (Maclean & Harden, 2014). In recognition of the complexity of CYC praxis in present-day Canadian contexts, it may not be an either-or situation, but rather an approach to care that is in constant flux and requires the practitioner to continually re-evaluate and adjust how services are tailored for each family context. Also, in the absence of policies, CYC practitioners can be left to use their own discretionary power to determine the best course of action for a family, which might be informed more by their personal experiences and biases rather than on what might be in the best interests of child and adult family members. Organizational policies, practice frameworks, and professional development opportunities may better support the advancement of children's agency and autonomy in the context of their family and community.

A further implication of this research is the potential of CYC practitioners to influence environments that may not be considered typical sites for CYC praxis. For example, in the pediatric ICU child life specialists play a prominent role in the support of families. Similarly, in hospice care, child, youth, and family counsellors provide guidance and support to families experiencing the illness and loss of a loved one. Both these contexts are positioned close to adult critical care units and may inform and support how families are cared for in the ICU. As such, CYC practice is brought into the ICU.

5.6 Limitations of the Study and Recommendations for Future Research

The limitations of the research fall broadly into two categories: those related to the scope of the study as part of a master's program and those resulting from researching during a global pandemic.

As part of a master's program, the small scale of this research barely touches the surface of a complex yet under-researched topic. A desire to gain experiential insights led to the prioritizing of depth rather than breadth of data and is reflected in the small sample size. Considerably more research is needed to inform policy and practice related to children visiting in the ICU. I hope that the preliminary insights offered in this study might lead to more extensive inquiry.

One primary limitation was that I gathered the remembered experiences of children, and although these stories provided meaningful insights into children's experiences, more research with children is recommended. Obtaining harmonized ethics approval to include child family members of all ages in an interview about a family member's critical illness was considered beyond the scope of a master's thesis study. Instead, I planned to seek ethics approval once specific children were identified and their ages were known. However, the complications of undertaking data collection remotely due to COVID-19 meant that the inclusion of children could not happen. Future research might incorporate play and arts-based approaches as a way to "interview" children with more recent experience of the ICU, without negatively impacting their recovery from what is often a stressful and challenging time.

A further limitation was researching a global pandemic. A Provincial State of Emergency was declared on March 18th, 2020 and is still in effect at the time of writing. This meant that I was not able to interview Island Health staff, which included child life specialists, hospice counsellors, social workers, spiritual health practitioners, as well as ICU doctors and nurses. I am conscious that their voices were not heard in this research. Future research with a range of interdisciplinary practitioners who support, or could support, families with children during an ICU stay is suggested. Furthermore, additional research is needed to explore the structural reorganization necessary to staff and resource the support of child and adult family members while a loved one is receiving care in the ICU.

The pandemic meant that recruitment of storytellers was conducted remotely as most organizations shut down and were in the process of moving services online. I relied on circulating information electronically but recognized that it would have been easier if I could have described what I was researching in person. It was difficult for people to grasp that I was exploring the experiences of children during an adult family member's critical illness. Added to this limitation, I had several people who expressed an interest in the research but felt that they could not participate until the pandemic was over. Additionally, the ability to recruit storytellers more broadly may have resulted in insights into how various population groups experience an ICU stay. Although this study included two biracial families, the stories gathered did not include BIPOC families. Further research is needed to explore how intersecting social identities including race, class, or sexual orientation might impact the experiences of families during an ICU stay.

Pandemic protocols made interacting and connecting with others difficult. Before the pandemic, I imagined conducting interviews in a family's home, perhaps sitting at the kitchen table. Adult and younger family members might have shared their experiences while little children participated through drawings or play. Due to the pandemic, interviews took place remotely via phone or Zoom. I found conducting interviews remotely created a different kind of intimacy. As we talked, storytellers folded laundry, prepared meals, received grocery deliveries, and invited me into the every-day-ness of their lives as they sheltered at home. Added to this unique invitation into their lives, I could not help but be aware that the backdrop to our conversation was one in which images and stories of a world profoundly affected by illness flooded our news feeds. Discussion of the pandemic invariably became woven into participant's stories of critical care.

Initially, I had thought of the gap in time between the ICU stay and when the storyteller shared their story as a limitation. Over time, I came to appreciate the unique insights offered through each story. The varying lengths of time between the critical illness experience and the sharing of their story enabled me to consider the impact of hospitalization from a range of temporal perspectives. In particular, I believe that the stories reflecting over 60 years provided valuable insights into how a child's experiences during the hospitalization of a loved one can have a long-term impact on life afterwards. Thus, what I initially considered a limitation came to be appreciated as a strength. As exploratory research, I believe this worked, but perhaps future research might take a narrower approach to inclusion criteria. Additionally, future research might also include the length of time a family member is in the ICU as this too might influence how a child is involved.

5.7 Personal Learning

Much learning has occurred while conducting this research, but I will limit my discussion to three main areas: coming to accept myself as shaping the story told, learning to be attentive to the senses as the embodiment of knowledge, and learning how to let go.

Intellectually, I understood that I was embedded in the research. Yet, it was not until I was gathering and analyzing people's stories that I came to fully appreciate the extent to which I was shaping the story told (Brown et al., 2009). This inquiry began with a request from a 4-year-old asking if he could see his dying father in the ICU. Initially, I thought that I needed to let go of Aiden's hand before proceeding with the study. Through reflexive writing based on what Richardson refers to as "writing-stories" (2001, p. 34), I came to accept my bias towards the perspective of a child. Writing-stories aided me in coming to see that I needed to acknowledge Aiden's hand in mine throughout the study. In reading Richardson's (Richardson & St. Pierre, 2018) explanation of crystallization, I understood that what I saw was based on the angle from which I viewed the data. The goal of the research was never to present one absolute truth but rather to "engage audiences to rethink and reimagine" (Clandinin, 2013, p. 51). While other equally valid interpretations of the data are possible, I came to an acceptance that the story I have re-told is a "thoroughly partial understanding of the topic" (Richardson & St.Pierre, 2018, p. 823). The story told is influenced by several narratives, including, but not limited to, my encounter with Aiden. Added to understanding myself as embedded in the research was also a growing attentiveness to my senses.

While analysing data, I was mindful of embodied knowledge experienced through "tastes, discomfort, or pain" (Law, 2008, p. 3). Maclure (2013) talks about data making itself known in "abstract or intangible" ways and of understanding "resonating in the body as well as the brain" (p.661). As I moved through this study, I noticed an increasing awareness of embodied knowledge. I believe that in giving space to sensing the data, I amplified personal experiences of knowing in ways beyond the intellectual. At times, holding the stories was a painful process. The stories themselves were moving but added to this, I was listening to them at a time when the news was full of images of the ICU, and as the lives of friends and family were being deeply impacted by COVID-19.

The third area of learning is related to learning how to let go. One of the challenges of using a storied approach is the amount of data collected. Each interview was approximately one hour long, which amounted to more than fifteen pages of single-spaced transcription. I wanted to handle each story with the tenderness I felt that it deserved but equally recognized that every detail could not find its way into the thesis. Figuring out what to pick up and what to let go was incredibly challenging. There were, what I felt to be, significant parts of people's stories that I had to leave out. In doing so, I felt that I was in some way betraying the trust they had placed in me by sharing it. Initially, I had felt that I would contact the storytellers once after the interview for them to review the transcript. In reality, we had several brief interactions back and forth through email or phone as I felt I needed to check in with them about something in the writing of this thesis, or as they remembered something that they wanted to share. I was continually amazed by the generosity of the storytellers as they frequently told me to let them know what I needed. Several indicated how important the opportunity to share their story was. I only wish I could have included everything in the study. Instead, I had to continually return to the purpose of the inquiry and to be willing to only pick up the pieces that contributed to that purpose.

5.8 Concluding Thoughts

The purpose of this exploratory study was to provide preliminary insights into supporting families with children during the ICU stay of a family member. Additionally, many of the findings of this study have implications for child and youth care practice more generally. An exploration of the experiences of individuals with lived experience of an adult family member's ICU stay, and a review of policy and practice documents within BC led to a list of seven preliminary recommendations that might inform the policies and practices associated with child and adult family members as visitors in the ICU.

This study has seen that children often witness the arrival of critical illness and can be acutely aware that something is wrong. As a result, children may experience the same mix of fear and concern as their adult family members; therefore, shielding them from the impact of a loved one's critical illness may not be possible. Furthermore, segregating children from the illness event may not only add to the distress they feel in the short term, but also impact the health and wellbeing of the child in the future. The most protective course of action might be to invite children into the family illness experience in a way that works for them. Children, just like adult family members, may derive comfort from gathering at the hospital, seeing the care that their loved one is receiving, and receiving regular, transparent updates.

While children visiting in the ICU remains a contentious issue, research does not indicate that children would be harmed by visiting. The findings of this study highlight the importance of taking a highly personalized approach to a child's participation in a loved one's critical illness. If a child wishes to visit, it seems best to support them in doing so unless extenuating circumstances make this impossible.[18] In situations where an in-person visit is not possible or desired, a virtual visit, or an alternative way for the child to connect with their loved one is suggested. Although seeing a critically sick family member can be a shocking experience for both adults and children, the stories in this study highlight that preventing children from visiting can be equally detrimental, particularly if the loved-one does not survive. Resources to support children, caregivers, and healthcare providers are recommended.

FCC was evident in the languaging of BC's healthcare literature; however, this approach was not found to address the needs of child family members during an ICU stay and reframing as CFCC is suggested. Furthermore, Article 12 in the UNCRC (United Nations, 1989) established children's right to be involved and heard in matters that are important to them. However, it may not be possible for children's rights to be realized until they are conceptualized as competent and capable, and adults position themselves as coming alongside rather than deciding for children from a position above.

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[18] There are situations where an in-person visit is not possible for instance, during the COVID-19 pandemic visiting has not been permitted due to concerns of infection. Many hospitals have created alternative ways to facilitate family members staying connected.

Detailed policy and practice frameworks, professional development opportunities, as well as consideration of staffing, are necessary if ICUs are to improve the care and support of child and adult family members. Naming a member of the ICU team to provide care to a patient's family is proposed as one way to ensure that families with children receive the support they need. A family support person may be particularly important in helping caregivers consider the needs of children during a family member's critical illness.

In this study physical spaces, such as waiting areas, were considered not only as providing support to families with children but also as communicating the institutional story of critical care in BC. Making waiting rooms more comfortable was proposed to align with the understanding that long hours of waiting are often associated with an ICU stay. Also, adding child-friendly elements to waiting areas would raise the visibility of children and communicate that they are considered an important part of the family and welcome in the ICU.

It is hoped that the findings of this study have gone some way towards enhancing our understanding of the experiences of families with children during the critical illness of an adult family member. As we talked through the findings of this study, an ICU nurse educator within Island Health told me how many questions this research raises and that it will help them moving forward as they look at how they can improve the support of visiting child and adult family members (personal communication, November 3rd, 2020). Since the findings barely touch the surface of the complexities of critical illness, it is hoped that this study has laid the groundwork for future research into supporting families with children during the ICU stay. The study may also lead to a consideration of how children's preferences, needs, and agency are accounted for in other contexts providing services and supports to families.

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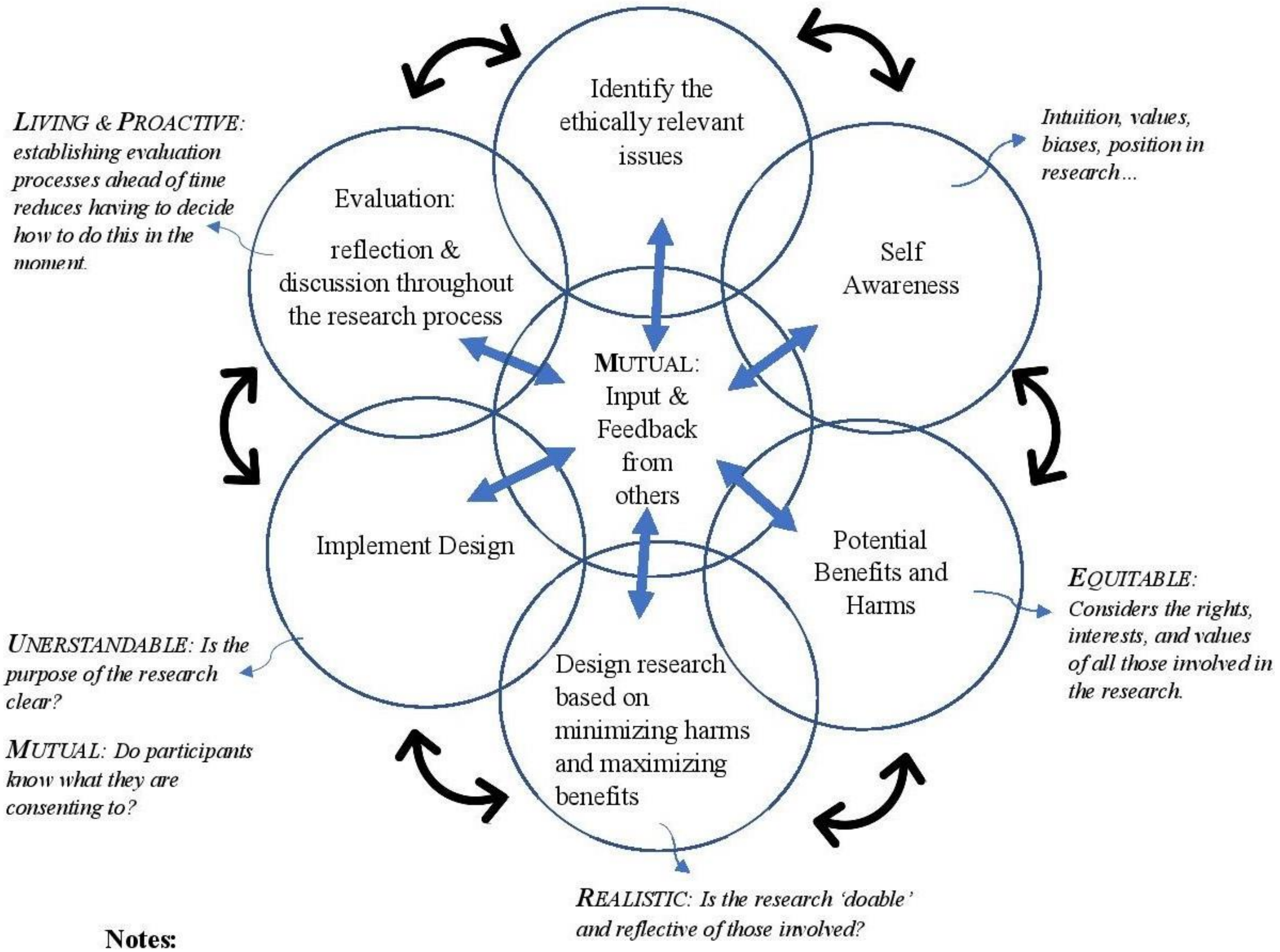
Appendices

Appendix A: Ethical Decision-Making Model

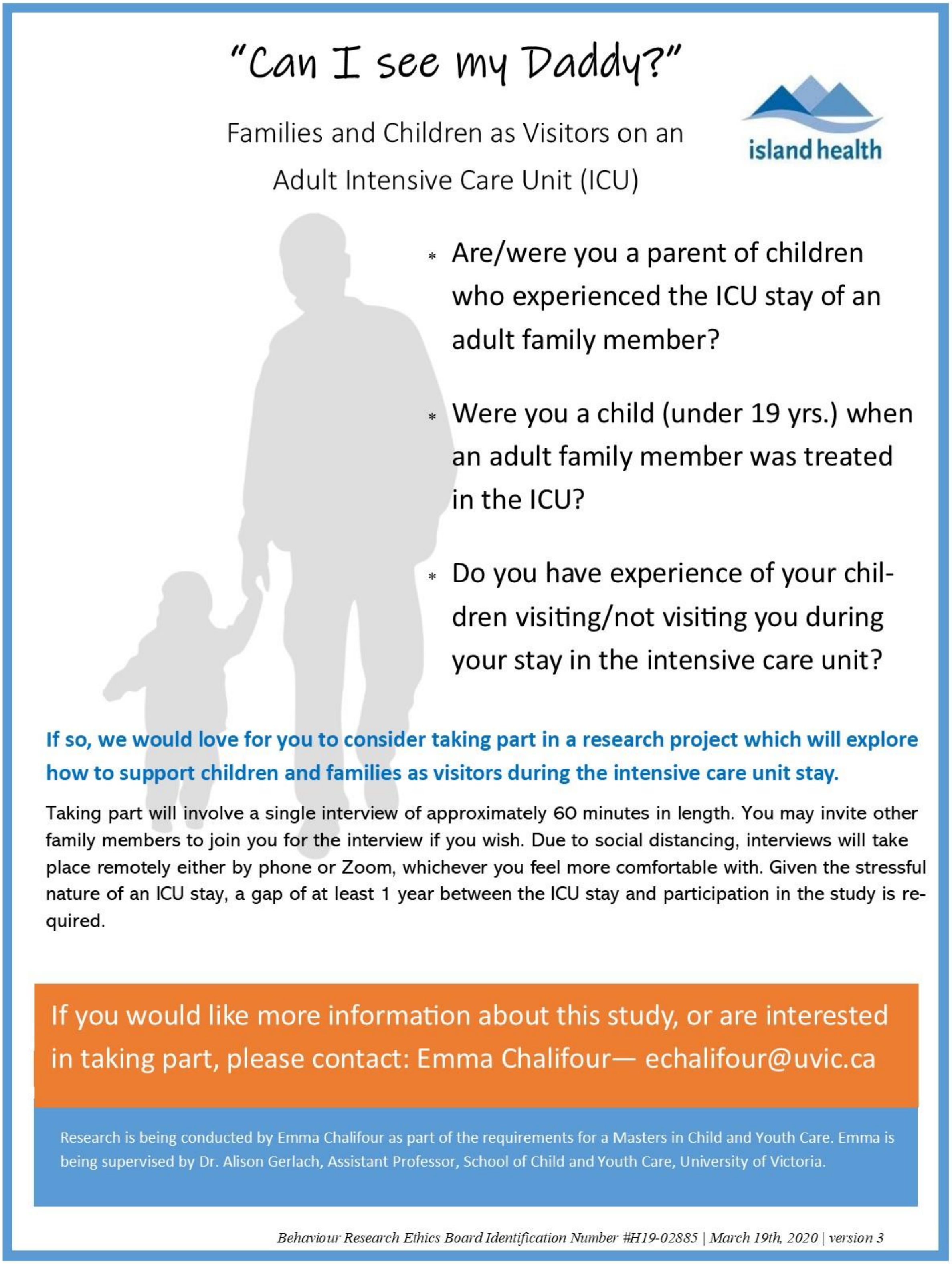


Notes:

1. **1.** Amalgamated from the BCACC Guide to Ethical Decision Making (B.C Association of Clinical Counsellors, 2018), Health Canada (2010), RUMPLE (J. Newbury & Z. Ludski, personal communication, 2019), and Lehr & Sumarah (2004).
2. Circular and interconnected to emphasize a non-linear understanding of ethical decision making and the need to continually revisit areas throughout the research process.
3. Fluid and in motion: the multiple arrows suggest a sense of constant movement as ethical dilemmas appear and resolve perpetually throughout the research.
4. Feedback from others is placed in the middle to centre the idea that collaboration with others (supervisor, participants…) is vital throughout. Connects to Lehr & Sumarah (2004) and the importance of moving decision-making into the interpersonal realm and seeking reasonable consensus.
5. Identify the Ethically Relevant Issues **–** both before and throughout the research process.

6. Self Awareness**:** where am I positioned in this research? What lens am I viewing ethical decision making through? Who am I as a researcher?
7. **Potential Risks/Benefits –** Consideration at both the micro and macro level. Who is involved in the research? How might this affect them both now and in the future?
8. **Research Design -** Based on an understanding that the research question is ethical, design research that contributes to answering the question without crossing ethical boundaries, personal or otherwise.
9. **Implement Design –** Implement design with an understanding that research including people is unpredictable. Be alert to ethical situations as they arise.
10. **Continual Reflection and Discussion –** Throughout the research, from question through to dissemination, identify new ethical dilemmas and flow back around the circle.

Appendix B: Recruitment Poster



"Can I see my Daddy?"

Families and Children as Visitors on an Adult Intensive Care Unit (ICU)

island health

- Are/were you a parent of children who experienced the ICU stay of an adult family member?
- Were you a child (under 19 yrs.) when an adult family member was treated in the ICU?
- Do you have experience of your children visiting/not visiting you during your stay in the intensive care unit?

If so, we would love for you to consider taking part in a research project which will explore how to support children and families as visitors during the intensive care unit stay.

Taking part will involve a single interview of approximately 60 minutes in length. You may invite other family members to join you for the interview if you wish. Due to social distancing, interviews will take place remotely either by phone or Zoom, whichever you feel more comfortable with. Given the stressful nature of an ICU stay, a gap of at least 1 year between the ICU stay and participation in the study is required.

If you would like more information about this study, or are interested in taking part, please contact: Emma Chalifour— echalifour@uvic.ca

Research is being conducted by Emma Chalifour as part of the requirements for a Masters in Child and Youth Care. Emma is being supervised by Dr. Alison Gerlach, Assistant Professor, School of Child and Youth Care, University of Victoria.

Behaviour Research Ethics Board Identification Number #H19-02885 | March 19th, 2020 | version 3

Appendix C: Consent Form

FAMILY CONSENT FORM

For the Research Project:

‘Can I see my daddy? Families & Children as Visitors on the Adult Intensive Care Unit.’

Who is conducting the study?

Principal Investigator: Dr. Alison Gerlach, Assistant Professor, School of Child and Youth Care, Faculty of Human & Social Development, University of Victoria. Phone: 250-721-8550. Email: alisongerlach@uvic.ca

Co-Investigator: Emma E. Chalifour, MA Student. School of Child and Youth Care, Faculty of Human & Social Development, University of Victoria. Email: echalifour@uvic.ca

Why are we doing this study?

There has been virtually no research into how to support visiting families and children during the intensive care unit (ICU) stay of an adult family member. This study aims to provide preliminary insights to inform dialogue around what families and children need when visiting the adult ICU. This study is being completed as partial fulfilment of the requirements for a Master of Arts degree in Child and Youth Care. There is no external funding associated with this research.

Why are you being invited to take part in this study?

As a family with children who have experienced the ICU stay of an adult family member, we believe you have valuable insights to share. Your experiences are important in informing how ICUs can enhance their support for families and children while visiting an adult family member.

What does participation in this study involve?

Participation in this study is completely voluntary. If you say ‘Yes’, this is what participation will involve:

- You will be asked to take part in an interview with the co-Investigator, Emma Chalifour. The interview will be in a conversational style and will be approximately 60 minutes long and, with your permission, the conversation will be audio-recorded using a handheld device and later transcribed in full. A copy of the transcription will be shown to you to verify that the account reflects your story.

- Due to COVID-19 and the need to maintain social distancing, interviews will take place remotely. You will be asked if you would prefer to be interviewed by phone or through Zoom. You will be given the option of inviting another adult family member to join you for the interview. If more than one family member is present, you will be encouraged to share only what you feel comfortable discussing in front of them.

- You will be invited to share stories about your experiences while visiting on the AICU. You are encouraged to bring artefacts, such as a card, letters, or a child's drawing if these would help you to share your experiences. You are encouraged to ask permission from family members before sharing artefacts. Please note: artefacts will not be copied or included in research data.

What if you change your mind?

Taking part in this study is your choice. You are free to choose not to answer a question(s), to end the interview, or to leave the study at any time without giving any reason. Your decision to not participate in this study, or to leave the study is kept confidential. If you withdraw, you will be given the option of withdrawing the information you have shared in the interview or having the information remain in the study.

What are the benefits of taking part in this study?

Taking part in this study will provide you with an opportunity to share some of your family's insights and experiences during the ICU stay of an adult family member. Although participation in the interview may not be of immediate personal benefit to you, it may shape the experiences of future families and children while their loved one is receiving treatment on the adult ICU. Your experiences may help inform the training and orientation of staff on the ICU and guide the creation of an updated visitor's pamphlet.

Are there any risks in taking part in this study?

Given the stressful nature of an ICU stay, a gap of at least 1 year between the ICU stay and participation in the study is required. A story-centred approach will allow you to determine what you share and how much detail you choose to go into. However, taking part in an interview may cause painful emotions to surface. If this happens, you will have the option of taking a break from, or ending, the interview. Although Alison Gerlach and Emma Chalifour are unable to provide counselling, you will be provided with the contact information of available counselling resources in your community.

How will your family's identity and privacy be protected?

All identifying information from the study will be kept strictly confidential and will not be included in any written materials. If you choose to be interviewed via Zoom, the record option will not be utilized. You will be asked to avoid providing identifying information about family members as much as possible. Your name, and the name of anyone you mention, will not be included in any written material. Only Alison Gerlach (principal investigator) and Emma Chalifour (co-investigator) will have access to the data. Consent forms, and any other hard copies of data, will be stored in a locked cabinet in Dr Gerlach's locked office. Electronic data will be encrypted and securely stored on a password-protected computer. After a period of 5 years, all data will be disposed of appropriately.

How will the results of this research be shared?

A summary report and 2-page brief will be provided to participants who provide a mailing/email address for this to be sent to (please see bottom of the consent form). The summary report will also be shared with the AICU staff at the Victoria General Hospital and the Royal Jubilee Hospital.

The preliminary findings of this study will be reported in a graduate thesis which will be made available on the internet via “UVicSpace.” The findings may also be published in journal articles.

Will you receive any payment for taking part in this study?

Although the time and contribution you give to this study are greatly appreciated, there is no honorarium for participating in this study.

Who can you contact if you have any questions about this study?

If you have any questions or concerns about the study, please do not hesitate to contact Alison Gerlach or Emma Chalifour – contact information can be found at the top of page 1.

Who can you contact if you have complaints or concerns about the study?

You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Consent

Taking part in this study is your choice. If you agree to take part in this study, please indicate the following:

You agree to have the interview audio-recorded: Yes _______ No ____________

You would like to *receive a final summary report of this study: Yes _______ No ____________

*Please send a copy of the study findings to me at (please provide an email address or mailing address:

____

____

Your signature below indicates that you consent to participate in this study. You are also indicating that you have received a copy of this consent form for your own records.

____________________	____________________	____________________
Printed name of participant	Signature	Date

Please keep Pages 1-3 of this consent form and return page 4 to Emma Chalifour in the self-addressed envelope provided. Alternatively, you may sign, scan, and email copy of page 4 back to Emma at echalifour@uvic.ca.

Appendix D: Interview Guide

Interview Guide for Families

Overarching Question – Can you tell me about your experiences as a family visiting the ICU?

1. Artefacts – families will be invited to bring an artefact from their ICU experience to share. An artefact might be something like a card, letter, a child's drawing, a photograph. If the family brings an artefact to the interview, they will be asked:
    a. To describe the artefact.
    b. To share the story behind its importance.
2. Can you tell me about your experience when you first visited the ICU?
3. Can you tell me about a time when you felt most supported during a visit to the ICU?
4. Can you tell me about a time when you felt most challenged during the ICU visit?
5. Is there anything else that you would like to share with me about your experiences visiting the ICU?

Appendix E: Island Health ICU Family Visiting Brochure

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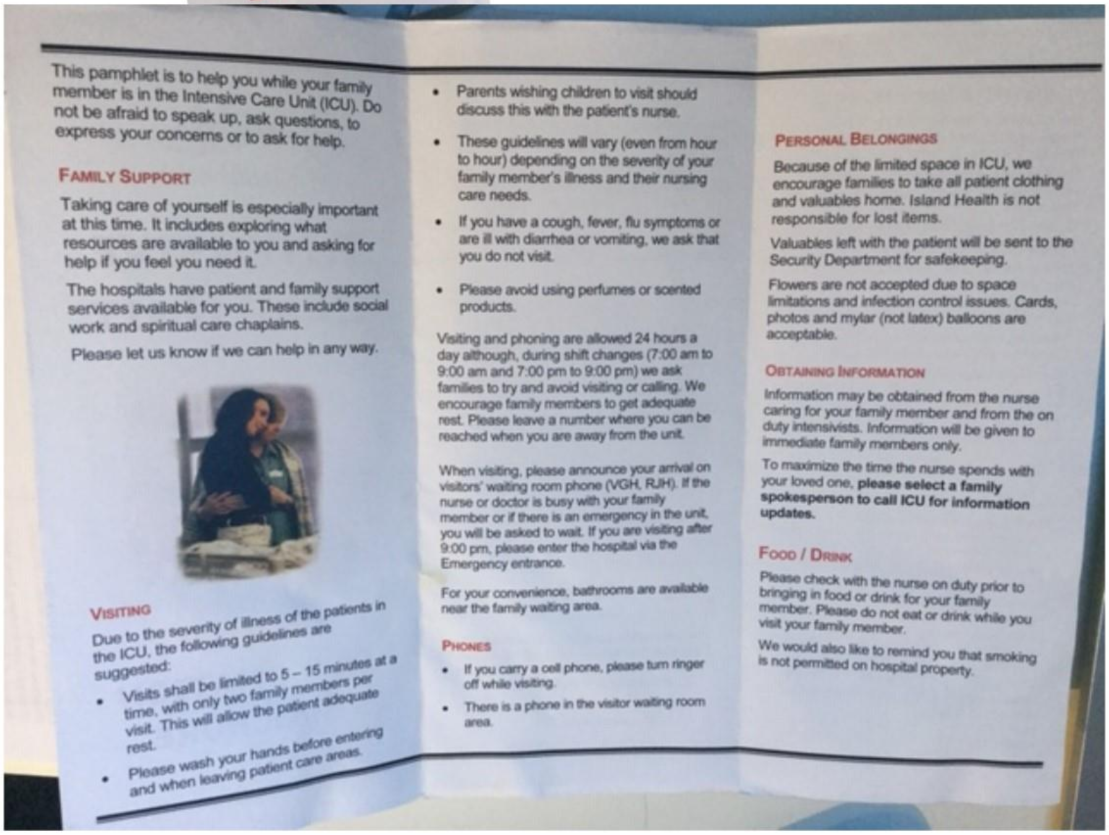
INTENSIVE CARE UNIT

FAMILY INFORMATION BROCHURE

"Parents wishing children to visit should discuss this with the patient's nurse."



This pamphlet is to help you while your family member is in the Intensive Care Unit (ICU). Do not be afraid to speak up, ask questions, to express your concerns or to ask for help.

FAMILY SUPPORT

Taking care of yourself is especially important at this time. It includes exploring what resources are available to you and asking for help if you feel you need it.

The hospitals have patient and family support services available for you. These include social work and spiritual care chaplains.

Please let us know if we can help in any way.

VISITING

Due to the severity of illness of the patients in the ICU, the following guidelines are suggested:

- Visits shall be limited to 5 – 15 minutes at a time, with only two family members per visit. This will allow the patient adequate rest.
- Please wash your hands before entering and when leaving patient care areas.
- Parents wishing children to visit should discuss this with the patient's nurse.
- These guidelines will vary (even from hour to hour) depending on the severity of your family member's illness and their nursing care needs.
- If you have a cough, fever, flu symptoms or are ill with diarrhea or vomiting, we ask that you do not visit.
- Please avoid using perfumes or scented products.

Visiting and phoning are allowed 24 hours a day although, during shift changes (7:00 am to 9:00 am and 7:00 pm to 9:00 pm) we ask families to try and avoid visiting or calling. We encourage family members to get adequate rest. Please leave a number where you can be reached when you are away from the unit.

When visiting, please announce your arrival on visitors' waiting room phone (VGH, RJH). If the nurse or doctor is busy with your family member or if there is an emergency in the unit, you will be asked to wait. If you are visiting after 9:00 pm, please enter the hospital via the Emergency entrance.

For your convenience, bathrooms are available near the family waiting area.

PHONES

- If you carry a cell phone, please turn ringer off while visiting.
- There is a phone in the visitor waiting room area.

PERSONAL BELONGINGS

Because of the limited space in ICU, we encourage families to take all patient clothing and valuables home. Island Health is not responsible for lost items.

Valuables left with the patient will be sent to the Security Department for safekeeping.

Flowers are not accepted due to space limitations and infection control issues. Cards, photos and mylar (not latex) balloons are acceptable.

OBTAINING INFORMATION

Information may be obtained from the nurse caring for your family member and from the on duty intensivists. Information will be given to immediate family members only.

To maximize the time the nurse spends with your loved one, **please select a family spokesperson to call ICU for information updates.**

FOOD / DRINK

Please check with the nurse on duty prior to bringing in food or drink for your family member. Please do not eat or drink while you visit your family member.

We would also like to remind you that smoking is not permitted on hospital property.

Appendix F: Island Health Visiting Policy

Policy Relationships: Clinical
General Patient Care: Standards of Patient Care
Effective Date: June 1, 2011

Section Number: 9.0
Sub-section Number: 9.1
Policy Number: 9.1.5

9.0 General Patient Care

9.1 Standards of Patient Care

9.1.5 Visitors

1.0 Philosophy

Visitors play a vital role in patients' care and recovery. VIHA encourages patient visits and invites family and friends to participate in patient, client, and residents' care as appropriate.

. 2.0 Visitor Policy

1. Visitors are welcome to visit patients, clients, and residents in VIHA facilities at times that are appropriate to the patient's medical condition, care requirements, and the needs of other patients e.g. in shared rooms.

2. VIHA staff will work with the patient and their family/ friends to establish appropriate visitation guidelines. VIHA staff may invite and support visitors to assist with the patient's care as appropriate e.g. feeding, walking, personal care.

3. On occasion, staff may need to restrict visits due to patient acuity, infectious disease outbreaks or other reasons specific to a unit or patient care. Staff will explain the restrictions to the visitors. Staff will instruct visitors to wear appropriate protective clothing (eg: gown and gloves).

Issuing Authority: Executive Management Committee

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Date Issued: June 1, 2011
Date Last Reviewed(r)/Revised(R):