

**The Lived Experiences of Nurses and Physicians
Caring for Children with Complex Care Needs in
Paediatric Intensive Care Units during the First
Eighteen Months of the COVID-19 Pandemic.**

A thesis presented to Trinity College Dublin
for the degree of Doctor in Philosophy

By

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Declaration

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Summary

Background

The global pandemic caused by COVID-19 has affected the health and wellbeing of children across the world. Children with complex care needs (CCNs) have a range of health and social care needs, including physical, developmental, behavioural and/or emotional conditions, which can put them at risk of more severe illness and complications from COVID-19. Due to their medical complexity, this cohort of children accounts for an increasing proportion of paediatric intensive care unit (PICU) admissions worldwide. There is limited research conducted about the impact of the COVID-19 pandemic on children with CCNs; instead, research has focused primarily on the impact of care delivery in the home as a result of public health restrictions. However, there is a scarcity of literature about care delivery for this cohort of children in paediatric intensive care units (PICUs).

Aim and Objectives

The aim of this research was to explore and understand the meaning given to care delivery to children with CCNs in PICUs by nurses and physicians during the first 18 months of the COVID-19 pandemic. The first of three objectives was to examine experiences internationally of caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. The second objective was to articulate what has been learned from experiences during this specific time frame of the COVID-19 pandemic, to support ongoing care in PICUs for this population of children. The final objective was to present implications for the enhancement of care in PICUs following the pandemic, including changes to care delivery.

Methodology

A hermeneutic phenomenological approach, guided by the work of van Manen (1990), underpinned this research. Following ethical approval, purposive sampling was used to gather data from nurses and physicians who were working in PICUs during the first 18 months of the COVID-19 pandemic. Online interviews were conducted using Zoom in adherence with public health

advice against travel and face-to-face meetings during this time in the pandemic. Van Manen's method for data analysis was used to analyse the data and to deduce the key essential themes (van Manen 2014a).

Findings

The data from the interviews with 18 nurses and 22 physicians was analysed together as the overall aim of the research was to explore and understand the meaning given to care delivery to children with CCNs in PICUs by nurses and physicians during the first 18 months of the COVID-19 pandemic. Five themes and eight sub-themes emerged from data analysis. These sub-themes were: provision of care to children with CCNs in PICUs; decision-making affecting children with CCNs in PICUs; effect of COVID-19 on children with CCNs and on clinical activity in PICUs; visiting restrictions within PICUs for children with CCNs; relationships between healthcare professionals and families of children with CCNs; learning from COVID-19 in the context of children with CCNs in PICUs; changes in day-to-day practices due to COVID-19 relating to children with CCNs; and allocation of resources in PICUs for children with CCNs. Overall, participants experienced very little difference in their care delivery to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.

Conclusion

This research provided a unique insight into the nurses' and physicians' lived experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. The presentation and interpretation of findings - alongside the in-depth discussion - resulted in identification of implications for research, education and policy, including the use of telemedicine to enhance care for children with CCNs in PICUs. Through the exploration of these lived experiences, key elements can be extracted for progressing care delivery in a PICU. Considerations for further research in this area have also been identified.

List of Abbreviations

CCNs	Complex Care Needs
CICU	Cardiac Intensive Care Unit
COVID-19	Coronavirus Disease 2019
CP	Cerebral Palsy
ED	Emergency Department
ERC	European Research Council
FCC	Family-Centred Care
GDPR	General Data Protection Regulation
ICU	Intensive Care Unit
ICUs	Intensive Care Units
IPA	Interpretive Phenomenological Analysis
MERS	Middle East Respiratory Syndrome-related coronavirus
NHS	National Health Service
NMBI	Nursing and Midwifery Board of Ireland
PICANet	Paediatric Intensive Care Audit Network
PICU	Paediatric Intensive Care Unit
PICUs	Paediatric Intensive Care Units
PIMS	Paediatric Multisystem Inflammatory Syndrome (PIMS-TS)
PPE	Personal Protective Equipment
RCPCH	Royal College of Paediatrics and Child Health
RSV	Respiratory Syncytial Virus
SARS	Severe Acute Respiratory Syndrome
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
TBI	Traumatic Brain Injury
TCD	Trinity College Dublin
UK	United Kingdom
U.S.	United States of America
WHO	World Health Organization
Zoom	Zoom Video Communications Inc.

Table of Contents

Declaration	ii
Acknowledgements	iii
Summary	iv
Background	iv
Aim and Objectives	iv
Methodology	iv
Findings	v
Conclusion	v
List of Abbreviations	vi
Table of Contents	vii
List of Tables	xiii
List of Figures	xiv
<i>My PhD Journey</i>	1
<i>Chapter One: Background</i>	4
1.1 Introduction	4
1.2 Background and Context	4
1.3 Significance of the Research	7
1.4 Aim and Objectives	8
1.5 Terminology	9
1.5.1 Nurses and physicians working in PICU	9
1.5.2 Children with CCNs	10
1.5.3 PICUs	13
1.5.4 COVID-19	14
1.6 The Research Design	18
1.7 Structure of the Thesis	18
1.8 Conclusion	19
<i>Chapter Two: Scoping Review of the Organisation of Care in PICUs</i>	21
2.1 Introduction	21
2.2 Background	21
2.3 Methods	25

2.3.1	Scoping review design and data collection.....	25
2.3.2	Identification of relevant studies.....	26
	<i>Table 1: Keywords for the literature search strategy</i>	27
2.3.3	Study selection	27
	<i>Figure 1: PRISMA flow diagram of the study selection process</i>	29
2.3.4	Data charting	30
2.3.5	Results overview.....	30
2.3.6	Study types and countries.....	30
2.4	Results	31
2.4.1	Reorganisation of space for increased capacity	31
2.4.2	Staffing and support.....	35
2.4.3	The challenges associated with the reorganisation of PICUs.....	42
2.5	Discussion	45
2.5.1	Limitations.....	48
2.6	Conclusion	48
	<i>Chapter Three: Philosophical and Methodological Issues</i>	51
3.1	Introduction	51
3.2	Research Methodology	52
3.3	Hermeneutic Phenomenology	54
3.4	The Case for Hermeneutic Phenomenology	56
3.5	Key Philosophers who Influenced van Manen’s Work on Hermeneutic Philosophy	57
3.5.1	Martin Heidegger (1889 - 1976).....	57
3.5.2	Hans-Georg Gadamer (1900 - 2002)	59
3.5.3	Maurice Merleau-Ponty (1908 - 1961).....	60
3.6	Max van Manen	61
3.6.1	Explicating pre-understandings.....	64
3.6.2	Language and dialogue.....	65
3.6.3	Existential Lifeworld.....	66
3.6.4	Hermeneutic circle	67
3.7	Van Manen’s Guidelines	67
3.7.1	Turning to the nature of lived experience.....	68
3.7.2	Investigating experience as we live it rather than as we conceptualise it.....	69
3.7.3	Reflecting on essential themes, which characterise the phenomenon.....	69
	<i>Table 2: Summary of van Manen’s six guidelines (1990)</i>	70
3.7.4	Describing the phenomenon through the art of writing and re-writing	71
3.7.5	Maintaining a strong and orientated relation to the phenomenon.....	72
3.7.6	Balancing the research context by considering the parts and the whole.....	72

3.8	Conclusion	73
	Chapter Four: Research Design and Methods	74
4.1	Introduction.....	74
4.2	Aim and Objectives of the Research	74
4.3	Sample and Sampling Process	75
4.3.1	Gaining access.....	77
4.3.2	Inclusion criteria.....	77
4.3.3	Exclusion criteria	78
4.4	Recruitment and Access	78
4.5	Data Collection	79
4.5.1	Interviews	79
4.5.2	Gaining consent.....	87
4.5.3	Reflection on the data collection process.....	87
4.6	Data Analysis	89
4.6.1	Van Manen’s method for thematic analysis	90
	<i>Figure 2: Data analysis (van Manen 2007, 2014a)</i>	90
4.6.1.1	Transcribing, reading and re-reading – turning to the nature of lived experience	91
4.6.1.2	Constructing a qualitative database – investigating experience as we live it	91
	<i>Table 3: Phases of Data Analysis</i>	92
4.6.1.3	Selective and holistic reading approach and creating initial and essential themes – reflecting on the essential themes which characterise the phenomenon.....	93
4.6.1.4	Writing – describing the phenomenon through the art of writing and re-writing.....	93
4.6.1.5	Remaining focused on the research aim – maintaining a strong and orientated relation to the phenomenon	94
4.6.1.6	Adopting an existential approach – balancing the research context by considering the parts and the whole	95
4.6.2	Five lifeworld existential themes of human experience	95
4.6.2.1	Lived other (relationality)	96
4.6.2.2	Lived body (corporeality)	96
	<i>Table 4: Five lifeworld existential themes of human experience</i>	97
4.6.2.3	Lived space (spatiality).....	98
4.6.2.4	Lived time (temporality).....	98
4.6.2.5	Lived things (materiality).....	98
4.6.3	Summary of data analysis.....	98
4.7	Ethical Considerations	99
4.7.1	Respect for autonomy.....	99
4.7.2	Beneficence and non-maleficence.....	100
4.7.3	Justice.....	102
4.7.4	Confidentiality.....	103
4.7.5	Veracity.....	104
4.7.6	Fidelity.....	104

4.8	Integrity of the Research – Quality and Rigour	105
4.8.1	Credibility.....	107
4.8.2	Dependability.....	1088
4.8.3	Confirmability.....	109
	<i>Table 5: Key strategies adapted from Lincoln and Guba (1985)</i>	<i>110</i>
4.8.4	Transferability.....	111
4.9	Conclusion.....	111

Chapter Five: Presentation of Findings 112

5.1	Introduction	112
5.2	Demographic Data	112
	<i>Table 6: Profile of participants.....</i>	<i>112</i>
5.3	Adopting Lived Existential Themes	11313
	<i>Figure 3: Lived existential themes with themes identified</i>	<i>114</i>
5.4	Lived Body: Daily Experiences of the Care Provided for Children with CCNs during the COVID-19 Pandemic.....	114
5.4.1	Provision of care to children with CCNs in PICUs	115
5.4.2	Decision-making affecting children with CCNs in PICUs.....	117
5.4.3	Summary of Lived Body: Daily experiences of the care provided for children with CCNs during the COVID-19 pandemic.....	122
5.5	Lived Other: Therapeutic Relationships Developed during Care Delivery for Children with CCNs during the COVID-19 Pandemic ..	122
5.5.1	Relationships between healthcare professionals and families of children with CCNs	123
5.5.2	Summary of Lived Other: Therapeutic relationships developed during care delivery for children with CCNs during the COVID-19 pandemic.....	124
5.6	Lived Space: Connections between the Child with CCNs and the Space they Occupy within PICUs.....	124
5.6.1	Effect of COVID-19 on children with CCNs and on clinical activity in PICUs.....	125
5.6.2	Visiting restrictions within PICUs for children with CCNs	128
5.6.3	Summary of Lived Space: connections between the child with CCNs and the space they occupy within PICUs.....	129
5.7	Lived Time: Perspectives from a Moment in Time During the COVID-19 Pandemic within PICUs	129
5.7.1	Learning from COVID-19 in the context of children with CCNs in PICUs.....	130
5.7.2	Summary of Lived Time: Perspectives from a moment in time during the COVID-19 pandemic within PICUs.....	133
5.8	Lived Things: The Influence of Material Things on Nurses and Physicians Experiences when Caring for Children with CCNs in PICUs during the Pandemic	134
5.8.1	Changes in day-to-day practices due to COVID-19 relating to children with CCNs.....	134

5.8.2	Allocation of resources in PICUs for children with CCNs	136
5.8.3	Summary of Lived Things: The influence of material things on nurses and physicians experiences when caring for children with CCNs in PICUs during the pandemic.....	138
5.9	Conclusion	139
<i>Chapter Six: Discussion.....</i>		<i>141</i>
6.1	Introduction.....	141
6.2	Lived Body: Daily Experiences of the Care Provided for Children with CCNs during the COVID-19 Pandemic	142
6.3	Lived Other: Therapeutic Relationships Developed during Care Delivery for Children with CCNs during the COVID-19 Pandemic .	150
6.4	Lived Space: Connections between the Child with CCNs and the Space they Occupy within PICUs	154
6.5	Lived Time: Perspectives from a Moment in Time During the COVID-19 Pandemic within PICUs.....	157
6.6	Lived Things: The Influence of Material Things on Nurses and Physicians Experiences when Caring for Children with CCNs during the Pandemic.....	162
6.7	Conclusion	166
<i>Chapter Seven: Conclusion and Implications.....</i>		<i>169</i>
7.1	Introduction.....	169
7.2	Implications of the Research.....	169
7.2.1	Implications for research.....	170
7.2.2	Implications for practice	170
7.2.3	Implications for education	171
7.2.4	Implications for policy.....	172
7.3	Limitations of the Research.....	172
7.4	Unique Strengths of the Research.....	174
7.5	Dissemination	177
7.6	Conclusion	178
<i>References</i>		<i>180</i>
<i>Appendices</i>		<i>242</i>
Appendix 1: Scoping Review Protocol.....		242
Appendix 2: Summary Characteristics of Included Studies		248
Appendix 3: Sample Participant Information Leaflet.....		248

Appendix 4: Online Informed Consent Form	259
Appendix 5: Sample Follow Up Email.....	264
Appendix 6: Interview Schedule	265
Appendix 7: Template for Interview Notes	265
Appendix 8: Probing Questions for the Interview Process.....	267
Appendix 9: Sample Thank You Email.....	268
Appendix 10: Van Manen Stages and NVivo R1 Process.....	270
Appendix 11: Categories and Codes Leading to Theme Development.	271
Appendix 12: Peer Reviewed Conference Presentations and Publications	273

List of Tables

Table 1: Keywords for the literature search strategy.....	27
Table 2: Summary of van Manen’s (1990) six guidelines.....	70
Table 3: Phases of data analysis.....	92
Table 4: Five lifeworld existential themes of human experience.....	97
Table 5: Key strategies adapted from Lincoln and Guba (1985).....	110
Table 6: Profile of participants.....	112

List of Figures

Figure 1: PRISMA flow diagram of the study selection process.....	29
Figure 2: Phases of data analysis.....	90
Figure 3: Lived existential themes with themes identified.....	114

My PhD Journey

Initially this research journey began, with the intention of conducting a research study aiming to explore and understand siblings' lived experiences of living with a child following a traumatic brain injury (TBI); an incident which affects the entire family. These children would typically spend prolonged periods in a paediatric intensive care unit (PICU) post injury, before transferring to a step-down or rehabilitation unit prior to discharge home in the community. TBI is defined as a type of non-degenerative acquired brain injury as a result of an external impact or insult to the brain including a blow, bump or a penetrating head injury that disrupts normal brain functioning, as a result of a cognitive nature, degenerative conditions and birth injuries (Centers for Disease Control and Prevention 2015). TBI in children comes under the growing phenomenon of complex care and chronic illness, as the symptoms may change and develop over time (DePompei & Tyler 2010). Brenner *et al.* (2018a) highlight that complex care needs in children are dynamic, individual and continuing over time, with TBI firmly situated within this area.

The original study was created to give these siblings a voice and an opportunity to share their experiences of living with a child following a TBI. Given the lack of research evidence, there was a need to understand these siblings' experiences to inform the development of best practice for the care for children with TBI and their families. Through doing this, the life of the sibling living with a child post TBI may be made more understandable for the wider multidisciplinary team and other healthcare professionals, both in PICU and post discharge, into the community.

Adams and van Manen (2008) argue that phenomenology focuses on describing and interpreting the experience as it is lived, and not in conceptualising or theorising experience. Interpretative Phenomenological Analysis (IPA) aims to explore, in detail how participants make sense of their personal and social world and lived experiences, rather than by pre-existing

preconceptions (Smith & Osborn 2015). Smith & Osborn (2015) acknowledge that IPA is an effective methodology when exploring complex and emotionally laden topics, such as that of the siblings' experiences. IPA is useful in examining this area due to the detailed attention given to enabling the participant to recount as full as possible account of their experiences.

As children who have had a TBI are a relatively small population in Ireland, there was significant consideration given to the point of access for recruitment prior to seeking ethical approval. Ethical approval was granted from Faculty Ethics in Trinity College Dublin (TCD), in addition to seeking approval from the Data Protection Officer in TCD and completing a Data Protection Impact Assessment. The ethical processes were subsequently sought from three separate locations initially a clinical setting, secondly by a respite and hospice service, and finally through a community agency. At various stages of the process, significant obstacles were presented, primarily difficulty identifying suitable participants due to lack of accepted definitions of TBI, lack of coordination and care, an absence of data registries and coherent understanding, and gaining access to these not easily identifiable families, which contributed to significant delays and the need to access the additional sites.

Since COVID-19 was first identified in December 2019, feedback from clinical sites were increasingly concerning regarding access to families for research purposes. Due to the highly infectious nature of this disease, and the increasingly stricter government restrictions being imposed, homes were closing, and links were shutting down. I was unsure how this was going to affect ongoing access to an already hard to access population. Simultaneously, earlier that year an opportunity had arisen to join another research project, "TechChild. Just because we can, should we? An anthropological perspective on the initiation of technology dependence to sustain a child's life," situated also within the area of complex care. The aim of TechChild is to explore influences on the initiation of technological support which will be required long-term to sustain a child's life and to

develop a theory to explain the initiation of technology dependence in the context of contrasting health, legal and socio-political systems.

As time progressed and with COVID-19 spreading across the world, a parallel piece of work was happening mapping out potential issues around COVID-19 and the impact it may have in the arena of caring for children with complex care needs. This parallel process was continuing with both areas of research throughout. Within this TechChild project, an opportunity arose to pivot from my previous work and to explore the impact of care delivery to children with complex care needs during a global pandemic in PICUs from the perspective of nurses and physicians. This builds on the work already completed in this area of children with complex care needs and also in keeping with the phenomenological methodology, building on the knowledge already gained, but adopting a different approach to answer the research question.

I believe that I have shown resilience and determination to complete this PhD, despite the initial setbacks and challenges I faced, which required me to pivot midway through this process. On reflection, I believe these challenges have helped me to grow and learn as a researcher.

Chapter One: Background

1.1 Introduction

The purpose of this research was to gain an understanding of the experiences and meaning given to care delivery to children with complex care needs (CCNs) in paediatric intensive care units (PICUs) by nurses and physicians during the first 18 months of the coronavirus disease (COVID-19) pandemic. This chapter provides the introduction to the thesis, the background to the topic and the context. It includes a discussion on the care of the child with CCNs in a paediatric intensive care unit (PICU) and what is known about the impact of COVID-19 on these children and on the healthcare system. The chapter begins with providing the background and context for this research, and this is followed by outlining the significance of the research, detailing the aim and objectives of the research, defining key terminology, briefly outlining the research design and providing an overview of the structure of the thesis.

1.2 Background and Context

The global pandemic caused by COVID-19 has affected the health and wellbeing of children across the world (Ashikkali *et al.* 2020, Chanchlani *et al.* 2020, Dokken *et al.* 2020, Fore 2020, Organization for Economic Cooperation and Development 2020). Early research and prevalence rates indicated that COVID-19 predominantly affected older age groups with children generally appearing resilient to more severe disease (Cruz & Zeichner 2020, Ludvigsson 2020, She *et al.* 2020, Zimmermann & Curtis 2021, Chou *et al.* 2022), with evidence suggesting children have a lower susceptibility to infection caused by Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) in comparison to adults (Liguoro *et al.* 2020, Viner *et al.* 2021). From a physical health perspective, children are less directly affected than adults, with different disease characteristics and presentations exhibited in children (Ashikkali *et al.* 2020, Swann *et al.* 2020,

Zheng *et al.* 2020). Hospitalisation rates remained significantly lower in children than in adults with COVID-19, with those with underlying conditions more at risk of hospitalisation (Harwood *et al.* 2022) and intensive care unit (ICU) admission (National Health Library and Knowledge Service Evidence Virtual Team 2021a).

More recent research has highlighted that whilst COVID-19 is usually of short duration in children, with low symptom burden, there are some children who are experiencing prolonged illness duration resulting from COVID-19 (Molteni *et al.* 2021). Children with CCNs are identified as being at an increased risk from severe illness from COVID-19 (National Health Library and Knowledge Service Evidence Virtual Team 2021a) than children with no underlying conditions or comorbidities (Tsankov *et al.* 2021). Despite the lesser impact on physical health, COVID-19 has had a severe impact on children – with significant emotional, social and psychological effects reported in children of all ages, both nationally and internationally (de Avila *et al.* 2020, Gupta & Jawanda 2020, Henderson *et al.* 2020, Idoiaga *et al.* 2020, Jiao *et al.* 2020, Joseph *et al.* 2020, Larcher *et al.* 2020, Lee 2020, McDonnell *et al.* 2020, National Clinical Programme for Paediatrics and Neonatology 2020, Panda *et al.* 2020, Serlachius *et al.* 2020, Shah *et al.* 2020, Singh *et al.* 2020, Chawla *et al.* 2021, Creswell *et al.* 2021, Jones *et al.* 2021, Ravens-Sieberer *et al.* 2021, Sancho *et al.* 2021, Geweniger *et al.* 2022, Senft *et al.* 2022, Sifat *et al.* 2022).

In addition, there has been an unprecedented impact on children's hospitals and healthcare services globally (Ravikumar *et al.* 2020, Zanin *et al.* 2021), for example, many PICUs were transformed into intensive care units (ICUs) to meet the increasing demands of adult patients (Kneyber *et al.* 2020, Levin *et al.* 2020, Paquette *et al.* 2020, Philips *et al.* 2020, Remy *et al.* 2020, Yager *et al.* 2020, Fernandes *et al.* 2021, Mohta *et al.* 2021, Sinha *et al.* 2021). Alongside the changes required in care delivery in PICUs, the COVID-19 pandemic has brought challenges to health services for children. This includes a decrease in usual hospital activity (Hernández-Platero *et al.* 2022), delays presenting to the Emergency Department (ED) (Oostrom *et*

al. 2022) out of fear of contracting COVID-19, and a decline in attending for scheduled hospital appointments leading to serious health consequences for children (Balistreri *et al.* 2021, Lynn *et al.* 2021). Similar findings have been reported across numerous countries including Ireland (Dann *et al.* 2020, McDonnell *et al.* 2020, Conlon *et al.* 2021, Power *et al.* 2021), the United Kingdom (UK) (Harwood *et al.* 2020, Isba *et al.* 2020, Ng *et al.* 2020, Roland *et al.* 2020a, Roland *et al.* 2020b, Sugand *et al.* 2020), Italy (Lazzerini *et al.* 2020, Rabbone *et al.* 2020, Scaramuzza *et al.* 2020, Vierucci *et al.* 2020, Brisca *et al.* 2021), the Netherlands (Jansen & Illy 2020), Germany (Dopfer *et al.* 2020), Canada (Goldman *et al.* 2020), the United States of America (U.S.) (Chaiyachati *et al.* 2020, Cherubini *et al.* 2020, Gerall *et al.* 2020, Sokoloff *et al.* 2021) and Australia (Lawrence *et al.* 2021).

The first identified variants of COVID-19, detected in late 2020 and early 2021, were Alpha (B.1.1.7), Beta (B.1.351) and Gamma (P.1) (Health Protection Surveillance Centre 2022). Since this research was conducted, there have been numerous developments regarding COVID-19 in children. In the summer and winter of 2021, the spread of newer, more contagious variants – including the Delta (B.1.617.2) (King *et al.* 2022) and Omicron (B.1.1.529) (Wang *et al.* 2022) variants – saw children representing a growing percentage of COVID-19 cases. Despite this increase of cases amongst children, leading to a subsequent increase in hospitalisations, reports from the U.S. (Wang *et al.* 2022), South Africa (Cloete *et al.* 2021) and the UK (Scientific Advisory Group for Emergencies 2022) identified that children admitted during these periods had a lower risk of severe clinical outcomes and that hospitals did not report the same intense pressures experienced during the earlier period of the pandemic reported above. Although the emergence of these new variants has led to a rise in paediatric cases, this may have a subsequent impact on children with CCNs, who are more susceptible to serious illness (Driansky *et al.* 2022). However, further research will be needed to determine the ongoing threat of COVID-19 to this cohort of children. The introduction of vaccinations for children against COVID-19 began in a number of countries including Ireland, the U.S. and

Australia during the summer of 2021 and continued to roll out in early 2022 (National Health Library and Knowledge Service Evidence Virtual Team 2021b, Furlong *et al.* 2022, King *et al.* 2022). When the interviews were conducted for this research, there were no vaccinations available outside of clinical trials.

1.3 Significance of the Research

This research is part of the wider programme of research in the *TechChild* project. The *TechChild* project, titled *Just because we can, should we? An anthropological perspective on the initiation of technology dependence to sustain a child's life*, is a five-year programme of research funded by the European Research Council (ERC) which is exploring international influences on the initiation of technological support for children. The overall aim of *TechChild* is to develop a theory to explain the initiation of technology dependence in the context of contrasting health, legal and socio-political systems. This is a multi-method study. This study fits within work package 2, *Exploration of the formal and informal influences on the initiation of technology dependence required long-term to sustain life*. One of the key advantages of being funded by the ERC is that there was funding available within the project at the discretion of the principal investigator to explore any significant issue that arose as a result of early project findings. The organisation of care in PICU was a significant issue that required examination based on early qualitative findings in the wider project. Within this project, my PhD research is specifically examining the lived experiences of nurses and physicians caring for children with CCNs in PICUs across three countries during the first 18 months of the COVID-19 pandemic.

Teti *et al.* (2020, p.1) refer to a pandemic as a “social event that is disrupting our social order”. Aside from the social disruption, pandemics also lead to significant disruptions in economic stability, politics, education and, most significantly, human health (Sergeant *et al.* 2020). As humans, we strive to find meaning and make sense of experiences when life is uncertain (Christianson & Barton 2021). There is a great need for researchers to

explore the lived experiences of healthcare professionals providing care in these disrupted and uncertain times in healthcare delivery. The findings of this research will contribute to understanding the care of children with CCNs in PICUs during a pandemic. Specifically, it will illuminate how the challenge of caring for children with CCNs was managed across international sites and will explore the lived experiences of nurses and physicians providing care in PICUs for children with CCNs during the first 18 months of the COVID-19 pandemic. The challenges which emerge will inform policy and practice across a variety of areas of care for children with CCNs requiring care in PICUs nationally and internationally, including healthcare, education and policy-making.

1.4 Aim and Objectives

The aim of this research was to explore and understand the meaning given to care delivery to children with CCNs in PICUs by nurses and physicians during the first 18 months of the COVID-19 pandemic.

The objectives of this research were:

- 1) To examine experiences internationally of caring for children with CCNs – during the first 18 months of the COVID-19 pandemic – in PICUs.
- 2) To articulate what has been learned from these experiences during a specific time frame of the COVID-19 pandemic, to support ongoing care in PICUs for this population of children.
- 3) To present implications for the enhancement of care and changes to care delivery in PICUs following the pandemic.

1.5 Terminology

Van Mil and Henman (2016) emphasise the importance of providing precise definitions of key terminology when presenting a study to avoid divergent

meanings or misunderstandings occurring. Therefore, key terminology used within this research is further explained in relation to nurses and physicians working in PICU, children with CCNs, PICUs and COVID-19.

1.5.1 Nurses and physicians working in PICU

A multidisciplinary team works within a PICU and comprises professionals such as paediatric physicians, nurses, pharmacists, physiotherapists, dieticians, speech and language therapists, occupational therapists, social workers and psychologists (National Clinical Programme for Critical Care 2019). Nurses and physicians are the core multidisciplinary team members working alongside each other delivering consistent care to children who are critically ill in PICU, supported when necessary, by other members of the multidisciplinary team (Kvande *et al.* 2017, Wheeler *et al.* 2018). Discussions around decision-making in initiating life-sustaining health technology are complex and are usually conducted in a PICU, between physicians, nurses and parents (Larcher *et al.* 2015, Shapiro *et al.* 2017), where teamwork and shared decision-making are crucial. PICUs are high-pressured environments (Prentice *et al.* 2016) and require interprofessional collaboration and good communication to ensure the best possible care is delivered within PICU by physicians, nurses and the wider medical team (Kahveci *et al.* 2014, Kvande *et al.* 2017).

COVID-19 created added complexities for nurses and physicians working in PICU, with radical adjustments required for care delivery. Mostly, nurses and physicians advocated to remain working in PICU, with their well-established working relationships within the PICU teams and familiar environment to care for adult patients there, rather than redeploy to other units (Kneyber *et al.* 2020, Pereira *et al.* 2022). The nurses and physicians worked together to redesign the existing processes of care and educational resources to effectively care for adult patients within PICU (Pereira *et al.* 2022). Whilst, other alternatives were implemented in some PICUs to accommodate the growing number of patients requiring care, including

redeployment of staff to other units (Kanthimathinathan *et al.* 2021a), when nurses and physicians remained in PICU and changed their policies and protocols to accommodate adults, the experiences and feedback from the staff focused around personal and professional growth and positive meaning for the PICU teams (Pereira *et al.* 2022).

1.5.2 Children with CCNs

Children with CCNs refer to children with “multidimensional health and social care needs in the presence of a recognised medical condition or where there is no unifying diagnosis” (Brenner *et al.* 2018a, p.1641). Many children with CCNs have specific medical complexities and intensive care needs, with health and social care services struggling to deliver high quality, responsive care (Brenner *et al.* 2018a), and are affected by a chronic, often very severe condition for the duration of their life (Gordon *et al.* 2007, Dewan & Cohen 2013, Agostiniani *et al.* 2014, Glader *et al.* 2016, Kuo *et al.* 2016, Cohen *et al.* 2018, Kuo 2019, Murphy *et al.* 2020, Gallo *et al.* 2021). Complex care is a growing phenomenon, attributed to advances in western medical, pharmaceutical and technological therapies (Brenner *et al.* 2018a). With these continued advances in medicine and technology, it is anticipated that the need for complex care services for children will continue to increase in the coming years (Hewitt-Taylor 2005, Brenner *et al.* 2018a) and, all the while, the impact of the needs of these children on health systems is constantly growing.

Children with CCNs may have a range of conditions, including acquired or congenital multisystem disease and severe neurological conditions with significant functional impairment – and/or may require technology dependence (Cohen *et al.* 2011, Cady *et al.* 2015, Huth *et al.* 2018, Gallo *et al.* 2021). Children who have CCNs are dynamic with individual needs and require the highest standard of care delivery (Brenner *et al.* 2018a). The child may experience acute exacerbations of illness where hospitalisation and potentially PICU admission is required (Brenner *et al.* 2018b). Disease

progression for these children can also lead to new problems emerging, with some of these children potentially requiring palliative care at some stage throughout their disease trajectory (Brenner *et al.* 2018b). The symptoms and diseases associated with complex care interfere with normal activities, routines and day-to-day living (Hobson & Noyes 2011, Hillis *et al.* 2016, Brenner *et al.* 2021). There is a strong multidisciplinary consensus that social and community service developments often struggle to keep pace with medical progress for this population (Woodgate *et al.* 2016, Ranade-Kharkar *et al.* 2017, Verberne *et al.* 2017, Brenner *et al.* 2018b).

Many children with CCNs can survive for months to years, although their ongoing needs can require intensive medical care. There is an increasing number of children with CCNs who are dependent on clinical, life-sustaining technology to save lives (Amin *et al.* 2014, Weiss *et al.* 2016) including long-term ventilation (Alexander *et al.* 2021) – with this dependence most commonly initiated in a PICU. Children with CCNs are living longer due to overall improved medical treatment and technological advances of recent decades (Cohen & Patel 2014, Brenner *et al.* 2018b, Brenner *et al.* 2018c). These children often spend substantial periods in hospital, resulting in extensive utilisation of PICU resources, prolonged PICU stays due to fluctuations in care needs, and persistent exacerbations of their illnesses (Simon *et al.* 2010, Simon *et al.* 2012, Agrawal *et al.* 2016, Chan *et al.* 2016, Pordes *et al.* 2018). Additionally, numerous studies found that children with more complex and chronic conditions had an increased rate of PICU admissions (Dosa *et al.* 2001, Namachivayam *et al.* 2012, Edwards *et al.* 2013, Oztek Celebi & Senel 2021).

Children with CCNs are commonly being discharged home with complex medical interventions requiring the oversight of highly-skilled medical and nursing care (Elias & Murphy 2012, Page *et al.* 2020). Additionally, children who are ventilator or technology dependent as a result of these complex care conditions or underlying healthcare needs can thrive outside of the ICU and hospital setting when they can be cared for at home with appropriate supports in place (Preutthipan 2015, Moore *et al.* 2016, Edwards *et al.* 2017,

Choi & Park 2019, Brenner *et al.* 2020, Saddi *et al.* 2020). These associated medical interventions and treatments can contribute to a disruption of daily living (Elias & Murphy 2012). Most often, the provision of these expert medical skills and care coordination activities falls on the parents or primary guardians, placing additional demands on the family (Breneol *et al.* 2019).

Many of the children who have repeated and extended stays in hospital fit within this category of CCNs (Brough *et al.* 2014, Salem & Graham 2021). Numerous blueprints, such as the Complex Chronic Conditions Algorithm and Pediatric Medical Complexity Algorithm, have been created to identify this subset of the paediatric population (Cohen *et al.* 2011, Feudtner *et al.* 2014, Simon *et al.* 2014). These blueprints outline a range of underlying medical conditions which account for >50% of patients admitted to PICUs (Chan *et al.* 2016). This cohort of children has cognitive, functional and neurological impairments with some requiring chronic dependence on technology, including feeding tubes (Nelson *et al.* 2019), cerebrospinal fluid shunts (Hanak *et al.* 2017) and mechanical ventilation (Chiang & Amin 2017). These children have an increased risk of admission to a PICU and are at high risk of prolonged stays in PICUs (Chan *et al.* 2016, Gold *et al.* 2016).

Families with children who have CCNs in a PICU need open, honest communication with healthcare professionals, provided in a timely manner (Rennick *et al.* 2019). Continuity of nursing care for children with CCNs is highly valued by parents within the PICU (Baird *et al.* 2016), alongside a partnership approach to care with the child and their family (Micalizzi *et al.* 2015, Rennick *et al.* 2019). Decision-making in the best interests of the child is a fundamental concept in children's nursing (Birchley *et al.* 2017, Fernandez *et al.* 2019), and is crucial for children with CCNs and their families. Healthcare professionals within PICUs are faced with the challenge of shared, decision-making with parents on a continuous basis, with all decisions made focused around the best interests of the child and family (Richards *et al.* 2018). Additional supports and counselling for families, from healthcare professionals are required when making complex care decisions

for these children (Michelson *et al.* 2013, Mitchell *et al.* 2019, Wool *et al.* 2021). These decisions within PICUs include the need for tracheostomy placement, possible dependence on mechanical ventilation, withdrawal of treatment or the need for additional, invasive procedures (Jurasinski & Schindler 2014, Rhee & Morrison 2018).

1.5.3 PICUs

A PICU provides an increased level of clinical observation, invasive monitoring, specialised interventions and technical support to care for critically ill children over an indefinite period of time (Menzies *et al.* 2016). PICUs care for children from birth and typically to their 18th birthday, although some children from the age of 16 will be cared for in an adult ICU (Brick & Parslow 2019). Globally, children are admitted to a PICU for a variety of reasons including: post complex surgery requiring continuous monitoring (Thavagnanam *et al.* 2018); exacerbations of medical conditions including asthma and diabetes (Ibiedebele *et al.* 2018); management of neurological conditions (Haque *et al.* 2015); post severe accident or injury (Namachivayam *et al.* 2010); the requirement of mechanical ventilation (Oxford University Hospitals NHS Trust 2015) and life-limiting or complex conditions (Fraser & Parslow 2017).

Admission rates to PICUs vary across the world. According to the Paediatric Intensive Care Audit Network (PICANet 2020a) the number of admissions per year to PICUs in the UK and Ireland showed a steady increase between 2017 and 2019 from 19,869 to 20,383. Between the years of 2017 and 2019, PICUs across the UK and Ireland delivered, on average, approximately 142,000 bed days (PICANet 2020a). Admission rates to PICUs varied, ranging from 132 per 100,000 children in the Republic of Ireland to rates of 165 and 168 in Northern Ireland and Scotland, respectively (PICANet 2020a). The Australian and New Zealand Paediatric Intensive Care Registry recorded 12,619 paediatric admissions to PICUs, equating to 45,157 bed days used during 2018 and 2019 (Australian and New Zealand Intensive Care Society 2019). In the U.S., Horak *et al.* (2019) also reported an

increase in PICU bed use over a 15-year period (2001 to 2016), due to an increase in the U.S. paediatric population over this time period.

Children who have CCNs have a greater risk of PICU admission if they become acutely unwell, along with having extensive medical needs which continue long after the reasons for admission to the PICU have been resolved – needs which require extensive discharge planning (Rennick & Childerhose 2015, McAllister *et al.* 2021). This concept is reflected throughout international literature (Edwards *et al.* 2012, O'Brien *et al.* 2016, Kalzén *et al.* 2018, López *et al.* 2020, Piva & Fontela 2020). As a result of the global COVID-19 pandemic, there has been a direct impact on care delivery within PICUs, with some PICUs having to support adult ICUs, resulting in many PICUs experiencing significant disruptions with elective surgical activity for children requiring postoperative PICU admission, as well as trying to cope with the problems associated with the redeployment of PICU staff to ICUs and restricted visiting within PICUs (Kanthimathinathan *et al.* 2021a).

1.5.4 COVID-19

The current COVID-19 pandemic has been caused by a coronavirus named SARS-CoV-2 (World Health Organization [WHO] 2020). At present, the zoonotic source of the coronavirus is unknown. However, all available evidence indicates that SARS-CoV-2 is not a manipulated or constructed virus but has a natural animal origin with the biggest link currently to bats (WHO 2020). Ongoing research is occurring to determine the exact source of the outbreak in China (Wu & McGoogan 2020). The first human cases of COVID-19 were reported from Wuhan, China in December 2019 (WHO 2020) and since then COVID-19 has spread rapidly across the globe (Kumar *et al.* 2021). The outbreak was declared a Public Health Emergency of International Concern in January 2020, and a pandemic in March 2020 due to the worldwide spread of this new disease (Cucinotta & Vanelli 2020).

COVID-19 is a disease which affects the lungs and airways (Brosnahan *et al.* 2020). While fewer children have been sick with COVID-19 compared to the adult population, children can become infected with COVID-19 (Zanin *et al.* 2021). Data published to date indicates that the main reason for children to be admitted to PICUs with COVID-19 has been respiratory illness, particularly in children with comorbidities and complex conditions (Shekerdemian *et al.* 2020). It is estimated that between 1 and 5 children in 100,000 need to be admitted to hospital for COVID-19 and even fewer of this cohort require PICU admission (RCPCH 2021a). In Wuhan, China at the centre of the COVID-19 outbreak, a retrospective study was carried out at three hospitals over a nine-day period and found that of 366 children hospitalised with respiratory infections, just six children had COVID-19 detected, with only one child requiring admission to a PICU (Liu *et al.* 2020). Over a three-month period in the U.S., a total of 74 children were admitted to PICUs across 19 states (Pathak *et al.* 2020). Additionally, another study conducted in the U.S. across 184 hospitals showed that 78 children were admitted to PICUs with COVID-19 during a seven-month period (Kim *et al.* 2021), with only one child dying during this period. In a six-month period in the UK, 90 children were admitted to a PICU with a positive diagnosis of COVID-19, testing positive for the virus either prior to being admitted or during their stay in the PICU (PICANet 2020b).

Children can get very sick from clinical presentations linked to COVID-19, for example, acquiring paediatric multisystem inflammatory syndrome (PIMS) – and children can spread the virus to others (Makiello *et al.* 2020, Centers for Disease Control and Prevention 2021). PIMS is an extremely rare inflammatory condition and occurs in less than 0.5% of children who have, or previously had, COVID-19 (Royal College of Paediatrics and Child Health [RCPCH] 2021a). Children with PIMS usually require admission to PICUs for medical treatment and close observation (Nijman *et al.* 2020). There have been reports from a number of countries – including France (Pouletty *et al.* 2020), Italy (Verdoni *et al.* 2020), Switzerland (Belhadjer *et al.* 2020), the UK (Hameed *et al.* 2020, Whittaker *et al.* 2020), and the U.S. (Capone *et al.* 2020) – confirming children requiring PICU admission due

to PIMS. One report from the UK indicated that, over a six-week period, 78 cases of PIMS were reported in 21 out of 23 PICUs (Davies *et al.* 2020). Whilst the immediate survival rate is high in this cohort, the long-term outcomes for children with PIMS are unknown (Davies *et al.* 2020).

COVID-19 has also led to increased conversations in healthcare and in the media around the allocation of resources for children with CCNs and to discussions around the provision of care where there is a significant deterioration in a child's clinical condition. Children with CCNs, particularly those with immune and neuromuscular problems, or those with chronic illnesses, may be more at risk of complications from COVID-19 (Leoni *et al.* 2020, Thompson & Rasmussen 2020, Wong *et al.* 2020). Children with CCNs are susceptible to not just the primary complications of COVID-19, but also the related indirect effects and consequences of the pandemic (Canadian Paediatric Society 2020, Wong *et al.* 2020). Children with CCNs have had care delivery significantly affected by the pandemic, including disruption to regular medical services (Chanchlani *et al.* 2020), postponing of hospital admissions for medical procedures, and an interruption of necessary therapies (Driansky *et al.* 2022). These changes have occurred alongside the indirect impact of the pandemic including outcomes such as poorer child health and development, school closures, poorer parental mental health, increased household stress, and reduced family income due to job losses (Goldfeld *et al.* 2022). These factors, resulting from the COVID-19 pandemic have the potential to widen existing disparities in child health for these children and their families (Goldfeld *et al.* 2022). There is limited research available in this area at present, with one study by Hall *et al.* (2022) recognising the challenges associated with caring for children with tracheostomies during the COVID-19 pandemic for both healthcare professionals and parents. The healthcare professionals and parents in this study reported on the significant adaptations required to care for these children, including adapting to continual changing guidelines regarding best practice, coping with uncertainty, and disrupted support and isolation for families.

COVID-19 has impacted all aspects of healthcare delivery – including the care delivered in PICUs, both for children admitted with COVID-19 and associated complications and those without COVID-19 – alongside the general adjustments required for effective care delivery during a pandemic. These adjustments include, but are not limited to, the reallocation of resources and redeployment of staff to manage a surge of patients within PICUs (Jenkins *et al.* 2020, Chomton *et al.* 2021, Fernandes *et al.* 2021), the specific practices around the management of patients infected with COVID-19 (Kache *et al.* 2020), the visiting restrictions within PICUs (Zeng *et al.* 2020, Lorenzi *et al.* 2021, Moraes & Mendes-Castillo 2021), and the additional training and education required for healthcare staff (Temsah *et al.* 2021a).

These adjustments to care delivery have a significant impact on healthcare staff, requiring them to adjust their own practices, learn new skills and in some circumstances become competent in caring for different cohorts of patients, for example, caring for adults instead of children (Fernandes *et al.* 2021, Sinha *et al.* 2021). Recent research has begun to explore the psychological impact of COVID-19 on healthcare staff working within critical care (Ffrench-O'Carroll *et al.* 2020, Gavin *et al.* 2020, Jain *et al.* 2020, Kang *et al.* 2020, Khanal *et al.* 2020, Shen *et al.* 2020, Montgomery *et al.* 2021), the challenges faced as a result of COVID-19 (Ulrich *et al.* 2020, Moradi *et al.* 2021, Razu *et al.* 2021, Setiawan *et al.* 2021), and their experiences of working during the COVID-19 pandemic (Ardebili *et al.* 2020, Montgomery *et al.* 2021, Andersson *et al.* 2022). However, to the best of my knowledge, no research has been carried out exploring the experiences of nurses and physicians delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. It is important to examine what has been learned from the healthcare professionals delivering care during the COVID-19 pandemic to support ongoing individualised care for this population of children. Through using a hermeneutic phenomenological research design, this learning will be explored in this research.

1.6 The Research Design

Hermeneutic phenomenology aims to provide an understanding of a phenomenon from the perspective of those who have experienced it, with an emphasis on interpretation and analysis of texts (van Manen 1990). Through examining historical and methodological perspectives, differentiations between phenomenology and hermeneutic phenomenology can be made (Sloan & Bowe 2014). Hermeneutic phenomenology was closely aligned with the goals of this research, and the rationale for this choice is further explored in Chapter Three. Due to the emergent nature of COVID-19, little is known about the subject area of nurses' and physicians' experiences of care delivery in PICUs for children with CCNs. As this research is concerned with increasing the knowledge base, hermeneutic phenomenology and the in-depth exploration of the meaning given to care delivery in PICUs during a pandemic was the preferred research design. Examples of studies in the adult population using hermeneutic phenomenology include those conducted by Bagherian *et al.* (2017) and Limbu *et al.* (2019) who examined the lived experience of intensive care nurses caring for critically ill patients. The approach of van Manen combines descriptive and interpretive features (Matua & Van Der Wal 2015) and through the adoption of van Manen's approach (1990, 1997), structure was provided to the research process.

1.7 Structure of the Thesis

Chapter Two presents existing national and international research in the form of a scoping review on what is known about the organisation of care delivery in PICUs during the first 18 months of the COVID-19 pandemic.

Chapter Three considers the epistemological, ontological and philosophical assumptions that underpin this research. Hermeneutic phenomenology and its tenets are explored in the context of this research, and the rationale for choosing this approach is presented.

Chapter Four presents the methods employed and the research design implemented. This includes detail on the approach and processes of sampling and recruitment, ethical considerations, gatekeeping and data collection methods. The rigour and integrity of the research is discussed and the mechanisms for data analysis are explained.

Chapter Five focuses on the presentation of the findings through the use of van Manen's (1990) framework for thematic analysis.

Chapter Six provides a critical discussion of the key findings from this research and the relationship with current published research.

Chapter Seven concludes with a final summary of the findings related to the research objectives and the significance and implications of the research. The strengths and limitations of the research are discussed. Implications for consideration for future research are also presented.

1.8 Conclusion

This chapter began with providing the background and context for this research, including providing an overview of what is known about COVID-19 in children and briefly exploring the impact of COVID-19 on children. This was followed by outlining the significance of this research and detailing its aim and objectives. Key terminology was then defined in the context of this research including exploring the concepts of children with CCNs and PICUs. This was followed by briefly outlining the research design and providing a rationale for the purpose of this research. Finally, a brief synopsis of each chapter was presented to provide an overview of the structure of the thesis.

This chapter was key to contextualising this research and setting the scene. The research was underpinned by the desire to explore nurses' and physicians' lived experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. Currently, to the best of my knowledge, there is no such research which has investigated

this area and given the impact of the situation COVID-19 is having on healthcare services globally, it is one of significant importance. In conclusion, this chapter has identified where this research has emerged from and the importance of this research in a global arena. The next chapter presents a scoping review of the relevant literature pertaining to the organisation of care in PICUs during the COVID-19 pandemic.

Chapter Two: Scoping Review of the Organisation of Care in PICUs

2.1 Introduction

Building on Chapter One, this chapter provides a scoping review of the organisation of care in PICUs during the first 18 months of the COVID-19 pandemic. It includes background information for the study, and presents the context for the experiences of the nurses and physicians, across PICUs during the COVID-19 pandemic, while delivering care to children with CCNs. The framework for this scoping review is presented, followed by detailed findings from the literature and a discussion of what was reported about the organisation of care during the specified time period.

2.2 Background

On 11th March 2020, the WHO officially declared COVID-19 a pandemic (WHO 2020), and it placed an extraordinary demand on global adult critical care services, even causing some health systems to collapse (Huang *et al.* 2020, Philips *et al.* 2020, Girona-Alarcon *et al.* 2021). This was evident early on in healthcare services in Spain and Italy, with clear evidence that other countries, including the UK and the U.S. would face similar challenges (Rosenbaum 2020). During the first 18 months of the pandemic, the ethical principles of fair resource allocation and the concept of doing all that is possible, required that resources for caring for critically ill patients be shared (Chomton *et al.* 2021), to ensure the maximum benefit from collective resources (Jansen *et al.* 2020). This unprecedented demand for healthcare services had a substantial impact on children's hospital services. Researchers reported the restructuring of entire children's hospitals (Philips *et al.* 2020, Villa-Guillén *et al.* 2021), with practices being adjusted in children's EDs (Doná *et al.* 2020, Raucci *et al.* 2021), children's outpatient departments (Kumar *et al.* 2020), children's surgical services (Farooq *et al.* 2021), and within PICUs (Levin *et al.* 2020). Worldwide, there is a strong emphasis in the literature on changes in care being delivered to those in adult ICUs and PICUs.

Paediatric critical care medicine is a relatively young subspeciality, with the paediatric section of the Society of Critical Care Medicine only being established in 1981, and the first PICU was created in Sweden by Goran Haglund as late as 1995 (Epstein & Brill 2005). Since then, paediatric critical and intensive care medicine have rapidly evolved into a highly complex and intricate medical field (Epstein & Brill 2005). PICUs are high-acuity units that provide an increased level of clinical observation, invasive monitoring, specialised interventions and technical support, to care for critically ill children around the clock, over an indefinite period of time (Menzies *et al.* 2016, Rodriguez-Rubio *et al.* 2020). PICUs typically care for children from birth, up to the age of 18, although some children might be cared for in an adult ICU from the age of 16 (Brick & Parslow 2019). Within a PICU, there are multidisciplinary teams of highly-skilled specialists and professionals such as paediatric physicians, nurses, pharmacists, physiotherapists, dieticians, speech and language therapists, occupational therapists, social workers and psychologists (National Clinical Programme for Critical Care 2019).

In addition to the general adjustments required for effective care delivery during a pandemic, COVID-19 has had an impact on all aspects of healthcare delivery, including the care delivered in PICUs, both for children admitted with COVID-19 and associated complications and those without COVID-19. Recent research has begun to explore the psychological impact of COVID-19 on healthcare staff working within critical care (Ffrench-O'Carroll *et al.* 2020, Gavin *et al.* 2020, Jain *et al.* 2020, Kang *et al.* 2020, Khanal *et al.* 2020, Shen *et al.* 2020, Rasmussen *et al.* 2022), the challenges faced as a result of COVID-19 (Ulrich *et al.* 2020), and healthcare staff experiences while working during the COVID-19 pandemic (Ardebili *et al.* 2020, Bennett *et al.* 2020, Vindrola-Padros *et al.* 2020, Liberati *et al.* 2021).

As the demands on the resources of adult ICUs increased worldwide during the pandemic, there were significant adjustments required in some PICUs, including transitioning into adult ICUs to meet the increasing demands of

adult patient needs (Kneyber *et al.* 2020, Levin *et al.* 2020, Paquette *et al.* 2020, Remy *et al.* 2020, Yager *et al.* 2020, Fernandes *et al.* 2021, Sinha *et al.* 2021). Lynn *et al.* (2021), found that in Ireland and the UK, the COVID-19 pandemic brought additional challenges to healthcare for children. These ranged from delays in presenting to the ED out of concern for contracting COVID-19, to a decline in presenting for scheduled hospital appointments, leading to serious health consequences for children. Similar findings have been reported in additional studies in Ireland (Dann *et al.* 2020, McDonnell *et al.* 2020, Power *et al.* 2021), the UK (Harwood *et al.* 2020, Isba *et al.* 2020, Ng *et al.* 2020, Roland *et al.* 2020a, Sugand *et al.* 2020), and across numerous other countries including Italy (Lazzerini *et al.* 2020, Rabbone *et al.* 2020, Scaramuzza *et al.* 2020, Vierucci *et al.* 2020), the Netherlands (Jansen & Illy 2020), Germany (Dopfer *et al.* 2020), Canada (Goldman *et al.* 2020), the U.S. (Chaiyachati *et al.* 2020, Cherubini *et al.* 2020, Gerall *et al.* 2021), and Australia (Lawrence *et al.* 2021).

Christian and Kissoon (2020), discuss a specific issue that arose in the UK and Canada, relating to the access to life-supporting technology in PICUs. This discussion focused on concerns around the fact that many ventilators in PICUs were not being used. They argue that allowing adults to die while ventilators in PICUs sit unused is unethical and reason there must be a process in place within healthcare systems to make decisions regarding the allocation of critical care resources, while being cognisant of the ethical dilemmas and medical complexities of allocating resources between children and adults. This is mirrored across government publications and other research, which highlight the importance of allocating resources fairly and maximising the benefit gained, despite the limited availability (Department of Health 2020, Kirby *et al.* 2021, Zanin *et al.* 2021).

Globally, children are admitted to PICUs for respiratory and or haemodynamic monitoring for a variety of reasons. These include post trauma, post-surgery, the management of medical conditions, the management of complex implications in life-threatening illnesses, and post complex surgery, requiring continuous monitoring (Thavagnanam *et al.*

2018). Additionally, children with exacerbations of medical conditions (Haque *et al.* 2015, Ibiebele *et al.* 2018), post severe accident or injury (Namachivayam *et al.* 2010), and those with life-limiting or complex conditions, can also be admitted to PICUs (Oxford University Hospitals NHS Trust 2015, Fraser & Parslow 2017).

The restructuring of PICUs and paediatric hospitals to accommodate critically ill adults, must take into consideration these categories of children who are admitted to PICUs on a daily basis. Across the U.S., França and McManus (2020), suggest the consolidation of paediatric hospital beds, and a coordinated approach between services to benefit both adults, and paediatric populations. It was previously suggested in the U.S., that at least 1 in 5 admissions to children's hospitals can be considered elective, with admissions to general hospitals tending to have a shorter length of stay (Leyenaar *et al.* 2016). While the clinical presentation of children in hospital during the pandemic did not meet these statistics, nonetheless, it does suggest some opportunity for a review of resources, with the potential to accommodate adult patients. The practicalities of this, however, would depend on numerous factors, including local practice operating guidelines and the surge in patients associated with COVID-19 (Children's Hospital Association 2020).

Since the emergence of COVID-19 in December 2019, the experience in China and Italy suggested that 98% of all infections were in adults, with at least 5% of adults infected with COVID-19 requiring critical care admission (Sinha *et al.* 2021). Only 2% of infections were in the paediatric population, with just 1-2% of those requiring admission to PICUs (Dong *et al.* 2020, Guan *et al.* 2020, Livingston & Bucher 2020, Wu *et al.* 2020). In the initial surge of COVID-19, the occurrence of the disease in children was uncommon, with a reported mean age for most patients in adult ICUs being between 65 and 70 years (Huang *et al.* 2020, Murty *et al.* 2020, Wang *et al.* 2020, Zheng *et al.* 2020, Zhou *et al.* 2020). Where COVID-19 has presented in children, those with symptoms rarely develop into requiring admission to PICUs (Ong *et al.* 2020). In adults, the virus causes severe acute respiratory

distress syndrome (Girona-Alarcon *et al.* 2021). In children, the disease appears to be milder, but a severe multisystem inflammatory syndrome (PIMS) has been reported, with children in this category, most frequently requiring admission to PICUs (Ahmed *et al.* 2020, Shobhavat *et al.* 2020, Asseri *et al.* 2021, Hasan *et al.* 2021).

Within this context, the primary aim of this scoping review was to categorise the evidence, map out the existing studies and explore what was known about the organisation of PICUs during the first 18 months of the COVID-19 pandemic. It aimed to explore and summarise the evidence available and the diversity of the studies published. The secondary aim was to identify any knowledge gaps in the literature and recommend areas for future research.

2.3 Methods

2.3.1 Scoping review design and data collection

As a result of rapidly emerging new research studies, the knowledge of the COVID-19 pandemic within the healthcare system is dynamic. A scoping review was chosen as the most appropriate approach to collating and critiquing the current research and the transitions in the organisation of care occurring in PICUs as a result of the pandemic. The scoping review method is used to describe and map out existing literature, and commonly includes findings from a range of different study designs and methods (Pham *et al.* 2014). This method can be particularly useful when the information on a topic has not been comprehensively reviewed, which is the case with the continuing emergence of evidence regarding healthcare practices during the COVID-19 pandemic (Sucharew & Macaluso 2019).

This scoping review employed a recommended framework introduced by Arksey and O'Malley (2005) and further developed in more recent works (Pham *et al.* 2014, Tricco *et al.* 2016, Munn *et al.* 2018).

The steps in the framework include:

- 1) Identification of the research question with a broad scope: *How was care organised in PICUs during the first 18 months of the COVID-19 pandemic?*
- 2) Identification of relevant studies.
- 3) Selection of the studies as per the scoping review protocol (Appendix 1) (Hill *et al.* 2022).
- 4) Data charting and extraction of relevant information from the reviewed literature into an Excel sheet.
- 5) Collation, summarising and reporting results in tables according to the key themes.
- 6) Consultation with experts – as outlined in the review protocol the reviewers were experienced in children's nursing, with one having a background in children's intensive care nursing. Relevant experts working in PICUs were consulted to confirm that the keywords and inclusion criteria were appropriate. No further consultation was required throughout the process.

2.3.2 Identification of relevant studies

A comprehensive search was conducted using the following databases: CINAHL Complete, MEDLINE, PsycINFO, PsycARTICLES and EMBASE. These sources included journals in the area of healthcare. Grey literature was explored due to the speed with which services have had to respond to the pandemic since recommendations may have been made through guidelines, emergency directives and consensus pieces, which may not be available through other sources. It was included in the data searching to ensure all relevant evidence in this arena was explored and was accessed via the OPENGREY and the Grey Literature Report databases. The inclusion criteria for this review were based on the population-concept-context framework, as recommended by the JBI (formerly known as the Joanna Briggs Institute) (Peters *et al.* 2020). Table 1 (below), outlines the keywords that were used as search terms.

Table 1: Keywords for the literature search strategy

Population	Concept	Context
Paediatric/pediatric intensive care units OR PICU OR intensive care units OR ICU OR high dependency units OR HDU OR critical care unit OR CCU OR nurses OR physicians OR healthcare staff	Organisation OR organization OR activity OR development OR changes OR adjustments OR advances OR modifications OR transitions OR transformations OR shift OR revision OR switch OR reversal	Worldwide OR global OR national OR international OR pandemic OR COVID-19 OR coronavirus

These keywords were used to search across all fields for items that were published relating to the first 18 months of the COVID-19 pandemic. The search took place between the 15th and 20th of June 2021, and re-run during the same period in June 2022 to check for any updated literature, resulting in 82,803 papers. They included peer-reviewed academic articles, discussion papers, research studies, editorials and commentaries. Given the diversity of publication types, the assessment of methodological quality was not feasible in any meaningful way. This is a common feature of scoping reviews and makes them different to systematic reviews (Munn *et al.* 2018). Manual searches of the reference lists from the included articles were carried out to cover the breadth of existing evidence, resulting in an additional 479 articles published within the time period and fulfilling the scoping review protocol for full-text reading.

2.3.3 Study selection

The criteria used for study selection were narrow, with articles included for full-text reading if they focused on activity in PICUs from any country. Any articles focusing on other areas of paediatric healthcare e.g., EDs or outpatients, were excluded. Any articles that focused only on adult hospitals were excluded.

After the first, title-based, screening process, 82,439 had been excluded, leaving 843 for next stage screening. Based on the screening of abstracts, 671 were excluded, with 172 articles selected for full-text reading. Following the removal of 61 duplicates, the final number of articles for full-text reading was 111. On reading, 25 articles met the criteria for the extraction of relevant information. The inclusion and exclusion of articles was discussed and agreed between the reviewers (Levac *et al.* 2010). No discrepancies occurred with any of the decisions, therefore an additional reviewer was not consulted. The reasons for excluding articles included, those focused on non-PICU settings including general wards in children's hospitals or adult wards, some that explored healthcare professionals' experiences not working in PICUs and some that related to the impact of COVID-19 on child health. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 1) was produced after the completed searches to ensure transparency of reporting (Peters *et al.* 2020) and outlined the process through which articles were included and excluded from the review (Moher *et al.* 2009).

A small number of PICUs retained their sole purpose, that of looking after children, and did not admit adult patients (Araujo *et al.* 2020, Ong *et al.* 2020, Zeng *et al.* 2020, Esposito *et al.* 2021, Sperotto *et al.* 2021, Tedesco *et al.* 2021, Williams *et al.* 2021). Articles dealing with this circumstance were subsequently excluded from this review as they did not meet the criteria. Other studies reported on the redeployment of staff from PICUs into adult ICUs, as a result of the pandemic, to increase the capacity for adult ICU beds (Kerr-Elliot & Bichard 2020, Arizcun *et al.* 2021). These studies were also excluded from this review as their aim did not meet the inclusion criteria.

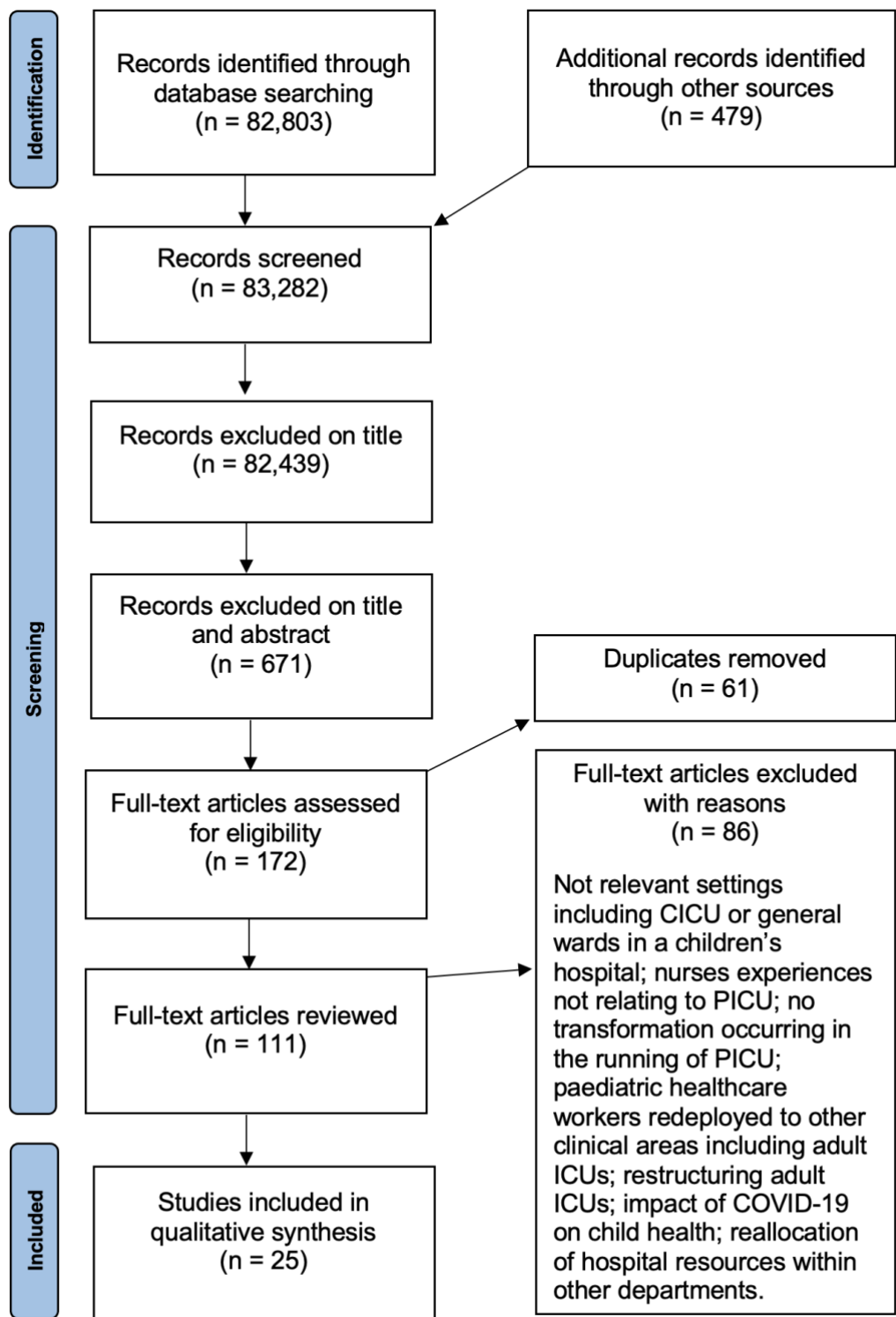


Figure 1: PRISMA flow diagram of the study selection process

2.3.4 Data charting

A data chart template was created for each article and included: the title, authors, journal/source, country, type of study, the aim, setting, study participants, main results, limitations, strengths and recommendations. Where the authors did not provide certain data e.g., regarding limitations, not applicable ('N/A') or not disclosed was entered into the table under the relevant headings. As recommended by Daudt *et al.* (2013), each data charting form was given a unique code to assist with identification and discussion within the review team. The first few data extractions and categorisations of articles were completed independently by two reviewers (KH & MB) and were compared to pilot the tool, while also assessing if the results were consistent with the research question. Daudt *et al.* (2013) advocate this approach to improve the data charting phase, to ensure the review question could be answered. Following the successful completion of these initial data extractions, the extraction and categorisation of data for each subsequent article was completed by one of the reviewers (KH), while a second reviewer (MB) assessed the process to identify any errors, although none were noted.

2.3.5 Results overview

The extracted data was used to produce a summary overview according to the key themes presented within the results section (Pham *et al.* 2014), and to make recommendations based on the conclusions discussed in the studies. Thematic analysis was used to analyse the findings of the studies, using qualitative descriptive methods to review the literature as advised by Levac *et al.* (2010). Findings were grouped into thematic categories and the key findings are presented below. The results illustrate the changes occurring within PICUs during the first 18 months of the COVID-19 pandemic.

2.3.6 Study types and countries

There were a variety of study designs and publication types included within the selected articles of this review. They were studies with primary data,

commentaries, reviews and opinion pieces. Specifically, there were 11 studies with primary data including retrospective chart reviews, and 14 review papers which included literature reviews, reflective pieces and discussion papers. The list of publications included articles from the U.S. (13), the UK (3), the UK and Canada (1), the UK and the U.S. (1), France (3), Spain (1), Australia (1), the Netherlands (1) and a study across a European Network (Ireland, Italy, Spain, Finland, Latvia, Poland, the Netherlands) and the UK (1). Interestingly, no studies were found from China or Italy that met the criteria, which were initially two of the worst affected countries by COVID-19 (Chen *et al.* 2020). Appendix 2 provides the study characteristics of the included studies.

2.4 Results

Three main themes emerged from the articles reviewed: 1) the reorganisation of space for increased capacity incorporating equipment and supply changes; 2) increases in staffing and support including training, clinical care and governance; and 3) the resulting challenges.

2.4.1 Reorganisation of space for increased capacity

A number of PICUs reorganised their structures to accommodate both child and adult patients (Abulebda *et al.* 2020, Deep *et al.* 2020, Gerall *et al.* 2020, Kneyber *et al.* 2020, Levin *et al.* 2020, Sachdeva *et al.* 2020, Girona-Alarcon *et al.* 2021, Indolfi *et al.* 2021, McNamara *et al.* 2021, Sinha *et al.* 2021, Siva *et al.* 2021), with others refocusing to care for adult patients only (Joyce *et al.* 2020, Yager *et al.* 2020, Chomton *et al.* 2021, Fernandes *et al.* 2021, Geslain *et al.* 2021, Gist *et al.* 2021, Poncelet *et al.* 2021, Potts *et al.* 2021, Wasserman *et al.* 2021). These hybrid models required significant adaptation to manage two very different cohorts of patients, by the same staff and within the same space (Deep *et al.* 2020).

The transformation of PICUs to accommodate critically ill adults occurred rapidly, usually in less than 2-3 weeks, with some units transforming within as little as 10 days (Levin *et al.* 2020) In some hospitals, the restructuring of

departments and units occurred alongside the cancellation of non-emergency theatre lists to free up critical care capacity. This enabled an expansion to care for children alongside adults on ventilators (McNamara *et al.* 2021). A number of other studies during this period, reported on this hybrid model of caring concurrently for children and adults (Deep *et al.* 2020, Levin *et al.* 2020), as a result of the declining needs of children undergoing elective surgeries, and the low disease burden associated with COVID-19 in children. The reported facilitation and benefits of transforming PICUs when a children's hospital was situated within an adult hospital, included shared administration, management, resources and supply chains. Although preparation time was very short, strong multidisciplinary team cooperation helped to maximise the effective transformations from PICUs into adult ICUs (Sinha *et al.* 2021).

In a prospective, observational, cohort study in a PICU in Spain – which cared for both adults (n = 16) and children (n = 4) – children and adults showed different manifestations of COVID-19 (Girona-Alarcon *et al.* 2021). Children were admitted due to shock and haemodynamic issues, with adults requiring mainly respiratory support. The authors believe this could be due to how the inflammatory response to COVID-19 differs in adults and children, being localised within the lungs and generalised as a multisystem syndrome, respectively. The adult patients who were referred to the PICU were mainly young adults with little or no history of disease. The author highlights that she only had a small sample size, and that since the adults were young, the results may not be transferable to other populations (Girona-Alarcon *et al.* 2021). However, these results are strengthened by similar findings reported across other studies (Joyce *et al.* 2020, Levin *et al.* 2020).

A number of studies reported on hospitals completely converting their PICUs to care for adults instead of sending their resources to adult hospitals (Joyce *et al.* 2020, Remy *et al.* 2020, Yager *et al.* 2020, Chomton *et al.* 2021, Fernandes *et al.* 2021, Geslain *et al.* 2021, Wasserman *et al.* 2021), and moving children out of PICUs to other locations including the operating

theatre recovery rooms (Christian & Kissoon 2020). During the early months of the pandemic, the reported number of patients cared for in these units varied, as did the length of stay. For example, three PICUs in France cared for 75 adults with confirmed COVID-19 (Geslain *et al.* 2021), another PICU in France cared for 21 adult patients with COVID-19 during a 5-week period (Chomton *et al.* 2021), and a 14-bed PICU in the U.S. cared for 37 adults during an eight-week period (Fernandes *et al.* 2021).

Within these reorganised PICUs, the physical space was adjusted to care for adults (Joyce *et al.* 2020, Siva *et al.* 2021). This involved creating different areas for donning and doffing personal protective equipment (PPE) for staff (Levin *et al.* 2020, Sinha *et al.* 2021), and also included major construction such as building additional walls to restructure units to accommodate increased patient loads (Abulebda *et al.* 2020), and changing ventilation systems (Levin *et al.* 2020). Additionally, remote patient monitoring was introduced in some areas to prevent unnecessary donning and doffing of PPE (Abulebda *et al.* 2020).

A cross-sectional web-based survey of eight hospitals in Finland, Italy, Ireland, Latvia, the Netherlands, Poland, Spain, and the UK, discovered that all of the hospitals in the study reorganised spaces and the flow of patients (Indolfi *et al.* 2021). Multidisciplinary planning committees were created to develop written preparedness plans. Routine activities, including the cancellation of elective procedures, reduced admissions into the PICUs to allow adults with COVID-19 to be cared for. The introduction of telemedicine and telehealth services were implemented across all hospitals to improve care delivery (Indolfi *et al.* 2021), and as reported across other studies, clinical support to staff in PICUs was extended (Deep *et al.* 2020, Jenkins *et al.* 2020).

Sachdeva *et al.* (2020) report on the impact of COVID-19 across 180 PICUs in the U.S. and Canada. A significant number of patients were over 18 years old, with 40% of those, being admitted to PICUs during the peak of the COVID-19 wave, with approximately 12% of over 30 year olds being

admitted in April 2020. The hospitals within this study were diverse, comprising 74 free-standing paediatric hospitals, 107 children's hospitals within adult hospitals and two speciality paediatric hospitals providing a specific, limited range of services for designated medical specialities. A number of the PICUs in this study had increased patient age limits to admit adult patients. Although, the study did note, that a number of these adults represented former PICU patients, or adults with diseases commonly seen in children and often cared for in PICUs, which eased the burden of care for the staff in the PICU.

Similarly, Wolfe *et al.* (2020), recognise that although staff from PICUs and adult ICUs are not entirely interchangeable, many staff from PICUs can provide safe care to adults with common diseases also seen in PICUs. Likewise, a retrospective chart review by Gist *et al.* (2021), explored the experiences of repurposing a PICU into an adult critical care unit and compared the outcomes for adults admitted to a paediatric (n = 9) and medical adult ICU (n = 140). The average age of those admitted to the PICU was lower than those admitted to the adult ICU and those admitted to the PICU presented less complex cases, and fewer to no comorbidities, allowing the PICU to function with relative independence. The outcome for patients cared for in the PICU was no worse than for those in the medical adult ICU. Since this was an observational study with a small number of patients within a single PICU, this limits the power and generalisability of the conclusions. However, it suggests that careful assessment of critical illness taking into account the age and comorbidity type, are the most appropriate for PICUs in general hospitals, which corresponds with the aforementioned studies (Sachdeva *et al.* 2020, Gist *et al.* 2021).

The task of caring for adults within a PICU required not only the reorganisation of physical space, but also a redistribution of equipment and supplies. Further consideration regarding physical space, involved the requirement for larger beds and infrastructure for adult patients, in addition to upskilling with respect to manual handling practices and the positioning of adult patients (Christian & Kisson 2020). A number of studies reported

on restocking their storerooms within PICUs with adult appropriate equipment (Christian & Kisson 2020, Chomton *et al.* 2021, Sinha *et al.* 2021). Other studies highlight PICUs stocking adult and paediatric equipment and medications together (Jenkins *et al.* 2020), including easily recognisable adult and child resuscitation equipment (Levin *et al.* 2020, Sinha *et al.* 2021). In addition, modes were changed on ventilators and monitors in the PICUs to accommodate both child and adult variables (Levin *et al.* 2020, Gist *et al.* 2021). Pharmacy staff, laboratories and radiology departments were also organised to cater for the adult population (Gist *et al.* 2021).

Despite the decrease in the usual PICU bed availability due to this reorganisation, it was reported that this did not compromise the paediatric population due to the reduced requirement for paediatric admissions (Chomton *et al.* 2021, Geslain *et al.* 2021). The conversion of PICUs to adult ICUs was made possible due to the decrease in child PICU patients with seasonal illnesses – a secondary benefit of social restrictions during lockdowns – and a significant reduction in the number of planned surgeries. However, Jansen *et al.* (2020) highlight that the reallocation of resources is not simple in practical terms. It increases the risk to patient safety, creates overall challenges in extending the scope of practice for staff, and extends systems within a previously functioning unit.

2.4.2 Staffing and support

The studies within this review emphasised the changes that also occurred with respect to staffing when accommodating adult patients in PICUs, both alongside children and in units solely dedicated to the care of adults. Providing care to critically ill adults in PICUs produced staffing considerations that included the assessment of the clinical experience, skills and capabilities of staff (Christian & Kisson 2020). Changes in staffing requirements, involved employing more staff, adjusting rosters, implementing staff shadowing systems, cooperation between hospitals and the redeployment of staff (Jenkins *et al.* 2020, Kneyber *et al.* 2020, Yager

et al. 2020, Chomton *et al.* 2021, Fernandes *et al.* 2021, Geslain *et al.* 2021, Gist *et al.* 2021, McNamara *et al.* 2021, Sinha *et al.* 2021, Siva *et al.* 2021).

Staff in PICUs cared for adult patients in close consultation with adult clinical teams, although specific service delivery models varied across PICUs (Sinha *et al.* 2021). PICUs opted for various models. Some stand-alone children's hospitals increased their capacity to take children from other repurposed units, some gave up their space and equipment for adults, while others adopted a hybrid approach and cared for both adult and child patients within the PICU. All PICUs operated a supervised staffing model, with paediatric staff supported by adult staff, whether virtually or in-person (Gerall *et al.* 2020, Wasserman *et al.* 2021) and dual-trained providers were utilised where available (Deep *et al.* 2020).

Cooperation and collaboration between adult and paediatric teams was regarded as fundamental. In a number of hospitals, paediatric physicians conducted morning rounds followed by afternoon rounds with the adult critical care specialists, and adult specialists performed additional consults as requested by the paediatric team (Gist *et al.* 2021). Given the anticipated knowledge and skills gap, the assistance from adult providers offered a reframing of the clinical models of care and allowed for consultative and collaborative processes to be implemented between adult and paediatric staff (Fernandes *et al.* 2021). Yager *et al.* (2020) concur and advocate for strong cooperation between institutions to regionalise critical care and intensive coordination between hospital services. Siva *et al.* (2021) and Wasserman *et al.* (2021) report on the importance of adult ICU staff and services remaining readily accessible to assist the PICU team and to provide subspecialty consultations. Hospital-wide teams were available to offer support for procedures, including intubation, leaving the PICU staff able to focus on day-to-day care, including, ventilator management, which fell within their skill set. Specialised emergency teams could be activated for consultation and management recommendations where necessary (Wasserman *et al.* 2021).

In addition to collaboration between the PICU and adult ICU physicians, other members of the multidisciplinary teams were drafted in to support and increase staffing levels, including paediatric anaesthetic teams, members of paediatric palliative care teams, physiotherapists and the psychologists who provided a support system for healthcare workers and families (Chomton *et al.* 2021, Geslain *et al.* 2021). Former PICU nurses and non-PICU nurses were also drafted in to assist (Chomton *et al.* 2021), alongside occupational therapists and social workers who continued to staff the units with support from adult critical care physicians (Joyce *et al.* 2020).

Extensive changes to staffing models occurred to accommodate this patient diversification within the PICU (Abulebda *et al.* 2020). Staffing levels were increased in a number of PICUs with one PICU reporting an increase from 58 nurses to 95, plus 30 to 74 nursing assistants to provide patient care and carry out the disinfection of patient rooms (Chomton *et al.* 2021). Medical and nursing rosters were constantly changing to provide additional tiers of cover for COVID-19 related illness or self-isolation requirements to ensure safe care was provided at all times (Sinha *et al.* 2021). Poncelet *et al.* (2021), conducted a questionnaire in seven COVID-19 ICUs (2 PICUs and 5 adult ICUs), to investigate whether changes in care conditions for the staff in PICUs that switched from caring for children to adults, during the first wave of the pandemic, caused increased job stress. The results of the study found that despite the drastic changes required due to the pandemic, and the resulting revisions to clinical practice, the prevalence of job strain was similar to that reported by Dodek *et al.* (2019) in 13 Canadian adult ICUs under usual pre-pandemic conditions. Poncelet *et al.* (2021), conclude that PICUs can be used to admit adult patients, without an increased risk of additional job stress among staff in PICUs.

Some hospitals opted for nurses to operate within a team or shadow system, pairing those with adult experience together with a PICU nurse (Deep *et al.* 2020, Gist *et al.* 2021, Wasserman *et al.* 2021), and in one PICU, adult respiratory therapists supported their paediatric counterparts, because being situated within a general hospital, they were well-positioned to

facilitate this (Gist *et al.* 2021). Wasserman *et al.* (2021) reports staff being assigned to existing adult COVID-19 adult ICUs and paired with experienced staff for two shifts before returning to care for adults in the PICU. These 'trained' nurses were then paired with nurses who had not received the training, to share practice and knowledge, with rounds conducted jointly between paediatric and adult physicians. Similar findings were reported by McNamara *et al.* (2021), where multidisciplinary collaboration with a neighbouring adult ICU, facilitated a consistent approach to management, and adult and paediatric clinicians could work cohesively to share skills and knowledge. Ongoing communication with adult critical care consultants was in-person daily over the phone, or as needed (Deep *et al.* 2020). Critical care clinical psychologists and family liaison teams also supported staff and family wellbeing (McNamara *et al.* 2021).

Conversely, early on in the pandemic, some hospitals opted to deploy a subset of staff from PICUs to adult ICUs to rapidly gain experience and training (Levin *et al.* 2020), and they were then returned to the PICUs to care for patients, supported by adult staff 24/7, with additional support provided over the phone. In a study by Chomton *et al.* (2021) paediatric intensivists visited an adult ICU to anticipate difficulties and management issues and the fact that adult ICU staff were available for advice throughout the duration, proved invaluable. Similarly, Deep *et al.* (2020) reported on virtual rounds completed with adult staff including physical therapists, occupational therapists and dieticians. Consistent with pre-COVID-19 practices, team huddles were continued daily, to ensure the effective and efficient running of the PICU (Wasserman *et al.* 2021).

Responding to the surge in COVID-19 patients also involved developing a multi-stakeholder team consisting of paediatric and adult leaders to discuss how best to respond to the needs of patients (Jenkins *et al.* 2020). Keeping PICU teams together in a familiar environment while caring for adults, mitigated certain patient safety risk factors and encouraged resilience during this emotionally and physically challenging time (Deep *et al.* 2020).

Kneyber *et al.* (2020) discuss the experience in the Netherlands of retaining their PICU capacity but expanding it to include adults and finding, their main hurdle was how to staff the unit. PICU staff wished to stay in their familiar environment to care for adults, with some contracts upgraded to full-time equivalents, and leave of absences revoked until further notice. The nursing team were segregated, with one group of nurses who had experience in an adult ICU, before moving to the PICU, allocated as the primary care providers for adults. The care was reviewed by an adult ICU consultant twice a day. PICU occupancy remained >80% and this supported their decision not to reduce capacity or redeploy staff (Kneyber *et al.* 2020).

Similarly, Yager *et al.* (2020) report that PICU nurses and physicians, rather than redeploying to other areas, opted to stay in their familiar environment and take advantage of the years of established relationships to optimise performance, despite caring for a different patient cohort. Paediatric intensivists and trainees were primary care providers, with a medical resident and adult ICU consultant reviewing patient plans twice a day (Yager *et al.* 2020). Adult and paediatric-trained critical care physicians worked together to support each other and provide optimum care through these challenging times (Christian & Kissoon 2020, Remy *et al.* 2020). Furthermore, Chomton *et al.* (2021) report that caring for adult patients was easier within the staff's own familiar unit, instead of being redeployed to a unit with unfamiliar colleagues and equipment. Strong hospital support, particularly from the adult medical teams was seen as fundamentally important, and a key concept noted in all of the studies.

Success within PICUs was highly dependent on collaboration and support from the adult care team (Jenkins *et al.* 2020) and through the preservation of team composition by minimising unnecessary personnel changes (Yager *et al.* 2020). To provide the necessary resources to deliver safe care to adults at the bedside, there was a need for a clear chain of command, in addition to excellent leadership and constant support (Christian & Kissoon 2020). PICU physicians were well situated to care for adult patients in this pandemic. They reported it as both an overwhelming and humbling

experience, being forced to adapt quickly, to grow, and broaden their comfort zones but also developed greater collegiality within their teams (Joyce *et al.* 2020). Alongside the redistribution of staff and the changes in staffing models to accommodate the increase in adult patients, additional training and education was essential, not to mention, the additional amendments to governance within hospitals.

As a result of the reorganisation of care within the units and required staffing changes, significant upskilling of staff occurred across all of the hospitals. A number of hospitals provided rapid accreditation of paediatric-trained staff with previous experience in an adult ICU (Joyce *et al.* 2020, Sinha *et al.* 2021), updated accreditation (Remy *et al.* 2020) and expanded emergency credentials (Levin *et al.* 2020, Yager *et al.* 2020) for those with previous training experiences within their clinical settings (Fernandes *et al.* 2021). In some areas, due to the public health emergency, the scope of practice was also extended for professionals (Wasserman *et al.* 2021).

Adult competencies of staff were addressed with appropriate training arranged where necessary (Jenkins *et al.* 2020). Gaps in knowledge were identified and nursing educators from an adult ICU provided education and coaching (Deep *et al.* 2020). All of the hospitals provided rapid, intensive training, utilising different methods for their staff, including remote training, virtual meetings, online learning, videos, lectures, face-to-face sessions, team training and simulated education sessions (Abulebda *et al.* 2020, Levin *et al.* 2020, Chomton *et al.* 2021, McNamara *et al.* 2021, Sinha *et al.* 2021, Siva *et al.* 2021). The majority of PICUs reported developing and implementing PPE safety procedures. Training sessions included the donning and doffing of PPE (Abulebda *et al.* 2020, Levin *et al.* 2020) and simulation training which explored common scenarios to build the multidisciplinary response in emergency scenarios (Jenkins *et al.* 2020). These training sessions enhanced the ability of staff to safely care for critically ill adults (Fernandes *et al.* 2021), and training was reported as reducing anxiety and promoting a sense of preparedness within teams (Deep *et al.* 2020).

A joint statement from the Statutory Regulators of Health and Care Professionals (General Medical Council 2020) provided reassurance to paediatric healthcare workers that working in cooperation with adult specialists and using the best available evidence was acceptable to the relevant regulatory bodies (Sinha *et al.* 2021). Development of adult-specific guidelines, including checklists and quick guides, were rapidly distributed and regularly updated to support the management of critically ill adults (Sinha *et al.* 2021). Pocket-sized cards were printed to familiarise staff with adult medication doses and protocols (Joyce *et al.* 2020). There were regular multidisciplinary team meetings to ensure all staff were up-to-date with new clinical care guidelines (Sinha *et al.* 2021), protocols and algorithms (Chomton *et al.* 2021, Wasserman *et al.* 2021). Educational plans and guidelines were adapted from adult ICUs (Geslain *et al.* 2021). Sustainable changes in guidelines and protocols ensured the safety of healthcare workers, optimum care delivery for patients and maximised available resources (Gerall *et al.* 2020).

Due to the scarcity of resources, new policies were established to care for children and adults needing extracorporeal membrane oxygenation (Gerall *et al.* 2020). Some paediatric policies were transferred to caring for adult patients, including safe medication administration practices. Potts *et al.* (2021) highlight the importance of continuing standard practices and processes, because large changes that deviate from standard practice are error prone and increase chances of risk. Potts *et al.* (2021) recommend acceptance of adult patients as if they were paediatric patients. In the U.S., other 'paediatric practices' that were maintained, included the tradition of the 'Honor Guard' where staff lined the hallways as deceased patients were escorted to the morgue (Levin *et al.* 2020).

Positive clinical outcomes, including decreased mortality, and the provision of safe and effective care, were reported in all of these studies. Fernandes *et al.* (2021) report good clinical outcomes for patients when the PICU staff were supported by adult colleagues and dedicated operational processes were implemented. Sinha *et al.* (2021) also find that paediatric teams can

give excellent care to adults with outcomes comparable to adult ICUs, provided there is effective communication and strong leadership. Guidelines written for adult patients, directing clinicians to the corresponding paediatric guidelines, with decision-making processes for determining ICU eligibility and priority, were designed in a consultative transparent way (Jansen *et al.* 2020). These processes were clearly documented and reviewed regularly to ensure effective running of PICUs (Jansen *et al.* 2020). Despite the provision of this training and the techniques implemented to support staff, there were numerous challenges with the transition of patient loads and the changes required within PICUs.

2.4.3 The challenges associated with the reorganisation of PICUs

Although the majority of studies report a positive experience when caring for adults within their PICUs, it was not without its challenges. The establishment of adult COVID-19 ICUs within PICUs was demanding and required coordinated multidisciplinary efforts to convert the space, equipment and teams to adequately care for adult patients (Levin *et al.* 2020). The rapidly evolving clinical management of patients with COVID-19 was testing for staff, but the creation of cohesive guidelines helped (Deep *et al.* 2020). Effective communication with staff, patients, families and the wider paediatric hospital community was critical in overcoming challenges (Christian & Kissoon 2020).

PICU staff highlighted challenges associated with working outside of their normal scope of practice (Sinha *et al.* 2021). Deep *et al.* (2020) report on the difficulties associated with maintaining team morale during these challenging times. Staffing changes and redeployment caused additional stress, due to non-PICU staff requiring significant oversight from adult ICU staff in ensuring safe delivery of care and adherence to adult ICU protocols (Chomton *et al.* 2021, Wasserman *et al.* 2021). There were issues around the availability of ventilators and where safe, neonatal and portable ventilators were used for children, to free up ventilators for adult use (Deep *et al.* 2020). Additionally, some units reported medications and supplies

running low, with aseptically compounded medications being used beyond their expiration dates, and intravenous tubing changed less frequently, which was against standard hospital procedures (Deep *et al.* 2020).

Furthermore, challenges arose around specific issues in adults that were unfamiliar to paediatricians, including, various comorbidities and anatomical differences (Chomton *et al.* 2021) and a difference in practices between adults and children, such as sedation (Levin *et al.* 2020). Inexperience with specific equipment and pharmacy protocols also caused distress for staff (Siva *et al.* 2021). Shortages of medical equipment prevented the opening of additional beds, which posed challenges for the staff working in these units (Chomton *et al.* 2021). Other challenges included PPE shortages, and fear, relating to PPE availability (Abulebda *et al.* 2020, Joyce *et al.* 2020), confusion regarding continuous changes in PPE protocols as a result of availability and health recommendations (Chomton *et al.* 2021), and the rationing of essential medical equipment (Joyce *et al.* 2020).

Staff members wore cleanable pictures with their names on, to reduce the barriers associated with wearing PPE, which allowed patients to connect with them (Levin *et al.* 2020). However, the noise generated by filters made communication difficult. Wasserman *et al.* (2021) discusses some adaptations that were necessary for efficient communication, including, implementing hand-held radios to discuss care and writing updated settings and results on glass windows. Similarly, Levin *et al.* (2020) and Sinha *et al.* (2021), report the use of boards, markers and hand-held devices to improve team communication and using iPads, speakers and online collaboration platforms to facilitate communication with families.

The quick transition within these units left staff little time for emotional processing, giving rise to feelings of relief and pride, mixed with severe anxiety, stress and fear (Joyce *et al.* 2020, Levin *et al.* 2020). As a result of visitor restrictions, staff reported concerns, particularly around end-of-life care, because of the high degree of isolation for patients who were alone and without family members (Joyce *et al.* 2020, Chomton *et al.* 2021, Indolfi

et al. 2021, Wasserman *et al.* 2021). Discussions regarding advanced directives and resuscitation were held with family members over the phone, which was a major deviation from normal family-centred care (FCC) practices in the PICU. The requirement to provide care as quickly as possible to protect healthcare professionals was challenging, as this could not be further away from the normal environment of care in PICUs (Joyce *et al.* 2020, Chomton *et al.* 2021). The normal ethos within paediatric healthcare is, “to care for a child is to care for their family”, and the absence of family was “unsettling” and “heart-breaking” for staff (Joyce *et al.* 2020, p.2). Staff reported the ways in which they tried to make the best of these difficult situations, using video conferencing, and allowing one person a compassionate visit if death was imminent. This helped somewhat with improving practices during end-of-life situations (Joyce *et al.* 2020).

Despite the highlighted difficulties and challenges, there did not appear to be any adverse adult patient outcomes reported (Deep *et al.* 2020, Joyce *et al.* 2020, Chomton *et al.* 2021). Staff described finding it rewarding, and an opportunity for growth (Chomton *et al.* 2021). Teams reported coming together to provide excellent care for those admitted to their PICUs (Joyce *et al.* 2020, Levin *et al.* 2020). The reorganisation and sharing of staff and equipment was easier in children’s hospitals that were already physically part of larger centres (Wolfe *et al.* 2020). In stand-alone hospitals, this sharing of resources required additional planning and was more challenging than in facilities where children’s hospitals and adult hospitals were in close proximity (Wolfe *et al.* 2020). Despite different logistical issues, the ethical issues remained the same. Wolfe *et al.* (2020) also highlight that although there were strong ethical grounds for justice, fairness and social utility, in treating all intensive care resources as equal during a pandemic, there were correspondingly strong grounds for considering that paediatric healthcare professionals may need to practice outside of their usual scope of practice and comfort zone to care for critically ill adults.

2.5 Discussion

The COVID-19 pandemic has changed professional practices in adult ICUs and PICUs due to the sudden and increased number of critically ill patients (Poncelet *et al.* 2021). PICUs have been significantly impacted by the pandemic, providing care not only to children but also to adults (Sachdeva *et al.* 2020). Since the knowledge base in this area is still being created and evaluated, the rationale for choosing a scoping review over other types of review was to map the scientific evidence in this area, to inform further research.

Three dominant themes emerged from the literature: 1) the reorganisation of space for managing increased capacity; 2) increased staffing and support; and 3) the resulting challenges. These themes are consistent with published recommendations about repurposing adult ICUs to care for critically ill adults (Aziz *et al.* 2020, Goh *et al.* 2020). PICU involvement in caring for adults during the current COVID-19 pandemic, may constitute a reliable option for expanding the adult ICU bed capacity beyond the traditional boundaries (Geslain *et al.* 2021). However, a 'one size fits all' approach, is not universally effective, as different hospitals will implement alternative scenarios based on the availability of resources.

The overall consensus, across studies, was that it may be easier for PICUs to set up their own adult unit instead of redeploying PICU staff to the unfamiliar setting of an adult ICU, and in some areas this was a necessity as many adult ICUs were out of space (Qiu *et al.* 2020, Chomton *et al.* 2021). Preserving the PICU team ensured a rapid transition and boosted staff morale, while creating a strong relationship between adult and paediatric critical care medicine within the hospital (Kneyber *et al.* 2020). Globally, the transformation of a PICU into an adult ICU was based around clearly outlined principles, applied to local requirements, to allow a number of adult critical care patients to be successfully cared for by PICU teams (Qiu *et al.* 2020, Sinha *et al.* 2021).

Hybrid models of care successfully facilitated an expansion into caring for critically ill adults, while also providing essential services for critically ill children (Deep *et al.* 2020, Levin *et al.* 2020, Sinha *et al.* 2021, Siva *et al.* 2021, Tedesco *et al.* 2021). Simultaneous care for children and adults within the same ICU space can be sustained, if teams of healthcare professionals work collaboratively, exhibit clear leadership and provide ongoing support and training for all staff (Deep *et al.* 2020, Levin *et al.* 2020). By implementing a dynamic, hybrid model, the services remain responsive to the rapidly changing demand for critical care beds, provide increased capacity for critical care adults at the right time, and can continue to provide ongoing specialist paediatric services (Deep *et al.* 2020). This flexible system means the PICUs have been upskilled to care for adult patients, which is a valuable resource for any additional surges with unpredictable demands and outcomes (Deep *et al.* 2020). Deep *et al.* (2020), acknowledge that the hybrid model may not be generalisable to all institutions, but for children's hospitals operated within adult organisations, the collaboration with adult colleagues can be facilitated with relative ease.

The literature highlighted that during the COVID-19 pandemic there were many obstacles to creating a shift to care for adult patients in PICUs. They included, staffing shortages, lack of equipment and medications, resource allocation issues, and rationing, all of which were universal in the global ICU community (Deep *et al.* 2020, Remy *et al.* 2020, Yager *et al.* 2020). Working together as a multidisciplinary team to identify potential barriers and to create solutions to overcome them was essential (Remy *et al.* 2020). Critical to the success of the transition into caring for adult patients in PICUs, was collaboration between key stakeholders, rapid training, oversight and support from adult physicians to ensure competency (Remy *et al.* 2020, Wasserman *et al.* 2021).

The overall consensus was that the pandemic will have lasting effects on all staff and will allow them to practice with increased empathy (Yager *et al.* 2020). A large body of research is emerging concerned with the physical, mental and emotional impact the pandemic is having on staff (Bergman *et*

al. 2021, Mehta *et al.* 2021, Montgomery *et al.* 2021, Silva & Barbosa 2021). However, these features were not predominant during this scoping review. Despite the challenges, it was reported that adult patients were cared for effectively and safely in PICUs. Staff reported finding their experiences rewarding, with opportunities for professional and personal growth while caring for adults in a PICU (Chomton *et al.* 2021). Staff reported positive experiences of effective team working and successful collaboration, which is consistent with the wider literature reporting on the concepts of strong teamwork, camaraderie and fulfilment that were associated with working in ICUs during the pandemic (Montgomery *et al.* 2021). Future research into the reorganisation of care within PICUs during subsequent waves of the pandemic and exploring staff experiences within these units, is essential to ascertain any ongoing challenges that may arise. Changing situations might well present themselves within different time periods of the pandemic.

This pandemic is not unprecedented. Previous pandemics include, the Spanish Flu in 1918 – 1919, the Asian Flu in 1957 – 1958, the Severe Acute Respiratory Syndrome (SARS) pandemic in 2002 and the emergence of Middle East Respiratory Syndrome (MERS) in 2012. Interestingly, there is very limited data available on the impact of paediatric experiences including care delivery in PICUs during the SARS pandemic in 2002 and MERS in 2012 (Cherry & Krogstad 2004, Hon *et al.* 2020). This might be because children were reported as being less commonly and less severely affected by these infections than adults (Iannarella *et al.* 2020). Reports about care delivery in paediatric EDs identified similar themes, with decreased visits and reduced lengths of stay due to the pandemic (Boutis *et al.* 2004). No published studies were found that reported on caring for adults in PICUs during these pandemics. Al-Dorzi *et al.* (2016) reports the use of an old PICU to care for adults, but this was merely for extra space, as the PICU had been vacated when a new paediatric hospital had been opened. However, the consistent message from the SARS and MERS experiences, in common with COVID-19, was that although children were affected by these diseases, overall, the greater disease burden and higher mortality rate was in the adult populations (Li & Ng 2005, Memish *et al.* 2014, Thabet *et*

al. 2015, Iannarella *et al.* 2020, MacIntyre *et al.* 2020, Zimmermann & Curtis 2020).

Following these pandemics, previously proposed strategies to provide surge capacity if adult ICUs were overwhelmed, was to utilise the availability of PICUs (Biddison *et al.* 2014, Christen *et al.* 2014, Dries *et al.* 2014, Einav *et al.* 2014). Children's hospitals must work with public health agencies to determine the best way to support adult hospitals and the wider community when these situations arise (McIntosh *et al.* 2020). This scoping review, offered a valuable opportunity to learn from the COVID-19 pandemic. The reports on the experiences of PICUs caring for adults, prompts recommendations for future global pandemics in a PICU setting – something that is absent from the research literature. This scoping review will contribute to ensuring that future research in this area can be planned appropriately to address any gaps in the scientific knowledge, and continue to provide recommendations for best practice.

2.5.1 Limitations

The quality of evidence included within this scoping review was not formally evaluated or quality assessed, since the information was obtained from a variety of study methods and designs, a common trait of scoping reviews. The studies included in this review were all in the English language. This review only focused on the initial 18 months of the pandemic. Additional findings could have been reported in the period since then, as the pandemic evolved and hospitals have continued to adjust and manage this increased burden of care.

2.6 Conclusion

COVID-19 has strained institutional resources across the globe. This scoping review examined the reorganisation of care within PICUs during the first 18 months of the COVID-19 pandemic. To relieve the burden on adult ICUs, some PICUs adjusted their units to care for critically ill adults, with other PICUs making significant changes, including the redeployment of staff

to adult ICUs to provide extra care for adults. Overall, PICUs were collectively well equipped to care for adult patients, with care enhanced by implementing elements of holistic, family-centred PICU practices. The pandemic fostered a collaborative approach among PICU teams and wider hospital communities. However, specific healthcare guidelines had to be created and adhered to in order to safely care for adult patients. The findings highlighted the complex requirements to effectively care for adults in the PICU, including the reorganisation of space, staffing changes, training and clinical governance requirements and the resulting challenges that arose.

This scoping review has provided the preparatory actions which were effective, including the required training, the reorganisation of physical space in the PICU and what lessons can inform and improve care in PICUs for any subsequent COVID-19 waves or future pandemics. It is imperative that the individual patient – regardless of their age, family circumstances and healthcare needs – is taken into account, and situated at the centre of care delivery. Building relationships between adult and paediatric services can strengthen health systems and healthcare communities beyond this pandemic. Through educating staff and retaining many elements of paediatric practice, healthcare teams can meet pandemic demands and provide excellent, safe patient care. Overarching guidelines are difficult to create as each hospital setting is unique. For example, some are stand-alone children's hospitals, others are situated near to an adult general hospital and specific considerations must be taken into account when creating protocols.

This scoping review has contributed beneficial knowledge in the event of further waves of COVID-19, but also in the face of other inevitable, future healthcare crises. Further research exploring specific hospital responses to patient outcomes can inform planning for other events in the future. Further research exploring healthcare professionals' experiences of working in PICUs during COVID-19 is critical to build on the knowledge gained through this review, to give the nurses and physicians who are working in these areas a voice to express their experiences of caring for vulnerable

populations, including children with CCNs, during the COVID-19 pandemic. In conclusion, this scoping review has highlighted a knowledge gap and provided recommendations for further research, including emphasising a justification for this research.

Chapter Three: Philosophical and Methodological Issues

3.1 Introduction

This chapter critically discusses the philosophical underpinnings and methodology used in this research. Research methodology is an approach implemented to systematically answer the aim and objectives of the research (Patel & Patel 2019). Collins and Stockton (2018) refer to the methodology as the theory behind the research method and the justification for selecting particular approaches. The methods should consider the implications of a particular philosophical perspective and use procedures that align with the chosen philosophical framework and methodology (Bleiker *et al.* 2019, Saunders *et al.* 2019). The research methods are the strategies and procedures used to collect and analyse data in order to answer the research aim or phenomenon of interest (Gentles *et al.* 2016, Busetto *et al.* 2020), and these are presented across Chapters Three and Four.

Phenomenology involves a process of describing the meaning as it is experienced and lived in a person's everyday life (van Manen 1990). This research focused on interpreting and understanding the meaning given to care delivery for children with CCNs in PICUs by nurses and physicians during the first 18 months of the COVID-19 pandemic. Therefore, hermeneutic phenomenology – the science and art of interpretation – provided an appropriate philosophical underpinning for this research (Sloan & Bowe 2014). This chapter begins with an exploration of hermeneutic phenomenology, discussing relevant philosophers in this area and the evolution of modern hermeneutics, which is paramount in setting the context for the chosen methods. The rationale behind selecting van Manen's framework (1990) to guide this research is also provided.

3.2 Research Methodology

Paradigms are perceived as a way of viewing the world that frames a research topic and influences the way researchers think about a topic (Hughes 2010). There are two main approaches to research design – namely, qualitative and quantitative research. Quantitative research focuses on prediction, control and measurement of data (Lavery 2003, Ahmad *et al.* 2019). Quantitative research is formed from a deductive approach where the emphasis is on testing theories and is used to find patterns and cause-effect relationships between the variables under investigation (Apuke 2017). Conversely, within qualitative research there is an emphasis on discovery, description and meaning (Hammarberg *et al.* 2016, Aspers & Corte 2019). Qualitative research is used to understand people's beliefs, perspectives, behaviours and experiences (Pathak *et al.* 2013).

Historically, little value was placed on qualitative research as these research designs could not be scientifically explained (Streubert & Carpenter 2011). However, in recent years, humanistic qualitative approaches have gained recognition and respect as an authentic approach to research (Queirós *et al.* 2017), which is important in the study of human experiences and interactions. Qualitative research is recognised for its ability to bring a new dimension and depth of understanding to studies that cannot be obtained through measuring variables alone (Pathak *et al.* 2013), where participants are able to freely disclose their experiences and thoughts without constraints. Qualitative research approaches use an emergent design that may evolve as the researcher makes ongoing decisions and reflects on what has been learnt during the process (Pailthorpe 2017).

Qualitative paradigms offer an opportunity to establish an idiographic understanding of participants, and what it means to live in a particular situation or under specific conditions (Sławecki 2018). Qualitative methodologies allow questions on human experiences as well as on connections with individuals in their natural environments – and can generate rich, descriptive data that aids understanding of their experiences

and attitudes (Bradshaw *et al.* 2017). Qualitative research also explores the context of participants' subjective experiences, which can contribute to the development of healthcare service provision and policies (Green & Thorogood 2018). This is the case, in the context of COVID-19. For these reasons, a qualitative approach was deemed appropriate for this research.

Phenomenology is both a philosophy and method used to describe a phenomenon (van Manen 1997). Phenomenology attempts to explore phenomena as they are experienced by individuals within the social context of daily life (Moran 2002) and to provide a deeper understanding of the phenomena under exploration (Phillipson & Roche 2018). Exploring the phenomenon in the real world allows the researcher to observe and understand it as it is lived and experienced by the participants (Moran 2002). Through intense exploration, the true essence of the lived experience can be revealed (Dahlberg 2006). The underlying theoretical principles are based on the view that an individual's behaviours are determined by the experience which is gained through their direct interaction with the specific phenomena. During these interactions, individuals endeavour to understand these phenomena by attributing meaning to behaviours and situations, and subsequently constructing new experiences and ideas (Neubauer *et al.* 2019). Hermeneutic phenomenology is one of the methods situated within the qualitative realm which underpins this research (Neubauer *et al.* 2019).

Before deciding on hermeneutic phenomenology, alternative qualitative research approaches were considered. Firstly, grounded theory was considered as an approach for this research. Grounded theory relies on generating a framework or theory from the collected data which explains human behaviours in context (Noble & Mitchell 2016, Tie *et al.* 2019). Within this research, there was no existing theory to build on or available research in this unique area. The uniqueness of this cohort of healthcare professionals makes it difficult to formulate theoretical propositions, given the unprecedented circumstances caused by COVID-19. Therefore, grounded theory was not deemed suitable for this research.

Ethnography was also considered as a methodology for this research. An ethnographic approach requires the researcher to adopt an insider or an observer role, completing onsite fieldwork and ongoing engagement with the research process and participants (Reeves *et al.* 2013, Jones & Smith 2017). However, due to the international sites within this research and the restrictions associated with the global pandemic, this was not practical or achievable.

3.3 Hermeneutic Phenomenology

There are two main approaches to phenomenology: descriptive and interpretive. Hermeneutics sits within the interpretive realm and is derived from the Greek word '*hermeneuin*' meaning 'to interpret' (Heidegger 1962). The development of hermeneutics arose from the works of Heidegger (1962), Gadamer (1976) and Ricoeur (1976). Hermeneutic phenomenology concentrates on philosophies that underpin hermeneutics and phenomenology (van Manen 1990). Hermeneutic phenomenology focuses on the human experience as it is lived and the lifeworld (Sloan & Bowe 2014) and endeavours to discover the world as experienced by the individual through telling their own lifeworld stories and experiences (Suddick *et al.* 2020). The focus within hermeneutic phenomenology is on creating meaning (Suddick *et al.* 2020) and on highlighting details of experiences that individuals give particular meaning to. Heidegger (1962) suggests that this helps to achieve an understanding about the phenomenon. In contrast to epistemology – which is the study of nature, origin and theory of human knowledge (Hetherington 2019) – hermeneutic phenomenology renounces the concept of suspending personal thoughts and opinions (Kafle 2011) and focuses on the subjective experience of individuals.

Both descriptive and hermeneutic approaches are frequently used to guide nursing research as they are concerned with understanding human phenomena (Bowie & Wojnar 2015, Matua & Van Der Wal 2015). Differences between descriptive and interpretive phenomenology include how the findings are generated and how these are used to generate

knowledge (Lopez & Willis 2004). Descriptive phenomenology, as developed by Husserl, uses bracketing to maintain objectivity and to remove biases from the research (Dowling 2007, Christensen *et al.* 2017, Dörfler & Stierand 2020). Husserl believed that knowledge was the focus of phenomenology (1990). Heidegger (1962), who developed hermeneutic phenomenology, studied under Husserl. However, Heidegger was opposed to bracketing, believing that the focus of phenomenology was the nature of being (1962). Heidegger's hermeneutic view of phenomenology promotes interpretation in context, particularly social and linguistic contexts (Horrigan-Kelly *et al.* 2016).

Hermeneutic phenomenology, informed by van Manen (1990, 1997) is a phenomenological approach focused on interpreting and understanding a phenomenon from the perspective of those who have experienced it. Hermeneutic phenomenology is a human science that studies people within the social context of their lifeworld (van Manen 1990). Van Manen (1997) refers to conducting research because of a prior interest, and this cohort of children with CCNs and care delivery within PICUs is of interest to me, the researcher, as I am a children's nurse with a specific interest in caring for children with CCNs.

An interpretive paradigm was used as a lens to explore the approaches to care delivery during COVID-19 through individual interviews with nurses and physicians working internationally in PICUs. Hermeneutics goes beyond the simple description of core concepts and essences to look for meaning embedded in day-to-day life practices (Frechette *et al.* 2020). Hermeneutics is concerned with the nature of existence and the study of ways of 'being in the world'. Van Manen's (1990) methodological approach for doing practical phenomenological research was used to guide this research. This method is a systematic process which describes the internal meaning and structure of a participant's day-to-day life within the world they are living in (van Manen 1990).

3.4 The Case for Hermeneutic Phenomenology

Hermeneutic phenomenology is situated amongst the interpretive phenomenological methodologies (Sloan & Bowe 2014). In this research, the lived experiences of nurses and physicians caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic were explored, and the meaning the experience held for them was the phenomenon of interest. Manifestations of this phenomenon were revealed in the rich descriptions relayed by the nurses and physicians about their own lived experiences. Interpretive qualitative research often reflects questions about social aspects of health and illness and is helpful where there is little known about a topic (Green & Thorogood 2018). Hermeneutic phenomenology was selected to investigate this phenomenon for two reasons. Firstly, phenomenology is appropriate when little is known or understood about a phenomenon (Crabtree & Miller 1999). This is particularly true given the recent arrival of the COVID-19 pandemic (Wu *et al.* 2020). The experiences of nurses and physicians caring for children with CCNs in PICUs during the COVID-19 pandemic are not fully understood. This research will contribute knowledge to the research evidence in this area.

Secondly, hermeneutic phenomenology provides a foundation for human science research required to provide rich descriptions of how a person experiences the world (van Manen 1997, Dahlberg 2006). This research allowed access to the lived experiences of the nurses and physicians, and the meanings these experiences held for them. These insights facilitated the creation of descriptions to reveal the essence of the lived experience for these healthcare professionals. To gain a better understanding of how nurses and physicians can learn from these experiences and to improve care delivery in the future, the human science approach has value because it explores human experiences as they are lived by the individuals.

Hermeneutic phenomenology has been widely used in understanding the meaning given to lived experiences within healthcare, for example, nurses in practice (Van der Zalm & Bergum 2000), nurses and physicians dealing with difficult situations (Lindseth & Norberg 2004), and nurses' experiences of end-of-life care (Chu 2019). However, challenges can arise as a result of the complex and ambiguous language used in the literature when trying to understand the concepts in hermeneutic phenomenology (Miles *et al.* 2013). Examples and recent interpretations of these concepts include the hermeneutic circle (Sebold *et al.* 2017), lifeworld existentials (Rich *et al.* 2013) and 'being in the world' (Leidlmaier 2020). The origin of these concepts will be explored further when looking at the prominent philosophers in more detail. Philosophers associated with the creation of ontology and hermeneutic phenomenology are Heidegger (1962), Gadamer (1976), Merleau-Ponty (1945), Sartre (1964) and Ricoeur (1976). The next section will briefly explore the works of Heidegger, Gadamer and Merleau-Ponty. These philosophers are explored as they are recognised as key influencers on van Manen's position within hermeneutic phenomenology (van Manen 1990, 1997).

3.5 Key Philosophers who Influenced van Manen's Work on Hermeneutic Philosophy

3.5.1 Martin Heidegger (1889 - 1976)

Heidegger was a German philosopher who studied under Husserl and combined existential philosophy with the phenomenological method (Tillich 1944). Through his work – *Being and Time* (1927 translated in 1962) – Heidegger extended phenomenology beyond Husserl's works by applying the method to study the meaning of 'Being' (Moran 2002) and conceived a more ontological view of phenomenology. Heidegger (1962) believed that the study of 'Being' could only be accomplished through hermeneutic phenomenology, and the interpretation of human existence must include

researcher involvement. Heidegger hypothesised that 'Being' or presence in the world, was the primary concern of phenomenological inquiry.

Heidegger (1962) introduced the concept of *dasein*, which is the human way of 'being in the world'. He posited that humans cannot remove themselves from the circumstances that influence their choices that give meaning to lived experiences (1962). Therefore, a central principle of hermeneutic inquiry is what the individual's narratives imply about their everyday experiences (Lopez & Willis 2004). Heidegger attempted to address the situatedness of an individual's *dasein* relating to the broader social, cultural and political contexts. He believed that existence takes place in time, and subsequently 'Being' must also be understood in terms of time (Moran 2002). I can relate to this 'being in the world', having worked with children with CCNs for the last ten years. My previous knowledge and expertise which I gained from working with children with CCNs – and conducting research in this area – are a valuable asset to this interpretive inquiry.

Heidegger used the term *lifeworld* to identify those realities that are influenced by the world in which one lives (1962). The objective world, *das Vorhandene*, is a result of immediate personal experience (Tillich 1944). As a result, an individual can reflect on past experiences in an objective way. However, Tillich (1944) identified that the principle of personal existence is not exclusively objective or subjective. Individuals may discuss their experiences based on their own perceptions of reality, although their experiences are also influenced by their *lifeworld* (Tillich 1944). In addition to this, an individual's perception of their experiences is constructed by the social context of their daily lives (Werkmeister 1941). Heidegger (1962) referred to these assumptions of *dasein* and situatedness as the *fore-structure* of understanding, which is closely linked with how one understands the world and subsequently interprets reality. As a result, hermeneutic phenomenology requires the researcher to reflect on past experiences relating to that phenomenon, before conducting an inquiry in order to ensure that during the interpretive process the researchers can more clearly access the *fore-structure* of the understanding of the

experiences under investigation held by the participants (Wojnar & Swanson 2007). The fore-structure of understanding is related to the structure of fore-having, fore-sight and fore-conception, involved in every interpretation (Ginev 2012). Through this reflection on my own past experiences and understanding of the phenomenon, I was able to effectively assess the fore-structure of understanding held by the participants. Thus, a fusion of the participants' and my own lifeworlds occurred which created a new understanding (McManus-Holroyd 2007).

3.5.2 Hans-Georg Gadamer (1900 - 2002)

Gadamer was a philosophy student, influenced by the earlier works of Husserl and Heidegger, and worked under and with Heidegger for a period of time. Gadamer (1975) moved to extend Heidegger's work into a practical application. Gadamer believed that phenomenology becomes hermeneutical when its method is taken to be interpretive and principally orientated to the explication of texts (1998). Similar to Heidegger, Gadamer (1975) argued that individual prejudices are impossible to eliminate from an individual's perceptions – and suggested eliminating them is unnecessary and that interpretation becomes limited without the researcher's personal experience.

Gadamer adopted two positions of prejudgement: (1) acknowledging that an individual's preconceptions are part of their linguistic experience and make understanding possible, and (2) accepting universality – that individuals are connected by common human consciousness which also makes understanding possible (Clark 2008). Gadamer proposed that through pre-understandings, understanding is possible and if pre-understandings are not considered, there is a risk that meaning may be misunderstood (1996). Transcripts should be read with an open mind, considering the larger significance of the text as opposed to criticising narrow statements (Gadamer 1996). Gadamer supported Heidegger's views that both understanding and language, are interrelated aspects of humans 'being in the world'. The meaning of 'inquiry' from Gadamer's

perspective sees the researcher and the phenomenon being studied together as a combination.

Gadamer's 'fusion of horizons' identified that the views of the participants and that of the researcher spiral into a new understanding (Gadamer 1975, Vessey 2009). For this fusion process to be created, the researcher must be willing and open to listen to each participant's story and to make interpretations from these stories (Vessey 2009). This occurred throughout the research process, including during data collecting, interpreting and writing (Miles *et al.* 2013). Gadamer also suggested that questioning is an essential aspect of the interpretive process as it contributes to creating new horizons and understandings (Laverty 2003). From Gadamer's perspective, interpretation and understanding are bound together, with interpretation being an evolving process. Similar to Heidegger, Gadamer also believed that bracketing was impossible (Annells 1996).

3.5.3 Maurice Merleau-Ponty (1908 - 1961)

Merleau-Ponty further developed the work of Husserl and Heidegger. The goal of Merleau-Ponty's work (1945) was to allow individuals to view experiences in a new light without a reliance on pre-reflective or reflective experiences. Following on from Husserl, the process of phenomenological reduction was developed further by Merleau-Ponty (1945). Phenomenological reduction is where the inherited preconceptions of conscious phenomena are reduced or removed to reveal their essence (Cohen 1987). Merleau-Ponty (1945) highlighted that the researcher must be aware of their own lived experiences within a research study, contributing to the clarification about what is meaningful about the phenomenon under investigation. Similar to Heidegger, Merleau-Ponty (1962) affirmed the importance of considering an individual's own preconceived ideas when interpreting a phenomenon. Merleau-Ponty's notion of intentionality explored the ways in which individuals are directed towards their world (Reuter 1999). Intentionality means that every mental act is related to some

object (Moran 2002) and indicates that all perceptions have meaning (Owen 1996), which is a concept that van Manen (1990) agreed with.

Merleau-Ponty (1945) identified that as human beings, access to the world is gained through the body, as the body is the particular point of reference to the world. He considered embodiment as an essential element of human existence (1945). The concept of this 'being in the world' through the perspective of an individual was fundamental (Streubert & Carpenter 2011), and that humans experience 'being in the world' through their body (Merleau-Ponty 2012). Merleau-Ponty (1945) added four existential lifeworlds to facilitate inquiry, writing, and reflection – namely, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality). Together, these existential themes demonstrate a fusion of the hermeneutic circle and form a complex unification called the *lifeworld* (Merleau-Ponty 1962, van Manen 1997).

3.6 Max van Manen

Max van Manen (1990) suggests that phenomenology is the study of the lifeworld, where life experience is viewed as it is lived — as experiences actually occur in daily life — without categorising or conceptualising them. He considers hermeneutic phenomenology to be a descriptive and interpretive form of human science. An advantage of his approach, is the possibility of being in more direct contact with the world and subsequently gaining insight, by describing a structure of the phenomenon in its truest essence (van Manen 1990). The experiences are both descriptive and interpretive, with the essence of interpretation central to the process of symbolically capturing the phenomenon. If the description effectively captures the essence, it will demonstrate the significance and the quality of the lived experience in a deeper and fuller manner (van Manen 1990). Van Manen (1997) recommends that a methodological approach assists in guiding an inquiry. The originality of van Manen's (1990) approach resides in the translation of the epistemological foundations of Merleau-Ponty (1962) and Gadamer's (1975) philosophies, but has evolved into a

methodology which attends to the lived experience. As an approach, this provides a deep understanding of the participants' experiences. Thus, adopting this methodology will enable me to achieve a deeper understanding of what it means for the nurses and physicians delivering care in PICUs while also taking into consideration the sociocultural and healthcare issues that contribute to their individual experiences.

The aim of phenomenology is to begin with the lived experience, transform the experience into an expression of essence, and achieve phenomenological research. Van Manen (1990) suggests that the research design should be flexible and suitable for the phenomenon under investigation, because no one method will be appropriate for all inquiries. His phenomenology allows the researcher to use experiences known to the researcher and participants, to conduct a structured analysis of what is most familiar and self-evident to those involved. Through the use of a hermeneutic phenomenological approach to the participants' in-depth descriptions of their experiences, I was able to ascertain the meaning given to care delivery by the nurses and physicians. Van Manen's approach promotes a hermeneutic understanding of the lived experiences of the nurses' and physicians' working in PICUs delivering care to children with CCNs during the first 18 months of the COVID-19 pandemic (van Manen 1997).

When compared to Heidegger and Gadamer, van Manen offers a more contemporary hermeneutic expression of the philosophy that proposes a "phenomenology of professional practice, a phenomenological practice of doing phenomenology, and a phenomenology of the practice of living" (van Manen 2014a, p.21). This approach is socially situated and can be applied to practical, everyday situations beyond the constraints associated with Heidegger and Gadamer's phenomenological approaches, which were more focused on phenomenology as a way to understand the world. For this reason, van Manen's approach was chosen for this research. This research aimed to explore nurses' and physicians' experiences while delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19

pandemic, and hermeneutic phenomenology is considered the most appropriate methodology with which to study the complexities of the challenging lifeworld (Neubauer *et al.* 2019). In this research, using hermeneutic phenomenology enabled access to the nurses' and physicians' day-to-day reflections on their lived experiences while working in PICUs during the COVID-19 pandemic, and opportunities were provided to share what may have been concealed and unknown in their experiences (Green & Thorogood 2018).

All research of a qualitative nature is contextual, occurring within a specific time and place between more than one person (Dodgson 2019). Acknowledgement of the influence a researcher has within qualitative research is essential (Ráheim *et al.* 2016). A researcher must be sure to clearly describe the contextual, intersecting relationships, between themselves and the participants, while engaging in a continuous process of reflection, using a process known as reflexivity (Dodgson 2019). The concept of reflexivity is important, as phenomenological research is a self-critical human science, continually examining its own methods of evaluating the structures of meaning associated with the lived human world (van Manen 1990). This process includes the researcher reflecting on their own actions, values and perceptions which may impact upon the research setting, data collection and analysis (Mortari 2015). Reflexivity can be considered as a central component of being human, and having the ability to position oneself. This includes the capacity to reflect on and consider, intersubjective dynamics, which may arise between the researcher and the collected data (Palaganas *et al.* 2017). This process increases the credibility of the findings (see section 4.8.1., Chapter Four, for further detail around credibility), while also deepening the understanding of the work (Dodgson 2019).

Hermeneutic phenomenology involves a search for the fullness of living with its highest aim to "become more fully who we are" (van Manen 1990, p.12). The concept of bracketing out individual interpretations of the phenomenon under investigation would be impossible, and thus, this research will fuse

the horizon of my own experiences and beliefs, with those of the participants. Therefore, van Manen's (1990) methodological approach for doing practical phenomenological research was used to guide this research which acknowledges the place of the researcher's personal experience and its influence on the research process.

Using this hermeneutic phenomenological approach allowed me to discern the meaning given to care delivery for children with CCNs by nurses and physicians in PICUs during the first 18 months of the COVID-19 pandemic. This framework is particularly applicable and suited to complex issues within child health research (Rosigno & Swanson 2011, van Manen 2014b). The understanding of the interplay of activities within the context of the phenomenon under exploration, which this theoretical framework facilitates, offers the potential to understand the whole, rather than focusing on only part of the experience (Carel 2011, Rodriguez & Smith 2018). Using van Manen's approach, a hermeneutic understanding of the day-to-day experiences of nurses and physicians caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic was created (van Manen 1997). There are a number of key concepts that van Manen (1990, 1997, 2014a) considers within his approach – explicating pre-understandings, language and dialogue, existential lifeworld and the hermeneutic circle. These will be explored briefly, before explaining van Manen's guidelines (1990).

3.6.1 Explicating pre-understandings

Possessing too much knowledge about a phenomenon without it being acknowledged by the researcher, can be problematic (van Manen 1990). Pre-understandings and assumptions, before embarking on the research, influence a researcher when interpreting the nature of a phenomena. Similar to Heidegger (1962), van Manen does not adopt bracketing but argues that knowledge obtained from pre-understandings should be included. However, it is crucial that pre-understandings are made explicit prior to commencement of the research (van Manen 1997). I acknowledged my

previous experiences, beliefs and knowledge and how they influenced the process before commencing the research and throughout all phases of data collection, analysis and interpretation. This was achieved through writing in a reflective journal, creating an awareness and disclosure of my own experiences and beliefs around the subject area (Nadin & Cassell 2006). Reflective journals are recommended throughout the literature as key to recording thoughts and notes throughout the research process and to identify important learning events (Browne 2013, Annink 2016, Bashan & Holsblat 2017, Barrett *et al.* 2020). I began writing in a reflective journal at the start of the research process, documenting personal feelings along the journey, recording what was seen, said and done during the interviews with the participants. These notes acted as a constant reminder throughout the process concerning the initial impressions of concepts and allowed continuous evolution throughout the research process.

3.6.2 Language and dialogue

Phenomenology is the application of language to a particular phenomenon with the emphasis on writing as the form for interpreting (van Manen 2001). Language reveals contexts, which are understood by the participants and researcher (van Manen 1997), and experiential descriptions can be obtained through numerous ways, including interviewing. The relationship between the researcher and participant was transactional, with knowledge construction occurring through interactions during the interview process. This co-construction of understanding captured a description of the lived experience of the nurses and physicians. By using van Manen's approach – achieving rich description and interpretation – the written text in the analysis described the essence of the participants' lived experience. During the process of data analysis and writing up findings, the importance of the language used by the participants was crucial, as researcher bias had the potential to affect the findings due to the interpretation of meaning from the researchers' own perspective. Van Manen (2002, p.238) acknowledges challenges associated with phenomenological research as trying to “be

allusive by orienting the reader reflectively to that region of lived experience when the phenomenon dwells in recognizable form”.

The processes of writing, re-writing and moving backwards and forwards to create an analytic piece, reflective of the true essence and meaning are important, due to the centrality of language and writing (van Manen 1990). I identified topics that were integrated into higher order themes to answer the research aim through systematically reviewing the texts (Braun & Clarke 2006). Van Manen (1990) provides three approaches to data analysis and attributing meaning to the data: detailed or line by line reading, selective approach and holistic reading approach. These approaches are explained in detail in Chapter Four. The use of the overall language and writing, illustrated elements of the essential nature of the lived experience (van Manen 2001).

3.6.3 Existential Lifeworld

Van Manen (2014a) proposes there are five existential themes that are fundamental to the lifeworld of all human beings regardless of social, historical or cultural influences. These themes allow researchers to reflect on how people experience the world and contribute to the process of questioning, reflecting and writing (van Manen 1990). These existential themes originated in Merleau-Ponty's (1945) work, and are discussed in Section 3.5.3: 'lived space', 'lived body', 'lived time', and 'lived human relations'. Following on from Merleau-Ponty's work, van Manen (2014a) introduced a fifth existential theme, 'lived things'. Lived things encompasses the importance of material things and how they may contribute to gaining certain insights. All these existential themes will be discussed in more detail in Chapter Four and will be adopted in the presentation and interpretation of findings.

3.6.4 Hermeneutic circle

Van Manen's method of analysis (1990) was informed by Heidegger's concept of the hermeneutic circle (1962). Both myself as the researcher, and the participants, had to work together to bring life to the experience being explored. The ability to move backwards and forwards between van Manen's six activities (Table 2, p.70) displayed the authentic adoption of the hermeneutic circle within this research. The flexibility and fluidity of the guidelines allowed for a dynamic movement within this circular process. Through the awareness and application of the hermeneutic circle, a fusion of horizons was created by acknowledging pre-understandings, adopting an analytic framework and using a data collection approach suitable to gaining in-depth meaning from the data within the research.

3.7 Van Manen's Guidelines

In contrast with other philosophers, van Manen puts forward explicit methodological guidelines for researchers to conduct phenomenological inquiries. The adoption of van Manen's (1990) approach brought structure to the research process. Instead of providing rules for addressing hermeneutic phenomenology, van Manen offers six guidelines or research activities for use within his approach. These guidelines, outlined in Table 2 (p.70), were used to guide the design and data analysis phases of this research. These guidelines assisted in gaining a deeper understanding of the nature of meaning within the everyday experience, which allowed me to interpret rich meaning from the data (van Manen 1997). This richness of meaning, allowed for the illustration of the 'lived experience' of participants (van Manen 2014a). However, to successfully access the 'lived experience' of each participant and to create an illustration of the phenomenon under review, the text was considered as a pre-reflective, pre-predicative or non-reflective experience (van Manen 2017a). Each experience was understood, and it was communicated without any predetermined conceptual or theoretical influences regarding what the meaning should be. This was achieved by analysing the stories of the participants through the

different lenses of lived experiences: 'lived other', 'lived body', 'lived space', 'lived time' and 'lived things' (van Manen 2014a).

This allowed for the interpretation of the meaning of what was said and captured the essences underlying the described phenomenon (van Manen 2017b). The guidelines also acknowledged any influences which may have affected the researcher during the interpretation (Norlyk & Harder 2010). This allowed for flexibility and was not intended to be a prescriptive, linear method for conducting research. The aim was to provide methodological structure that was dynamic and not necessarily sequential.

3.7.1 Turning to the nature of lived experience

This guideline (Table 2, p.70), focused on the development of the research aim and objectives (van Manen 2001). This research specifically focused on the meaning given by nurses and physicians, to the delivery of care to children with CCNs in PICUs, during the first 18 months of the COVID-19 pandemic. The research aimed to explore the lived experiences of care delivery to this population by these professionals. The research aim was explicit, focused and created in a way that encouraged rich description of these experiences – something that closely links with van Manen's (1990) beliefs. This aim remained continuously at the forefront, to ensure that the research methods were fit for purpose, in understanding these experiences.

Lived experience is the beginning and end point of phenomenological research (van Manen 1990). The lived experience of an individual increases hermeneutic significance since the individual reflects on the experience when reminiscing (van Manen 1990). The aim of this research was to understand the lived experiences of nurses' and physicians' in delivering care in PICUs to children with CCNs, during the first 18 months of the COVID-19 pandemic and to transform these experiences into a textual expression of their meanings. I was committed to understanding this phenomenon. The use of a reflective journal was important for documenting

my personal experiences, making them explicit, and not bracketing prior beliefs, attitudes or understanding.

3.7.2 Investigating experience as we live it rather than as we conceptualise it

To investigate the chosen phenomenon, data was collected from the nurses and physicians who had experienced it, via in-depth interviews. Through this process the participants and I became partners in the understanding of the lived experience being investigated. I maintained a reflective journal throughout the process, comprised of my personal experiences as it related to the subject matter. This allowed me to familiarise myself with the phenomenon under investigation and to increase conformability. The use of a reflective journal is a key element in demonstrating a critical level of reflection as identified by van Manen (1997).

3.7.3 Reflecting on essential themes, which characterise the phenomenon

True reflection on a lived experience necessitates a thoughtful, reflective understanding as to why a particular experience has special significance (van Manen 2001). Phenomenological research differentiates between appearance and essence (Groenewald 2004), implying the importance of the analytical approach used for each transcript. When each transcript was reviewed I reflected deeply on what each participant was saying and what contained a feature of their lived experience (van Manen 2014a). The process of analysing each transcript was important in working through van Manen's guidelines (Table 2). Van Manen's data analysis technique (see Figure 2, p.86) was used for the interpretation of emerging themes (2007).

Table 2: Summary of van Manen's six guidelines (1990)

Guidelines	Explanation of Guideline	Stage in the Research Process
<p>1. Turning to the nature of lived experience.</p>	<p>This includes familiarising with the phenomenon, creating a research aim and clarifying assumptions and pre-conceived understandings.</p>	<p>Development of the research aim to explore nurses' and physicians' experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.</p>
<p>2. Investigating experience as we live it rather than as we conceptualise it.</p>	<p>Influencing factors including how data is collected, with the recommendation of conversational interviews for understanding a lived experience.</p>	<p>Collecting data from nurses and physicians who have experienced this phenomenon, through in-depth interviews.</p>
<p>3. Reflecting on the essential themes, which characterise the phenomenon.</p>	<p>This refers to what it is that makes a particular experience significant. Three approaches to analysis are offered: 1) Holistic 2) Selective 3) Detailed</p>	<p>Interpretation of emerging themes using van Manen's (2007) data analysis technique (see Figure 2, p.86).</p>
<p>4. Describing the phenomenon through the art of writing and re-writing.</p>	<p>This indicates clear understanding of the phenomenon by writing and re-writing.</p>	<p>Use of a reflective journal to document experiences and related thoughts during the duration of data analysis, presentation of findings and discussion.</p>
<p>5. Maintaining a strong and orientated relation to the phenomenon.</p>	<p>This refers to the need to stay focused in the phenomenon, whilst continuously revisiting the research aim as a reminder.</p>	<p>Constant reference to the research aim. Maintaining methodological rigour throughout using established criteria of credibility, fittingness or transferability, auditability or dependability and confirmability.</p>
<p>6. Balancing the research context by considering the parts and the whole.</p>	<p>This ensures that the whole is balanced with the parts during the writing and re-writing phases.</p>	<p>Analysis and presentation of findings through constant reference to the research aim and objectives.</p>

Hermeneutic reflection involved practicing the heuristic activities outlined by van Manen (1990). The processes of phenomenological reflection and analysis occurred within the attitude of the *epoché* as described by van Manen (2014a), the reduction and reflection on the meaning of the lifeworld experiences. This process led to the creation of experiential themes. Within the realm of *epoché*, the objective was to keep a position of openness towards the data and to set aside, personal assumptions (van Manen 2014a). The nature of the experiences were exemplified through the experiential themes. This method was very relevant when the aim was to explore delivery of care during the COVID-19 pandemic as a lived experience. During the interviews and throughout the process of data analysis, the intention was to allow the emergence of any patterns, emotions and themes, as they related to the participants' experiences, rather than based on pre-defined ideas or themes. The aim was to explore and elaborate on the participants' lived experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.

3.7.4 Describing the phenomenon through the art of writing and re-writing

The essence of the lived experiences of nurses' and physicians' providing care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic was described and interpreted throughout the analysis phase. When analysing the data during the first phase, the focus was on immersing myself in the participants' lived experiences, while listening, reading and reflecting on the meaning of what the participants had shared during the interviews. During this process of analysis and writing up the findings, there was the potential for bias on my behalf due to the interpretation of meaning from my own perspective. During the next step of analysis, thoughts and questions were highlighted in the text to bring to the surface any preconceptions or any prejudices from my perspective (Engebretsen & Bjorbækmo 2020). All thoughts were documented with the use of the reflective journal to reduce potential bias (Ortlipp 2008). The intention throughout, was to keep a stance of openness throughout towards the participants' experiences. Re-writing was also supported through PhD

supervision sessions where initial findings were presented and discussed that led to revised iterations. The process of writing and re-writing these lifeworld experiences, aimed to show rather than tell the meaning of the experiences (Engebretsen & Bjorbækmo 2020). Van Manen (2014a) refers to these crafting processes as writing anecdotes which speak to the researchers' imagination, providing an essence of the phenomenon.

3.7.5 Maintaining a strong and orientated relation to the phenomenon

Van Manen (1997) acknowledges the potential for getting distracted when undertaking research. Therefore, I sought to maintain constant reference to the research aim to retain a strong orientation to the topic. The reflective journal was used to record personal reflections and focused my attention when required. Being self-aware and maintaining self-reflection, promoted focus on each individual experience and the overall phenomenon (Kreibich *et al.* 2020). Maintaining methodological rigour throughout the process – using established criteria of credibility, fittingness or transferability, auditability or dependability and confirmability – was also important. These concepts are explored in Chapter Four.

3.7.6 Balancing the research context by considering the parts and the whole

Both the analysis and presentation of findings involved making constant reference to the research aim and objectives. Through the act of deep reflection, writing and re-writing, I was immersed in the finer details of the data (van Manen 2014a). Van Manen (1990) discusses the importance of the researcher taking a step back at times to balance this immersion with the 'whole' or bigger picture. This allowed the whole experience to be viewed as well as the detailed description of its parts. Van Manen (1990) alludes to a phenomenological text being ultimately successful, only to the extent that the readers feel addressed by it. Therefore, the text must echo with ordinary life experience, as well as with a sense of life's meaning. He suggests that although human experiences are always more complex than

what can be captured through writing alone, the text, when viewed as a whole, is intended to represent the findings of the phenomenological exploration. I strived to achieve this through this research.

3.8 Conclusion

In conclusion, this chapter has explored the philosophical and methodological issues relating to this research. In exploring and understanding hermeneutic phenomenology, it became clear that the underpinnings of hermeneutic phenomenology are intricate and complex. Exploration of early and modern works in this field were discussed within this chapter. Research method applications are dynamic and continuously evolving and progressing, with different philosophers adopting distinctive interpretations of hermeneutic phenomenology. As a result, I had to familiarise myself with the individual philosophies and situate the research within the approach that would provide the most rigorous and accurate representation and interpretation of the phenomenon under investigation.

Hermeneutic phenomenology was deemed most appropriate to explore the lived experiences of nurses' and physicians' delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. The goal of hermeneutic inquiry is to identify and explore the meanings expressed by individuals from their personal descriptions, in conjunction with the researcher's understanding of the phenomenon, and therefore is well suited to this research. The justification for using hermeneutic phenomenology as the chosen philosophical underpinning was provided in this chapter, alongside an explanation of van Manen's (1990) framework which was used to guide this research. Van Manen's (1990) approach brought structure to the research. The six guidelines for approaching hermeneutic phenomenology which guided this research and data analysis process were also described. The following chapter, Chapter Four informs the reader of the methods adopted and how the research process was carried out.

Chapter Four: Research Design and Methods

4.1 Introduction

In this chapter, the methods used to investigate the lived experiences of nurses' and physicians' delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic are presented and discussed. The decisions made regarding the research methods are justified by supporting literature. The research process is explained using the headings: aim and objectives, sample and sampling, recruitment and access. The processes for data collection and analysis are also detailed, and the ethical considerations and integrity of the research are outlined.

4.2 Aim and Objectives of the Research

To recap, the aim of this research was to explore the lived experiences of nurses' and physicians' delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.

The objectives of this research were:

- 1) To examine experiences internationally of caring for children with CCNs – during the first 18 months of the COVID-19 pandemic – in PICUs.
- 2) To articulate what has been learned from these experiences during a specific time frame of the COVID-19 pandemic, to support ongoing care in PICUs for this population of children.
- 3) To present implications for the enhancement of care and changes to care delivery in PICUs following the pandemic.

4.3 Sample and Sampling Process

Polit and Beck (2020) define population as incorporating all individuals who comply to a specific set of criteria. When selecting a study population, it is considered a subset of the target population, from which, the sample should be taken (LoBiondo-Wood 2014). The sample refers specifically to the selected group of individuals necessary for conducting the research (Gerrish & Lacey 2012). The accessible population for this research were nurses and physicians working in a PICU during the first 18 months of the COVID-19 pandemic. Sampling is an important step, as it inevitably affects the research findings (Parahoo 2014).

In this instance, non-probability sampling was used to study the population of interest (Vehovar *et al.* 2016). Non-probability sampling deliberately allowed participants to be selected that reflected the required features of the population under research (Ritchie 2013). Within qualitative research, purposive sampling is used as the selected participants can inform and represent the fundamental phenomenon of the research (Palinkas *et al.* 2015). Within phenomenological research, participants are selected to provide personal accounts of the lived experience that is to be studied, and inform a detailed exploration of the central themes (Bryman 2012). Based on the aim and objectives of the research, homogenous purposive sampling was used, purposively seeking out nurses and physicians working in PICUs who had lived experience of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. Snowball sampling was also used to identify and invite any other nurses and physicians working in PICUs, either within the same institution or from other institutions in the country (Naderifar *et al.* 2017, Hensen *et al.* 2021). This process ensured that all participants self-selected to actively contribute and engage with the project.

In phenomenological research it is traditional to use small numbers, since the goal is to achieve a rich understanding of a lived experience and not

produce findings that are generalisable (Mason 2018). The concept of data saturation is widely acknowledged in the research literature, referring to the point at which no further insights are originating from the data (Constantinou *et al.* 2017, Vasileiou *et al.* 2018, Braun & Clarke 2019). However, van Manen (1990, 1997) does not express a specific sample size for his method and prefers the term 'example' over 'sample', indicating that examples of experiential descriptions should be apparent. Van Manen (2014a) explains that there are no rules regarding sample size for phenomenological research and does not advocate using the term data saturation, since this implies looking for patterns within the data, which is not the objective of phenomenology. Instead, phenomenology can illustrate a singular theme in an experience and does not necessarily count how many times certain words appear within the text (van Manen 2014a). The sample size was established for this research, and the recruitment of participants continued, until no new insights emerged during the data analysis phase. Previous qualitative research exploring healthcare professionals' experiences of caring for patients with COVID-19 in an ICU reported a sample size of fewer than 20 professionals, for example, Fernández-Castillo *et al.* (2021), Hu *et al.* (2021), and Gordon *et al.* (2021) explored nurses experiences $n = 17$, $n = 13$, and $n = 11$ respectively, with Leigh *et al.* (2021) exploring physician experiences $n = 15$.

Therefore, it was initially anticipated that a sample size of approximately 20 nurses and 20 physicians would be sought, bearing in mind the need to reflect deeply on each transcript, to allow for a greater depth of investigation, and thereby, not wanting too many that could result in a superficial analysis. After considering the richness and depth of the data, no new insights arose after 40 interviews (18 nurses and 22 physicians). Recruitment was deemed complete once I had reviewed the participants' transcriptions, and this was also independently confirmed by my two supervisors.

4.3.1 Gaining access

The ERC *TechChild* project was previously approved by the Research Ethics Committees in Trinity College Dublin and in each of the four participating national and international sites in Ireland, the U.S., Australia and the Netherlands. As previously mentioned, this was an initial purposive sample of nurses and physicians working in PICUs, experienced in the delivery of care to children with CCNs during the first 18 months of the COVID-19 pandemic, with further participants identified through snowball sampling. Participants were invited from three of the international sites in the *TechChild* study — Dublin, Boston and Melbourne. These sites were purposefully chosen to yield rich data due to the admission rates of children to their PICUs and the specialist care services available for complex interventions. The fourth site, the Netherlands, was not included in this research, as English was not the first language of the staff and the timeframe for this PhD did not include time for translation and back translation.

Inclusion and exclusion criteria were established. Inclusion criteria involved characteristics the individuals must have to participate and exclusion criteria detailed attributes which would exclude people from the study (Bloom & Trice 2017). The choice of the inclusion and exclusion criteria used for any study, has implications for the interpretation of the results (Polit & Beck 2020), and these were pre-defined at the outset to avoid any bias throughout the process.

4.3.2 Inclusion criteria

To be eligible to take part in this research, participants had to be working in PICUs during the first 18 months of the COVID-19 pandemic. Nurses and physicians, who form part of the multidisciplinary team in PICUs where children with CCNs were cared for, were included. There was no time limit placed on the duration of time participants had been working in PICUs, to

ensure all eligible staff who had experience of working during the first 18 months of the COVID-19 pandemic were included.

4.3.3 Exclusion criteria

The people excluded from this research were:

- Participants from the fourth site in the Netherlands as English was not their first language.
- Nurses and physicians who did not meet the inclusion criteria outlined above.
- Other members of the multidisciplinary team e.g., social workers, physiotherapists, dieticians and chaplains.
- All students.

4.4 Recruitment and Access

Purposive sampling was adopted with the sample population being nurses and physicians working in a PICU during the first 18 months of the COVID-19 pandemic. Three sites were accessed for the recruitment of a suitable sample. Each site had an appointed gatekeeper who was the Director of the PICU or the Director of the Complex Care Service in the hospital. Access to potential participants was through these gatekeepers. The positive influences of a gatekeeper can be valuable in promoting a research project and are well documented in the literature (Macfadyen & Rankin 2016, Singh & Wassenaar 2016, Kay 2019).

The gatekeepers were provided with information about the research and invited all nurses and physicians currently working in their PICU to participate in a semi-structured interview. All potential participants received an information sheet detailing the following: the reason they were asked to take part; information about the overall research; details on the confidentiality and anonymity of the research; the voluntary nature of participation in the research; and detailed information on the use of data

collected in the research (Appendix 3). All potential participants were invited to speak with me to ask any further questions they may have as part of their decision to participate. Following this, prior to the interview taking place, each potential participant was asked to electronically complete and sign an Informed Consent Form via Qualtrics (Appendix 4), with reminders sent after two weeks (Appendix 5).

At the start of each interview each participant was informed again about the purpose of the research and their right to withdraw. An opportunity was provided for them to ask questions before commencing the interview and assurances of confidentiality and anonymity were provided. Following the interview, each participant was asked to consider identifying any other colleagues working in a PICU who would be eligible to participate in the research.

4.5 Data Collection

Polit and Beck (2020) suggest that the success of research relates to the quality and implementation of the data collection methods, while van Manen (1990) indicates that *investigating experience as we live it* is affected by how the data is gathered. From the outset, I spent time thinking, writing and discussing with others about why this topic was of interest and importance to me. I considered my professional background and my experience of caring for this cohort of children, but acknowledged it was very much 'my own' experience. This awareness enabled me to be mindful when interviewing nurses and physicians and attempted to curb any researcher bias that might arise by using the same guiding framework in each interview.

4.5.1 Interviews

The most common form of data collection within hermeneutic phenomenology is conversational interview (van Manen 1990, Vandermause & Fleming 2011, Englander 2012, Sloan & Bowe 2014).

Phenomenological interviews are in-depth by nature, usually unstructured or semi-structured, and adopt open ended questions, that are carefully constructed to obtain the desired information (Balls 2009, Seidman 2012, Bevan 2014). The purpose of the interview was to gather and explore narrative materials to develop a comprehensive understanding of the phenomenon of interest, while developing a conversational relationship with the participant to understand the meaning given to the experience (Brinkmann & Kvale 2015). It is well documented that individual interviews are an effective means of gaining insight into an individual's experience of a given phenomenon (Ryan *et al.* 2009, Bolderston 2012, Creswell & Poth 2017, DeJonckheere & Vaughn 2019).

In this instance, one to one, semi-structured interviews were chosen to explore the nurses' and physicians' experiences of initiating technology dependence to sustain a child's life using long-term ventilation as an example. The interviews also included additional questions relating to contemporary issues including the participants' interpretation of the term technology dependence and finished with a open-ended question exploring the impact COVID-19 was having on care delivery in PICU, which specifically related to this study. Using an open-ended question exploring COVID-19 allowed a comprehensive look at the topic, giving participants the opportunity to provide opinions and created more diversity than with guided questions (Weller *et al.* 2018). In this instance, the use of an open-ended question worked well and allowed for collection of rich data pertaining to this topic. The protocol and schedule for multi-site interviews within the data collection for the TechChild project, which I participated in devising, is outlined in Appendix 6.

Semi-structured interviews allowed the participants time to process and articulate their experiences concerning the area of interest (Jamshed 2014, DeJonckheere & Vaughn 2019). Participants were allowed to choose dates and times for the interview that suited them, which is recommended in the literature to demonstrate sensitivity towards the participants (Dempsey *et al.* 2016, Melville & Hincks 2016). Conducting research during a global

pandemic has produced unprecedented insights into conducting qualitative research online (Dodds & Hess 2021). Due to the restrictions associated with restricted travel and movement during COVID-19, all interviews were changed from face-to-face and conducted using a teleconference software system; Zoom Video Communications Inc. software (Zoom) on a Zoom Pro plan. Zoom is compliant with the Health Insurance Portability and Accountability Act (Lobe *et al.* 2020). Ethical amendments were submitted and approved for this change, as discussed earlier (in section 4.3.1).

The interviews were digitally audio recorded with each participant. This was necessary as the participants' words needed to be transcribed verbatim to ensure meaning was preserved (King *et al.* 2018). Separate interview notes were also kept for additional commentary throughout the interview (Appendix 7). The saved files and interview notes were uploaded onto a secure server for backup purposes. Prior to transcribing, the interviews were anonymised using identification codes, and the original recordings were then destroyed after they were transcribed, and I had re-listened to check for accuracy. The transcriptions were imported into a qualitative analysis software package, NVivo R1, to support data management. Additionally, supplemental biographical and contextual data were collected prior to the start of each interview.

Recent research has identified participants' experiences of using Zoom for interviews as highly satisfactory and rated Zoom above other interviewing methods, including face-to-face, telephone or other videoconferencing platforms (Archibald *et al.* 2019, Gray *et al.* 2020). The benefits of using Zoom included, ease of use, cost-effectiveness, accessibility, security options such as locked meetings, waiting rooms, password-protected meetings, secure recording on local devices and data management features (Archibald *et al.* 2019, Gray *et al.* 2020, Burke 2021, Oliffe *et al.* 2021). Data management features allowed opportunities for unique approaches to knowledge generation by providing multimodal analysis of spatial, temporal and visual elements (Davitti 2019). Unlike Skype or some other

videoconferencing software programmes, a participant did not need to have a Zoom account to take part in the interview (Gray *et al.* 2020). I sent each participant a direct, live link to click on to join the meeting. They were asked via email if they were familiar with Zoom prior to the interview, to ascertain if any additional instructions were necessary. None of the participants required additional training or support to access the interview, possibly due to the recent society wide increase in the use of online programmes during the pandemic (Hacker *et al.* 2020).

The participants were able to conduct these online interviews at home, in work or in a location suitable for them. This ensured that if participants did not have a suitable internet connection at home, they would be able to access it elsewhere. In this situation, I was relying on the participant to choose a suitable location without distractions that could interfere with the flow of the interview and disturb the participants' concentration levels. The importance of effectively preparing for online interviews by ensuring participants are in a quiet location, free from distractions was highlighted in the literature (Deakin & Wakefield 2014, Seitz 2016). This was checked with the participants at the time of arranging interviews and also before commencing the interview.

However, issues still arose. Some participants conducted the interview in an office within a workplace, with other colleagues walking in and out during the process. Individuals also had to wear facemasks if they were in a shared office, which hindered communication at times and did not allow me to see their facial expressions, which would have been preferable (Seitz 2016). Within qualitative interviews, the researcher wants to capture the participant's experiences in their own words to illustrate how they can make sense of the phenomenon being explored (Yilmaz 2013). This can be challenging if the internet connection drops, if there is unexpected background noise or if inaudible segments are present in the recording. None of these issues presented themselves during the transcription of recordings.

Numerous studies have previously reported on the benefits of interviewing online using methods such as Skype, including practical benefits such as, the flexibility of scheduling interviews within the busy lives of the participants, ease of recording and downloading interviews using online software, low cost and ease of access to participants over a vast geographical area (James & Busher 2009, Sedgwick & Spiers 2009, Hanna 2012, Salmons 2012, Deakin & Wakefield 2014, Winiarska 2017). Unlike telephone interviews, video calls allow the participant to feel personally connected with the researcher (Gray *et al.* 2020). Until recently, reluctance and hesitation for participation in online interviews may have been cited as a disadvantage to online interviewing (Gray *et al.* 2020). However, the rapid uptake in social media (Pew Research Centre 2018), the increase in technology in daily life (Plowman *et al.* 2010, Garfin 2020) and increase in digital skills (Lobe *et al.* 2020) make online activities more accessible to all and does not seem to negatively impact on the willing participation in research interviews (Sipes *et al.* 2019).

In this research, online interviewing allowed for interviews to be conducted at the participants' convenience — early in the morning or late at night — to accommodate different time zones. Prior to the start of an interview, I asked the participant if they could hear me clearly and see me without any connection difficulties. In one case, the participant moved to another location to get a better connection before the interview commenced. Open ended questions formed the basis for questioning and were cautiously created so as to avoid imposing predetermined responses. As a result, the participant was placed in the role of expert within the subject area. The interview began with a few initial icebreaker questions to establish years of experience and current job role. Following this, the interview continued with a non-leading opening request “tell me about your experiences of how COVID-19 has or will have an impact on care delivery in the PICU”. The interview was non-directive and conversational in style. My role was one of active listening and less questioning, with the exception of clarifying comments or to encourage conversation. Additional probing and interpreting questions were established from the outset in order to clarify information or

to elicit a more detailed response during the interview if required (Appendix 8).

The disadvantages of using online interviews have been reported in the literature, including technological or signal problems, ethical issues, inability to read body language or verbal cues and difficulty building rapport with participants (James & Busher 2009, Deakin & Wakefield 2014, Seitz 2016). The interviews in this research, were not without technical hitches, for example, a faulty webcam or moments where the video froze. These occasional issues temporarily halted the interviews, but the participant was able to re-commence after a few seconds without significant disruption. There was also an issue with some absentees, where participants did not turn up online on the agreed date and time or were unable to attend due to work commitments. This was initially very disappointing and caused me some concern about whether the time zones had been calculated accurately or if instructions in the email had not been clear. However, the value of being part of the wider project offered solace, as my written communications to potential participants followed the overall standard operating procedures for the *TechChild* project and had been approved by the research ethics committees for use. I documented all of these concerns in my reflective journal throughout the process and they were consistent with the feelings of other researchers who have conducted interviews online (Deakin & Wakefield 2014).

After follow-up communications, and opportunities offered for rescheduling, all initial participants were interviewed. The use of live video partially contributed to overcoming issues around spatiality and physical interaction. Both the participant and I were able to remain in a neutral, 'safe location', without imposing on each other's personal space (Hanna 2012). Although the literature noted that participants may feel uncomfortable or embarrassed being filmed, none of the participants expressed concern over this (Hay-Gibson 2009). While it was permitted to video the interviews, it was agreed that, in line with the European Union guidelines for data management, all

videos would be destroyed immediately after the interview (excluding the audio) and this was made explicit to all participants.

Full interpretation of body language was not possible using video, because even with a full screen, you do not usually see more than the participant's face and upper body (Seitz 2016). This was true for most interviews, but there were moments where participants were crossing their legs or pulling their knees up to their chest during the interviews. In an interview where the participant pulled their knees up to their chest, they had just come off night duty and it was towards the end of the interview where they were becoming restless and distracted. The interview ended shortly after this, when the participant voiced they had nothing else to add. I consciously paid significant attention to the tone of the participant's voice and where possible, their facial expressions (Seitz 2016). Maintaining eye contact was also challenging at times until I was comfortable with interviewing online. As Seitz (2016) highlights, looking at the person on the screen is not the same as looking at the camera.

Full ethical consideration was given before conducting these interviews online (see section 4.7 for full details regarding ethical considerations). The participants were asked to complete an online informed consent form in advance of the interview (Appendix 4). If they had not completed this, I went through the form with them at the start of the interview. The participants were reminded of their right to voluntarily withdraw from the interview at any time. Lobe *et al.* (2020) highlight the ease of doing so in an online interview, through the simple act of disconnecting. However, no participants withdrew at any stage of the process. All participants were made aware that the audio and video interview would be recorded, but only the audio would be saved. All participants were happy with this and were willing to proceed with the interviews.

Building rapport online is different to a rapport built face-to-face (van Coller-Peter & Manzini 2020). Previous research has suggested that problems can arise in building a rapport online, including a lack of visual cues (Hay-Gibson

2009). Additional steps were taken prior to the interview to build a relationship with the participant and to ensure they felt as relaxed as possible throughout the process (Howitt 2019). A number of emails were exchanged with the participants prior to the interview to assist with rapport building. All of them opted to turn on their videos throughout the interview. Through this use of video, visual cues were observed, and subsequently the challenge of building rapport was overcome.

On reflection, consistent with previous research in this area of online interviewing (Hanna 2012, Deakin & Wakefield 2014, Archibald *et al.* 2019), I too, found that the benefits of using Zoom for data collection significantly exceeded the challenges experienced. For the majority of participants, they appeared well connected, focused and provided open discussion with rich insights on the phenomenon. I was surprised by how easy it was to build up a rapport with the nurses and physicians' online, and how open they were to sharing details of their daily professional experiences, despite having to conduct these interviews via Zoom. My initial concerns regarding not gaining insightful data, and the potential challenge of building rapport online were largely unfounded. Due to the widespread restrictions of COVID-19 and the impossibility of conducting in-person interviews, there was no alternative available to this research. Krouwel *et al.* (2019) discovered face-to-face, in-person interviews were marginally superior to video calls as participants said more in the face-to-face realm. However, on reflection the data gathered during the online interviews was more than sufficient for the analysis; proving that online interviewing is effective.

Phenomenological interviews can last between 45 to 90 minutes, sometimes longer (Mills & Birks 2014). The majority of the interviews completed within this research fell within this time frame. There were two complete interviews which were shorter, at 31 and 38 minutes – one of the participants had to leave to attend to a clinical matter and the other, had just finished night duty. None of the interviews required follow-up with the participants to clarify anything. At the beginning and end of each interview there was additional general conversation which assisted with the process

of engagement and disengagement, an essential component of the complete interview process (Edwards & Holland 2013). All of the participants remained focused during the interviews and the interviews came to a natural end following a brief discussion about topics such as the weather.

4.5.2 Gaining consent

Participants who were interested in participating contacted me via email. Further information was provided to the potential participant, using the participant information leaflet (Appendix 3). All participants were offered the opportunity to ask questions at this time, or to seek additional information. A suitable date and time were agreed with the participant via email. An online consent form was sent to each participant ahead of the scheduled interview asking them to give their informed consent. The purpose of the research was reiterated at the beginning of each interview and any questions answered. Confidentiality was discussed regarding the digital recordings and anonymity assured through the use of codes. Transcripts were available for any participant who requested to review it afterwards, but no participants opted to review their transcript. Any identifiable details, including names or locations were anonymised during transcription. Participants were reminded that they could withdraw from the research at any time, without any reflection on themselves and without needing to provide a reason for withdrawal. No participants opted to withdraw from the research once they consented to participate.

4.5.3 Reflection on the data collection process

Prior to the first interview, the participant was contacted to confirm the arrangements. Before commencing the 'formal' interview, a brief 'getting to know each other' conversation took place, talking about the weather, where the researcher was based etc. As well as the online consent, verbal consent was also obtained before commencement of the interview. There was quite an even split, with about half of the participants being at home for their

interviews and the other half completing the interview in the hospital workplace setting. There were slight differences noted as to how participants interacted based on their location, with some of those who were interviewed in the workplace appearing more distracted at times due to background activity including phones ringing, people entering the shared office spaces and other times when participants' communication flow was disrupted due to wearing masks because they could not socially distance from others. When these situations occurred, I asked the participant if they wished to continue the interview at an alternative time, but they were all happy to continue and all interviews were completed. However, these disturbances did not appear to impede the information provided and all participants were able to share detailed accounts of their experiences.

The very first interview was challenging, as the participant was not forthcoming with information about the phenomenon, and appeared distracted throughout the interview. They had just finished night duty and were not engaging with the interview process. The interview lasted only 31 minutes. It was a good test of my ability to engage with the interview process, but also the unpredictable nature of interviewing, and this experience prepared me for when things don't go 'to plan'. The participant apologised at the end for being "incoherent" or "not making sense at times". After the second interview my nervousness reduced, and I became confident in the interview process.

Following each interview, I listened to each recording, ensuring the quality was good and that nothing had been missed in the interview. A professional transcription service was used to transcribe the interviews. To ensure that no data would be compromised, a confidentiality non-disclosure agreement was signed by the project team and the company. The recordings and transcripts were saved on a password-protected secure server. Once the transcription process was complete, each transcript was read and checked while listening to the recording to ensure accuracy. All transcripts were checked for any potential identifiers, and none were present. Each transcript was allocated a code, to maintain the confidentiality of the participant, using

a site-discipline-participant number approach. A schedule of interviews and the related codebook were stored on the secure server. After each interview a follow-up 'thank you' email was sent to each participant (Appendix 9).

4.6 Data Analysis

The data analysis phase is central to any research and signifies the stage at which the phenomenon of interest can be understood. Following considerable deliberation, the decision was made to report the findings collectively. This was made based on the overall aim of the research as the focus was primarily on the organisation of care and not on the specific experience of one particular discipline. The decision was made to analyse the findings collectively as nurses and physicians are the key professionals responsible and involved in the care of children in PICUs. This allowed for a focus on the central issue, the organisation of care, rather than from the perspective of one particular discipline. This approach reflects the discourse in the literature on the working environment in adult ICUs (Stocker *et al.* 2016, Ervin *et al.* 2018, Aldawood *et al.* 2020).

Data analysis within phenomenology has received significant attention over the last 60 years or so, with a number of approaches existing for analysis (Spiegelberg 1965, Colaizzi 1978, van Kaam 1984, Giorgi 1985, van Manen 1990, Streubert 1991, Moustakas 1994). Within hermeneutic phenomenology, due to the ideological stances by some phenomenologists, definitive analytical steps are often not the focus. All hermeneutic phenomenological analysis adopts a process of close and repeated engagement with the data, regardless of the phenomenological approach taken. The complexities and intricacies of the phenomenon must be captured, and described, to allow others to engage with, and understand the data (Grbich 2013). The analysis part of this study concentrated on generating themes derived from my engagement with the data (Heinonen 2015). Contextualisation and making connections between the themes provided a coherent understanding of the phenomenon under investigation (Bazeley 2009). As highlighted by Oerther (2020) I, as the researcher, had

a central role in constructing meaning within this hermeneutic phenomenological research, and was guided by van Manen's (1990) methodological approach for undertaking phenomenological research.

4.6.1 Van Manen's method for thematic analysis

Gadamer (1975) stated that the method of hermeneutics, is, that there is no method. However, van Manen (1990) believes that within hermeneutics there is a history of traditions, a body of knowledge and insights and he developed methodological themes or features that influence researchers' development of the research methods. The data analysis was based on van Manen's method for thematic analysis, to capture the meaning of the nurses' and physicians' experiences as they portrayed their own story and their lived experiences. The data was analysed using van Manen's (2007, 2014a) three analytic steps, through writing and re-writing. This included the steps shown in Figure 2.

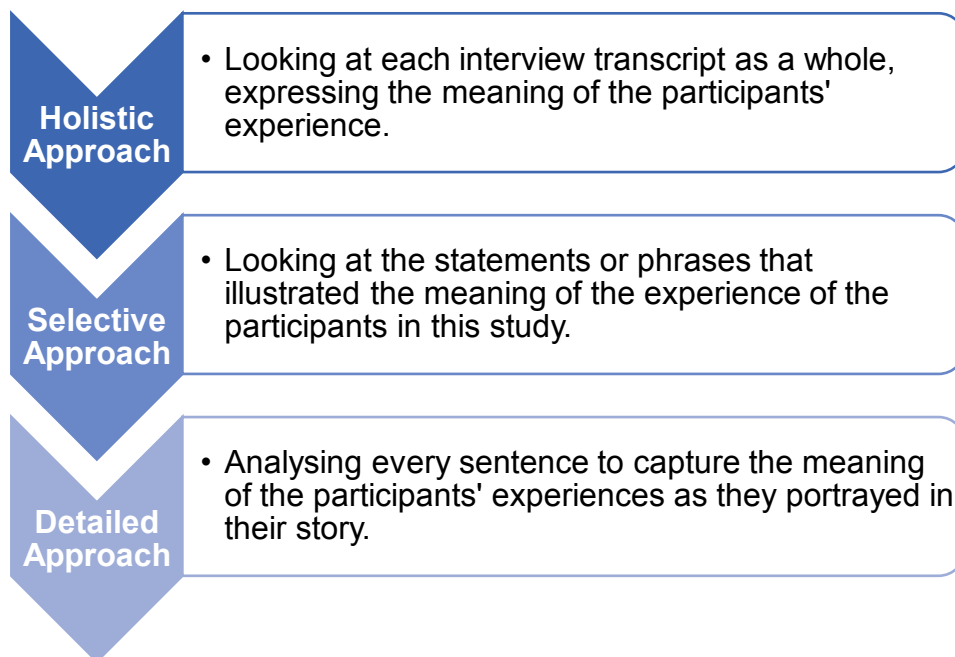


Figure 2: Data analysis (van Manen 2007, 2014a)

Van Manen's (1990, 1997, 2007) method for thematic analysis is described in Table 3 with the corresponding phase of data analysis within this research explained. This method of thematic analysis involved identifying,

interpreting and recording patterns and clusters of meaning within the data (Ritchie *et al.* 2013). A systematic approach was used to address the texts, to enable me to identify topics that emerged that were then integrated into higher order themes to answer the research aim (van Manen 1990, Braun & Clarke 2006). In addition to describing and analysing the phenomenon under investigation, the text also evokes an understanding of the most essential and meaningful points being studied, which would be difficult to address in any other way (van Manen 2014a).

4.6.1.1 Transcribing, reading and re-reading – turning to the nature of lived experience

Following each interview, transcription was undertaken by a professional transcription service. Transcription is the process of converting the audio from the interviews into text and is necessary prior to commencing data analysis (King *et al.* 2018). After transcription, I cross-checked the transcript with the audio file to ensure accuracy. I read the transcripts while I listened to the audio recording to become accustomed to any parts of the interview which may not appear in a transcript, for example, any emotions expressed. This assisted with understanding what was and was not said, or any extended pauses or breaks on the participant's side. The field notes and reflective journal were also valuable tools that were analysed on an ongoing basis to enhance the data collection and analysis processes. Following transcription, each transcript was analysed one at a time, using the same process for each.

4.6.1.2 Constructing a qualitative database – investigating experience as we live it

The construction of a database using NVivo R1 software was central to managing data analysis. There are numerous qualitative data analysis packages available online and I selected the NVivo R1 Qualitative Data Software Analysis package. This package allowed for coding a category directly from the participant's own words (Dollah *et al.* 2017).

Table 3: Phases of data analysis

Phase of Data Analysis	van Manen's (1990, p.30-31) Guidelines
Transcribing, reading and re-reading of the transcripts.	<i>Turning to the nature of lived experience</i>
Constructing a qualitative database using NVivo R1 software to capture the phenomenon through the data collected through the interviews.	<i>Investigating the experience as we live it rather than as we conceptualise it</i>
Selective reading approach and creating initial themes. Holistic reading approach and creating essential themes.	<i>Reflecting on the essential themes which characterise the phenomenon</i>
Through the process of writing, the goal is to ensure the feelings, thoughts and attitudes of the participants are made visible.	<i>Describing the phenomenon through the art of writing and re-writing</i>
Striving to remain focused on the research aim whilst writing and re-writing.	<i>Maintaining a strong and orientated relation to the phenomenon</i>
Adopting an existential approach.	<i>Balancing the research context by considering the parts and the whole</i>

There have been ongoing debates in the literature regarding the use of computer software to manage and organise qualitative data (Bassett 2004, Maher *et al.* 2018). While van Manen (1997) suggests there is no need to use a software package, I felt it was helpful for the storage and retrieval of quotes and text which subsequently would assist in the development of themes. A document was created for use during the analysis phase linking the steps in the NVivo R1 process with van Manen's six research guidelines (Appendix 10). This helped to ensure transparency for each stage (Bringer *et al.* 2004) and to guarantee I was staying true to the guidelines.

4.6.1.3 Selective and holistic reading approach and creating initial and essential themes – reflecting on the essential themes which characterise the phenomenon

Van Manen (1990) suggests three analytic methods for isolating thematic statements and attributing meaning to the data: the holistic reading approach, selective reading approach and detailed reading approach (see Figure 2, p.90). The selective reading approach included a comprehensive review of the text, reading it multiple times, with the aim of revealing phrases which appeared essential to the experience being recounted (van Manen 1990). Within this approach I read the text and highlighted essential statement(s) which related to the experience being discussed. The selective reading process allowed for the development of initial themes or codes. Coding involved identifying segments of meaning within the data and assigning specific codes for particular phrases or words that symbolically captured attributes within the text (Linneberg & Korsgaard 2019). Through the assigning of codes, the data was organised in a logical manner, while reflecting what each participant said.

In addition to the selective reading approach, the holistic reading approach was adopted to also view the text as a whole and notable phrases were identified that captured the fundamental meaning of the experiences, in addition to the selective reading approach. This varied with the depth of the analysis. After the holistic reading approach, in addition to the reorganisation, renaming and merging of constructs, and identifying initial themes in the selective reading approach, the essential themes were developed.

4.6.1.4 Writing – describing the phenomenon through the art of writing and re-writing

The writing, re-writing and data analysis aided the understanding of the phenomenon. Through the process of this writing and re-writing further reflection took place around the meaning and interpretation of the participants' experiences. This process enabled the continuous revision,

refinement and clarification of thoughts. Regular questioning and reflection of emerging themes contributed to a deeper understanding of the lived experience of the participants. The information was then integrated into a cohesive text and presented as overall findings. The writing involved continuous re-reading of the original transcripts to ensure the findings were a true representation of what the participant had said. Essential themes were presented at this stage, using quotes, to capture the essence of the phenomenon when writing up the findings. When discussing essential themes, van Manen (2001, p.107) explains, “in determining the universal or essential quality of a theme our concern is to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is”. Within this research I proposed that if the phenomenon under review lost its fundamental meaning without a particular theme, it was then regarded as essential.

Within van Manen’s framework for exploring lived experience (1990), I acknowledged my role as co-creator during the research process, where the meaning of the experiences was created through my own immersion in the text and data. Van Manen (2014a) suggests that writing enables the researcher to adopt a reflective attitude, that further enables them to remain focused on the meaning of the phenomenon to be explored. This was an important feature of this research design.

4.6.1.5 Remaining focused on the research aim – maintaining a strong and orientated relation to the phenomenon

Throughout the process, I had to remain focused on the research aim of exploring the lived experiences of delivering care to children with CCNs in PICUs by nurses and physicians during the first 18 months of the COVID-19 pandemic. Through keeping this focus at the forefront at all times, I was maintaining a strong and orientated relation to this phenomenon.

4.6.1.6 Adopting an existential approach – balancing the research context by considering the parts and the whole

Van Manen (1990) suggests a number of approaches for presenting study findings including thematically or analytically. He also suggests using an existential approach to present findings, while reflecting on transcripts and searching for the fundamental existential themes outlined in Table 4 (p. 97). These existential themes guided the questions and reflections, the search for meaning, and were used to frame the presentation of findings.

Reflections on the interview experiences were recorded within my journal, as recommended by Nadin and Cassell (2006), and focused on the practical issues as well as the experience of the interview as a social encounter — albeit online (see section 4.5.1 for full details of the online interview process). These notes were useful when making connections between transcripts, experiences and emerging themes. They were used to refer back to transcripts when a theme emerged to ensure that it was evident during the participant experience and not derived from my own biases or preconceptions. This part of reflecting between the parts and the whole of the text is firmly situated within van Manen's theory (1990). Throughout the process, I was constantly focused on measuring the overall design of the research and text, set against the significance that the parts played within the total textual structure (Penner & McClement 2008).

4.6.2 Five lifeworld existential themes of human experience

The five lifeworld existential themes proposed by van Manen (1997, 2014a), outlined in Table 4 underpinned the analysis and expression of the data. They are fundamental to the lifeworld of all human beings regardless of their historical, social or cultural circumstances (van Manen 2014a). Van Manen (1990) suggests these existential themes allow phenomenologists to reflect on how people experience the world and assists in the process of phenomenology for researchers. Four of these existential themes originated in the work of Merleau-Ponty: 'lived human relations', 'lived body', 'lived

time' and 'lived space' (Merleau-Ponty 1962). More recently, van Manen (2014a) introduced a fifth existential theme – 'lived things'. These five existential themes will be incorporated and discussed further in the analysis of the data and presentation of findings. They have been used as a guide for reflection on the data analysis process in many phenomenological research studies that explored the lived experience of patients and also that of parents of neonates in neonatal intensive care units (Larkin *et al.* 2007, Jessup & Parkinson 2010, Krumwiede & Krumwiede 2012, van Manen 2014b).

4.6.2.1 Lived other (relationality)

'Lived other', relates to how individuals relate to one another within an interpersonal space, how they develop an impression of what others like and how this is affirmed or altered in interactions with each other from a relational and non-relational perspective (van Manen 2007). This displays through the maintaining and developing of relationships with each other, for example, communicating in a certain way or how one behaves around another person.

4.6.2.2 Lived body (corporeality)

This incorporates the impact of the physical body presence on a situation and can reveal or conceal aspects about an individual, but does not always show what is going on inside on the outside. 'Lived body' relates to how individuals experience the world through the body (Merleau-Ponty 1962). The body, when looked upon by others, may respond in various ways, for example, revealing or concealing things about oneself, depending on how the gaze is perceived (van Manen 2007). This can be a conscious and unconscious process. 'Lived body' can also include the physical body space of a healthcare professional with a perceived particular role.

**Table 4: Five lifeworld existentials of human experience
(van Manen 1997, 2014a)**

Existential Theme	Description
Lived other (relationality)	“Is the lived relation we maintain with others in the interpersonal space that we share with them” (van Manen 1997, p.104).
Lived body (corporeality)	Refers to “the phenomenological fact that we are always bodily in the world” (van Manen 1997, p.102).
Lived space (spatiality)	As a “felt space ... It is largely proverbial; we do not ordinarily reflect on it. And yet we know that the space in which we find ourselves affects the way we feel” (van Manen 1997, p.102).
Lived time (temporality)	Refers to “subjective time as opposed to clock time or objective time ... and lived time is also our temporal way of being in the world” (van Manen 1997, p.104).
Lived things (materiality)	“The things are our world in its material thing like reality ... How are ‘things’ experienced and how do the experiences of things and world contribute to the essential meaning of the phenomenon” ... “the moral force things and technology exerts in our lives” (van Manen 2014a, p.307).

Depending on how we feel about someone, their appearance may be distorted to suit our thoughts and body language can adjust depending on the situation. In the same way, the environment where the participants are working, in this instance PICUs, can be perceived differently depending on the point of view of the individual.

4.6.2.3 Lived space (spatiality)

Spatiality is an important concept, closely related to embodiment and perception (Merleau-Ponty 1962). This can be thought of not solely as a physical space, but more of an interaction with another person and connects all things. Mackey (2005) recommends that 'lived space' positions the individual in a location. Conversely, Merleau-Ponty (1962) and van Manen (1990) suggest that there is a difference in how individuals feel in a space such as their home, compared with the impersonal space of their workplace. It could be considered as the felt space in the hospital – the world or landscape in which the participants work – the 'atmosphere', perspective and philosophy of the space. This can also relate to the mood in which the participants encounter their lived space.

4.6.2.4 Lived time (temporality)

'Lived time' is not only viewed as a passing of seconds, minutes or hours but relates to things or a situation (Merleau-Ponty 1962). This explores temporal things of the past determining the present and the future perceptions of the world. For instance, past experiences such as trauma, culture and spiritual beliefs can affect the way someone interprets their work and may emerge through the participants' lived experience. However, pressures of the present, and influences, may also change the past.

4.6.2.5 Lived things (materiality)

'Lived things', refers to how things are experienced in day-to-day life and focuses on the importance of material things. In this scenario, this could relate to the influence of available technology on care delivery and the related impact of this on the healthcare professional.

4.6.3 Summary of data analysis

Throughout the data analysis process, an audit trail was kept in the reflective journal, by documenting the decisions made, and to keep me focused. This

audit trail and evidence of decisions, including the creation of initial themes and essential themes, was recorded throughout each phase of the analysis. I had regular meetings with my supervisors to allow continuous reflection on the analysis process, and to ensure the writing of the findings was well orientated and derived from deep analysis.

4.7 Ethical Considerations

Ethical issues are part of the everyday practice of conducting research (Gray *et al.* 2017). They can arise at the beginning of the research and continue throughout the research process (Polit & Beck 2020). Ethical principles are used as a framework to guide the researcher through the research process ensuring the highest possible standard in every aspect of the process. I was obliged to ensure that the appropriate committees had approved the research and that the rights of the participants were protected at all times (Beauchamp & Childress 2019). I was familiar with all the relevant ethical procedures and policies (Gerrish & Lacey 2012). For this research, ethical approval was received for all the research sites both through Faculty Ethics in Trinity College Dublin and the relevant ethics committees in each of the clinical sites. The ethical permission obtained from the project host institution, protected any participants who contributed from snowballing. This section focuses on the ethical principles relevant to this research, as outlined by the Nursing and Midwifery Board of Ireland (NMBI) (2015): respect for autonomy, beneficence and non-maleficence, justice, confidentiality, veracity, and fidelity.

4.7.1 Respect for autonomy

Autonomy is one of the cornerstones of research ethics and relates to respecting the rights of the individual (Beauchamp & Childress 2019). Key elements are essential for ethical conduct in research inquiry: protection of human rights, the voluntary and informed decision of an individual's participation, and the right to withdraw from a study at any time without any penalty (LoBiondo-Wood & Haber 2014, Gray *et al.* 2017). This research

considered several aspects in upholding the respect for participants' autonomy. The participants had the right to choose whether they would participate in the research and their choice was free from coercion (Beauchamp & Childress 2019).

Participants were always granted privacy and respect and were fully informed of the research before the commencement of the study, which is another requirement for autonomy (Gray *et al.* 2017). The participant information leaflet (Appendix 3) clearly outlined the purpose of the research, the voluntary nature of the participant's involvement, highlighting there was no impact on themselves if they chose not to participate. Further information was provided via email if requested and shared verbally with the participants prior to commencing an interview. It was essential that participants understood what was required of them and what participation entailed, prior to taking part in the research. In qualitative research, consent has been referred to as a negotiation of trust, requiring continuous renegotiation rather than a one-off procedure (Manti & Licari 2018). For this reason, written consent was obtained in advance of the interview and verbal consent was sought just before commencing the interview.

All participants had my contact details, and if required, they could contact me via email at any stage. They could always speak freely, and they understood their right to withdraw at any stage, without explanation. This detail was outlined in the participant information leaflet (Appendix 3), the online informed consent form (Appendix 4) and reiterated verbally at the beginning of the interview. The participants were reassured that the information provided would be kept confidential and have no impact on their professional practice within their respective organisations (see section 4.7.4).

4.7.2 Beneficence and non-maleficence

The ethical principles of beneficence and non-maleficence are often interlinked. These principles place a duty on researchers to minimise harm

and discomfort, while maximising the benefits for the participants within the research (Polit & Beck 2020). It is recognised that benefits and risks should be balanced, with benefits ideally shown to a favourable ratio (Beauchamp & Childress 2019). In addition to respecting the participants' decisions and protecting them from harm, maximum efforts should be made to promote their wellbeing (LoBiondo-Wood & Haber 2014). I had to attempt to balance the risk of harm against the potential benefits from research participation. In addition, several factors were considered, including the types of harm that may occur, how likely they were to occur, ways to minimise these risks and approaches to maximising the benefits for the participants (Gray *et al.* 2017). A risk mitigation protocol was completed to identify potential risks, since discussion of a sensitive topic might cause potential distress to a participant or lead to the disclosure of unexpected findings.

Within social science research, there is a possibility that the researcher will intrude into people's lives, and the concept of harm is more than likely related to psychological distress, embarrassment, discomfort, or invasion of privacy (Kitchener & Kitchener 2008). However, in addition to emotional impact, harm and discomfort can also be physical, economic, or social (Gray *et al.* 2017). An in-depth exploration of participant experiences may result in distress or upset for the participant. Subsequently, appropriate measures were put in place, prior to the commencement of the research, to ensure that participants had their needs met during the research. Support services related to each organisation were available for the participants if needed. If any participant had shown any significant upset or undue distress, the interview would have been terminated. However, this scenario was not experienced by any participant. All participants were informed about the potential for unexpected findings and the management of such findings, defined in a policy for unexpected findings, created by the project team. Within this specific research there were no unexpected findings or issues arising.

Given the sensitive nature of the research topic, I might also have been vulnerable during the research process. There was a potential for me to

have been exposed to participants recounting distressing events or experiences during the interviews. My research supervision meetings were an appropriate form of support for me to debrief about the personal impact of the research while maintaining the confidentiality of the research participants (Dickson-Swift *et al.* 2007). The process of reflection and keeping a reflective journal, as described earlier, was another important element of the learning process for me.

The role of the ethics committee and the process of obtaining ethical approval was to ensure that participants were protected from harm. After initial ethical approval was granted, amendments were required for each site regarding additional changes, including the use of Zoom for interviewing online.

4.7.3 Justice

Justice ensures all participants are treated fairly and receive fair treatment (Parahoo 2014). All participants in this research were treated equally and fairly, regardless of their background or social status. They were all given equal opportunity to engage with the research if they wanted. Participants were selected for this research if they met the inclusion criteria and not because of easy availability, manipulability, friendship or my own professional connections (LoBiondo-Wood & Haber 2014). To eliminate any injustice with sample selection, participants were selected using purposive sampling. Within each organisation a nominated gatekeeper provided the research information to potential participants. I had no knowledge of who the information was provided to unless the participant made contact expressing an interest to take part in the research, or if they agreed to the gatekeeper passing on their details to me. This ensured fairness regarding access to the research and also that all eligible participants had an opportunity to take part in the research.

4.7.4 Confidentiality

This right refers to the extent and circumstances in which the private information of the participant is shared with others and in particular, concerns around privacy and anonymity (NMBI 2015). The confidentiality of data collected was observed, conforming with the Irish Data Protection Act (Irish Statute Book 1988, 2003, 2019), and the General Data Protection Regulations (GDPR) (Office of Government Procurement & Department of Public Expenditure and Reform 2018). All information about each participant, was treated as highly confidential, in compliance with the law and Data Protection Acts (Irish Statute Book 1988, 2003, 2019). Private information included individuals' opinions, records, and details (Kaiser 2009). By completing the informed consent form online (Appendix 4), and participating in this research, the participant agreed to share information with me relating to the aim of the research (see section 4.7.6).

Numerous measures were taken to protect the confidentiality of the participants. Due to the nature of a qualitative study and data collection measures, complete anonymity could not be assured, as the participants were known to me. Subsequently, it was compulsory that outside of the research relationship, the identity of the participants remained unknown. No identifiable features were disclosed about the participants in any transcripts, or in any other written material. Transcripts were identified by date and code only, and no identifying information, such as names were included. Any identifiable characteristics, including named places and hospitals, were removed. The names of participants will not appear in any subsequent reports or publications arising from the data collected. All computer records, including online informed consent forms, codes and digital audio recordings, were securely archived in an encrypted password-protected computer and on a secure server, with access only granted to the relevant members of the research team. These procedures were outlined in the participant information leaflet and assurances of confidentiality were reiterated verbally at the beginning of each interview. A professional transcription company

was used to transcribe the digital interview recordings and a non-disclosure agreement was signed prior to the commencement of transcription.

4.7.5 Veracity

Veracity focuses on the concepts of truth telling and the absence of deception (NMBI 2015). Participants have the right to be told the truth about the study with no aspects of the study hidden from them. Curtis and Drennan (2013) emphasise the importance of trust and openness with participants, while creating a safe environment for them. All relevant information was provided to the participants about this research, both written and verbally, with opportunities provided for the participants to ask any questions they had.

4.7.6 Fidelity

The fundamental concept within fidelity is trust, and is concerned with ensuring that all actions are in good faith, agreements are fulfilled, and promises made are kept (NMBI 2015). Fidelity requires a commitment from the researcher to ensure all participants are protected and have a good understanding of the potential risks involved in study participation, enabling them to make an informed choice (NMBI 2015). Fidelity is closely linked with justice. Gaining informed consent is crucial to any research study. Online written consent was obtained from the participants. These online informed consent forms provided documentary evidence that consent was given by the participant. The online informed consent form (Appendix 4) included the title of the research, the voluntary nature of their involvement and their right to withdraw their participation at any time, with no impact on themselves. All participants were given the opportunity to ask questions and have these answered prior to taking part in the research. Participants had access to my contact details if they wanted to contact me for further information at any stage. Additionally, verbal consent was obtained prior to each interview. While it is imperative to plan and ensure the participant is well informed, it can be more difficult to plan for any unexpected outcomes. Details of

additional support for the participants were available, had individuals appeared to require these in the course of the interview. However, no individuals required any additional support during, or after, any of the interviews conducted within this research.

4.8 Integrity of the Research – Quality and Rigour

Quality and rigour are imperative within phenomenological research (Gray *et al.* 2017). Quality of research is essential, and I aimed to ensure that the authentic reflections of nurses' and physicians' experiences of delivering care to children with CCNs during the first 18 months of the COVID-19 pandemic were portrayed. High-quality qualitative research must have a clear research aim and should be timely, original, relevant and rigorous (Stenfors *et al.* 2020). This research had a clearly identified aim, was original in nature and very relevant given the effect COVID-19 was having on healthcare services and settings, particularly PICUs across the world.

Rigour is defined as the strength of the research design, including the appropriateness of the methods selected to answer the research aim (Cypress 2017). Rigour was evidenced in the measures I took to confirm that guidelines and processes were accurately followed and that conflicting factors were eliminated to create dependable and trustworthy conclusions (Gerrish & Lacey 2012). In order to ensure rigour and enhance quality within research, the researcher must be reflexive and take account of their role (Rettke *et al.* 2018). These were two key elements that I was constantly aware of throughout the research process. Reflexivity is fundamental, particularly where the researcher and research are so closely intertwined (Attia & Edge 2017). It was important to acknowledge that I was part of the research setting, and context, while also ensuring the process of self-reflection about my own assumptions, biases, influences and preconceptions about the research (Norlyk & Harder 2010, Solbue 2011, Mason 2018). All knowledge is considered to be affected by social conditions and includes the observer (researcher) and the observed (participants) (Hesse-Biber 2016). Prior to commencing interviews with

participants, it was important to acknowledge the need to reflect on my own experiences to identify anything that might affect my ability to listen and hear the participants' experiences in a reliable manner (Mills & Birks 2014).

The research aim must be focused, and supported by a solid conceptual framework, both of which aid with the selection of appropriate research methods to enhance trustworthiness and minimise researcher bias (Johnson *et al.* 2020). However, there is no consensus in the literature on the best way to ensure rigour in qualitative research (Seale & Silverman 1997, Barbour 2001, Northcote 2012, Cypress 2017, Polit & Beck 2020). A structure needs to be in place to address the merit of a qualitative approach in research. The criteria used to ensure rigour and trustworthiness should be consistent with the philosophical and methodological assumptions on which the research is based (Demuth 2013). Lincoln and Guba (1985) argue that a study is credible when it portrays authentic descriptions, that those who experience the phenomenon, can relate to. Lincoln and Guba (1986), created rigid criteria in qualitative research for establishing trustworthiness, known as credibility, dependability or auditability, confirmability, and transferability or generalisability. Table 5 (p.110) illustrates the strategies applied in this research to achieve rigour. This framework has been successfully used to assess rigour in other qualitative research studies, for example, in Forero *et al.*'s (2018) study in emergency medicine.

When investigating the lived experience, I was aware of my own experience of the phenomenon in question. Van Manen (1990) advises that by becoming aware of their own experiences, the researcher could use these to relate to the phenomenon, and become part of the research process. I had professional experience in caring for critically ill children with CCNs and could relate closely to the phenomenon under investigation. Finlay (2011) recommends that, instead of bracketing, I needed to engage with my own subjectivity. In accordance with hermeneutic phenomenology, I did not bracket my own potential effect on the research, but through active reflexive practice, a transparency was brought to the research, contributing to the formation of knowledge (Neubauer *et al.* 2019). This transparency allowed

the power relationship between myself and the participants to be considered, highlighting any ethical issues, which contributed to the rigour of the research. It also gave others the opportunity to develop a deep understanding of how the research was carried out.

Throughout the process, reflexivity and an insight into my own biases and rationales for decision-making, were critical to rigour (Johnson *et al.* 2020). Additionally, I recognised the overlapping roles of being a researcher, interviewer, data analyst, and author of the narrative, as being a vital part of the research, while also being a threat to validity (Maxwell 2013). I acknowledged the need for an increased awareness of integrity and accountability throughout the research process.

4.8.1 Credibility

The participants were provided with participant information leaflets about the particulars of the research including my contact details for access to further information (Appendix 3). This strategy allowed the participants to become familiar with the research and myself (Forero *et al.* 2018). An additional step was taken to ensure I was familiar and comfortable with the research protocol, that improved the credibility of the collected data. I conducted a practice interview, using the interview protocol, to refine time-management skills and briefing meetings were held with the wider research team. The first interview I completed with a participant was a pilot interview to test the interview schedule, and no changes were required following this interview. The use of semi-structured interviews allowed flexibility during the interviews, but also ensured the focus remained on the topic of interest (Forero *et al.* 2018). Pre-defined prompts (Appendix 7) were created to provide the opportunity for seeking further information and to allow for the expansion of answers if required.

Miles and Huberman (1994) suggest that in order to demonstrate trustworthiness I needed to demonstrate: familiarity with the phenomenon and research context, adequate investigative skills, competency in

theoretical knowledge and skills regarding large datasets, along with an ability to adopt a multidisciplinary approach. I had several years' experience working with children with CCNs and was familiar with care delivery in a PICU. I also had experience with data collection methods and conducting semi-structured interviews.

I had some prior knowledge of the selected software and subsequently completed a training course in NVivo R1 software which was used to manage and code the qualitative data. All additional, relevant resources including field notes – which provided supplementary information relating to the context of the research and the interpretation of results – were gathered to aid the data analysis process (Guba 1981).

Credibility was enhanced by maintaining a reflective journal to provide an opportunity for personal reflection on strengths, weaknesses and feelings that may arise during the interview (Koshy *et al.* 2017). The journal also provided a space for reflection, and encouraged the process of reflective writing (Nadin & Cassell 2006).

It was very important that I immersed myself in the research data and reflected on my own interpretations of my lifeworld. Consequently, this process assisted with the overall credibility of the findings. Although the interviews were professionally transcribed, I cross-checked all transcripts, to ensure the accuracy and credibility of the verbatim material. In addition, numerous debriefing sessions were held with the research team after each interview or as required, to explore the data collection process to ensure the trustworthiness of the research (Figg *et al.* 2010). My supervisors reviewed the first interview transcript after it was annotated with the initial codes and themes, which also served as a credibility check.

4.8.2 Dependability

The quality of data gathered through interviews depends on the appropriateness of the methodological grounding and the research aim.

Dependability is an integral component of rigour (Ryan-Nichollas & Will 2009) and relates to consistency in following the steps of the research process (Creswell & Creswell 2018). Throughout this research, detailed drafts of the research protocol were developed and approved by my supervisors. All the changes were documented throughout the process and justification was provided for these changes, for example, the change from face-to-face to online interviews.

An interview protocol was agreed amongst the research team, along with the steps in coding to ensure consistency with all participants. Coding accuracy and intercoder reliability were measured in consultation with supervisors (Kuckartz 2014). All qualitative data files in NVivo R1 were stored on the secure server, with access only granted to the required personnel within the team. Dependability may be derived by the ability of the reader to find evidence of methodological decisions through the provision of clear rationales at each step of the process, as described above (Robson & McCartan 2015).

4.8.3 Confirmability

To enhance confirmability, I had to demonstrate how conclusions and interpretations within the research were reached (Ryan *et al.* 2007). I kept a reflective journal (Korstjens & Moser 2018), had regular supervision meetings, and team debriefings, to reflect and feedback on the process. Confirmability was ensured through the development of robust examples of the lived experience, together with a clear decision trail that parallels van Manen's (2007) method. Together, van Manen's three analytic approaches for data analysis (Figure 2, p.90), and the framework of five lifeworld existential themes (Table 4, p.97), assisted with this process. The use of this robust framework allowed me to reflect on what the participants had said, and their interpretation of the meaning given to care delivery for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.

Table 5: Key strategies adapted from Lincoln and Guba (1985, p.294-301)

Rigour criteria	Purpose	Example of original strategies	Strategies applied in this research to achieve rigour
Credibility	To establish confidence that the results are true, believable and credible.	<p>Interviewing process and techniques.</p> <p>Establishing investigators' authority.</p> <p>Peer debriefing.</p> <p>Prolonged and varied engagement with each setting.</p> <p>Collection of referential adequacy materials.</p>	<p>Interview protocol tested by myself and the overall <i>TechChild</i> research team.</p> <p>I had the required knowledge and research skills to perform the role.</p> <p>Regular debriefing sessions were held with the wider research team.</p> <p>I engaged with various participants amongst the team in each setting.</p> <p>Field notes from the interviews were uploaded and used during the analysis phase.</p>
Dependability	To ensure findings of the research are repeatable, if the research was repeated with the same cohort of participants, coders and context.	<p>Rich description of the research methods.</p> <p>Establishing an audit trail.</p> <p>Stepwise replication of the data.</p>	<p>Detailed drafts of the research protocol were developed and approved by supervisors.</p> <p>A detailed track record of the data collection process was developed.</p> <p>Coding accuracy and intercoder reliability was measured by consultation with supervisors.</p>
Confirmability	To extend the confidence that the results would be confirmed by other researchers.	<p>Reflexivity.</p> <p>Triangulation.</p>	<p>I kept a reflective journal and had regular supervision meetings.</p> <p>Investigator triangulation was applied to this research, with numerous researchers yielding similar data through the interviews with different participants.</p>
Transferability	To extend the degree to which results can be generalised to other settings or contexts.	Purposive sampling to form a nominated sample.	Purposive sampling techniques were used to recruit participants for this research.

4.8.4 Transferability

As outlined earlier in this chapter, a combination of purposive sampling techniques were used to ensure that the selected participants were representative of the required population. This representativeness was crucial for conducting data analysis from the different sites and to enhance the credibility of the findings (Forore *et al.* 2018). Transferability also related to the extent to which these findings can be applicable in another setting (Robson & McCartan 2015).

4.9 Conclusion

In conclusion, this chapter presented a description and discussion of the methods and procedures used to gather data, including providing a rationale for why they were appropriate in the context of this research. Justification for using a hermeneutic phenomenological design for this qualitative research, informed by the work of van Manen (1990), was provided. Rationale for the data collection methods chosen in this research were presented. Details regarding how the research was conducted and the underpinning ethical guidelines were explored. The research process, including the data analysis framework adopted has been examined, using van Manen's (1990) six guidelines as the basis for analysis. Issues surrounding the integrity of the research have also been highlighted. The process of reflexivity throughout this journey has been addressed in this chapter where I described how I was reflexive in designing the research, conducting the research and analysing the findings. In the next chapter, Chapter Five, the research findings are presented.

Chapter Five: Presentation of Findings

5.1 Introduction

This chapter presents the lived experiences of nurses' and physicians' delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. Due to the restrictions associated with the pandemic, all the interviews were conducted online, using Zoom, between April and November 2020. Direct quotations are used to illustrate the experiences of the participants. This chapter provides an interpretation of the relevant findings from these interviews.

5.2 Demographic Data

Demographic data gathered as part of the data collection process allowed the research to be placed within its own particular context. This data included information about the participants and their roles, and were important components for setting the context. The sample consisted of 18 nurses and 22 physicians from across three international sites in Ireland, the U.S. and Australia. A breakdown of the profile of participants from each site is illustrated in Table 6. These nurses and physicians all worked in a PICU, although some of their roles also included a community element.

Table 6: Profile of participants

Number of Participants	Ireland	Australia	U.S.	Total
Nurses	2	13	3	18
Physicians	10	6	6	22

The participating nurses were aged between 26 and 64, the physicians between 37 and 62 years of age. The mean age of the nurses was 39 years

and the mean age of physicians was 49. Two physicians did not provide their age. The nurses had between 2.5 and 35 years' experience working in a PICU, with the mean being 9 years across the sample. The physicians had between 1.5 and 27 years' experience working in a PICU, with the mean being 11.5 years across the sample. The majority of nurses and physicians had additional clinical experience before working in a PICU, ranging from 2 to 19 years. No additional details about the participants were shared, due to the potential for identification given the small number of professionals who work within these PICUs.

5.3 Adopting Lived Existential Themes

As noted in the previous chapter, five existential themes defined and described by van Manen (2014a) were used to guide the reflective process of data analysis (Figure 3). Contextually, van Manen (2007, 2014a) argued that these five existential themes belong to everyone's lifeworld, and they form "an intricate unity called our lived world" (van Manen 1990, p.105). This unity indicated that the five existential themes can be differentiated, but not separated, by all individuals experiencing the world (van Manen 2014a). The existential themes provided a framework to construct objective descriptions of the complex life experiences of the participants within this research.

The following sections present the lived existential themes that impacted on the lifeworld of the nurses and physicians caring for children with CCNs in a PICU during the first 18 months of the COVID-19 pandemic. The voices of the nurses and physicians are portrayed using selected extracts.

Figure 3 summarises the themes developed from the data obtained. The analytic, illustrative process from which the themes emerged is highlighted in Appendix 11, detailing how the themes were developed from the lived experiences of the nurses and physicians interviewed.

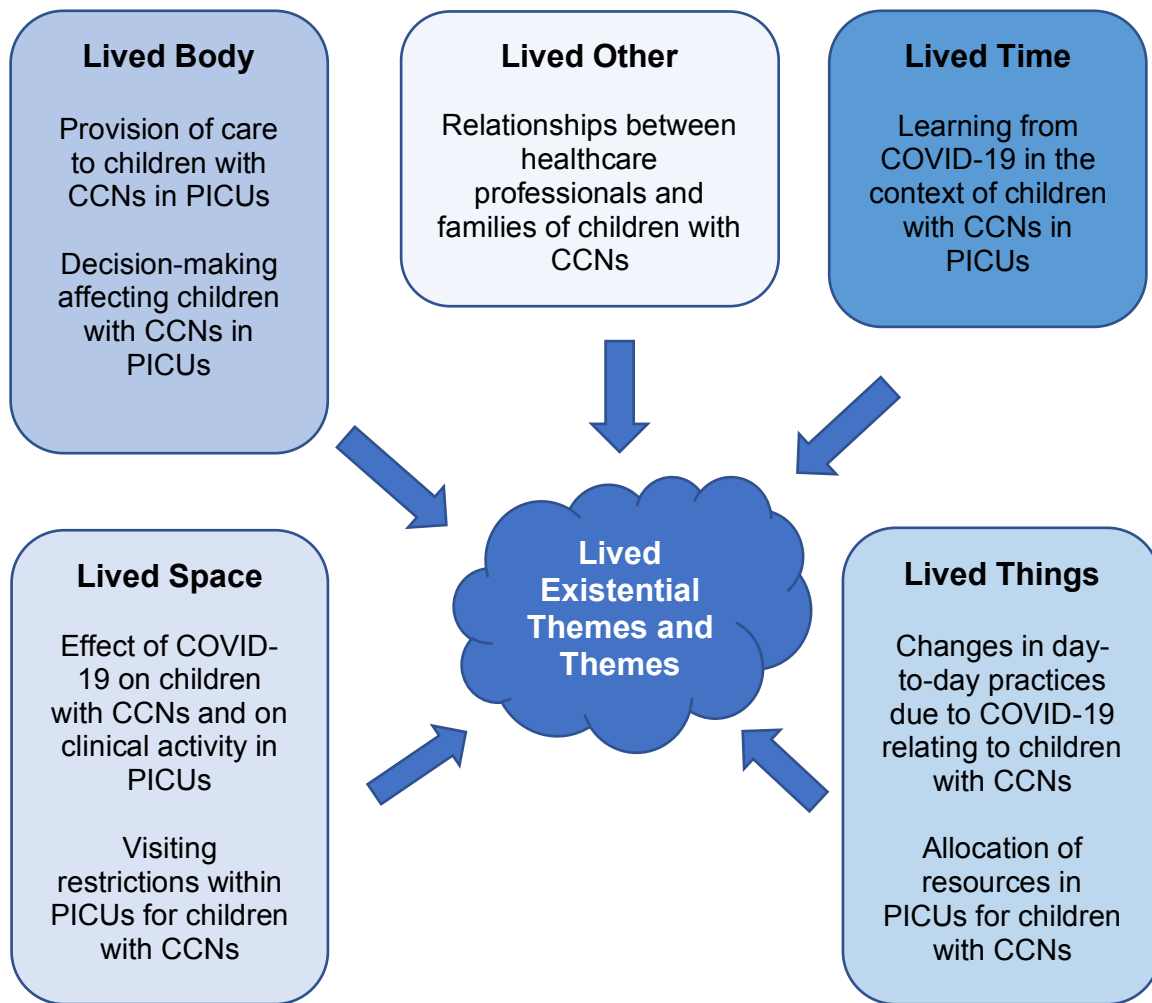


Figure 3: Lived existential themes with themes identified

5.4 Lived Body: Daily Experiences of the Care Provided for Children with CCNs during the COVID-19 Pandemic

The first overarching existential theme explored was ‘lived body’. Lived body relates to how individuals experience the world through the body (Merleau-Ponty 1962). Lived body can also include the physical body space of a healthcare professional with a perceived particular role (van Manen 2007). Depending on how a person feels about someone, body language can adjust depending on the situation. In the same way, the environment where the participants are working, in this instance PICUs, can be perceived differently depending on the point of view of the individual. This existential theme offered insights into various relational aspects of the participants’

day-to-day experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic and decision-making in PICUs.

This existential theme explored how the lived body was present in interviews relating to the lived experiences of the participating nurses and physicians during that time period. The physical and emotional impact of caring for children with CCNs (and their families) on nurses and physicians were explored alongside the way they experienced their lifeworld. The findings showed that nurses and physicians contextualised their experiences of delivering care, placing particular meaning on what their individual experiences were at a particular time point during the pandemic. The themes that emerged were identified as: provision of care to children with CCNs in PICUs and decision-making in PICUs.

5.4.1 Provision of care to children with CCNs in PICUs

Across all three sites, there was an agreement that, during a particular time frame in the pandemic (the first 18 months) the provision of care to children with CCNs in PICUs was not impacted by COVID-19, although a disruption had been anticipated. Similar findings were reported from each site. However, some nurses and physicians acknowledged that this lack of impact may be because children, including those with CCNs, had not been much affected by COVID-19 at the time the interviews took place:

COVID-19 doesn't seem to ... affect those kids. It just doesn't seem to be an issue at all, which is really interesting. And worldwide, it hasn't been an issue with long-term ventilated kids. (Physician 12, Ireland)

COVID-19 hasn't really affected the paediatric population in that way, so I don't think it will affect the decision to go on long-term ventilation. I don't think so. (Nurse 10, Ireland)

... But I think that's more because it hasn't affected kids as much ... (Nurse 11, Ireland)

A physician in Australia recounted the care delivery to a child with CCNs, who was admitted to the PICU with COVID-19 and required ventilation. Up to the time of interview, this was the only child they had admitted to PICU with COVID-19:

... We've been very lucky ... That's our only ICU admission.
(Physician 1, Australia)

A physician in Ireland believed that their institution was unusual compared with other PICUs internationally, as they had no children who were very sick with COVID-19 at the time of interview. However, these experiences were similar to those reported in the U.S. and Australia. This physician also referred to only one child with CCNs admitted to the PICU at the time of interview:

I think our institution has been very unusual compared to all the others. We've had virtually no children who are really sick with COVID-19. But I'm thinking of one or two of our long-term ventilated patients and if they got it, and we've had one of them back in and I can see quite a deterioration in his overall clinical status. (Physician 2, Ireland)

Likewise, similar experiences were reported with the site in the U.S., as demonstrated in the following excerpt, where a physician spoke of only one child with COVID-19:

I've taken care of a grand total of one child who has been COVID-19 positive, because we have not seen the surge yet in [place name] ... [place name] certainly has a lot more cases than we have ... that's where I saw the one kid ... I think it takes a lot for a kid to get to the ICU with COVID-19. Because ... kids appear to be amazingly resilient to the illness. (Physician 3, U.S.)

The overall reduction in other viral illnesses among children on long-term ventilation, resulting from increased infection-control precautions related to COVID-19, had a direct impact on reducing care delivery requirements in PICUs and were evident across the interviews:

We haven't yet seen it [COVID-19] transmitting in those families where these kids have been affected and I guess those families are highly sensitised to it and, you know, they would probably not let you in the house if they thought you might have had any symptoms. So they are probably selecting themselves out to be even safer than they normally are. And what we've seen paradoxically is this overall reduction in viral transmission in the community. We've seen no RSV [Respiratory Syncytial Virus]. We've seen no flu. (Physician 4, Australia)

At the time of interview, all nurses and physicians reported a reduced impact on their PICUs, with an overall reduction in the number of children admitted, as a result of the extra precautions families were taking due to COVID-19. However, they emphasised the importance of effective decision-making for those children with CCNs, who were admitted to PICUs.

5.4.2 Decision-making affecting children with CCNs in PICUs

Decision-making is a fundamental component of PICU care delivery for all children and their families, with an added intricate dimension for those children with CCNs. This theme reflects findings that emerged related to the impact and influences on nurses and physicians making decisions within PICUs. The nurses and physicians discussed their opinions and experiences regarding the impact of COVID-19 on decision-making. The clinical scenario of initiating long-term ventilation for this population of children was often used as an example of care delivery. The majority of nurses and physicians from all three sites reported that COVID-19 would not affect decision-making when initiating long-term ventilation for these children:

... No I don't think so ... We're still planning with patients and talking to families about the things that need to happen regardless of COVID-19. I think some logistic things around them are slightly different maybe but I don't think we're treating them any differently ... (Nurse 1, Australia)

None of the nurses or physicians reported an increase in the number of children requiring the initiation of long-term ventilation:

Actually, in this role you would think I would have done [cared for children who have gone onto long-term ventilation] but in the last, well certainly this year, not so much, because we've not got that demographic coming in, we've not got a lot of the respiratory kids coming in who eventually end up going onto long-term ventilation. We've got a lot of repeat people ... frequent flyers. They come back but actually this year, we've not started anybody on long-term ventilation. (Nurse 6, Australia)

We have had no children gain assisted ventilation from COVID-19. It's not something that seems to be affecting the children the same way it does [adults]. (Physician 15, U.S.)

The physicians spoke about COVID-19 as being “mostly an acute illness” (Physician 5, Australia) and “kind of acting like the other viral illnesses” (Physician 3, U.S.). Despite this, the physicians acknowledged that certain clinical situations and presentations would affect decision-making:

... [What] I could envisage might be a prolonged respiratory illness in a child with marginal respiratory function who might require longer term respiratory support beyond hospitalisation. And there again the same principles would drive that [decision to ventilate]. (Physician 5, Australia)

Some physicians also stated that although certain clinical situations may affect decision-making for children with CCNs, these decisions would not solely relate to COVID-19. They would also consider the child's individual prognosis and potential outcomes related to their condition:

Another scenario might be a chronic inflammatory and paediatric inflammatory syndrome associated with COVID-19, which may affect the heart and we would apply the same principles as to whether we think the child would be able to be bridged to a point of recovery or organ transplantation. I don't think COVID-19 in of itself would necessarily alter that. It would be based on the child and the degree of disease and the likelihood of them recovering. (Physician 5, Australia)

... This is probably not going to influence the decision-making as far as DNI [do not intubate] and DNR [do not resuscitate] it would be like any other illness when they [children with CCNs] come in. (Physician 3, U.S.)

The challenges specifically related to a child with CCNs on long-term ventilation were explored, along with the associated difficulties around

decision-making. This physician gave an example of a situation where they would not advocate to commence additional intensive therapies in the child's best interests if they got COVID-19:

Now he's chronically ventilated ... and I think if someone like him got COVID-19 and it hit his kidneys, I certainly would not advocate instituting renal support in someone like him, I would think that would not be appropriate. (Physician 2, Ireland)

While there were no reports of any increases with the initiation of long-term ventilation within this cohort of children with complex respiratory issues, the nurses and physicians reported the PICUs being well positioned to increase capacity if required:

The only thing is that respiratory illnesses in general have decreased so significantly that our workload is less. So at the moment we have a lot of capacity to increase. (Physician 7, Australia)

Overall, physicians caring for children with CCNs in PICUs reported that COVID-19 has made them consider more factors surrounding the initiation of short-term and long-term ventilation, and has generated discussion among the teams caring for this population cohort. One consideration was that mechanical ventilation was an aerosol-generating procedure with the potential procedure-related risk of spreading the virus:

... It certainly has affected how, probably not our long-term use, but our short-term use [of ventilation], because a lot of the technology we use is considered aerosolising. (Physician 6, Australia)

However, there were conflicting views about the lengths to which physicians would need to go if a child in PICU were to deteriorate, and what measures would need to be taken to sustain life:

... Death becomes more of a reality. There is this [opinion] because of technology, it was actually probably a few years ago, where they said logically people understand that you die but there's this anticipation that nobody dies. We can save everybody ... So I don't know how, if this is going to bring us back to people die, or actually, I think you know it's not because the discussion here is we

should have done all these things to avoid all these deaths.
(Physician 3, U.S.)

The physicians expressed that they did not feel COVID-19 would have an impact on the initiation of long-term ventilation. However, as a result of COVID-19 and the associated fears surrounding it, they acknowledged families may have some hesitation regarding long-term ventilation:

... The ICU is dirty and we could potentially have COVID-19 exposure. But I can't see, I think you would be hard pressed to say I'm not going to do that [initiate long-term ventilation] because my kid might get something ... (Physician 16, U.S.)

Although COVID-19 had generated discussions among the teams caring for children with CCNs in PICUs, leading them to think about their interventions and clinical decisions, there was a sense that long-term practices in PICUs would not change as a result of COVID-19:

So yeah, it certainly makes us think a lot more about it, but I don't think it's necessarily changed our use a lot, because we know it works. And so when we need it, we need it. But I don't know. It certainly hasn't changed long-term things. (Physician 6, Australia)

More specifically, nurses suggested that any differences in decision-making may be related to the physical space now available for meetings around decisions. Smaller numbers of professionals and family members could now attend, due to public health measures. The nurses also reflected on the changes associated with moving into a virtual world as opposed to face-to-face discussions:

... Like, meetings might be a little bit different with like all the COVID-19 things, with the COVID-19 precautions. So the meetings might have limited [numbers of] people in those formal meetings ... Or things might be more virtual ... (Nurse 3, Australia)

The general consensus from these changes was that there needed to be cross-representation from the key members of the multi-disciplinary team at these meetings, including nurses and physicians, in order to make the most

appropriate decisions in the best interests of the child. However, multiple members from the same discipline were not required at these meetings:

... I feel like, with the family meetings that often discuss the implementation of these measures, you do need a lot more of the allied health medical team involved to have their opinions on it ... I find often there's multiple team members from the same, like our ICU team that would be there, which I don't think is often necessary. I think it should be just one of the consultants or the fellows, because they're the ones that have the most impact on where the plan to go is from there ... (Nurse 4, Australia)

Some of the nurses also envisaged that, as a result of the restrictions and smaller numbers being allowed to attend meetings around decision-making, their presence may be excluded and their voices would be absent. As nurses have a vital role in care delivery in PICUs for children with CCNs, including being there for the child and family, communicating effectively and advocating on their behalf, any absence at critical meetings could hinder the building of this therapeutic relationship:

... They might only have a meeting with four people because of the size of the room, so the nurse might not be the person that's involved at the meeting so it might push, yeah it might push them away from the discussions ... (Nurse 4, Australia)

Conversely, some nurses recognised these practice changes of smaller, limited meetings as a positive. They felt in “an ideal world” the meetings should have a limited number of staff as families can find them “very overwhelming”. However, they did not specify which professionals should be excluded from the meetings in order to make them smaller:

... because obviously you can only have so many people in a room at one time. So I think yeah I think COVID-19 certainly has helped with that. (Nurse 6, Australia)

These issues arising within decision-making all impacted on the relationships between the nurses, the physicians, and the children's families, which will be explored in the next section.

5.4.3 Summary of Lived Body: Daily experiences of the care provided for children with CCNs during the COVID-19 pandemic

In this section, two themes – provision of care and decision-making – were identified and discussed, and provided an understanding of how these nurses and physicians experienced their world working in a PICU, caring for children with CCNs during the first 18 months of the COVID-19 pandemic. These themes corresponded with the nurses' and physicians' experiences of delivering care, including the practicalities and sometimes difficulties, associated with decision-making within PICUs. Van Manen's (2014a) existential theme 'lived body' offered an insight into the nurses' and physicians' relational aspects of their day-to-day experiences of delivering care. Similar experiences were found among participants across the three sites.

5.5 Lived Other: Therapeutic Relationships Developed during Care Delivery for Children with CCNs during the COVID-19 Pandemic

This existential theme, 'lived other', explored how individuals related to one another within an interpersonal space (van Manen 2007), investigating how relationships developed, including the nurses' and physicians' communication with families of children with CCNs. This was demonstrated through maintaining and developing relationships with each other, e.g. communicating in a certain way or how one behaves around another person. Only one theme emerged, which focused on relationships between healthcare professionals and families of children with CCNs. Relationships between these healthcare professionals and the wider multidisciplinary team did not emerge from the interviews and were not raised as an important element for discussion. The focus was solely on the relationships between the nurses, physicians and families, and not on those relationships between the nurses, physicians and other multidisciplinary team members.

5.5.1 Relationships between healthcare professionals and families of children with CCNs

Relationships between professionals and families emerged as important in caring for children with CCNs, including ways to maintain their strong relationships, keeping communication channels open and adopting a partnership approach to care. These relationships allowed the nurses, physicians and parents to navigate the pandemic together as a unit, with parents feeling supported by the familiar healthcare professionals:

And you know [with] at least half of them [the families], we spend almost the whole time talking about what's going on right now in the pandemic ... I think everyone is trying to figure out what's going on right now ... I think there's a couple of things that because again we have a relationship with these people, so we can sort of say what we think and if we're wrong, they are more forgiving. But one of the things that I try to emphasise is that I'm having these conversations with every other one of the [programme name] team families as well, just so you know ... (Physician 17, U.S.)

Physicians also recognised the value in providing support to these families of children with CCNs, as the “anxiety levels are through the roof” and subsequently parents required a “huge amount of support” as a result of COVID-19 (Physician 9, Ireland). The physicians also spoke about the importance of acknowledging the parents’ concerns and worries, creating a partnership approach to care, enabling them to keep their children at home and not require admission to PICUs during the COVID-19 pandemic. Without these trusting, therapeutic relationships, this parental confidence in managing their child with CCNs at home would not be possible:

... And you know so I'm talking to the family and I say, 'And you guys have a ventilator in your house, which you know how to manipulate. You know what the subtle signs are of your child ... and there's no one better prepared to care for mild to moderate illness than you ... You know, you had two pneumonias last year. We got you through it at home' ... , because they're [the parents], like 'Ah yeah, I guess I do all this but I never realised it ... ' (Physician 17, U.S.)

As a result of PPE requirements due to COVID-19 and having to communicate using online platforms instead of face-to-face, physicians acknowledged the barriers to communication with families of children admitted to the PICU setting, and the subsequent effect these had on relationships:

I think the masks are a huge barrier. Because the family is wearing masks, we are wearing masks, and I think that these are families who are already stressed by this whole thing and then you can't, you know half your communication is in your, you know, covered by your mask ... I really think that's affecting our communication with families. Or doing things by Zoom, [it's] just not the same ...
(Physician 16, U.S.)

These changes in PICU practices for healthcare professionals and families of children with CCNs, as a result of COVID-19, will be explored further in the section on 'lived time'.

5.5.2 Summary of Lived Other: Therapeutic relationships developed during care delivery for children with CCNs during the COVID-19 pandemic

Van Manen's (2014a) existential theme, 'lived other' offered insights into how the nurses and physicians related to the families of children with CCNs in PICUs. These experiences invoked how the nurses and physicians related to, and connected with, families within this interpersonal space, and how this changed through interactions with each other. Similar experiences were found from participants across the three sites.

5.6 Lived Space: Connections between the Child with CCNs and the Space they Occupy within PICUs

The existential theme, 'lived space' was concerned with the space the life occupied, in this case the life of the child. Mackey (2005) recommended that lived space positions the individual in a location. This can be thought of not solely as a physical space alone, but more of an interaction with, and connections to, other people and things. Two related themes emerged: the

effect of COVID-19 on families and the space they are living in, and visiting restrictions within PICUs.

5.6.1 Effect of COVID-19 on children with CCNs and on clinical activity in PICUs

Across all interviews, there was a common understanding that COVID-19 has had a significant impact on families and children with CCNs:

It's certainly affecting the families. (Physician 8, Australia)

So, I think if this is the way it's going to be for the next 12 to 18 months I think, yeah, it will have quite a negative impact on our families. (Nurse 6, Australia)

The nurses and physicians reflected that there was a significant level of fear and anxiety among these families, with a hesitation noted about parents of children with CCNs not wanting to bring their child in for scheduled appointments. This had a subsequent impact on care delivered, as the children with CCNs were not presenting to the PICU for the purposes of initiating long-term ventilation:

So, you know, it's (a) getting them through the wait list and then (b) convincing them to come in. And so the initiation isn't happening, but it's also the monitoring of the ones who have been initiated that isn't happening. (Physician 9, Ireland)

While many nurses and physicians focused on the potential challenges of care post-discharge from the PICU and their effect on families, there was no suggestion that this would impact on care delivery for children with CCNs while in a PICU. Some nurses recognised that there were uncertainties surrounding what would happen as time progressed, and reflected that further time was needed to understand the realities of the impact of COVID-19 on care delivery. There was also a recognition of the potential positive impact on a child with CCNs being cared for at home during the pandemic, which translated into fewer overall PICU admissions. This may evolve over

time as additional data is reported relating to care delivery and outcomes for this cohort of children during the pandemic:

I think looking at, like you look at the general side at the moment and even the last few weeks, we would have a lot more children with CP [cerebral palsy] and developmental delay, who would have respiratory infections, so isolation may reduce the admissions of those children and it may, you know, every time one of those children is admitted they, you know, they become deconditioned and their nutrition is decreased and their lung function is reduced, because of, you know, whatever illness. So look, it may reduce it, I think it will be interesting to see the data when it comes out. (Nurse 7, Australia)

Additional concerns were present for families relating to what hospital and PICU resources would be available for children with CCNs if their child deteriorated:

... if they have a problem and especially early on as we are seeing potentially, you know, limited allocation of resources, you know, are people going to judge me and my child differently or you know this young adult differently ... (Physician 18, U.S.)

Families were also concerned about what hospital they should present to if their child was transitioning out of children's services into adult services, with physicians believing that the parents' commitment to their young adult with CCNs had strengthened as a result of COVID-19. Families were focused on ensuring the best care would be provided to their young adult during the transition process:

So you know, we had families calling and saying, 'You know which hospital should we go to?' And actually for some of my young adults that I continue to follow, it's 'Should I go to the children's hospital or should I go to the adult hospital?' If anything, I'd say it's sort of, families have said it's sort of strengthened their commitment to support their family member ... (Physician 18, U.S.)

However, despite these concerns, physicians also perceived numerous positives, with families best placed to care for their children with CCNs at home, and as a result, avoid admittance to PICUs:

... like they've [the families] been less affected ... because they shut down. Number one people [the families] were paranoid [of risk of infection] to begin with ... And then they have, many of them have the tools to help ... support [them] through illnesses. And so, they were sort of hunkering down and readying themselves for it [COVID-19]. (Physician 18, U.S.)

The recognition of an overall improved health status among this population of children as an unexpected bonus of the pandemic was evident, with a subsequent effect on service delivery within PICUs and fewer admissions than would usually occur for these children at that time of year:

... So these kids just aren't getting any virus infections this season. So this winter has been very, very quiet, and we haven't seen any of these comorbid effects coming up on our kids. So the one effect of COVID-19 has actually been an incredibly positive one. Everyone has had their immunisations and no one is going to day care to catch all of the other viral infections they would normally catch ... (Physician 4, Australia)

Additionally, physicians felt that this pandemic has provided a catalyst for starting conversations around access to care in PICUs and advanced care planning with families of children with CCNs:

So if anything, I think it may not compel, but I think it may stimulate those families to say I think we should consider tracheostomy and vent [ventilation] earlier than later, because if there's going to be these global pandemics and if my kid gets SARs or, you know, H9N4 [subtype of Influenza A virus], the next pandemic strain of influenza, if my kid is that tenuous we should probably, this is again my gut, stimulate families to say maybe we should actually be a little bit more proactive with this, rather than waiting for the next global pandemic and having my kids debilitated. (Physician 20, U.S.)

However, despite this opportunity for starting these conversations around advanced care planning with families of children with CCNs, none of the physicians or nurses spoke specifically about what these conversations would look like or how this might impact on their delivery of care within PICUs to these families.

5.6.2 Visiting restrictions within PICUs for children with CCNs

Nurses and physicians spoke about the challenges associated with PICU visiting restrictions for families of children with CCNs, as a result of public health measures during the pandemic. They reported on the negative impact on families due to the lack of support during those difficult times. The adverse impact affected all members of the family, including siblings and grandparents:

I think it's changed a lot for the families and not in a good way. I think it's really challenging for families to be able to support each other during COVID-19 with visitor restrictions, and grandparents as well, who would come and help care for the siblings [but] just aren't allowed to be around ... (Nurse 8, Australia)

The thing that has affected them [the families], there's [a] clear effect to our patient load, is the effect on the families and their ability to be at the bedside. So I think it's harder to be in hospital. And when they're in hospital, their support systems are wayward and not in place and they [the families] can't access [them] ... (Physician 7, Australia)

In delivering end-of-life care in the PICU for children with CCNs, the differences between pre-pandemic and during the pandemic were made evident in the account of one participant. The nurse was reflecting on a time, pre-COVID-19, when a child with CCNs was at the end of their life and surrounded by extended family. The positives associated with this important time were noted, with the family being afforded the opportunity to create precious memories together and to support each other:

... the most beautiful death I think I've probably ever experienced in the unit and it was probably only about 18 months ago. And we filled up two rooms so the child is in one room surrounded by family, the room next door is full of family ... it was all completely nurse-led. We extubated the child. They were all there and part of it and it was a big group of people and they were all very supportive of each other ... (Nurse 8, Australia)

There was an acknowledgement that these moments were not currently possible within the PICU restrictions associated with the pandemic. There was also a recognition that the restrictions would “change the [end-of-life]

experience” (Nurse 8, Australia), and not in a positive way. However, the nurses spoke about doing the best they could, despite the limitations imposed by the restrictions, and accepted that things could not be as they were for these families pre-COVID-19:

... I've been involved in [caring for] children who have died during COVID-19 times and it's been a little different in the volume of people that can come through, but you know, we went to the bereavement room and so five other family and friends were allowed to come ... You can still do things to the best way given the restrictions, but it is different. (Nurse 8, Australia)

5.6.3 Summary of Lived Space: connections between the child with CCNs and the space they occupy within PICUs

The existential theme, ‘lived space’ was concerned with the space occupied by these families of children with CCNs, as viewed from the nurses’ and physicians’ perspectives within the PICU during the pandemic. In the first theme, emotional space was recognised, with the nurses and physicians perceiving a mix of feelings experienced by the families. In the second theme, nurses and physicians identified key challenges, in terms of the effect of visiting restrictions on the child and their extended family as it related to physical space within the PICU.

5.7 Lived Time: Perspectives from a Moment in Time During the COVID-19 Pandemic within PICUs

‘Lived time’ is not only viewed as a passing of seconds, minutes or hours, but as it relates to things or a situation (Merleau-Ponty 1962). This existential theme explores how the temporal things of the past determine the present and future perceptions of the world. This provided an understanding of the nurses’ and physicians’ daily lives in PICUs during the first 18 months of the COVID-19 pandemic, in terms of how they delivered care to children with CCNs and how they experienced time. Van Manen (2014a, p.306) argued that “we experience the time of waiting differently from when we are actively involved in something”. For these nurses and

physicians, they were actively delivering care within PICUs during this time period of the pandemic.

The focus was predominantly on the fact that few children were affected by COVID-19 at the time the interviews were carried out. The participants linked this with the fact that children with CCNs were ‘protected’, due to the lockdowns, social distancing restrictions and tighter infection-control measures for the children’s families. These factors all had a subsequent impact on care delivery within PICUs. The learning process for the nurses and physicians was explored, as it related to children with CCNs and their families.

5.7.1 Learning from COVID-19 in the context of children with CCNs in PICUs

Over half the nurses and physicians felt that there was learning to be gained from this time point of the pandemic, including through research around COVID-19. They recognised that there was plenty of current research focused on “how best to manage the patient and what drugs to use” (Nurse 9, Australia). However, at the time of interview, no substantial research evidence had emerged relating to children, or more specifically, children with CCNs and how care should be delivered to this population:

... I think because there’s been so few children affected by it [COVID-19] throughout the world, I don’t know that it’s going to ... there will be a little bit of research in kids as to why it doesn’t affect them, but I think most of the research around the world will be in adults ... (Nurse 9, Australia)

The nurses and physicians spoke about how the data available around child deaths and severe illness as a result of COVID-19 was associated with children of higher risk and those with CCNs. The only children reported to have died at that time had underlying conditions:

There have been some deaths associated with COVID-19, but those were the kids who have other [complex conditions], COVID-19 was not the only thing ... (Physician 3, U.S.)

However, there was also an acknowledgement that there was so much unknown about the disease at the time of interview, particularly regarding the outcome for children with CCNs. Other participants voiced their thoughts around learning in practice and about the new, innovative procedures occurring at this time during the pandemic. These were seen to have a positive impact on children with CCNs and their families, in trying to avoid unnecessary hospital and PICU admissions:

So we've tried to move a little bit and be innovative in doing some home studies ... We send some of our devices home now for people [parents] to do the [sleep] study and bring them back. Sometimes we fail, because they [the children with CCNs] are not very closely supervised [by the parents] ... But [with] others, we succeed. So yes, we are learning from that experience. (Physician 10, Ireland)

Nurses and physicians across all three sites anticipated that the COVID-19 pandemic would have little or no impact on their work within PICUs or around the initiation of long-term ventilation for children with CCNs:

My [hospital] world I don't think it has an [impact] whatsoever, no ... No impact at all. COVID-19 no impact, zero ... (Physician 15, U.S.)

It hasn't affected us at all, actually. (Physician 7, Australia)

I suppose in the paediatric world, I'm not sure it's having any real influence ... So it's not like we're totally overrun at the moment. I mean if that changes, I suppose it's different. But I don't see it having a massive influence for us anyway. (Physician 14, Ireland)

Although there was a recognition that in comparison to COVID-19, influenza A virus subtype H1N1 (or 'swine flu') had a much greater impact on children with CCNs, with those on long-term ventilation at higher risk:

Whereas H1N1 was very much [affecting kids], [and] kids with long-term ventilation were the highest risk. (Physician 12, Ireland)

Some nurses and physicians spoke about their day-to-day lived time, their hopes, and their concerns about what was to come for children with CCNs in the future. They discussed their uncertainty at the present situation and acknowledged not knowing what to expect in the following year. However, they remained hopeful that COVID-19 would have less of an impact as time went on, and that things would improve across healthcare and society:

Hopefully, 2021 will be better. (Physician 11, Ireland)

One major concern from a number of nurses and physicians was the potential effect of COVID-19 on the wider healthcare services for children with CCNs, in addition to the effect on services in PICUs. Again, at the time of interview, there were many uncertainties associated with the pandemic. The complexity of these children and the reluctance of parents to bring them to hospital, due to fears and uncertainties associated with COVID-19, were recurrent themes across the interviews. Additionally, the nurses recognised the challenges associated with COVID-19 when working within PICUs, including meetings with the team, educational sessions for the staff, and the extra time needed to complete tasks:

... I think it [COVID-19] slows everything down. I think it's just, it's harder to have face-to-face. It's harder to have meetings. It's harder to have education. It's harder to get people in when you need it ...
(Nurse 8, Australia)

Aside from clinical meetings and professional training taking longer, COVID-19 also had a significant impact on delivering parental education in caring for their child and on ensuring competency with this training:

But it's all very different from having that face-to-face and having parents just coming in whenever it's convenient and run through how to bag and mask their child or how to suction the trachea, you know ...
(Nurse 8, Australia)

Furthermore, the nurses and physicians acknowledged that uncertainties remained about the overall effect COVID-19 would have on this population of children with CCNs, with a subsequent effect on hospital services, including PICUs:

With this population, I don't think the children themselves will be affected so much but it probably definitely, in the short-term definitely, [will] be less face-to-face contact with all of their caregivers and support. How long that's going to last, I'm not sure. I guess it depends on how long COVID-19 takes to go away ...
(Nurse 12, Australia)

This acknowledgement of the impact on caregivers and lack of support was explored in the section, 'lived space'. Finally, nurses and physicians stated that at the time of interview, COVID-19 had created an opportunity for wider conversations around issues arising for children with CCNs (e.g. the initiation of long-term ventilation), not only within medical teams, but within the political and social arena of access to care:

I hope it [COVID-19] will encourage conversations, but someone has to be proactive in initiating those discussions ... But I think it's an opportune time to have those conversations and to broaden that discussion to include the issues that you're addressing. (Physician 19, Ireland)

Despite the hopes and wishes for changes in future discussion regarding advanced care planning and initiating technology for children with CCNs, it was noted that none of the physicians or nurses spoke specifically about changes they had made to their own practices or any specific discussions they'd had with families, based on those hopes and wishes.

5.7.2 Summary of Lived Time: Perspectives from a moment in time during the COVID-19 pandemic within PICUs

This existential theme, of 'lived time', referred to how time is experienced. Lived time is a felt time, how the nurses and physicians experienced it and how they perceived it, while working during the pandemic at a given moment in their day-to-day life. Within lived time, lessons to be learned from the

pandemic were uncovered in relation to caring for children with CCNs in PICUs, along with acknowledging the uncertain road ahead for this cohort of children, which may evolve and progress as time goes on. In the next chapter, these concepts will be considered further, while situating these findings in terms of the relevant literature in this arena.

5.8 Lived Things: The Influence of Material Things on Nurses and Physicians Experiences when Caring for Children with CCNs in PICUs during the Pandemic

The final existential theme examined was ‘lived things’. This referred to how things were experienced in day-to-day life, while focusing on the importance of material things (van Manen 2014a). Within this research, it translated to how materiality and certain material things in life influenced nurses’ and physicians’ lived experiences in PICUs when caring for children with CCNs during the pandemic. Van Manen (2014a) asserted that it would be difficult to overestimate the significance of things in our day-to-day life. Material reflection in interviews with participants explored how ‘things’ and technology played a role within care delivery. The material things they spoke about resulted in two themes: changes in day-to-day practices (namely telemedicine) and allocation of resources and equipment within PICUs.

5.8.1 Changes in day-to-day practices due to COVID-19 relating to children with CCNs

The majority of the nurses and physicians across all three sites reported on changes in practices due to COVID-19, including the use of telemedicine in caring for children with CCNs and their families. These changes in practices were largely viewed in a positive light and physicians and nurses felt this was an aspect of care delivery to take forward as a result of COVID-19. The use of telemedicine allowed for discussions around the initiation of long-term ventilation for children with CCNs and to prepare a child and the family for these procedures within PICUs. However, the nurses recognised that this preparation, conducted via Zoom or other online platforms with key

professionals and the child's family members, was not the same as face-to-face interaction, in terms of relationship building or maintaining rapport:

I don't think that's [online meetings are] necessarily a good thing either, because you lose that sense of getting to know people ... [with] this type of thing [using virtual platforms for online meetings]. Yeah you definitely are not getting that rapport with someone ... (Nurse 6, Australia)

These negative experiences with telemedicine and online meetings were shared across interviews, with numerous nurses reporting that they were not the same as face-to-face and did not work as well. Subsequently, things within PICUs were "not as good as it used to be" (Nurse 9, Australia):

I think the current COVID-19 situation communication is not as good [as face-to-face]. It's a shambles at the moment ... Zoom meetings are okay, but you know they are not the be-all-end-all. And I think you know it's a total different environment we are working in at the moment ... (Nurse 9, Australia)

There was also a belief that after the pandemic things would go back to how they were before, in terms of the use of technology and telemedicine within PICUs:

There won't be any long-term change. (Physician 6, Australia)

Additionally, nurses and physicians anticipated that there would be differences within PICUs in caring for children on long-term ventilation if they were COVID-19 positive and this would require long-term changes to practice. However, at the time of interview, the healthcare professionals in the PICUs had not faced such a situation:

If they're COVID-19 positive, then yes, it would make a huge difference. If they're negative, then I don't see it being too much of a difference. But obviously [ventilation] is aerosol producing [risking spread of infection] ... But it depends. We haven't had that situation yet ... (Nurse 3, Australia)

The required changes to practice were not discussed in detail by any of the participants during the interviews. Although there were some changes to

care delivery to children with CCNs highlighted during this time, there was little change noted to the overall delivery of care in PICUs.

5.8.2 Allocation of resources in PICUs for children with CCNs

Nurses and physicians from each of the three sites discussed the allocation of resources in PICUs related to caring for children with CCNs. However, no physician or nurse shared any actual experiences, issues or specific shortages arising in PICUs around allocation of resources when caring for this cohort of children, although this is something that had been talked about within their teams. Again, this may be related to the stage of the pandemic at which the interviews occurred and a different perspective may have been given at another point in time:

I think very, very early on [in the pandemic] ... the PICU wasn't full, but there was already a hint ... about access to intensive care for this particular child ... [who had a complex condition] ... Now you know we weren't overrun with COVID-19. But there was just this sense [that a surge of admissions would occur] ... We were all panicking a bit at that stage ... but I am certain that if our PICU were to be overrun with cases, COVID-19 positive patients, that [rationing of resources] would be an area that would be explored.
(Physician 8, Australia)

It was expected that any anticipated change in resource allocation would not affect decision-making or care delivery for children with CCNs. Participants acknowledged that decisions would always be made in the best interest of the child. In addition, physicians reported that they would not be hampered by resource allocation or capacity allowance in the PICU if it arose:

It has been mentioned at meetings with regard to management of resources and overall bed capacity ... Certainly, from our point of view in [the] PICU, it didn't impact on the decision that was made for the child. I think, you know, we still went ahead and made a decision with the child in mind. I mean, resources impact every day. It would be naïve to think otherwise. But I don't think it colours our judgement so much that we would not instigate treatment based on the fact that we didn't have enough capacity ... We just somehow find a way to make it happen. (Physician 21, Ireland)

There was discussion about, you know, if we were having to, to rationalise ventilators. [It] never actually arose but we talked about it ... (Physician 22, Ireland)

Participants reported policies being swiftly put in place within the PICUs to deal with any situations arising from a shortage of resources. These would assist the nurses and physicians when making decisions about resource allocation:

We've got quite an active ethics group at our hospital and some work was, some documentation was prepared about how we might approach rationing of resources. Because, you know, resources are finite. And we have explored that ... (Physician 8, Australia)

Also, there was a recognition that, in addition to these policies, discussions with the wider multidisciplinary team and specialist consultants from other areas may be necessary to guide resource allocation for children with CCNs, rather than individuals making decisions in isolation:

And I think we need to talk with each other about that, because you know, I might not have some of the detailed respiratory skills, for example. You know, if we look at some of the algorithms that are used to try and work out how unwell somebody is and how likely they are to survive their ICU admission. We need people with those skills to inform that ... (Physician 8, Australia)

These discussions would also involve the parents, to ensure they were aware that any decisions made regarding resource allocation would not be made based on their child's underlying complex condition, but in the child's best interests. However, physicians also acknowledged the importance of starting these discussions with families early on:

But I do go back to the point that offering children who have neurodevelopmental disability a good palliative, and an active palliative plan, is equally important ... Because I do think parents come to those discussions, often with their fists up ready for a fight, which is different to having a discussion about. They're often afraid that things are going to be withheld or not offered, because of their child's underlying disability ... (Physician 8, Australia)

Conversely, only one physician spoke about the challenges that may arise if a child with CCNs and another child with no underlying health conditions required a bed in a PICU and there was a shortage of resources available. No other healthcare professionals raised this issue or gave any indication this was something that had been discussed among their teams. If this instance were to arise, the physician believed it would create difficulties in making decisions and that the overall health of the child may need to be considered. The child with CCNs would be at a disadvantage for an escalation of care due to their prospects of a full recovery:

But I think it would be very difficult if you had a neurologically and developmentally appropriate toddler, who got a first dose of flu or COVID-19 and just happened to get a really bad respiratory [illness], not to prioritise that over somebody who had a life limiting condition that often a respiratory disease is the mode of death. I think it would, hmm ... I think you'd have to make a rational decision ... There is a difference that you may get one child through it and the other one not, and the other one might spend eight or ten weeks and then deprive many children of a PICU bed ... (Physician 22, Ireland)

Additionally, there was a strong belief that the pandemic had created a perfect opportunity to begin discussions around resource allocation, particularly at end-of-life for children with CCNs within a PICU setting:

I suppose for me, it would be really nice if society could have a discussion about these issues, you know, or in the COVID-19 pandemic ... there's been some murmurings about death and dying and end-of-life and resources. I think, in fact, it's probably an opportune time to have that discussion ... that there is a limited amount of resources ... (Physician 19, Ireland)

5.8.3 Summary of Lived Things: The influence of material things on nurses and physicians experiences when caring for children with CCNs in PICUs during the pandemic

The contribution of things to the exploration of care delivery was evident in the interviews with nurses and physicians – ranging from the changes associated with practices, including moving towards telemedicine and video

calls for children with CCNs and their families, instead of in-person meetings. This section reported on the strengths and advancements seen as a result of the COVID-19 pandemic for this cohort of children. The section also provided insights and discussions around the allocation of resources within PICUs. Nurses and physicians across all three sites spoke about the benefits of telemedicine for children with CCNs and their families and the positive impact this has had on care delivery, wishing to bring these forward after the pandemic. However, some participants believed that, with the use of telemedicine, there are core elements of paediatric care missing. This will be explored further in Chapter Six.

5.9 Conclusion

This chapter presented the findings that emerged from this research, which was aimed at exploring the lived experiences of nurses and physicians delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. This chapter outlined the themes that impacted on the experiences of the nurses and physicians interviewed. Van Manen's framework (2007, 2014a) was utilised to help create an in-depth understanding of the day-to-day lifeworld for these nurses and physicians. A total of eight essential themes were identified and aligned to each of the existential themes provided by van Manen (1990, 2014a).

Although the nurses and physicians were offered a chance to reflect on their experiences, they recognised little difference to their workload when caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic than before it. These interviews afforded the participants a chance to stop and think, and to give them time since the pandemic began to reflect on their experiences of care delivery. While the nurses and physicians reflected on how children with CCNs were managed in their PICUs during the COVID-19 pandemic, the overall impression was that care delivery had not changed for this cohort of patients.

The overall aim of the research was to: *Explore the lived experiences of nurses and physicians delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.*

In order to meet this overall aim, an analysis of the meaning of participants' experiences was undertaken as a basis for understanding and interpretation by others. This was represented through forming themes, which were underpinned by each existential theme. Relevant verbatim material from participants was provided in support of each theme. Chapter Six will provide a critical discussion and final interpretation of these findings, while considering the wider literature in this area, to allow for a deeper understanding of the nurses' and physicians' experiences.

Chapter Six: Discussion

6.1 Introduction

Chapter Five presented the findings from this research, which explored the lived experiences of nurses and physicians caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic. This enabled the first two research objectives to be met: an examination of international experiences during this time frame and an articulation of what has been learned from these experiences. In this chapter, the findings are critically discussed in the context of the literature in this area and the research objectives will be further elaborated on throughout the discussion. This chapter will also explore the significance of these findings.

Using van Manen's 'existential themes' approach allowed for an additional contribution to the body of knowledge in the area of caring for children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic (Errasti-Ibarrondo *et al.* 2018). However, I also acknowledge my role as a healthcare professional and recognise that my opinions may impact my analysis of the data. Van Manen's framework provided an appropriate lens through which to look at and explore the data to uncover the lived experiences of the nurses and physicians, without imposing categories upon the data (Rich *et al.* 2013). Through the use of this phenomenological approach, a deeper analysis of the data was provided, enabling a move from description to interpretation (Langdrige 2007). Reflexivity was at the core of the process when writing the findings and providing the discussion in this chapter. Throughout the research, including the analysis, I have attempted to be transparent and I have always acknowledged my own role in the research process. While writing the discussion relating to the findings, I considered the actual verbatim quotes from the participants, while also considering my own thoughts as documented in my journal. I acknowledged that my prior experiences working with children with CCNs, and my own assumptions and beliefs about the impact of COVID-19 on care delivery for

these children, gained from speaking with families through other research projects, may have influenced the research process.

Van Manen's framework was very useful within the context of this research to allow exploration of the lived experiences. This research tested the use of van Manen in the real world of critical care environments, specifically within the complexity of PICUs. Van Manen's framework has not been widely used within this environment or in the context of the pandemic. I had a natural curiosity going into this research and was interested to see how this framework would work. I found there were challenges in using this framework, regarding inflexibility of amalgamating themes. Some of the themes explored interconnected issues and could fit within multiple existential themes, although I found no guidance within the literature about merging these themes. Thus, each existential theme was presented separately. On balance, I believe that using van Manen's framework worked and allowed me to clearly illustrate the lived experiences of the nurses and physicians interviewed. This discussion is structured around the key themes, reflecting the literature and important findings from the nurses' and physicians' lived experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic.

6.2 Lived Body: Daily Experiences of the Care Provided for Children with CCNs during the COVID-19 Pandemic

The first overarching existential theme explored was 'lived body', offering insight into various relational aspects of the participants' day-to-day experiences of providing care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic and decision-making within PICUs. The findings in this study showed that nurses and physicians contextualised their experiences, placing on them their own particular meaning at that point in time.

The findings demonstrated a rich description of the impact of COVID-19 on the provision of care to children with CCNs and identified that they were less affected than anticipated in the first 18 months of the pandemic. The initial change preparations to care delivery, as discussed in the wider literature, were not reflected in the experiences of those interviewed. This may be because, in the general population, there was not as big a surge of cases requiring intensive care than was anticipated. The adult ICUs were capable of managing caseloads without looking to PICUs and their staff for assistance. The findings therefore were in contrast to the literature that found certain changes made to PICUs at this time, including: accommodating adults within a PICU setting (Kneyber *et al.* 2020, Levin *et al.* 2020, Paquette *et al.* 2020, Remy *et al.* 2020, Yager *et al.* 2020, Fernandes *et al.* 2021, Sinha *et al.* 2021) and restructuring PICUs to accommodate both children and adults (Abulebda *et al.* 2020, Deep *et al.* 2020, Gerall *et al.* 2020, Kneyber *et al.* 2020, Levin *et al.* 2020, Sachdeva *et al.* 2020, Girona-Alarcon *et al.* 2021). The reality of care delivery during this time did not meet the expectations of what was anticipated by these nurses and physicians. Again, this was potentially due to the fact that the PICUs were not required to alter their care delivery to accommodate adults, as they were all cared for within adult ICUs.

At the time of interview, the nurses and physicians in this research reported a decrease in the number of children with CCNs admitted to PICU, with a subsequent reduction in care delivery requirements across all sites. From physicians' comments, they believed this to be unique to their own experiences. However, these findings were supported by other literature from the same time point during the pandemic. For example, the UK and Ireland reported a significant reduction in unplanned hospital admissions, respiratory diseases and fewer deaths in PICU (Kanthimathinathan *et al.* 2021b). There were additional UK reports of unusually quiet periods in PICU (Baptiste 2021), potentially as a result of targeted public health interventions and the reduction of routine activities, including cancelling elective procedures. Similarly in Italy, it was reported that children with CCNs did not have a greater need for admission to PICUs and COVID-19 did not create

a significant increase in death rates among this population (Brisca *et al.* 2021). However, they did report a greater median length of stay for this population, potentially due to the lack of community services available to discharge these children, as a result of local lockdowns and reduced outpatient appointments (Brisca *et al.* 2021).

Similar to the findings presented in this study, Zee-Cheng *et al.* (2021) discovered across the U.S. that paediatric critical illness admissions to PICUs substantially decreased during the second quarter of 2020. This was also reported in Northern Italy (Sperotto *et al.* 2021) and South Central China (Yan *et al.* 2021). In contrast, this was not the experience in Brazil between March and June 2020 as children with CCNs accounted for 59.7% (n = 148) of patients in their PICUs with the majority requiring respiratory support in the form of mechanical ventilation (Junior *et al.* 2021). Conversely, Vásquez-Hoyos *et al.* (2021) reported a striking reduction in admissions to PICUs across South America for viral lower respiratory tract infections between January and August 2020, compared with previous years. This would have been due to the public health measures imposed to prevent the spread of COVID-19, which also had a direct effect for other respiratory infections. Vásquez-Hoyos *et al.* (2021) also suggested that the lockdowns may have decreased access to healthcare, with parents afraid to bring their child to hospital for fear of contracting COVID-19. This was a concern which was raised in the findings from this research, and in numerous other research studies (Prime *et al.* 2020, Conlon *et al.* 2021, Mitchell 2021).

However, it has also been suggested that the impact of COVID-19 on care delivery and the organisation of care in PICUs is hard to quantify (Kache *et al.* 2020, Soomann *et al.* 2022). Soomann *et al.* (2022) conducted an observational study in all eight Swiss PICUs, five of which were associated with adult hospitals, between February and June 2020 and found that there was a relatively low workload in some PICUs that were not fully occupied. However, where the PICUs engaged with adult services, whether taking patients or redeploying staff to care for adults, the burden was higher. This

redeployment of staff was also experienced across many other countries, including France (Chomton *et al.* 2021), England (Sinha *et al.* 2021), the Netherlands (Kneyber *et al.* 2020) and in some areas of the U.S. (Wasserman *et al.* 2021). However, none of the participants in this research reported their PICUs being affected by staff redeployment or reallocation to different areas to care for adult patients. This could also be due to the fact that the PICUs in this research were not co-located in facilities with adult ICUs and these PICUs were all situated in stand-alone children's hospitals.

The nurses and physicians across all three sites in this research reported the PICUs being well positioned to increase capacity if required to care for additional children, although this did not occur in any of their PICUs at the time of interview. This finding is supported by the Royal College of Paediatrics and Child Health (2021b) who identified that there was enough paediatric critical care capacity across the UK to increase if required. This potential for increased capacity was discussed across the wider literature, with options available of caring for adult patients in addition to children if needed. This was not an issue raised by participants within this research, where the focus was solely on caring for children. A number of PICUs in North America (Levin *et al.* 2020, Fernandes *et al.* 2021), France (Chomton *et al.* 2021), the UK (Siva *et al.* 2021) and England (Sinha *et al.* 2021) adapted to expand their roles and responsibilities outside of their established remit to increase capacity to care for adult patients.

Although COVID-19 was the catalyst for some discussions on care delivery among the teams in the PICUs caring for children with CCNs, there was a sense that long-term practices in PICUs may not change as a result of COVID-19. The changes reported in the literature outlined short-term changes about having to care for both critically ill adults and children side by side in PICUs (Gist *et al.* 2021, Siva *et al.* 2021) or repurposing their units to care for adults only (Yager *et al.* 2020). Neither of these events arose within the PICUs in this research. It must also be noted the available research predominantly focuses on PICUs within developed countries. Also, further studies have identified the need for additional research in the later

phases of the pandemic to understand the impact specifically on children with CCNs in more detail (Hall *et al.* 2022).

There were no conflicting reports in the literature about a greater number of children requiring initiation of long-term ventilation at that point in the pandemic, despite the physical effects caused by COVID-19 on the respiratory system as reported in the literature (Di Cicco *et al.* 2021, Hernández & Orozco 2021). The literature supported the results from this research: that children appeared to have a milder disease course than adults and critical illness and death were extremely rare in children at that time (Ludvigsson 2020, Shekerdemian *et al.* 2020, Zimmermann & Curtis 2020).

Despite the rarity of critical illness and death in children, those with CCNs are deemed to be at an increased risk of severe illness resulting from COVID-19 (Mitchell 2021). Decision-making relating to the medical needs of these children emerged within the interviews. This is a fundamental component of care delivery in the PICU for all children and their families (Richards *et al.* 2017, Smith *et al.* 2018, Sánchez-Rubio *et al.* 2021), with an added intricate dimension for those children with CCNs (Michelson *et al.* 2013, Mitchell *et al.* 2019). Parent and healthcare professional communication is critical when making decisions within PICUs, with most parents wishing to be the final decision-makers for their critically ill child (Wool *et al.* 2021). However, family support systems, parents' emotions and the child's clinical status all have an impact on decision-making (Wool *et al.* 2021).

In discussions around decision-making regarding clinical scenarios, the participants did not discuss family or parental involvement, but merely referred to decisions being made based on the child's individual prognosis and potential outcomes. A sense of paternalism was evoked within these interviews, as there was almost a complete absence of references to the importance of family involvement in decision-making. Paternalism occurs when a physician makes decisions for a patient without their explicit

consent, but the physician believes the decisions to be in the patient's best interests (Murgic *et al.* 2015). This is an area that would require more exploration in further research. This sense of paternalism is in complete contrast with the core concepts of FCC, identified as crucial within PICUs, including family involvement in care delivery, open communication and respecting families' wishes (Richards *et al.* 2017, Coyne *et al.* 2018, Hill *et al.* 2019). Although recent literature has also acknowledged the disruption of FCC as a result of the COVID-19 pandemic (Al-Motlaq *et al.* 2021, Goldschmidt & Mele 2021), the participants in this research did not acknowledge the importance or implementation of FCC within their PICU settings.

The physicians in this research suggested that COVID-19 would not have an impact on the initiation of long-term ventilation. However, they acknowledged that families may have some hesitation around these procedures as a result of COVID-19 and its associated fears. This resonates throughout the literature, where parents of children with CCNs reported being fearful of attending hospital during the pandemic for fear of infection and shutting down their homes due to the risks of infection (Prime *et al.* 2020, Conlon *et al.* 2021, Mitchell 2021). Additional and substantial challenges related to the impact of COVID-19 have been reported by parents and healthcare professionals caring for children with tracheostomies. These include uncertainty around changing best-practice guidelines and delayed healthcare seeking due to fears and restrictions associated with hospital visits, with limited access to or visits from extended family and supports reported (Canadian Paediatric Society 2020, Hall *et al.* 2022). All these issues posed challenges for families of children with CCNs to access ongoing, essential medical care during this time of uncertainty associated with COVID-19. Koffman *et al.* (2020a, p.215) recognised this period of uncertainty as a time for growth and learning to "change professional cultures". This will be explored further under the section, 'lived time'.

Given that these nurses and physicians had an opportunity to think about improvements in care delivery for the cohort of children in PICUs within this research, no specific recommendations were made by any of the participants. Considering all that is known of what could be enhanced in delivering care to children with CCNs in PICUs during the COVID-19 pandemic, none of these elements were discussed. Some ways to enhance the delivery of care, as reported in the literature, include: the promotion of child- and family-centred care (Efendi *et al.* 2022), the use of advanced respiratory management recommendations such as cuffed endotracheal tubes for mechanical ventilation (European Society Paediatric and Neonatal Intensive Care 2020, Krishnamurthy *et al.* 2020), the use of closed suction (Shekar *et al.* 2020) and early intubation for severe COVID-19 symptoms rather than non-invasive ventilation, which can produce aerosols (Kaushik *et al.* 2020). The last recommendation is in keeping with current best practice, indicating that production of aerosols should be minimised (Nicholas *et al.* 2020). The nurses and physicians were embedded in their ways of doing things and unanimously spoke about the pandemic's lack of impact on their clinical practices in PICUs for this cohort of children at the time of interview. This lack of discussion could be potentially related to the point in time at which the interviews occurred. At the time of interview, the nurses and physicians had cared for so few children with COVID-19 that there had been minimal impact on their workloads.

In the early stages of the pandemic, it is also possible that these nurses and physicians were coping with enormous social changes affecting their personal lives as a result of public health measures, which are highlighted across the literature (Lebni *et al.* 2020, Torales *et al.* 2020, Van Bavel *et al.* 2020, Corpuz 2021, Ventriglio *et al.* 2021). Individuals faced many challenges in adapting to their "new normal" as a response to COVID-19 (Corpuz 2021, p.e344) and subsequently, these nurses and physicians may not have had the space or opportunity to make changes in their professional practice as a result. At the time of interview, there was also an anticipation of potential further change and unprecedented uncertainty (Koffman *et al.* 2020a). This could have affected the nurses' and physicians' ability to think

critically and reflect on their current practice, due to anxiety and fear of the unknown (Koffman *et al.* 2020b). As reported in the literature, healthcare professionals may experience higher levels of stress (Balistreri *et al.* 2021), face struggles with higher workloads due to staff shortages, and encounter challenges regarding ethical dilemmas. For example, the allocation of resources may have also affected the nurses' and physicians' ability to critically reflect at this stage in the pandemic (Yarrow & Pagan 2020, Billings *et al.* 2021, Razu *et al.* 2021).

Interestingly, although there seemed to be more space and time to reflect on the positives associated with practice changes as a result of the pandemic, there was only limited discussion around these. These include greater infection-control measures in the home, the perceived impact of reduced admissions to PICUs for children with CCNs and the use of telemedicine. One nurse spoke about the positives of having smaller, limited meetings. The nurse felt that, in "an ideal world", the meetings should have a limited number of staff as families can find them "very overwhelming". Hybrid rounds and meetings have received a mixed reaction within the literature, with reported positives including decreased physical contact and subsequent potential decrease in COVID-19 transmission, and the negatives including fewer teaching opportunities and reduced interactions among the team members (Temsah *et al.* 2021a, Temsah *et al.* 2021b). These were similar to the challenges of moving into the virtual world, as reported in the interviews for this research.

However, some of the nurses also envisaged that, as a result of the restrictions and smaller numbers being allowed to attend meetings around decision-making, their presence may be excluded and their voices would be absent. Nurses have a vital role in care delivery in PICUs for children with CCNs, including advocating on behalf of the child and family, effectively communicating with families, and being there for the child and family (Curtis *et al.* 2016, Coats *et al.* 2018). This absence at critical meetings can hinder the building of therapeutic relationships between healthcare professionals

and families. The general outcomes from these changes to meetings was that there needed to be cross-representation from the key members of the multidisciplinary team, including nurses and physicians to make the most appropriate decisions in the best interests of the child. This importance of interprofessional team presence in PICUs is crucially important, in order to deliver high-quality, safe patient care (Curtis *et al.* 2006, Riley *et al.* 2013, Stocker *et al.* 2016).

This discussion that emerged relating to lived body have highlighted participants' day-to-day experiences of providing care to children with CCNs in PICUs and decision-making within PICUs at one particular time point during the COVID-19 pandemic. Issues around decision-making and the provision of care in PICUs during the same phase of the pandemic were explored within this research, with similarities drawn and differences highlighted in comparison to the wider literature in this area. Areas for further research have also been identified to enhance care delivery for this cohort of children.

6.3 Lived Other: Therapeutic Relationships Developed during Care Delivery for Children with CCNs during the COVID-19 Pandemic

This second existential theme, 'lived other', explored how individuals related to one another within an interpersonal space (van Manen 2007), exploring how relationships were developed with each other including communication among healthcare professionals and families, when a child has CCNs. Only one theme emerged in this research that focused on relationships between the healthcare professionals and families. The importance of navigating the pandemic together, with parents feeling supported by familiar healthcare professionals, was highlighted. Building therapeutic relationships between healthcare professionals and families is crucial to ensure effective care delivery for this cohort of children (Page *et al.* 2020, Brenner *et al.* 2021). Parents need to be recognised for their expertise in their child's condition

(Page *et al.* 2020). Partnership is essential between parents and healthcare professionals in PICUs to provide high-quality care for these children and their families (Micalizzi *et al.* 2015, Rennick *et al.* 2019).

These interviews afforded the participants a chance to stop and think, and to give them time, since the pandemic began, to reflect on their experiences of relationships among staff within PICUs when caring for children with CCNs. However, reflections about these relationships did not arise in any of the interviews and the focus was purely on healthcare professional relationships with families. As mentioned previously, this could be related to the psychological impact of COVID-19, including stress and anxiety, for these professionals working in an ICU (Balistreri *et al.* 2021, da Silva & Barbosa 2021, Moreno-Mulet *et al.* 2021, Silistre *et al.* 2022, Zhang *et al.* 2022). The nurses and physicians may not have had the space to reflect on relationships among their team, while delivering care to these children and focusing on maintaining therapeutic relationships with the families despite the social restrictions imposed by the pandemic. Additionally, as the nurses and physicians did not report many changes happening within their teams, with no redeployment of staff occurring, perhaps at that time of the pandemic there had been no changes to their professional relationships. The teams were continuing to work together as they were pre-pandemic; thus participants did not recognise the need to discuss these relationships. However, where their relationships with the families were impacted, the participants did wish to discuss these during the interviews.

Relationships between professionals and families emerged as important in caring for children with CCNs, including ways to maintain their strong relationships through keeping communication channels open and adopting a partnership approach to care;. All of these are key concepts in children's nursing (Kuo *et al.* 2012, Micalizzi *et al.* 2015, Brenner *et al.* 2021). These relationships allowed the healthcare professionals and parents to navigate the pandemic together as a unit, with parents feeling supported by the familiar healthcare professionals. The professionals recognised the value in building therapeutic relationships and providing support to these families,

acknowledging the parents' concerns and worries. This enabled them to keep their children at home and not require PICU admission during the first 18 months of the COVID-19 pandemic. This was consistent with the wider literature, which refers to parents wanting to protect their children with CCNs during the pandemic, particularly due to the potential high risk of complications associated with COVID-19 (Hall *et al.* 2021, Mitchell 2021). However, as mentioned previously, these relationships did not extend to joint decision-making, with nearly a complete absence noted regarding the importance of family involvement in decision-making. While the nurses and physicians spoke about building and maintaining these strong relationships with the families, this lack of partnership in the area of decision-making was evident.

Effective communication is a cornerstone of paediatric healthcare (Ali 2017, Mărginean *et al.* 2017), with barriers to communication subsequently impacting on care delivery. In this research, physicians acknowledged barriers to communication with families and the subsequent effect these had on relationships as a result of PPE requirements from COVID-19 and communicating using online platforms instead of face-to-face. This was consistent with the wider literature relating to communication barriers between families and healthcare professionals (Braun *et al.* 2021, Ferrari *et al.* 2021, Díaz-Agea *et al.* 2022).

In PICUs where repurposing occurred, either by shifting to care for adults only, or maintaining a hybrid model where adults and children were cared for in the same PICU, staff reported excellent communication among teams and strong leadership as being key elements for success (Levin *et al.* 2020, Sinha *et al.* 2021). Additionally, PICU staff reported the challenges of working outside of their normal scope of practice (Sinha *et al.* 2021). However, in this research, none of the staff were challenged outside of their normal scope, due to the lack of impact in their units. Similar findings were reported across the literature in other studies (Yager *et al.* 2020, Gist *et al.* 2021, Siva *et al.* 2021, Styles *et al.* 2021), with adaptability and team-work identified as key aspects of delivering successful care. Reports of

comradery and the provision of staff wellbeing hubs were positive interventions arising from these changes (Siva *et al.* 2021). The importance of teamwork and support were highlighted across settings, where paediatric nurses were redeployed to care for adults with COVID-19 (Baptiste 2021, Lulgjuraj *et al.* 2021, Read 2021). The need for physical and emotional support from their teams were reported as key to success.

Relationships between healthcare professionals did not emerge from the interviews in this research and were not raised in any of the interviews, despite interprofessional relationships being acknowledged as crucial to care delivery in PICUs (Bagnasco *et al.* 2013, Stocker *et al.* 2016). None of the physicians or nurses alluded to any opportunities for growth or development as a team during the COVID-19 pandemic. Perhaps at the time of interview, the staff in the PICUs had not experienced any opportunities for growth, given that their workloads remained relatively unaffected. Further research would be beneficial, in order to ascertain the nurses' and physicians' experiences at a later phase in the COVID-19 pandemic and to discover if there had been subsequent opportunities for growth and development if the care requirements in PICUs changed as time went on.

Using van Manen's (2014a) existential theme, 'lived other', offered insight into how the nurses and physicians related to families of children with CCNs in PICUs. Similar experiences were found across the three sites. The context of these relationships between families and professionals was discussed within the wider literature. These interviews afforded the participants a chance to stop and think. They gave the participants time, since the pandemic began, to reflect on their experiences of relationships among staff when caring for children with CCNs within PICUs. However, reflections about these relationships did not arise in any of the interviews, despite the importance of interprofessional relationships within PICUs, as reported in the literature. Potential reasons why these reflections may not have occurred at the time of interview have been discussed within this theme.

6.4 Lived Space: Connections between the Child with CCNs and the Space they Occupy within PICUs

This existential theme, 'lived space', was concerned with the space that the life occupied, in this case the life of the child with complex care needs, as perceived by the nurses' and physicians' caring for them. Lived space gave an understanding, from the nurses' and physicians' perspectives, of how COVID-19 affected families and how this impacted on care delivery for children with CCNs in PICUs in relation to visiting restrictions. Across all interviews, there was an understanding that COVID-19 had a significant impact on families and children with CCNs, including interruption of medical care, e.g. missed therapies and hospital appointments. This is reflected across the literature (Conlon *et al.* 2021, Mitchell 2021, Driansky *et al.* 2022) with an additional recognition that the overall effect of COVID-19 for this group of children continues to remain largely unknown (Brisca *et al.* 2021, Mitchell 2021). Throughout the interviews, the nurses and physicians acknowledged the uncertainty surrounding what would happen as time progressed and that further time was needed to understand the realities of the impact of COVID-19 on care delivery for children with CCNs and their families in PICUs.

The nurses and physicians reflected that there was a significant level of fear and anxiety among these families. They noted the hesitation among parents about bringing their child in for scheduled appointments. This was also reported across the literature (Page *et al.* 2020, Conlon *et al.* 2021, Mitchell 2021). This was reinforced in a study in the U.S., which found that specialist appointments due to the pandemic may disproportionately affect this cohort of children, who require more significant health resources and coordinated healthcare than the general population (Driansky *et al.* 2022).

No studies have yet evaluated the effect of COVID-19 on children with CCNs. However, children with COVID-19 who have CCNs or medical complexity are more likely to become critically ill in PICUs than children with

COVID-19 who are without underlying conditions (Shekerdemian *et al.* 2020). Children with CCNs are generally at a higher risk of developing respiratory complications due to factors such as impaired airway clearance, chronic respiratory diseases and additional ventilatory support (Proesmans 2016, Chiang & Amin 2017), which will likely put them at increased risk for morbidity and mortality resulting from COVID-19 (Driansky *et al.* 2022). However, Brisca *et al.* (2021) noted, a significant reduction in the number of children with pre-existing respiratory disease in Italy, as a result of restrictive measures and subsequent reduced viral and non-viral infections.

There was also a recognition of the potential positive impact on a child with CCNs being cared for at home during the pandemic, which again may evolve over time as additional data is reported on care for this cohort of children. The recognition of overall improved health among this population of children emerged as an unexpected bonus of the pandemic for PICUs across all sites within this research. There was a subsequent reduction in the service delivery of PICUs and fewer admissions than would usually occur for these children at that time of year. This was consistent with the wider literature reporting a reduction in PICU admissions during the COVID-19 pandemic up to that point (Kanthimathinathan *et al.* 2021b, Vásquez-Hoyos *et al.* 2021). However, it is acknowledged in the literature that current available data on the impact of the pandemic, including on the availability of information in PICUs (Loomba *et al.* 2020) and on this cohort of children, are scarce. Research mainly focused on the suspension of services, including rehabilitation and educational services (Iozzi *et al.* 2020, Negrini *et al.* 2020). Despite the positives associated with this reduction of activity in PICUs, there was a resulting negative impact on those children with CCNs and their families, for whom commencement of long-term ventilation and other elective procedures were delayed, due to the measures taken to protect PICUs mentioned previously.

On the occasions where children with CCNs were admitted to PICUs, the nurses and physicians spoke about the challenges associated with visiting restrictions resulting from COVID-19. Consistent with the wider literature

(Andrist *et al.* 2020, Virani *et al.* 2020, Balistreri *et al.* 2021, Camporesi *et al.* 2021, Hyczko *et al.* 2022), they reported the negative impact this lack of support had on families during those difficult times. This adverse impact incorporated all members of the family, including siblings and grandparents, with nurses and physicians in this research acknowledging the adversity associated with the lack of these support systems for this cohort of children and their parents. Camporesi *et al.* (2021) conducted a web-based international survey and found changes in visiting policies were observed in most of the PICUs worldwide, with some prohibiting nearly all family visitations, except for one parent at a time. The impact reported by Camporesi *et al.* (2021) was mirrored in this research, with the decreased possibility of parental participation in emotional support and shared decision-making, and a subsequent, negative impact on child and parental well-being. Similar findings were reported in studies in Canada by Virani *et al.* (2020) and in the U.S. by Hyczko *et al.* (2022). However within the study by Hyczko *et al.* (2022), parents expressed satisfaction with and an understanding of visitor policies, although 40% (n = 29.2) believed restrictions affected their own and their child's ability to cope during their hospitalisation. The other study, by Virani *et al.* (2020), did not discuss parental satisfaction or understanding regarding visitor policies.

Studies by Andrist *et al.* (2020) and Virani *et al.* (2020) discussed the need to develop a balance between the harm of visiting restrictions with the benefits of protecting others, within the COVID-19 pandemic. They also acknowledged that compassion-based exceptions were appropriate and must be considered in certain situations, including critical illness and death. These compassion-based exceptions were also referred to in this research in relation to end-of-life care within PICUs. Participants in this research acknowledged the significant differences between delivering end-of-life care pre-pandemic and during the pandemic with the associated restrictions. Core elements of paediatric palliative care in PICUs involve effective communication techniques, FCC and providing support to healthcare professionals (Doorenbos *et al.* 2012, Polikoff & McCabe 2013, Mitchell *et al.* 2019, Rubic *et al.* 2022).

One participant in this research reflected on a time, pre-COVID-19, when end-of-life care was delivered effectively with these elements, including having the child surrounded by extended family. The positives associated with this precious time were noted, with the family being afforded the opportunity to create special memories together. They were able to support each other when the child with CCNs was at their end-of-life. However, as a result of pandemic-related visiting restrictions in PICUs, the delivery of end-of-life care was negatively impacted, as reported in this research, with similar reports arising within the literature (Rosenberg *et al.* 2021, Weaver *et al.* 2021). The nurses in this research spoke about doing the best they could despite the limitations associated with the restrictions. There was a level of acceptance displayed, that things could not be how they were for these families pre-COVID-19.

This existential theme, 'lived space', was concerned with the space occupied by these families of children with CCNs, from the nurses' and physicians' perspectives within PICUs. The exploration of emotional space for families and the effect of visiting restrictions as a result of the pandemic were discussed in relation to the relevant, emerging literature in this area.

6.5 Lived Time: Perspectives from a Moment in Time During the COVID-19 Pandemic within PICUs

This existential theme, 'lived time', provided an understanding of nurses' and physicians' daily lives and how time was experienced, in terms of delivering care to children with CCNs during the first 18 months of the COVID-19 pandemic in PICUs. Van Manen (2014a) indicated that lived space and lived time are often interlinked. The focus of this research was predominantly on the fact that few children were affected by COVID-19 at the time the interviews were carried out. Particular emphasis was placed on those with CCNs who were 'protected', due to the lockdowns, social distancing restrictions and tighter infection-control measures for the families.

Lived time explored the learning obtained from COVID-19 and alluded to the uncertain road that lay ahead. This learning may be correlated with the stage of the pandemic at the time of interview and its associated impact. Subsequently, if the interviews were conducted at a different time point there may have been alternative views raised about the effect of COVID-19 and children with CCNs, particularly relating to PICU admissions and activities. It is acknowledged in the literature that COVID-19 does not exclusively affect adult ICUs and PICUs faced a variety of changes and transitions across the world (Soomann *et al.* 2022). However, the PICUs in this research remained relatively unchanged and unaffected at the time of interview. This could potentially be related to the time at which the interviews were conducted, with the possibility of obtaining different results if these interviews had been conducted at a later stage in the pandemic. As the pandemic continues, ongoing reflection and learning from experience, in addition to cooperation across PICUs, are essential to optimise resources and care delivery for children with CCNs.

Over half the nurses and physicians in this research felt that there was learning to be gained from this time point of the pandemic, including through research around COVID-19. They recognised that there was current research available that focused on how best to manage the patient and what drugs to use. However, there was no substantial, emerging research evidence that related to children, specifically children with CCNs, and how care should be delivered to this population. This is evident across the research literature. There was only one research study on this cohort of patients in PICUs currently available (Junior *et al.* 2021). The study found that the functional status of children with CCNs admitted to PICUs during the COVID-19 pandemic improved during their hospitalisation, mainly due to the provision of additional respiratory support. Research on caring for children with CCNs during the pandemic primarily focused around those receiving palliative care. The research mainly looked at the pandemic's impact on those services (Weaver *et al.* 2021, Grigoletto *et al.* 2022), the associated challenges experienced by the families (Mitchell 2021, Hall *et al.*

2022), and the social and mental health impact on the children and their families (Geweniger *et al.* 2022).

Nurses and physicians across all three sites unanimously perceived that the COVID-19 pandemic would have little or no impact on their work within PICUs or around the initiation of long-term ventilation for children with CCNs. However, some nurses and physicians within this research acknowledged that this lack of impact may be associated with the fact that children, particularly those with CCNs had not been affected much by COVID-19 at the time the interviews took place. There was a recognition that, in comparison to COVID-19, influenza A virus subtype H1N1 (or 'swine flu') had a much greater impact on children with CCNs (O'Riordan *et al.* 2010). They faced an increased risk for hospitalisation, PICU admission, and death (Louie *et al.* 2010, Cox *et al.* 2011, Randolph *et al.* 2011) and those on long-term ventilation were at higher risk (Peacock *et al.* 2012). As time progresses, a greater impact may be observed with later waves of the COVID-19 pandemic.

Some nurses and physicians in this research spoke about their day-to-day lived time, their hopes and the uncertainty of what was to come. They discussed their uncertainty with the present situation and acknowledged not knowing what to expect in the next year, although they were hopeful that COVID-19 would have less of an impact as time went on. This concept of remaining hopeful about brighter times ahead, including the roll-out of vaccinations against COVID-19, resonates throughout the literature (Pimlott 2020, Contreras 2021, Cohn *et al.* 2022).

Running concurrently against this hope were concerns from the nurses and physicians in this research about the potential effects of COVID-19 on the wider healthcare services for children with CCNs, in addition to the effect on services in PICUs. Again, at this moment in time, there were many uncertainties associated with COVID-19, including how the disease would progress and the effect it would have on children with CCNs (Koffman *et al.* 2020a). A number of participants in this research mentioned the complexity

of the needs of these children and the reluctance of parents to bring them to hospital, due to fears and uncertainties associated with the pandemic (previously discussed in the section, 'lived space'). One physician talked about how they could not bring children in to be assessed for initiation of long-term ventilation in their PICU, as a direct result of COVID-19. This was also reported by Williams *et al.* (2021). However, Rimensberger *et al.* (2021), acknowledged that treatment concepts and outcomes for children are based mainly on expert opinions with limited experience of a pandemic and identified that there is a significant lack of any completed controlled trials in children at this moment in time. As a result, the wider picture of the effects of COVID-19 remain largely unknown at present (Smith *et al.* 2020).

Additionally, the nurses recognised the challenges associated with COVID-19 when working within PICUs, including difficulties with team meetings, educational sessions for the staff and the extra time needed to complete tasks, as a result of COVID-19. Aside from the clinical meetings and professional training taking longer, there was also a significant impact on delivering parental education in caring for their child with CCNs and on ensuring competency with this training, which is reflected in the literature (Driansky *et al.* 2022). This acknowledgement of the impact on caregivers and lack of support was explored in the section, 'lived space'.

The nurses and physicians stated in this research at the time of interview, that COVID-19 had created an opportunity for wider conversations around issues arising for children with CCNs, using the initiation of long-term ventilation as an example, not only within medical teams, but within a political and social arena around accessing care. However, they did not expand on their personal beliefs or experiences around advanced care planning, or what they thought these conversations would look like. Despite wishes for changes in future discussions, it was noted that while these interviews were an opportunity to talk about advanced care planning and initiating technology for children with CCNs, none of the nurses or physicians spoke specifically about changes they had made to their own practices based on these wishes.

While COVID-19 has raised opportunities in numerous settings for discussions around advanced care planning in both the adult (Selman *et al.* 2020, Dassel *et al.* 2021, Dujardin *et al.* 2021) and paediatric population (Palat *et al.* 2020), this could be viewed as a missed opportunity within the practices of these healthcare professionals, given the disease profiles of children with CCNs. The nurses and physicians within this research, did not see any recognition of the need to adapt. Perhaps things might have been different if these nurses and physicians were heavily involved in caring for children impacted by COVID-19.

Evidently, there has been limited learning emerging within this research, in relation to changes to care delivery for children with CCNs in PICUs. Even with prompting during the interviews, there were no wishes to engage with families around advanced care planning. This is despite being highlighted in the literature as improving care delivery for children and improving palliative care knowledge and comfort (Mitchell & Dale 2013, Liberman *et al.* 2016, Hein *et al.* 2020, Carr *et al.* 2021, Carr *et al.* 2022). Within this research, engagement of the healthcare professionals with the child and family clearly emerged as not changed due to COVID-19. Perhaps at the time of interview, the staff in the PICUs were not ready to reflect further on these experiences or to discuss further practice changes, as they were also dealing with enormous social upheaval as a consequence of the severe public health measures associated with the pandemic (Nicola *et al.* 2020, De Kock *et al.* 2021, Long *et al.* 2021, Mousavi *et al.* 2021, Sun *et al.* 2021).

This existential theme, 'lived time', referred to the experience of time. Lived time was a felt time, or time as the nurses and physicians experienced it while working during the pandemic in PICUs at one moment in time, of their day-to-day life, and how they perceived it. Lessons to be learned from the pandemic were uncovered in relation to caring for children with CCNs in PICUs, along with acknowledging the uncertain road ahead for this cohort of children, which may evolve as time goes on. These are key concepts recognised throughout the research literature. It is a dynamic area of research, with new learning emerging all the time. Thus, in relation to care

delivery for children with CCNs within PICUs, the situation may become very different as time moves on.

6.6 Lived Things: The Influence of Material Things on Nurses and Physicians Experiences when Caring for Children with CCNs during the Pandemic

The final existential theme examined was 'lived things' and referred to how these were experienced in day-to-day life, focusing on the importance of material things (van Manen 2014a). Within this research, it translates to how materiality and certain material things in life influenced nurses' and physicians' lived experiences in PICUs, when caring for children with CCNs during the first 18 months of the COVID-19 pandemic. The material things the participants spoke about in this research included the impact of telemedicine and the allocation of resources and equipment within PICUs, which will be situated within the wider research through this discussion.

The majority of the nurses and physicians across all three sites, reported on changes in practices due to COVID-19, including the use of telemedicine to link in with, and support, children with CCNs and their families. These changes in practices were largely viewed in a positive light. Widespread use of telemedicine during the pandemic has shown promise in managing acute and chronic illness and providing routine care for children with CCNs (Brisca *et al.* 2021, Camden & Silva 2021, Garg *et al.* 2021, Onofri *et al.* 2021, Beight *et al.* 2022). The utilisation of technology as an innovative communication tool during the pandemic within adult ICUs has also been advocated across the literature (Chandra *et al.* 2021, Rose *et al.* 2021, Sasangohar *et al.* 2021, Temsah *et al.* 2021a, Thomas *et al.* 2021, Beight *et al.* 2022). Medical teams in PICUs have reported on the importance of 'telehealth' (Hasanpour *et al.* 2021) and the successful incorporation of telemedicine and virtual platforms to initiate multidisciplinary discussions to care for children (Temsah *et al.* 2021a). This resonated within the findings of this research. For example, the participants reported the use of

telemedicine allowing for discussions around the initiation of long-term ventilation for children with CCNs.

Recent research found that healthcare workers reported positive benefits using online communication platforms with families and the team in the PICUs (Temsah *et al.* 2021a, Temsah *et al.* 2021b). These professionals reported an increased focus on clinical rounds due to decreased family member presence, which meant fewer interruptions for the team dynamics, thus finishing medical rounds on time and being generally helpful for the workload (Temsah *et al.* 2021a). However, some nurses reported difficulty in keeping up with online rounds, a negative effect on relationship building, and challenges in delivering patient care at the same time (Temsah *et al.* 2021a). They also reported a more negative view of telemedicine, recognising that it was not the same as face-to-face in terms of relationship building and maintaining a rapport with these families. Similarly, the possibility of a decrease in face-to-face interactions between medical professionals, affecting family scenarios and interactions in PICUs was reported by Gaulton *et al.* (2020). The presence of family during medical rounds and shared decision-making (Johnson *et al.* 2015) is noted to increase family satisfaction during admission (Grzyb *et al.* 2014), but this was notably lacking due to restrictions associated with the COVID-19 pandemic.

These negative experiences with telemedicine and online meetings were shared across interviews in this research, with numerous nurses feeling that it was not the same as face-to-face, the online meetings did not work as well and subsequently things were not as good as they used to be pre-pandemic. Similar challenges were reported by Temsah *et al.* (2021a) in relation to relationship building among the team, including difficulties for bedside nurses being available to attend the virtual rounds and decreased interactions among team members. However, Temsah *et al.* (2021a) also acknowledged that several components of the hybrid approach should be optimised going forward, including the effectiveness of team meetings via

Zoom, as they can finish tasks during the rounds and finish orders more swiftly.

Conversely in this research, there was a belief that after the pandemic, things would go back to how they were before, in terms of use of technology and telemedicine within PICUs. On the other hand, additional studies report on the likelihood that telemedicine examinations will continue beyond the pandemic (Temsah *et al.* 2021a, Shaver 2022), given the wide availability of telemedicine use in caring for children with CCNs (Notario *et al.* 2019). There is also a recognition of the validity of virtual examinations (Ansary *et al.* 2019), with proposals for how their validity could be addressed (Benziger *et al.* 2021). Future directions should focus on expanding telemedicine to bridge care gaps for children with CCNs and their families (Driansky *et al.* 2022), while gaining additional experiences from healthcare professionals and families to continuously improve care delivery.

Within this research, nurses and physicians discussed allocation of resources in PICUs related to caring for children with CCNs. Participants reported that allocation of resources did not impact on decisions made for children with CCNs, and decisions would be made in the best interest of the child at all times. Physicians reported they would do everything they could to make the best decisions for a child in the PICU, and would not be hampered by resource allocation or capacity allowance. However, no physician or nurse shared any actual issues or specific shortages arising in PICUs around allocation of resources when caring for this cohort of children, although this concept of resource allocation is something that had been talked about within their teams. Similar discussions around resource allocation have been reported internationally, including the UK (Cook *et al.* 2020), Germany (Schmidt *et al.* 2021), Croatia (Sekulić *et al.* 2020), Italy (Riccioni *et al.* 2021), Singapore (Chia & Tay 2021), the U.S. (Emanuel *et al.* 2020, Laventhal *et al.* 2020), China (Wang & Jia 2021), and in a combination of countries reported together (Fiest *et al.* 2020, Supady *et al.* 2021). This is supported by other research examining the preparedness of PICUs for the pandemic (Abulebda *et al.* 2020). While many changes and

adaptations were made in the early stages of the COVID-19 pandemic, resource shortages for children were not prominent within their PICUs (Abulebda *et al.* 2020, Tedesco *et al.* 2021). Adequate provision of care in PICUs was maintained for critically ill children, albeit in other units if the PICUs were full of adult patients (Sinha *et al.* 2021). These experiences around resource allocation may be related to the time the interviews occurred. An alternative perspective may be given at a different point in time if the nurses and physicians in this research were to face a shortage of resources within their PICUs.

Additionally, nurses and physicians in this research noted there would be differences to caring for children on long-term ventilation if they were COVID-19 positive, and this would require changes to practice. However, the staff in the PICUs within this research had not faced these situations at the time of interview. The changes to practice required were not discussed in detail by any of the participants during the interviews. However, Kache *et al.* (2020) and Rimensberger *et al.* (2021) highlighted changes that would be required for children who were COVID-19 positive and requiring respiratory support, including the use of PPE, using cuffed endotracheal tubes for intubation and adapting ventilator settings. However, none of these issues were discussed by participants in this research. Perhaps this is because the nurses and physicians had not cared for children with CCNs who also had COVID-19.

Policies were swiftly put in place within the PICUs in this research to deal with any situations which may arise as a result of a shortage of resources, to assist the nurses and physicians in making decisions about resource allocations. Consistent with the wider literature, similar standards and policies were put in place in other PICUs (Kache *et al.* 2020, Kirby *et al.* 2021, Soomann *et al.* 2022). These discussions around decision-making should also involve the parents, to ensure that parents were aware that any decisions made regarding resource allocation would not be made based on their child's underlying complex condition, but in the child's best interests, a

concept widely reflected on in the literature (Birchley 2014, Birchley *et al.* 2017, Streuli *et al.* 2021).

The contribution of ‘things’ to the exploration of care delivery was evident in the interviews with nurses and physicians, e.g. the changes associated with practices that are moving towards telemedicine and video calls for children with CCNs and their families, instead of in-person meetings. The many benefits and challenges of telemedicine for children with CCNs and their families have been explored, with reference to the wider literature. Although mixed views were evident between the participants in this research and the wider research about the benefits of telemedicine long-term in PICUs post COVID-19. Additional research is required in this area to further understand and implement the use of telemedicine, in order to improve care delivery for this cohort of children and their families in PICUs.

6.7 Conclusion

The findings of this research have been synthesised and the relevant literature reviewed to inform discussion of the findings. A number of experiences were illustrated throughout this discussion, from the perspective of nurses and physicians caring for children with CCNs, which were in line with the following objectives of this research:

1. *To examine experiences internationally of caring for children with CCNs – during the first 18 months of the COVID-19 pandemic – in PICUs.*
2. *To articulate what has been learned from these experiences during a specific time frame of the COVID-19 pandemic, to support ongoing care in PICUs for this population of children*

Issues were identified that were of significance to the participants, which were evident across all the existential themes, but particularly apparent in ‘lived time’. Although, as previously noted, the overall impression from the nurses and physicians was that care delivery and supports required for ongoing care for this population of children in PICUs during this time frame of the pandemic, had not significantly changed at that moment in time.

While individually, all of the nurses' and physicians' stories were unique, commonalities existed between the participants, as illustrated in the essential themes, with similarities drawn and contrasting views highlighted with reference to the relevant literature. Overall, the nurses and physicians in this research had some similar experiences to those reported in the literature relating to care delivery during the pandemic. Within this research, the nurses and physicians reported little impact on their day-to-day workload during the first 18 months of the pandemic. Similar findings were reported across all three sites. However, additional research, both within the same countries and in other countries, highlighted significant differences, including repurposing PICUs to care for adults alongside children, or to care only for adults. Redeployment of staff to cope with the increased adult patient caseloads was another commonality across many research studies. However, these nurses and physicians did not experience this, possibly because the PICUs in this research were in standalone children's hospitals, not co-located with adult ICUs.

Key issues were identified and discussed as important in learning from these experiences, including the importance of initiating discussions around advanced care planning. The benefits associated with telemedicine have been explored in relation to care delivery, with positives emerging as implications for the enhancement of care in PICUs during future pandemics. However, it was also noted that at the time these interviews were conducted, staff in the PICUs were perhaps not yet ready to reflect further on their experiences or to discuss further practice changes. One reason for this may be that they were also dealing with enormous social upheaval as a consequence of the severe public health measures associated with COVID-19.

In conclusion, this discussion has successfully illustrated that useful information has been gathered throughout this research and interlaced with relevant literature to present a basis for understanding and interpretation by others, while meeting the objectives of this research set out at the beginning. This research highlights the various components of care delivery to children

with CCNs in PICUs during the first 18 months of the COVID-19 pandemic, while signifying the importance of acknowledging the nurses' and physicians' own lived experiences. Through explicating these lived experiences, many aspects of care delivery have been explored and presented here as a foundation for understanding and interpretation by others, which was a core objective of this research. The interpretation of the existential themes and the essential themes in combination with the discussion, led to the development of key implications presented in the following and final chapter. Chapter Seven discusses the implications for research, practice, education and policy arising out of this research.

Chapter Seven: Conclusion and Implications

7.1 Introduction

Chapter Six provided a discussion of the key findings from this research. The discussion was supported with relevant literature in this area. The findings explored nurses' and physicians' lived experiences of delivering care to children with CCNs in PICUs during the first 18 months of the COVID-19 pandemic, thus enabling the research aim and objectives to be met. This chapter considers the implications of the key findings in relation to research, education, policy and practice, which was in line with the third objective of the study:

To present implications for the enhancement of care and changes to care delivery in PICUs following the pandemic.

The chapter also sets out the strengths and limitations of the research and concludes by outlining a plan for the dissemination of its key findings.

7.2 Implications of the Research

This research provided a voice for nurses and physicians in sites in Ireland, the U.S. and Australia, and in doing so, provided a rich description of their experiences. It brings to light the experiences, learnings and challenges associated with delivering care in PICUs to children with CCNs during the first 18 months of the pandemic. This research afforded the participants time to stop and think, and to reflect on their experiences. To my knowledge, this is the first research that provides a detailed description of the nurses' and physicians' experiences within such an environment. Therefore, this research can inform practice and policy implementation for service providers, with a clear vision based on these healthcare professionals' lived experiences. The knowledge gained highlights the implications for future research, practice, education and policy. These implications are discussed in detail in the following sections.

7.2.1 Implications for research

This research afforded the nurses and physicians the opportunity to reflect on, and discuss, their own lived experiences of delivering care in PICUs to children with CCNs during the first 18 months of the pandemic. It provides a baseline for further research that may explore the lived experiences of those delivering such care later in the pandemic and in other less developed countries. This research discovered that at time of interviews, there had not been much of an impact in PICUs due to COVID-19, and the workload of the nurses' and physicians' was not affected as much as had been anticipated. However, there was an acknowledgement that there were many uncertainties associated with the impact that COVID-19 would have at a later timepoint of the pandemic and the possibility that things may look different. As the majority of PICUs work within a similar model of care in developed countries, it was not surprising that there were similar findings across the sites accessed in this research. Additional research would be beneficial to identify this impact that later waves of COVID-19 had on care delivery for children with CCNs in PICUs.

7.2.2 Implications for practice

This research provided data and an awareness of care delivery for children with CCNs in PICUs during the first 18 months of the pandemic, from the nurses' and physicians' perspectives. However, as mentioned previously, the nurses and physicians did not recognise the need to adapt care delivery in PICUs for this cohort of children during that time frame. While the participants did not report any extensive change to care delivery during those 18 months, they reported being well positioned to increase capacity if needed.

Decision-making was affected within PICUs as a result of COVID-19. Changes to decision-making included using virtual platforms to host conversations and meetings, with smaller face-to-face meetings occurring due to public health restrictions. Some nurses felt smaller numbers at meetings meant their voices would be absent from family meetings and their

presence would be excluded from the decision-making conversations. As nurses have a key role in advocating for children and their families, this absence at meetings could hinder the building of therapeutic relationships. Barriers to communication amongst healthcare professionals and families, were also created by the use of PPE.

The following implications for practice are suggested:

- To implement and continue exploration of the value of using telemedicine to deliver care in PICUs to children with CCNs and their families.
- To continue the use of hybrid rounds in PICUs due to their effectiveness within care delivery and the subsequent potential decrease in COVID-19 transmission.
- To encourage and promote a positive environment for discussions with the multidisciplinary team around resource allocation, particularly at end-of-life, for children with CCNs within PICUs during the pandemic, given that the participants acknowledged the importance of having wide multidisciplinary involvement in these conversations.

7.2.3 Implications for education

There was a recognition that discussions with the wider multidisciplinary team and specialist consultants from other areas may be necessary to guide resource allocation for children with CCNs, rather than having individuals make decisions in isolation. Decision-making, resource allocation and advanced care planning were identified as key areas for ongoing discussion around care delivery in PICUs as a result of COVID-19.

The following implication for education is suggested:

- To develop a learning package for training and educating healthcare professionals, to enhance care delivery for children with CCNs in PICUs during future pandemics, including topics such as effective

team work, decision-making, resource allocation and advanced care planning.

7.2.4 Implications for policy

The allocation of resources did not impact on decisions made for children with CCNs in PICUs, with participants stating decisions would always be made in the best interest of the child. Physicians reported they would do everything they could to make the best decisions for the child in the PICU, and would not be hampered by resource allocation or capacity allowance. Policies were swiftly put in place within the PICUs to deal with any situations that may arise as a result of a shortage of resources, to assist the nurses and physicians in making decisions about resource allocations.

The following implications for policy are suggested:

- To map service provision necessary for the care of this cohort of children within PICUs and to examine capacity increase, including the availability of staff and equipment.

7.3 Limitations of the Research

While the findings of this research are rich and provide valuable insights into nurses' and physicians' lived experiences of delivering care in PICUs to children with CCNs during the first 18 months of the pandemic, there are also limitations as with any research (Polit & Beck 2020). Researchers have an obligation to present honest and complete limitations of the research study (Ross & Bibler Zaidi 2019). The aim and objectives of this research were clear from the outset. The research was carried out within the processes described in detail throughout this thesis. Although the findings are in some instances vastly different from what has been previously reported in the literature, in terms of repurposing PICUs during the first 18 months of the pandemic, this is not a limitation of the research design. The research was representing a specific period in time, capturing the lived experiences of the nurses and physicians who participated in this research.

Other varying experiences may have been reported during later waves of the pandemic.

This research represented care delivery in PICUs that were all well established and developed within their health systems. Conflicting experiences may have been reported from other PICUs in less developed countries and in other areas where adult ICUs were co-located with PICUs. It would have been interesting to explore these experiences to ascertain whether events such as staff redeployment would have occurred.

As with any qualitative research, previous background knowledge, past experiences and my own subjectivity could have influenced the research process. Although measures were adopted throughout to minimise this influence, including the use of reflective journaling and regular discussions relating to the data analysis and interpretation with my supervisors, these limitations are acknowledged.

Due to the COVID-19 pandemic, the participants were interviewed online using Zoom, instead of face-to-face as originally planned. This restriction could have potentially limited opportunities for interpretation of the conversations, in terms of non-verbal engagement and communication techniques. However, as explained in section 4.5.1, additional steps were taken to build a relationship with each participant, including introductory emails and icebreaker questions at the beginning of the interviews. These measures appeared to be effective in ensuring that participants felt as relaxed as possible throughout the interview process and that rich data was obtained. However, it was a relatively new way of communicating for all concerned and may have impacted on the participants' responses during the interviews.

The results of this research should be interpreted in light of these limitations. While the pandemic continues to evolve in each of these countries, with dynamic adjustments made within PICUs, additional research is necessary

to capture the ongoing changes required for effective care delivery for children with CCNs.

7.4 Unique Strengths of the Research

After acknowledging the limitations of this research, it is crucial to highlight its unique strengths (Parahoo 2014), which far outweigh the potential limitations highlighted in the previous section. Van Manen (2007, p.151) highlighted four conditions to evaluate any phenomenological text: “Our texts need to be orientated, our texts need to be strong, our text needs to be rich, and our text needs to be deep”. The use of semi-structured, in-depth interviews was adopted to gather rich research data in relation to the phenomenon under exploration. This method helped me to understand the meaning of these lived experiences and to make sense of each individual experience (van Manen 2007). Within this context, phenomenology was used in an attempt to describe and interpret the meaning associated with the nurses’ and physicians’ experiences (van Manen 2007). The processes involved within phenomenological reflection are retrospective rather than introspective, meaning “reflection on experience that is already passed or lived through” (van Manen 2007, p.10). The lived experiences in this research were reflected on in order to be understood.

Van Manen’s (2014a) five lived existential themes acted as a guide for reflection and were used as a systematic attempt to uncover the lived experiences of the nurses and physicians. It is different from other methodologies in that it strives to gain a more comprehensive perspective of how the phenomenon is experienced in its entirety (van Manen 2014a). I listened to presentations and read extensively about van Manen’s (1990) framework. At the beginning, when reading van Manen’s work it was challenging and took time to fully understand the clarity of his meaning. However, the earlier works of Heidegger, Gadamer and Merleau-Ponty were considered to explore the nature of hermeneutic phenomenology more fully and historically. These works were valuable in enhancing and expanding my understanding of what I found a complex language at the

beginning. I found this methodology to be intense, constantly revisiting my philosophical understanding at all times.

What stood out for me was the concept that one must do phenomenology to grasp its significance, as van Manen states (2015, p.8): “A real understanding of phenomenology can only be accomplished by ‘actively doing it’”. After experiencing this journey, I feel I have a much better understanding of the complex language of hermeneutic phenomenology and van Manen’s process of data analysis. My depth of engagement with the analysis increased daily throughout the research process, which further enhanced my understanding and my overall PhD journey. For these reasons, van Manen’s framework was useful within the context of this research and met my needs in order to complete it. If I were to engage with similar research again, I would also adopt van Manen’s (1990) framework to explore and understand the lived experiences of the participants.

I chose to review the transcribed data using NVivo R1, a qualitative data analysis computer software package (Phillips & Lu 2018). Although van Manen warns against “the mechanical application of frequency counts or coding of selected terms of transcripts and text” (1990, p.78), I found the use of NVivo R1 beneficial. When using NVivo R1, I was very mindful of van Manen’s stance on using software packages, and was aware at all times throughout the process of the risk of over-coding. When immersing myself within the data, it was essential to maintain awareness of the philosophical underpinnings throughout the process. Additionally, I believe I have displayed that using NVivo R1 can be used within hermeneutic phenomenological research for ease of management, once the researcher is aware of the possibility of over-coding.

To sustain a “hermeneutic awareness” (van Manen 2007, p.69), the importance of reflexivity was acknowledged throughout the process of designing and implementing the research to reflect on the meanings of the experiences, rather than accepting my own pre-conceptions and interpretations at face value. The use of a reflective journal throughout

helped to create transparency in the research process (Ortlipp 2008). This reflective journal allowed me to reflect on my own experiences, feelings and thoughts and was acknowledged as part of the research design, data collection, analysis and interpretation process. The first page of my journal reflected on my uncertainty about what I should be writing. As time progressed that 'green book' has been filled from cover to cover with many thoughts and reflections. This process of writing my thoughts and reflections was cathartic, with many different emotions documented throughout those pages. I also reflected on the understanding that another researcher may take the same stories and experiences from the participants and have a different interpretation, something that can be common in hermeneutic phenomenology. I found the entire journey very insightful, but there were times during the analysis process that I wondered if I would be able to write a text that would do justice to the meaning of their experiences. In completing this research, I feel on reflection that this is something I have successfully achieved.

This research allowed a first-hand understanding of the nurses' and physicians' experiences, from three sites, of delivering care in PICUs to children with CCNs during the first 18 months of the COVID-19 pandemic. The range of time they had spent working in PICUs varied from 2.5 to 35 years, which allowed for different perspectives based on their levels of clinical experience and expertise. However, despite these varying experiences, the results were largely consistent.

This research provided evidence of the issues that arose in delivering care to children with CCNs in PICUs during the specified time frame and also provided an opportunity for the nurses and physicians to reflect on their experiences. The research has also presented a baseline for further research studies in this area, which have been outlined throughout this chapter.

7.5 Dissemination

Dissemination is a fundamental aspect of undertaking research, as there is little value in research if the findings are not shared with others (McElfish *et al.* 2019). Curtis *et al.* (2017) believe the research process is not fully complete until the findings have been disseminated and published. Dissemination is essential for the communication of findings, by sharing knowledge with professionals to inform current practice and to use the findings to develop guidelines and local policies (Nieswiadomy & Bailey 2018). Dissemination can take place in numerous ways, including publication in academic journals, oral and poster presentations at conferences, and delivery of workshops or education training sessions for healthcare professionals (Brownson *et al.* 2018).

While considering dissemination of research, the target audience is of critical importance (Ashcraft *et al.* 2020). The target audience related to this research comprises healthcare professionals and stakeholders. The results of this research will be made available to add to the existing and emerging knowledge base in this area, to encourage development of guidelines and implications that will inform future policy development for PICUs. I have a responsibility to promote the application of the research findings to nursing practice, and this is my intention as outlined in section 7.2.2., 'Implications for practice'.

I also believe there is an ethical obligation to the participants, who gave freely of their time in contributing to the research, to disseminate the findings. Some research findings have already been disseminated at a conference presentation and in peer-reviewed journal articles (see Appendix 12), with additional academic papers in progress for submission to peer-reviewed journals over the next few months.

7.6 Conclusion

This final chapter discussed the implications of this research for future research, practice, education and policy. The unique strengths and limitations of the research were outlined, in addition to dissemination strategies. It is hoped that, through this research, the lived experiences of the nurses and physicians have provided a richer and deeper understanding of the delivery of care in PICUs for children with CCNs during the first 18 months of the COVID-19 pandemic, and that this research will support and generate future research. The challenges that emerged from this research can inform policy and practice across PICUs as highlighted in this chapter, including resource allocation and decision-making for children with CCNs.

This pandemic offered a unique opportunity for nurses and physicians delivering care to children with CCNs in PICUs to reflect on their experiences of care delivery, which have been explored throughout this research. Nurses and physicians were embedded in their ways of doing things and unanimously spoke about the pandemics' lack of impact on their clinical practices. It is also possible they were coping with enormous changes affecting their personal lives as a result of public health measures and thus were not in a position to reflect fully on their experiences. As healthcare professionals begin to move forward and learn from their experiences in the earlier waves of COVID-19, PICUs should consider and implement the strategies highlighted in this research. This research has provided ways in which care delivery to children with CCNs in PICU can be improved during a global pandemic or other times of crisis including implementing the use of telemedicine and hybrid models of clinical care to enhance care delivery, maintaining good communication with the team and families, and promoting a positive environment for discussions around resource allocation.

In conclusion, this research has contributed to an objective within the wider TechChild project; to explore the formal and informal processes

internationally that influence the initiation of technology dependence from the perspective of those who make the decisions, during a specific timeframe of the COVID-19 pandemic. Ultimately, the provision of care in PICU's was not impacted, as had been previously anticipated for this cohort of children. Resource allocation and advanced care planning within PICU remain key issues. Telemedicine and hybrid models of care emerged as alternative approaches to care delivery. Key practice issues arising from this research included the changes to decision-making in PICU as a result of COVID-19 such as smaller numbers of individuals present at meetings, the use of virtual platforms instead of face-to-face meetings and barriers to communication as a result of PPE. One key concern emerging as a result of these smaller meetings was that nurses' felt their voices would be absent due to their presence being excluded. As nurses have a key role in advocating for children with CCN's and their families, this absence at meetings can hinder the building of important therapeutic relationships. As the COVID-19 pandemic continues, ongoing reflection and learning from the experiences of nurses and physicians working with children with CCNs in PICUs are essential, in order to optimise and manage resources in an ethical, efficient manner.

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Appendix 1: Scoping Review Protocol

Open access

Protocol

BMJ Open Organisation of care in paediatric intensive care units during the first 18 months of the COVID-19 pandemic: a scoping review protocol

Katie Hill ¹, Catherine McCabe,² Maria Brenner²

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ABSTRACT

Introduction The emergence of COVID-19 has had a significant impact on hospital services, particularly care delivered to those in intensive care units (ICUs) and paediatric ICUs (PICUs) across the world. Although much has been written about healthcare delivery and the healthcare setting since COVID-19 began, to the authors' knowledge, this is the first scoping review to investigate the organisation of care and changes implemented in PICUs during the COVID-19 pandemic. The aim is to conduct a scoping review of the literature to map out the existing studies about care delivery in PICUs during the COVID-19 pandemic and the changes made to the organisation of care in these units during the first 18 months of the pandemic. This review will also identify gaps in current knowledge in this area.

Methods and analysis This study will be guided by the Joanna Briggs Institute's methodology for scoping reviews, using Arksey and O'Malley's six-stage scoping review framework: (1) identifying the research question; (2) identifying relevant studies; (3) selecting the studies; (4) data charting; (5) collating, summarising and reporting results; and (6) consulting with experts. A comprehensive search will be conducted using the following databases: CINAHL Complete; MEDLINE; PsycINFO; PsycARTICLES and EMBASE. A search strategy with predefined inclusion and exclusion criteria will be used to uncover relevant research in this area. This study will include quantitative, qualitative and mixed research methods studies published in English from 2019 to May 2021.

Ethics and dissemination Ethical approval is not required for this scoping review. The results from this study will be disseminated through conferences and in peer-reviewed academic journals for those working in the healthcare arena.

INTRODUCTION

The first human cases of COVID-19 were reported from Wuhan, China in December 2019; and since then, COVID-19 has spread rapidly across the globe.¹ The outbreak was declared a Public Health Emergency of International Concern in January 2020, and a pandemic in March 2020 due to the worldwide spread of this new disease.² As a result of COVID-19, there has been a substantial

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review protocol will provide the basis for a scoping review exploring this critical area of the organisation of care in paediatric intensive care units (PICUs) during the first 18 months of the COVID-19 pandemic; to the authors' knowledge, this is the first of its kind.
- ⇒ This scoping review will conform to the rigorous Joanna Briggs Institute methodology manual.
- ⇒ Limitations of the review include: inclusion of English texts only, due to non-availability of translators for this review; and potential bias towards high-income countries, although the search of grey literature limits this risk.

impact on hospital services, particularly care delivered to those in intensive care units (ICUs) and paediatric ICUs (PICUs) across the world. Globally, children are admitted to PICUs for respiratory and or haemodynamic monitoring for a variety of reasons including post-surgery for continuous monitoring³; with exacerbation of medical conditions^{4,5}; post-severe accident or injury⁶; and children with complex conditions.^{7,8}

PICUs provide an increased level of clinical observation, invasive monitoring, specialised interventions and technical support to care for critically ill children over an indefinite period of time.⁹ PICUs care for children from birth, typically to their 18th birthday, although some children from the age of 16 years will be cared for in an adult ICU.¹⁰ A multidisciplinary team works within a PICU and comprises of professionals such as paediatric intensivists, nurses, pharmacists, physiotherapists, dietitians, speech and language therapists, occupational therapists, social workers and psychologists.¹¹

Since the beginning of the pandemic in December 2019, there have been significant adjustments in some PICUs worldwide, including transitioning into adult ICUs to

meet the increasing demands of patient needs.^{12–19} Lynn *et al*²⁰ discovered in Ireland and the UK that the COVID-19 pandemic has brought additional challenges to health-care for children ranging from delays to presenting to the emergency department for fear of contracting COVID-19 and decline in presenting for scheduled hospital appointments leading to serious health consequences for children. Similar findings have been reported in additional studies in Ireland^{21–23} and the UK,^{24–28} and across numerous other countries including Italy,^{29–32} the Netherlands,³³ Germany,³⁴ Canada,³⁵ the USA^{36–38} and Australia.³⁹

COVID-19 has impacted all aspects of healthcare delivery, including the care delivered in PICU, both for children admitted with COVID-19 and associated complications, alongside the general adjustments required for effective care delivery during a pandemic. Recent research has begun to explore the psychological impact of COVID-19 on healthcare staff working within critical care,^{40–45} the challenges faced as a result of COVID-19⁴⁶ and their experiences of working during the pandemic.^{47–50}

AIMS AND OBJECTIVES

The aim of this scoping review is to:

- ▶ Identify the existing studies and explore what is known about the organisation of care in PICUs during the first 18 months of the COVID-19 pandemic.

This review also aims to explore and summarise the evidence available and the diversity of the studies published. This review will also identify any gaps in the literature to identify areas for future research.

METHODS AND ANALYSIS

Knowledge regarding the effects of COVID-19 pandemic within the healthcare system is dynamic, with new research studies rapidly emerging. A scoping review was chosen as the most appropriate approach to collating and critiquing the current research on the transitions in the organisation of care occurring in PICUs as a result of the pandemic. The organisation of care within PICU will consider factors including resources, staffing, equipment and technology.^{51–52} As scoping reviews are useful for examining emerging evidence, this was selected as the most appropriate method for reviewing the evidence in this area.³³ This scoping review will follow Arksey and O'Malley's⁵⁴ six-stage scoping review framework: (1) identifying the research question; (2) identifying relevant studies; (3) selecting the studies; (4) data charting; (5) collating, summarising and reporting results; and (6) consulting with experts. This scoping review protocol will outline how each stage will be addressed.

Stage 1: identification of the scoping review research question

The research question and focus of the scoping review was clearly identified through an initial search using the key search terms to capture the most appropriate literature.

As recommended by Anderson *et al*⁵⁵ and Joanna Briggs Institute (JBI),^{56–57} the population, concept and context framework was applied to form the research question.

The research question for this scoping review is exploring:

How was care organised in PICUs during the first 18 months of the COVID-19 pandemic?

Stage 2: identifying relevant studies

Three researchers identified the databases for the literature search process. A comprehensive search will be conducted in the following databases: CINAHL Complete; MEDLINE; PsycINFO; PsycARTICLES and EMBASE. These sources include journals in the area of healthcare. Grey literature will be included in the data searching to ensure all relevant scientific evidence in this arena will be explored. The inclusion criteria for this review will be based on the population–concept–context framework recommended by the JBI.⁵⁶ Discussion among the three researchers regarding inclusion and exclusion criteria at the start of the review process occurred, with each researcher agreeing with the final criteria. The eligibility criteria for this study is outlined in [table 1](#).

Stage 3: selecting studies

There is debate in the literature about the need for additional researchers to undertake the initial screening of reviewing titles and abstracts from the search results.^{58–59}

The researchers have agreed that two reviewers will independently undertake all steps in the process as outlined below. Three reviewers will collaborate to create search keywords to uncover relevant research using Arksey and O'Malley's framework.⁵⁴ A brief literature search in journals of relevance will be conducted to identify any additional keywords, in addition to consultation with experts in the area and healthcare professionals working within PICU. These provisional keywords are outlined in [table 2](#).

Arksey and O'Malley⁵⁴ advocate that scoping reviews should retrieve all relevant studies of all design types, thus all design types will be included in this review. Two reviewers will independently screen the results for inclusion based on title and abstract to ensure transparency. Full-text reviews of the selected studies will be conducted based on the prespecified inclusion and exclusion criteria relevant to the research question. The reviewers will meet at each stage of the review process to debate challenges, clarify any inconsistencies and make refinements to the search.⁵⁸ If there are any discrepancies with any of the decisions, an additional reviewer who is an expert in the field will be consulted. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart will be produced after the completed searches to ensure transparency of reporting⁵⁶ and detail the search strategy and how decisions were made.⁶⁰ Rationale for exclusion of articles will be clearly documented.

**Table 1** Eligibility criteria for this study

Selection criteria	Inclusion criteria	Exclusion criteria
Population Target group characteristics	Paediatric intensive care units and healthcare staff working in this area.	Other departments within the hospital.
Concept Type of activity	Discussion around activity in paediatric intensive care units.	Discussion around activity in any other hospital setting.
Context Study location	Paediatric intensive care units both locally and internationally.	Any other healthcare setting, for example, emergency departments, children's wards or outpatient departments.
Types of articles	Studies from peer-reviewed journals including papers using qualitative, quantitative, mixed methods and case study examples; grey literature.	Non-peer-reviewed documents.
Year of publication	Articles published between December 2019 and May 2021.	Any articles published before the emergence of COVID-19, pre-December 2019.
Language	Publications written in English.	Any language aside from English.

Stage 4: data charting

Data charting will be carried out independently by two reviewers and focuses on details of the individual studies. Data extraction will occur using a checklist or data charting form influenced by the JBI Reviewer's Manual.^{56 58} The charting characteristics and associated data extraction details are outlined in table 3. This process will be flexible to integrate new characteristics of the included studies if this will improve the data analysis, for example, any additional characteristics about the participants within the studies. This stage will support the next stage of reporting results and identifying themes. As recommended by Daudt *et al.*,⁶¹ each data charting form will be given a unique code to assist with identification and discussion with the review team. These charts, which have been completed independently by two reviewers, will be compared to pilot the tool, while assessing if the results are consistent with the research question. Daudt *et al.*⁶¹ advocate this approach to improve the data charting phase to ensure the review question can be answered. Scoping review processes are iterative processes, and this systematic repetition of tasks will be completed for each study and discussed with the review team. If there are any changes made to the data charting form, these will be noted in addition to any decisions made regarding screening, as a result of meetings with the review team, reflections and actions taken.⁶²

Stage 5: collating, summarising and reporting the results

This scoping review will be reported following the PRISMA Extension for Scoping Reviews⁵³ and the guidelines outlined by JBI Reviewer's Manual for Scoping Reviews.⁵⁶ Quality appraisal and risk of bias of the included articles are not consistent within the conduct of a scoping review.⁵⁸ Subsequently, the methodological quality of each article will be outlined not appraised in detail, and the researcher will report this throughout the discussion and synthesis of findings. As scoping reviews are not aimed at producing critically appraised results to the review question, but more so provide an overview of the available evidence, methodological assessments will not be completed on the studies included in this review.⁶³ Thematic analysis will be used to analyse the findings of the studies, using qualitative descriptive methods to review the literature as advised by Levac *et al.*⁵⁸ Findings will be grouped into thematic categories and the key findings will be presented.

The general characteristics of the studies, relevant to the scoping review aim, will be identified; the data will be extracted and charted and the findings will be described and summarised.⁵⁶ The conclusions, strengths and limitations identified within this review will be documented. This review will illustrate the changes occurring within PICUs during the COVID-19 pandemic.

Table 2 Keywords for the literature search strategy

Population	Concept	Context
Paediatric/pediatric intensive care units OR PICU OR intensive care units OR ICU OR high dependency units OR HDU OR critical care unit OR critical care OR CCU OR nurses OR physicians OR healthcare staff	Organisation OR organization OR activity OR development OR changes OR adjustments OR advances OR modifications OR transitions OR transformations OR shift OR revision OR switch OR reversal	Worldwide OR global OR national OR international OR pandemic OR covid-19 OR coronavirus

Table 3 Characteristics of the studies identified

Characteristics	Aspects to be identified
Authors, year, journal, country	Who conducted the study? When was the study conducted? Where was the study conducted? Where was the paper published?
Target group	Who were the participants in the study? Who was the target audience?
Aim	What was the aim of the study?
Primary research question	What was the primary research question of the study?
Hypothesis	What was the hypothesis of the study? If appropriate,
Setting	Where was the study conducted? What was the setting and context?
Activity	What was the activity occurring in the setting during the specified time period?
Participant recruitment	How were the participants recruited?
Research methods	What types of research methods were applied in the study?
Ethical approval	Was there evidence of ethical approval? Were their specific ethical considerations identified?
Data analysis	How was the data analysed: what methods were used?
Main results	What were the main results of the study?
Limitations	What were the main limitations of the study?
Strengths	What were the main strengths of the study?
Recommendations	What were the recommendations and practical implications of the study?

Stage 6: consultation

Two of the reviewers are very experienced paediatric nurses, with one having a background in children's intensive care nursing. Consultation will be also made with relevant experts working in the PICUs at the outset of the review for selecting keywords to ensure all relevant areas are covered, for example, a paediatric nurse working in PICU during the pandemic. Networking with relevant individuals will continue to occur virtually, due to the current restrictions associated with COVID-19. As advocated by Levac *et al.*,⁵⁸ a cross-disciplinary consultation will occur in the planning of this study, selecting keywords and identification of inclusion and exclusion criteria if required. Further consultation will be sought if necessary at any stage during the review and will be explained in the review where required.

Patient and public involvement

No patient involvement will be sought for this review, but there is patient and public involvement engagement in the wider programme of research of which this review is a part of.

DISCUSSION

A scoping review protocol has been explained in relation to the current literature available.^{56–58 61} This scoping review will contribute to knowledge in this area and inform a research project in this area. The rationale for choosing a scoping review over other reviews is to map the scientific evidence in this area to inform further research as the knowledge base in this area is still being created and evaluated.

This pandemic is not unprecedented, with other pandemics occurring previously including the Spanish Influenza in 1918–1919,⁶⁴ the Asian Influenza in 1957–1958⁶⁵ and the SARS pandemic in 2002.⁶⁶ Previous research has highlighted some guidelines for the management of children with COVID-19 in PICU, although a number of these are acknowledged as weak or having insufficient evidence to make recommendations.⁶⁷ This review offers an opportunity to learn from this pandemic and provide recommendations for future global pandemics in a PICU setting. A scoping review will contribute to ensuring that future research in this area can be planned appropriately to address any gaps in the scientific knowledge.

The authors believe that the information gained through this scoping review will:

- ▶ Contribute to the knowledge in the field about adaptations and transitions occurring in PICUs during a global pandemic.
- ▶ Assist in providing recommendations and planning for the practical implications that may be required in future during another global pandemic.
- ▶ Offer an opportunity for mitigating the negative impact of COVID-19 on the health services and support change and growth in PICUs across the world.
- ▶ Contribute beneficial knowledge in the event of further waves of COVID-19, but also in the face of other inevitable, future healthcare crises through the findings and recommendations resulting from this review.

Research ethics

Ethical approval is not required for this scoping review. However, this study is part of the TechChild Project; 'Just



because we can, should we? An anthropological perspective on the initiation of technology dependence to sustain a child's life'. TechChild, funded by the European Research Council, is a programme of research exploring international influences on the initiation of technological support for children. Ethical approval was previously obtained from the relevant academic and clinical Research Ethics Committees, nationally and internationally for the TechChild Project.

Dissemination

The results from this study will be disseminated through conferences and in peer-reviewed academic journals for those working in the healthcare arena.

Contributors KH provided the original idea and drafted the first manuscript. All authors (KH, CM, MB) made revisions and contributed to the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

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Appendix 2: Study Characteristics of Included Studies

Studies (Reference)	Country	Aim	Study Design	Setting
Abulebda <i>et al.</i> 2020: National preparedness survey of pediatric intensive care units with simulation centers during the coronavirus pandemic.	U.S.	To describe the current COVID-19 (1) preparedness efforts among a set of PICUs within a simulation-based network nationwide (2) Changes in policies/procedures /guidelines (3) Training modalities and innovations including use of simulation for COVID-19 care.	A cross-sectional multi-center national survey of PICU medical director(s).	Children's hospitals in the United States.
Chomton <i>et al.</i> 2021: Transforming a paediatric ICU to an adult ICU for severe Covid-19: lessons learned.	France	To share the lessons learned when they set up an adult ICU within a paediatric hospital.	Short communication.	Adult ICU within a paediatric hospital.
Christian & Kissoon 2020: Caring for Critically Ill Adults in PICUs Is Not "Child's Play"	UK and Canada	To discuss caring for critically ill adults in PICU.	Discussion paper.	PICU.
Deep <i>et al.</i> 2020: A Hybrid Model of Pediatric and Adult Critical Care During the Coronavirus Disease 2019 Surge: The Experience of Two Tertiary Hospitals in London and New York	UK and U.S.	To explore the experiences of two tertiary hospitals providing care to adult and pediatric patients in PICU.	Retrospective cohort study.	Two PICUs in urban tertiary hospitals in London and New York.
Fernandes <i>et al.</i> (2020): Adult COVID-19 Patients Cared For in a Pediatric ICU Embedded in a Regional Biothreat Center: Disease Severity and Outcomes.	U.S.	To describe the clinical characteristics and outcomes of adult coronavirus disease 2019 (COVID-19) patients admitted to a PICU.	Retrospective cohort study.	14-bed PICU embedded in a mixed adult and pediatric hospital.

Gerall <i>et al.</i> 2020a: Allocation of resources and development of guidelines for extracorporeal membrane oxygenation (ECMO).	U.S.	To describe the changes in consultation, cannulation, and daily care of COVID-19 positive patients requiring ECMO as well as discusses strategies for ensuring safety of their ECMO healthcare personnel and optimal allocation of resources.	Discussion article.	Pediatric hospital in the epicenter of the pandemic.
Geslain <i>et al.</i> 2021: Pediatric intensive care Unit mutation to adult unit during the initial covid-19 wave: does it make sense?	France	To report on the experience of three French PICUs that converted to only adult care during the initial COVID-19 wave.	Letter to the editor.	PICU converted to caring for adults only during the pandemic.
Girona-Alarcon <i>et al.</i> 2021: The different manifestations of COVID-19 in adults and children: a cohort study in an intensive care unit.	Spain	To describe and compare the characteristics of the severe COVID-19 disease in adults and children.	Prospective observational cohort study.	ICU.
Gist <i>et al.</i> (2021): Repurposing a PICU for Adult Care in a State Mandated COVID-19 Only Hospital: Outcome Comparison to the MICU Cohort to Determine Safety and Effectiveness.	U.S.	To describe the experiences after repurposing a PICU and its staff for adult critical care within a state mandated COVID-19 hospital and compares the outcomes to adult patients admitted to the institution's MICU during the same period.	Retrospective chart review.	PICU repurposed into an adult critical care unit.
Indolfi <i>et al.</i> 2021: Impact of SARS-CoV-2 Pandemic and Strategies for Resumption of Activities During the Second Wave of the Pandemic: A Report From Eight Paediatric Hospitals From the ECHO Network	Italy, Spain, Ireland, Finland, UK, Latvia, The Netherlands and Poland	To evaluate the preparedness for the pandemic among a European network of children's hospitals and to explore the strategies to restart health care services.	Structured cross-sectional web based survey.	Eight paediatric hospitals from the ECHO Network.
Jansen <i>et al.</i> 2020: Ethical considerations for paediatrics during the COVID-19 pandemic.	Australia	To describe the unique risks and burdens for children and their care givers during the COVID-19 pandemic.	Discussion paper.	Children's hospitals.

Jenkins <i>et al.</i> 2020: Children's Hospitals Caring for Adults During a Pandemic: Pragmatic Considerations and Approaches.	U.S.	To highlight important principles that pediatric facilities and providers should prioritize if they anticipate caring for hospitalized adults during this pandemic.	Discussion paper.	Free-standing pediatric hospitals.
Joyce <i>et al.</i> 2020: Critical Care for Coronavirus Disease 2019: Perspectives From the PICU to the Medical ICU	U.S.	To describe the unique perspective of pediatric intensivists caring for critically ill adults during the coronavirus disease pandemic.	Observational study.	Academic medical center.
Kneyber <i>et al.</i> 2020: Paediatric and adult critical care medicine: joining forces against Covid-19	The Netherlands	To share experiences of paediatric and adult critical care medicine joining forces.	Letter to the editor.	PICU.
Levin <i>et al.</i> 2020: Transforming a PICU Into an Adult ICU During the Coronavirus Disease 2019 Pandemic: Meeting Multiple Needs	U.S.	To describe the conversion of half of their PICU into an adult negative-pressure COVID-19 ICU.	Letter to the editor.	PICU partly converted to adult COVID-19 ICU.
Mcnamara <i>et al.</i> 2021: Caring for adults with COVID-19 in a standalone PICU.	UK	To describe the experience, challenges and learning outcomes of a standalone PICU in managing critically unwell adults with COVID-19.	Narrative review and reflection.	PICU caring for adult patients with COVID-19.
Poncelet <i>et al.</i> 2020: Job stress in paediatric ICU staff caring for adult COVID-19 patients: An observational study during the first COVID-19 wave.	France	To investigate whether changes in care conditions increased the stress at work of PICU staff switching from paediatric patients to adult COVID-19 patients during the first wave of the pandemic in Paris.	Letter to the editor, using results from a questionnaire.	7 COVID-19 ICUs (2 PICUs and 5 adult ICUs)
Potts <i>et al.</i> 2021: Safely caring for adult patients in a pediatric hospital during the COVID-19 pandemic: A focus on the medication-use process.	U.S.	The goal of this summary was to provide a strategic approach on how pediatric hospitals can ensure safe medication practices for adult patients as well as offering tools to aid in risk assessment and mitigation planning.	Commentary.	PICU caring for adult patients.

Remy <i>et al.</i> 2020: Caring for Critically Ill Adults With Coronavirus Disease 2019 in a PICU: Recommendations by Dual Trained Intensivists.	U.S.	To prepare PICUs to manage critically ill adults with COVID respiratory failure drawing on the experience of combined adult and pediatric critical care experts.	Narrative review / report.	PICUs.
Sachdeva <i>et al.</i> 2020: The Impact of Coronavirus Disease 2019 Pandemic on U.S. and Canadian PICUs.	U.S. and Canada	This hypothesis-generating report aims to 1) summarize the reported national experience with COVID-19 in PICUs 2) highlight the geographic variations in patterns of resource use in the PICUs with the greatest number of effected admissions 3) identify hypotheses that need urgent research to better understand the pediatric implications of COVID-19.	Self-reporting survey.	PICUs.
Sinha <i>et al.</i> 2021: Caring for critically ill adults in paediatric intensive care units in England during the COVID-19 pandemic: planning, implementation and lessons for the future.	England	To describe the experience of PICUs in England that repurposed their units, equipment and staff to care for critically ill adults during the first wave of the COVID-19 pandemic.	Descriptive study.	7 PICUs.
Siva <i>et al.</i> 2021: COVID-19: trainee perspectives from unprecedented changes on PICU.	UK	To share trainee perspectives.	Reflective piece.	PICU caring for adults.
Wasserman <i>et al.</i> 2020: Rapid Transition of a PICU Space and Staff to Adult Coronavirus Disease 2019 ICU Care	U.S.	To describe the process by which a PICU and a PICU care team were incorporated into a hospital-wide ICU care model during the coronavirus disease 2019 pandemic.	Descriptive, retrospective report.	Single-center PICU.
Wolfe <i>et al.</i> 2020: Children's Hospital ICU Resource Allocation in an Adult Pandemic	U.S.	To consider children's hospital ICU resource allocation in an adult pandemic.	Discussion paper.	Children's hospital and PICU.
Yager <i>et al.</i> 2020: Repurposing a Pediatric ICU for Adults.	U.S.	To share experiences on repurposing a pediatric ICU for adults.	Notes on experiences.	PICU caring for adults.

Appendix 3: Sample Participant Information Leaflet



Participant Information Leaflet

Name of Study: Just because we can, should we? An anthropological perspective on the initiation of technology dependence to sustain a child's life (TechChild)

Principal Investigator(s) and Co-Investigator(s)	Ms Katie Hill, PhD Candidate, Trinity College Dublin,
Gatekeeper	
Data Controllers	Trinity College Dublin (for research data)
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2

You are being invited to take part in an international research study by Trinity College Dublin and led by

Before you decide whether or not you wish to take part, please read this information sheet carefully. Ask any questions. Don't feel rushed or under pressure to make a quick decision. You should understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You may wish to discuss it with others first.

This leaflet has five main parts:

- Part 1 – The Study*
- Part 2 – Data Protection*
- Part 3 – Costs, Funding and Approval*
- Part 4 – Future Research*
- Part 5 – Further Information*

Part 1 – The Study

Why is this study being done?

The purpose of this study is to explore influences on the initiation of long-term ventilation as an example of technology dependence in a PICU.

Why have I been invited to take part?

You have been asked to consider taking part in this international study given your experience in the initiation of technology dependence to sustain a child's life.

Do I have to take part? Can I withdraw?

The study is completely voluntary. You are free to withdraw at any time, without giving a reason. If you choose not to take part, it will not affect you in any way. Consent can also be withdrawn up to seven days after the completion of your interview. After this time your data will be anonymised, and we will no longer be able to identify your data. If you wish to opt out, please contact the site coordinator, @tcd.ie, who will be able to organise this for you.

What happens if I change my mind?

You can change your mind at any time during the interview by letting the interviewer know. If you choose not to continue to take part, this will not affect your work in any way. We will no longer use or share your data for research from this point onwards.

How will the study be carried out?

If you wish to take part please email the site coordinator, @tcd.ie. A member of the research team will then speak with you to confirm or arrange a suitable time to complete the interview.

What will happen to me if I decide to take part?

The interview will be audio recorded locally, with your permission, and subsequently typed out for analysis. The interview will take approximately 45 minutes and will take place remotely using an encrypted version of Zoom. During the interview you will be asked about your experience of initiating technology dependence. You will be offered an opportunity to listen back to your recording. All data will be collected according to EU General Data Protection Regulations.

What will happen to my data?

Your data will be saved on to the TCD secured research drive accessible only to the research team. The interview will be transcribed and if any identifying information is recorded it will be anonymised during the transcription process. Once transcription is complete, all audio files will be deleted. An electronic copy of your consent form will be retained for a period of 7 years in order to provide evidence of consent in accordance with Trinity College Dublin (TCD) best practice guidelines requirements.

Are there any benefits to taking part in this research?

Taking part in this study may not directly benefit you. Data gathered will assist in the development of a theory on the initiation of technology dependence.

Are there any risks to me or others if I take part?

We recognise that any topic on high intensity care has the potential to cause distress. Each member of the research team is experienced and skilled in interviewing and they will carefully guide you in discussing your experience. You may stop the interview at any point and withdraw from the study without penalty if you wish.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The results will be compiled in a report for the EU Commission who are funding this project. A summary of the report will be provided to each site via the site gatekeeper and you will have the opportunity to speak with the researchers about the overall findings of the project. The results will also be written up and published in academic theses, in appropriate peer-reviewed journals and presented at appropriate conferences. All data from the study will be destroyed as soon as we have completed this process, this includes deleting all files and on-site shredding of any project documents. There is the potential for unexpected findings in any study of this nature. If this occurs the research team will examine the significance of these findings and will report them based on policy frameworks approved by the University Ethics Committee.

Part 2 – Data Protection

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

Your electronic consent form will be stored separately from study data for a period of seven years in accordance with University Best Practice Guidelines. Interview data will be transcribed and stored in written form only, once transcriptions have been completed. Any identifying information on the audio files will be anonymised during the transcription process. Once transcribed, audio files will be deleted. Only minimal personal information regarding years of clinical experience and gender will be included in this study.

What will happen to my personal data?

- Personal data will be processed only as is necessary to achieve the objective of the research study and will not be processed in a way that damage or distress will be caused to the participant.
- The consent forms will be stored for a period of 7 years. Interview data will be anonymised during the transcription process and only these transcriptions of the interviews will be retained.
- The PI will be responsible for destroying all data from the project.
- All data will be stored on the TCD secured research drive accessible only to the research team.

Who will access and use my personal data as part of this study?

-
- The data will be saved directly on a TCD secured research folder accessible only to the research team via encrypted TCD approved laptops.

Will my personal data be kept confidential? How will my data be kept safe?

Your electronic consent form will be retained in a folder on the secured research folder. All interview information, collected from you during the course of the research, will be anonymized and kept strictly confidential. All audio data will be downloaded and stored on a secured research folder on an encrypted computer immediately after each interview and deleted from the audio device. Audio recordings saved to the research folder will be deleted once transcription has been completed. The final report of the research will not contain information about your identity so that you cannot be recognized from it. It will not be possible to identify you in the final results. If, during the interview, something is raised that leads the researcher to think a child is at risk, they will discuss this with you. They are required by law to report any concerns to the appropriate person. A Data Protection Impact Assessment was carried out and indicated a low level of risk. The research team carrying out the research are bound by a



contractual code of confidentiality. All members of the team with access to the data have completed training in data protection practice.

What is the lawful basis to use my personal data?

We will ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations. We can use your personal information for the scientific research only as specified in the consent form.

What are my rights?

You are entitled to:

- The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you (except where it is de-identified)
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format and to have it transferred to another data controller
- The right to request deletion of your data

By law you can exercise the above rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research. You can exercise these rights by contacting your study PI.] or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email:

Part 3 – Costs, Funding and Approval

Has this study been approved by a research ethics committee?

This study has been reviewed, and passed, by the Research Ethics Committee in Trinity College Dublin on 4th March, 2019 (and most recently updated 6th April, 2020;) None of the research team have a link to the committee or the institution behind the committee. Any changes to the study will be reported to the committee. Each committee will be notified when the study is completed.

Who is organising and funding this study? Will the results be used for commercial purposes?

The PI of the project is

This project is funded by the EU Commission.

The study or its results are not being generated for commercial purposes

Is there any payment for taking part? Will it cost me anything if I agree to take part?

No, we are not paying participants to take part in the study.

Part 4 – Future Research

Will my personal data be used in future studies?

Your personal information will not be used in any future studies unrelated to the current study

Part 5 – Further Information

Who should I contact for information or complaints?

If you have any concerns or questions, you can contact:

- *Principal Investigator:*
- *Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email:*

If you are not satisfied with how your data is being processed, you have the right to lodge a complaint with the Irish Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website:

Will I be contacted again?

On the consent form you will be asked if you wish to give permission for your personal contact information to be stored for the period of the project. This will only permit the researchers to contact you and invite you to discuss further key findings identified from the initial phase of the study. Consent will be sought at the time of any future research and the research will be approved by a Research Ethics Committee. Any contact information stored for this purpose will be destroyed once data collection is complete.

If you would like to take part in this study, you will be asked to submit an online Consent Form. You will be given a copy of this information leaflet and can access the consent form template by clicking the online link sent to you by email.

Appendix 4: Online Informed Consent Form

You are asked to answer each statement below if you agree.

Please ask any questions you may have when reading each of the statements.

Thank you for participating.

If you have any questions when reading the statements, or if there is something you do not understand, please contact us and we will be in touch as soon as possible.

Ms Katie Hill, TechChild PhD Candidate,



I confirm I have read and understood the Information Leaflet for the above study. The information has been fully explained to me. I have been able to ask questions, all of which have been answered to my satisfaction.

Yes

I understand that this study is entirely voluntary. If I decide that I do not want to take part, I can stop taking part in this study at any time without giving a reason

Yes

I understand that the research team will collect data which will be anonymized. I agree that this data can be used for scientific purposes without identifying me.

Yes

I understand that all data collected will be managed and processed according to European and international law and best practice.

Yes

I understand that I will not be paid for taking part in this study.

Yes

I know how to contact the research team if I need to.

Yes

I am over 18 years of age and I am competent to supply consent.

Yes

I agree to take part in this research study having been fully informed of the risks, benefits and alternatives which are set out in full in the information leaflet which I have been provided with.

Yes

I agree to being contacted by researchers by email/phone/teleconferencing as part of this research study.

I freely and voluntarily consent to be a part of this research study, though without prejudice to my legal and ethical rights.

I understand that personal information about me will be protected in accordance with the relevant General Data Protection Regulations.

I understand that there are no direct benefits to me from participating in this study. I understand that results from analysis of my personal information will not be given to me.

I give permission for my contact details to be stored until the end of the project. This will only permit the researchers to contact me in relation to the TechChild project. Consent will be sought at the time of any future TechChild-related research and the research will be approved by a Research Ethics Committee. Any contact information stored will be destroyed once data collection for this phase of the project is complete.

 Yes

Full name (For confirmation of completion purposes only)

Email address (For confirmation of completion purposes only)

By clicking the blue button at the bottom of this form I am confirming that I agree with each item above and I am willing to participate in an interview for the TechChild project.



Appendix 5: Sample Follow Up Email

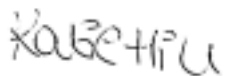
Dear (participant),

I am just checking that my last email reached you successfully.

If you are still interested in participating in our research interviews, we would love to hear from you. I realise that these are unprecedented and very busy times for healthcare professionals, so there is really no pressure to reply or participate until it is convenient for you.

Please do not hesitate to get in touch if you have any further questions about the research study.

Best wishes,

A handwritten signature in black ink that reads "Katie Hill". The signature is written in a cursive, slightly slanted style.

Katie Hill.

Appendix 6: Interview Schedule

<p>During interview</p> <p>Acknowledge distress STOP if required Discuss issues arising Direct to local supports</p>	<p style="text-align: center;"><u>Physician</u></p> <p>Tell me about your experience of initiating technology dependence to sustain a child's life (give example LTV)</p> <ul style="list-style-type: none"> - Ask to give an example of an infant/child they most recently cared for who had LTV initiated <p><u>Listen for:</u></p> <ul style="list-style-type: none"> • Impact of the ethos of the organisation on the initiation of technological support. • Perspectives on the children and families who are more likely to have long-term technological support and the reasons for this. • Engagement with bioethicist <p>At the end ask two quick questions relevant to contemporary issues as follows:</p> <ul style="list-style-type: none"> • What are your views on how COVID may influence the initiation of LTV and • View on the term technology dependence. <p>Probing and Interpreting Questions Can you elaborate on what you mean by ...? Could you give more detail on that? Do you have any examples of that? Do you mean that...?</p> <p style="text-align: center;"><u>Nurse</u></p> <p>Tell me about your experience in your role, when technology dependency is initiated to sustain a child's life (with LTV as an example).</p> <ul style="list-style-type: none"> - Ask to give an example of an infant/child they most recently cared for who had LTV initiated <p><u>Listen for:</u></p> <ul style="list-style-type: none"> ○ Impact of the ethos of the organisation on the initiation of technological support. ○ Perspectives on the children and families who are more likely to have long-term technological support and the reasons for this. ○ Engagement with bioethicist • Experience of being involved in the initiation of technology dependence for a child. • Vision for the role of the MDT in the future, at the time / around the time of the initiation of technology dependence. <p>At the end ask two quick questions relevant to contemporary issues as follows:</p> <ul style="list-style-type: none"> • What are your views on how COVID may influence the initiation of LTV and • View on the term technology dependence. <p>Probing and Interpreting Questions (as above)</p> <p>Thanks / Anything they wish to add at that point</p>
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Appendix 7: Template for Interview Notes



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



European
Research
Council



Interview Notes

Researcher name:		Participant code:	
Site:		Date	
Current post title:		Years in current post:	
Overall years' experience in the area		Age:	
Gender (no need to ask, just fill in):			

Notes / observations during Interview

Notes / observations of the interview (within 24 hours).

For example:
Context or organisational
Any feelings on how the interview went (well or found it difficult)
Thoughts on process of the interview
Body language or other non-verbal observations
Doesn't need to be an academic piece it is to capture your thoughts
Something to be noted for future interviews

Appendix 8: Probing Questions for the Interview Process

- Tell me more...
- Can you elaborate on what you mean by ...?
- Could you give more detail on that?
- Do you have any examples of that?
- Do you mean that ...?

Appendix 9: Sample Thank You Email

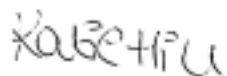
Dear (participant),

Thank you very much for taking the time to share your experiences with me on (date). It was extremely insightful and valuable for our study to have your input.

In the meantime, we would be delighted to hear from other colleagues who meet the inclusion criteria and may wish to speak with us to share their perspectives for this study.

I have attached a flyer that you could share with them, and we would be delighted to link in with any colleagues who are interested.

Many thanks and best wishes,

A handwritten signature in black ink that reads "Katie Hill". The signature is written in a cursive, slightly slanted style.

Katie Hill.

Just because we can, should we? An anthropological perspective on the initiation of technology dependence to sustain a child's life (TechChild)

Principal Investigator:

Project summary

TechChild is a five-year programme of research, funded by the European Research Council (ERC). An increasing number of children with complex care needs are dependent on clinical technology to sustain their lives. The aim of this study is to explore influences on the initiation of long-term technological support (e.g. the initiation of long-term ventilation); and to develop a theory to explain the initiation of technology dependence in the context of contrasting health, legal, and socio-political systems.

What the research will involve

This phase of the study consists of qualitative inquiry; we will conduct semi-structured interviews with clinical staff (via Zoom) who have experience of caring for children where technology dependence is initiated.

Research participants

Four international sites are included in this phase of the project, based in Australia, Ireland, Netherlands, and the United States. A local gatekeeper has been identified at each site;

If you are interested in taking part please contact [redacted] and she will arrange a time for remote interview that works with your schedule.

Participation in the project is entirely voluntary, will be confidential and all participants anonymised in the data.

Data collection and storage

The interviews will be recorded and transcribed, and securely stored, and all qualitative data will be anonymised. All data will be managed in line with GDPR regulations 2018. No patient data will be collected in this research, and no hardcopies of data will be retained. The study locations will not be identified in the write up or dissemination of the findings.

Ethical agreement

This study has been reviewed, and passed, by the Research Ethics Committee in Trinity College and approved by the Ethics Committee.

Further information.

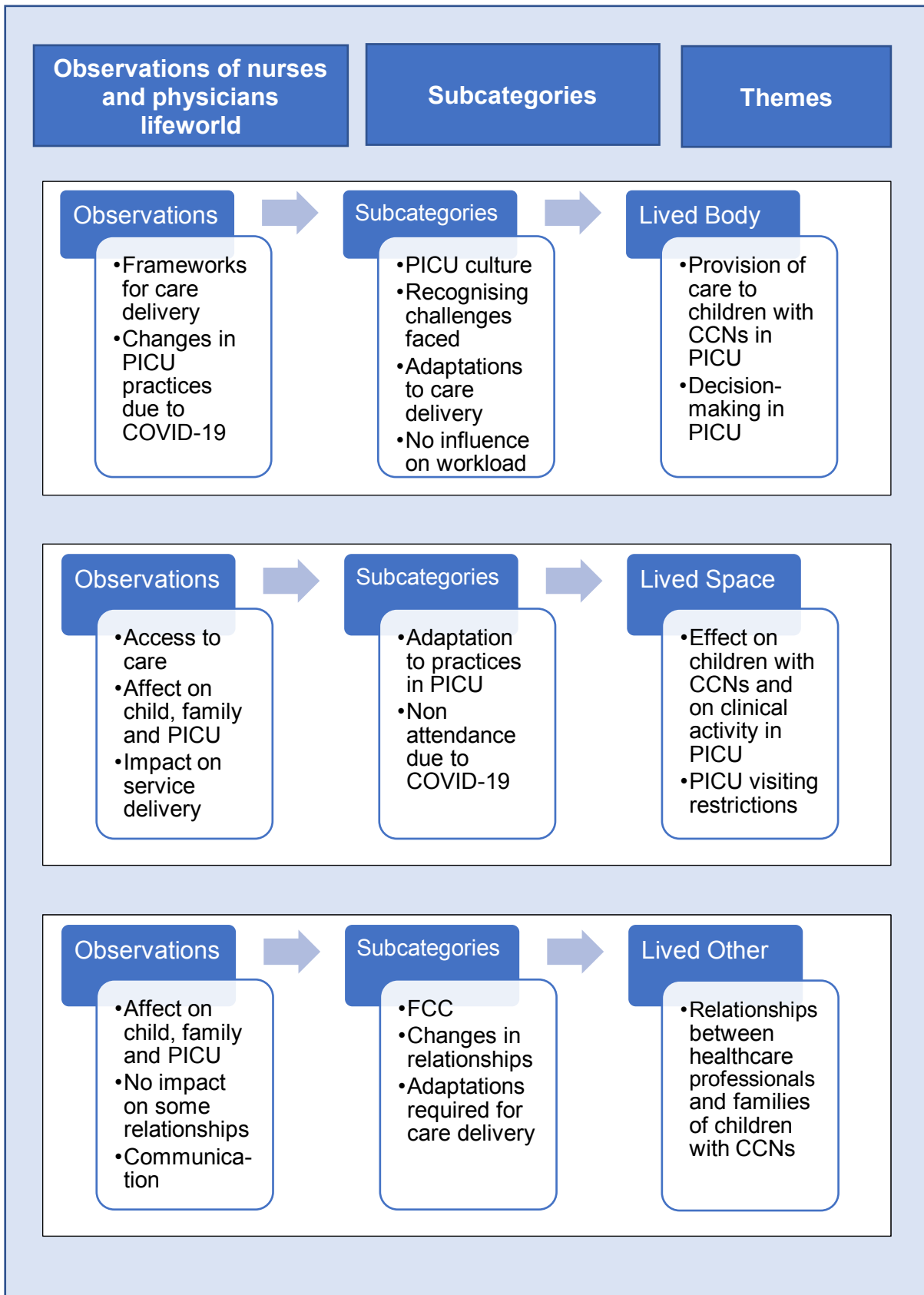
You can obtain further information from:

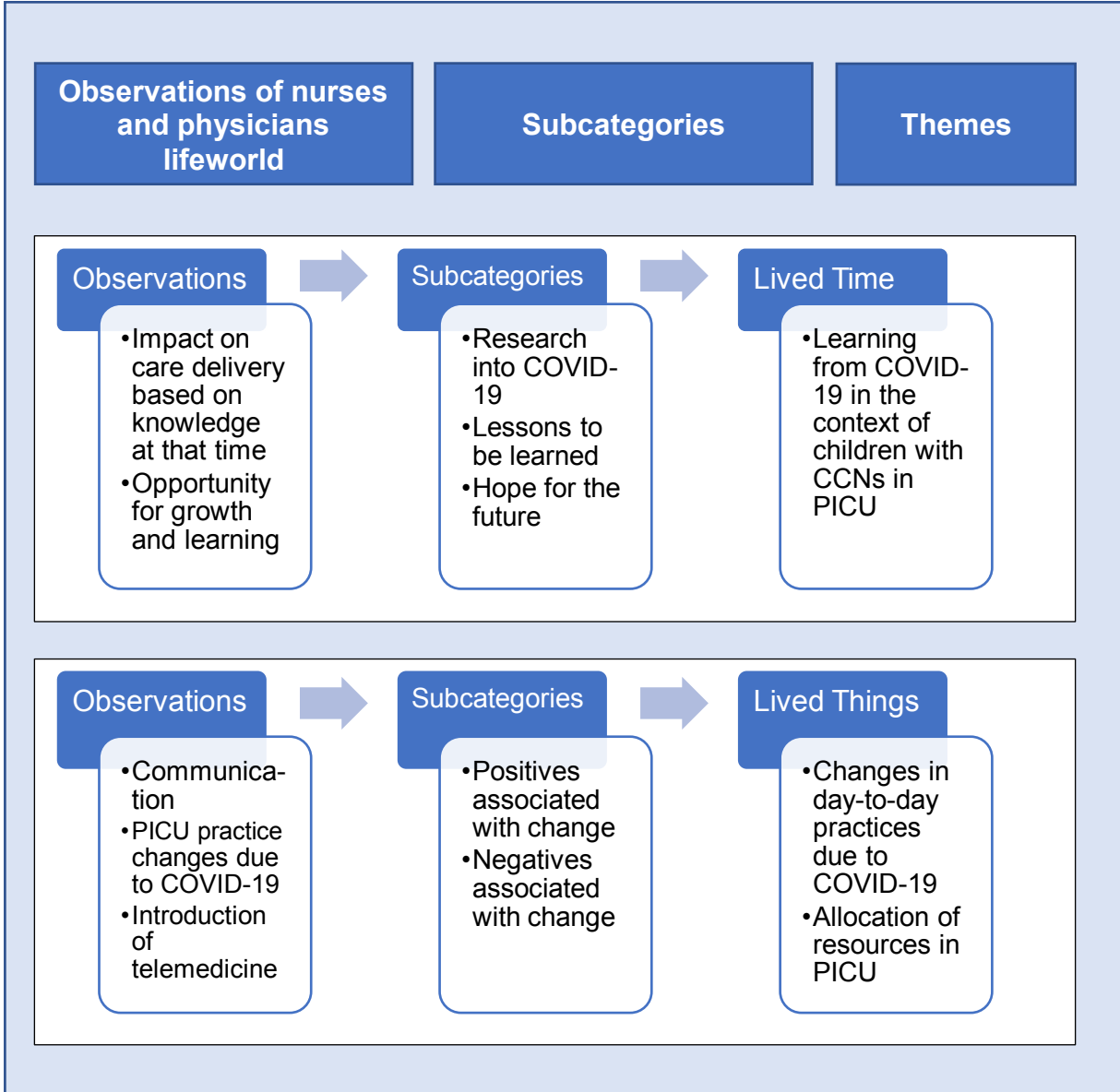
[redacted]

Appendix 10: Van Manen Stages and NVivo R1 Process

van Manen's (1990) Guidelines	Process in NVivo R1
Turning to the nature of lived experience.	In-depth interviews, transcribing, reading and re-reading transcripts and constructing the qualitative database in NVivo R1.
Investigating experience as we live it rather than as we conceptualise it.	Open coding of the transcripts and the identification of initial themes. Van Manen's (1997) selective reading approach was adopted in this stage.
Reflecting on the essential themes, which characterise the phenomenon.	Managing nodes, cases and relationships – by reorganising, renaming, and clustering related nodes into categories and identifying essential themes. Van Manen's (1997) holistic reading approach was adopted in this stage.
Describing the phenomenon through the art of writing and re-writing.	Writing summary statements to synthesise the stories within the essential themes and to create solid descriptions of the phenomenon. The use of memos in NVivo R1 and my own reflective journal were used in this phase. Writing of the findings.
Maintaining a strong and orientated relation to the phenomenon.	Writing memos throughout and revisiting the aim and objectives during the phases of data collection, data analysis and writing up the findings.
Balancing the research context by considering the parts and the whole.	Synthesising and reducing the findings into a cohesive and coherent document where only the parts relevant to the broader research context are included. This stage created a narrative that was true to the experiences and stories as told by the participants.

Appendix 11: Categories and Codes Leading to Theme Development





Appendix 12: Peer Reviewed Conference Presentations and Publications

Hill K., McCabe C. & Brenner M. (2022) Adjusting resources in PICU in the early months of the COVID-19 pandemic: a scoping review. THE CONF 2022. Trinity College Dublin. 10th March 2022. Online. *Oral presentation*.

Hill K., McCabe C. & Brenner M. (2022) The organisation of care in paediatric intensive care units during the first 18 months of the COVID-19 pandemic: a scoping review protocol. *BMJ Open* **12**, DOI: 10.1136/bmjopen-2021-054398.

Hill K., McCabe C. & Brenner M. (Under review in BMJ Open September 2022) The organisation of care in paediatric intensive care units during the first 18 months of the COVID-19 pandemic: a scoping review.