

Children's Rights to Participate in Health Care Decision-Making and the Role of
Child Life Specialists in the Netherlands: A Critical and Focused Ethnography

by

Amarens Matthiesen

M.A. (Hons), University of Dundee, Scotland, United Kingdom, 2013

M.A., University of Victoria, British Columbia, Canada, 2017

A Dissertation Submitted in Partial Fulfillment of the
Requirements for the Degree of

DOCTOR OF PHILOSOPHY

in the School of Child and Youth Care

© Amarens Matthiesen, 2022

University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy
or other means, without the permission of the author.

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

Supervisory Committee

Children's Rights to Participate in Health Care Decision-Making and the Role of
Child Life Specialists in the Netherlands: A Critical and Focused Ethnography

by

Amarens Matthiesen

M.A. (Hons), University of Dundee, Scotland, United Kingdom, 2013

M.A., University of Victoria, British Columbia, Canada 2017

Supervisory Committee

Dr. Alison Gerlach

School of Child and Youth Care, University of Victoria

Supervisor

Dr. Donna Koller

School of Child and Youth Care, University of Victoria

Departmental member

Dr. Fiona Moola

School of Early Childhood Studies, Toronto Metropolitan University

Departmental member

Abstract

Children's participation in decision-making is widely recognized as an important and beneficial legal right with moral and ethical implications. In pediatric health care settings, however, many children are not provided with adequate opportunities to express their wishes, needs, and desires regarding their care or hospital-wide decision-making. While adults (e.g., caregivers, health care providers) play a pivotal role in shaping children's opportunities for decision-making, a lack of research exists on the role of child life specialists (CLSs) in shaping children's participation rights. CLSs are psychosocial health care providers who are charged with garnering the trust of children and families and soliciting children's views in health care contexts. Therefore, child life practice represents an ideal profession in which to explore children's participation rights.

Through a theoretical lens rooted in critical sociology- and nursing-based scholarship, the purpose of this study was to explore the role of CLSs in shaping children's participation rights in the context of two children's hospital in the Netherlands. Semi-structured interviews were conducted with CLSs (n=12) and hospital directors (n=5) and pertinent legal, institutional, and professional documentation (e.g., policies, hospital booklets) were analyzed. Thematic analysis of the data revealed that children's participation in decision-making was characterized as a complex and relational process that was shaped by various inter- and intra-personal and contextual complexities. Findings demonstrated that participants associated value and importance to children's participation in decision-making processes. However, children's participation processes were predominantly conceptualized as adult-dominated and shaped by developmental discourses on children's age-based decision-making abilities.

The study findings underscore the potential for embedding relational and inherently critical understandings of children's participation rights in pediatric health care practices (e.g., child life, nursing), education, and policy development. The knowledge generated by this study can contribute to efforts in bridging a gap between an idealized rhetoric of children's participation rights and their implementation in complex health care contexts.

Table of Contents

Supervisory Committee	ii
Abstract.....	iii
Table of Contents	iv
List of Figures.....	x
List of Tables	xi
List of Abbreviations	xii
Acknowledgements	xiii
Dedication	xiv
CHAPTER ONE: INTRODUCTION.....	1
1.1 Study Background	1
1.2 Theoretical Framework.....	2
1.3 The Research Problem	3
1.4 Research Questions.....	5
1.5 Research Outcomes.....	6
1.6 Overview of Dissertation Structure.....	7
CHAPTER TWO: LITERATURE REVIEW	9
2.1 Chapter Overview.....	9
2.2 Conceptualizations of Children’s Participation	10
2.2.1 Understanding ‘Agency’ and ‘Autonomy’ in Children’s Participation	11
2.2.2 Rights-Based Understandings of Children’s Participation	13
2.2.3 Children’s Individual and Collective Decision-Making in Health Care.....	16
2.2.4 Dominant Theoretical Approaches Towards Understanding Children’s Participation .	20
2.3 Personal Factors Influencing Children’s Participation.....	29
2.3.1 The Role of Adults in Children’s Decision-Making.....	29

2.3.2	Children’s Health Status	34
2.4	Organizational Factors in Health Care Contexts Influencing Children’s Participation	36
2.4.1	Health Care Policies, Guidelines, and Initiatives on Children’s Participation	36
2.4.2	Time Constraints	44
2.4.3	Fostering a ‘Culture of Participation’	45
2.5	Children’s Experiences of Participating in Decision-Making	46
2.5.1	Individual Decision-Making	46
2.5.2	Collective Decision-Making	48
2.5.3	A Gap Between Child Participation Practices and Policies	50
2.6	Child Life Practice	51
2.6.1	The Historical Development of Child Life Practice	52
2.6.2	Child Life Practice in North America and the Netherlands	53
2.6.3	Developmentalism in Child Life Practice	55
2.6.4	Connecting Child Life Practice to Children’s Participation	56
2.7	Chapter Summary	58
CHAPTER THREE: SITUATING CHILDREN’S PARTICIPATION IN THE CONTEXT OF THE NETHERLANDS		60
3.1	Chapter Overview	60
3.2	Socio-Demographic and Economic Overview of the Netherlands.....	60
3.2.1	The Dutch Health Care System.....	62
3.3	The Development of a Child Participation Agenda in the Legislative Context of the Netherlands.....	62
3.3.1	Children’s Participation in Dutch Health Care Contexts	66
3.4	Chapter Summary	71
CHAPTER FOUR: THEORETICAL FRAMEWORK.....		72
4.1	Positionality Statement.....	72
4.1.1	Ontology and Epistemology	75

4.2	The Sociology of Childhood: Children as Social Actors.....	76
4.2.1	The Historical Development of the Sociology of Childhood	77
4.2.2	Childhood as Socially Constructed.....	80
4.3	Engaging with Key Critiques in the Sociology of Childhood.....	81
4.3.1	Relationality in Sociological Scholarship	83
4.3.2	Relationality in Sociological Scholarship on Children: Relational Autonomy and Interdependent Agency	85
4.3.3	Relational Inquiry	87
4.3.4	Relations of Power	89
4.4	Conclusion	91
CHAPTER FIVE: METHODOLOGY		92
5.1	Introduction.....	92
5.2	Research Timeline and a Note on COVID-19	92
5.3	Research Design: Critical and Focused Ethnography.....	94
5.3.1	Epistemological Commitments	96
5.3.2	Focused Ethnography.....	97
5.3.3	Critical Ethnography	98
5.4	Research Settings	99
5.4.1	Negotiating Access and Ethical Approval	100
5.5	Sampling Strategy.....	103
5.5.1	Inclusion Criteria	105
5.6	Participant Recruitment.....	105
5.6.1	Recruitment of CLSs.....	106
5.6.2	Recruitment of Directors.....	107
5.6.3	Informed Consent.....	108
5.6.4	Overview of Participants.....	108
5.7	Data Collection Methods and Procedures	109
5.7.1	Semi-structured Interviews	109

5.7.2	Document Analysis.....	115
5.8	Data Analysis.....	116
5.8.1	Familiarization With the Data.....	118
5.8.2	Generating Initial Codes	119
5.8.3	Searching for and Reviewing Themes	120
5.8.4	Defining and Naming Themes	121
5.8.5	Producing the Report	121
5.8.6	A Note on Translation.....	122
5.9	Trustworthiness.....	122
5.9.1	Credibility	123
5.9.2	Dependability and Confirmability	125
5.9.3	Transferability.....	125
5.9.4	Reflexivity.....	126
5.10	Ethical Considerations.....	129
5.10.1	Informed Consent and Voluntary Participation	130
5.10.3	Anonymity, Confidentiality and Data Management.....	130
5.10.3	Beneficence.....	131
5.10.4	Knowledge Mobilization	132
5.11	Study Limitations.....	133
5.12	Chapter Summary	134
CHAPTER SIX: FINDINGS	135
6.1	Chapter Overview.....	135
6.1.1	Overview of Chapter Themes and Subthemes.....	136
6.2	Inter- and Intrapersonal Complexities of Children’s Participation	138
6.2.1	“Making Decisions About Children Without Children”: The Adult-Centric Nature of Shared Decision-Making	138
6.2.2	“Listening to the Voice of the Child”: Contrasting Conceptions of Children’s Autonomy	142

6.2.3	“It’s Very Much Tied to the Development and Age of a Child”: Developmentalist Understandings of Children’s Participation	148
6.2.4	“I Can’t Do it Alone”: Tensions in Adopting a Collaborative Approach Towards Children’s Participation	152
6.3	Contextual Complexities of Children’s Participation	155
6.3.1	“Sometimes it Doesn’t Work”: Complicating Children’s Participation in (Time-Restricted) Acute- and Palliative Care Settings	155
6.3.2	“They Don’t Show us How to do it”: The ‘Problems’ with Policies and Legal Guidelines	160
6.3.3	“Dutch Society Values Children’s Participation”: Contrasting Conceptions of Children’s Autonomy in the Socio-Cultural Context of the Netherlands	163
6.3.4	“It’s a Child-Friendly Environment”: The Design of Hospital Spaces in Facilitating Children’s Participation	166
6.4	Chapter Summary	168
CHAPTER SEVEN: DISCUSSION		169
7.1	Bridging the Gap Between the Rhetoric and Relational Reality of Children’s Rights to Participate in Decision-Making	169
7.1.1	Fostering a Relational View of Children’s Participation Rights	171
7.1.2	Confronting Practice and Knowledge Hierarchies in Health Care Institutions	174
7.1.3	Attending to the Role of Hospital Policies and Legal Guidelines in Realizing Children’s Participation Rights.....	176
7.2	Advancing Relational Theoretical Scholarship on Children’s Participation	178
7.2.1	Building on Non-Hierarchical Models of Children’s Participation: Lundy’s (2007) Rights-Based Model.....	179
7.2.2	Advancing the ‘Relational Turn’ in the Sociology of Childhood.....	186
7.2.3	Promoting Alternative ‘Ways of Knowing’ in Child Life Practices and Educational Curricula	188
7.3	Key Recommendations for Policies, Practices and Education.....	189
7.3.1	Recommendations for Pediatric Health Care Policy Development	189
7.3.2	Recommendations for Pediatric Health Care Practices	191

7.3.3 Recommendations for Child Life Educational Curricula	192
7.5 Future Research	193
7.4 Conclusion	194
References	197
Appendices.....	243
Appendix A: Research Ethics Board Certificate(s) of Approval.....	243
Appendix B: Recruitment Poster (English and Dutch)	245
Appendix C: Consent Form (English).....	247
Appendix D: Consent Form (Dutch).....	251
Appendix E: Participant Socio-demographic Information.....	255
Appendix F: Interview Guide (CLSs)	257
Appendix G: Interview Guide (Directors).....	265
Appendix H: Overview of Documents Included for Analysis	268
Appendix I: ‘Mind map’ Depicting Main Themes and Sub-themes	270
Appendix J: Children’s Storybook: “Charlie Makes Choices”	271

List of Figures

Figure 1: Multifaceted Factors Influencing Children’s Participation.....	10
Figure 2: Visual Overview of Interrelatedness Between the Concepts of Autonomy, Agency, and Participation.....	13
Figure 3: Hart’s (1992) ‘Ladder of Participation’ Model.....	21
Figure 4: Mannion’s (2003) ‘Fountain’ of Child Participation Model.....	24
Figure 5: Lambert’s (2008) Continuum of ‘Visible-ness’	25
Figure 6: Lundy’s (2007) Model of Children’s Participation.....	27
Figure 7: Timeline of Research Project.....	93
Figure 8: Interior of Hospital Unit – Artwork on Walls.....	102
Figure 9: Interior of Hospital Unit – Hallway with Floor Wayfinding Markers.....	102
Figure 10: Interior Hospital Unit Depicting Child Playing on Play Structures.....	103
Figure 11: Overview of Participant Sample.....	104
Figure 12: Visual Overview of Questions Used During Semi-Structured Interviews.....	111
Figure 13: Visual Overview of Themes and Sub-Themes of Study Findings.....	137
Figure 14: Poster Depicted in the Hospital Titled: “Three Good Questions”.....	144
Figure 15: Page Entry of Storybook Written for Children Titled; “Emma Goes to Hospital”.....	145
Figure 16: Front Cover of the ‘Hospital Passport’	146
Figure 17: The Content of the ‘Hospital Passport’	146
Figure 18: The Application of Interrelated Factors in Shaping Children’s Participation Rights in Health Care to Lundy's (2007) Model of Participation.....	181
Figure 19: ‘Everyday Spaces’ Checklist for Service Providers.....	183
Figure 20: Planning Checklist for Decision-Makers.....	184
Figure 21: Evaluation Checklist for Decision-Makers.....	185

List of Tables

Table 1: Overview of Professional Titles of Hospital ‘Directors’	104
--	-----

List of Abbreviations

ACLP	Association of Child Life Professionals
CBS	Centraal Bureau voor Statistiek (Dutch Central Office of Statistics)
CCLS	Certified child life specialist
CLS	Child life specialist
EACH	European Association for Children in Hospital
EHCI	Euro Health Consumer Index
EU	European Union
FCC	Family-centered care
SDM	Shared decision-making
UDHR	Universal Declaration of Human Rights
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

Acknowledgements

This doctoral dissertation has been a collaborative enterprise in which it has been a privilege to learn and receive support from those who have formed part of this journey. I express my sincerest gratitude to my supervisor, Dr. Alison Gerlach, whose expertise and encouragement have been invaluable in completing this research. Thank you, Alison, for investing copious hours in my research and helping me grow as a researcher by furthering my critical thinking, analytical, and writing skills. Your guidance has provided me with an instrumental avenue to attend to the inherent complexities, tensions, and contradictions of children's lives.

I also extend my sincere gratitude to my committee members, Dr. Donna Koller and Dr. Fiona Moola for their respective expertise, insights and time invested in this research. Donna, thank you for helping me to instill a critical approach to the theoretical foundations and principles of child life practice. Fiona, I have sincerely appreciated how your expertise and intersectional approach to the social dimensions of childhood illnesses and disabilities has allowed me to deepen my thinking on children's complex participation rights. I also convey my warmest thank you to Dr. Lucy Bray for sharing your professional area of expertise and for posing thought-provoking questions that allowed me to further refine my thinking on this topic and the practical research implications.

My gratitude also goes to other faculty members of the School of Child and Youth Care; Dr. Doug Magnuson and Dr. Marie Hoskins for their support during the initial stages of the program. I am also grateful for the mentorship I have received from Dr. Roy Ferguson during my early graduate school days. Your positive words of encouragement have left a lasting impact on me.

I am also especially grateful to all who participated in this study. Thank you for your willingness to speak freely about your personal insights and for finding the time (and space) to do so during a global pandemic. Your contributions were essential to this research.

To my former colleagues in pediatric health care, thank you for engaging in discussions with me about children's involvements in making decisions. Your valuable insights on your first-hand experiences in caring for children and families aided me in shaping the research topic of this dissertation.

Lastly, this research could not have been made possible without the unwavering support and encouragement of my family – Heit, Mem and Tina.

Dedication

“Even if people are still very young, they shouldn’t be prevented from saying what they think.”

Anne Frank

This dissertation is dedicated to all the children and families whom I have had the privilege to care for in hospitals during challenging periods of their lives. My inspiration for this work stems from the children who felt safe and brave enough to tell me about their wishes and worries in their own forms of expression.

In particular, I dedicate this research to “Lily”, whose early life has been shaped by the systemic inequalities and injustices that continue to exist within and beyond health care systems. Thank you, Lilly, for teaching me about the importance (and challenges) of truly listening to and acting on the ideas, opinions and wishes of children, especially for those who may be ‘falling through the cracks’.

CHAPTER ONE: INTRODUCTION

1.1 Study Background

My initial personal rationale for conducting this study is based on my professional experiences of working as a child life specialist (CLS¹) in children's hospitals across Canada in a range of hospital departments. These experiences allowed me to witness first-hand how children who were hospitalized were not sufficiently involved in participating in decision-making in varying ways, for example, in decisions regarding children's everyday care (e.g., choice of meals, clothing, activities) and decisions related to their medical treatment (e.g., medications, procedures, plan of care). I also observed that providing psychosocial support to children who wished to be included in decision-making processes could increase children's psychosocial wellbeing. Reinforced by the learning gained from graduate-level academic courses in child and youth care, I identified a gap between the recommendations set out by the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989) regarding children's rights to participation and what was occurring in health care practices.

Additional professional and personal experiences in working with and for children in Belgium, Scotland, and the Netherlands led me to identify socio-cultural nuances in the way in which children, childhood, and children's participation can be perceived and conceptualized in varying cultural contexts. Particularly my experiences as a dual Dutch/Canadian citizen in the Netherlands allowed me to witness how adults emphasized children's autonomous decision-making capacities in a variety of everyday settings, including family life and school. For example, from an

¹ I use the term 'child life specialists' to refer to pediatric health care professionals who use therapeutic play, education and advocacy as tools to help children and families cope with hospitalization, illness and/or grief in hospital and community settings. In the Netherlands, CLSs are primarily referred to as 'medical pedagogical care provider' [medisch pedagogisch zorgverlener].

early age, I noticed how many children are provided with an ‘equal’ seat at the dining table, in which children’s views are explicitly sought in conversations. Such examples can reflect and reinforce the collective socio-cultural importance attributed to children’s rights in the Netherlands, as a country that ranks highly on numerous scales measuring children’s well-being. My experiences in the Netherlands informed my belief that children are capable and autonomous decision-makers, standing in direct opposition with what I was witnessing in pediatric health care in Canada.

Collectively, my professional, academic, and personal experiences shaped several key assumptions that I brought to this study. These assumptions influenced how I approached the study topic, data collection, and analysis. My assumptions were:

- a) Children who have been hospitalized should be involved in decision-making according to their varying abilities, social situation, needs and wishes,
- b) CLSs are ideally positioned to support children’s own involvement and participation in their care,
- c) Socio-demographic factors such as socio-economic status, race, ethnicity, and language can affect children’s opportunities for participation in decision-making,
- d) Professional and organizational practices, guidelines and frameworks can shape the way in which children can be provided with opportunities to participate.

1.2 Theoretical Framework

Different theoretical currents or areas of scholarship construct particular conceptualizations of children, childhood, and children’s participation (Alderson, 2014; Brady, 2017). As discussed in more detail in Chapter Four, the theoretical framework of this study is grounded in the sociology of childhood as a critical field of scholarship that constructs children as agentic agents with decision-making rights (Mayeza, 2017; Prout, 2011; Prout & James, 1997). The field’s focus on social constructionism also supports an understanding of childhood as a social and symbolic space in

which dominant cultural narratives can shape understandings of children and childhood (Wyness, 2015). Building on social constructionist perspectives of children and childhood, I also draw on the ‘relational turn’ in the sociology of childhood to inform a relational ontology and epistemology on the nature of reality and knowledge, respectively.

My alignment with relational scholarship allowed me to build on (critiqued) social constructionist understandings of children and childhood to engage with more critical theorizing on the interdependent role of context (i.e., institutions and adults) in shaping children’s agency and decision-making (Abebe, 2019; Alanen, 2011; Alanen & Mayall, 2002; Mayall, 2001; Hammersley, 2016; Oswell, 2013; Prout, 2000; Qvortrup, 2005; Spyrou, 2018; Valentine, 2011; Wyness, 2006). An alignment with relational scholarship also allowed me to include CLSs and the institutional context in shaping children’s participation and consider how complex relations of power operate across health care systems and broader socio-economic, legal and political contexts to shape children’s participation in decision-making.

1.3 The Research Problem

The UNCRC spurred a global interest in children’s² right to participation in all matters affecting them (King, 2004; United Nations, 1989). The past 30 years have been characterized by advocating to promote and legitimate the concept of participation and explore strategies for translating children’s participation into institutional and national practices (Percy-Smith & Thomas, 2009). Children’s right to participation in decision-making has become an increasingly prominent concept in international legislation and public policies across various domains, such as education (Smith, 2007; Stamatovic & Zunic Cicvaric, 2019), domestic family life (Brown & Johnson, 2008;

² Any single definition of ‘children’ does not do justice to the dynamic, complex and multifaceted nature of childhood (James & Prout, 2003). For practical reasons of consistency, coherency and commonality, this study will refer to the term ‘child’ as including any person below 18 years of age (United Nations, 1989).

Pecnik et al., 2016), child protection (Bijleveld et al., 2015; Duncan, 2019; Jolles & Wells, 2017; Serbati, 2017; Vis et al., 2011), participatory research (Bradbury-Jones et al., 2018; Mayne & Howitt, 2019; Water et al., 2017), and health care (Bjønness et al., 2020; Coyne, 2008; Coyne et al., 2014; Koller, 2017; Schalkers et al., 2016; Vis et al., 2011; Water et al., 2017).

In the context of pediatric health care, a relatively limited yet growing body of research conducted in diverse settings such as palliative care (Hinds et al., 2001), oncology (Coyne et al., 2014; Joffe et al., 2006; Zwaanswijk et al., 2011), and outpatient care (Quaye et al., 2019) report that children often prefer to be active participants in their health care, or at least have the choice to participate. Children's involvement in decision-making can help enable children to develop a sense of confidence, mastery, and control, enhance communication skills and increase children's general wellbeing (Bijleveld et al., 2015; Coyne et al., 2014; Runeson et al., 2002; Vis et al., 2011).

However, despite the legal recognition and benefits associated with children's right to participation, studies also report that legislation is not always translated into health care practices (Jeremic et al., 2016). Primarily in Minority World contexts³, children have expressed a desire for increased opportunities to participate in health care decision-making (Coyne et al., 2014; Jeremic et al., 2016; Lambert et al., 2008; Sjöberg et al., 2015). The diverging opinions, attitudes and beliefs on children's decision-making held by children, their caregiver(s) and health care providers can complicate children's opportunities for making 'shared' decisions (Coyne, 2008; Jeremic et al., 2016; Runeson et al., 2002; Siew Pien, 2018; Tisdall, 2017). In 'shared' decision-making triads, caregivers and health care providers have expressed uncertainty about children's abilities to participate (Aarthun et al., 2019; Aarthun & Akerjordet, 2014; Hinds et al., 2001; Young et al., 2006) and the 'burdens' associated with children's decision-making (Coyne et al., 2014). While

³ The term 'Majority world' is refers to the populations who live in Africa, Asia and Latin America. The term 'Minority world' refers to populations who live in Europe, North America and Australia (Punch, 2003).

some children may prefer adults to make decisions on their behalf (Coyne et al., 2014), children can also feel neglected in decision-making processes (Coyne & Kirwan, 2012; Pena & Rojas, 2013) due to adults responding on children's behalf (Butz et al., 2007). Children's lack of involvement can lead children to feel increased fears and anxiety, feeling unprepared for procedures and reduced self-esteem (Coyne, 2006; Dorscheidt & Doek, 2018).

Children's participation in decision-making remains an area that is characterized by conflicting opinions and uncertainty regarding the degree to which children should be involved in decision-making (Coyne et al., 2014; Joffe et al., 2006). Drawing on the perspectives of CLSs and hospital directors, this study employs a critical perspective on children's participation to contribute to new knowledge on the various interrelated factors that can shape and complicate children's participation in decision-making in pediatric health care contexts in the Netherlands.

1.4 Research Questions

This study aimed to answer the following research questions:

- a) How do CLSs experience children's participation in decision-making?
- b) Which types of professional and institutional supports and barriers can enable or constrain children's opportunities for participating in decision-making?
- c) How can contextual dimensions specific to health care institutions and/or socio-cultural, legislative, and economic landscapes shape children's participation in decision-making?
- d) How could the study findings inform the development of professional practices, guidelines, policies, and educational curricula regarding children's participation in decision-making in the field of child life, as well as in wider pediatric healthcare

professions (e.g., social work, physical therapy, occupational therapy, recreational therapists)?

To the best of my knowledge, no previous studies have explored the perspectives of CLSs in children's participation in decision-making. Previous studies have primarily focused on the role of other health care providers such as physicians (Coyne et al., 2014; Ehrich et al., 2015; Gabe et al., 2004; Jeremic et al., 2016; Kahveci et al., 2014; Shay & Lafata, 2014; Tates & Meeuwesen, 2001), nurses (Coyne et al., 2014; Hemingway & Redsell, 2011; Kahveci et al., 2014; Quaye et al., 2019), physical therapists (Young et al., 2016), psychologists (Runeson et al., 2011), and social workers (Gabe et al., 2004; Hultman et al., 2019; Vis et al., 2012). As discussed in more detail in Chapter Two, CLSs are ideally situated to promote children's participation in decision-making because (a) children's feelings of fear, anxiety and uncertainty can inhibit children's ability or willingness to participate (Gilljam et al., 2016), and (b) child-focused interventions that attend to children's self-advocacy may serve to improve children's participation in decision-making (Shay & Lafata, 2014).

1.5 Research Outcomes

I anticipate that the knowledge generated from this study will contribute to increased understandings of: (a) how children's participation is conceptualized in pediatric health care practices, (b) the extent to which children's participation in decision-making is embedded and reflected in clinical health care practices and wider institutional initiatives and policies, and (c) the facilitators and barriers that can constrain or enable children's involvements in decision-making. This knowledge can inform pediatric health care practices by generating new insights on the role that health care providers can play in children's decision-making processes and how hospital-wide initiatives and policies can shape children's opportunities for decision-making. In turn, this knowledge may also benefit children and families in health care contexts in the Netherlands and

internationally by promoting increased understandings of the various factors that may shape children's opportunities for engaging in meaningful decision-making alongside adults.

Through key knowledge mobilization strategies, I also anticipate that the knowledge gained from this study can contribute to critical reconsiderations of the normative and standardized developmental theoretical foundations on which the child life field is built, in the Netherlands and internationally. As described in more detail in Chapter Two, the developmental theories that inform and sustain child life practices and educational curricula can promote exclusion in children's participatory processes by perpetuating universalized beliefs about children's decision-making capacities. Rooted in alternative, more critical theoretical approaches to understanding children and childhood, it is anticipated that this study will provide more contextualized and nuanced understandings of children's participation in the context of the Netherlands.

As explained in more detail in Chapter Five, this research took place during a global pandemic which inhibited the possibility to include the perspectives of children and/or their caregivers. The knowledge generated from this study may therefore also act as a starting point for additional research that explores the experiences of children and families in children's decision-making processes in health care contexts. These research outcomes are significant because there is a paucity of research on the perspectives of CLSs on children's participation rights, and children's participation remains characterized by uncertainty and complexity in the delivery of health care practices and implementation of health care policies.

1.6 Overview of Dissertation Structure

In this dissertation, I outline my research in seven successive chapters. **Chapter One** introduces the research background, theoretical framework, research problem and questions. **Chapter Two** provides an overview of the key literature that informs this topic, including dominant narratives, models, and approaches towards understanding children's participation and children's

experiences of decision-making. In this chapter, I also introduce child life practice and its connection to children's participation. **Chapter Three** builds on Chapter Two by providing a more contextualized discussion of children's participation in the Netherlands. I offer a brief socio-demographic and economic overview of the Netherlands, discuss pertinent local policies, legislation and guidelines on children's decision-making and children's experiences of participating in decision-making in Dutch health care contexts. In **Chapter Four**, I discuss the theoretical perspectives, concepts, and currents that shaped the theoretical framework for this research. This includes a discussion of my positionality and my alignment with a relational epistemology in the sociology of childhood to inform my understandings of children, childhood, and children's participation. **Chapter Five** describes the focused and critical ethnographic study methodology, including the methods used to collect data, as well as how this methodology is congruent with the research aims, and my epistemological and theoretical assumptions. In **Chapter Six**, I discuss the findings of the research, followed by my discussion of the key implications of these findings in **Chapter Seven**. In this final chapter, I also provide concluding comments to close this dissertation.

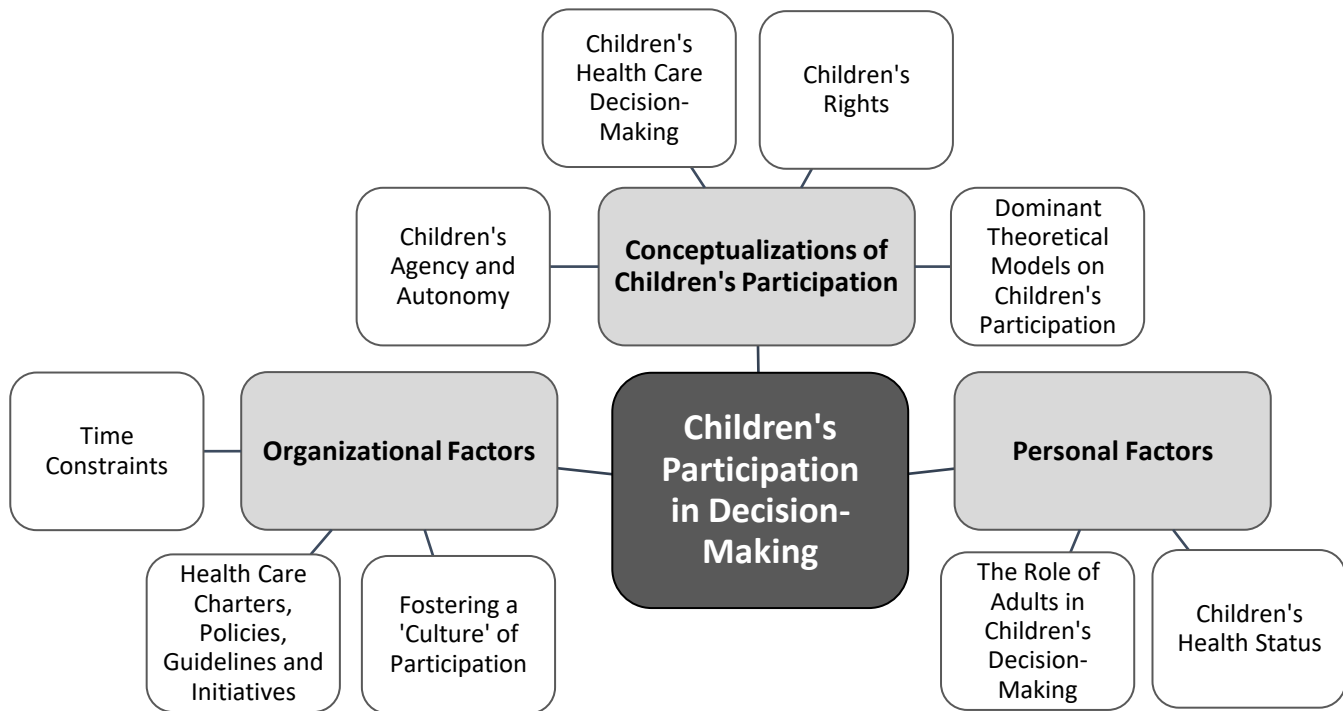
CHAPTER TWO: LITERATURE REVIEW

2.1 Chapter Overview

In this chapter, I discuss pertinent literature spanning the domains of sociology, psychology, nursing, medicine, ethics, and law to shed light on what is known about children's participation in decision-making in the context of pediatric health care. Extant literature characterized children's participation as being shaped by various multifaceted factors. As illustrated in Figure One, this chapter has been organized to discuss three overarching factors in influencing children's participation, namely: 1) varying ways of conceptualizing children's participation (including rights-based understandings and dominant theoretical models of children's participation), 2) personal factors (including the role of adults and a child's health status), and 3) organizational factors (including policies, time constraints and organizational child participation 'cultures'). These factors introduce children's participation from a broader, non-health care specific perspective (e.g., in my discussions on dominant theoretical models of children's participation) as well as a health-care specific perspective to offer insights into how children's participation has been linked to health care practices and policies. I also approach this chapter from a critical perspective by engaging with tensions, challenges, and critiques in the literature to align with the critical nature of the study methodology and the theoretical perspectives that inform this research.

I begin this chapter with a discussion of various dominant conceptualizations of children's participation, followed by how various personal and organizational factors can influence children's participation in decision-making. I end this chapter with a discussion of children's experiences of participating in health care decision-making and how children's participation can be linked to child life practice.

Figure 1: Multifaceted Factors Influencing Children’s Participation



2.2 Conceptualizations of Children’s Participation

Over the past 30 years, a rich uptake in activity under the ‘buzzword’ (Cornwall, 2008) of children’s ‘participation’ has occurred within academic, practice and policy spheres across the global North and South (Johnson & West, 2018; Percy-Smith & Thomas, 2010a; Toros, 2021). Scholars across interdisciplinary⁴ fields of study have referred to children’s participation in decision-making as involving children expressing their views in matters affecting them and for children’s views to be acted upon as appropriate (Kennan et al., 2018). However, ‘children’s participation’ remains a multi-layered and sometimes contested ‘concept’ (Lansdown, 2006),

⁴ Advocates of participation have come from many subject backgrounds, including sociology, child development, geography, community development, as well as cultural, social and environmental psychology (Davis & Smith, 2012).

‘praxis’⁵ (Cornwall, 2008) or (continuous) ‘process’ (Guerreiro & Fløtten, 2017; Littlechild, 2000; Percy-Smith & Thomas, 2010b) that has been applied to a broad range of practices across various theoretical and conceptual domains (Brady, 2020; Kennan et al., 2018). For example, children’s participation can be shaped by the varying social, economic, and political situations in which children and their participation are situated⁶ (Percy-Smith & Thomas, 2010).

To shed further light on the varying ways in which children’s participation has been conceptualized, in this section, I focus on; 1) how the interrelated concepts of agency and autonomy can be linked to participation, 2) rights-based understandings of children’s participation, 3) children’s individual and collective decision-making in health care contexts, and 4) four dominant theoretical models of children’s participation.

2.2.1 Understanding ‘Agency’ and ‘Autonomy’ in Children’s Participation

Arguments for children’s increased participation in decision-making are often discussed in relation to the concepts of agency and autonomy (Valentine, 2011). Particularly Western cultures’ emphasis on autonomy has led to “an international trend in law and policy toward recognizing the role of children in health care decision-making” (Salbatello et al., 2018, p. 1). However, the terms autonomy and agency have been treated as synonymous (Cummins, 2014) and have been used interchangeably in health literature which can complicate understandings of children’s participation (Montreuil & Carnevale, 2016). While agency and autonomy share similarities, in that they both broadly encompass “how we make our lives our own” (White, 2016, p. 7), they can also be characterized by distinguishing attributes (Montreuil & Carnevale, 2016).

⁵ I refer to the concept of ‘praxis’ as: “an ethical, self-aware, responsive and accountable action, which reflects dimensions of knowing, doing and being” (White, 2007, p. 226).

⁶ In war-torn countries, for example, child participation efforts often occur against the backdrop of conflict, weak governance, corruption and poverty. The recruitment of child soldiers, for example, illuminates that children’s participation is not always inherently positive or desired. These conditions render the recognition of children’s participation in decision-making more difficult when compared to politically ‘stable’ contexts (Ehlers & Frank, 2008).

The term autonomy derives from Greek and combines ‘auto’, meaning ‘self’ and ‘nomos’, meaning ‘rule or law’ (Kalaja & Ruohotie-Lyhty, 2021). Autonomy has traditionally been understood as the “human capacity for self-determination” (Buss & Westlund, 2018, p. 8) that acknowledges “the right of an autonomous agent to make decisions as guided by his/her own reason” (Katz et al., 2016, p. 2). Autonomy can therefore be understood as the power to make free choices, unconstrained by external agencies (Beauchamp & Childress, 2001).

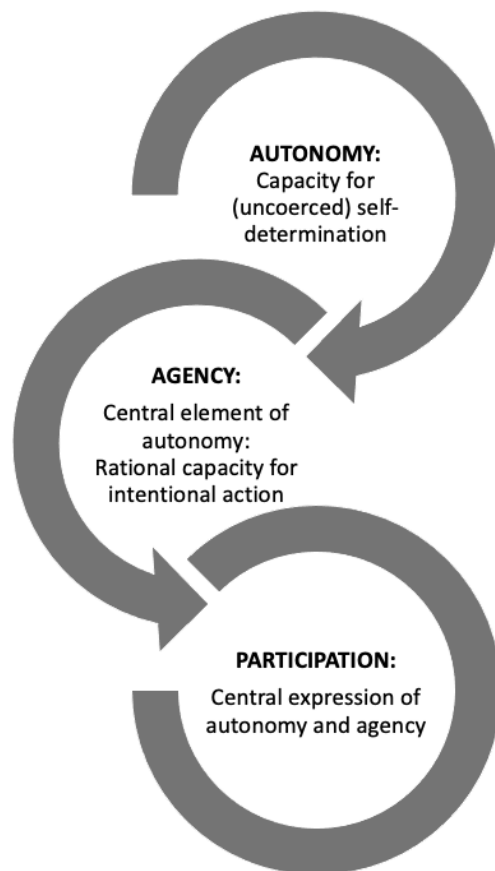
Attention devoted to personal autonomy became prominent during the 1970s to justify (legal) informed consent requirements (Buss & Westlund, 2018). In a review of health literature, for example, autonomy referred “almost exclusively to the capacity to make an informed decision” in a legal context related to children’s capacity to consent (Montreuil & Carnevale, 2016, p. 509). Personal autonomy has also been referred to as the ‘foundation’ of human rights that entails complete rationality, self-control and knowledge of relevant facts (e.g., laws) (Gumbis et al., 2008). Autonomy therefore requires ‘freedom of action’ in that one’s reasons, values and desires should be ‘authentically’ one’s own in order to make ‘uncoerced’ decisions (Gumbis et al., 2008).

Agency is a derivation of the Latin term *agentem*, meaning ‘to act’ (Kalaja & Ruohotie-Lyhty, 2021, p. 250). Agency is a key element of autonomy and has been taken up in diverse fields of scholarship to refer to “one’s rational capacity for intentional action” (Katz et al., 2016, p. 2), including the “capacity or incapacity of making autonomous choices” (Hanson, 2016, p. 471). Agency can therefore be regarded as an inherent quality or capacity to self-regulate, self-organize and actively engage with one’s environment(s) (Mukherjee, 2020; Sorbring & Kuczynski, 2019).

Overall, the concepts of autonomy and agency can complement each other since self-governing autonomy is a central feature of human agency (Schroeter, 2004). While agency broadly focuses on ways of participating, autonomy focuses on developing a degree of independence and control of that participation, particularly in the context of legal decision-making (Kalaja &

Ruohotie-Lyhty, 2021). Thus, “agency can perhaps be viewed as a point of origin for the development of autonomy” (Kalaja & Ruohotie-Lyhty, 2021, p. 255). Children’s participation can be considered as an overarching, central expression of children’s autonomy and agency (Duramy & Gal, 2020). The interrelations between autonomy, agency and participation are depicted in Figure Two, below.

Figure 2: Visual Overview of Interrelatedness Between the Concepts of Autonomy, Agency and Participation.



2.2.2 Rights-Based Understandings of Children’s Participation

Children’s participation in decision-making is “not just a model of good pedagogical practice, but a legally binding obligation” (Welty & Lundy, 2013, p. 1). (Inter)national legal guidelines, charters and conventions offer particular understandings of children’s participation and

can also shape how children's participation is conceptualized and practiced. The ratification of the UNCRC (United Nations, 1989) was the first 'hard-law' instrument to explicitly acknowledge children's vulnerability, need for protection, and children's agency (Sabatello et al., 2018). By offering a set of internationally recognized set of civil, economic, social, and cultural rights that are unique to children (Lee, 2001; Strandell, 2012), the UNCRC recognized children's participation as being crucial to the development of society and the fulfilment of children's rights (Montà, 2021). Primarily in Western societies, children's participation has now become particularly pertinent in the domains of policy, practice, and research across a variety of fields (Strandell, 2010; Qvortrup et al., 2009).

The 54 articles of the UNCRC categorize children's rights into protection, provision and participation, and advocate for the inclusion of children in all matters affecting them (United Nations, 1989). Particularly the UNCRC's Articles 3⁷, 12⁸ and 13⁹ became the "building blocks for the development and implementation of child participation in policies, programs, and legislation" (Dorscheidt & Doek, 2018, p. 62). In this study, I align my definition of children's participation with the UNCRC (United Nations, 2009), which outlines children's participation as an:

Ongoing process, which includes information-sharing and dialogue between children and adults based on mutual respect, and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes.

This definition recognizes that children's rights "do not operate in a vacuum" (Brady, 2020, p. 13) but recognizes the interdependency of children's rights in terms of the duties of caregivers and governments to provide 'protective direction' to the child in accordance with the child's 'age and

⁷ Article 3 denotes that "the best interests of the child must be a top priority in all decisions and actions that affect children" (United Nations, 1989).

⁸ Article 12 refers to children's right to express their views and for their views to be taken seriously (United Nations, 1989).

⁹Article 13 refers to children's right to freedom of expression (United Nations, 1989).

maturity' and 'evolving capacities' (Percy-Smith & Thomas, 2010a). In conceptualizing children's participation, the UNCRC therefore integrated two premises related to (1) children's agency, in terms of children being deserving of opportunities to be heard, and (2) the protection of children, in terms of recognizing children as vulnerable and dependent persons who require 'special' protection from adults (Chawla, 2004).

2.2.2.1 Critiques of the UNCRC

Despite the widespread acknowledgement of the UNCRC's commitment to children's participation across (inter)national government and non-government organizations (NGOs), children's rights have also been critiqued (Montà, 2021). The pedagogical ideas on children and childhood that underpin the UNCRC have been critiqued for ambiguously viewing children as agentic subjects of rights (e.g., Article 12) and as vulnerable beings in need of protection from adults (e.g., Article eight) (Montà, 2021). Characterizing children as 'vulnerable' has repercussions for children's lives and their decision-making, in that such vulnerability risks children solely being perceived as objects of protection and of adults' decisions (Montà, 2021). Rather than considering children 'vulnerable' by definition, the UNCRC could benefit from specifying the conditions which could make children susceptible to vulnerability (e.g., poverty, war, illness) (Montà, 2021).

The UNCRC has also been critiqued for primarily focusing on collecting children's 'views' or 'voices' rather than on achieving change (Johnson & West, 2018). The onus has frequently been placed on 'listening to' children's 'voices' rather than on the meaningful and effective implementation of children's rights (Lundy, 2007). As a result, children's voices often remain ignored or addressed only superficially in practice and research (Murray, 2019). The phrase 'children's voices' has also frequently been used as an abbreviation for Article 12, diminishing its impact by providing an imperfect summary of the full extent of the obligation of Article 12 (Lundy, 2007).

The act of listening to children's 'voices' in children's rights legislation has also been critiqued for the assumption that all children always share one autonomous and individualized view (Alderson, 2017; Murray, 2019). The rhetoric of listening to 'children's voices' has therefore faced criticism for assuming that it is possible to capture children's 'true' and 'unadulterated' 'voices', leading to the illusion of the 'empowerment' of children (James & Prout, 2003; Leonard & Rojek, 2016). Children's 'voices', however, "very often consist of the recycling and reworking of adult talk" (Hammersley, 2017, p. 120), in which adults communicate children's 'authentic' knowledge to other adults (Baraldi & Cockburn, 2018; Leonard & Rojek, 2016). Therefore, "the sole act of 'listening' to the voices of children does not ensure that their views will be accounted for in decision-making processes that affect their lives" (Koller, 2017, p. 2657), since children's decisions will lie, at least in part, with an adult (King, 2007; Lundy, 2007). The UNCRC has therefore critique for acting as an illusion of children's 'empowerment' by perpetuating tokenistic forms of children's participation that disregard the role of context, including adults, in shaping children's participation (Abebe, 2019; Gabe et al., 2004; Lundy, 2018; Percy-Smith & Thomas, 2009; Tisdall & Punch, 2012). Overall, these critiques have contributed to challenges in implementing children's rights in practice, pedagogy and politics (Montà, 2021).

2.2.3 Children's Individual and Collective Decision-Making in Health Care

As noted in Section 2.2, multiple conceptualizations of children's participation exist - largely due to the various forms that children's participation can take in different contexts (Brady, 2020; Percy-Smith & Thomas, 2010). In health care contexts, pediatric participation in decision-making has been referred to as the 'default' position in pediatric care services (Katz et al., 2016). In this 'default' position, the terms 'participation', 'shared decision-making', 'partnership' and 'inclusion' are often used interchangeably when discussing the involvement of children in decision-making in health care settings (Brady, 2020). Pertinent literature also places a heavy focus on

distinguishing between children’s participation at the level of individual and collective decision-making (Johnson & West, 2018). Children’s ‘individual’ health care-related decisions largely pertain to a child’s care, such as providing consent to medical treatment or not (Alderson, 2007; Hein et al., 2012). Children’s individual decisions have been further categorized into ‘minor’ (i.e., decisions that affect the child’s care delivery and not the child’s wellbeing) and ‘major’ decisions (i.e., decisions that affect the child’s treatment trajectory and wellbeing) (Coyne et al., 2014).

The concept of shared decision-making (SDM) has also encapsulated the various ways in which children can contribute to individual decision-making processes, independent of who makes the final decision (Coyne et al., 2014). In health care, SDM generally positions children in a three-way relationship or ‘triad’ with adults, including health care providers and caregivers (Coyne, O’Mathúna, et al., 2016; Zwaanswijk et al., 2007). In such ‘triads’, SDM aims to engage children in making decisions “that are supported by the best available evidence and aligned with the patient’s values, preferences and treatment goals” (Wyatt et al., 2015, p. 574). While SDM can involve only two participants, such as the health care provider and the child (Coyne et al., 2016), SDM aims to “*really* put patients at the centre of health care” (Stiggelbout et al., 2012, p. 1).

In contrast to individual decision-making, children’s opportunities for collective decision-making in health care contexts predominantly occur in ‘participation structures’ that take the form of children and/or family advisory groups or councils¹⁰ (Crowley, 2015; Cunningham & Walton, 2016). As a formal mechanism for the collaboration of children, families and/or health care providers in decision-making, these groups are based on the idea that children and/or families are

¹⁰ Child and/or family advisory groups can currently be found in most major hospitals across North America and Europe. In Canadian pediatric hospitals, examples of organizational participation structures include a child and youth advisory council (Alberta Children’s Hospital, 2022), family advisory network, including a children’s council (Sick Kids Hospital, 2022) and family advisory committee (BC Children’s Hospital, 2022). Such groups are generally composed of fewer than 20 participants and topics of discussion can range from selecting a food menu or choosing a new electronic medical record system (Kuhn et al., 2016).

involved with an organization on an ongoing basis to inform health care policies and practices (Brady, 2020). Children’s advisory groups have also been implemented to help prepare and train children for participation in clinical research (Arunkumar et al., 2018; Gaillard et al., 2018), for example, in relation to palliative care research (Roach et al., 2021).

While distinguishing between children’s individual and collective decision-making can offer clarity in understanding children’s health care participation, children’s involvements in decision-making in each of these levels can take very different forms (Horgan, 2017). The meanings that individual actors who are involved in decision-making (e.g., children, service providers, policy makers) associate with children’s participation can also vary significantly (Cornwall, 2008). This degree of ambiguity with regards to conceptualizing children’s participation was encapsulated by Chawla (2001), who stated that; “participation can mean different things to different people... and the form of participation varies with circumstances, including culture, age, gender, setting, political conditions, available resources, and participants’ goals” (p. 1). In child participation scholarship, the key challenge is to reflect the diverse life worlds of children, including ‘lesser heard’ children such as children with disabilities, children living in the care system and migrant children, for example (Horgan & Kennan, 2021). This remains particularly important in the context of health care, as ‘lesser heard’ and marginalized children, including children with disabilities and/or medical complexities, for example, are also most likely to use health services (Brady, 2017).

2.2.3.1 Outcomes of Children’s Participation in Health Care Decision-Making

The intended outcomes of children’s involvement in individual decision-making relate to gaining children’s cooperation and compliance, giving back a sense of control to children, building trusting relationships between children and health care providers and positively influencing children’s general wellbeing (Coyne et al., 2014; Katz et al., 2016; Runeson et al., 2002a; Spinetta et al., 2002; van Bijleveld et al., 2014; Vis et al., 2011). Children’s participation in decision-making

can “enable children to develop a sense of themselves, instil confidence, enhance communication skills, and improve the effectiveness of services” (Coyne et al, 2014, p. 274). In turn, children’s participation in decision-making can support social and emotional outcomes by creating opportunities for social and moral agency (Coyne et al., 2014; Katz et al., 2016). Similarly, young children’s involvements in providing assent for medical interventions has been associated with fostering children’s moral growth and development of autonomy (Katz et al., 2016).

When children are not involved in decision-making or informed about their health care, children can experience increased fears and anxiety, feeling unprepared for procedures and reduced self-esteem (Bray et al., 2019; Coyne, 2006; Dorscheidt & Doek, 2018). The outcomes of SDM (shared decision-making) have also been described as “essential for respecting [human] autonomy”, “reducing cost [of health care] and “increasing equity” by involving every patient in SDM regardless of socio-economic status, education and or language proficiencies, for example (Stiggelbout et al., 2012 p.1). In a systematic review of SDM in pediatric health care, the intended outcomes of SDM interventions in pediatrics were described as increasing patient knowledge and decreasing decisional conflict (Wyatt et al., 2015).

Desired outcomes of children’s participation in collective decision-making in child/family advisory groups can pertain to enhancing patient experience by delivering health care that is more ‘patient-centered’ (Brady, 2020; Jiang et al., 2017; Kuhn et al., 2016), leading to health care system cost savings (Kuhn et al., 2016). Attending to children’s collective decision-making “should ensure that the services better reflect their needs and concerns [to result in] better patient experience, better outcomes and provide better value for money” (Brady, 2020, p. 8). In turn, child and/or family advisory groups belong to a set of strategies that make family-centered care ‘come alive’ in hospitals (Halm et al., 2006), intended to result in (similar) improved health outcomes, health care delivery and health care system transformation (Kuo et al., 2012).

2.2.4 Dominant Theoretical Approaches Towards Understanding Children's Participation

In addition to the varying conceptualizations of children's participation afforded by health care-related literature and children's rights, the rich uptake of children's participation in research, policy and practice has also led to the development of various dominant models, theories, and approaches towards understanding children's rights to participation (Brady, 2020; Cornwall, 2008). In this sub-section, I discuss various theoretical models that have been particularly influential in shaping dominant understandings of children's participation in literature. By engaging with critiques of the widely referenced and 'traditional' hierarchical 'ladder of participation' model by Roger Hart's (1992), I introduce three alternative, relational models of children's participation, including a Mannion's (2003) 'fountain' of participation model, Lambert et al.'s (2008) continuum of participation, and Lundy's (2007) rights-based model.

While I acknowledge the rich variety of theoretical approaches towards children's participation, I discuss these dominant theoretical models because they can act as a useful starting point for differentiating forms and degrees of children's participation (Cornwall, 2008). They also shed light on the theoretical and conceptual grounds on which my discussions regarding children's participation are based, which can respond to the lack of a sufficiently strong theoretical basis for children's participation (Johnson & West, 2018; Percy-Smith & Thomas, 2010b).

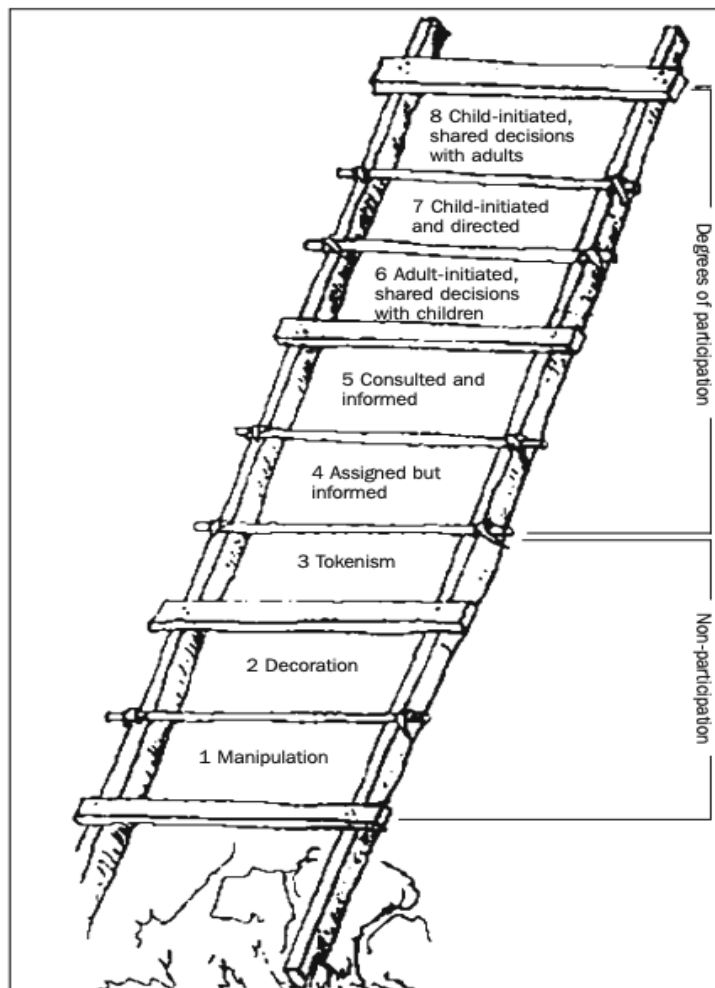
2.2.4.1 Hart's Ladder of Participation (1992)

Hart's ladder of participation model developed in 1992 remains central to discussions about children's participation (Brady, 2020). Purporting the belief that children's participation can improve society (Toros, 2021), his model was intended to offer simplicity and clarity in implementing the goals of children's participation for a wide range of projects and programmes in professional groups and institutions (Percy-Smith & Thomas, 2010). Before the introduction of Hart's (1992) ladder, a paucity of scholarship on the conceptual nature of children's participation

existed (Hart, 2008). After being published by UNICEF in a report entitled ‘Children’s Participation: From Tokenism to Citizenship’ in 1992, the ladder spurred an international movement towards children’s participation (Hart, 2008; Hart & Schwab, 1997).

Hart (1992) defined participation as “the [active] process of sharing decisions which affect one’s life and the life of the community in which one lives” (Hart, 1992, p. 5). Hart’s (1992) model employed a ladder as a metaphor to illustrate eight (hierarchical) types of adult-child interactions represented in participatory practice, ranging from manipulation (or ‘non-participation’) to child-initiated shared decisions with adults (depicted in Figure Three). On the top rung, ‘child initiated-shared decisions with adults’ is considered the top, or ‘most participatory’ level of children’s participation.

Figure 3: Hart’s (1992) ‘Ladder of Participation’ Model



Hart's (1992) model has been considered a "useful framework for assessing the level and authenticity of children's participation processes" (Ehlers & Frank, 2008, p. 115). Positioned on the lower rungs of the model, Hart's (1992) model also brings attention to the ethical dangers of 'tokenism', 'decoration' and manipulation' in children's decision-making. Tokenism, decoration and manipulation relate to the unethical acts of "merely paying lip service to international conventions" when children are 'consulted', preventing children from "mak[ing] a real impact on the issues that affect their lives" (Ehlers & Frank, 2008, p. 115). These are common traps into which organizations involved in the promotion of children's participation can fall (Ehlers & Franks, 2008).

Despite the proposed value of Hart's (1992) model of children's participation, it has also faced critique for asserting the idea that participation, and different forms of participation, always occur in a hierarchical, rigid and orderly sequence in which everyone must reach the 'top' (Reddy & Ratna, 2002; Kirby & Woodhead, 2003). Scholars questioned whether the model's implication that 'full empowerment' is the ultimate aim of participation since children's desired level of involvement in decisions can vary (Brady, 2020). Moreover, the step-wise, orderly sequence of the model also "seems to imply a necessary [developmental] sequence to children's developing competence in participation" (Hart, 2008, p. 23).

Lastly, critiques were directed at the model for not sufficiently recognizing the range of children's participatory activities in their everyday lives in various situations and contexts, since they were limited to organizational projects and programmes (Hart, 2008; Horgan & Kennan, 2021; Johnson & West, 2018). Hierarchical models, including Hart's (1992) model were therefore critiqued for being "inadequate to conceptualize the complex and multidimensional reality of children's participation in society" (Shier, 2010, p. 25).

In light of these critiques, Hart began “stepping back from the ‘ladder’ to critically reflect on the ongoing debates that the model engendered” (Hart, 2008, p. 19). Hart (2008) acknowledged the need to “think more broadly about how children [informally] participate in society” and “describe the varying roles that adults play in relation to children’s participation” (p. 20). Moreover, while the ladder was drawn from the perspective of an author living in a Minority World context, Hart (2008) later acknowledged how the participation of children of mixed ages and varying abilities can differ across Minority and Majority World contexts. (p. 20). Hart subsequently conceptualized children’s participation as a “dynamic constructive process” (Hart, 2013, p. 9) in which a range of individual and contextual factors such as ‘individual and cultural differences’, ‘special needs’ and ‘diversity of cultures and social classes’ (Hart, 2013) can shape children’s participation.

2.2.4.2 Non-Hierarchical Models of Children’s Participation

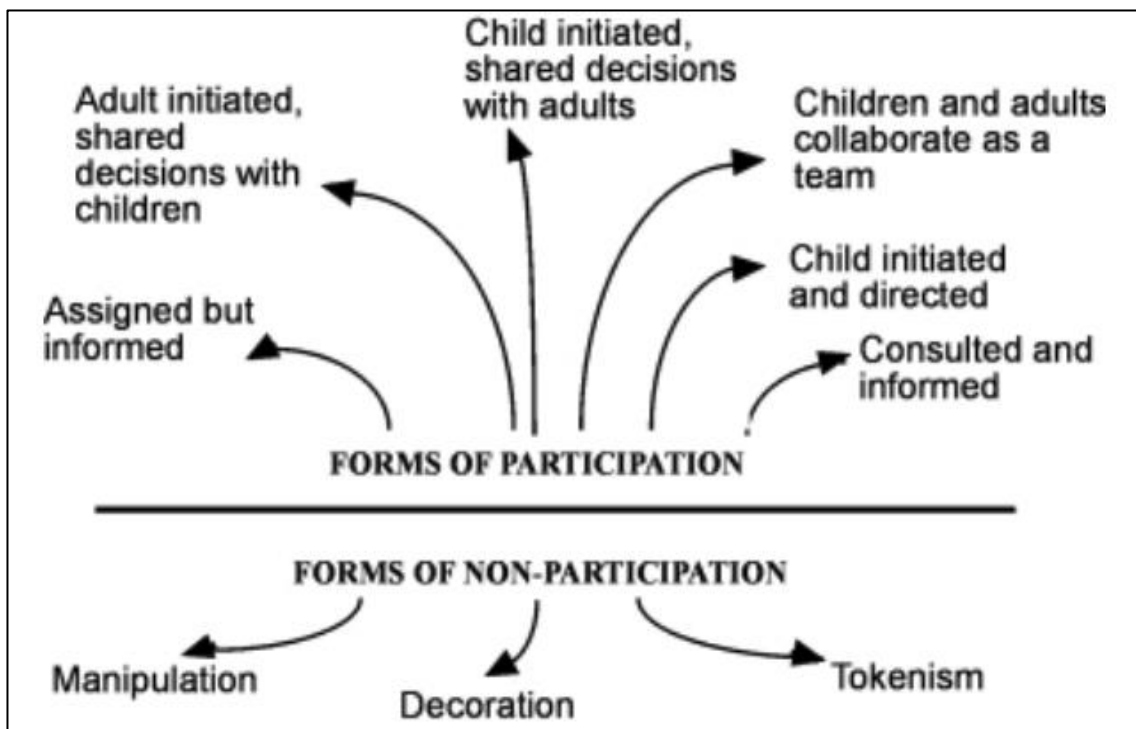
As a result of the critiques of Hart’s (1992) model, several other theoretical models for understanding children’s participation were introduced to move beyond hierarchical conceptions of children’s decision-making and focus on the interdependency between the lives of children and adults and the role of context in shaping children’s participation in decision-making (Johnson & West, 2018; Mannion, 2007). In this section, I discuss three non-hierarchical models of children’s participation: 1) Mannion’s (2003) ‘fountain of participation’, 2) Lambert et al.’s (2008) ‘continuum’ of participation, and 3) Lundy’s (2007) rights-based model of participation.

2.2.4.2.1 Mannion’s Fountain of Participation Model

Rather than adhering to hierarchical levels of decision-making, Mannion’s (2003) ‘fountain of participation’ model (Figure Four) accounts for adults in shaping various forms of children’s (non)participation. According to this model, examples of different forms of children’s participation include: ‘*child initiated, shared decisions with adults*’ (i.e., children have the ideas, set up projects and come to adults for advice, discussion and support – adults offer their ‘expertise’ to children for

consideration), *'consulted and informed'* (i.e., the project is designed and run by adults, but children are consulted and have full understanding of the process – children's opinions are taken 'seriously') or *'assigned but informed'* (i.e., adults 'decide' a project and invite children to volunteer for it – adults 'respect' children's views) (Ramey, 2017). Mannion's (2003) model also brings attention to various forms of non-participation, including manipulation, decoration and tokenism¹¹.

Figure 4: Mannion's (2003) 'Fountain' of Child Participation Model



By differentiating between different forms of children's participation in which adults play a role, Mannion (2010, as cited in Percy-Smith & Thomas, 2010) suggested that: "what we call children and young people's participation, knowledge does not emerge from individuals, but rather emerges within intergenerational and interpersonal dialogues within spaces that are also 'part of the

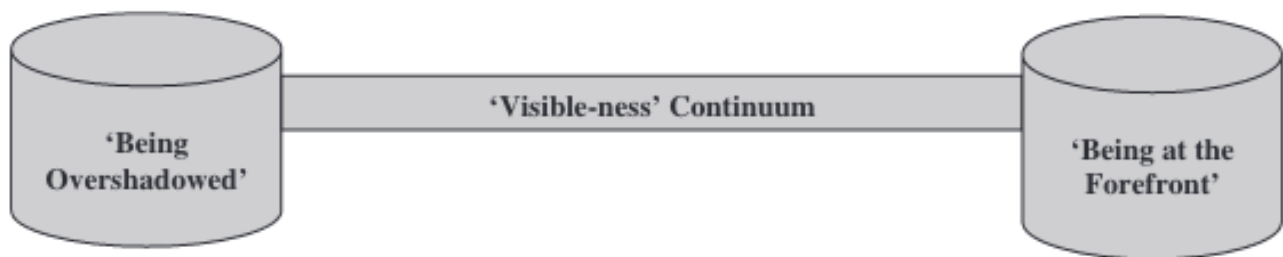
¹¹ According to Lundy (2018), a review of key literature on children's participation suggests that the term 'tokenism' is attributed to the experiences of children whose views have been sought by adults but not taken seriously.

action”” (p. 338). In emphasizing the relational interdependence between children and adults, Mannion (2003) claimed that this model could “potentially present practitioners with greater choice of participatory approaches than a linear ladder” (p. 13).

2.2.4.2.2 Lambert’s (2008) Continuum of Participation

In contrast to differentiating between different ‘forms’ of (non)participation, Lambert et al. (2008) positioned children’s involvements in communication processes (and decision-making) that occur between children and adults on a continuum of ‘visible-ness’ (Figure Five).

Figure 5: Lambert’s (2008) Continuum of ‘Visible-ness’



Placing children’s involvements in communication processes on a continuum allows for a recognition of children’s preferences in their level of involvement in decision-making processes (Lambert et al., 2008). Rather than exclusively occupying a frontal or background position on the continuum, Lambert et al. (2008) suggested that: “children may be in constant motion – back and forth, along the continuum of between the two extreme poles of ‘being overshadowed’ and ‘being at the forefront’ according to children’s own preferences and the particular situation in which decision-making occurs” (p. 3100). By further accounting for the varying roles of children and adults in children’s decision-making processes, Lambert et al. (2008) concluded that this model could assist health care providers in embracing each individual child’s specific communication needs in participation processes.

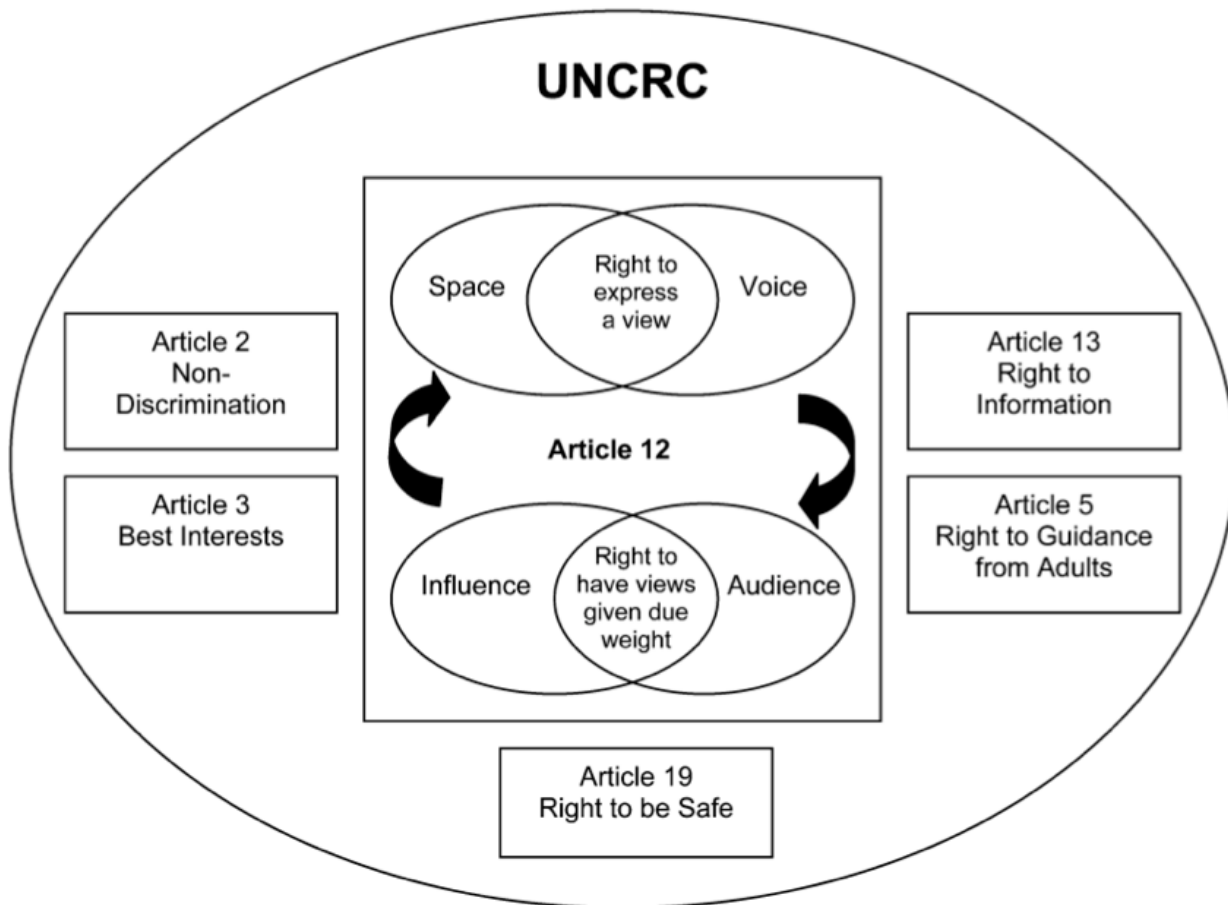
2.2.4.2.3 Lundy's Rights-Based Model of Participation (2007)

To further attend to the interdependency between children and adults in children's decision-making and the contextual nature of children's rights, Lundy's (2007) widely-adopted¹² rights-based model of children's participation (depicted in Figure Six) represents a more nuanced and contemporary way of conceptualizing UNCRC's Article 12 (respecting children's views). Among children's rights principles, Article 12, which is inherently connected to children's participation, remains one of the most widely cited yet most commonly misunderstood articles of all the provisions of the UNCRC (Iusmen, 2018; Lundy, 2007). Limited awareness of the provision of Article 12 also exists and its inherent connections to other relevant UNCRC provisions, including Articles 2 (non-discrimination), 3 (best interests), and 5 (right to guidance) (Lundy, 2007).

Lundy's (2007) model aims to remove the barriers towards the effective and meaningful implementation of Article 12 (Lundy, 2005, 2007). According to Lundy (2007), meaningful participation requires four interrelated elements: **space** (children must be given the opportunity to express a view), **voice** (children must be facilitated to express their views), **audience** (the view must be listened to) and **influence** (the view must be acted upon, as appropriate). Collectively, these elements represent the distinct facets of Article 12 in a "legally sound yet user-friendly format" (Lundy, 2007, p. 941).

¹² Lundy's (2007) model has had far-reaching implications in practice, policy and research (Murray et al., 2019; Children's Research Network, 2020). For example, it was implemented in Ireland's first national, government-led child participation strategy entitled 'Ireland's National Strategy on Child and Youth Participation in Decision-Making' (Horgan & Kennan, 2021). While the right to be heard is a strategic priority in Europe and other global regions, this strategy was the first of its kind among European countries (Horgan & Kennan, 2021).

Figure 6: Lundy’s (2007) Model of Children’s Participation



Lundy (2007) developed this model as a direct result of the critiques associated with the concept of children’s (autonomous) ‘voice’. According to Lundy (2007), the concept of children’s ‘voice’ is commonly used as an abbreviation for Article 12, thus diminishing its impact and providing an “imperfect summary of the full extent of the obligation [Article 12]” (Lundy, 2007, p. 927). ‘Hearing children’s voice’ also does not denote a transfer of power¹³ or place children’s participation in collaborative relationships with adults (Brady, 2020).

¹³ ‘An extensive discussion of how I define ‘power’ is presented in Chapter Four.

Lundy's (2007) rights-based understanding of children's participation aims to ensure that children are "involved in decision-making, their views are listened to, taken seriously and given due weight, with the intention that these views will influence the outcome of initiate change" (Horgan & Kennan, 2021, p. 5). By emphasizing the interrelation between four key elements in shaping children's decision-making, Lundy (2007) highlights that "[merely] being involved in a process is not equivalent to having a voice" (Cornwall, 2008, p. 278) and that children's decision-making processes are rarely static (Frankel & McNamee, 2020).

Giving children's views 'due weight' through *space, voice, influence, and audience* also inherently recognizes that children need support from adults to participate in decision-making, albeit to varying degrees (Wyness, 2013). In turn, children's participation can be considered an active process where children and adults engage in dialogue to act upon children's decisions, as appropriate. This model also recognizes that the articles of the convention need to be contextualised to be meaningfully implemented in various practice contexts, as children's rights vary by country and are influenced by training, policy agendas and legislation (O'Sullivan et al., 2021). In this manner, Lundy's (2007) model responds to universalist critiques associated with children's rights by perceiving children's rights as "being dependent on where children are placed or what services they receive, rather than being the entitlement of *every* child" (Children's Rights Alliance of England, 2015, p. 1).

While Lundy's (2007) model was designed for the examination of children's participation in an educational contexts, its value also lies in its practical applicability to other contexts of children's everyday lives and for fostering dialogue between different stakeholders in influencing decision-making (Toros, 2021). Thus, it offers a model for "informing understanding, developing policy and examining existing practice related to participation with children" (Frankel & McNamee, 2020, p. 44).

Overall, the non-hierarchical models of children's participation share a commitment to upholding children's 'meaningful' participation. The theoretical notion of 'meaningful participation' surfaced in the early 2000s to "develop a more nuanced understanding of how children can contribute in a truly meaningful way to discussions of issues affecting them" (Ehlers & Frank, 2008, p. 116). Meaningful participation is associated with the idea that participation should attend to the concept of agency and negotiations with adults rather than being "seen within the mindset of the right of the individual child to have their say" (Johnson & West, 2018, p. 57). These theoretical models of children's meaningful participation therefore bring attention to whose 'voice' is heard and which forms of participation are enabled in specific contexts (Johnson & West, 2018).

2.3 Personal Factors Influencing Children's Participation

In addition to varying conceptualizations of children's participation, pertinent literature also points to various personal (i.e., within or between children and adults) factors in influencing children's participation processes. In this section, I discuss two particularly prominent personal factors that were described in the literature: 1) the role of adults in children's decision-making, including adult-led developmentalist and protectionist discourses and 2) children's health status.

2.3.1 The Role of Adults in Children's Decision-Making

As reflected in the conceptual models of children's participation outlined by Mannion (2003), Lambert et al. (2008) and Lundy (2007), pertinent literature suggests that adults (e.g., caregivers and health care providers) can adopt prominent roles in shaping children's participation in decision-making. Adults can be positioned as key 'actors' in children's decision-making processes (Cornwall, 2008) and children's potential for agency can be shaped by the ways in which adults listen to, interpret and act upon children's views (Brady, 2020; Carter et al., 2014; Hallström & Elander, 2004; Koller, 2021; Montà, 2021; Tates & Meeuwesen, 2001). As a key aspect of

decision-making, the ways in which children are informed and prepared for medical procedures can also be heavily influenced by the adults (parents and health care providers) around them (Bray et al., 2019).

It can be reasonable to suggest that children are dependent on their caregiver(s) for most aspects of their daily life and children “usually have limited experience with making any medical decisions” (Katz et al., 2016, p. 7). Some children, particularly young children (Coughlin, 2018) and children with complex needs or communication challenges (Franklin & Sloper, 2009) may require guidance and support from adults in decision-making (Brady, 2017). Health care providers and caregivers can act as co-ordinators, interpreters, advocates and information buffers to facilitate children’s decision-making (Coyne et al., 2016; Runeson et al., 2002). While some children may feel reassured and supported by adults in decision-making, particularly when making ‘major’ decisions or when children are very unwell (Carter et al., 2014), the role of caregivers and health care providers can also complicate children’s decision-making. Caregivers, for example, may experience stress and uncertainty in making decisions for their child in the context of new diagnoses of cancer or other life-threatening illnesses (Katz et al., 2016).

Varying family dynamics (Carter et al., 2014) can also play a role in children’s decision-making processes. Caregivers and health care providers may have different opinions and attitudes towards a child’s ‘best interest’ and children’s decision-making capacities which are grounded in personal values and beliefs, complicating children’s decision-making (L.-M. Brady, 2020; Bricher, 2000; Coyne & Harder, 2011; Feenstra et al., 2014; Jeremic et al., 2016; Mårtenson & Fägerskiöld, 2008; Runeson et al., 2002a). Health care providers may, for example, have different understandings and attitudes towards the application of legal guidelines on children’s rights in practice (Brady, 2020). Differing attitudes towards what may be in a child’s ‘best interest’ also represents an ethical conflict in deciding between supporting a child’s view or following hospital

‘routine’ (Runeson et al., 2010). By holding interests that are separate from children, adults may be more (inadvertently) focused on “fulfilling their own needs and desires” (Runeson et al., 2001, p. 76).

These findings suggest that there are “inequalities and injustices in the way power is exercised and decision-making is controlled by adults” (Percy-Smith, 2016, p. 401), which can constrain children’s decision-making (Bricher, 2000; Fokala & Rudman, 2020; Mårtenson & Fägerskiöld, 2008; Runeson et al., 2001, 2002b). Health care providers, particularly physicians, are often ascribed with paternalistic ‘power’ by virtue of managing health services, as well as their knowledge and skill-set that children and caregiver(s) typically do not possess (Aarthun & Akerjordet, 2014; Fokala & Rudman, 2020). A position statement published by the Canadian Pediatric Society (Coughlin, 2018) reflects this idea by describing children’s decision-making as being “...guided by the medical knowledge and experience of health care providers” (p. 138).

In order to ‘confront’ medical paternalism, Percy-Smith and Thomas (2010) suggest that children’s participation should involve children confronting adult authority and challenging adult assumptions about their competence. However, health care providers have experienced difficulties in relinquishing power in their relationships with children and caregivers due to their level of accountability and ‘routinized’ thinking (Aarthun & Akerjordet, 2014). Children may also find it challenging to “question or ‘go against’ the perceived ‘wisdom’ of adults around them” (Carter et al., 2014, p. 9), further complicating the implementation of children’s participation in practice.

Health care providers’ paternalistic dominance can also shape caregiver-provider relationships, as “...parents are rarely free from controlling influence by the professionals” (Hallstrom & Elander, 2004, p. 368). In children’s decision-making, the responsibilities of caregivers and health care providers can intersect, but do not necessarily coincide (Dorscheidt & Doek, 2018). Caregivers have experienced pressure in decision-making due to health care

providers' expectations (Fiks et al., 2011; Guerriere et al., 2003; Kirk, 2001; MacKean et al., 2005) and caregivers' decision-making depended on how sensitive the provider was in identifying their needs (Hallström & Elander, 2004). The mobilization of power by health care providers can also extend towards the complex practice of health policy implementation (Nunes & Lotta, 2019), which can (re)produce inequalities in children's opportunities for decision-making.

While children's participation inherently depends on their relationships (and decisions of) adults (Sabatello et al., 2018), the prominent role of adults in shaping children's participation necessitates "paying closer attention to who is participating, in what and for whose benefit" (Cornwall, 2008, p. 269) at multiple levels of health care practice (Ocloo et al., 2020). Unequal power relations between children and adults points to a 'top-down'¹⁴ conceptualization of children's participation which directly contrasts with an understanding of children's autonomy as the power to make 'free' choices unconstrained by external agencies (Beauchamp & Childress, 2001). According to Brady (2020), the views of caregivers and health care providers should therefore be incorporated alongside rather than as a proxy for children's views.

2.3.1.1 Adult-Led Developmentalist and Protectionist Discourses

Particularly in health care contexts, social discourses of protectionism and developmentalism that are shaped and perpetuated by adults and adult-led structures can further influence children's participation (Brady, 2020; Gallagher, 2008; Kehily, 2008; Pinkney, 2011; Spyrou, 2018). Adults in pediatric health care contexts such as caregivers and health care providers "often take a protective stance towards children to act in their best interests" (Coyne & Harder, 2011, p. 312). Taking a protective stance may be based on adults' assumptions about children's

¹⁴ A top-down perspective on participation implies that the scope of children's influence in 'shared' decision-making processes is largely determined and controlled by adults (Brady, 2017) and occurs in pre-established practices and structures that did not include children in their design and delivery (Davis & Smith, 2012).

limited decision-making competence or assuming that children's participation is potentially disruptive to children's wellbeing (Brady, 2020; Coyne & Harder, 2011; Feenstra et al., 2014; Vis et al., 2012). Protectionist discourses can construct hospitalized children who are ill as 'vulnerable' 'victims' prone to 'problems' such as separation anxiety, post-traumatic stress, and isolation, as well as in need of 'protection' from adults in order to survive and develop 'successfully' (James & Curtis, 2012; Kehily, 2008a; Young, 2003).

Discourses of protectionism also shape legal debates about the abilities of children to consent to decisions regarding their health care (Alderson, 2007). Obtaining children's legal consent appears to respect children's decision-making rights by assuring that children can receive treatment and advice but may be more influenced by adults' own motives to 'protect' themselves (Alderson, 2007). Debates concerning children's 'protection' can therefore be viewed as more concerned with "adults' freedoms than with children's rights" (Alderson, 2007, p. 2273).

In contrast to protectionist discourses, developmentalist discourses are based on the supremacy of developmental psychology in constructing rigid, age-based images of children and childhood throughout the past century (Corsaro, 2005; James et al., 1998; James & James, 2004; Prout, 2011). By using children's age as a marker of their competence and abilities, developmentalist discourses also shape and perpetuate the widespread belief that particularly younger children are not capable of participating in decision-making and providing consent, as will be discussed in Section 2.4.1.2 (Alderson, 2007; Feenstra et al., 2014; Greene, 2006; Hemrica & Heyting, 2004; James & Curtis, 2012; Kehily, 2008).

Developmentalism also perpetuates problematic universalized images of children's abilities as rigid, age-based stages of growth along predefined paths are assumed to be applicable to *all* children (Matthews, 2007; Quennerstedt & Quennerstedt, 2014). In turn, developmentalism maps images of a primarily "white, middle-class, Western society on to models of development which are

then treated as universal” (Burman, 2008, p. 70). By viewing children as universalized ‘objects’ of psychological enquiry, developmentalism fails to theorise the *context* children inhabit, which contributes to individualist interpretations of socially structured phenomena (Burman, 2008). Structuring dimensions of development, such as gender, culture, and class, therefore become omitted (Burman, 2008). This becomes particularly problematic in the context of the complexity that characterizes today’s pediatric health care settings (Koller & Wheelwright, 2020).

Overall, discourses of protectionism and developmentalism are problematic because they can inhibit children’s opportunities for active participation in decision-making (Brady, Lowe, & Lauritzen, 2015; James & James, 2012; James & Prout, 1997; Koller, 2017, 2019). Despite participation “invoking a warm ring of inclusion” (Cornwall, 2008, p. 277), the protectionist and developmentalist discourses that underlie children’s participation can exclude some children from decision-making, such as young children, children with disabilities and/or communication challenges, and children in palliative care settings (Brady, 2020; Franklin & Sloper, 2009; Kirby et al., 2003; Noyes, 2000; Sinclair, 2004; Underwood et al., 2015). The problematic dominance of developmentalist theories and assumptions is further discussed in relation to child life practice in Section 2.6.3.

2.3.2 Children’s Health Status

An additional interpersonal factor that can influence children’s participation pertains to the ways in which children’s health status can shape children’s participation rights (Carter et al., 2014; Coyne et al., 2014; Koller et al., 2018; Moore & Kirk, 2010). The decision-making preferences and abilities of children with chronic, critical, complex and/or palliative conditions, for example, may be different than those of children who experience a single episode of (acute) illness (Carter et al., 2014). However, there is little evidence on the experiences of children with complex, palliative, chronic or critical illnesses in decision-making (Coyne, O’Mathúna, et al., 2016; Wijngaarde et al.,

2021). For example, Bray et al. (2012) demonstrated that the information needs of children with chronic medical conditions are not being met. Similarly, Kirk (2008) suggested that children with complex health care needs can encounter difficulties in influencing decisions about their condition.

For children who are critically or palliatively ill, the lack of research may be explained by children's incapacities to participate in decision-making due to the severity of their condition(s) (Wijngaarde et al., 2021). In pediatric palliative care, most existing studies therefore focus on caregivers' complex and highly emotional experiences of decision-making for their child (Carroll et al., 2012; Chen, 2020; Kars et al., 2015; Lang & Quill, 2004; Mitchell et al., 2019; Yazdani et al., 2022). These studies point to the nuanced nature of end-of-life decision-making, in which caregivers can experience various decisional conflicts (Yazdani et al., 2022). Therefore, the information needs and preferences of each family need to be understood by care providers on an individualized basis (Mitchell et al., 2019). Clinical practice guidelines regarding SDM in pediatric palliative care should also offer more detailed, practical recommendations on *how* to practice SDM (Dreesens et al., 2019).

In the context of pediatric oncology, the majority of studies also focus on the perspectives of caregivers and/or health care providers on children's decision-making (Badarau et al., 2017; Kilicarslan-Toruner & Akgun-Citak, 2013; Pyke-Grimm et al., 1999; Rost et al., 2017; Stewart et al., 2005), while few focus on the perspectives of adolescents and caregivers and/or health care providers (Hinds et al., 2001; Ingersgaard et al., 2018; Ruhe et al., 2016). Collectively, these studies reaffirm children's limited involvements in decision-making, in which health care providers have justified not involving children by referencing the 'best interest' argument (de Vries et al., 2010). Among children with medical complexities and their caregivers, research has also demonstrated that these families can experience significant ethical challenges in defining and upholding their children's 'best interest' in decision-making processes (Carnevale et al., 2017). The views of

children with medical complexities who also have communicative impairments are often not sufficiently elicited or judged as ‘invalid’ when expressed (Carnevale et al., 2006, 2017; Teachman, McDonough, Macarthur, & Gibson, 2017). In addition, in providing complex medical care for their children, caregivers of children with medical complexities are also often tasked with the major (and often distressing) responsibility of being given decisional authority (Carnevale et al., 2017). Therefore, this literature suggests that what may be in a child’s ‘best interest’ is inherently multifaceted and needs to be determined on a case-by-case basis (Dorscheidt & Doek, 2018).

2.4 Organizational Factors in Health Care Contexts Influencing Children’s Participation

In addition to various personal factors in shaping children’s participation, pertinent literature also sheds light on multiple organizational factors in influencing children’s decision-making processes, including: 1) health care charters, policies, guidelines and initiatives on children’s participation, such as child- and/or family-centered care, 2) guidelines on children’s consent to medical treatment, 3) time constraints, and 4) the degree to which a health care organization fosters a ‘culture of participation’.

2.4.1 Health Care Policies, Guidelines, and Initiatives on Children’s Participation

Over the past decade, children’s participation in health care decision-making has become an increasingly prominent issue on health care policy and practice agendas (Horgan & Kennan, 2022). As a result, children’s participation has become reflected in various (inter)national pediatric health care policies, guidelines and initiatives (Coyne & Harder, 2011; Flynn et al., 2006). As an example of a global initiative in promoting children’s participation, the World Health Organization’s ‘Adolescent friendly health services: An agenda for change’ (WHO, 2003) initiative aims to meet the unique needs of children aged 10-19 in the delivery of health services. According to this report, “the participation of young people is needed to provide relevant, acceptable and effective health

services” (WHO, 2003, p. 42). Similarly, in a European context, the Council of Europe’s ‘guidelines on child-friendly health care’ (Council of Europe, 2011) was set out to promote policies to deliver “child-oriented services based on child-specific developmental needs and evolving capacities, ensuring children’s participation at every level of decision-making in accordance with their age and degree of maturity” (p. 5). Aligning with the UNCRC (1989), these guidelines “recognize children as bearers of rights, including the right to the enjoyment of the highest attainable standard of health” (Council of Europe, 2011, p. 4).

In addition to the UNCRC, children’s participation in decision-making has been promoted by regional legal guidelines and charters published by (inter)national health care associations. A particularly well-known charter is the ‘Charter of the European Association for Children in Hospital’ (EACH) ¹⁵, published in 1988 – shortly before all European countries ratified the UNCRC (EACH, 2016). The EACH charter “calls upon all governments, policy-makers, staff in hospitals and in all other health care facilities to respect the needs and rights of all children and their families” (EACH, 2016, p. 3). Similar to the UNCRC, the EACH charter contains ten articles that endorse children’s rights before, during and after hospitalization regardless of age, disability, origin, social or cultural background (EACH, 2016). Since its publication, the EACH has become a widely accepted European standard of recognizing the rights of sick children (EACH, 2016). In several European countries, including the Netherlands, Germany, and Italy, the EACH has served as a basis for health care legislation and professional guidelines (EACH, 2016). In the Charter, Articles Four¹⁶ and Five¹⁷ are particularly relevant to children’s participation.

¹⁵ EACH is an international umbrella organization open to European non-governmental, non-profit national associations involved in the welfare of children in hospital and other health care services (EACH, 2016).

¹⁶ Article Four stipulates that “children and parents shall have the right to be informed in a manner appropriate to age and understanding” (EACH, 2016, p. 11), in which children also have the right to “express and have their views taken into consideration” (p. 13).

¹⁷ Article Five denotes that “children and parents have the right to informed participation in all decisions involving their health care” (EACH, 2016, p. 15).

Local professional pediatric health groups and associations such as the American Academy of Pediatrics (2016) and the Canadian Pediatric Society (2004) have also issued policy statements that promote the case for children’s decision-making rights in pediatric care delivery. The Canadian Pediatric Society, for example, stipulates that: “Children and adolescents should be involved in decision-making to an increasing degree as they develop, until they are capable of making their own decisions about treatment” (p. 99). As written policies, guidelines and documents informed by children’s rights principles can have the power to shape what a child can or can’t do in any given society (Montà, 2021), they can have important implications for children’s participation in health care practices.

2.4.1.1 Family-Centered Approaches to Pediatric Health Care Delivery

In health care contexts, children’s opportunities for participation in decision-making can also be influenced by family-centered care (FCC) principles. FCC is a widely used standard (Kuo et al., 2012), model (Nicholas et al., 2014; Shields et al., 2006, 2007), foundation (Butler et al., 2014) or philosophical approach (Carter et al., 2014; Gerlach & Varcoe, 2021) to informing the design, delivery and evaluation of pediatric health care practices and policy development. FCC explicitly incorporates children’s participation in decision-making and therefore promotes a recognition of children’s agency in pediatric health care (Coyne et al., 2016).

FCC broadly involves a partnership approach to health care decision-making between children, caregivers, and health care providers to improve policy, programs and infrastructure (Hill et al., 2017; Kuo et al., 2012). Health care providers are expected to recognize and strengthen families’ knowledge and skills whilst creating the ‘right’ environment for the child (Coyne, Hallström, et al., 2016). The central attributes of FCC are building trust, listening to caregivers’ concerns, valuing caregiver knowledge of their child (Smith et al., 2015). However, these attributes

are not necessarily applicable to children and therefore remain adult-focused (Clark, 2016; Coyne et al., 2018a; Coyne, Hallström, et al., 2016).

From a FCC approach, the child is always perceived as belonging to a family, but “the child is the key and active agent in the partnership and should be at the center of thinking and practice” (Coyne et al., 2018, p. 53). Families' needs will differ from the child's depending on the situation. Since FCC recognizes that “the child is included as an actor by its own, getting space, being respected and involved in communication by receiving information, discussing options, voicing preferences to negotiate and make choices” (Coyne et al., 2016, p. 498), FCC has been considered as an appropriate mechanism to promote children’s participation in their own care and decisions (Sew Pien, 2010).

While FCC is a strongly valued and widespread approach to delivering pediatric care (Nicholas et al., 2014), FCC has also been faced with significant conceptual and practical critiques and challenges. A consistent and unanimous definition of FCC is lacking (Nicholas et al., 2014; Söderbäck et al., 2011) and the interchangeable use of different kinds of ‘centeredness’ (i.e, child-, person-, client-, patient- and/or family-centered care) to denote the focus of care can create confusion despite sharing more conceptual similarities than differences (Coyne et al., 2018b). As a result, misunderstandings and confusion persist about what FCC and their associated terms mean (Coyne et al., 2018; Kuo et al., 2012).

Limited evidence on the scope and quality of the implementation of FCC also suggests that FCC continues to be insufficiently implemented into clinical practice (Coyne et al., 2018b; A. Gerlach & Varcoe, 2021; Jeremic et al., 2016; Kuo et al., 2012; Nicholas et al., 2014). From the perspectives of pediatric nurses, for example, the philosophy of ‘parent partnership’ encapsulated by FCC does not adequately address the actual experiences of children, caregivers and nurses in hospitals (Coyne & Cowley, 2007). Furthermore, FCC has also paid inadequate attention to children

and families whose health and health care is compromised by social and structural factors (e.g., racialization, poverty), creating the potential for promoting health and health care inequities (Gerlach & Varcoe, 2021).

Considering these critiques, and the dearth of high quality research on the implementation and outcomes of FCC (Gerlach & Varcoe, 2021; Kuo et al., 2012; Shields et al., 2007), system-level changes are required in order to fully implement ‘true’ FCC that is inclusive for all children and families. Despite that the “sharing of power” acts as an overarching goal in FCC health policies, these policies do not fully capture the different ways in which power can (unequally) operate in clinical health encounters (Nimmon & Stenfors-Hayes, 2016, p. 1). FCC-related policies must therefore pay more attention to the issues of power, contextual factors, and agency to align with the realities of health care encounters and environments (Ocloo et al., 2020).

2.4.1.2 Children’s Consent to Medical Treatment

Within health care organizations, legal guidelines on children’s informed consent to medical treatment further guide the ways in which children can participate in making ‘major’ decisions (Kuther, 2003). Informed consent incorporates two duties: disclosing information to patients and their caregivers and obtaining legal authorization before undertaking any health interventions (Katz et al., 2016). Informed consent has roots in ethical theory and law, in which a respect for children’s personal autonomy forms the moral basis for the concept of informed consent (Katz et al., 2016). Children are frequently believed to “lack the agency required to be truly autonomous agents” (Katz et al., 2016, p. 2) primarily due to developmental, age-based ideas on children’s decision-making capacity and competence¹⁸. As noted by the American Academy of Pediatrics (Katz et al., 2016):

¹⁸ Capacity and competence are concepts that are frequently blurred in medical discourse (Katz et al., 2016). Capacity is a clinical determination that addresses the integrity of mental abilities. Competence is a legal determination that addresses society’s interest in restricting decision-making when capacity is in question. Health care providers can determine whether a child is *capable* of making decisions, while courts generally determine children’s *competence* (Katz et al., 2016).

“pediatric practice is unique in that developmental maturation allows, over time, for increasing inclusion of the child’s opinion in medical decision-making in clinical practice and research” (p. 1).

In pediatric health care, obtaining children’s (age-based) informed consent remains a challenging endeavor as children’s capacity to consent can be shaped by health care provider relationships, previous knowledge, a child’s (changing) health status, as well as emotional and religious considerations (Lipstein et al., 2012; Salbatello et al., 2018). Cases in which children refuse treatment can be also emotionally and ethically challenging for caregivers and health care providers and can further influence informed consent procedures (Katz et al., 2016). Moreover, in the presence of critical or palliative illness, for example, relying on children’s individual liberties and autonomy may not always be “realistic or legally accepted” (Katz et al., 2016, p. 2). In these circumstances, adults such as caregivers or other surrogates must provide ‘informed permission’ for medical treatment, with the possible assent¹⁹ of the child in cases when a treatment or intervention is not required (Katz et al., 2016).

The concept of pediatric assent, however, has been met with limited understanding and endorsement among health care providers (Katz & Webb, 2016) and “can mean many things” (Salbatello et al., 2018, p. 2). Children’s assent has been equated to children’s consent (without the legally binding authority) or a way of making “doctors, lawyers, and bioethicists ‘feel better’ without truly empowering children to participate in decisions” (Salbatello et al., 2018, p. 2). Regardless of children’s level of involvement in informed consent processes, Katz et al. (2016) emphasize the importance of providing the child with “as much control over the actual treatment as possible” (p. 8) (e.g., choosing the location of the catheter placement).

¹⁹ The concept of assent pertains to reaching an agreement of a child who is not able to give legal consent and is essential in recognizing and respecting any child’s intrinsic value (Coughlin, 2018).

The challenges associated with informed consent processes become further heightened in the recognition that the statutory ‘legally accepted’ age of consent to medical treatment can vary considerably between countries (Alderson, 2007). In the Netherlands, the Dutch Medical Treatments Contracts Act (WGBO)²⁰ stipulates that caregivers make decisions on behalf of children aged 12 and younger (Hein et al., 2012). For children aged 12 to 16, informed consent is required from children and their caregiver(s), provided the child is ‘competent’ to decide. Physicians are, however, legally obligated to inform children older than 12 years about the therapeutic prospects and options that are available to them (Sabatello et al., 2018). For children aged 16 and older, children are deemed fully competent in medical decision-making (Hein et al., 2012). Obtaining children’s consent therefore requires contextualization in terms of who is (legally) involved in decision-making and where it takes place (Salbatello et al., 2018).

In contrast to the Netherlands, Canadian legal guidelines do not tie children’s decision-making capacity to children’s age. Ontario, Alberta, British Columbia, Manitoba and Saskatchewan, for example, do not identify a minimum age at which children can consent to health care (Coughlin, 2018). Rather, these provinces follow the ‘mature minor doctrine’, which recognizes that the level of patient understanding of the nature and consequences of the treatment have determinants beyond age (Coughlin, 2018). Determining the decision-making capacities of children therefore mirrors that of adults and involves demonstrating an understanding of 1) the magnitude of the intervention, 2) the probabilities of harm and benefit, and 3) the consequences of consent or refusal (Coughlin, 2018).

²⁰ The WGBO stands for ‘Wet Geneeskundige Behandelovereenkomst’ (KNMG, n.d.) and governs the relationship between health care providers and patients.

2.4.1.2.1 Children’s Age-Based Decision-Making ‘Capacities’

Closely related to how developmentalist discourses dominate children’s consent to medical treatment processes outlined in Section 2.3.1.1, the assumption that children’s age is the most accurate determining factor for a child’s decision-making ‘competence’ prevails in health care practices (Dorscheidt & Doek, 2018). However, age-based standards for determining children’s competence have been criticized for disregarding (especially younger) children’s individual abilities and previous health care experiences in shaping their capacities for making decisions, including providing informed consent (Alderson, 2007). Rather than relying on age as a single determinant of decision-making competence, factors such as social experience, maturity, psychological state (Alderson, 2007; Hein et al., 2012), moral intelligence (Katz et al., 2016) can shape children’s decision-making.

In terms of children’s age, it is reasonable to assume that two-year-old children will be less able to make ‘major’ decisions about their care compared to 12-year-olds (Carter et al., 2014). However, young children can be attributed with varying levels of decision-making capacities. Children as young as two have also been shown to know the names and purpose of their cancer drugs (Kendrick et al., 1986). Similarly, children aged between three and four years with chronic conditions such as cystic fibrosis or diabetes are knowledgeable about the importance of food intake (i.e., limiting sugar) (Alderson et al., 2005; Alderson et al., 2006). Even infants can be attributed with participation rights since they ‘speak’ in an expressive language of sounds, facial expressions and body movements that can be ‘read’ and understood as a means of participating in social relationships (Alderson et al., 2005). These findings are suggestive of significant “sense-making abilities” (Alderson, 2007, p. 2277) to underscore children’s decision-making capacities.

Young children with significant health care experiences, particularly long-term conditions, can also be “highly informed [but] dismissed as ‘precocious’ or ‘outliers’ (Alderson, 2007, p. 2276).

As these children may know more about their illness and health care than children with acute or emergency conditions, they may be able to evaluate potential treatment options (Alderson, 2007). A sole focus on age in informed consent legislation may inadvertently exclude some children who *want* to take part in various forms of decision making and are capable of doing so (Hein et al., 2012). Therefore, (inter)national, institutional and professional guidelines, including informed consent procedures, may need to be assessed on a more individualized basis than is presently the case (Hein et al., 2012).

2.4.2 Time Constraints

According to health care providers, insufficient time for including children in decision-making due to heavy workloads acts as an additional organizational factor that can constrain children's participation (Aarthun & Akerjordet, 2014; Boland et al., 2019; Quaye et al., 2019; Runeson et al., 2001; Schenker et al., 2011). In the face of the realities of clinical practices, shared decision-making, for example, has been described as “effortful and [as] taking time to integrate into practice” (Abrines-Jaume et al., 2016, p. 28). However, limited evidence exists that incorporating children in decision-making takes more time in practice (Schenker et al., 2011).

When health care providers take time to secure a relationship with a child and prepare children for medical procedures, the child's possibility of participating in decision-making increases (Runeson et al., 2001). Thus, it could be suggested that “time spent on SDM is time spent ‘differently’ with the potential to increase downstream efficiencies, treatment adherence, and build decision-making capacity in children” (Boland et al., 2019, p. 20). Enabling children's decision-making requires health organization structures, policies and practices to ensure that there is time allocated to involving children in decision-making, including in professional training opportunities, for example (O'Connor et al., 2021a; Runeson et al., 2001).

2.4.3 Fostering a ‘Culture of Participation’

In the context of health care organizations, an additional and interrelated factor that can further shape children’s participation in decision-making pertains to the state of the organizational ‘culture of participation’ (Gallagher, 2008; O’Connor et al., 2021b; Vis & Fossum, 2015). An organizational culture of participation relates to the ethos of an organization, shared by all staff and service users which demonstrates a commitment to participation (Gallagher et al., 2012). The development of policies, guidelines and standards in collaboration with children can create and sustain an organizational culture of participation in which children’s participation becomes a standard of practice rather than a ‘once-off’ activity (Boland et al., 2019; O’Connor et al., 2021b; Sinclair, 2004).

Strong organizational cultures of participation are important because children’s participation can be impeded by overly bureaucratic and managerial practice cultures in which a perceived lack of time can hinder to development of trusting relationships between children, families and care providers (Gallagher et al., 2012). Rather than placing institutional accountability for protecting children’s rights solely on health care providers, organizations hold a great deal of responsibility in ensuring that children’s rights to participation are respected and implemented across all levels of health care (London, 2008). Children’s participation can be fostered by increasing attention paid to FCC practices, decreased pressure for maximum consultation lengths, and incorporating SDM in clinical practice guidelines and accreditation standards (Boland et al., 2019; Grad et al., 2017).

A culture of participation requires strong leadership and adaptive health care provider engagement and expertise ‘on the ground’ (Brady, 2020). The values and ideologies of providers and senior level decision-makers should align with the priorities and concerns of children (Brady, 2020). It may also be valuable to identify staff with in-depth understandings of children’s participation (‘participation professionals’) to help ensure that this topic remains on the agenda,

encourage and support the sharing of good practice, and challenge existing practices (Brady, 2017). For organizations to foster a shared commitment to children’s participation, health care providers, decision-makers and ‘participation professionals’ “should be seen as the people who facilitate and enable participation, rather than the only people who ‘do’ it” (Brady, 2020, p. 253).

2.5 Children’s Experiences of Participating in Decision-Making

In order to explore if and how the intended outcomes of children’s participatory initiatives, legislation and policies have been realized in pediatric health care practices, this section attends to pertinent research that sheds light on children’s experiences of participating in decision-making. In discussing children’s experiences of participating in decision-making, this section also reaffirms the presence of various conceptualizations of children’s participation, as well as interpersonal and organizational factors described above in influencing children’s participation. I begin this section with a discussion of children’s experiences of participating in individual decision-making, followed by children’s experiences of being involved in collective decision-making in various (inter)national health care contexts.

2.5.1 Individual Decision-Making

Research based on children’s perspectives on individual decision-making conducted in diverse hospital settings such as palliative care (Dixon-Woods et al., 2002; Hinds et al., 2001), oncology (Coyne, Amory, et al., 2016; Coyne et al., 2014; Gibson et al., 2010; Ruhe et al., 2016; Siew Pien, 2018), occupational therapy (O’Connor et al., 2021b), outpatient care (Quaye et al., 2019) and wider health care (Carter, 2002; Coyne & Gallagher, 2011; Gutman et al., 2018; Runeson et al., 2002a) suggests that children are not sufficiently involved as often or consistently as children desire. The majority of research describes caregivers as proxy decision-makers for children as opposed to obtaining the child’s own views and experiences (Coyne et al., 2014; Dixon-Woods et

al., 2002; Hinds et al., 2001). This finding was also evident in a systematic review of pediatric shared decision-making (SDM), in which “SDM interventions rarely targeted children but mainly focused on parents” (Wyatt et al., 2015, p. 577).

In various health care contexts, children have reported feeling neglected in decision-making processes (Coyne & Kirwan, 2012; Pena & Rojas, 2013) and unhappy about caregivers leading communication with health care providers on children’s behalf (Gibson et al., 2010). Children have been encouraged to make a decision that had in principle already been made by adults (Bray et al., 2012). Children have also expressed receiving insufficient explanation regarding medical procedures (Donnelly & Kilkelly, 2011) and inconsistent information (Sjöberg et al., 2015) to inform their decision-making. For example, hospitalized children on a haematology/oncology unit in Ireland held a minimal role in decision-making as health care providers and caregivers controlled the process of shared decision-making (Coyne et al., 2014).

Few studies report on children’s positive experiences of being involved in health care decision-making in Irish (Coyne et al., 2006; Children’s Hospital Group Board and the Ombudsman for Children Office, 2018), Swedish (Sjöberg et al., 2015) and British (Lambert et al., 2008) children’s hospitals. Sjöberg et al. (2015), for example, demonstrated that children had *some* level of involvement in decision-making in perioperative care and that children felt listened to by having their questions answered. Across three children’s hospitals in Ireland, the majority of hospitalized children reported that health care providers asked them what they thought and listened to what they had to say (Children’s Hospital Group Board and the Ombudsman for Children Office, 2018). However, nearly half of the children also reported that there was room for improvement on how information was shared and how care providers explained and facilitated children’s rights to decision-making (Children’s Hospital Group Board and the Ombudsman for Children Office, 2018). In a systematic review of pediatric health care decision-making literature, Boland et al.

(2019) identified that “most health care providers, parents and children had positive attitudes about SDM” but most children expressed uncertainty about SDM’s utility (p. 20).

Findings that point to children’s marginalization in decision-making processes are problematic since children generally prefer to be active participants in decisions regarding their health care, or at least have the choice to participate (Coyne et al., 2014; Hinds et al., 2001; Moore & Kirk, 2010; Zwaanswijk et al., 2011). While children’s exclusion from decision-making can arise from “a failure to make spaces for children’s participation” (Cornwall, 2008, p. 279), it is also important to highlight the potential (and largely unrecognized) reasons for children’s ‘self-exclusion’ from health care decision-making (Cornwall, 2008). Despite children’s participatory processes being premised on the assumption that *all* children *always* want to participate, children’s preferences for participating in decisions may vary (Ruhe et al., 2016; Siew Pien, 2018; Zwaanswijk et al., 2007). Some children may also not be able to take part in decision-making (e.g., children who are not conscious as a result of critical illness) (Cornwall, 2008), and some children may prefer adults to make decisions on their behalf (Boland et al., 2019; Coyne et al., 2014) which can be based on children’s previous (health care) experiences (Cornwall, 2008). For example, children in a study conducted by Coyne et al. (2014) appeared ‘content’ that adults held responsibility for making ‘major’ treatment decisions. Other hospitalized children have viewed “doctors as knowledgeable and firm decision-makers about their [children’s] care” (Horstman & Bradding, 2002, p. 83), but also expressed a desire for health care providers to provide clear, honest, accurate and more in-depth information to facilitate their decision-making (Horstman & Bradding, 2002; Lambert et al., 2008).

2.5.2 Collective Decision-Making

The facilitation and implementation of children’s collective participation in the commissioning, delivery or evaluation of health services and/or policies lags even further behind

children's participation at the individual level (Blades et al., 2014; Schalkers et al., 2016b). While there have been some reported benefits of collective participation structures such as children's advisory groups, including improved quality of care, cost-savings (Meyers, 2008; Wynn, 2015) and opening dialogue to support 'meaningful' participation (T. M. Collins et al., 2020), pertinent literature also suggests that "children's views are still not universally heard in policy and operational discourses" (Charles & Haines, 2019, p. 140).

In children's forums and councils, children are typically expected to speak for themselves with adults playing a more supportive role in the background as advisors and facilitators (Wyness, 2009). In these contexts, adults can both facilitate and prohibit children's "power to make a real change" (O'Kane et al., 2021, p. 198). According to Wyness (2009), adult agendas prohibited children's full participation in a 'youth council' as adults tried to ensure that the council was 'effective' by re-articulating children's ideas to match institutional priorities of the adult structures. Similarly, in a pediatric hospital in the Netherlands, divergent perspectives between children, caregivers and health providers on the purpose, meaning and execution of children's participation contributed to children's limited involvement in organizational decision-making such as the assessment of hospital services (Schalkers et al., 2016).

Other barriers that have been reported to limit children's opportunities for collective decision-making in children's advisory structures pertain to the lack of high-level mandates to engage children in organization decision-making and governance (O'Kane et al., 2021). In the adult-dominated, hierarchical structure of organizations such as hospitals, children's participation becomes dependent on the individual mindset and motivation of adults rather than strategic prioritization and support (O'Kane et al., 2021). Ethical and logistical challenges, in terms of balancing children's participation and protection, and managing time constraints in obtaining informed consent and compensation to participate in organizational processes have also been

reported as barriers to children's collective decision-making (O'Kane et al., 2021). In turn, children's participation can risk becoming conceptualized as "a nice thing to do if you have time" (Brady, 2021, p. 18), raising concerns about tokenism (Tisdall, 2015). Moreover, when children who have been consulted about health care policies and practices "see nothing happen as a result, self-exclusion [from participation] may be a pragmatic choice" (Cornwall, 2008, p. 280).

2.5.3 A Gap Between Child Participation Practices and Policies

Despite a growing commitment to children's participation on a global scale, these findings suggest that child participation legislation and policies are not always translated into health care practices (Brady, 2017; Jeremic et al., 2016). Children's decision-making processes are often adult-led, limiting children's opportunities for decision-making (Baston, 2008; L.-M. Brady, 2020; O'Connor et al., 2021b; Odigwe, 2004). This suggests that children's participation "boils down to engaging children in marginal choices when *real* decisions are clearly being made elsewhere" (Cornwall, 2008, p. 279). Children's participation therefore does not always present as "clearly and unambiguously" as presented by legal guidelines, policies, and dominant hierarchical theoretical models such as Hart's (1992) ladder of participation (Cornwall, 2008, p. 274). Rather, the boundaries of 'meaningful' participation can become more complex as a result of the engagements of a variety of different actors in participatory processes in different contexts, "each of whom may have a rather different perception of what participation means" (Cornwall, 2008, p. 274).

Compounded by the various factors that can influence children's participation, a lack of guidance also exists on how to facilitate children's participation in legislation, policies, and practices (Percy-Smith et al., 2015). Limited studies exploring the implementation of children's rights (including the UNCRC or the EACH) in health care practices point to the under recognition and unawareness of children's rights to express their opinions about their care in Italian pediatric hospitals (Bisogni et al., 2015) and to information and participation across Europe and Australia

(Simonelli et al., 2010). Collectively, these findings suggest that the implementation of children's participation as outlined by Article 12 is very far from complete (Landsown, 2014).

The implementation of children's participation is further influenced by being under-researched and complicated by conflicting opinions (Brady, 2020; Coyne et al., 2014; Young et al., 2006). A paucity of research explores how participation is understood by those who work with children in health care, and how these understandings may affect participation cultures and practices (Brady, 2017; 2020). As suggested by children's experiences of participating in decision-making, disparities also exist in terms of who participates, the types of decisions children are involved in, and the extent to which participation is meaningful and effective for both children, health care providers and decision-makers (Davey, 2010; Percy-Smith, 2010).

Knowledge and understanding of how to best involve children in health care services is therefore at an early stage (Horgan & Kennan, 2022), contributing to a lack of evidence on the degree of match between children's preferred and actual participation roles during decision-making (Tariman et al., 2010). Knowing the extent to which the rights of hospitalized children, as established by global and regional conventions and charters such as the UNCRC and EACH, respectively, is of paramount importance for developing measures to guarantee the rights of children and their psychosocial wellbeing in hospitals (Bisogni et al., 2015).

2.6 Child Life Practice

In this sub-section, I introduce child life practice by describing the key job responsibilities of child life specialists (CLSs) in the context of North America and the Netherlands. I also briefly discuss the historical development of the child life field, followed by a problematization of developmental discourses in child life practice. I end this sub-section by discussing how the key job responsibilities of CLSs be connected to children's participation rights.

2.6.1 The Historical Development of Child Life Practice

Particularly in Western countries, it is common for health care teams in major pediatric hospitals to include one or multiple providers who are specifically trained to assist children and their families in coping with the stress of hospitalization (Claridge et al., 2020). CLSs represent a type of psychosocial health care provider who are clinically trained in minimizing the negative impacts of illness and injury on children and their families in health care and community settings. CLSs are also referred to as ‘medical pedagogical care providers’ (*medisch pedagogisch zorgverleners*) in the Netherlands, ‘child life therapists’ in Australia (Hyland et al., 2015) or ‘health play therapists’ in the United Kingdom (Pérez-Duarte Mendiola, 2022).

Child life practice represents a relatively novel profession. Prior to the 1950s, pediatric care in Western countries largely neglected the emotional needs of children who were hospitalized (Bisogni et al., 2015; Thompson, 2018). By conducting observational studies, René Spitz (1945) was one of the first researchers to coin the term ‘hospitalism’ to refer to children’s hospitals as ‘psychotoxic’ settings in which children can experience trauma when separated from their caregivers. Emma Plank became a leading authority figure in advocating for the educational, social, and psychological needs of children receiving medical treatment (Thompson, 2018). In 1955, Emma Plank founded the Child Life and Education Division of the Department of Pediatrics at the Cleveland City Hospital (Thompson, 2018). In turn, Plank’s (1962; 1971) professional and academic contributions have become known as key foundations upon which the child life profession is built in North America (Rubin, 2014).

In the Netherlands, the provision of psychosocial care for children was spurred by the development of family-centered care practices after the end of the second World War (Kind & Ziekenhuis, 2018). Alongside increased attention paid to family-centered care practices (e.g., using play-based activities with children and preparing children and families for medical procedures), the

profession ‘medical pedagogical support worker’ was introduced in the 1970s (Kind & Ziekenhuis, 2018). Today, the field of child life continues to grow and evolve on a global scale, reflected in an increasing amount of literature that focuses on child life practice (Boles et al., 2021). Outside pediatric health care contexts, however, child life practice continues to be characterized by a lack of awareness about child life services and responsibilities (Lookabaugh & Ballard, 2018).

2.6.2 Child Life Practice in North America and the Netherlands

In North America, the child life profession is governed by the Association of Child Life Professionals (ACLP), a non-profit organization established in 1982 (ACLP, n.d.). Through the ACLP, CLSs can obtain the regulated credential certified child life specialist (CCLS)²¹. The ACLP maintains professional standards, fosters research, and promotes the standards of child life practice for CCLSs (ACLP, n.d.). In the United States, there are currently over 4,000 CCLSs certified by the ACLP, compared to 367 CCLSs in Canada. Outside North America, fewer CLSSs practice in Japan (61), United Kingdom (10), Singapore (4), and Australia (4), for example (ACLP, 2022). CLSs who are certified by the ACLP require a minimum of a Bachelor’s degree and the successful completion of 10 university courses focusing on various domains (e.g., child life, child development, family systems, play, loss/bereavement, research). Whereas CLSs require a minimum of a Bachelor’s degree, child life assistants require a minimum of an associate’s degree (Lookabaugh & Ballard, 2018).

In a North American context, child life practice is largely grounded in developmental theory²² (Thompson, 2009). CLSs broadly use therapeutic play, education and fostering children’s self-advocacy skills as valuable tools in helping children and their families cope with illness,

²¹ For the purpose of consistency, I refer to CLSs as encompassing all child life ‘professionals’, including certified child life specialists (CLSs), child life assistants, child life specialists who entered practice before the ACLP’s certification requirement was introduced in 1998 in North America.

²² Foundational developmental theories that inform and uphold child life practice include Erikson’s psychosocial theory (1963) and Piaget’s cognitive theory (1959).

trauma, disability, loss, and bereavement while protecting and enhancing children’s development (Boles et al., 2020; Thompson, 2009). CLSs also facilitate patient autonomy in care in the context of providing psychosocial support during medical procedures (e.g., anesthesia inductions, bloodwork, IV line access), for example (Boles et al., 2021; Koller, 2017). While there is limited empirical support specific to child life services (Claridge et al., 2020), Boles et al. (2020) suggest that CLSs can “significantly reduce the financial, developmental, and psychological costs associated with the discomfort and distress that persist far beyond each episode of care” (p. 1).

In the Netherlands, there is no governing body that oversees the practice of CLSs on a similar scale to the ACLP. A Dutch foundation known as ‘Child and Hospital’ (*Kind en Ziekenhuis*) provides a broad overview of the job responsibilities of CLSs in the Netherlands in a published document entitled ‘An expertise profile: Medical pedagogical care provider’ (*Expertiseprofiel: Medisch pedagogisch zorgverlener*) (Kind & Ziekenhuis, 2018). In this document, the job descriptions of CLSs in the Netherlands overlap with their North American counterparts. In the Netherlands, child life practice is also rooted in developmental psychology, child and/or family-centered care and ‘system-focused’ care, which centers the child in their surrounding ‘system’ (e.g., family members, school setting) (Kind & Ziekenhuis, 2018).

The educational requirements of CLSs in the Netherlands consists of a Bachelor’s degree (also known as a ‘Higher Professional Education’ degree – or ‘HBO’ education) from a recognized ‘university of applied sciences’²³ (Kind & Ziekenhuis, 2018). CLSs in the Netherlands often pursue this type of degree in ‘pedagogy’²⁴ (*pedagogiek*) or ‘social work’ (with a specialization in the

²³ In the Netherlands, a university of applied science are practice-oriented, in which academic programs are intended to prepare students for practice in a specific profession. In contrast, universities place an overarching emphasis on research, technical, theoretical and critical thinking.

²⁴ In the Netherlands (as well as Belgium) pedagogy is an independent field of study that focuses on the ways in which adults (parents, educators, teachers) raise and educate children and young people for a specific purpose (Ijzendoorn & Frankrijker, 2005).

[health] care sector for children, youth and families). CLSs also frequently engage in obtaining additional education in medical hypnosis, ‘focus language’²⁵ (*focustaal*), as well as grief/bereavement and ‘infant mental health’ (Kind & Ziekenhuis, 2018).

2.6.3 Developmentalism in Child Life Practice

Aligning with critiques of age-based conceptions of children’s informed consent processes noted in section 2.4.1.2 the prominence of developmental theory in child life practice can be critiqued for similar reasons. Dominant child development theories can promote a singular and standard view of childhood that is particularly problematic when applied to hospitalized children (Koller, 2019). The development of children who are hospitalized and/or sick may not ‘align’ with developmental standards because children’s abilities often develop through experience rather than age (Alderson, 2007; Alderson, Sutcliffe & Curtis, 2005; Black, 2013; James & Curtis, 2012; Koller, 2019). Children’s development and abilities can therefore vary significantly across age groups (Black, 2013; James, 2004; Koller, 2019). For example, children who face adversity such as illness can experience intellectual and physical impairments that impede their ability to attain standardized developmental ‘milestones’ (Craft & Killen, 2007). In contrast, Alderson (2007) noted that children with chronic or long-term illnesses can also “know more than children with acute or emergency conditions”, suggesting that “adversity may increase children’s knowledge, skills, and courage” (p. 2276).

Developmentalist notions, including standardization, measurement, and normalcy, can therefore “problematize difference and promote exclusion” by disregarding potential variations in children’s abilities in different contexts (Black, 2013, p. 745). Developmentalism continues to be applied in child life practice “without any apparent critical appraisal” (Koller, 2019, p. 11), as

²⁵ Focus language refers to a method of framing one’s language use to positively reinforce and distract children from medical procedures, which has been suggested to result in less fear and pain (Kind & Ziekenhuis, 2021b).

reflected in the profession's certification exams, textbooks, and practices (Thompson, 2009).

Therefore, the child life field could benefit from a critical (re)consideration of the benefits, risks and limitations of all theories that inform practice (Koller, 2019).

2.6.4 Connecting Child Life Practice to Children's Participation

Child life practice can be connected to children's participation by considering: (1) the overlap that exists between the documented benefits of children's participation in health care decision-making and the job responsibilities of CLSs, and (2) pertinent literature that sheds light on the value of CLSs in participation in decision-making. As described in Section 2.5, children's participation in decision-making has been associated with increases in children's sense of mastery, control, and confidence (Söderback, Coyne & Harder, 2011; Gilljam et al., 2016). Participation in decision-making can also increase the likelihood of children cooperating in their care by, for example, understanding when and why to take medication (Franklin & Sloper, 2009; Runeson et al., 2002). Moreover, releasing children's fear and uncertainty during hospitalization can also instill a sense of confidence, which creates space for participation, whereas children's fear and uncertainty can create a lack of trust and feelings of stress that can inhibit their participation (Gilljam et al., 2016). These benefits overlap with the key job responsibilities of CLSs, including supporting children's general coping during hospitalization through developmentally appropriate play, education, and advocacy (ACLP, n.d.). CLSs can therefore be considered as being uniquely positioned to facilitate children's participation in decision-making and achieve its document beneficial outcomes.

Pertinent literature linking the role of CLSs to children's participation can further strengthen the notion that CLSs can be valuable health care providers in facilitating children's participation. Scholars have made either direct (Koller, 2017; Mills, 2006; Schalkers et al., 2016) or indirect (Canadian Pediatric Society, 2004; Hannan, 2019; Katz et al., 2016; McConnell & Frafer, 2004;

Thompson, 2009) references to the role of CLSs in shaping children’s participation across North America and Europe. According to the ACLP²⁶, facilitating the participation of children *and* their caregivers in all matters regarding children’s health care is considered a key skill of CLSs (ACLP, 2020). The ability of CLSs to communicate with children in a developmentally appropriate manner, including the use of creative methods (e.g., art, music, storytelling) can facilitate children’s participation (ACLP, 2020; McConnell & Frager, 2004). A key operating principle of the profession outlined by the ACLP also pertains to “advocating for the rights of children and support political, legal and ethical responses to their psychosocial needs” (ACLP, 2001, p. 2). The ACLP has also published a ‘pediatric bill of rights’ (ACLP, 2002) to ‘clearly’ outline the rights of children and caregivers in health care. In the context of the Netherlands, the ‘Child and Hospital’ foundation also explicitly centers the provision of psychosocial care around children’s rights outlined by the UNCRC (United Nations, 1989).

Developmentally-appropriate communication with children about their disease, treatment and care has been considered a key element of children’s participation in health care but is often poorly performed by a range of health care providers (e.g., physicians, nurses) (Coyne, Hallström, et al., 2016). Therefore, the creative methods of communication used by CLSs can enhance children’s understanding of their health and health care and thus allow children to more actively participate in decision-making (ACLP, 2020; Blazin et al., 2018; Coyne, 2008; Coyne et al., 2016; Mills, 2006; Schalkers et al., 2016) and informed consent procedures (Katz et al., 2016).

Furthermore, a position statement published by the Canadian Paediatric Society (2004) further highlights the value of CLSs in children’s decision-making processes by noting CLSs’ “expertise in gaining children’s trust and cooperation” (p. 101). CLSs can facilitate children’s

²⁶ The Association of Child Life Professionals

participation in decision-making by investing time to create a safe space in which children can feel comfortable and empowered to speak about their concerns and ideas (Surko et al., 2005; Todres & Diaz, 2017).

Lastly, key components of child- and/or family-centered care practices that relate to children's decision-making remain at the forefront of child life practice (ACLP, 2020; Lookabaugh & Ballard, 2018). CLSs are educated to focus on the entire family system, in which children and family members "should be actively involved in the care and decision-making processes" (Lookabaugh & Ballard, 2018, p. 1728). For example, through a family-centered lens, CLSs can facilitate caregiver participation in their child's care by implementing the use of 'comfort positioning'²⁷ during medical procedures (ACLP, 2020). In turn, caregiver participation can lessen caregivers' distress, which, in turn, can help children cope with medical experiences (Koller, 2008; Small & Melnyk, 2006; Svendsen et al., 2018).

2.7 Chapter Summary

This chapter provides insights into how various factors can influence children's decision-making processes, including varying theoretical conceptualizations of children's participation, as well as interpersonal and organizational factors. The evidence on children's experiences of participating in decision-making and the uptake of initiatives, guidelines and policies in health care practices points to a "gap between the high tide of the rhetoric of participation and the low tide on effective delivery of improved services" (Badham, 2004, p. 153). The varying factors that can influence children's participation, combined with children's experiences of decision-making, emphasize the challenges of implementing children's 'meaningful' participation into pediatric

²⁷ Comfort positioning is a physical strategy that is frequently used by CLSs (Bandstra et al., 2008) which involves sitting the child in an upright position while being held by their caregiver which has been shown to reduce children's distress, improve cooperation and give caregivers a more active role during procedures (Skaljic et al., 2020).

health care policies and practices (Brady, 2020). While the importance of and willingness to facilitate children's participation have been acknowledged, this does not necessarily mean that children's participation is necessarily implemented in practice (van Bijleveld et al., 2014). There appears to be a disconnect between how children *want* to be involved in decision-making and the reality of children's limited participation in decision-making in health care contexts.

CHAPTER THREE: SITUATING CHILDREN'S PARTICIPATION IN THE CONTEXT OF THE NETHERLANDS

3.1 Chapter Overview

This chapter builds on Chapter Two by situating literature on children's participation in decision-making in the particular context of the Netherlands. Providing a contextual discussion of children's participation offers insight into specific socio-demographic, economic, and organizational considerations that can shape children's participation in this country and aligns with the focused ethnographic research methodology. I open this chapter by reviewing socio-demographic characteristics of the population in the Netherlands, followed by a discussion of the development of the country's child participation agenda. I close this chapter with a discussion of children's experiences of participating in decision-making in Dutch hospitals, and how these findings may align or contrast with similar research findings presented in Chapter Two.

3.2 Socio-Demographic and Economic Overview of the Netherlands

The Netherlands has a population of 17.7 million (CBS²⁸, 2022a), in which the medium age is 43 years and 21% of the population are age 20 and under (CBS, 2021a). The Netherlands is also the fifth most densely populated country in Europe (CBS, 2022). The most densely populated cities are situated around an area known as the 'Randstad', anchored by the cities of Amsterdam, Rotterdam, the Hague, and Utrecht (Index Mundi, 2021).

While most of the population identify as Dutch (79%), various ethnic minority groups include other European ethnicities (5.7%), Turks (2.4%), Indo-Europeans (2.3%), Moroccans (2.2%), Surinamese (2.1%), Caribbeans (0.9%), Poles (0.6%), Chinese (0.3%), Iraqis (0.3%) and other ethnic groups (3.9%). In 2021, 26% of the population in the Netherlands migrated from either

²⁸ CBS stands for 'centraal bureau voor statistiek' or central office of statistics.

a Western (12%) or non-Western country (14%) (CBS, 2022b). Based on these demographics, the Netherlands, alongside the United Kingdom, have traditionally been viewed as the “standard-bearers of EU multiculturalism” in Europe (Mattei & Broeks, 2018, p. 24), particularly in relation to policies aimed at ‘integrating’ minority groups such as immigrants into Dutch society.

The majority of individuals over 15 years of age (75%) speak Dutch as their primary language (CBS, 2021c). Other spoken regional languages include Frisian, Limburgisch and Nedersaksisch (10%) or a regional dialect (5%). A minority of the Dutch population speak primary languages other than Dutch, including English (1.6%), Turkish (0.9%), Arabic (0.8%), Mandarin (0.4%), and Polish (0.4%) (CBS, 2021c).

From an economic perspective, the Netherlands is characterized as a ‘stable’ democratic country with a robust economy being the 18th largest in the world (Harzer & Weber, 2022). This robust economy has contributed to low unemployment rates (6.9%) below the European Union (EU) average of 9.4%, and a well-established educational system (Harzer & Weber, 2022). These factors may contribute to why the Netherlands ranks consistently high on numerous global and European rankings on a number of indices. The Netherlands has ranked sixth on the 2020 World Happiness Report (World Happiness Report, 2020). Similarly, on a range of global rankings published by the United Nations, the Netherlands scores consistently highly, including on population wellbeing, health, and gender equality (United Nations Development Programme, 2019). The Netherlands has also ranked first in a UNICEF report on children’s wellbeing among 29 developed countries, in comparison to Canada’s ranking at number 17 (UNICEF, 2013). Evaluated by children themselves, 95% of children in the Netherlands rated their own lives above the midpoint of the ‘life satisfaction scale’ (including measures such as housing, environment, education, and health) (UNICEF, 2013).

3.2.1 The Dutch Health Care System

In this socio-demographic and economic context, the Dutch health care system has been characterized as ‘inclusive’ (van der Weijden et al., 2017) and “one of the best in the world” (Dorscheidt & Doek, 2018, p. 97). The Netherlands has ranked second on the Euro Health Consumer Index (EHCI), which measured the ‘consumer friendliness’ of 37 health care systems across Europe (EHCI, 2018). This result could be attributed to the Netherlands forming part of the top European countries with the highest costs per capita spent on health care (van der Weijden et al., 2017). For example, there are 3.7 physicians per 1000 inhabitants in the Netherlands, compared to 2.4 physicians per 1000 inhabitants in Canada and 0.2 physicians per 1000 inhabitants in a lower income-country such as Uganda (Dorscheidt & Doek, 2018; Wordbank Data, 2020). Each year, there are over one million children who visit a hospital for admission, outpatient- or day treatment in the Netherlands (Schalkers, 2016). Considering the consistent high rankings of the Netherlands on a myriad of indices related to children’s well-being and health care, the Netherlands offers a fruitful context in which to explore children’s participation in health care.

3.3 The Development of a Child Participation Agenda in the Legislative Context of the Netherlands

In 1948, the Netherlands, as a member state of the United Nations (UN), pledged to foster human rights (e.g., to freedom, security, privacy, education) proposed in the Universal Declaration of Human Rights (UDHR; United Nations, 1948). Shortly after the ratification of the UDHR, a post-World War II ‘wave of interest in children’ as a focus for policy and investment occurred in many Western countries, including the Netherlands (Montà, 2021). During the 1950s through to the 1980s, cultural changes in understandings of family dynamics and children’s agency spurred a particular interest in ‘children’s participation’ in Dutch society. Whereas an authoritarian (i.e., paternal) structure ruled family dynamics in the 1950s, this has gradually changed over time to

emphasize the cultural norm of joint decision-making processes, giving children opportunities to influence decisions in matters affecting them (Brakel & Pickles, 2015).

Shortly after the ratification of the UDHR and spurred by cultural changes in understandings of children and childhood, the Netherlands was among the first countries in the world to ratify the UNCRC in 1995 (United Nations, 1990). The ratification of the UNCRC embedded the articles of the convention, including children's rights to participation, in Dutch legislation and law (Brakel & Pickles, 2015). Today, cultural attitudes towards children's participation in the Netherlands broadly revolve around the notions of 'self-empowerment' and 'autonomy' in the context of 'having a voice' at home in the family, including child rearing practices, as well in local policy development:

Whether it be in school co-decision councils, or a choice in a municipal funding opportunity, the intent and understanding of taking a child's perspective into consideration appears to be to help children be better citizens and better understand their ability and role in society at large... participation [also] improves social and interpersonal competences and skills regarding 'thinking for yourself', 'challenging your thinking' and 'sharing ideas' (Brakel & Pickles, 2015, p. 30).

In the Netherlands, a country-wide commitment to the child participation agenda is reflected in the work of a 'children's rights collective' (*kinderrechtencollectief*), made up of several organizations (e.g., Defence for Children, Save the Children, UNICEF Nederland), work to ensure that children's rights are safeguarded in policy, law and practice (Kinderrechten, 2022). The Dutch 'youth institute' also compiles and disseminates knowledge on matters concerning children, including their participation in policy developments, particularly in the context of education (Nationaal Jeugd Instituut, 2022). Similarly, an association named 'Stichting Alexander' (Alexander Foundation) focuses on the empowerment of children by conducting of child-led research and setting up projects to attend to children's everyday 'problems' they may encounter at school, in health care and general life (e.g., debt, access to municipal services) (Brakel & Pickles, 2015).

As a country that “sets a high standard for human rights protection” (Government of the Netherlands, 2020, p. 5), ‘children’s ministers’ (*kinderministers*) form part of various Dutch government departments, including the Ministry of Digital Affairs and Internal Affairs. These children’s ministers aim to “make policies better and more child-friendly” (Digitale Overheid, 2020, p. 1). On a municipal level of decision-making, 87 ‘children’s mayors’ (*kinderburgemeesters*) also form part of local councils across the country to embed children’s participation in decision-making in all policy matters (Kinderburgemeesters, 2022). The Dutch government funds an umbrella organization entitled the Dutch National Youth Council (*Nationale Jeugdraad*) in which all staff are under 28 years of age to further stimulate and support children’s participation in legislation and political processes (Brakel & Pickles, 2015).

In addition to these initiatives, a country-wide commitment to children’s participation is also reflected in the existence of a national ‘children’s ombudsman’ (*kinderombudsman*). Since 2011, the ombudsman aims to ensure that all government bodies (including hospitals) in the Netherlands respect children’s rights, as laid out by the UNCRC (Kinderombudsman, 2022). The children’s ombudsman published a ‘child rights monitor’ (*kinderrechten monitor*) in the form of a report that provided a thematic overview of the implementation of the UNCRC in the Netherlands (Brakel & Pickles, 2015). In the last published report, the ombudsman called for “putting children’s participation into action” because “there are few opportunities for children to participate in decisions and policies that concern them” (Kinderombudsman, 2015, p. 182), overlapping with findings noted in Chapter Two. The child rights monitor was subsequently halted in 2015 due to being “too labour intensive and resulting in insufficient effects” (van Lomwel, personal communication, July 6, 2022). Similarly, in a national review of the Netherlands’ implementation

of the UNCRC organized by the Dutch Children's Rights Coalition²⁹, a primary area of concern was that children's 'best interests' were not always considered in decision-making processes on a national scale (Eurochild, 2022).

With similar findings to the children's rights monitor and the Children's Rights Coalition, the Dutch central office of statistics publishes annual data on the wellbeing of children in the Netherlands, including the state of children's rights outlined by the UNCRC (CBS, 2021d). Its latest report has "made visible that insufficient data is available to monitor the implementation of the articles outlined by the UNCRC" (CBS, 2021d, p. 132). The report therefore underscored the need for children to be actively involved in any questions on the extent to which their rights are being respected in practice (CBS, 2021d). The report also recommended to "engage in collective discussions concerning how and with which indicators children's rights can be monitored in the Netherlands" (CBS, 2021d, p. 132).

These findings and recommendations that point to the need for strengthening children's opportunities for decision-making and therefore contrast with how the Netherlands has been characterized as demonstrating progressive understandings of children's decision-making in society (Schalkers, 2016). Considering the 'multicultural' nature of the Dutch population, efforts must also be made to increase the low levels of involvement that children who form part of 'at risk' groups currently have in decision-making. Such groups include first- or second-generation migrants, children from lower socio-economic backgrounds, and children with disabilities (Brakel & Pickles, 2015).

²⁹ The Dutch Children's Rights Coalition is an NGO that aims to monitor and implement UNCRC nationally in the Netherlands (Children's Rights International Network, n.d.).

3.3.1 Children’s Participation in Dutch Health Care Contexts

Alongside a strong patient participation movement in the Dutch health care system, the Netherlands has been characterized as “one of the pioneering countries in recognizing the rights of minors to participate in treatment decision-making” (Schalkers et al., 2016, p. 45). At the macro level, patient representatives are increasingly involved in setting national research agendas and developing clinical practice guidelines (van der Weijden et al., 2017). At the micro level (i.e., in clinical-encounters), ‘children’s participation’ in ‘shared decision-making’ (SDM) is on the agenda of patient representative groups, policy makers and professional bodies across the Dutch health care system (Bovenkamp et al., 2010; van der Weijden et al., 2017). SDM even represents a ‘buzzword’ that has inspired a “culture shift in the minds and hearts of health care providers that has started but is still ongoing” (van der Weijden et al., 2017, p. 69). Dorscheid and Doek (2018), for example, have considered it “an achievement that Dutch civil law³⁰ gives formal power of decision-making to ‘competent’ children in health care from the age of 12” (p. 110). The country’s commitment to children’s participation rights is also reflected in its fifth ranking on the ‘KidsRights Index’, an annual global index that measures the extent to which countries are committed to improving the rights of children (KidsRights Index, 2021).

Moreover, the establishments of child and/or family advisory boards/councils in the majority of Dutch pediatric hospitals represents an expression of taking children’s (participation) rights in health care seriously (Dorscheidt & Doek, 2018). However, from the little available evidence that exists on children’s collective participation activities in such councils, children (primarily over 12 years) appear to largely only have a say in ‘soft issues’ such as food options (Brakel & Pickles,

³⁰ As noted in Chapter Two, the Dutch Medical Treatment Contract Act of 1995 stipulates that minors aged 16 and older are capable to decide on their own about medical treatment. Children aged 12–16 have the right to consent to medical treatment with their caregivers’ consent (Kranendonk et al., 2017).

2015). This finding could point to the risk of children's councils acting as a 'checkbox' solution (Brakel & Pickles, 2015).

Further underscoring a country-wide commitment to children's health care participation, pediatrics in the Netherlands has set high quality standards to ensure safe, effective and 'child-friendly care' (Dorscheidt & Doek, 2018). To encapsulate 'child friendly' care, 'patient-centredness' or a child- and/or family-centered care approach to pediatric health care delivery are consistently emphasized in pertinent literature as facilitators of children's shared involvements in health care decision-making (Bovenkamp et al., 2010; Schalkers, 2016).

For example, based on the premises of FCC, an organization known as 'Child and Hospital' (*Stichting Kind en Ziekenhuis*) developed a quality mark (the 'Smiley') to assess the degree to which hospitals deliver 'family integrated care'³¹ (ranked gold, silver, bronze) (Kindenziekenhuis, 2022). This quality assurance mark represents an institutional commitment to children's participation in health care decision-making. For a university teaching hospital, however, this quality assurance mark comes at an annual cost of € 3000, with multiple additional options for purchase (e.g., the implementation of an 'experience monitor'³²) (*ervaringsmonitor*) (Kinderziekenhuis, 2022b).

As an additional example of the Netherlands' commitment to children's health care decision-making, the organization 'Child and Hospital' has also published pertinent documents, including manual for setting up children's advisory councils, (including a manual written for children) (Kind & Ziekenhuis, n.d.), and a 'practical introduction to children's participation' (Kind & Ziekenhuis, 2012). This latter document calls for the structural integration of children's

³¹ Family-integrated care is a model of health care delivery families as partners in the care team, and provides a structure that supports the implementation of family-centered care (Family Integrated Care, 2020).

³² An 'experience monitor' encompasses a digital platform on which children and caregivers can provide feedback on the care received, including likes/dislikes and recommended areas for improvement. The tool can be accessed via: <https://story.storyconnect.nl/index.php/812692?lang=nl>

participation in Dutch children's hospitals by outlining the meaning of children's rights to (meaningful) participation³³ and methods to elicit children's views regarding their care (e.g., photo voice, writing letters to the hospital director) (Kind & Ziekenhuis, 2012).

3.3.1.1 Dutch Legislation on End-of-Life Decision-Making

Advances in the Dutch child participation agenda are also reflected in legal guidelines concerning progressive understandings of pediatric end-of life decision-making. Developments in legislation on children's end-of-life decision-making can be rooted in the historical importance that the Dutch pay to the notion of 'discussability' (*bespreekbaarheid*) – the idea that societal and moral problems can best be discussed by handling them openly (Youngner & Kimsma, 2012). For example, during the 1960s and 1970s, the Dutch followed American scholars in making the issue of death and end-of-life decision-making 'discussable' rather than conceiving of death as a repressive 'taboo' subject (Younger & Kimsma, 2012). In turn, the Netherlands became the first country in the world to legalise euthanasia³⁴, with an officially tolerated euthanasia practice since 1985, leading to a fully-fledged euthanasia law in 2002 (Groenewoud et al., 2021).

Euthanasia involves the intentional termination of the life of a patient by an individual other than the patient at the patient's request (Vizcarrondo, 2014). This can be done at the patient's voluntary request, which has been legally accepted for competent persons older than 16 years of age in the Netherlands since 1985 (Verhagen & Sauer, 2005). More recently, euthanasia for children under 12 was legalized, including the possibility of ending the life of newborns who fulfil strict specific conditions (Vizcarrondo, 2014).

³³ According to the authors, 'meaningful' participation involves aligning the decision-making process with children's experiences, lifeworld and needs, as well as ensuring that the process leads to *change* (Kind & Ziekenhuis, 2012).

³⁴ Euthanasia refers to 'physician-assisted-death' with specific conditions, such as voluntariness, unbearable suffering, and certain procedural requirements (Dorscheidt, 2015).

Of the 200,000 children born in the Netherlands every year, the death of approximately 600 children in their first year of life is preceded by a medical decision regarding the end of life (Verhagen & Sauer, 2005). The ‘Groningen Protocol’ was developed in 2001 to regulate ethically permissible euthanasia (termination of life) practices for infants with either: 1) no chance of survival, 2) very poor prognosis and dependent on intensive care, or 3) hopeless prognosis with ‘unbearable suffering’ (Verhagen & Sauer, 2005). Since newborns are not able to provide informed consent and both caregivers’ informed consent is required (Verhagen & Sauer, 2005), decisions regarding termination of life among newborns highlight the interconnections between the agency of children and adults. Broader, pediatric euthanasia regulations in the Netherlands highlight how individual autonomy and informed consent practices can be adapted to the particular circumstances of end-of-life decision-making.

In the next section, I discuss children’s experiences of participating in pediatric health care settings in the Netherlands and how these findings contrast or align with the research discussed in Chapter Two.

3.3.1.2 Children’s Experiences of Participating in Decision-Making in the Netherlands

Despite promising efforts and initiatives such as FCC policies and children’s councils, studies on children’s experiences of hospitalization in the Netherlands also broadly point to children’s dissatisfaction with their involvements in decision-making – overlapping with the research findings noted in Chapter Two. Solely one, albeit dated research study, reported on children’s increasingly active role in decision-making based on observations of child-doctor-caregiver communication triads over a period of 20 years (Tates & Meeuwesen, 2000). Children’s conversational contributions to these triads were “strongly related to the age of the child” (Tates & Meeuwesen, 2000, p. 151), underscoring developmentalist assumptions about children’s decision-

making noted in Chapter Two. However, the trend towards children's increasing involvements in decision-making is not consistently reflected in more current research.

In a study exploring children's insights on the quality of health care received across eight children's hospitals in the Netherlands, Schalkers (2016) obtained conflicting findings regarding the degree to which children felt listened to and informed about treatment, planning and procedures. While some children felt well-informed, listened to, and expressed a desire to 'have a say' in their treatment, some children (especially children with chronic illnesses) felt insufficiently informed and did not have their decisions taken into account. On occasion, children also felt uncertain about whether they have a choice in decision-making. This study also demonstrated that children articulated multiple priorities for hospital care and services, some of which were acted upon by hospital managers and health care providers (e.g., blinding the doors and windows, child-friendly menus) (Schalkers et al., 2016).

Similar conflicting findings regarding the involvement of children with chronic illnesses in decision-making were also obtained by van Staa et al. (2011), in which some children wanted to be more involved in decision-making while others already felt 'listened to'. Other studies have pointed to children with diabetes feeling 'uninvited' to actively participate in consultations with medical professionals (Dedding et al., 2015) and feeling uncertain about if and when they are 'allowed' to participate (Dedding, 2009), echoing Schalkers (2016). Dedding (2009) also emphasized the prominent role of caregivers and health care providers in children's decision-making processes underscored in Chapter Two.

In contrast to children's experiences of individual decision-making, research reporting on children's involvements in making collective decisions are scarcer. Scholars have discussed patient increasing involvements (i.e., adults) in collective health care decision-making (Bovenkamp et al., 2010), and children's (lack of) involvements in collective decision-making in other contexts, such

as the child protection system (Rap et al., 2019). However, children's involvements in collective health care decision-making (i.e., in children's councils) remain in their infancy in the Netherlands (Schalkers, 2016). This lack of research may be explained by the Dutch legal system denoting that children's participation in collective health care decision-making, as service-users or in policy-making processes, is not a legal requirement (Schalkers, 2016).

3.4 Chapter Summary

This chapter provides insights into the demographic, socio-cultural, legislative, political and economic context in which children's participation is embedded. Children's participation in decision-making has been reflected in Dutch law, regulations, policy documents, as well as national and local initiatives (e.g., child advisory councils). Despite children's participation in decision-making being embedded in Dutch society, limited research on children's experiences of health care decision-making point to children's exclusion from decision-making. This finding reaffirms a lack of evidence for; 1) whether and how children's participation rights are enabled in practice, and 2) whether this has led to improved outcomes for children, service delivery or policy-making (Brady, 2017).

Providing a contextualized discussion of children's participation is important because the values and principles conveyed in policy documents, for example, constitute the political framework in which socio-cultural constructions of children, childhood and children's participation are embedded. Informed by children's rights, this framework can hold the power to shape what children "can do and can be given in a given society", including children's opportunities for decision-making (Montà, 2021, p. 1).

CHAPTER FOUR: THEORETICAL FRAMEWORK

In this chapter, I discuss the (interrelated) theoretical perspectives, concepts, and currents that iteratively evolved to shape the theoretical framework of this focused and critical ethnographic inquiry. I discuss how I became drawn to particular theoretical perspectives, concepts and currents over the course of this research study and how they can generate critical and nuanced understandings of children's agency, autonomy, and children's participation. In the next section, I outline my positionality, including my epistemology and ontology, as well as my rationale for selecting the theoretical perspectives that inform this study.

4.1 Positionality Statement

“Very little in the social field is or can be value-free” (Darwin Holmes, 2020, p. 2). Researchers are therefore encouraged to expand upon how their positionality influenced what the researcher chose to investigate, how the research was conducted, and its outcomes and results (Darwin Holmes, 2020). Positionality describes how the social-historical-political locations and world view³⁵ of the researcher influenced and shaped their research (Coghlan & Brydon-Miller, 2014). In this section, I outline how my positionality informed and shaped my rationale for choosing *what* to study and *how* the research was conducted in the context of the Netherlands, including my alignment with theoretical movements and concepts. I articulate my positionality by adopting a reflexive approach to research, allowing me to unveil how I arrived at certain positions during the knowledge construction process (Darwin Holmes, 2020; Subramani, 2019). In my discussion of reflexivity in Chapter Five, I build on this discussion by outlining how my positionality influenced my relationships with the research participants.

³⁵ One's 'world view' encompasses “where the researcher is coming from” (Darwin Holmes, 2020, p. 1), including **ontological** assumptions (i.e., beliefs about the nature of social reality and what is knowable about the world), **epistemological** assumptions (i.e., beliefs about the nature of knowledge) and assumptions about human nature and agency (i.e., how we interact with our environment and relate to it) (David Holmes, 2020).

My distinct interest and fascination with the notion of children's participation in decision-making in the context of child life practice in the Netherlands was shaped by various 'culturally-ascribed' (i.e., race, nationality, gender, ethnicity) and 'fluid' (i.e., personal life-history and experiences) aspects of my positionality (Darwin Holmes, 2020). During my time spent practicing as a CLS in various acute- and non-acute hospitals across Canada, I gained first-hand insights into children's involvement in various types of decision-making. While I perceived my job responsibilities to ideally position me to attend to children's participation in decision-making, I was struck by children's seemingly limited opportunities for participation in decision-making and the negative effects that this limited involvement can have on children's psychosocial wellbeing. During my time spent practicing as a CLS, I associated children's limited participation in decision-making to various contributing factors.

First, I witnessed that the child life field is predicated on normative and standardized developmental theories that can perpetuate (problematic) assumptions about children's decision-making capacities that are based on age and cognitive 'abilities' (Koller, 2019). I believe that such developmentalist discourses structure "what is knowledge is reasonable, possible and practical" (Sanyal Tudela, 2014, p. 154), leading to the exclusion of particularly young children and children with varying forms of disabilities from decision-making. I also observed how adults involved in children's care, including health care providers and caregivers, can hold varying beliefs and assumptions about children's participation. When contrasting perspectives and beliefs collide in health care encounters, tensions can arise which complicates and hinders children's decision-making.

Moreover, I witnessed that initiatives and policies that are implemented by institutions (i.e., hospital) can facilitate or hinder children's participation. At certain hospitals, children's participation would be directly and clearly implemented in institutional policies. From my

perspective, this would result in practices that clearly facilitated children's involvements in decision-making. For example, one hospital's institutional policy allowed children to be included in interdisciplinary family meetings with the interprofessional health care team, giving children an opportunity to voice their concerns and be included in all matters that concern them. At other hospitals, 'family' meetings would not include children themselves, unless specifically requested. Collectively, these insights led me to perceive children's participation as an inherently complex concept that is shaped by the *people* and *context* in which it occurs. These insights also formed the basis for my assumptions that *all* children are capable of participating in decision-making, albeit to varying degrees in different contexts.

Various other cross-cultural personal, academic, and professional experiences in Belgium, Scotland and the Netherlands allowed me to grow a particular interest in how children's participation in social and civic forms of decision-making appears to be a particularly salient concept in the Netherlands. I was raised in Belgium as a 'third culture kid'³⁶ by a Dutch mother and a German/Danish father. Being in close proximity to the Netherlands, I often travelled to the country to visit family and friends. Complimented by time spent living in and working with children and families in Belgium, Scotland and Canada, my experiences in the Netherlands exposed me to dominant values and principles regarding children's agency and autonomy in Dutch society. In the Netherlands, I witnessed that even young children are generally consistently encouraged to express their own opinions, wishes and desires in all aspects of everyday life, including at home and at school.

These first-hand insights into the role of children's participation in Dutch society formed the basis for my decision to conduct the research in the Netherlands in the context of child life practice.

³⁶ A 'third culture kid' (TCK) refers to a child who spends a significant portion of their developmental years in a culture outside their parents' passport culture(s) (Cockburn, 2002).

This decision, however, was undoubtedly facilitated by my intersecting identities as a white, female, CLS, novel researcher and Dutch/Canadian citizen. Considering that the child life professional workforce continues to be “monopolized by White females” (Koller & Wheelwright, 2020, p. 29), also echoed by Lookabaugh and Ballard (2018), I relied on my identities as a white, female CLS and fluent Dutch-speaker to facilitate access to the field and to build relationships with participants and gatekeepers. Recognizing that one’s personal positionality can vary and evolve according to particular situations and contexts (Darwin Holmes, 2020), these aspects of my positionality led to a certain degree of ‘insiderness’ with research participant groups. This ‘insiderness’ is discussed in more depth in Chapter Five.

4.1.1 Ontology and Epistemology

As a result of these personal, academic, and professional experiences described above, I sought to align myself with theoretical scholarship that respects and honors children’s decision-making capacities and the profound role that adults and hospital policies can have in shaping children’s decision-making in particular sociocultural contexts. A key challenge in conducting this research was the lack of a clearly defined body of literature related to my research questions. I therefore engaged with literature spanning the fields of health studies, law, ethics, psychology, and sociology. Prior to and during the collection and analysis of data, I became drawn to the sociology of childhood, and particularly the ontological thinking offered by critical relational sociological scholarship that is based in sociology (Dépelteau, 2018b; Dépelteau & Powell, 2013; Donati, 1994; Emirbayer, 1997; Kim et al., 2021), nursing (Bell & Balneaves, 2015; Doane & Varcoe, 2021), and medical ethics (Dove et al., 2017; Ho, 2008; Walter & Ross, 2014).

A critical relational sociological perspective informed my relational ontological worldview in which I propose that social relations are the essential basic units of society (Donati, 1994; Raittila & Vuorisalo, 2021). The basic contention of relational ontology is that “the relations between

entities are ontologically more fundamental than the entities themselves” (Wildman, 2010, p. 55). From an epistemological standpoint, this relational sociological scholarship also instilled an epistemological belief that the knowledge generated by this study is constructed through relationships between individuals at a particular time and place. I therefore contend that practices, such as children’s participation, therefore exist in relation to “particular situations and places that give rise to them” (Slife, 2004, p. 157). Collectively, this relational epistemology and ontology can respond to and reinforce the complexities of social reality and knowledge (Gerlach, 2018) in which people, and children’s participation, are both “shaped by and shape other people’s responses, situations, experiences and contexts” (Doane & Varcoe, 2021, p. 77). In section 4.2.2, I further discuss how social constructionism further refined my relational ontology and epistemology.

In the following section, I provide an overview of the sociology of childhood as the overarching theoretical field of inquiry in which I situate my theoretical framework. I outline the historical development of the sociology of childhood and discuss how this field contributed to my theoretical perspective on children as ‘social actors’ in socially constructed childhoods.

4.2 The Sociology of Childhood: Children as Social Actors

The theoretical framework of this research is rooted in an interdisciplinary³⁷, international and critical field of inquiry known as the (new) sociology of childhood pointing to the importance of studying childhood as a conceptual category (James & James, 2004; Jenks, 2004; Kehily, 2008; Matthews, 2007; Qvortrup, 2005; Tisdall & Punch, 2012). Several key concepts or ‘mantra’s’ underlie the sociology of childhood, including children’s agency, social constructionism, and children’s rights (Canosa & Graham, 2020; Tisdall & Punch, 2012). These key concepts supported the development of a conceptual shift in understanding children and childhood by emphasizing

³⁷ The field³⁷ consists of a growing body of interdisciplinary literature with roots in anthropology, history, law, sociology, geography, and psychology (Kehily, 2008).

children's agency and children's contributions to the social environment they inhabit (Mayall, 2002; Morrow, 1996). As a result of this conceptual shift, children were no longer characterized as 'dependents' who are relatively incapable and require care and protection. Rather, the sociology of childhood supports the theoretical perspective that children are social actors – who are entitled to respect, rights and participation (Mukherjee, 2020), encouraging practitioners to focus on children's abilities rather than inabilities (Davis & Smith, 2012).

The sociology of childhood has made significant contributions to the growing child participation agenda through its framing of children as agentic beings (Horgan, 2017). This field therefore informed the rights-based theoretical framework that I adopted in this study to recognize children's agentic decision-making as an ethical and human right in the daily practice of health care providers, including CLSs (Todres & Diaz, 2017). In turn, rooting my research in this theoretical field also allowed me to critically engage with existing assumptions and practices concerning children's participation and children's rights (Brady, 2017). In Chapter Seven, I expand on the key contributions that the sociology of childhood can offer in the context of pediatric health care practices, including child life practice.

In the next section, I briefly discuss the practical and theoretical currents that led to the development of the sociology of childhood, as well as the outcomes of this development in practice and research.

4.2.1 The Historical Development of the Sociology of Childhood

The groundwork for the new sociology of childhood was carried out in the 1970s, most notably in the United States and Germany (Tisdall & Punch, 2012). During this time, the sociology of childhood emerged as a reaction against prevailing views of the child purported by developmental psychology and traditional socialization theories (Corsaro, 2015; James & James, 2004; Quennerstedt & Quennerstedt, 2014). Theories of developmentalism and socialization,

including sociological concerns about the relationship between ‘structure’ and ‘agency’, contributed to the development of a ‘representational crisis’ in the sociology of childhood (Kehily, 2008).

Various scholars, mainly anthropologists and sociologists (Hardman, 1973; MacKay, 1973; Richards, 1974), referred to this crisis as the ‘disappearance of childhood’ (Qvortrup, 2005) or the “conceptual homelessness of childhood” (Qvortrup, 2007, p. 395).

Theories of socialization perpetuated the idea that children should internalise adult-centered societal norms to become ‘competent’ members of society (James & James, 2004; Leonard & Rojek, 2016; Qvortrup, 2005). A major concern with the socialization perspective is that it renders children as ‘incomplete’ and cognitively ‘immature’ “adults in waiting”, rather than as full members of society (Alanen, 2014, p. 3). Similar to theories of socialization, the dominant principles of developmental psychology can construct dominant and universal images of childhood by framing children’s development within rigid, age-based stages of growth (Quennerstedt & Quennerstedt, 2014). Childhood is subsequently perceived as an apprenticeship for adulthood that can be charted through stages related to age and cognitive ability (Gabriel, 2014; Woodhead, 2008), reflecting inherently adultist³⁸ discourses. As developmentalism can be understood as a dimension of ableism (Biermann, 2015), ableist discourses can also contribute to perpetuation of normalized and standardized assumptions about ‘ablebodiedness’ as humanity’s ‘default’ state (Dolmage, 2014). Collectively, theories of socialization and developmentalism contributed to why children were not being taken ‘seriously’ in social science research (James & Prout, 2003; Kehily, 2008; Qvortrup, 2005). Children’s experiences and perspectives were not considered ‘worthy’ of consideration because scholars in the social sciences undermined children’s competencies in interpreting the social world (Leonard & Rojek, 2016; Tisdall & Punch, 2012).

³⁸ Adultist discourses can marginalize and oppress children due to their age and experience (Bettencourt, 2020).

During the 1980s, the new sociology of childhood emerged as a sharp critique of previous theorization and research conducted *on* rather than *with* children (Burman, 2012; Tisdall & Punch, 2012). During this time, scholars such as Jenks (1982, 1996) and Allison and Prout (1997) began to rethink and challenge the view that children were passive recipients of socialization and developmentalism. Spurred by the socio-political conditions of the children's rights movement, including the ratification of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989), scholars in the sociology of childhood began to explore children's own perspectives as well as the social and cultural³⁹ factors impacting children's lives (James & Prout, 1990; Kehily, 2008; Qvortrup, 2005). A commitment to developing a more sensitive awareness of the plurality in childhoods and children's experiences as they construct their own lives (Gabriel, 2014; James & Prout, 1997).

Following the emergence of the sociology of childhood, a growth in focus on childhood studies in academic institutions could be observed, reflected in the launch of international journals such as *Childhood* and *Children's Geographies* (Johnson & West, 2018). Today, the importance of including children's wishes, views and opinions in policy and practice has been taken up in research in fields such as education (Smith, 2007; Stamatovic & Zunic Cicvaric, 2019), domestic family life (Brown & Johnson, 2008; Pećnik et al., 2016), child protection (Bijleveld et al., 2015; Duncan, 2019; Jolles & Wells, 2017; Serbati, 2017; Vis et al., 2011), participatory research (Bradbury-Jones et al., 2018; Mayne & Howitt, 2019; Water et al., 2017), and health care (Bjønness et al., 2020; Coyne, 2008; Coyne et al., 2014; Koller, 2017; Schalkers et al., 2016; Vis et al., 2011; Water et al., 2017).

³⁹ While recognizing that there is no single 'accepted' definition of 'culture', in this study, *culture* refers to "the complex, patterned and socially-acquired beliefs, values, morals, customs, thoughts, actions, communications that are shared and characterized by a group of people or institution" (Hollins, 2009, p. 5) and guide how the social world is organized (Langdon & Wiik, 2010).

4.2.2 Childhood as Socially Constructed

In the sociology of childhood, a multitude of scholars have incorporated at least some aspects of social constructionism as central to their work (Montgomery & Kellet, 2009; Wyness, 2015). In the social sciences, social constructionism represents a social ontology that largely emerged as a critique of positivism and materialism entrenched in the phenomenological work of Husserl (1970) and Schutz (1962) (Kehily, 2008). Husserl (1970) and Schutz (1962) characterized reality and meaning making as fluid and multiple, emerging within interactions. The social sciences broadly consider constructionism as a distinctive vocabulary, idiom, and language for the epistemological interpretation for understanding how knowledge is constructed through social interactions (Holstein & Gubrium, 2008).

Based on the understanding that knowledge of the world is an interpretation between people that is crafted in a contextualized space, a social constructionist perspective is primarily concerned with *what* is constructed and *how* such constructions are produced and unfold (Holstein & Gubrium, 2008). Particularly in relation to childhood, social constructionism assumes that any claims to ‘truth’ and definitive accounts of what childhood ‘should be’ are relative to the particular concept of childhood that society has constructed (King, 2007). From birth, children are attached to childhood as particular *social* and *symbolic* spaces that are socially and culturally constructed (Kjørholt, 2004).

In this study, a theoretical perspective rooted in social constructionism aligns with the ontological and epistemological underpinnings of the ethnographic study methodology (Holstein & Gubrium, 2008). My engagements with social constructionism in the sociology of childhood also allowed me to further refine my relational epistemology (outlined in my positionality statement in Section 4.1) with regards to children and childhood. From an epistemological standpoint, social constructionism provided a way of framing childhood as a social construction that is shaped by

dominant social discourses⁴⁰, ideologies, cultures and values which (re)produce dominant belief systems and change over time and space (May & Mumby, 2004). It is important to attend to the role of discourses, as developmentalist and protectionist discourses (highlighted in Chapter Two) can shed light on how spoken words and text, such as policies, are culturally constructed in a particular time in history aimed at serving certain interests, such as perpetuating implicit ideals of normative, Western childhoods (Kjørholt, 2004).

In the next section, I discuss how my critical engagements with the key ‘mantra’s’ of the sociology of childhood, and critiques thereof, further guided and shaped the theoretical perspectives that I brought to this study regarding children, childhood, children’s agency and children’s participation.

4.3 Engaging with Key Critiques in the Sociology of Childhood

The sociology of childhood also provided me with a theoretical basis for exploring children’s participation by purporting children as knowledge social ‘actors’ in diverse, socially-constructed childhoods (James, 2010; Johnson & West, 2018; Qvortrup et al., 2009). However, in line with the critical ethnographic approach to this study, my engagements with two key critiques directed at the sociology of childhood led me to sharpen and deepen my theoretical perspectives on children and children’s agency. A dominant critique that has been directed at the sociology of childhood relates to the field’s assumption that childhood is socially constructed (Canosa & Graham, 2020). Some have questioned what social constructionism helps the field to achieve theoretically (Alanen, 2015; Spyrou, 2018). The ‘motto’ that childhood is socially constructed is “simply a mantra and not theoretically articulated to a significant degree” (Ba, 2021, p. 74). While

⁴⁰ Discourses can be understood as “linguistic and communicative practices that reflect particular notions of social phenomenon such as children and childhood at a particular time and in a particular place” (Kjørholt, 2004, p. 42).

some scholars have characterized social constructionism as a critical enterprise⁴¹ (Burr, 2015; Elder-Vass, 2012; Jørgensen & Phillips, 2002), Tisdall and Punch (2012) contend that the social construction of reality leads the sociology of childhood to become “complacent and uncritical on a more theoretical level” (p. 251).

A second and interrelated key critique that has been directed at the sociology of childhood pertains to conceptual weaknesses associated with individualized understandings of children’s agency (Canosa & Graham, 2020; Hanson, 2016; Tisdall & Punch, 2012). As discussed in chapter Two, agency has traditionally been understood as a child’s “capacity or incapacity of making autonomous choices” (Hanson, 2016, p. 471). This traditional, individualized conception of children’s agency in the sociology of childhood, in which children make ‘autonomous’ choices, has been critiqued for disregarding the complex and multidimensional nature of children’s agency, and associated autonomy, in a range of contexts, including health care (Doane & Varcoe, 2021). This conceptualization of children’s agency therefore largely ignores “the negative, challenging and limiting contexts where such agency is circumscribed or not possible” (Tisdall, 2012, p. 185), including instances where children’s expressions of agency go against moral values and social order⁴² (Tisdall, 2016).

As a result of these conceptual ‘flaws’ regarding social constructionism and children’s agency, scholars (Abebe, 2019; Alanen, 2011; Alanen & Mayall, 2002; Mayall, 2001; Hammersley, 2016; Oswell, 2013; Prout, 2000; Qvortrup, 2005; Spyrou, 2018; Valentine, 2011; Wyness, 2006) in the sociology of childhood began to critically account for contextual factors, including adult-driven

⁴¹ Social constructionism can be perceived as a critical enterprise in challenging taken-for-granted knowledge, rejecting inherently positivist, realist, neutral and objective interpretations and observations of the social world (Burr, 2018; Holstein & Gubrium, 2008). Constructionism can unmask dominant, taken-for-granted understandings of socially-constructed concepts such as race, gender and children’s participation by attending to discursive practices in the social world (Holstein & Gubrium, 2008; Jørgensen & Phillips, 2002).

⁴² Such as in situations associated with child labour and child soldiers in regions of the Global South, for example (Canosa & Graham, 2021).

processes, in shaping conceptualizations of childhood and children's agency. During the initial stage of my research (i.e., literature review), unequal child-adult relations were identified as a prominent barrier to children's participation, as noted in Chapter Two. With this finding in mind, during later (i.e., data collection and analysis) stages of my research, I questioned how a theoretical framework rooted in the sociology of childhood, that does not engage with more critical dialogues on children, childhood, and children's agency, could attend to the relational and inherent complex narratives on children's participation in health care contexts. In turn, I chose to position my theoretical perspective on children's agency within a relational ontology "to avoid the pitfall of considering children's agency an essential identity, position or characteristic" (Tisdall, 2016, p. 365).

In the next section, I expand on my conceptualization of relationality rooted in sociology and how relationality became embedded in the sociology of childhood. Following this discussion, I introduce children's interdependent agency (Abebe, 2019) and relational autonomy (Dove et al., 2017; Ho, 2008; Walter & Ross, 2014) as two interrelated approaches towards generating relational and complex understandings of children's participation.

4.3.1 Relationality in Sociological Scholarship

My emphasis on a relational approach to children's agency, and their associated participation, is rooted in the 'relational turn' in the broader field of sociology (Crossley, 2010; Dépelteau & Powell, 2013; Gabriel, 2017, 2021). Relational ontologies are rooted in poststructuralism (e.g., Gallagher, 2008; Oswell, 2013), feminism (e.g., Anderson, 2017; Greene & Hogan, 2005) and posthumanism (Barad, 2001; Fox & Alldred, 2017). The field of sociology emerged in the first half of the 19th century to respond to questions about "the meaning of, and the transformations in, social relations of knowledge" (Keller, 2011, p. 43). Initiated by Italian sociologist and philosopher Pierpaolo Donati (1994), the relational 'turn' in sociology refers to the

‘epistemological rupture’ that occurred in describing, understanding, and explaining social and cultural phenomena as inherently relational in nature rather than purporting a ‘static’ view of the social world (Fernandes, 2016). This epistemological rupture was rooted in the early relational philosophy proposed by Marx, who contended that “society does not consist of individuals, but expresses the sum of interrelations, the relations within which these individual stand (Marx, 1973, p. 265). This philosophy was also embedded in the work of American sociologist Mustafa Emirbayer, whose ‘manifesto for a relational sociology’ published in 1997 became one of the most quoted articles on relationality in sociology (Alanen, 2011). In the manifesto, he states: “Sociologists today are faced with a fundamental dilemma: whether to conceive of the social world as consisting primarily in substances or in processes, in static ‘things’ or in dynamic, unfolding relations” (Emirbayer, 1997, p. 281).

The main aim of relational sociological scholarship is to challenge the objectivist and deterministic assumption that isolated individuals are driven by internal properties, and that social phenomena are only driven by external and solid social ‘structures’ (e.g., societies and institutions) (Dépelteau & Powell, 2013). Relational scholarship assumes the position that social phenomena are dynamic and fluid processes in which social actors and social structures are interdependent (Dépelteau & Powell, 2013, p. 16). From this perspective, society can become conceptualized as a network of social relations (Fernandes, 2016) in which our so-called objects (e.g., societies, institutions, social patterns, social classes) are perceived in a processual way, that is, as being made of fluid, dynamic relations” (Dépelteau, 2018a, p. 445). The relations between individuals and social structures can “influence decisions, actions and choices, and forms the context for the unfolding of everyday life” (Smart, 2011, p. 18).

4.3.2 Relationality in Sociological Scholarship on Children: Relational Autonomy and Interdependent Agency

Coinciding with the broader field of sociology, scholarship in the sociology of childhood also aligned with the ‘relational turn’ to rethink and challenge the nature of knowledge on children, childhood and children’s agency (Alanen, 2011; Gabriel, 2014). According to Alanen (2011), this relational turn revolved around “moving the sociology of childhood field forward by making transparent the ontology on which research is based and knowledge is generated” (Alanen, 2011, p. 21). As a result, the sociology of childhood began to critically account for the role of social contexts, including relationships between children and adults, in shaping childhood and children’s decision-making capacities (Leonard, 2016; Prout, 2011). A ‘relational’ turn in the sociology of childhood also fostered a deeper understanding of the diversities in (plural) childhoods and differences in how children develop in the sociology of childhood (Twum-Danso Imoh, 2016).

Building on the relational turn in the sociology of childhood, Carnevale et al. (2020) in Canada, proposed an “ontological advancement for childhood studies” referred to as ‘childhood ethics’ in order to move beyond individualistic conceptions of personhood, agency and autonomy (p. 112). A childhood ethics lens aims to illuminate the ethical implications of understanding children’s agency as being relationally embedded (Carnevale et al., 2015, 2020). Carnevale et al. (2020) proposed that “agency is not ‘individualistic autonomy’ because the views of others are ethically significant for agents” (p. 113); aligning with a relational or ‘thick’ conception of children’s ‘voices’⁴³ (Carnevale, 2020). A sole recognition of children’s agency therefore does not always entail a full accommodation of their decisional preferences (Carnevale et al., 2020). Considering the paucity of knowledge on how agency should be recognized in practice and policy,

⁴³ According to Carnevale (2020), a ‘thick’ conception of children’s ‘voices’ recognizes that children’s expressions are relationally embedded expressions of their agency.

this ethical ontology may further clarify and strengthen the theoretical relational framing of children's decision-making processes that I have adopted in this research.

In the 'relational turn' in the sociology of childhood and childhood ethics (Carnevale et al., 2015, 2020), the interrelated concepts of 'relational autonomy' (Baumann, 2008; Bell & Balneaves, 2015; Dove et al., 2017; Gómez-Vírveda & Usanos, 2021; Ho, 2008) and interdependent agency (Abebe, 2019) also hold particular implications for understanding children's decision-making. Relational autonomy developed as a result of feminist critiques directed at 'atomistic' ideals of personhood that portrayed individuals as self-sufficient and abstracted from the social relationships in which moral agents are embedded (Schlosser, 2019). Relational autonomy therefore counters traditional Western bioethical paradigms for medical decision-making in which children are seen as independent decision-makers guided by rational logic (Salbatello et al., 2018). This concept has been applied to children's participation in health care contexts to highlight the social contexts in which decision-making occurs (Baumann, 2008; Bell & Balneaves, 2015; Dove et al., 2017; Gómez-Vírveda & Usanos, 2021; Heidenreich et al., 2018; Ho, 2008; Walter & Ross, 2014). In this research, a relational conception of autonomy provides a more nuanced interpretation of this individualistic conception of autonomy to include social context, including health care providers and caregivers, in children's decision-making (Ho, 2008; Walter & Ross, 2014).

To compliment a relational view of children's autonomy, I also draw on the concept 'interdependent agency' to further conceptualize children's participation in health care decision-making (Abebe, 2019; Schlosser, 2019). Relational views of children's agency derive from relational accounts of autonomy (Schlosser, 2019), further emphasizing the interdependency between the complimentary concepts of agency, autonomy and participation highlighted in Chapter Two (Kalaja & Ruohotie-Lyhty, 2021; Sutterlüty & Tisdall, 2019). Similar to children's autonomy, an interdependent view of children's agency "goes beyond the recognition that children are social

actors to reveal the contexts and relational processes within which their everyday agency unfolds” (Abebe, 2019, p. 1). This perspective builds on ‘traditional’, ‘micro-constructionist’ views of agency, which have (problematically) equated children with ‘being a social actor’ with an independent ‘voice’ (Alanen, 2011; Jenks, 2005; Lundy, 2007).

In the following section, I introduce a distinct, yet complimentary theoretical concept or approach to health care practice known as ‘relational inquiry’ (Doane & Varcoe, 2021) to further shape the inherently relational theoretical framework of this study.

4.3.3 Relational Inquiry

My draw to relational ontologies on children’s agency and autonomy informed my alignment with a concept known as ‘relational inquiry’ that is rooted in nursing scholarship (Doane & Varcoe, 2021). Relational inquiry is a pragmatic, self-reflective and critical approach to health care practice and knowledge development with emancipatory political aims (Doane & Varcoe, 2021). Its central premise is that:

It is the relational interplay between the intrapersonal (what happens within the people involved), interpersonal (what happens between and among individuals) and contextual (what happens around people in terms of structures and forces) dimensions that shapes and determines people’s experiences and actions in health care situations (Doane & Varcoe, 2021, p. 29).

The two key components of relational inquiry are a ‘relational orientation’ and ‘inquiring action’ (Doane & Varcoe, 2021). A relational orientation involves ‘going beyond’ the interpersonal level to examine the intrapersonal, interpersonal, and contextual dimensions of health care. ‘Inquiring action’ involves continually asking questions of yourself *about* other people, not only *of* other people to gain a wider and deeper understanding of health care situations (Doane & Varcoe, 2021). In assessing a patient, a nurse, for example, may ask themselves questions about how they may be

influencing the situation, which factors may be influencing the patient, and how the wider context may be shaping the nurse, the patient, and the exchange.

During the data analysis stage of my research, it became evident to me that I required a practical, yet critical theoretical lens to engage with rather than reduce the complexities of health care practices that were reflected in participants' narratives (Doane & Varcoe, 2021). I therefore became drawn to relational inquiry for its ability to attend to complexity in terms of "intentionally turning attention towards the details" in the ways in people, situations, contexts and environments, and processes are integrally connected and shaping each other in the context of health care (Doane & Varcoe, 2021, p. 34).

Relational ontologies are also well positioned to respond to the notion of complexity because relationality "searches for metaphors of mobility, fluidity and complexity" (Gabriel, 2014, p. 122) to perceive society as inherently complex (Qvortrup, 2005). Relationality also resists categorical thinking in favour of recognizing the complexity of children's lives, including the notions of power relations and dominant knowledge claims purported by social discourses in shaping human experience (Frankel & McNamee, 2020; Woermann et al., 2018).

In Chapters Six and Seven, I return to and expand on relational inquiry, children's interdependent agency and relational autonomy in conceptualizing my findings and their implications, respectively. In Chapter Seven, I also discuss how these concepts, as well as a theoretical perspective informed by the sociology of childhood, can be of value to pediatric health care practices, including child life practice.

In the following section, I discuss why relations of power are a central consideration in (sociological) research informed by relational ontologies. I end this upcoming section with a discussion of how I define 'power' in the context of relational scholarship on children, childhood, and children's agency.

4.3.4 Relations of Power

Any knowledge informed by relational ontologies (Dobson, 2015) or produced by sociological scholarship, including the sociology of childhood, is inherently intertwined with power (Kaposy, 2020, p. 95). Sociologist Castells (2016), for example, emphasized the influential presence of power relations in society:

Power relationships are embedded in the institutions of society and particularly within the state, they permeate all dimensions of human activity—particularly in finance, production, consumption, trade, media, communication, culture, health, education, science, technology, and the social construction of space and time (p. 2).

Within the sociology of childhood, however, power is generally under-theorised in discourses on children's participation (Johnson & West, 2018). When power *is* acknowledged in research concerning children and childhood, it can “work to aid the interpretation of children's actions and experiences” (Burman, 2008, p. 221). Focusing on power relations involves critiquing social practices which can also help to advance the critical nature of the sociology of childhood (Wall, 2019).

My conceptualization of power was shaped by relational scholarship in the sociology of childhood. In the sociology of childhood, children's interdependent agency and autonomy direct our attention to relational processes between adulthood and childhood, including how adults use their positions of power to define differences between adults and children (Gabriel, 2014). As a result, agency “needs to be understood against the backdrop of wider fields of power” (Abebe, 2019, p. 6) or as a “product of power” (Valentine, 2011, p. 350). Unequal child-adult relations, and some social and economic conditions may shape children's opportunities for expressing agency. Children's participation can therefore involve children “confronting the power of adult authority, challenging adult assumptions about their competence to speak and make decisions about issues that concern them” (Percy-Smith & Thomas, 2009, p. 22). Relations of power can also adopt a prominent role in

situations where children may prefer adults to make decisions regarding their health care on their behalf (Todres & Diaz, 2017), as noted in Chapter Two.

Based on this scholarship, I propose a relational and discursive definition of power that aligns with Burman (2017) and Kim et al., (2021). According to Burman (2017), power “is not a property to be possessed or exercised by one individual over another, but is a position set out within relationships” (p. 217), in which individuals can adopt multiple positions of power which are made available through discursive practices⁴⁴. A relational, poststructuralist perspective on power offered by Kim et al. (2021) compliments Burman’s (2017) view of power by considering power as a flexible discursive experience, rather than ‘bad’ or ‘good’ (Kim et al., 2021). Kim et al. (2021) contend that “everyone is always participating in relations of power” and that “power cannot be separated from our language, experiences, meanings and discourses” (Kim et al., 2021, p. 153).

Drawing on a relational inquiry approach to nursing (Doane & Varcoe, 2021), my conceptualization of power relations also acknowledges that individuals are situated within (pre-existing) relational networks of power with effects at the interpersonal, intrapersonal and contextual levels (Doane & Varcoe, 2021). Such networks of power are ‘pre-existing’ because “each of us are born into particular social locations and into larger economic, geographic, historical, and social locations” (Doane & Varcoe, 2021, p. 102). One’s position of power in relation to others is determined by their social positioning in a social world that is structured by power-laden factors such as race, class, gender, as well as everyday ‘taken-for-granted’ (ideologies) such as developmentalism, heteronormativity and ableism with perpetuate ideals about ‘normativity’ and ‘ability’ (Doane & Varcoe, 2021).

⁴⁴ Burman (2017) arrives at this definition by considering limitations associated with developmental psychological models that treat individual experience as a possession or property rather than the outcome of structural positions and relationships.

4.4 Conclusion

The theoretical perspectives, currents, and concepts outlined in this chapter that are rooted in sociological and nursing scholarship have framed the theoretical framework that emerged in an iterative and reflexive manner to shape this study. These perspectives, currents and concepts offer distinct ways of understanding children, childhood, children's agency, and autonomy, and how the social world is inherently shaped by power relations. In addition to understanding children's agency and autonomy as interdependent and relational, respectively, relational inquiry offers a complimentary practical, yet critical way of attending to the uncertainty and complexities of health care contexts and practices, including children's participation.

CHAPTER FIVE: METHODOLOGY

5.1 Introduction

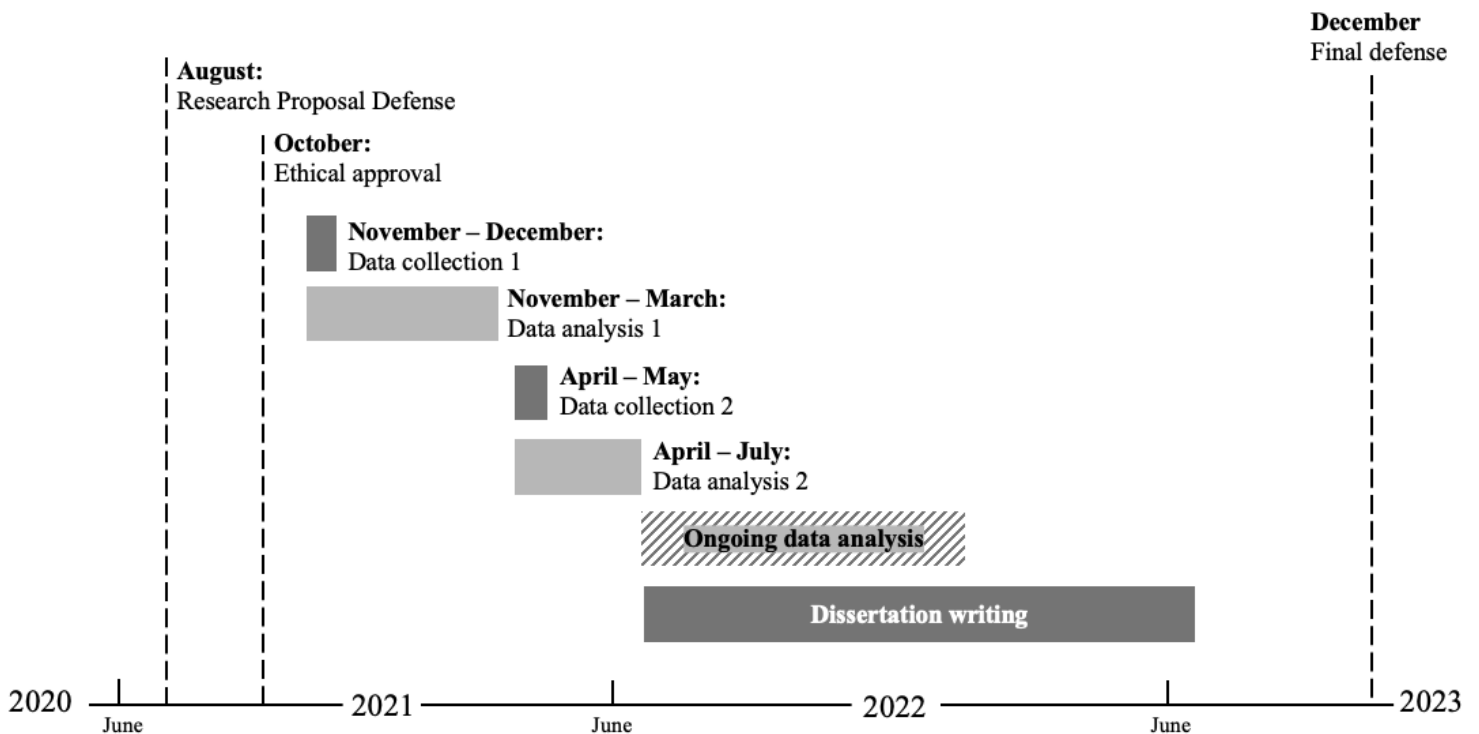
This chapter provides an overview of the key methodological considerations that were included in this study. I discuss my rationale behind selecting a critical and focused ethnographic methodology, including how the key characteristics and epistemological commitments of this methodology align with my study objectives and theoretical perspectives. I also describe the research settings and participant groups, as well as the sampling and participant recruitment strategies. Procedures related to data collection and analysis will be outlined, followed by a discussion of key ethical considerations and study limitations. Throughout this chapter, I refer to how the COVID-19 pandemic impacted the research process, particularly in terms of data collection.

5.2 Research Timeline and a Note on COVID-19

The initial research proposal for this research project was defended in August 2020, as depicted in Figure Seven. During this time, the COVID-19 pandemic caused a significant degree of uncertainty regarding the possibility to recruit participants in hospital settings, both virtually and in-person. To account for this uncertainty, my original research proposal contained two research phases. Phase One involved interviewing CLSs remotely via video-conferencing technology, as well as analyzing relevant professional and institutional documents. Depending on ongoing developments in the pandemic, Phase Two was intended to include in-person interviews with children who have been hospitalized, one or more of their caregivers and CLSs. This phase also included in-person observations of the interactions between children, their caregivers and CLSs in the hospital setting(s).

In October 2020, the Human Research Ethics Board (HREB) of the University of Victoria approved Phase One of this project (certificate of approval included in Appendix A). Data collection Phase ‘One’ began in November 2020, in which I interviewed CLSs via video-conferencing technology. Subsequent to Phase One, ongoing restrictions on travel and hospital visitors (including researchers) in Canada and the Netherlands prevented me from commencing Phase Two (conducting in-person interviews and observations). To account for this (unexpected) development, and to add more in depth and contextual nuance to the research topic, I interviewed hospital directors via video-conferencing technology in April 2021 (referenced as data collection ‘Two’ in Figure Six). Interviews with CLSs were conducted between November to December 2020. Interviews with hospital directors took place from April to May 2021. Data obtained from the interviews were concurrently gathered and initially analyzed between November 2020 and July 2021. From July 2021 to June 2022, additional time was spent analyzing the data throughout the duration of writing the dissertation. The final defense took place in December 2022.

Figure 7: Timeline of Research Project



5.3 Research Design: Critical and Focused Ethnography

As outlined in Chapter One, the research questions were set out to explore how CLSs conceptualized children's participation and consider how children's participation was reflected and embedded in institutional and national policies, laws and guidelines. In order to meet the study objectives, I selected a focused and critical ethnography as the study methodology. In this section, I first discuss why I deemed ethnography to be congruent with the research aims, as well as epistemological and theoretical assumptions. I end this section with a discussion of why I selected focused and critical forms of ethnography.

Ethnography is situated within a qualitative research paradigm, which broadly aims to understand the rich, complex and dynamic texture of social experience by posing 'what', 'why', and 'how' questions (Ritchie et al., 2013). Therefore, a qualitative design aligned with the research questions that guided this study. Within qualitative research, ethnography aims to understand shared cultural⁴⁵ practices and beliefs, and how the social context shapes and is shaped by individuals, collectives, organizations and wider social structures (Rashid et al., 2019). Hospitals can "represent cultures within themselves by reflecting and reinforcing the dominant cultural belief system(s) of the society in which they are located" (van der Geest & Finkler, 2004, p. 1995). Moreover, health care professionals (Chen, Yang, Zhang, & Tan, 2017; Viitanen, Wiili-Peltola, Tampusi-Jarvala, & Lehto, 2007) and individuals who have been hospitalized (James & Curtis, 2012; Langdon & Wiik, 2010) can also hold unique cultural beliefs, values and moral assumptions regarding socio-cultural concepts related to illness, health, and participation in decision-making (Helman, 2000). Therefore,

⁴⁵ I conceptualize culture as "the complex, patterned and socially-acquired beliefs, values, morals, customs, thoughts, actions, communications that are shared and characterized by a group of people or institution" (Hollins, 2009, p. 5) and guide how the social world is organized (Langdon & Wiik, 2010). Culture can therefore be understood as a concept that is "learned, shared and patterned" by specific social groups in particular contexts (Langdon & Wiik, 2010, p. 461), and informs how people define socio-cultural activities (Harrison, 2018).

ethnography enabled me to explore how the research settings and children's participation in health care decision-making could be "mediated and permeated by cultural meaning" (Langdon & Wiik, 2010, p. 461).

Moreover, by "immersing themselves in the field"⁴⁶, ethnographers broadly aim to understand the context of a problem (Rashid et al., 2019). Similarly, my study objectives also intended to understand how context can shape children's participation in decision-making. Despite not having been able to conduct in-person research in the 'field', I also recognized that "simply being in a setting does not mean that the researcher is employing an ethnographic perspective" (Hesse-Biber & Leavy, 2010, p. 135). Rather, in an effort to adapt to the restrictions imposed by the pandemic, I considered the key principles and methods (i.e., interviewing and document analysis) of ethnographic research to allow me to adopt a contextual view of the research problem. I therefore considered children's participation in decision-making at three interconnected 'levels' of (contextual) analysis with relationships within and between these levels standing at the core of knowledge transmission and practices (Rashid et al., 2019). These levels include the micro-level (e.g., patients, caregivers, health care providers), meso-level (e.g., organizations, groups), and macro-level (e.g., historical, legal, political, socio-economic, societal) (Rashid et al., 2019).

Lastly, I deemed ethnography to be appropriate for use in this study because ethnography has been applied to study a wide range of health care-related topics (Atkinson et al., 2001; Hackett & Hayre, 2020; Roberts, 2009). According to Hackett and Hayre (2020), ethnography can offer researchers the opportunity to critically engage with contemporary healthcare and provide the opportunity for innovation and change within a health discipline (Hackett & Hayre, 2020).

⁴⁶ The 'field' refers to the place/space where the ethnographic research is conducted (Harrison, 2018). Participant-observation-based fieldwork is known as the 'core' of traditional ethnography (Reeves et al., 2013). Fieldwork, as a contextual, relational and embodied practice (Sultana, 2007), refers to the researcher's active and prolonged engagement in the setting (i.e., field) under study (Denzin & Lincoln, 2018; Reeves et al., 2013).

5.3.1 Epistemological Commitments

Any selected methodology must align with a researcher's epistemological, ontological, and theoretical assumptions (Hall, 2003). An ethnographic methodology aligned with my epistemological and ontological beliefs that are rooted in social constructionism and relationality, as outlined in Chapter Four. The field of ethnography has become particularly 'captivated' by social constructionism after the 'crisis of representation' that occurred in the social sciences during the 1980s (Burr, 2006; Lindlof & Taylor, 2017). During this time, ethnographers aimed to promote the idea that social reality is inherently linked to human perception and interpretation, thus aligning with interpretivism⁴⁷ (Denzin & Lincoln, 2018; Holstein & Gubrium, 2005). Interpretivism has informed ethnography by describing reality as something that "can only be described from individuals' diverse representations of reality, in which none of them are more 'true' than others" (Chen, Shek & Bu, 2011, p. 133). The study objectives, which were to elicit the (diverse) perspectives of participants regarding children's participation in decision-making in the context of hospitals, align with social constructionism and interpretivism by considering all 'truth' concerning knowledge and reality as socially constructed, plural, and relative to the social and cultural context in which the research occurs (Bélanger et al., 2016; Gergen, 2015; Yudin, 2008).

In addition to social constructionism, ethnography can also be conjoined with relationality (Raittila & Vuorisalo, 2021). As suggested by (Burawoy, 2017) "ethnography has always been relational" (p. 264). Ethnographic research occurs in particular contexts, in which the focus of the research is on local sites of social relations and cultural forms (Hammersley & Atkinson, 2007). Social relations, according to relational ontology, are the essential basic units of society (Donati,

⁴⁷ Interpretivists assume a relativist epistemology in that we cannot separate ourselves from what we know because knowledge is relative to the knower (Denzin & Lincoln, 2018; Pulla & Carter, 2018).

2015). Therefore, the logic underlying relational thinking is compatible with ethnography by focusing on what happens in a particular locale or social institution (Raittila & Vuorisalo, 2021).

5.3.2 Focused Ethnography

Over time, ethnography as a methodology has changed to adapt to the specific needs and contexts of different fields of research (Rashid et al., 2019). Contemporary forms of ethnographic practices, such as focused ethnography, have been developed. Focused ethnography emerged in the 1980s and can be described as the study of more specific, predetermined cultural phenomenon in specific sub-groups in specialized settings (Higginbottom et al., 2013; Knoblauch, 2005; Rashid et al., 2019; Wall, 2015). I employed the use of focused ethnography in this study because its key characteristics align with the research objectives and my personal characteristics as a researcher.

The key characteristics of focused ethnography are:

- 1) The study is guided by specific research questions which may remain open to evolution throughout research process,
- 2) The researcher has a degree of background knowledge of the cultural group/context under study which usually informs the research question(s),
- 3) The intent is to complete relatively short-term field visits in which data saturation dictates sample size, and
- 4) The recruitment of generally small sample sizes to facilitate in-depth study (Hammersley & Atkinson, 2007; Knoblauch, 2005).

Based on these key characteristics, focused ethnography acted as a well-suited methodology to explore a specific phenomenon (i.e., children's participation) among a specific sub-culture (i.e., child life practice) in specific contexts (i.e., two children's hospitals in the Netherlands) while collecting context-sensitive and culturally appropriate data in an efficient, pragmatic, and rapid way (Rashid et al., 2019).

5.3.3 Critical Ethnography

Critical ethnography developed during the 1990s after ethnographers critiqued traditional ethnographies for portraying cultural phenomena in overly essentialist and simplistic manners (Wall, 2015). Howell (2013) defines the key characteristics of critical ethnography as:

- 1) Reflection on the research purpose and intent,
- 2) Identification of consequences and potential harm,
- 3) Ongoing collaboration between researcher and participants,
- 4) Consideration of the relationship between local and general context,
- 5) Reflection on how the research ensures equity.

Critical ethnographers aim to engage in cultural critique by examining larger political, social and economic factors that focus on oppression, conflict, struggle and power relations (Cook, 2005; Palmer & Caldas, 2015; Rashid et al., 2015). By assuming that society is unfair, unequal and oppressive for many people, critical ethnography highlights the role of often hidden and taken-for-granted forces and assumptions at play in particular social settings (May, 1997; Palmer & Caldas, 2017). Since children have been identified as a marginalized community (Biddle, 2017; Razack, 2009), critical ethnographies can explore the ways in which hospitalized children may be excluded, constrained, or repressed in the process of participating in health care decision-making.

Critical ethnography therefore largely differs from traditional ethnographies in that aim of critical ethnography is not simply to describe cultural phenomena, but to generate change in society by advocating for silenced and marginalized populations (Atkinson et al., 2001; May, 1997; Oladele, Richter, Clark, & Laing, 2012; Palmer & Caldas, 2017; Rashid et al., 2015). In this manner, critical ethnography considers the relationships between knowledge, society, systems of power, domination, and political action, while intending to make research relevant to policy and professional practices and contributing to social justice and change (Cook, 2005; Denzin & Lincoln, 2018; Healy, 2001; Wall, 2015).

In its aim to generate ‘change’ in society, critical ethnography is also well suited to attend to the colonialist underpinning of ‘conventional’ ethnography in anthropology, which remains a “troublesome issue” in ethnographic fieldwork (Uddin, 2011, p. 460). While ethnographers have largely shifted away from conducting research on distant ‘Others’, ethnography cannot be separated from the historical context in which it emerged (Pels, 2008; Uddin, 2011). Uddin (2011) suggests that ethnographers can begin to “decolonize ethnography both as a way of doing fieldwork and its product” by practicing reflexivity (p. 463). I believe that the practice of reflexivity can bring attention to relations of power including how I, as a researcher, positioned myself in relation to participants in a postcolonial context (Merriam et al., 2011). While I recognized my privileged position as a female, white, educated researcher, I positioned myself as a learner vis-à-vis participants and engaged in the practice of “listening with raw openness” (Denzin & Lincoln, 2018, p. 250). Therefore, while early colonialist ethnographies represented cultural ‘Others’, I did not subscribe to an ‘insider/outsider’ binary in representing the participants nor my role as a researcher. Ultimately, engaging in ‘countercolonialism’ in research involves analyzing and calling into question the self and world, as well as the conflicts that can arise from privileging particular (universal) ways of knowing (Denzin & Lincoln, 2018). Recognizing such generative issues can be a powerful act and a “necessary beginning to engage in changing social conditions of oppression and injustice” (Denzin & Lincoln, 2018, p. 253).

5.4 Research Settings

The main objective of this study was to explore children’s participation in decision-making from the perspectives of CLSs and hospital directors in the context of the Netherlands. In order to meet this objective, I recruited participants from two large-scale children’s hospitals in different geographical locations in the Netherlands (referred to as hospital A and B). Hospital A and B are

university teaching hospitals that each contain 164 and 150 in-patient pediatric beds, respectively. Each year, approximately 6000 children are admitted to each hospital.

Hospital A was located in the largest city in the Netherlands. In this city, 27% of the population represent ‘children and young people’ between the ages of zero and 25. Moreover, 55% of the population represent immigrants, with Turkey, Surinam and Morocco representing the dominant countries of origin (Centraal Bureau voor Statistiek, 2021a). Hospital B was located in the Netherlands’ sixth-largest city, in which 34% of the population represent ‘children and young people’ between the ages of zero and 25. Moreover, 25% of the population represent immigrants, with the Antilles, Turkey and Surinam representing the dominant countries of origin (Centraal Bureau voor Statistiek, 2021b).

5.4.1 Negotiating Access and Ethical Approval

Approximately one year prior to data collection (and before the onset of the pandemic), I visited three children’s hospitals in the Netherlands, including the two research sites. These visits allowed me to network and connect with individuals practicing at the sites, including CLSs, child life team managers, research department managers, and pediatricians. As a result, I was able to gain insight into how psychosocial care is delivered, the composition of psychosocial care teams, and the design of the hospitals and the working culture(s). During these visits, I was particularly struck by apparent importance paid to children’s participation in all aspects of care delivery. In turn, the visits sparked my interest to conduct research at these particular sites. Pictures of the interior of one of the hospital sites, depicting child-friendly décor and designs, are included in Figure Eight, Nine and 10. Approximately six months after visiting these sites, I inquired about the possibility to conduct research at these sites with departmental child life and research managers. In negotiating access to the hospital, it was helpful to rely on these pre-established relationships with these individuals.

Ethical approval⁴⁸ was obtained by the Human Research Ethics Board (HREB) at the University of Victoria (Appendix A). HREB approval was dependent on the inclusion of written notices of permission to conduct the research from child life team managers and psychosocial research leaders at each hospital. Formal approval from hospital-specific research ethics board was not required as my research did not involve pediatric patients. I was not able to conduct research at a third hospital site since this site required an extensive application to a national and hospital-specific HREB. The time that would be required completing these applications, with the help of a research department manager and postdoc student, was deemed too intensive when weighed against the benefits gained by this research approval.

Overall, the process of negotiating access was a time-consuming process. Particularly translating all relevant documents (e.g., research proposal, study overview, tentative interview question lists) was time-consuming since the documents were required to reflect the professional language and jargon surrounding my topic area in the Dutch language. Negotiating access was further complicated by restrictions put in place as a response to the COVID-19 pandemic. With many health care professionals and hospital administrators working from home, communication was somewhat restricted (i.e., limited possibilities to communicate via phone). Moreover, at the time of negotiating access to the research sites, CLSs were adapting their practices to the hospital restrictions (e.g., no group programming). These issues required me, as a researcher, to approach the process of negotiating access with a great deal of sensitivity and flexibility. Despite these challenges, my research proposal was generally met with enthusiasm, which facilitated the process of negotiating access to the research sites.

⁴⁸ Ethical approval to conduct interviews with hospital directors was obtained through a research amendment submitted to the HREB approximately five months after receiving initial ethical approval.



Figure 8: Interior of hospital unit – artwork on walls (Vasculitis International, n.d.)



Figure 9: Interior of hospital unit – hallway with floor wayfinding markers (Dutch Design Daily, n.d.)



Figure 10: *Interior hospital unit depicting child playing on play structures* (Amsterdam UMC, n.d.).

5.5 Sampling Strategy

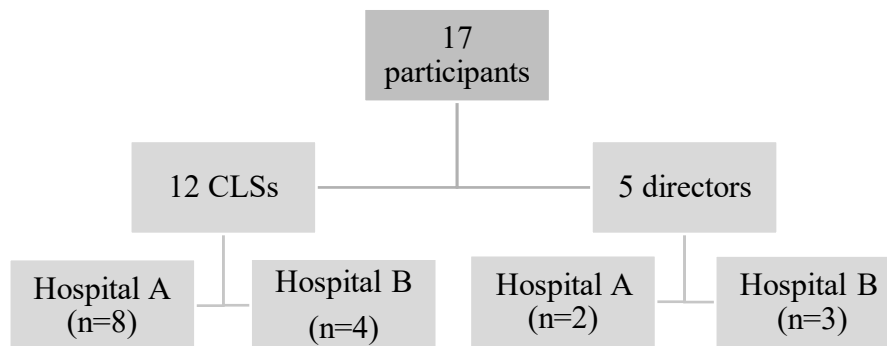
At both research sites, participants were recruited using purposeful sampling. According to Patton (1990)⁴⁹, the logic and power of purposeful sampling lie in selecting ‘information-rich cases’ for in-depth study. Information-rich cases represent those who provide “a great deal of insight about issues of central importance to the purpose of the inquiry” (Suri, 2011, p. 3). I selected purposeful sampling because this method of recruitment is most frequently used in focused ethnographies (Higginbottom, Pillay & Boadu, 2013). Purposeful sampling also aligned with the research objectives because it allowed for selecting participants based on specific, pre-determined characteristics. Since I considered the participants as ‘experts’ knowledge holders about their

⁴⁹ Patton (1990) has been referred to as a frequently cited author or an ‘authority’ on purposeful sampling by proposing 16 strategies for purposeful sampling in qualitative research (Suri, 2011).

professional practice(s) (Raheim et al., 2016), purposeful sampling also aligned with my theoretical, ontological, and epistemological assumptions. Overall, the sample size was not predetermined but was dictated by obtaining data saturation⁵⁰ and ensuring that the sample represented diversity in terms of participant age, background, and levels of experience to obtain rich perspectives on the research questions.

As depicted in Figure 11, the total research sample consisted of 17 participants (N=17), including CLSs (n=12) and hospital directors (n=5). The professional titles of hospital directors are listed in Table One, below:

Figure 11: Overview of Participant Sample



Participant ID	Hospital	Title
DIR01	B	- Manager children’s advisory council
DIR02	B	- Supervisor children’s advisory council - Physician - Minor appointment as researcher
DIR03	B	- Head of pediatrics department - Pediatrician - Attorney
DIR04	A	- Executive board member - Physician (non-active)
DIR05	A	- Hospital Director - Head of Department of Pediatrics and Division Chair - Pediatrician

Table One: Overview of Professional Titles of Hospital ‘Directors

⁵⁰ Data saturation refers to the recruitment of participants until the topic has been fully investigated and no new interpretations are generated from additional participation (Cruz & Higginbottom, 2013).

5.5.1 Inclusion Criteria

No restrictive inclusion criteria were set to increase the possibility to obtain a participant sample that was diverse in terms of participant age, background, and experience in the field. For CLSs, the inclusion criteria were:

- 1) Practicing as a CLS for an any amount of time (i.e., ranging from new hires to senior CLSs),
- 2) Working on a casual, part-time or full-time basis.

For hospital directors, the sole inclusion criteria pertained to holding professional job responsibilities that relate to the organizational development, oversight and/or implementation of children's decision-making across the health care context(s), such as a unit manager or director of a specific department. No criteria were set regarding the length of time in practice or working on a full-time, part-time, or casual basis.

5.6 Participant Recruitment

Two groups of participants were recruited in this study, including CLSs and hospital directors across two children's hospitals in the Netherlands. In line with the research questions outlined in Section 1.4, CLSs were recruited to gain in-depth understandings of their experiences with children's participation rights. As outlined in Section 5.7, restrictions to in-person contact imposed by the pandemic created challenges in recruiting children and families. Hospital directors were therefore recruited with the understanding that they are particularly well-positioned to provide insights into contextual elements that can shape children's participation rights, such as policies, legislation and/or socio-cultural ideologies. The following sections outline the process of recruiting participants in each group.

5.6.1 Recruitment of CLSs

A third-party recruitment strategy was used to recruit CLSs. At each hospital site, a manager of the psychosocial research department and/or child life department manager distributed an e-mail message to CLSs containing the following items:

- 1) Information about the study⁵¹
- 2) A recruitment poster⁵²
- 3) A web-link to a short video-message⁵³ in which I introduce myself and the objectives of the research.

Following the distribution of the e-mail, CLSs who expressed interest in partaking in this study contacted me directly by e-mail. I replied to participants' e-mails expressing their interest to participate by outlining the process for obtaining consent and providing further information on the study. After responding to any remaining questions about the study, I communicated with each participant to set a date and time for the interview. Overall, the recruitment process was met with very few⁵⁴ challenges.

My primary (ethical) reasoning behind selecting this recruitment strategy was to ensure that CLSs' voluntary decision to participate or not would not influence participants' employment status or relationship with the child life department manager and/or psychosocial research manager.

⁵¹ 'Information' was included on the research objectives, method of data collection, voluntary participation, anonymity, and researcher contact details.

⁵² The recruitment poster (Appendix B) depicted the 'what' (i.e., study background and objectives), 'who' (i.e., inclusion criteria) and 'where' (i.e., methods of data collection) of the study, as well as my personal contact information.

⁵³ The video-message was (privately) uploaded to YouTube by using the 'unlisted' feature which only allows individuals with a direct web-link to access the video.

⁵⁴ The main challenges that arose related to 1) setting a date for the interviews around what is typically known as the busiest time of year (Christmas) for the child life staff, and 2) accounting for the time difference (8 hours) between the location of the researcher (Calgary, Canada) and participants (the Netherlands) in setting up interview times.

However, since participants contacted me directly with an expression of interest to participate, research and child life departmental managers were therefore not aware of which CLSs expressed interest to participate or not and were not recruited as participants. Moreover, documents outlining issues related to consent contained information on the voluntary nature of participation, and that participants' participation or non-participation would not affect participants' employment status nor the relationship between the researcher and the third-party recruiter (child life manager or psychosocial research manager).

5.6.2 Recruitment of Directors

At both hospital sites, individuals who met the inclusion criteria were purposefully contacted via publicly available e-mail addresses found on the hospital websites. An e-mail message was sent to the potential participants containing a brief message with the study background and objectives, as well as my contact information. In the case of two participants, this e-mail message first reached their respective administrative assistant, who then forwarded the message directly to the participants. Participants, or their administrative assistant(s) on participants' behalf, replied to me directly with an expression of interest to participate in the study. Out of six directors who were contacted, five participated in the study.

Following an expression of interest, a date and time was set to conduct the interview with each participant. In this regard, a primary challenge pertained to completing the interviews within the pre-established timeframe. For two directors, the time allotted to complete the interview was shorter (30 minutes) than the proposed (1 hour) due to their busy work schedules. This required several small adaptations to be made to the interview guide to fit within the desired timeframe, while attempting to gain participants' complete and in-depth perspectives on the study topics.

5.6.3 Informed Consent

Prior to commencing each interview, a signed consent form⁵⁵ (English and Dutch version included in Appendix C and D, respectively) was obtained from each participant. Additional time was also allocated to provide a verbal re-iteration of key issues outlined in the consent form prior to beginning the interview. During this time, I verbally re-iterated participants' rights to (a) refuse to participate, (b) refuse to answer a question, (c) withdraw from the interview at any time, and (d) ask the researcher any questions related to the research or the research process before, during or following the interview. Additional time was also allocated to answering any remaining questions about the study.

5.6.4 Overview of Participants

Consistent with the theoretical framing of the study, socio-demographic information was collected regarding CLSs' age, length of time in practice as a CLS, area of practice, ethnicity, gender, languages spoken and educational background. Socio-demographic information was organized by variable and displayed in a visual one-page summary, including graphs and pie chart. A summary of CLSs' socio-demographic information is displayed in Appendix E. Obtaining such socio-demographic information facilitated my ability to consider how intersecting factors related to participants' age and ethnicity, for example, may shape children's participation in decision-making in the first-hand delivery of care. In this manner, I recognized that human experiences, including children's participation in decision-making, are not universal and homogenous in nature (James & James, 2012).

⁵⁵ The consent form outlined (in plain language), the study purpose and objectives, importance of the research, inclusion criteria, what is involved in participating, inconveniences, risks, benefits and provided information on voluntary participation, anonymity, confidentiality, dissemination of results, disposal of data, and contact information.

5.7 Data Collection Methods and Procedures

The main methods of data collection in this study were semi-structured interviewing (via video-conferencing technology), including reflexive memos, and an examination of pertinent documents. Semi-structured interviewing and document analysis represent key ethnographic data collection methods that allow researchers to gain as complete an understanding as possible of people, places, and events of interests (Roper & Shapira, 2000). Remote interviews with children and families or participant observation, as an additional key ethnographic data collection method, were not utilized due to ongoing challenges imposed by COVID-19. In each hospital, I inquired with child life and research department managers about the possibility to utilize this data collection method via video-conferencing technology with or without children and their families. However, the necessary ethical, digital, and practical logistics that accompany this data collection method were deemed as being too time-intensive during a time in which the health care staff were experiencing high workloads and changes to programming brought on by the pandemic.

The following sections will expand on how semi-structured interviewing and critical document analysis were implemented in this study. Particular attention will be devoted to personal reflections on the interview process and the necessity to conduct interviews remotely.

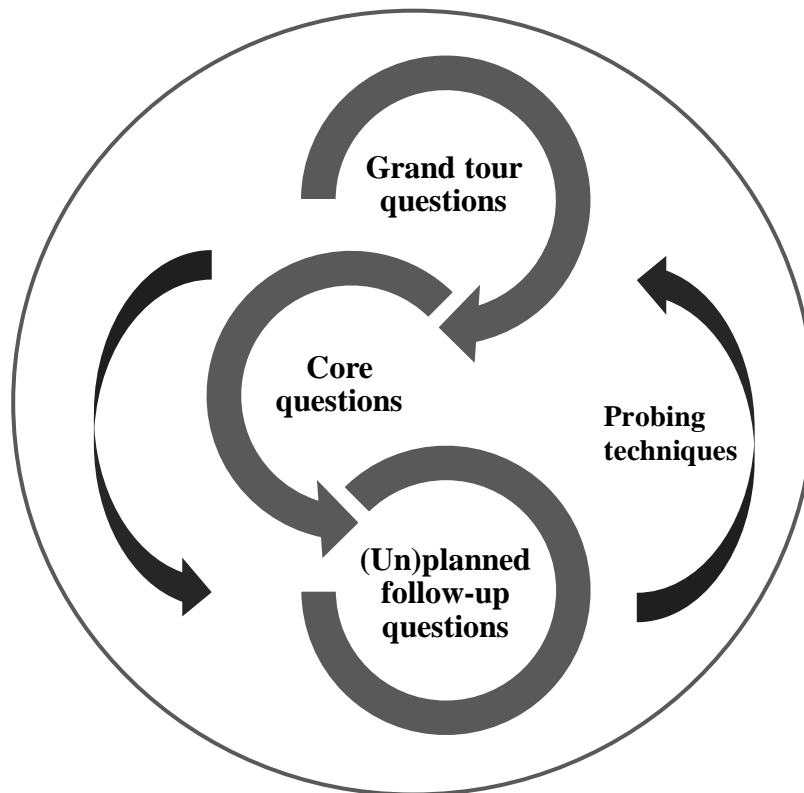
5.7.1 Semi-structured Interviews

Semi-structured interviews were conducted with CLSs ($n = 12$) and directors ($n = 5$) on an individual basis with the aim of understanding the meaning of central themes of participants' lived worlds (Brinkmann & Kvale, 2018). Two directors requested to be interviewed simultaneously due to overlapping job responsibilities. Interviews were conducted with participants over a duration of two months for CLSs and one month for directors. Twelve interviews were conducted via video-conferencing technology applications, including Zoom, Skype and Microsoft Teams according to participants' preferences. These applications were accessed from a secure, university-based server

to assure optimal levels of privacy and safety following a consultation with the university's chief privacy officer. The remaining four interviews were conducted by phone, as per participants' preferences. Each interview ranged from 30 to 80 minutes in length, with an average duration of 60 minutes.

Through ongoing collaboration with my doctoral committee, separate interview guides for CLSs (Appendix F) and directors (Appendix G) were developed to guide the semi-structured interviews. Interview questions for directors were developed after completing interviews with CLSs, as particular issues of interest arose during interviews with CLSs that I wished to discuss with directors. In the interview guides, the semi-structured nature of the interviews allowed me to use a mixture of 'grand tour' questions (1-3 general questions to help initiate interview), 'core' questions (5-10 specific questions that relate to key domains of interest), and (un)planned follow-up questions (questions that ask for more detail) in order to gain insight into participants' life lived worlds (DeJonckheere & Vaughn, 2019). Throughout the interviews, I also consistently used probing techniques (e.g., silence, echoing, verbal agreement, as well as seeking expansion and clarification) to encourage participants to provide further details and providing participants with a sense of reassurance and comfort during the interview (DeJonckheere & Vaughn, 2019). The process of balancing grand tour, core, (un)planned and probing questions is depicted in Figure 12.

Figure 12: Visual Overview of Questions Used During Semi-Structured Interviews



‘Grand’ questions pertained to: “Broadly speaking, what does children’s participation mean to you?” or “in which way(s) do children have a say in their health care in your hospital?”. ‘Core’ questions related to more specific key ‘domains of interest’⁵⁶ to guide the conversations (Angrosino, 2007; Cruz & Higginbottom, 2013). Each interview guide also contained planned follow-up questions, such as “Could you tell me more about that?” or “What do you mean by that?” in order to gain deeper insights into key domains of interest. Unplanned follow-up questions were primarily

⁵⁶ For CLSs, interview questions addressed the following six domains of interest: (1) participants’ descriptions of the meaning of ‘participation’, (2) perspectives on the role of CLSs in children’s participation, (3) challenges associated with children’s participation, (4) perspectives on what may facilitate CLSs’ ability to promote children’s participation, (5) the role of the institution and legal, political, social and cultural ideologies and regulations in shaping children’s participation, and (6) recommendations for child life practice and the institution. For directors, interview questions revolved around: (1) the meaning of children’s participation, (2) who plays a role in shaping children’s participation, (3) children’s involvement in personal and wider, institutional decision-making, and (4) recommendations for health care practices and policies.

informed by non-verbal (e.g., maintenance of eye contact, facial expressions) and verbal cues (e.g., the rate at which participants spoke, tone of voice). To me, these cues often indicated an issue of particular significance for the individual requiring either further elaboration or a shift in conversation topic (Roper & Shapira, 2000).

5.7.1.1 Reflections on Remote Interviewing

In-person interviews have traditionally been the ‘gold standard’ in qualitative data collection as they situate interviews in settings that are often comfortable and familiar to participants and facilitate researchers’ abilities to recognize non-verbal cues (Reñosa et al., 2021). The use of remote interviewing was becoming a more common research method alternative before the COVID-19 pandemic (James & Busher, 2006; Mirick & Wladkowski, 2019; Salmons, 216). However, the social distancing measures introduced during the pandemic has led to a surge in literature on the benefits and challenges of obtaining interview-based data via the use of videoconferencing technology such as Zoom (Gray et al., 2020; Howlett, 2022; Lobe et al., 2020; Naganathan et al., 2022; Oliffe et al., 2021; Reñosa et al., 2021; Wahl-Jorgensen, 2021), including in the context of health care (Archibald et al., 2019). My experiences of conducting remote interviews led me to identify with several benefits and challenges in conducting remote interviews described in this scholarship.

An overarching benefit pertained to the convenience and flexibility of videoconferencing technology to facilitate long-distance communication with a varied sample of participants (Gray et al., 2020; Oliffe et al., 2021). Multi-site remote interviewing led to the elimination of costs that are typically associated with in-person interviews, such as researcher travel and accommodation charges (Archibald et al., 2019; Gray et al., 2020; Johnson et al., 2019; Oliffe et al., 2021). By eliminating the need for travel, videoconferencing in qualitative research can also lead to time savings for the researcher (Gray et al., 2020). As an additional benefit, videoconferencing

technology allowed participants to conduct the interviews in a location that is most comfortable to them, including participants' homes or private hospital office spaces. Being interviewed at home can facilitate 'rich conversations' by increasing participants' sense of comfort and familiarity and encouraging them to talk more freely about their experiences and feelings (Olliffe et al., 2021).

In contrast to these benefits, I also experienced some challenges with conducting interviews via videoconferencing technology. Building remote rapport (Reñosa et al., 2021) with participants was, at times, challenged by unstable internet connections, as well as loud background noises in the hospital settings (e.g., alarms and other PA system announcements). These issues caused some issues with audio quality and led to lag times in conversations between participants and myself (Archibald et al., 2019; Gray et al., 2020; Olliffe et al., 2021). Moreover, these issues also interrupted the 'flow' of several interview conversations, which required me, as the researcher, to remain flexible in taking appropriate pauses to overcome lag times and minimize crosstalk between participants and I (Olliffe et al., 2021). When such lag times were overcome, I reinstated the interviews by either repeating the last interview question or taking the participant's lead in 'resuming' the conversation. During one interview, internet connectivity issues required the interview to be conducted via telephone, which did not allow for the recognition of non-verbal cues (e.g., facial emotions, micro-expressions) to contextualize and augment the transcribed interviews (Olliffe et al., 2021).

While telephone-based interviews omitted participants' non-verbal cues, I also found it challenging to fully attend to participants' non-verbal cues via videoconferencing technology when compared to previous in-person interview experiences. Notwithstanding internet connectivity issues, the quality of the video streams made it difficult to fully attend to participants' micro-expressions (e.g., pursed lips, dropped jaw) (Gray et al., 2020; Olliffe et al., 2021) to inform the 'flow' of the interviews. I consider this issue, as well as not being able to observe participants' full

body language cues (e.g., fidgeting) (Gray et al., 2020; Reñosa et al., 2020), as disadvantages in obtaining interview-based data in qualitative research.

Lastly, while most participants had access to a private office in the hospital to conduct the interviews, several CLSs had limited options for conducting interviews in a quiet and private area of the hospital due to a lack of available portable laptops. Despite encouraging participants to choose a private location to conduct the interview, two CLSs were required to conduct the interview in shared office spaces. Despite wearing personal headphones, the distractions (e.g., colleagues walking in and out of the room) in these shared spaces caused occasional interruptions during the interviews and raised questions about privacy concerns and participants' abilities to share their experiences freely in the presence of other people (Howlett, 2022). Conducting online research during a global pandemic can therefore heighten the complexities associated with consistently ensuring privacy and confidentiality issues in interviews (Howlett, 2022; Reñosa et al., 2020).

5.7.1.2 Reflections on the Interview Process

Before commencing each interview, I implemented a 'briefing' (Brinkmann & Kvale, 2018) in which I explained the topic and purpose of the interview, the use of a sound recorder, and reminded participants of how I intended to maintain participants' privacy and confidentiality, as noted in the consent form. During this time, I also asked participants if they had any remaining questions and asked for participants' permission for me to take written notes (memos) during the interview. In my reflexive memos, I recorded key terms, ideas and beliefs that were raised during the interview, as well as personal reflections on the interview process (e.g., what worked, what worked less well, associated feelings/emotions). While writing memos as interviews progressed, I also began to recognize key similarities and contrasts in participants' statements, indicating that my analysis of the data had begun. I aimed to minimize the possibility that writing notes during the interviews would be perceived as distracting by participants by visually focusing on participants as

often as possible. Conducting video-based interviews also allowed me to take notes out of focus of the camera, minimizing their distractive and obtrusive effects.

Throughout the process of conducting interviews, I gradually became more familiar with the research questions and key domains of interest. As a result, I became increasingly comfortable in relying less on the interview guide, fostering a more ‘informal’ style of dialogue. While aiming for interviews to resemble informal conversations, I noticed a challenge in balancing taking ‘control’ of the conversation versus following participants’ ‘lead’ (Rubin & Rubin, 2005). In order to obtain enough depth and clarity on statements of interest, I relied heavily on the use of follow-up questions and probing techniques. I was therefore highly aware that my role as an interviewer set the interviews apart from everyday ‘conversations’.

Each interview concluded with a *debriefing* (Brinkmann & Kvale, 2018) in which I asked participants about their experiences as an interviewee and concluded with informal conversation. Participants responded positively to their experiences in partaking in this study. During this time, participants were also asked if they would like to receive a summary of the research findings, to which all participants agreed.

5.7.2 Document Analysis

An additional method of data collection included collecting and analyzing pertinent documents. In qualitative research, collecting and analyzing pertinent documents is known as a systematic methodological process for eliciting meaning from documentary data (Wood et al., 2017). Particularly in health care-related research, document analysis has been referred to as “one of the most commonly used and powerful research methods in health policy research” (Dalglish et al., 2020, p. 1424). Rigorous document analysis can enrich other methods such as interviewing by helping researchers critically consider the content, processes, and discourses around health-related policies (Dalglish et al., 2020).

In line with the social constructionist theoretical perspective that I brought to this study, I considered ‘documents’ as “social products representing a reality reflective of wider norms and values, rather than independently ‘adequate’ reflections of fact” (Miller & Alvarado, 2005, p. 351). Document analysis provided additional contextual data to supplement the interview-based data, aligning with ethnography’s aim to capture a holistic view of the lifeways of a population or phenomenon of interest (Roper & Shapira, 2000). Considering that I was not able to implement participant observation as a data collection method, the inclusion of document analysis became essential since documents “may be the most effective means of gathering data when events cannot be observed” (Bowen, 2009, p. 31).

In this study, documents included hospital booklets, pamphlets, and posters that were collected during previous in-person visits to the research sites, as well as web-based national policies, guidelines, informational booklets and other relevant web-pages. A total of 14 documents were analyzed, in which the quality rather than quantity of documents informed the number of documents included as data, given the purpose and design of the study (Bowen, 2009). These 14 documents were included based on their alignment with the research questions. Specific documents (e.g., legislation, hospital posters) that were mentioned during interviews with participants were also included for analysis (e.g., legislation on medical consent, hospital posters).

In the interest of demonstrating transparency in qualitative document analysis (Bowen, 2009), an overview of documents analyzed is included in Appendix H. Additional insights into how I analyzed the documents are provided in the following section describing the data analysis process.

5.8 Data Analysis

In order to make ‘sense’ of what was learned during the research experience, I took a thematic approach to data analysis with the goal of producing a narrative account of children’s participation in two children’s hospitals in the Netherlands. Thematic analysis represents a method

for identifying, analyzing, and interpreting patterns of meaning ('themes') within qualitative data (Clarke & Braun, 2017). Thematically analyzing data aligns with an ethnographic approach to data analysis, which has been referred to as "a process and procedure of breaking up or segmenting raw data into small pieces and then reassembling them into patterns or wholes" (Roper & Shapira, 2000, p. 103).

Thematic analysis is a widely used, yet "poorly demarcated and rarely acknowledged" qualitative analytic method of which various versions and varieties of exist (Braun & Clarke, 2006, p. 77). Recognizing the rich diversity and flexibility of thematic approaches to data analysis (Clarke & Braun, 2017; Willig & Rogers, 2017), my epistemological and ontological orientation(s) informed by relational sociological scholarship and social constructionism shaped how I theorized about the meaning of knowledge (Braun & Clarke, 2006). Through my theoretical lens(es), I considered the purpose of thematic analysis to largely revolve around "interrogating dominant patterns of meaning and theoretically understand language as creating rather than reflecting reality" (Willig & Rogers, 2017, p. 18). I considered 'meaning' to be socially produced and reproduced rather than inhering within individuals, aligning with an interpretive approach to data analysis (Clark & Bluebond-Langner, 2003). Interpretive research considers knowledge to be symbolically mediated by human action and culture, in which language can be seen as a cultural representation (Clark & Bluebond-Langner, 2003). Interpretive research thereby invites the exploration of nuances of meaning within participants' accounts (Braun & Clarke, 2006).

My approach to thematic analysis resembled a 'theoretical thematic analysis' that was shaped by the researcher's theoretical and/or analytic interests, in which research questions can (inductively) evolve throughout the analysis process (Braun & Clarke, 2017). Integral to this approach is the recognition that the researcher is integral to the process of analysis (Braun & Clarke, 2019). Therefore, as I describe in an upcoming section on 'reflexivity', I recognize that the

data analysis represents “something that is created by the researcher, at the intersection of the data, their theoretical and conceptual frameworks, and research skills and experience(s)” (Willig & Rogers, 2017, p. 20).

Analysis of the data commenced during data collection, in which interview and document data were analyzed concurrently and triangulated. Concurrently analyzing these forms of data allowed me to compare and contrast participants’ accounts, as reflections of “*what they say they do*”, with documents, as reflections of “*what people and organizations would like to be thought to be doing*” (Murphy & Dingwall, 2017, p. 66). This aligns with an ethnographic approach to research, in which data analysis is considered a continuous process that begins during data collection, or ‘fieldwork’, and extends into the process of writing (Davis et al., 2008; Punch, 2009). Overall, the data analysis process consisted of several key steps, including: (1) familiarization with the data, (2) generating initial codes, (3) searching for and reviewing themes, (4) defining and naming themes, and (5) producing the report (Braun & Clarke, 2006). Each of these steps are described in more detail below. These steps, however, were not followed in a linear manner. Rather, data was analyzed in an iterative manner, in which I repetitively moved back and forth between data analysis steps. Approaching data analysis in an iterative manner allowed me to adapt data collection and analysis in response to the needs of the study, including, for example, deciding to recruit hospital directors as participants (Mills et al., 2010).

5.8.1 Familiarization With the Data

Becoming familiar with the data, as a first step in the data analysis process, commenced during data collection. During interviews and the collection of pertinent documents, I noted comparisons, contrasts, as well as initial analytic interests and thoughts (Braun & Clarke, 2006). Following completion of the interviews, audio recordings were transcribed verbatim, during which I

wrote additional memos, including noting participant cues that were suggestive of emotions such as laughter, silence, sighing.

5.8.2 Generating Initial Codes

Following familiarization with the data, I began the process of coding⁵⁷ the data in order to identify aspects in the data set that may form the basis of repeated patterns (themes) (Braun & Clarke, 2006). I coded extracts by making (color-coded) notes on each interview transcript and document to indicate noteworthy concepts, ideas, and ideologies, and potential patterns between and among them. During this stage of the data analysis, a critical approach to thematic analysis informed how I coded data excerpts. According to Lawless and Chen (2019), who draw on Foucault (1972), a ‘critical approach’ to thematic analysis accounts for how overarching discourses in the data can be linked to larger social constructions, grand narratives, and social ideologies. Aligning with a critical ethnographic methodology, I therefore aimed to attend to participants’ individual experiences, including participants’ varying (socio)cultural identities, while being aware of the economic, social, historical, and political contexts in which participants’ experiences were situated (Lawless & Chen, 2019). In order to help me implement this critical approach to the coding process, and to adhere to the focused and critical nature of this ethnographic study, I posed various critical questions (Lawless & Chen, 2019; Lincoln, 2017; Mills & Birks, 2014) while coding the data, including:

- “How are everyday discourses enabled and constrained by social systems, dominant ideologies, and power relations?”
- “What knowledges are silenced, privileged, or erased?”
- “What are examples of oppressions that are being made to sound equitable through various discourses?”

⁵⁷ ‘Codes’ refer to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Braun & Clarke, 2006, p. 88).

- What implications does the ethnographic project have for the stakeholders involved? Are there policy implications? How can those implications be disseminated?

During coding of documents, critical questions (Dalglish et al., 2020) included:

- “Under which circumstances was the document produced?”
- “Which voices are (not) represented in the document?”
- “What could be the ‘agenda’ of the document creator(s)?”
- “What was repeated, recurrent and/or forceful in the document?”
- “How does the information from documents compare to interview-based data?”

Following the creation of initial codes, I created two separate codebooks (i.e., one based on CLS interviews, one based on director interviews), in which I grouped all colour-coded notes and associated participant quotes under codes. Codes emerging from document data were included under relevant codes in the codebooks. My doctoral supervisor reviewed the codebooks and several (translated) transcripts, after which I further refined coding categories, including un- or re-coding excerpts and reorganizing codes to remove similar codes.

5.8.3 Searching for and Reviewing Themes

Once I initially coded all data, codes were sorted into potential themes with the aim of re-focusing the analysis at the broader level (Braun & Clarke, 2006). While adhering to the theoretical perspectives that informed my research and data analysis, I visualized the relationship(s) between codes and potential themes, as well as between different levels of themes (e.g., main themes and sub-themes) by manually drawing mind maps. Paper copies of individual participant quotes were also cut out and grouped together on a large paper sheet to create a visual overview of potential major themes and sub-themes. This stage of the analysis process reflected the ‘messy reality’ of qualitative data analysis (Clarke & Braun, 2013), involving multiple rounds of (re)organizing themes (e.g., combining, refining, separating and discarding (sub)themes), returning to the literature and notes, as well as revisiting the study objectives to ensure that potential themes aligned with the

study objectives. This ‘messy’ stage of data analysis also involved multiple conversations with my doctoral supervisor to refine the organization and content of themes and sub-themes.

5.8.4 Defining and Naming Themes

Once I established a set of potential themes and sub-themes, further refinements to the themes were made by ‘applying’ each theme to the raw data (i.e., transcribed interviews). Reviewing at the level of the data excerpts allowed me to consider whether the themes ‘worked’ in relation to the data set, and if any themes were problematic and required modifications (Braun & Clarke, 2006). Minor modifications were made to theme headings and some data excerpts were removed and/or reorganized to align with the themes. Following this process, I displayed an overview of the themes in a digital mind map (see Appendix I) to help me consider the relationship(s) between themes, and the overall story they tell about the data (Braun & Clarke, 2006).

5.8.5 Producing the Report

An established set of themes and sub-themes was incorporated into the research findings, denoting the final stage of data analysis. This phase involved telling the complex ‘story’ of the data by including quotes and excerpts from interview and document data to demonstrate the essence of each (sub)theme (Braun & Clarke, 2006). Following feedback from my doctoral research committee members, the final research findings were written with the aim of reflecting a convincing and analytical narrative that goes beyond description of the data (Braun & Clarke, 2006) in relation to the key research questions. Reaching a point of going ‘beyond’ describing the data, however, occurred over a period of time throughout the duration of the 4 preceding steps, culminating in this final step of producing the report.

5.8.6 A Note on Translation

All interviews were conducted in the Dutch language and documents included for analysis were written in Dutch. Therefore, a key consideration in the data collection and analysis process pertained to translating all sources of data (e.g., interview transcripts, documents) and research materials (e.g., consent forms, interview guides) from Dutch to English, and vice versa. As a native English/Dutch speaker, I initially attempted to maintain equivalence in the translation of texts to capture the essences, nuances and idioms in participant's quotes and document excerpts. In cross-language research, 'equivalence' refers to "the effectiveness of translation in conveying the same meaning as was intended in the language in which the research was conducted" (Mandal, 2018, p. 92). However, during the process of translating, I became aware of the challenges in attaining complete 'equivalence' between two languages. For example, some Dutch words have ambiguous meanings when translated into English, and vice versa (some Dutch words have no English equivalents). I therefore contend that any language is characterized by complex distinctive features which make it impossible to attain absolute equivalence (Baker, 2018; Mandal, 2018). Recognizing the challenges in attaining equivalence in translations in this study, I included full participant quotes in both Dutch and English in the research findings with the aim of capturing the essence of participants' narratives.

5.9 Trustworthiness

This section will discuss the criteria I have chosen to follow in evaluating the methodological *trustworthiness* of the research. Trustworthiness, also referred to as rigour, refers to the degree of confidence in data, interpretation and methods used to ensure the quality of a study (Connelly, 2016). Ethnography is characterized by relative creative autonomy, freedom and flexibility in choosing which particular steps to follow in writing ethnography (Newnham et al.,

2021). While valuing this creative aspect of ethnographic research, establishing *trustworthiness* of the research knowledge, was central to this critical ethnographic inquiry (Denzin & Lincoln, 2008).

Many scholars have proposed varied markers to assess quality in quantitative research (J. Mills & Birks, 2014; O'Brien et al., 2014; Sim & Sharp, 1998; Tracy, 2010; Walsh & Downe, 2006). In this study, I followed original and widely adopted criteria proposed by Guba and Lincoln (1985), which include: **1) credibility, 2) dependability and confirmability, and 3) transferability**, as a guide in ensuring trustworthiness in qualitative research. Some scholars contend that applying fairly prescriptive and generic criteria for the evaluation of qualitative research is antithetical to qualitative research because it imposes boundaries on what is intended to be an open process of discovery (Mills & Birks, 2014). I chose to use the criteria proposed by Guba and Lincoln (1985) due to 1) their pragmatic characteristics, 2) their relevance in ensuring trustworthiness of research for a variety of stakeholders, 3) their alignment with a constructionist approach to qualitative research (Nowell et al., 2017), and 4) their frequent use by funding, ethical and publication review panels (Mills & Birks, 2014). In line with the focused and critical nature of this ethnographic inquiry, I also recognize that the evaluation criteria I chose to apply to the research are not rigid, but rather contextually and temporally bound (Newton et al., 2012).

In the following sections, I discuss the criteria of credibility, dependability, confirmability, and transferability in more detail. I will conclude this section with a discussion of my use of reflexivity as a rigour-enhancing method and important quality criterion in ethnographic research, further aligning with the critical and subjectivist epistemologies that shaped this study (Denzin & Lincoln, 2008b; Korstjens & Moser, 2018).

5.9.1 Credibility

Credibility refers to the 'fit' between participants' views and the researcher's accurate and truthful representation of them (Lincoln & Guba, 1985). In this study, I employed the use of four

credibility-enhancing strategies, including: 1) prolonged engagement with the research context(s), 2) triangulation, 3) member checking, and 4) methodological congruence.

My familiarization with the research fields commenced one year prior to data collection. Scheduling meetings with front-line CLSs and departmental managers, as well as shadowing CLSs in practice, allowed me to build trust and rapport with key individuals involved with this research study. Engaging with and observing the research settings also allowed me gain insights into the context in which the research phenomena were embedded, including daily routines, staffing models, working culture(s) and the physical design of hospital spaces (Cypress, 2017).

Triangulation was implemented in terms of *method* (i.e., by using different data sources and methods of data collection), *theory* (i.e., using different theories to analyze and interpret the data), *space* (i.e., by collecting data at multiple research sites), and *person* (by gathering data from different ‘types’ of individuals, including CLSs and departmental directors and managers) (Guba & Lincoln, 1985). Overall, triangulation acted as a credibility-enhancing strategy to achieve a broader and more in-depth understanding of the phenomenon of interest (N. Carter et al., 2014; Higginbottom et al., 2013; Roper & Shapira, 2000; Santos et al., 2020).

As an additional credibility-enhancing strategy, all participants were provided with a copy of summarized research findings and were invited to discuss their reflections on these findings. An overview of the research and research findings was also presented in a webinar for certified CLSs facilitated by the Association of Child Life Professionals (ACLP) in June 2022. ‘Testing’ the research findings in this webinar provided an opportunity to revisit the data through different perspectives (Korstjens & Moser, 2018) and identify key areas of priority for the inclusion of children in decision-making (including helpful practical strategies, tools and resources). Since this webinar invited CLSs that primarily practice in North American contexts, this webinar also provided an opportunity to apply the findings to a North American context.

Lastly, I employed the use of a credibility-enhancing strategy known as methodological congruence (Mills & Birks, 2014). I attempted to demonstrate methodological congruence by transparently and consistently noting the accordances(s) between my philosophical and theoretical position(s), the stated aims of my research, and the methodological approach I employed to achieve these aims throughout the research process. According to Tracy (2010), achieving ‘meaningful coherence’ between these elements acts as the foundation of credible research.

5.9.2 Dependability and Confirmability

Dependability refers to the stability or consistency of the research findings over time (Lincoln & Guba, 1985). This concept is closely related to confirmability, which pertains to the degree to which findings can be confirmed by other researchers and that the findings clearly derive from the data (Lincoln & Guba, 1985). In order to address issues related to dependability and confirmability, I aimed to ensure that the research process was traceable and clearly documented in a transparent and logical manner (Newnham et al., 2021; Nowell et al., 2017). Throughout conducting research, I kept a written audit trail in which key research developments, decisions and procedures were noted. These developments and decisions have been transparently incorporated in my discussions outlined in this chapter, including decisions related to research design including decisions related to research design (section 4.3), data collection (section 4.7) and analysis (section 4.8). As a result, I aimed to demonstrate procedural logic as a dependability- and confirmability-enhancing strategy (Mills & Birks, 2014).

5.9.3 Transferability

Transferability refers to the degree to which research findings can be transferred to other contexts or settings (Lincoln & Guba, 1985). A key strategy in increasing the degree of transferability pertains to the use of ‘thick’ descriptions (Geertz, 1973) of the research phenomena, in which not ‘just’ behaviors and/or experiences are described, but in which *contextual* factors are

made transparent (Korstjens & Moser, 2018). On one hand, the focused nature of this ethnographic inquiry required me to place a heavy focus on situating participants' accounts in their respective contexts. On the other hand, I recognize that findings generated by ethnographic research cannot be generalized to other settings due to the subjective nature of the interpretations made, and the highly contextual and focused nature of this inquiry (Cruz & Higginbottom, 2013; Mills & Birks, 2014). Thus, rather than aiming to *generalize* the findings, I consider the elements of research expertise, congruence and procedural precision to allow ethnographers to generate a credible, rigorous and authentic account of people's perspectives of a *specific* aspect of their culture in their respective context(s) (Nowell et al., 2017). As a result, I contend that ethnographic findings can inform directions for future practice and insights using similar or different methodologies (Cruz & Higginbottom, 2013).

5.9.4 Reflexivity

In qualitative research, practicing reflexivity⁵⁸ requires researchers to identify, construct, critique and articulate how their positionality⁵⁹ intersects with the research context and process (Mills & Birks, 2014) and research relationships with participants (Darwin Holmes, 2020; Korstjens & Moser, 2018). As discussed in Chapter Four, critical self-reflection on one's positionality acknowledges that researchers are not "separate from the social processes they study" (Darwin Holmes, 2020, p. 3). In this section, I build on my discussion of my positionality outlined in Chapter Four to reflect on how my positionality influenced and shaped my relationships with the research participants. I chose to adopt a reflexive stance throughout the research process to benefit

⁵⁸ I refer to the term 'reflexivity' as involving examining one's own conceptual lens(es), explicit and implicit assumptions, preconceptions and values, and how these may affect all phases of research (Denzin & Lincoln, 2018; Korstjens & Moser, 2018).

⁵⁹ As described in Chapter Four, the term positionality both describes an individual's world view and the position they have chosen to adopt within a research study and its social and political context (Darwin Holmes, 2020).

from its quality-enhancing properties in qualitative research (Mills & Birks, 2014) and to align with the methodological and theoretical perspectives that guided this research (Brown, 2018; Darwin Holmes, 2020; Davies, 2012).

In ethnography, reflexivity is particularly well known for increasing research quality and transparency due to the researcher's "deep immersion in the community or context under study" (Mills & Birks, 2014, p. 93). Reflexivity is also paramount in focused ethnographies since researchers typically have personal experience(s) with the culture or phenomenon being studied (Higginbottom et al., 2013). Moreover, since reflexivity forms an integral part of critical theoretical perspectives to research, I was compelled to critically engage with how my interrelated social divisions (e.g., race, gender, and class) and power, privilege, and life histories shaped the research, and my relationship with research participants (Chapman, 2011; Mills & Birks, 2014).

During the data collection process, I adopted a reflexive stance on how elements of my positionality emerged in and shaped my interactions with research participants. With regards to the widely-discussed 'insider-outsider' dialectic in qualitative research (Darwin Holmes, 2020; Greene, 2014; Savvides et al., 2014; Wiederhold, 2015), I entered the research as an 'outsider' by virtue of my affiliation with a university, formal level of education, and research experience, as well as my relative unfamiliarity with child life practice in the Netherlands and the specific research contexts. However, my identities as a female, Dutch national and CLS also positioned me, to a certain degree, as an 'insider' in the phenomenon under investigation. Therefore, I viewed my role and positioning as a researcher on a complex, multi-faceted continuum rather than as an insider *or* outsider dichotomy (Wiederhold, 2015). Rather, I believe that "we are all multiple insiders and outsiders" (Deutsch, 1981, p. 174). As noted in the memo below, I reflected on doing 'identity work' (Lavis, 2010) during the interview process, noting (seemingly) shared commonalities between the identities of a participant and I:

During this interview, I noticed that the participant the participant and I shared certain elements of our identities/social positionalities. Some of these were made verbally explicit during conversation (e.g., we both speak the same minoritized language, Frisian, that is only spoken in the North of Holland).

Other elements were made apparent more implicitly as they were based on my assumptions that stemmed from (unspoken) visual cues. These visual cues portrayed certain normative ideals about social constructions of race, ethnicity, and gender for example.

While I try to remain cognizant of the dangers inherent to making such assumptions, I wonder if these seemingly shared aspects of our identities helped to facilitate a sense of trust and familiarity during the interview process? This led me to question:

- *Which elements of my multiple identities am I drawing on to facilitate the research process and why?*
- *How may I be perpetuating stereotypes and 'taken-for-granted' based on race and ethnicity?*

As reflected in this memo, a particularly noteworthy element that reflected my 'insider' positioning in the research pertains to the shared level of 'whiteness' among participants and myself. In this regard, I reflected on the potential impacts of predominantly white females representing the child life profession on a global scale, a question also posed by Wheelwright, Ferrer and Porter (2020). As a result of the interviews, I wondered about the invisibility of whiteness in child life practice and how this could contribute to the perpetuation of problematic categories of 'difference' that exclude children and families who do not meet the 'dominant' criteria (e.g., based on visual markers of race or languages spoken) from decision-making. Knowing that the Netherlands receives a high influx of refugees and immigrants, the way in which whiteness appeared to operate in child life practice and those who hold decision-making authority in the health care system emerged as a particularly thought-provoking, yet problematic, element that required much reflection and attention in the data analysis process.

Overall, having a sense of 'lived familiarity' and level of a priori knowledge of the research topic aligns with the focused nature of this ethnographic inquiry and facilitated my ability to build

rapport and trust with participants (Darwin Holmes, 2020; Kerstetter, 2012). In turn, I experienced my 'insider' positioning to diminish the power imbalance that was present by virtue of my role as a researcher (Dwyer & Buckle, 2009; Kerstetter, 2012; Merriam et al., 2001). Other strategies that I employed to mitigate power imbalances between the participants and I included: 1) using plain language to clearly convey both verbally and in writing the voluntary nature of the study, 2) offering flexibility for participants to choose the timing of the interview, 3) ensuring that third-party recruiters nor any other participants will not be made aware of who participated in the study, 4) ensuring that the recruitment e-mail script and consent form clearly state that participants' participation or non-participation will not affect participants' employment status or the relationship between the researcher and the third-party recruiters.

5.10 Ethical Considerations

Since "methodological, epistemological, and ethical dimensions [of research] are intertwined" (Ortega, 2005, p.317), ethical principles pertinent to the protection of participants were integral throughout the entire research process (Pietilä et al., 2020). The importance of developing and adhering to ethical principles can become particularly pronounced in inherently 'vulnerable' and 'sensitive' contexts such as hospitals (Iphofen, 2005; Morse, 2007). In such 'sensitive' contexts, I was particularly mindful of the added burden that was imposed on participants by the COVID-19 pandemic. Thus, I approached the recruitment and data collection phases of the research with due sensitivity to remain cognizant of the fact that participants may have been experiencing disrupted work schedules, higher workloads, and heightened levels of stress, worry and uncertainty.

In this section, I discuss four key elements that I considered essential in conducting ethical research, including: 1) informed consent and voluntary participation, 2) anonymity, confidentiality, and data management, 3) beneficence, and 4) knowledge mobilization.

5.10.1 Informed Consent and Voluntary Participation

The purpose of the ethical principle of informed consent/assent is to provide potential participants with the necessary information in relation to the study so that they can make a voluntary and informed decision on whether to participate in the study or not (Gobo, 2008; Mayeza, 2017). In this study, informed consent was obtained verbally and in writing from participants before commencing the interviews, which purpose, aims, and process of the research study. Attention was also devoted to the voluntary nature of the study, including participants' right to (a) refuse to participate; (b) refuse to answer any question; (c) leave the interview at any time; and (d) ask the researcher any questions related to the research or the research process during or following the interview. During the process of obtaining consent, participants were also informed of the steps taken to protect their anonymity and confidentiality during the analysis and dissemination of the study findings (Gobo, 2008), discussed in more detail below.

5.10.3 Anonymity, Confidentiality and Data Management

To protect participants' confidentiality and anonymity, participants' names were replaced with pseudonyms during the data collection, analysis and reporting stages. The names and locations of the hospitals at which participants practiced were also removed in the data dissemination process. However, certain factors undermined the possibility to fully protect participants' confidentiality and anonymity, including: (a) the recruitment of a relatively small group of participants practicing at each hospital, and (b) the nature of this study's research topic may elicit information on participants' personal identifiers (e.g., length of time in practice, area of practice, language(s) spoken), and (c) the relative small number (eight) of children's hospitals in the Netherlands. Participants were informed of the potential risk of being identified in the study findings and offered the option to withdraw from the study. In the use and disposal of data, all electronic data files (e.g.,

audiotapes, transcripts, documents) were kept on a password-protected laptop. Hard copies of the transcripts, paper records and documents were stored in a locked cabinet in a home office.

5.10.3 Beneficence

In terms of the ethical principle of beneficence, I proposed that participants' participation in this study held the following potential benefits: (1) *practical significance*: participation can be linked to empowering participants to view their practice and lives in different ways, and liberating individuals from injustice, (2) *theoretical significance*: by participating, participants could contribute to extending, building and critiquing disciplinary knowledge regarding children's participation in pediatric healthcare settings, and (3) *heuristic significance*: participation in this study could a variety of audiences, such as policy makers, or the lay public, to engage in action or change regarding children's participation in decision-making (Johansen et al., 2008; Orb et al., 2001). Despite these benefits, I also identified the following risks associated with participation: (1) interview questions may lead participants to discuss challenging and/or emotionally sensitive issues in relation to healthcare, illness, accidents and/or injury, and (2) loss of time. The following six steps were taken in order to minimize and mitigate the severity of these risks: (1) interviews were relatively short in nature (maximum one hour), (2) interview questions were provided prior to commencing interviews, (3) interview questions enquired about participants' general experiences with children's participation, (4) interview questions were not set out to inquire about any other aspects of participants' personal life, (5) participants were provided with the option to refuse or discontinue participation, and (6) clarification that participants' participation or non-participation will not affect their employment status nor their relationship with the research recruiter (child life manager and/or CLSs).

5.10.4 Knowledge Mobilization

Knowledge mobilization, also known as knowledge translation, has become a popular umbrella term to denote the practices of dissemination⁶⁰, knowledge transfer and knowledge translation between researchers and knowledge users (e.g., individuals, professional groups, institutions) (Levin, 2008). Knowledge mobilization has also been suggested to be particularly useful in health care contexts, where there is a great deal of emphasis on evidence-based practice and measurement of outcomes (Fitzgerald & Harvey, 2015; Ungar et al., 2015).

In this research, my main aim in mobilizing the knowledge generated by this study pertains to tailoring the findings in ways that will make them easily comprehensible, practical, and meaningful to professionals practicing in health care settings (e.g., child life specialists and directors) as well as academic audiences. Taking key steps to mobilize this study knowledge aligns with a suggested need for more wide-spread and effective knowledge translation of ethnographic research both within and beyond the academic realm (Vannini, 2018). A key strategy of knowledge mobilization will involve conducting three presentations, including: a professional development webinar for the professional child life associations of North America (June 2022) and Australia (December 2022). The goal of these presentations was to share the research findings and recommendations with CLSs and contribute to bridging a gap in knowledge in child life practice across various international contexts. Sharing the findings with North American CLSs also allowed me to apply the recommendations arising from this study to a North American health care context.

Other key methods used of knowledge mobilization will include: 1) sharing a brief written summary of the study findings, implications and associated recommendations with CLSs and

⁶⁰ 'Dissemination' involves a process of extracting the main messages or key implications derived from research results and communicating them to targeted groups of decision makers and other stakeholders in a way that encourages them to factor the research implications into their work (Levin, 2008).

hospital directors, 2) developing a written resource on children's health care decision-making in the form of a storybook for children, caregivers, CLSs and other health care providers (Appendix J), 3) sharing a research brief document (i.e., a short, non-technical summary of the research findings and implications) with key decision-makers with a focus on pertinent policy-relevant findings, and 4) publishing papers in peer-reviewed journals related to childhood, health care, sociology, and child life practice.

5.11 Study Limitations

The absence of the perspectives of children and families represents an overarching limitation because any research concerning children and childhood must, ideally, be conducted with rather than on children (Pope et al., 2017). In order to minimize the disadvantages of this limitation, I relied on weaving research studies that include children's perspectives throughout this dissertation. Considering this limitation, future research could benefit from exploring children's participation in decision-making in pediatric hospitals from the perspectives of children, as well as CLSs and hospital directors in and outside of the Netherlands.

The exclusion of participant observation, as a key ethnographic data collection method (Atkinson et al., 2001; Hackett & Hayre, 2020; James, 2001) limited my inability to gain contextual and primarily non-verbal data on: (1) the interactions between children, caregivers and health care professionals in the hospital settings, (2) embodied aspects of participants' narratives (e.g., feelings and emotions), and (3) the amount of time that is spent on various elements of in children's participation in decision-making (Balcom et al., 2021). Therefore, the study findings presented in this research prioritized interview- and document-based data to gain a certain degree of personal and contextual insights into children's participation in health care decision-making.

An additional limitation pertains to the homogenous nature of CLSs' socio-demographic characteristics. All CLSs identified as white women. The perspectives of health care providers who

identify with marginalized and equity-seeking communities were therefore absent. As a result, this dissertation does not challenge or de-centre the normative narratives of Whiteness⁶¹ or dismantle the oppressive forces of gender, class, race and/or ethnicity-based inequities that result from the “unspoken assumption of White-as-norm” (Jensen, 2020, p. 25).

5.12 Chapter Summary

This chapter has provided an overview of the critical and focused ethnographic research methodology that guided this study, including the recruitment and sampling strategy, data collection methods and procedures, and analysis procedures. Restrictions imposed during the COVID-19 pandemic necessitated the adaptation to virtual data collection methods. Using virtual data collection methods was only made possible as a result of participants’ flexibility and willingness to arrange the technological modalities and private spaces required for remote interviews. By modifying the implementation of this methodology, I attempted to provide contextual, critical, and nuanced understandings of children’s participation.

⁶¹ In Chapter Seven, I discuss the implications of the overarching degree of ‘Whiteness’ in the child life field.

CHAPTER SIX: FINDINGS

6.1 Chapter Overview

This chapter presents the research findings that seek to address how child life specialists (CLSs) experience children's participation in decision-making and how contextual⁶² dimensions can shape children's participation. Narrative data from CLSs focuses on children's participation in the provision of psychosocial care. Narrative data generated by directors and textual data from hospital-based documents provide insights on broader, organizational perspectives on children's participation in practice, policy, and research within the institutional context of the pediatric hospitals in this study.

During my preliminary analysis of the findings, it became clear that children's participation represented a complex phenomenon, shaped by multiple relations within and between individuals and wider contextual dimensions. To help unpack the complex and relational nature of children's participation in my analysis, I draw on Doane and Varcoe's (2021) concept of 'relational inquiry'⁶³ to frame my findings in terms of what may be occurring *at* and *between* the intra- and interpersonal and contextual dimensions of health care encounters that can shape children's participation in decision-making. Intrapersonal dimensions focus on *what is going on within the people involved*. Interpersonal dimensions place attention on *what is going on among people*. Contextual dimensions refer to *what is going on around people and the health care situation* (Doane & Varcoe, 2021).

⁶² I define 'contextual dimensions' as encompassing (interrelated), personal, structural, and institutional factors that can shape health, wellbeing, and health care practices, including children's participation. Personal factors refer to elements such as beliefs, values, experiences and interpersonal relationships. Structural factors refer to elements such as the wider political, social and economic system, including policies and funding. Institutional factors refer to interrelated operational attributes, processes or conditions within an institution (e.g., hospital), such as communication styles, clinical routines, and financial and material resources (Valaitis et al., 2018).

⁶³ As described Chapter Four, I define relational inquiry as a "way of orienting and responding to people, situations, and knowledge" that attends to the complexity of human life, the world, and nursing practice (Doane & Varcoe, 2021, p. 34).

In my analysis, I also draw on other complimentary theoretical concepts rooted in relationality⁶⁴ (Alanen, 2019; Baumann, 2008; Bell & Balneaves, 2015; Carnevale, 2020; Cohen Konrad, 2020; Ho, 2008; Mayall, 2015; McAllister, 2021; McLaughlin, 2020; Walter & Ross, 2014) to help generate complex, nuanced, and fluid understandings of children’s agency, autonomy and participation. I also integrate pertinent literature on children’s health care decision-making to further interpret the findings and highlight instances in which discourses of developmentalism (including ableism and adultism) and children’s rights acted as pervasive undercurrents in the findings. I contextualize the findings by including quotes written in Dutch and translated into English to retain the integrity and essence of the original participant quotes, including idioms.

6.1.1 Overview of Chapter Themes and Subthemes

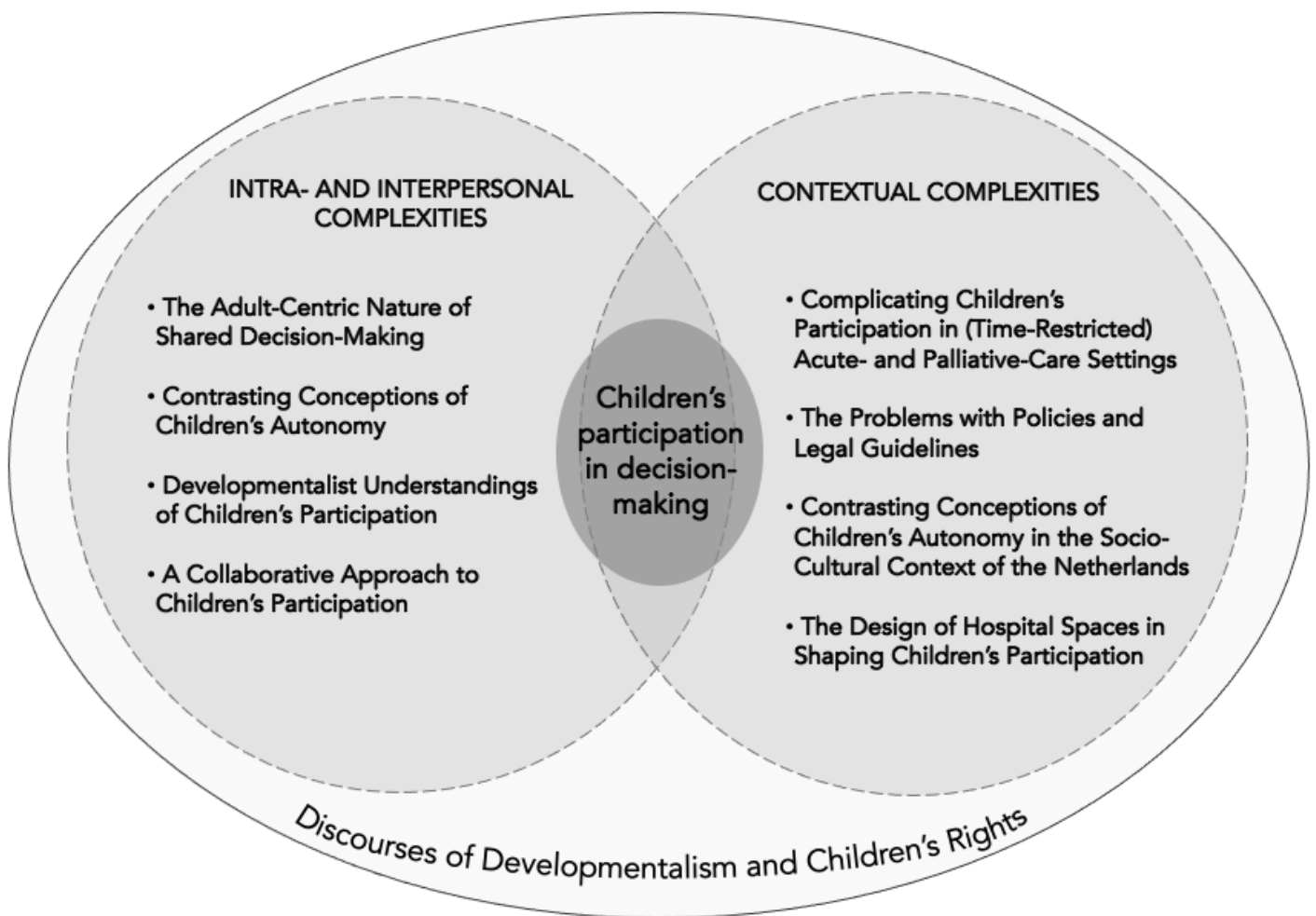
As Illustrated in Figure 13 below, this chapter has been organized to discuss two main themes; intra- and interpersonal complexities and contextual complexities in shaping children’s participation. In the first main theme of ‘intra- and interpersonal complexities in children’s participation’, sub-themes include: (1) the adult-centric nature of shared decision-making (2) independent and relational conceptions of children’s autonomy⁶⁵, (3) developmentalist understandings of children’s participation and (4) tensions in adopting a collaborative approach towards children’s participation. The sub-themes within the second main theme of ‘contextual complexities in children’s participation’ relate to: (1) children’s participation in acute- and intensive-care contexts, (2) the problems with policies and legal guidelines, (3) contrasting conceptions on children’s autonomy in the cultural context of the Netherlands, and (4) the design of

⁶⁴ As described in Chapter Four, I define ‘relationality’ as a philosophical mode of thinking that emphasizes the connectedness of the self with others, which “influences decisions, actions and choices, and forms the context for the unfolding of everyday life” (Smart, 2011, p. 18).

⁶⁵ As discussed in Chapter Two, I refer to ‘agency’ as one’s “broader capacity to act intentionally” (Schollser, 2019, p. 19), including the capacity to make autonomous choices (Hanson, 2016). I refer to ‘autonomy’ as a central feature of human agency, as one’s ‘uncoerced’ capacity for self-determination specifically in the context of legal decision-making (Gumbis et al., 2008).

hospital spaces in shaping children’s participation. While the sub-themes have been ordered according to their degree of prominence in the findings, I regard the themes and sub-themes within and between the intra-, interpersonal and contextual complexities as interrelated and in a constant state of flux. Therefore, I reference interlinking findings within and between themes and sub-themes. A summary of key points raised is provided at the end of the chapter.

Figure 13: Visual Overview of Themes and Sub-Themes



6.2 Inter- and Intrapersonal Complexities of Children's Participation

In the first main theme, my analysis of the data points to how various interrelated intra- and interpersonal complexities can shape children's participation. In this section, I will discuss four interrelated sub-themes:

- 1) The adult-centric nature of shared decision-making,
- 2) Independent and relational conceptions of children's autonomy,
- 3) Developmentalist understandings of children's participation, and
- 4) Tensions in adopting a collaborative approach to children's participation.

6.2.1 "Making Decisions About Children Without Children": The Adult-Centric Nature of *Shared Decision-Making*

In the overarching theme of intra- and interpersonal complexities in children's participation, recurring findings highlighted the relational and adult-centric nature of *shared decision-making*⁶⁶ involving children, caregivers⁶⁷, and health care providers, as reflected in the following quote by a CLS:

CLS06: When I think about children participating in decision-making... I think about something that we do together... in which children are not overlooked by, for example, only considering caregivers' or health care providers' views.

Als dan denk ik aan kinderen mee laten beslissen... dan denk ik aan iets dat we samen doen... en dat er niet over de hoofden van kinderen heen wordt gepraat... bijvoorbeeld alleen naar de ouders of zorgverleners onderling...

The interpersonal nature of participation as a shared decision-making process, and the challenges inherent to including children in this process, is also reflected in an excerpt provided by a director:

⁶⁶ As described in Chapter Two, 'shared decision-making' (SDM) is an approach where health care providers and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options and to achieve informed preferences (Elwyn et al., 2012).

⁶⁷ I use the term 'caregivers' to refer to the primary individuals who provide care and support for a child, including biological, adoptive, step, or foster parents or guardians.

DIR03⁶⁸: What comes to mind for me when I think of children’s participation is... decision-making and shared-decision-making with children, parents and providers... and we do struggle quite a bit with the question of: ‘how and when can children be involved with that?’
Wat er dan in mij opkomt wanneer ik aan kinderp participatie denk is... decision-making en shared-decision-making met kinderen, ouders en zorgverleners... en... daar worstelen we best wel mee met de vraag van: ‘hoe en wanneer kunnen kinderen daarbij betrokken zijn?’

My analysis of a hospital document entitled a “patient manifest” [*patiëntmanifest*] provided further insight into a taken-for-granted assumption about the shared nature of decision-making. This document, containing child-centered language to help children understand the key elements of hospitalization, positioned children’s decision-making in the relations between ‘children, parents, doctors, and nurses’:

If you are admitted to the hospital, we will tell you everything about your illness and what we will do about it. We will make those decisions together with you and your parents. Every day when the doctors and nurses visit your room, you can talk about this.
Als je opgenomen wordt, zullen we je alles vertellen over je ziekte en wat we daarna gaan doen. Die besluiten nemen we samen met jou en je ouders. Elke dag als de dokters en verpleegkundigen op bezoek komen in jouw kamer, kun je hierover praten.

In contrast to this seemingly ‘unproblematic’ description of decision-making triads, my analysis of the data also alluded to the inherently adult-centric nature of children’s participation in (shared) decision-making, including the ‘attitudes’ and ‘personalities’ of health care providers and decision-makers. This finding was evident at the level of health care practices and at an institutional level. At the institutional level, analysis of directors’ accounts suggests that adult-centric and paternalist attitudes shape how children can participate in decision-making. According to one director, the hospital represented “an adult-dominated structure in which adults are needed” [*in een volwassen structuur zijn volwassenen nodig*] (DIR02), and in which “**we often make decisions about children without children**” [*we beslissen vaak over kinderen maar doen dat meestal zonder*

⁶⁸ Participants are identified by using the numeric codes assigned to each participant in the following two groups: CLS = child life specialist and DIR = directors and managers.

kinderen] (DIR03). In this ‘adult-dominated structure’, pediatricians can have paternalistic tendencies that can impede children’s opportunities for decision-making:

DIR04: I think that we in pediatrics often have paternalistic tendencies and want to think for the patient... and *real* shared-decision-making is still underdeveloped...

Ik denk dat wij in geneeskunde nog best vaak paternalistische neigingen hebben en voor de patient willen denken... en echt shared decision making is denk ik nog weining ontwikkeld..

Several CLSs’ attitudes towards the benefits of children’s participation were also paternalistic.

Some CLSs conveyed a belief that “giving children choices gives children the *feeling* of participating... so that they offer less resistance during medical procedures” [*kinderen keuzes bieden*

zodat ze het gevoel hebben dat ze participeren... zodat ze minder tegenstand bieden tijdens

handelingen] (CLS07). In addition to ‘offering less resistance’, some CLSs identified how “gaining

the cooperation of a child makes our practice easier” [*de medewerking van het kind meekrijgen*

werkt gewoon veel fijner] (CLS12). Similarly, there was also evidence of the paternalistic

tendencies of adults who manage and facilitate children’s advisory councils in shaping children’s

participation in decision-making regarding hospital-wide policies:

DIR02: They [CAC projects] are primarily dependent on a few enthusiastic adults who find them [initiatives] important and are ready to take that extra step to also really get them [initiatives] off the ground...

Die [initiatieven] zijn vooral afhankelijk van een paar enthousiaste volwassenen die dat belangrijk vinden en ook bereid zijn om even die extra stap te zetten om dit [initiatief] ook echt van de grond te krijgen...

At the level of health care practices, the ‘personalities’ and ‘attitudes’ of health care providers in shaping children’s participation was also evident:

DIR01: I also think that it kind of depends on your personality... and your attitude towards it [shared decision-making]... some [health care providers] just find it easier to speak to adults and they’re used to talk to adults in their line of work.

Ik denk dat het ook een beetje aan je persoonlijkheid af hangt en hoe je ertegen aankijkt.. sommigen vinden het ook gewoon makkelijker om met een volwassenen te praten of zijn het in hun carrière ook

gewoon gewend dat het met de volwassenen besproken wordt.

Further reflecting the prominent role of adults in complicating children's participation at the level of health care practices, my analysis of the data also points to how some CLSs' viewed the "important role of parents" [*ouders hebben een belangrijke rol*] (CLS02) as a challenge in facilitating children's participation. I identified tensions in how CLSs attempted to 'reach agreements' amongst all three persons involved in shared decision-making:

CLS04: Parents can be very supportive... and parents are also very important... but what you often do see is that almost all children want the approval of their parents when making decisions... so it's important to consider: 'am I following the child's wishes or am I indirectly following the parent who wants something?

Ouders kunnen wel heel steunend zijn hoor en ouders zijn ook heel belangrijk.. maar wat je wel vaak ziet is dat bijna alle kinderen goedkeuring van hun ouders willen als ze een keuze maken... dus het is wel belangrijk om te zien; 'volg ik nu het kind of volg ik nu indirect de ouder die iets wil?'

When 'reaching agreements' between children and caregivers in shared decision-making, several CLSs also conveyed that "many parents generally speak on behalf of children a lot" [*veel ouders praten heel veel voor het kind*] and "make decisions for themselves rather than for their child" [*soms maakt de ouder de keuze voor zichzelf dan voor z'n kind*] (CLS12). While some CLSs expressed that "you don't just always blindly have to follow what the parents want" [*je hoeft niet altijd maar klakkeloos te doen wat ouders willen*] (CLS10), there was a recurring theme in CLSs' narratives which suggested that parents largely held the 'final say', as captured in a quote by a CLS:

CLS09: A decision still has to be made... and then it's usually a given that mom and dad decide; 'this is what we're going to do' but that you still give the child space to have a say in that.

Er moet toch een keuze gemaakt worden... en dan is het eigenlijk een vanzelfsprekendheid dat mama of papa dan beslist 'dit gaan we doen' maar wel dat je het kind de ruimte om mee denken.

In order to assist with reaching 'agreements' between children and caregivers in shared decision-making, my analysis of other findings underscores contrasts in the use of legal guidelines in balancing children's 'best interests' and caregivers' (legal) decision-making capacities. A CLSs

described relying on “what’s in the best interest of the child” [*in het belang van het kind denken*] (CLS07), a phrase which is contained in the UNCRC’s Article Three⁶⁹ (United Nations, 1989). On the other hand, a director emphasized that “parents often make the final decision... because that’s legally the case” [*ouders moeten uiteindelijk toch beslissen en dat is juridisch natuurlijk ook zo*] (DIR02) in local laws⁷⁰ concerning children’s consent to medical treatment.

The above findings highlight the varying ways in which adults (e.g., caregivers, health care providers) formed part of children’s decision-making processes. These findings emphasize the relational and complex nature of children’s participation. In the next sub-theme, I discuss how contrasting conceptions of children’s autonomy can shed further light on the relational and complex nature of children’s participation.

6.2.2 “Listening to the Voice of the Child”: Contrasting Conceptions of Children’s

Autonomy

In the overarching theme of intra- and interpersonal complexities in shaping children’s participation, a second, inter-related subtheme pertains to the findings that highlight contrasting conceptions of children’s autonomy in decision-making. In contrast to the findings in the previous sub-theme on the adult-centric nature of children’s participation in (shared) decision-making, several CLSs, directors, and hospital documentation associated a child’s individual ‘voice’ with children’s individual ‘autonomy’ and ‘empowerment’ in decision-making. One CLS, for example, noted:

CLS02: When I think about children’s participation... I think about taking children seriously and **listening to the voice of the child**... and also... well...allowing children to stand up for

⁶⁹Article Three of the UNCRC recognizes that ‘the best interests of the child’ must be taken into account when making decisions that affect children (United Nations, 1989).

⁷⁰ On the basis of the Dutch Medical Treatment Contract Act of 1995, minors aged 16 and older are in principle capable to decide on their own about medical treatment. However, children aged 12–16 have the right to consent to medical treatment (unless they are not yet capable to do so, for instance, due to a cognitive impairment), but they cannot exercise this right independently: their parents need to consent too (Kranendonk et al., 2017).

their opinion and make their own choices. Deciding things on your own is important for the autonomy of a child – and that gives the child their own power.

Als ik aan kinderp participatie denk, dan denk ik aan kinderen serieus nemen en luisteren naar de stem van het kind... en ook nou... kinderen voor hun mening laten opkomen en hun eigen keuzes laten maken. Zelf dingen bepalen is belangrijk voor de autonomie van het kind en dat zet het kind in zijn eigen kracht.

Individualistic conceptions of a child's 'voice', which do not attend to the role of adults in shaping a child's 'voice', were also linked to the broader context of the children's hospital, as evidenced in an excerpt provided by a director:

DIR03: In the children's hospital, it is important that we hear the voice of children themselves in one way or another... so children's participation in organizational and structural things that happen in the children's hospital... So then it's about practical things like: 'which voice does the child have during decision-making?'

In het kinderziekenhuis is het belangrijk dat we de stem van kinderen zelf op één of andere manier te horen krijgen... dus kinderp participatie in organizatorische en structurele dingen die gebeuren in het kinderziekenhuis... Dus dan gaat het over praktische dingen zoals; 'welke stem heeft het kind bij besluitvorming?'

Some CLSs and directors also described children's personal decisions – decisions that revolve around a "child's health and health care trajectory" [*dat gaat om de gezondheid van het kind en hun traject in het ziekenhuis*] (CLS11) as expressions of children's independent voice and associated autonomy. In personal forms of decision-making, children "have a voice in decisions that affect their own body" [*een stem hebben in keuzes die te maken hebben met hun eigen lichaam*] (CLS11) and their illness [*zijn eigen of eigen ziekte*] (DIR03).

Furthermore, my analysis of three hospital-based documents also revealed a broader, institutional emphasis on an individualistic outlook on children's 'voice' and associated autonomy. One document (depicted in Figure 14) entitled; 'Three Good Questions' that was displayed around a hospital unit, emphasized children's autonomous abilities to 'voice' their own questions and concerns. In the document, children were encouraged to pose "three good questions" [*drie goede vragen*] during medical consultations, including "This is what I feel. What is it?" [*Dit is wat ik voel.*

Wat is het?], “What can we do about it?” [Wat kunnen we er allemaal aan doen?], and “What does this mean for me now and later?” [Wat betekent dit voor mij nu en later?].

Figure 14: Poster Depicted in the Hospital Titled: “Three Good Questions”



My analysis of a second document, a hospital’s storybook distributed across hospital wards titled: “Emma Goes to Hospital”, provided further examples of attending to a child’s autonomous voice. In the storybook, children were encouraged to note their likes [*dit vind ik leuk!*], and dislikes [*dit vind*

ik stom!], questions for doctors [*vragen aan de dokter*], and questions for nurses [*vragen aan de verpleegkundige*]. A page entry of this storybook is depicted in Figure 15.

Figure 15: Page Entry of Storybook Written for Children Titled; “Emma Goes to Hospital”



Similarly, a third document entitled a ‘hospital passport’ [*Ziekenhuispaspoort*] also emphasized children’s autonomous abilities to ‘voice’ their own preferences in medical procedures. By filling out this document in writing, children can ‘voice’ key preferences such as 1) “who I want to have with me” [*ik heb graag bij me*], 2) “what I do/don’t want to know” [*ik wil graag weten of niet weten*], and 4) “I want to be distracted (yes/no) [*ik wil graag afgeleid worden*]. The front cover and content of this document are depicted in Figures 16 and 17, respectively.

Figure 16: Front Cover of the 'Hospital Passport'



Figure 17: The Content of the 'Hospital Passport'



In contrast to the above individualized conceptions of a child's 'voice', my analysis of narrative data with CLSs and directors highlights how children's voice and autonomy can also be facilitated by adults. In the following excerpt, a CLS' role in 'making the child's voice heard' and 'giving the child autonomy' becomes evident:

CLS10: Look... I do think that it's our job to make the child's voice heard... so when things become a little difficult, then I do always try to think: 'how could I give the child more autonomy in this situation?'

Kijk... ik denk wel dat het onze taak is om de stem van het kind te laten horen... dus als dingen even moeilijk gaan dan probeer ik altijd wel te denken van; 'hoe kan ik het kind meer autonomie geven in deze situatie?'

The role of hospital directors in shaping the organizational implementation of a child's 'voice' in hospital policies is emphasized in the following excerpt:

DIR02: It's [children's participation] really not *just* about placing a 'tick in the box' to simply say that 'we did it!' but it's also about ensuring that you let children know what you actually *did* with their voice.

Het [kinderparticipatie] is echt niet een soort van 'tick in de box' van 'we hebben het gedaan hoor!' maar het gaat ook over het laten weten wat je dan daadwerkelijk hebt gedaan met hun stem.

Moreover, in contrast to children's 'personal' decisions, some CLSs' and directors' accounts also underscored the role of other children and adults in shaping children's 'collective' decisions in children's advisory councils. In these councils, children make decisions in a kind of... democratic group context... together with other children" [*dan maken kinderen keuzes in een soort van... democratische groep... samen met andere kinderen*] (CLS10), allowing children to "have a say about policies in the hospital" [*meepraten over beleid in het ziekenhuis*] (DIR04).

In this second sub-theme, the findings shed light on participants' contrasting conceptions of children's 'voice' and children's associated decision-making autonomy. As will be discussed in Section 6.3.3, contrasting conceptions of children's autonomy were also shaped by participants' (societal) beliefs on childhood in the broader socio-cultural context of the Netherlands.

6.2.3 “It’s Very Much Tied to the Development and Age of a Child”: Developmentalist Understandings of Children’s Participation

In the overarching theme of intra- and interpersonal complexities in shaping children’s participation, a third, recurring sub-theme pertains to how dominant developmentalist discourses on children’s age-based ‘abilities’ permeated the data on children’s participation. Throughout this subsection, I make explicit references to how the data in this sub-theme relates to the previous sub-themes focusing on adult-centric shared decision-making and contrasting perspectives on children’s autonomy.

Evidence of developmentalist discourses were particularly apparent in my analysis of the data concerning participants’ age-based perspectives on children’s decision-making ‘capacities’. One CLS, for example, stated: “everyone deserves the same chance to make a decision... provided that you’re capable enough” [*iedereen verdient dezelfde kans om een keuze te maken... mits je hier capabel genoeg voor bent*] (CLS08). According to another CLS, children’s participation “**is very much tied to the development and age of a child**” [*kinderparticipatie is heel erg ontwikkelings- en- leeftijdsgebonden*] (CLS04), a perspective that was also shared by a director:

DIR03: The degree to which children contribute to decision-making on their own increases with age, so... it [decision-making capacity] has to be there by age 12.
De mate waarin kinderen zelf mee beslissen die neemt toe met de leeftijd dus... die [capaciteit] moet er zijn bij 12 jaar.

Further supporting a developmentalist outlook on children’s participation, I identified in the data that ‘older’ children were often characterized as being more ‘capable’ of making ‘big’ decisions⁷¹, whereas ‘younger’ children were primarily offered ‘small’ decisions, as captured in the following:

CLS03: Look... an eight-year-old child really can’t decide if they even want to have surgery or not.. and he generally cannot choose whether an injection is needed but you can let the

⁷¹ CLSs described ‘small’ decisions as “not hindering the effectiveness of the medical treatment” [*dat ze niet de effectiviteit van de handeling belemmeren*] (CLS11). In contrast, ‘big’ decisions were described as having a “direct impact on a child’s medical treatment” [*die een directe invloed hebben op de zorg van het kind*] (CLS10).

child choose *how* they want to undergo the injection so to speak...

Kijk... een kind van acht kan echt niet meebeslissen of 'ie überhaupt geopereerd wil worden of niet... en over het algemeen kan hij niet kiezen of de prik benodigd is maar je kan het kind wel laten kiezen hoe hij de prik kan ondergaan bij wijze van spreken.

Similarly, CLSs referred to younger children's *inabilities* to make decisions:

CLS04: I do think that there are limits to children's participation in a hospital... when you're very little, you can't decide on your own if you do or don't need a certain medication.

Adults then do that for you. So that's why your mom or dad sometimes makes a decision for you in that safe world... that's also why you're still a child, I think.

Ik denk wel dat er ook grenzen zitten aan kinderp participatie in een ziekenhuis. Op het moment dat je heel klein bent.. Kun je niet zelf beslissen of je bepaalde medicatie wel of niet nodig te hebben. Dan doen de volwassenen voor je. Dus dat daarom soms je vader of moeder ook een keuze voor je maakt in die veilige wereld.. daarom ben je ook nog kind.. denk ik.

These findings suggest that developmentalist understandings of children's participation can shape the types of decisions that children are deemed 'capable' of participating in. Particularly in the case of younger children, caregivers acted as 'surrogate decision-makers' (Lipstein et al., 2015), which further supports a relational framing of children's autonomy (Ho, 2008).

Developmentalist discourses also permeated narratives on the decision-making of children who '*refused*' medical treatments. As reflected in a CLS' narrative, an 'older' child's refusal to wear his oxygen mask represented a 'complicated form of participation':

CLS04: I'm currently working with an older 15-year-old boy who is refusing to wear his oxygen mask... despite him having low saturation levels. In the end, I told him; 'You can figure this out by yourself' – but, to me, that represents a complicated form of participation because I'm not physically there and medically speaking he does need it but I can't put that oxygen mask on his face because he's 15... and a big guy... So I've left him on his own for now – and, to me, that's also participation.

Ik ben net bezig bent met een oudere jongen van 15 die weigert nu zuurstof terwijl hij wel een te lage saturatie heeft... Uiteindelijk heb ik gezegd; 'Weet je, zoek het even uit met je zuurstof' - maar dat vind ik een ingewikkelde soort participatie van hè ik sta er niet achter en medisch gezien heeft hij het wel nodig maar ik kan niet zo 'n zuurstofsnor bij hem op zn gezicht doen, hij is 15... en een grote knul... dus ik hem nu even gelaten - dat vind ik ook participatie.

Another CLS shared her experiences with a child who was deemed ‘old enough to make a decision’ and refused ‘get the bloodwork done’:

CLS09: ...And then he simply refused to get the bloodwork done... which meant that we couldn’t proceed with giving him that medication that he needed. So, his decision had a big impact on his physical health... but I have to respect his own decision... of course... also because he’s old enough to make that decision for himself.

.... En toen weigerde hij het gewoon om dat bloed af te nemen... wat dus betekende dat we hem niet die medicatie konden geven die hij zo nodig had. Ik voelde me daar nogal gefrustreerd door omdat zijn keuze een groot effect had op zijn fysieke gezondheid... maar tegelijkertijd respecteer ik zijn keuze ook... natuurlijk... ook omdat ‘ie oud enough is om die keuze te maken.

These findings suggest that the findings on children’s refusal to participate in decision-making, as expressions of a child’s right to participation (Bell, 2008), represent examples of situations in which children exerted their independent autonomy. Children’s refusal to participate in decision-making also aligns with existing evidence indicating that not *all* children *want to* participate in decision-making (Abebe, 2017; Coyne & Gallagher, 2010; King, 2007; Punch & Tisdall, 2012) in the complex realities of health care practice (Doane & Varcoe, 2021).

In the sub-theme pertaining to developmentalist understandings of children’s participation, I also identified how some CLSs and directors discussed the decision-making ‘abilities’ of children with disabilities and/or developmental delays:

CLS01: If the child is not able to speak for example or if they’re developmentally delayed... that makes the child’s participation in those situations [medical procedures] quite a bit more difficult...

...Als een kind niet kan praten bijvoorbeeld of heel erg gereterdeert is... dat maakt de participatie van het kind in die situates [medische handelingen] toch wel wat moeilijker...

Despite some CLSs associating ‘developmental delays’ with ‘difficulty’, some CLSs also described using ‘customized’ non-verbal strategies to facilitate the decision-making capacities of children with disabilities. Strategies included “pointing our thumbs up or thumbs down” [*dan doen we duimpje of hoog of naar beneden*] (CLS09) or using personal communication books and/or

pictures, for example, to facilitate children's participation. One director also commented on customizing the decision-making of children with 'developmental problems':

DIR03: There are so many different patients around here... maybe a quarter or a third has developmental problems, and one developmental problem is not the same as the other... so each child is unique... and you really have to customize the way in which you approach them... I think.

Er lopen hier zoveel verschillende patienten rond.. misschien een kwart of een derde heeft ontwikkelingsproblemen en de ene ontwikkelingsprobleem is het andere niet... dus elk kind is uniek en dan moet je ook echt maatwerk leveren.. er is niet één ding van te zeggen... denk ik.

As an additional example of a customized approach to children's decision-making, another director described tailoring the ways in which children participate in collective decision-making in children's advisory councils to specific medical conditions:

DIR05: My advice to children's advisory councils is that – that you need to involve children who have had relevant experience with a procedure or medical condition. In these councils, the problem is often that there often children who are asked to speak about something that they have never experienced. So... for example... when children are asked to speak about how children with scoliosis experience our hospital, we got very different insights from two children who had just undergone scoliosis surgery.

Mijn advies aan al die KARREN [kinder advies raad] is dat je eigenlijk per onderwerp kinderen moet vragen – kinderen die ervaring hebben met bepaalde ingrepen of medische aandoeningen. In deze KARREN is het vaak zo dat kinderen vaak gevraagd worden om over dingen te praten wat ze nooit hebben meegenemaakt. Dus... bijvoorbeeld... wanneer kinderen gevraagd worden om iets te zeggen over hoe kinderen met scoliose ons ziekenhuis ervaren kregen we een total ander beeld van twee kinderen die net een operatie voor scoliose hadden ondergaan.

These findings speak to participants' developmentalist understandings of children's participation and represent an example of an additional intrapersonal complexity that further accentuates the relational and complex nature of children's participation and autonomy⁷². Developmentalist (and inherently ableist and adultist) discourses appeared to shape participants' conceptualizations of children's decision-making capacities, particularly among young children and

⁷² As discussed in section 2.2.1, children's participation can be considered a central expression of children's autonomy (Duramy & Gal, 2020).

children with disabilities and/or developmental delays. These findings raise questions about the degree to which adults allow children to participate in the confines of developmentalist and ableist understandings of children (Collins, 2009; Gabriel, 2021; James & James, 2004).

6.2.4 “I Can’t Do it Alone”: Tensions in Adopting a Collaborative Approach Towards Children’s Participation

The final sub-theme relating to intra- and interpersonal complexities in shaping children’s participation focuses on the data that shows further relational tensions and challenges when adopting a *collaborative* approach towards children’s participation in a health care *team*. CLSs in particular emphasized the importance of working and listening ‘together’ with physicians:

CLS10: **I can’t do it alone...** we need to do it together... and I’d say 9 out of 10 doctors and nurses also want that [include children in decision-making]... then you’re really doing it together... so sometimes I notice that I need a physician to do that, but that the physician also very much needs me. So if you can work together... and listen together... then I think it can mean a lot to a child.

Ik kan dat niet alleen... dat moeten we met elkaar doen... en ik merk ook dat 9 van de 10 artsen en verpleegkundigen da toek willen... dan ben je echt met elkaar bezig... en soms merk ik ook ‘ik heb een arts nodig’ om dat te doen maar die arts heeft mij ook heel erg nodig. Dus als je samen kan werken... en luisteren... dan denk ik dat het veel kan betekenen voor een kind.

Despite emphasizing that “we [CLSs] work very well together with pediatricians and nurses” [*we werken heel goed samen met kinderartsen en verpleegkundigen*] (CLS04), I also identified tensions in CLSs’ narratives when members of the health care team are ‘not on the same line’:

CLS05: It helps when we’re wearing the same glasses within our team... like ‘we’re doing it together’... because sometimes we’re not on the same line... and then I find it very important to always clearly remind ourselves; ‘hey, how are we thinking about children’s participation with each other?’... and then our practice also becomes more pleasant when we have a collaborative outlook... also within your medical team.

Het helpt wel wanneer we binnen ons team dezelfde bril ophebben... van ‘we doen het samen’ zeg maar... want ja soms zitten we niet op één lijn... en dan vind ik toch een hele belangrijke om die steeds weer helder voor de bril te houden met elkaar, van; ‘hey, hoe kijken we met elkaar naar kinderp participatie?’... en dan werkt het ook fijner als onze neuzen dezelfde kant op staan... ook binnen je medisch team.

According to this CLS (CLS05), a key challenge that can impede a collaborative approach to children's participation are instances when: "not all pediatricians find it [children's participation] as important as me" [*niet alle kinderartsen vinden het [participatie] net zo belangrijk als mij*] (CLS05). CLSs often described pediatricians as being "more medically-oriented and we're [CLSs] more developmentally-oriented" [*zij [kinderartsen] zijn meer medisch gericht en wij meer ontwikkelingsgericht*] (CLS04). Another CLS adds:

CLS10: In interdisciplinary team discussions... I think the social team, so the psychologists and social workers and us of course are always an important counterpart to protect children's rights to participation... because doctors are usually practicing from a different point of view... so you need to keep each other in check on that.

Ik denk ook dat in multidisciplinaire overleggen.. dat daar ook,, dan vooral de sociale kant, dus de psychologen het maatschappelijk werk en ook zeker wij altijd wel een belangrijke tegenhanger zijn om die rechten op participatie te beschermen... omdat dokters natuurlijk vanuit een andere visie soms bezig zijn.. dus je moet elkaar daar scherp op houden.

Similarly, I also identified a tension in CLSs' and pediatricians' 'leadership' roles in relation to children's decision-making. CLSs attributed importance to "having someone in charge, so that you make a plan ahead of time with each other to decide how you're going to handle it [children's participation] [*dat er één iemand in de lead is... dat je vooraf bespreekt hoe je het [kinderparticipatie] gaat doen*] (CLS08) and highlighted their own leadership in 'standing up' for children's participation:

CLS09: I think it's very much our job to... stand up for the child's participation... and I think that we do that in a more powerful way than other disciplines... but I do see more shifts being made in disciplines... from doctors too... that they're trying.

Ik denk wel dat het ook heel erg onze taak is om... voor het kind op te komen euh.. en ik denk dat wij dat soms een stuk sterker doen dan andere disciplines maar ik zie wel dat er meer verschuiving komt in disciplines.. vanuit de dokters... dat er geprobeerd wordt.

CLSs also shared how they experienced doctors' 'leadership' in children's participation:

CLS05: The doctors do adapt to our job and in helping children participate...But some doctors do also still have the feeling of: “I’m in charge here because I am the doctor and you’re only here for a piece of relaxation, distraction and preparation’...

De artsen die buigen helemaal mee... in ons werk maar ook in de kinderparticipatie. Maar sommige artsen hebben nog heel erg het idee van: “Ja ik ben hier sturende want ik ben hier arts en jij bent puur voor een stuk ontspanning, afleiding, en voorbereiding’...

In contrast, directors primarily emphasized pediatricians as ‘leaders in patient-centered care’:

DIR04: [They’re] definitely leaders in patient-centered care... because pediatrics considers the systemic involvement of children in care... So as a pediatrician, you are already used to involving the family and especially the child’s parents in the treatment... but it also means that you’re used to thinking according to the best interest of the child and where possible, to involve the child in the treatment... so I think that pediatricians are definitely leaders in patient-centered care... and I think that other disciplines could learn from pediatricians.

Mijn vooroordeel is dat de kinderartsen verder zijn dan andere dokters... omdat er bij de kindergeneeskunde systemisch wordt nagedacht over het betrekken van kinderen bij de zorg. Je bent als kinderarts van oudsher best gewend bent om ook in het belang van het kind te denken en waar mogelijk het kind te betrekken bij die behandeling... dus ik denk dat kinderartsen sowieso voorlopen in patientgerichte zorg... [en] ik denk dat andere vakken dan weer van kinderartsen kunnen leren.

The findings in this fourth sub-theme highlight further complexity and tensions associated with interprofessional collaborative practice⁷³ in relation to children’s participation in decision-making. The findings suggested that discrepancies exist in CLSs’ and directors’ self-perceived ‘leadership’ in including children in decision-making in the hierarchical structure of health care organizations.

In line with a relational inquiry approach (Doane & Varcoe, 2021) to my analysis, I contend that the findings on the inter- and intrapersonal complexities of children’s participation are interlinked with the findings in the following section, which focus on the contextual complexities of children’s participation.

⁷³ The WHO Framework for Action (WHO, 2010) refers to IPCP as “collaborative practice [that] happens when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care. It allows health workers to engage any individual whose skills can help achieve local health goals” (p. 7).

6.3 Contextual Complexities of Children’s Participation

In this overarching theme, I build on Doane and Varcoe’s (2021) scholarship on relational inquiry to help frame how contextual complexities, in terms of what may be occurring *around* people, can further shape children’s participation. I consider ‘complexities’ as representing key tensions, challenges, and considerations relating to how structural elements, including governments, health care institutions, that are embedded in socio-cultural, political and economic systems can shape children’s participation in health care decision-making (Doane & Varcoe, 2021). Within this overarching theme, there are four interrelated sub-themes:

- 1) Complicating children’s participation in (time-restricted) acute- and palliative care settings,
- 2) The ‘problems’ with policies and legal guidelines,
- 3) Contrasting perspectives of children’s autonomy in the socio-cultural context of the Netherlands, and
- 4) The design of hospital spaces in shaping children’s participation.

6.3.1 “Sometimes it Doesn’t Work”: Complicating Children’s Participation in (Time-Restricted) Acute- and Palliative Care Settings

In the overarching theme on contextual complexities in shaping children’s decision-making, the first sub-theme pertained to how clinical health care settings, including (time-restricted) acute- (i.e., emergency- and intensive care) and palliative care settings can further complicate children’s participation.

In my analysis of directors’ narratives, clinical care is broadly characterized as being “quite busy” [*best wel druk*] (DIR02) in which children’s participation was described as “something that just takes a lot of time” [*het is iets dat gewoon lang duurt*] (DIR02). Directors conveyed the belief that clinical duties took priority over children’s participation in decision-making (and the

implementation of a hospital quality- and safety-assurance standard⁷⁴) since “many policy-makers⁷⁵ also have clinical duties of course... which stand at number one” [*een deel van beleidsmakers hebben natuurlijk ook klinische taken... en die staan op nummer een*] (DIR02). As a result, including children in decision-making in time restricted health care environments required an acceptance that ‘it [children’s participation] **sometimes doesn’t work**’:

DIR01: I also think that you need to be realistic that you’re working in an environment in which things sometimes need to get done and that we all need to find it [children’s participation] important and need to keep challenging it... but also accept that it sometimes doesn’t work...

...ik denk ook dat je reeel moet zijn dat je ook in een omgeving werkt waarin soms dingen gewoon moeten en doorgemaakt moeten worden en dat we het allemaal belangrijk moeten blijven vinden en het ook moeten blijven uitdagen... maar ook accepteren dat het soms ook even niet gaat...

Similarly, in the context of acute care, my analysis of CLSs’ narratives identifies that children’s involvement in decision-making can “sometimes be completely ruled out” [*je kan het soms geheel uitsluiten*] (CLS09) when it occurs “at the expense of health” [*als het ten koste gaat van de gezondheid*] (CLS08). In “medical procedures that *have* to happen” [*medische handelingen die moeten gebeuren*] (CLS05) in acute care, CLSs described how “there is no room or time” [*er is geen tijd of ruimte*] (CLS02) to include children in decision-making. As reflected in the following excerpt provided by a CLS, children’s physical wellbeing took precedence which rendered children’s autonomy ‘irrelevant’:

CLS04: I understand very well *when* you can let children participate and when there is no choice... because... there are also situations... because we’re still a hospital... where physical wellbeing stands at number one and where we still have to try our best to support mental wellbeing but if it’s about life or death, then everyone can think about participation but...

⁷⁴ One director (DIR03) stated that they no longer use the ‘Smiley Quality Assurance Standard’ due to high time and cost commitments. This ‘Smiley’ quality assurance standard is based on the criteria of delivering PFCC. Pediatric hospitals or other health care settings that meet these criteria are awarded with various versions of the Smiley (e.g., gold, silver, bronze). The standard was developed by the association Child & Hospital [Kind & Ziekenhuis) (Kind & Ziekenhuis, 2020).

⁷⁵ In this study, several directors held simultaneous appointments as physicians.

there actually isn't any room for it... So then, discussions about how you can increase a child's autonomy become irrelevant.

Ik begrijp heel goed wanneer je kinderen enorm kan laten participeren en wanneer er geen keus is... want... er zijn ook situaties.. want wij blijven een ziekenhuis hé.. waarbij het fysieke welzijn op nummer één staat wat we nog steeds zo goed mogelijk proberen te ondersteunen voor het mentale welzijn maar als het gaat om leven of dood dan heeft iedereen echt wel dingen rondom participatie in zijn hoofd... maar ja... daar is eigenlijk geen ruimte voor... Dus vragen rond hoe je de autonomie van het kind kan vergroten... zijn dan ook niet echt van toepassing.

While these findings suggest that CLSs acknowledged the time-restricted nature of acute care settings, my analysis of several CLSs' narratives also point to CLSs' 'resistance' to physician-imposed 'time-pressures', as reflected in the following excerpt:

CLS05: Sometimes the doctors want it [medical procedure] to happen very quickly... so more and more often now, we as CLSs aren't afraid to ask for more time... We also feel that time pressure from doctors... like it has to happen now... and we do try to resist that sometimes to ensure children do have a say in things...

Soms willen de artsen dat het [medische behandeling] allemaal heel snel gaat... dus we hebben al veel meer dat we nu ook als PMers durven zeggen wij willen meer tijd.... Ook wij voelen we de tijdsdruk van artsen... het moet nu van dit moet nu gebeuren... natuurlijk zijn er wel bepaalde protocollen zoals met bestralingen... die moeten echt snel gebeuren... maar we proberen altijd wel samen te kijken [met het kind] naar wat wel kan...

Similarly, in contrast to directors, another CLS problematized the idea that children's participation is 'time-consuming':

CLS06: I think that one of the biggest challenges is that certain providers have the idea that it [children's participation] takes a lot of time and think in the short term... but in the long term, you can win a lot if you give the child a lot of choices... but in the short term it will probably take just two minutes longer.

Ik denk dat een van de grootste moeilijkheden is dat bepaalde zorgverleners het idee hebben dat het veel tijd kost en dus op korte termijn denken... maar op lange termijn win je hier heel veel mee als je het kind veel keuzes geeft... maar op korte termijn zal het misschien net twee minuten langer duren ja...

In addition to findings that speak to children's participation in acute care settings, my analysis of the extensive narratives from one director⁷⁶ (DIR03) offer insights into how children's participation in palliative care settings can act as an additional factor in shaping and complicating children's participation. According to this director, children's participation can be shaped by local laws and protocols concerning euthanasia⁷⁷ in the Netherlands:

DIR03: There is not one country in the world where active termination of life among newborns is made possible so we're the only one in that regard... and now that we're moving to 12 years of age that is even more exceptional...

Er is geen enkel land in de wereld waar bij pasgeborenen levensbeëindiging mogelijk is gemaakt dus daarbij zijn we echt de enige in de wereld.. en dat we nu naar 12 jaar gaan is nóg uitzonderlijker...

Against this contextual backdrop, the director referred to a 'complicated spectrum' of children's participation in palliative care decision-making:

DIR03: In that complicated spectrum of how to handle it [children's participation] in the context of complex medical conditions... in terms of which role you *want to* and *can* give a child... there is no standard answer to give to that... it's a learning trajectory, that's how I see it. We want it, we're doing it, but it could be better.

In dat ingewikkelde spektrum van 'hoe pak je dat nou aan bij ingewikkelde ziektebeelden... en met name welke rol we dan aan het kind kunnen en willen geven... daar is geen standaard antwoord op te geven... het is maatwerk... een leertraject, zo zie ik het. We willen het, we doen het, maar het kan beter.

On the 'complicated spectrum' of children's participation in palliative care, many children with 'severe cerebral or brain abnormalities' were deemed as 'unable' to make decisions:

DIR03: When it comes to active termination of life, then in theory you have to assume that it is completely unthinkable of performing termination of life when a child does not agree

⁷⁶ The director, pediatrician, and attorney, developed a protocol to assist physicians with assessing termination of life decision-making for infants aged zero to one who are severely ill.

⁷⁷ In the Netherlands, euthanasia is based on the notion that the person seeking assistance to die is able to make an 'autonomous' decision (van der Geest & Satalkar, 2021). Euthanasia is legal for children aged 12 years and over. For children aged 12 to 16, their opinion is sought (Youngner & Kimsma, 2012) but parental consent is required (Rijksoverheid, n.d.). The Netherlands is currently also considering legalizing physician-assisted termination of life for children aged one-12 who are incurably ill, in which euthanasia was referred to as 'termination of life for newborns' or 'termination of life for older children' [*levensbeëindiging bij pasgeborenen of levensbeëindiging bij oudere kinderen*] (DIR03).

with it... so then it's not possible... but on the other hand, you also have to think about the fact that the children involved most probably, 100% or maybe 90%... have severe cerebral or brain abnormalities through which they *cannot* make decisions or never have been able to make decisions or never will be able to make decisions... so that is somewhat of a theoretical discussion...

Als het gaat over actieve levensbeëindiging dan in theorie moet je er helemaal vanuit gaan dat het helemaal ondenkbaar is dat een levensbeindiging zal toepassen als het kind er niet mee eens is... dus dan is het niet mogelijk.. maar aan de andere kant moet je ook bedenken dat de kinderen waar het over gaat hoogstwaarschijnlijk 100% of misschien 90%... ernstige cerebrale of hersenafwijkingen hebben waarbij ze helemaal niet kunnen beslissen en nooit hebben kunnen beslissen en nooit zullen kunnen beslissen dus... dat is een beetje een theoretische discussie...

In addition to children with 'brain abnormalities', my analysis of the data also links children under three years of age who are 'seriously ill' with reduced decision-making capacities in palliative care contexts. In these cases, the director referred to the prominent role of caregivers in shaping children's decision-making:

DIR03: Look... there are many children who are so young - they will not be able to say anything... so I think that if you look at seriously ill children – an important piece is infants – or children under three – they really won't be able to say anything about their treatment... but they do need to be represented... so those parents often want to speak on behalf of their children.

Kijk er zijn een heleboel kinderen die zijn zo jong, die gaan niks kunnen zeggen... dus ik denk dat als je kijkt naar ernstig zieke kinderen – een belangrijk deel is babies - of is onder de 3 – en die gaan echt niet zelf iets kunnen zeggen over hun behandeling... maar iemand moet het wel doen! Dus er zijn kinderen die nooit zullen kunnen participeren in besluitvorming of in de zorg en die moeten wel vertegenwoordigd worden... dus die ouders die willen echt vaak het woord hebben.

Caregivers' roles as surrogate decision-makers for 'young' and 'seriously ill' children aligns with a relational framing of children's autonomy (Dove et al., 2017), yet reinforces the presence of developmentalist perspectives on children's participation as discussed in the previous theme.

The findings presented in this sub-theme can offer insight into how the (time-restricted) and complex realities of acute- and palliative care contexts can shape the intra- and interpersonal experiences of children, families and health care providers (Doane & Varcoe, 2021). Since directors

can hold a great deal of decision-making power over children’s decision-making, these findings raise questions about the value placed on children’s participation in biomedical, hierarchical and neoliberal health care systems that push for ‘efficiency’ and ‘high performance outputs’ (Cylus et al., 2016).

6.3.2 “They Don’t Show us *How to do it*”: The ‘Problems’ with Policies and Legal

Guidelines

In this overarching theme, an additional and inter-related sub-theme pertains to the challenges associated with implementing hospital policies and legal guidelines about children’s participation. Some directors and CLSs referred to policies that represented “successful examples of how children formed part of decision-making” [*dat zijn wel succesverhalen van hoe kinderen een rol gespeeld hebben in keuzes maken*] (DIR04) and helped children “decide what each individual child may want and need” [*beslissen wat elk kind als individu wil and nodig heeft*] (CLS10). Two directors referred to policies initiated by a children’s advisory council (CAC) concerning children’s food options and choices of games on hospital units, non-smoking hospital regulations, and children’s preferences in how health care providers interact with them (i.e., encouraging providers to sit down when communicating with children versus standing up). Further to the latter policy, a director noted:

DIR01: Well, an example of a policy is that they [children] have said that when they’re in the hospital and a doctor or other health care provider comes to see them, that they find it very unpleasant if they’re standing up because that results in a type of inequality... like ‘here’s the child and there’s the doctor’... so then they asked the doctors to sit down on a chair while talking to them.

Nou een voorbeeld is is dat ze bijvoorbeeld hebben aangegeven dat als ze in het ziekenhuis liggen en dan komt een arts of een zorgverlener komt bij hun - dat ze het dan heel vervelend vinden dat de dokter staat want dan krijg je een soort ongelijkheid... van ‘hier ligt het kind en daar staat de dokter’ – en dan is hun gevraagd om op een stoel te gaan zitten wanneer ze met hun praten.

In addition to referencing the beneficial effects of hospital policies about children's preferences with regards to food and game options, as well as communication styles with health care providers, CLSs and directors also identified key (interrelated) policy challenges. According to one director, existing policies related to patient-and family-centered or family-integrated (DIR05) care⁷⁸, 'value-based health care'⁷⁹ and family-integrated care 'do not show *how*' to include children in decision-making:

DIR03: Policies never specifically show exactly *how* to do it [*include children in decision-making*]. They only describe a kind of philosophy in which we really emphasize that we want to deliver care that is important to parents and children... and that... that requires that they have a voice in that.

In beleidsstukken staat nooit precies hoe je het [kinderen meenemen in besluitvorming] moet doen. Er staat alleen een soort filosofie waar we echt benadrukken dat we zorg willen leveren die voor ouders en kind belangrijk is... en dat dat dus vereist dat ze daar een stem in hebben.

In the absence of policy guidelines on *how* to include children in decision-making, a CLS touched on the challenge of providing generalized decision-making supports for children:

CLS07: I don't think that it [participation] is embedded in it [policy] and that's also kind of difficult... I don't think it's even possible to provide generalized [decision-making] supports for *all* children...

Ik denk dat dat [participatie] er nog niet zo heel erg inzit [in het beleid] en dat is ook nogal moeilijk denk ik... omdat algemene ondersteuning te moeten bedenken voor alle kinderen...

Some CLSs noted that the challenge of providing supports for *all* children contributed to why other, broader institutional policies relating to patient-and family-centered care and 'value-based health care' "are being considered but isn't really there yet" [*ze zijn er wel over aan het nadenken maar*

⁷⁸ 'Patient- and family-centered care' is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life. A core component of this approach includes sharing complete, honest, and unbiased information with patients and their families so that they may effectively participate in care and decision-making to the level they choose (American Academy of Pediatrics et al., 2006).

⁷⁹ 'Value-based health care' (VBHC) was introduced in 2006 in the United States to place 'patient value', defined as valuing health outcomes over costs, as central in the organization and delivery of care (Porter, 2006). In the Netherlands, VBHC is being adopted by a growing number of healthcare organizations (Nat et al., 2020).

het is er nog niet echt] (CLS06) at one hospital site. Due to this challenge, a director recommended a more customized approach to legal policies concerning children's consent to medical treatment:

DIR03: The legal limit is 12 years... for consent... but we all know that the provision of information and the involvement of patients in decision-making *could* and *should* happen much earlier in a way that suits the age of the child... That's because children's care is dependent on the illness... treatment... the patient... in terms of what they can do and want. So, age is one element but often it's not *really* about age but about the child themselves... So, on one hand, there's the legal limits that we all know about when children *always* have to participate in decision-making... but there's also the practical limits... that children can become involved in decision-making much earlier than the legal age... and sometimes that works and sometimes it doesn't...

Wettelijk is de grens 12 jaar... voor toestemming... maar we weten ook dat het geven van informatie en het betrekken van patienten al veel eerder kan en moet plaatsvinden op een manier die passend is bij de leeftijd van het kind... Als het gaat over hun zorg, dan is het heel erg afhankelijk van de ziekte... van behandeling die nodig is... van de behandelaar..en van de patient... wat 'ie kan en wil. Dus leeftijd is één ding maar het gaat vaak niet echt over leeftijd maar over het kind zelf... Dus enerzijds zijn er de juridische grenzen die we allemaal kennen van wanneer kinderen altijd moeten participeren en in besluitvorming... maar ook praktische grenzen.. dat kinderen eigenlijk ook veel eerder dan de wettelijke leeftijd worden betrokken... en dat het soms lukt het en soms niet...

This director's emphasis on a more customized approach to children's legal consent to medical treatment directly contrasts with developmental perspectives on children's participation in the aforementioned findings. Several CLSs, however, stated that they weren't *aware* of legal guidelines on children's participation⁸⁰, leading them to 'assume' that children have decision-making rights:

CLS09: They [children's rights] play an indirect role because I think that we, as health care providers, are very aware of them and they're very much interwoven in our professional job responsibilities... we actually assume that children have those rights.

Ze [kinderrechten] spelen wel indirect een rol omdat ik denk dat wij als zorgverleners daar ons heel erg bewust van zijn en dat ze heel erg verweven zijn in onze functie... ja.. dat wij daar... eigenlijk gaan wij ervan uit dat het zo is.

⁸⁰ As discussed in section 6.2.3, participants referred to 'legal guidelines' as including (1) the universal declaration of children's rights [het universeel verdrag van de rechten van het kind], (2) the children's rights collective [kinderrechtencollectief], and (3) the youth law [jeudgwet].

In the absence of policies about children's rights to participation, some CLSs described how they tended to rely "more on personal successful experiences [of children's participation] in practice rather than theories or policies" [*meer eigen success ervaringen dan theorieën of beleid*] (CLS10).

Rather than being reflected in 'rules or policy', another CLS perceived children's participation as 'a way of being':

CLS07: I don't think that it [children's participation] is embedded in the hospital by default or embedded in rules or policy, but that it's more of a 'way of being'.

Ik denk niet dat het [kinderparticipatie] standaard in het ziekenhuis ingebed is – de participatie – maar dat het meer een manier van omgang is... niet zozeer in regels of beleid.

The findings presented in this sub-theme speak to the varying ways in which institutional can inform health care practices. Several directors referenced relevant institutional policies as well as their shortcomings. In child life practice, pertinent policies and legal guidelines on children's rights to participation largely played an 'indirect' role.

6.3.3 "Dutch Society Values Children's Participation": Contrasting Conceptions of Children's Autonomy in the Socio-Cultural Context of the Netherlands.

In this overarching theme, an additional and inter-related sub-theme pertains to how participants' narratives on childhood in relation to the broader socio-cultural context of the Netherlands shed further light on contrasting perspectives of children's autonomy in decision-making. This section therefore builds on the findings discussed in Section 6.2.2.

In analyzing several CLSs' narratives, children's (independent) ability to 'express their own voice' was influenced by broader, societal beliefs on children, childhood and their participation in the Netherlands:

CLS12: **Dutch society values [children's] participation...** We find it important that the child can contribute to thinking about all things that concern them... And I also think that started from an early age at home... that you're allowed to contribute... express your voice... that's somethings that's been instilled since childhood.

De Nederlandse samenleving hecht waarde aan [kinder]participatie]... Men vindt het wel belangrijk dat het kind mee mag denken in alles wat hen aangaat...En ik denk eigenlijk dat dat vroeger er ook al wel thuis erin is gekomen... dat je mag meedenken... je stem laten horen... dus dat zat er vanuit je jeugd zat het er al een beetje in...

Similarly, a director alluded to societal beliefs in shaping his views on children's independent autonomy:

DIR03: In the Netherlands, the idea that you have the right to self-determination – that you're autonomous as a patient or parent of a patient – *a lot* of weight is attributed to that – more so than in many other countries I think...

In Nederland wordt dat idee dat je zelfbeschikkingsrecht hebt – dat je autonoom bent als patient of ouders van de patient - daar wordt heel zwaar aan getild – zwaarder dan denk ik in heel veel andere landen...

In contrast to the findings above on children's independent 'freedom' to exercise their 'own' autonomy, the findings also show how CLSs' perspectives on childhood were associated with adults' responsibility to 'protect' children:

CLS01: Childhood is especially about being vulnerable... and also that sense of safety, trust and protection during that time... So children need to be safe and protected by us in everything that they do.

De kindertijd gaat vooral om kwetsbaar zijn... en vooral dat veiligheid, vertrouwen en bescherming tijdens die tijd... Dus kinderen moeten veilig zijn en beschermd worden door ons in alles wat ze doen.

CLSs expressed the need to protect children due to their 'vulnerable' status in hospital settings, which can be perceived as inherently "unsafe":

CLS10: [Children's participation] very much relates to that piece of safety... which I think a child has a lot of right to and that is something that you always try to protect in a hospital because it's already *such* an unsafe environment where children can feel unsafe and afraid. *[Kinderparticipatie] gaat heel erg om een stukje veiligheid... waar ik vind dat het kind ook enorm veel recht op heeft en dat is iets wat je altijd probeert te waarborgen in een ziekenhuis omdat het allemaal al zó'n onveilige omgeving is waar kinderen zich onveilig en angstig kunnen voelen.*

Further references to the protection of ‘vulnerable’ children became evident in my analysis of a 2021 report published by the children’s rights collective on the status of children’s rights in the Netherlands (Kinderrechtencollectief, 2021). In this report, I identified additional relational or ‘thick’⁸¹ conception of children’s ‘voice’ and associated autonomy since the protection of children was deemed “a necessity considering the vulnerable position of children” [*de bescherming van kinderen is een noodzaak gezien de kwetsbare positie van kinderen*] (Kinderrechtencollectief, 2021). Similarly, in my analysis of CLSs’ and directors’ narratives, legal frameworks on children’s rights were linked to the ‘protection’ of children. Legal frameworks, including the “universal declaration of children’s rights” [*het universeel verdrag van de rechten van het kind*] (DIR01), the “children’s rights collective”⁸² [*Kinderrechtencollectief*] (DIR02), and the ‘youth law’⁸³ [*jeugdwet*], acted as:

CLS03: Something protective... something overarching on which you can rely to better protect children.

Het iets beschermends... iets overkoepelend waar je op terug kan vallen om kinderen beter mee te beschermen.

A director added to this discussion:

DIR02: When it comes to children’s rights to participate in all matters that concern them in the UNCRC.... then it is a way to protect children in practice... protecting their right to care, a safe home, nutrition, and education.

Als het gaat om de rechten van kinderen om mee te denken in alles wat hen aangaat in het universeel gedrag van de rechten van het kind... dat is toch wel een manier om kinderen te beschermen in de praktijk... beschermen van het recht van kinderen op zorg...veilig onderdak...eten en drinken... en opleiding.

⁸¹ According to Carnevale (2020), a ‘thick’ conception of children’s ‘voice’ recognizes that children’s expressions are relationally embedded expressions of their agency.

⁸² The ‘children’s rights collective’ was founded in 1995 and consists of six core members: Defence for Children, the National Youth Council, ‘Kinderpostzegels’, UNICEF the Netherlands, and Save the Children. Together, the members hold the mission to ensure the rights of children in the Netherlands (Kinderrechten.nl, n.d.).

⁸³ The ‘youth law’ was implemented in 2014 and provides municipal responsibility to ensure the prevention, support and care for children and parents in the context of developmental- and child-rearing problems, psychological problems, and disorders (Nederlandse Overheid, 2021).

These findings presented in this sub-theme can shed further light on how contrasting and complex perspectives on childhood rooted in Dutch society can further complicate understandings of children's autonomy and their decision-making. While participants' narratives placed value on children's 'freedom' in Dutch society, childhood and children's autonomy was also characterized by children's need for 'protection' due to their 'vulnerability'. This finding raises questions about how to reconcile children's protection and freedom as "complementary rather than competitive" (Bissell et al., 2008, p. 5).

6.3.4 "It's a Child-Friendly Environment": The Design of Hospital Spaces in Facilitating Children's Participation

The final sub-theme on the contextual complexities of children's participation focuses on the influence of the physical hospital environment on children's participation. In recognizing the interdependency between physical environments and individual health care experiences (Doane & Varcoe, 2021), my analysis of CLSs narratives suggests that the design of hospital spaces shaped the ways in which CLSs could include children in decision-making. One CLS discussed a recent renovation of the physical hospital spaces and its relation to her ability to include children in decision-making:

CLS04: ...We've also had a complete renovation, in which I think that children's wishes... what's important to children in terms of color, light, play areas are taken into account... of course... those types of things... they definitely play a role in... not only in how children experience the hospital I think but also in how I think we can help children make decisions when they're in an environment that's comfortable to them.

...we hebben een hele nieuwbouw gehad en ik denk dat er zeker rekening is gehouden met... welke wensen hebben kinderen.. wat is belangrijk voor kinderen.. qua kleur, qua licht, qua speelruimtes.. natuurlijk.. dat soort dingen... die spelen zeker een rol.... in hoe kinderen het ziekenhuis ervaren denk ik... maar ook in hoe we kinderen kunnen betrekken in keuzes maken wanneer ze in een ruimte zijn waar ze zich comfortabel voelen.

Another CLS shared how the presence of multiple playrooms, school spaces and designated beds for children's caregivers in hospital rooms provides children with opportunities to engage in decision-making:

CLS10: On each unit we have a playroom where children can go to so that they're out of their room for a while... we also have a room in which children go to school and rooms for children's massages, children's workshop, music making... and 'snoezel' rooms... yes... due to COVID we're not offering that at the moment but children normally do have that option... to make decisions about where and what they want to do next. And well... a parent can always sleep on the couch next to their child what I think is very important... and we also try to use the bicycles and to create active spaces for children to what they would like to do... so we absolutely try to do that.

Op elke afdeling hebben we een speelkamer waar kinderen naartoe kunnen zodat ze even uit hun eigen kamer zijn... we hebben ook een kamer waarin kinderen naar school gaan en ook ruimtes voor kindermassages, kinderathelie, muziek maken... en ook snoezelkamers.. ja door de corona nu allemaal even niet maar normaal is de mogelijkheid voor kinderen er wel. Dat ze dan keuzes kunnen maken in waar en wat ze willen doen. En nou ja... een ouder kan ook altijd blijven slapen op de bank naast een kind wat denk ik heel erg belangrijk is... en we proberen fietsjes te gebruiken en actieve ruimtes te creëren voor kinderen om te doen wat ze zouden willen doen... dus we proberen dat absoluut ...

Specific 'child-friendly' design features of the hospital building, such as accommodating the use of children's bicycles, was further elaborated upon as a tool for facilitating children's decision-making:

CLS06: **It's a child-friendly environment** that we have here... yes... and we also have a lot of bicycles in the hospital so children are allowed to bike in the hallways and sometimes I'll use that when you want to get a child into the procedure room then you can say: 'do you want to park your bike here or in the playroom?', so then you give them a choice but not a choice of going to the treatment room or not because we're doing that regardless [laughter]... but you do get a choice of where you want to park your bicycle.

Het is wel een kindsvriendelijke omgeving die we hebben en we.. ja... we hebben ook wel fietsjes hier in het ziekenhuis dus kinderen mogen over de gang heen fietsen en dat gebruik ik ook altijd wel als je een kind naar de prikkamer wil krijgen dan zeg je: 'wil je de fiets hier parkeren of in de speelkamer'? dus dan geef je een keuze maar niet we gaan naar de behandelkamer want dat gaan we sowieso doen... [lachen] maar je krijgt wel een keuze waar je je fiets neer wilt zetten..

The findings in this final sub-theme shed light on the varying ways in which hospital architectural spaces, including factors such as design, finish and décor, can influence children's experiences of hospitalization and participation in decision-making.

6.4 Chapter Summary

The findings discussed in this chapter highlight the interdependency of people, situations, and contexts (Doane & Varcoe, 2021) in shaping children's participation and provide clear evidence of children's participation and autonomy as inherently complex and relational (Ho, 2008; Walter & Ross, 2014; Wheeler, 2000). Participants attributed importance to children's participation and at times portrayed an 'idealized' viewpoint about children's autonomous 'voice' and associated (age-based) decision-making capacities. However, in the reality of complex and time-restricted health care settings, a relational perspective on children's participation helped to illuminate how intra- and interpersonal (e.g., adult-centric and developmentalist understandings of children's participation, interprofessional tensions) as they interact with contextual (e.g., acute and palliative care, hospital policies and building designs) complexities shape children participation in healthcare decision making as a highly complex, dynamic and relational process. The complexity of children's participation processes was also supported by my analysis of hospital documentation which reflected conflicting conceptions and ideas about children's participation in decision-making.

CHAPTER SEVEN: DISCUSSION

In this final chapter, I discuss the key implications of the findings from this research and discuss how the key findings can help to advance more critical and nuanced understandings of children's participation and further inform health care practices (including child life practices) and policies. I close this chapter by discussing key recommendations for future research and concluding comments.

7.1 Bridging the Gap Between the Rhetoric and Relational Reality of Children's Rights to Participate in Decision-Making

The ways in which many CLSs and directors described the value of listening to children's 'voice', as a commonly used abbreviation for the UNCRC's Article 12 (Lundy, 2006), is consistent with literature that refers to a 'default' position of children's participation in pediatric health care. In this 'default' position, the 'voice' of all children is considered inherently valued and positive (Brady, 2017; Katz et al., 2016; Lundy, 2007; Olszewski & Goldkind, 2018b). This default position also points to an idealized, transformative, universalized, and cosmetic rhetoric of children's participation rights in which all children are optimally involved in decisions that affect them (Cornwall, 2008; Imms et al., 2021), as outlined by the UNCRC (United Nations, 1989). However, given the complex realities of pediatric health care, this research also emphasized that "children's participation was about more than children" (Brady, 2017, p. 175). While the findings reaffirm the presence of multifaceted factors influencing children's participation noted in Chapter Two, this inquiry can extend our understanding of their inherent interdependency and complexity in conceptualizing children's participation as a complex process (Coyne, 2011; Montà, 2021). As

interrelated contextual⁸⁴ dimensions (e.g., child-adult relations, policies, legal guidelines) can play a role in the ways in which CLSs and directors can act on children's decisions, this research illustrates that "it is one thing to endorse the empowerment of children... and another to operationalize it" (Sabatello et al., 2018, p. 2). Even in the context of the Netherlands, as a leading country on children's wellbeing, rights, and happiness, the research findings reaffirm an implementation gap⁸⁵ between children's rights to participation and the actual fulfilment of these rights in health care practices (Brady, 2020; Charles & Haines, 2019; Cornwall, 2008; McKee, 2019; Stiggelbout et al., 2012; Tisdall, 2013).

To offer a starting point for bridging the gap between the rhetoric and reality in children's participation, I propose that Doane and Varcoe's (2021) scholarship on relational inquiry (outlined in Chapter Four) can help advance more relational and inherently critical understandings of children's rights to participation, autonomy, and their agency. Relational inquiry can do so by offering a conceptual framework for recognizing the impact of interrelated complex, contextual dimensions in shaping health care practices (Doane & Varcoe, 2021; Ocloo et al., 2020). In the following sub-sections, I discuss three key ways in which, using a relational inquiry approach (Doane & Varcoe, 2021), the research findings can advance more critical and contextual understandings of children's participation rights and their implications for health care practices and policies. These include:

- 1) Fostering a relational view of children's participation rights,
- 2) Confronting practice and knowledge hierarchies in health care institutions, and

⁸⁴ As noted in Chapter One, for the purpose of consistency and clarity this chapter, I define 'contextual dimensions' as encompassing (interrelated), personal, structural, and institutional factors that can shape health, wellbeing, and health care practices, including children's participation (Valaitis et al., 2018).

⁸⁵ Other scholarship that speaks to the challenges of translating the rhetoric of children's participation to practices in the context of health care in the Philippines (Bessell, 2009) and children's participation in public policy in Wales (Crowley, 2015), for example, suggests that this implementation gap is not unique to the Netherlands.

- 3) Attending to the role of hospital policies and legal guidelines in realizing children's participation rights.

7.1.1 Fostering a Relational View of Children's Participation Rights

The overarching conceptualization of children's participation that emerged from my research with CLSs and directors characterizes participation as a shared, albeit complex, process in which children are 'listened to', 'protected' and 'empowered' by adults. In their conceptualizations of children's participation, participants also interdependently referred to children's autonomy and agency, a finding that was also noted in Chapter Two. The interchangeable use of agency and autonomy can strengthen the inherent complexity of children's participation (Montreuil & Carnevale, 2016) and suggest that confusion exists around which conception of children's autonomy (or agency) is used to guide clinical practice (Walter & Ross, 2014).

Participants' focus on the need to 'protect' and 'empower' children also highlights an overarching focus on 'child first' focused practice (Ocloo & Matthews, 2016; Tisdall, 2008). In 'child focused' practice, the rhetoric of 'hearing children's universal, protected, and developmentally self-sufficient voices' does not address power imbalances (Brady, 2020; Boland et al., 2019), attend to ethical concerns in defining children's 'best interests' (Carnevale et al., 2017), or bring about meaningful and effective participation outcomes (Davis & Smith, 2012; Tisdall, 2008). Relational inquiry can offer a helpful avenue for shifting away from 'child focused' practice by recognizing the role of adults and social contexts in shaping children's complex decision-making rights (Hammersley, 2017; King, 2007; van Bijleveld, Bunders-Aelen & Dedding, 2020). A relational approach can challenge dominant (and problematic) binary conceptions of children's decision-making (e.g., decisional in/capacity and im/maturity) in favour of the "multiple forms and dimensions of agential experience and expression" (Carnevale et al., 2020, p. 116). From a

relational ethics⁸⁶ perspective, the research findings have demonstrated that children can be simultaneously agential and legally and morally dependent with an entitlement to protection (Carnevale, 2015; Carnevale et al., 2017). Thus, when children and adults' interests are relationally intertwined, care providers such as CLSs can balance supporting children's needs (to protection) and their agency in decision-making (Horgan & Kennan, 2021). The research findings have therefore also supported a contextual rather than singular view of children's decision-making rights (Carnevale et al., 2015).

In child life practice, a particularly noteworthy finding pertained to the prominent role that CLSs can adopt in facilitating children's participation rights (Boles et al., 2021; Koller, 2017) in 'minor' decision-making during medical procedures. By 'widening' CLSs' point of reference in health care situations, relational inquiry can encourage CLSs to consider how children's "relational embeddedness can favourably and unfavourably affect their experiences" (Carnevale et al., 2020, p. 119) during medical procedures. For CLSs, this 'widening' approach can be achieved by asking reflexive questions of themselves and others (Doane & Varcoe, 2021). Based on the study findings, such reflexive questions may include:

- 1) How can my assumptions, beliefs, experiences, and values shape the ways in which I provide children with opportunities for decision-making – particularly for young children and children with disabilities? (*intrapersonal*)
- 2) What are children and caregivers' preferences regarding children's decision-making? (*intrapersonal*)

⁸⁶ As discussed in Section 4.3.2, 'relational ethics' refers to an "ontological advancement for childhood studies" to move beyond individualistic and atomistic conceptions of personhood, agency and autonomy (p. 112). A childhood ethics lens aims to illuminate the ethical implications of understanding children's agency as being relationally embedded (Carnevale et al., 2015, 2020). e

- 3) How can the ways in which I am interrelating with children, caregivers and other health care providers shaping children's decision-making? (*interpersonal*)
- 4) How can the medical, legislative, and socio-cultural context in which I practice shape children's decision-making? (*contextual*).

Such reflexive questions can therefore further challenge CLSs to move beyond dominant protectionist and developmentalist discourses in shaping children's participation noted in Chapter Two (Carnevale et al., 2017; James & Curtis, 2012; Kehily, 2008a; Young, 2003).

From a health care organization perspective, this study also highlights how a relational framing of children's participation in medical consent processes and collective decision-making in participation 'structures' such as children's advisory councils (Crowley, 2015; Cunningham & Walton, 2016) can contribute to bridging the implementation gap. Directors' calls for more 'customized' approaches to children's decision-making bring attention to scholars who have proposed customized views on children's consent (Hein et al., 2012), as well as fluid and continual (Olszewski & Goldkind, 2018), personalized (Sabatello et al., 2018), and situational (Coyne & Harder, 2011) approaches to children's decision-making. From a relational inquiry perspective, these customized and inherently relational approaches underscore: 1) the ways in which children's (collective) participation is shaped by children's relationships with (and decisions of) adults, and 2) how children's evolving decision-making capacities can be shaped by their preferences and life experiences, rather than solely their age, developmental level, or abilities (Koller, 2017; Salbatello et al., 2018). Framing children's participation in this relational manner can avoid rendering children's decision-making as a top-down and tokenistic organizational 'tick in the box' (Brady, 2017) in which children's participation is only facilitated through adult-led, developmentalist invitations to participate (Cornwall, 2008; Davis & Smith, 2012; Moss & Petrie, 2005).

7.1.2 Confronting Practice and Knowledge Hierarchies in Health Care Institutions

Several CLSs and directors described an institutional culture of participation⁸⁷ in which health care providers engaged in interprofessional practice⁸⁸ with collaborative power sharing⁸⁹ to facilitate children's decision-making (Nugus et al., 2010). This finding is well-aligned with the idea that interprofessional collaborative practice is 'foundational' to the child life discipline (Boles et al., 2021). In contrast to this 'collaborative' form of interprofessional practice, the research findings also point to tensions and contrasts in CLSs' and directors' self-perceived 'leadership' in facilitating children's participation and the 'time consuming' nature of children's participation.

While health care providers' 'leadership' in children's decision-making can reflect an attempt to exercise agency (Nugus et al., 2010), this finding also raises questions about which forms of 'expert' knowledge are prioritized in biomedical health care contexts (Bluhm, 2016; Doane & Varcoe, 2021) and whose 'best interests' are considered in children's decision-making (McLaughlin, 2015; Taylor, 2016). From a relational inquiry approach (Doane & Varcoe, 2021), the tensions and contrasts in participants' narratives suggest that the biomedical⁹⁰, and inherently paternalistic⁹¹, and neoliberal⁹² health care institutions (Murgic et al., 2015), and the organizational cultures that underpin them (Brady, 2017; 2020), can shape health care practice and knowledge

⁸⁷ A culture of participation is the ethos of an organization shared by service providers and users, in which participation is seen as a wider concept than 'just' specific events or activities that promote children's participation (Kirby et al., 2003; Wright et al., 2006).

⁸⁸ Interprofessional practice refers to the desire for collaboration among health care providers to share roles, power, and responsibility for care as an incentive to enhance patient outcomes, reduce health care costs and compensate for staff shortages (Nugus et al., 2010).

⁸⁹ Collaborative power sharing refers to the diverse and distributed ways in which power can be negotiated and shared by different health care providers in the ways in which treatment and care are organized (Nugus et al., 2010).

⁹⁰ Biomedicine is an umbrella theoretical framework or approach to refer to how most powerful institutions envision the relations between biological sciences and medicine that is woven into Western culture (Valles, 2020).

⁹¹ Medical paternalism was the dominant model of the doctor patient relationship for more than 25 centuries and entails that the doctor uses his skills and knowledge to serve the best interest of the patient as a moral obligation (Laher, 2021).

⁹² Neoliberalism can be linked to biomedicine as neoliberal economic restraints on health care practices have pressured providers to adopt medicalized, short-term strategies legitimized by 'evidence-based' practices (Brown, 2022). Both neoliberalism and biomedicine also emphasize individuality in terms of individual rationality and viewing health, illness and disability as individual experiences, respectively (Gerlach et al., 2018).

hierarchies (Doane & Varcoe, 2021) to influence children’s opportunities for decision-making.

While biomedical knowledge is vital to health care (Doane & Varcoe, 2021), relational inquiry can highlight how directors’⁹³ ‘paternalistic’ tendencies in thinking *for* the child reflects the privileging of biomedical, paternalist knowledge over other forms of knowledge in children’s decision-making processes (Brown et al., 2022).

The dominance of medical paternalism can be considered problematic because the view that only physicians have the expertise to make decisions stands in direct opposition to viewing patients as autonomous agents (Laher, 2021; Murgic et al., 2015). A relational inquiry approach can therefore emphasize how hierarchies in health care practices and forms of knowledge can permeate professional working practices and cultures to assign children, families, and health care providers to particular positionings of power (Doane & Varcoe, 2021), further contributing to an implementation gap. For CLSs, these findings raise questions about how the structural embeddedness of medical dominance (Bourgeault & Mulvale, 2006) and biomedical knowledge can subordinate CLSs’ expertise in other forms of knowledge to influence children’s decision-making. For example, in contrast to biomedical approaches, CLSs are trained in ecological (Bronfenbrenner, 1974) and sociocultural (Vygotsky, 1978) theories to assess the psychosocial wellbeing of children and families (Koller & Wheelwright, 2020). As some forms of knowledge “only offer a partial picture” (Doane & Varcoe, 2021, p. 51), relational inquiry can challenge health care providers and decision-makers to (1) reflect on how they experience sharing roles and responsibilities in health care teams, and (2) consider how different forms of knowledge can work in concert to shape children’s decision-making processes in health care.

⁹³ In this study, several directors held simultaneous appointments as physicians.

Participants' contrasting perspectives on the 'time consuming' nature of children's decision-making can also extend our understanding of the neoliberal agenda of biomedical health care institutions in shaping health care practices. In the busy realities of health care, neoliberalism can be held responsible for promoting managerialism in creating excessive workloads and increased time pressures (Rogers, 2021). Neoliberalist ideologies can take service providers away from the activities they were trained for and want to do (Rogers, 2021), such as consistently involving all children in health care decision-making. CLSs' resistance of the 'time-pressures' imposed by physicians in children's decision-making processes point to a neoliberal, hierarchical social order in which CLSs and physicians engaged in a competitive form of power sharing⁹⁴ (Indah, 2021; Nugus et al., 2010).

Neoliberalism can also disregard how contextual dimensions (e.g., socio-historical and political contexts) can shape the complexities of people's lives by prioritizing individualism over collective mutual interests and supports (Gerlach et al., 2018). For CLSs and other health care providers and decision-makers, relational inquiry can counter individualist ways of knowing and acting in health care (Bluhm, 2016; Brown et al., 2022; Gerlach et al., 2018), including beliefs about health as an individual choice and responsibility (Doane & Varcoe, 2021). In this manner, relational inquiry offers an approach to children's participation that is more reflective of the realities of health care providers and decision-makers.

7.1.3 Attending to the Role of Hospital Policies and Legal Guidelines in Realizing Children's Participation Rights

In the context of hierarchical biomedical health care institutions, this study also draws attention to how hospital policies and national legal guidelines on children's rights can shape

⁹⁴ In contrast to collaborative power, competitive power sharing involves health care providers from one occupation dominating other types of health care providers (Nugus et al., 2010).

children's opportunities for decision-making and further contribute to the implementation gap (Brady, 2017; Boland et al., 2019). In health care, participation policies are an essential element in ensuring children's involvements in decision-making (Ehrich et al., 2015). Children's involvements in decision-making were reflected in some hospital documents (e.g., posters, booklets) and children were involved in several hospital policy developments. These findings perpetuate the normative child participation rhetoric in which "children's participation is valued as a normative principle by policy-makers" (Bessell, 2009, p. 299). This rhetoric is also underscored by Coyne (2008), who suggests that: "hospital policies accept that services should be child-centred, and children should be active partners in their decisions about their health and care" (p. 1682).

In contrast to this rhetoric, the study findings also underscore that hospital policies lacked practical guidance on how to implement children's rights to participation. Such lack of guidance reaffirms the inherent challenges and complexities in implementing key principles of the UNCRC (United Nations, 1989) in pediatric health care policies and practices (Byrne & Lundy, 2015). Several CLSs also described 'assuming' that children have rights to participation and an 'unawareness' of children's rights (including the UNCRC), suggesting that children's rights tend to be accepted at face value with little critical reflection in health care practices (Brady, 2017; Hammersley, 2015). This lack of critical reflection can have problematic implications because taking children's rights for granted can pose a risk for children's rights not being actualized in health care practice, thus limiting children's opportunities for decision-making (Yigitbas & Top, 2020).

Doane and Varcoe's (2021) scholarship on relational inquiry can offer a starting point for stimulating critical reflections on children's rights and contribute to closing the "gap between the rhetorical "vision and reality of children's participation" (Bessell, 2009, p. 300). Relational inquiry can do so by considering the adequacy of policies, guidelines, and laws as contextual constraints in

shaping individual health care practices (Doane & Varcoe, 2021). According to Doane and Varcoe (2021), policies can reflect the normative values of the health care culture and shape individual actions and beliefs. For CLSs, relational inquiry can invoke critical reflection on: “which rules, laws, or policies may be at play”, and how these rules, laws, and policies, or lack thereof, “may be conveying certain messages” (Doane & Varcoe, 2021, p. 72) in the health care environment to shape children’s opportunities for decision-making. In turn, it is the responsibility of health care decision-makers to develop clear guidelines and policies on information sharing and decision-making that reflect all stakeholder views, including children (Coyne & Gallagher, 2010; Schalkers et al., 2016). While “policies in isolation do not necessarily change practices” (Schalkers et al., 2016, p. 1042), this relational perspective can provide a much-needed avenue for heightening an awareness of children’s rights among pediatric health care providers, such as CLSs, and decision-makers. Such an awareness can act as a first step in promoting an understanding of children’s participation rights, with the aim of progressing children’s participation in a direction that is meaningful and influential (Schalkers et al., 2016).

7.2 Advancing Relational Theoretical Scholarship on Children’s Participation

Based on the various ways in which relational inquiry (Doane & Varcoe, 2021) can attend to contextual factors in shaping children’s participation that were evident in the findings, I propose that the study findings can contrast with, advance or build on existing theoretical models and approaches to children’s participation discussed in Chapter Two. In this section, I discuss how the knowledge generated by this study can: 1) build on non-hierarchical models of children’s participation, and 2) advance the ‘relational turn’ in the sociology of childhood. I end this section with a discussion of the associated implications for promoting alternative ‘ways of knowing’ in child life practice and child life educational curricula.

7.2.1 Building on Non-Hierarchical Models of Children’s Participation: Lundy’s (2007)

Rights-Based Model

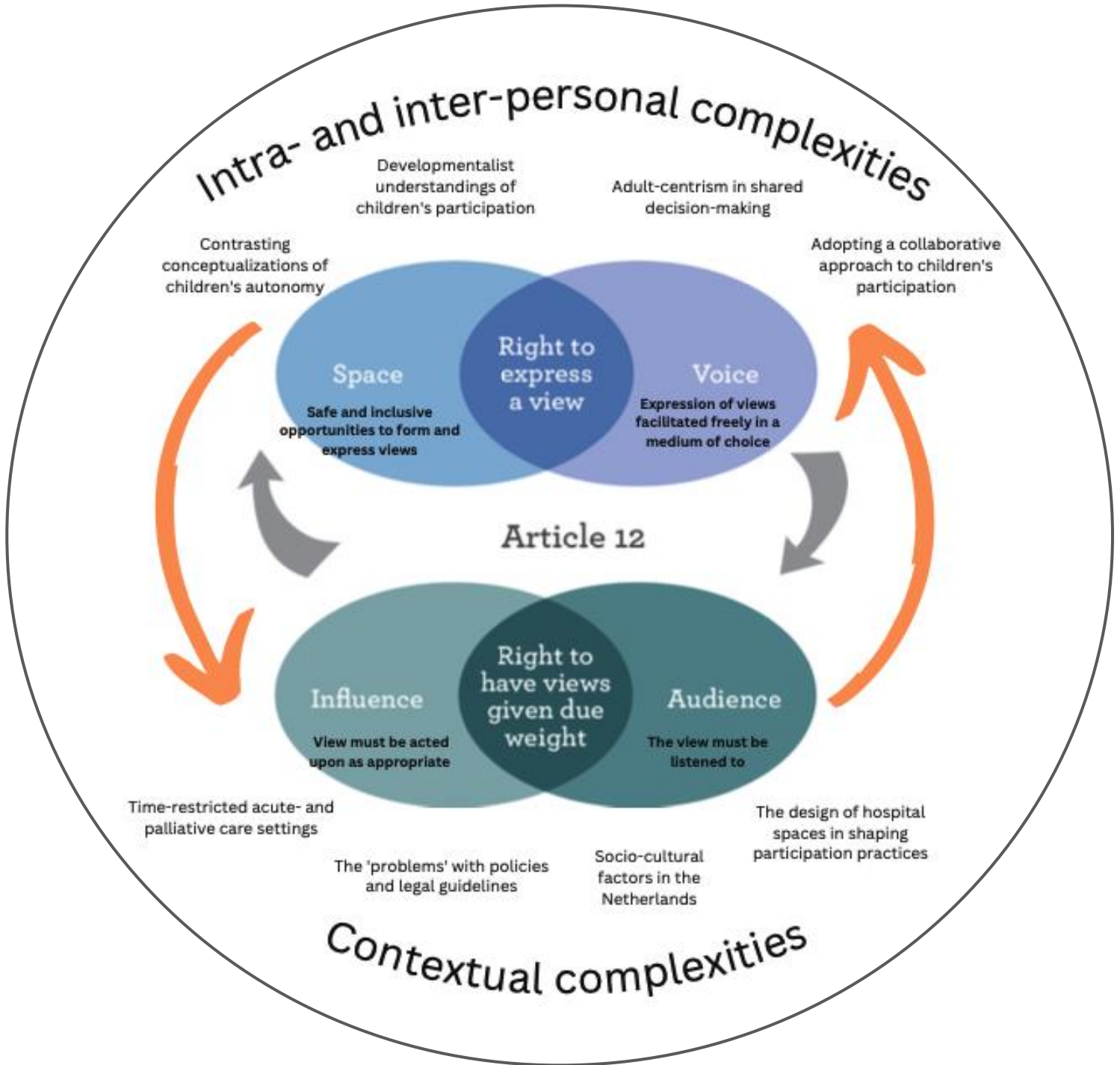
As this study emphasized the complex, relational, and dynamic nature of children’s participation processes, the research findings disrupt simplistic and linear hierarchical models of children’s participation, such as Hart’s (1992) widely-referenced model. Rather, this inquiry aligns with and/or builds on non-hierarchical conceptualizations of children’s participation processes to underscore the idea that children’s participation is rarely a ‘seamless’ process in the complex realities of health care (Cornwall, 2008; Doane & Varcoe, 2021). This study’s dynamic stance of children’s participation supports Lambert et al.’s (2008) continuum of participation to emphasize the ways in which children may move back and forth between higher and lower degrees of involvements in communication processes (and decision-making) in health care depending on various factors (e.g., medical acuity, child preferences). This study can expand on this model by bringing attention to how interrelated factors that are specific to health care contexts can shape children’s positioning on this decision-making continuum (Lambert et al., 2008).

In addition to a non-hierarchical ‘continuum’ of participation, the study findings also align with Lundy’s rights-based model (2007) of children’s participation. The findings overlap with this model in terms of contributing to a shift in conceptualizations of children as active citizens and genuine commitments to inclusive relational and collaborative practices with children in decision-making processes or continuums (Brady, 2017; Lambert et al., 2008). By valuing child-adult relations in the elements of ‘space’, ‘voice’, ‘audience’ and ‘influence’, Lundy’s (2007) model can also problematize the widely referenced and problematic imperative in sociological literature on childhood known as ‘listening to children’s (individualized) voice’ (Carnevale et al., 2020). Lundy (2007) acknowledges that “voice is not enough” in fulfilling children’s participation rights (Lundy, 2007, p. 927). A relational inquiry approach (Doane & Varcoe, 2021) can further build on this idea

by denoting that translating ‘voice’ into meaningful practices and policies requires attention to be paid to ‘above’ (i.e., institutional policies, guidelines, cultures of participation) and ‘below’ (i.e., individual commitments, beliefs, practices) (Cornwall, 2008). According to a relational or ‘thick’ conception of children’s voices, this research recognizes children's expressions and related meanings as relationally embedded articulations of their agency (Carnevale, 2020). For children with medical complexities or disabilities, for example, their ‘voices’ or agential expressions are not always tied to verbal articulation (Carnevale et al., 2020). A thick conception of children’s ‘voices’ can therefore also attend to the ambiguity that exists around “how children's voices should be heard and understood, and how they should be related to their agency” – broadening our ‘moral compass’ (Carnevale et al., 2020, p. 118).

Considering these key areas of alignment, the knowledge generated by this study can therefore expand on Lundy’s (2007) model by highlighting the interrelated ways in which health care-specific contextual elements can complicate the actualization of Lundy’s (2007) notions of ‘space’, ‘voice’, ‘audience’ and ‘influence’ in a health care context. Figure 18 depicts a visual representation of the application of the contextual elements introduced in this study to Lundy’s (2007) model.

Figure 18: The Application of Interrelated Factors in Shaping Children’s Participation Rights in Health Care to Lundy's (2007) Model of Participation (Model adapted from Horgan et al., 2015)



Overlapping with the study findings, some scholars have noted a lack of guidance on how Lundy's (2007) child participation model can be operationalized in practice (Kennan et al., 2018; O'Kane et al., 2021). To provide practical guidance on implementing this model in different professional contexts with children, I propose that several 'checklists' can facilitate the implementation of children's participation in practices and policies. On the following pages, checklists are included for service providers and decision-makers that are based on Lundy's (2007) rights-based model and published by an Irish national centre of excellence and coordination (referred to as 'Hub na nÓg')⁹⁵ that aims to facilitate children's involvements in decision-making. While these checklists must not reduce the complexities of children's participation, they can provide a practical first step in encouraging health providers and decision-makers to draw attention to children's rights in children's relational decision-making processes while being mindful of avoiding being reductionistic. Figure 19 depicts a checklist for service providers (e.g., CLSs):

⁹⁵ The Department of Children, Equality, Disability, Integration, and Youth (DCEDIY) set up Hub na nÓg to support implementation of the *National Strategy on Children and Young People's Participation in Decision-Making* (2015-2020).

Figure 19: ‘Everyday Spaces’ Checklist for Service Providers (Hub na nÓg, 2021)



Figures 20 and 21 depict planning and evaluation checklists for decision-makers, respectively, to consider children’s involvements in policies, plans, services, programs, and legislation.

Figure 20: Planning Checklist for Decision-Makers (HUB na nÓg, 2021)



Figure 21: Evaluation Checklist for Decision-makers (HUB na nÓg, 2021)



Expanding on the rights-based approach offered by Lundy's (2007) model can be valuable to children's decision-making scholarship because children's participation "cannot [conceptually] stand on its own" (Percy-Smith & Thomas, 2009, p. 344). Echoing Brady (2017) and Percy-Smith and Thomas (2009), children's rights (and the UNCRC) are an essential pre-condition for embedding meaningful, effective and sustainable ways of participation. Despite the critiques of the UNCRC noted in Chapter Two, children's rights reinforce the importance and universality of children's participation rights based on social justice (Bessell, 2009). In the context of child life practice, however, incorporating children's rights in practice can have particular implications. As noted in Chapter Two, CLSs are trained from a predominant developmental perspective (Boles et al., 2020) and the developmental theories that underlie child life practice can promote exclusion by adopting age-based conceptions on children's abilities (Black, 2013). In health care institutions that celebrate the rhetoric of children's rights, in which 'any' child who is capable of forming a view can participate (United Nations, 1989), a simultaneous focus on developmentalism and children's rights to participation becomes a polarizing idea. If CLSs are passionate about adopting a rights-based approach to children's participation, they need to critically (re)consider the effects of developmentalist understandings of children on their opportunities for decision-making in complex health care settings. In section 7.2.3., below, I discuss how a relational inquiry approach (Doane & Varcoe, 2021) can aid CLSs in (re)considering and moving beyond developmentalist discourses in health care practices and educational curricula.

7.2.2 Advancing the 'Relational Turn' in the Sociology of Childhood

This study can also advance sociological scholarship on childhood by highlighting participants' contrasting beliefs on the divisions between childhood and adulthood, as socially-constructed categories or sociological 'units' of analysis (Baraldi & Cockburn, 2018; Graham, 2011; Mayall, 2000; Sarmiento et al., 2018). Several participants' narratives characterized childhood

as a distinct and normative category from adulthood in which children were ascribed with age-based labels such as being in need of ‘protection’, ‘vulnerable’, and ‘incapable’ of exercising autonomous agency in decision-making. In contrast, the majority of CLSs’ and directors’ narratives disrupted normative conceptions of childhood by underscoring contextual and complex relations between the socially-constructed categories of childhood and adulthood (Baraldi & Cockburn, 2018; Brady et al., 2015; Mayall, 2000; Powell & Depelteau, 2013; Tisdall, 2008). From a relational perspective, this ‘disruption’ emphasizes that both children and adults can belong to the same relational order of reality (Powell & Depelteau, 2013). Informed by a relational inquiry approach (Doane & Varcoe, 2021), the knowledge generated by this inquiry can therefore contribute to much-needed efforts in “pushing sociological scholarship in a relational direction” (Powell & Depelteau, 2013, p. 69).

By redefining familiar sociological concepts such as participation, agency, and autonomy, as dynamic, interrelated relational processes rather than static entities (Powell & Depelteau, 2013), the study findings can also advance understandings of the ‘relational turn’⁹⁶ in the sociology of childhood (Alanen, 2018; Depelteau, 2014; Gabriel, 2014). This dynamic stance on children’s participation can strengthen a recognition of the plurality of childhoods (Carnevale et al., 2020) in which “one size or form of participation does not fit all” (Brady, 2017, p. 249) (also reflected in non-hierarchical models of children’s participation noted in Section 7.2.1). In sociological scholarship, such theoretical advances can promote greater clarity about human social life and how to study the interrelations within them (Powell & Depelteau, 2013, p. 68). Such sociological advances can also provide a firm basis for working towards the implementation and operationalisation of children’s participation rights in practices (Mayall, 2000).

⁹⁶ Outlined in Chapter Four, this relational turn calls for more attention to be paid to child-adult relations and the wider, social, organizational, and systemic contexts within which children participate (Tisdall, 2008).

7.2.3 Promoting Alternative ‘Ways of Knowing’ in Child Life Practices and Educational Curricula

In addition to varying practical ways in which a relational inquiry perspective (Doane & Varcoe, 2021) can be of value to CLSs outlined in Section 7.1, the theoretical advances described in this section can also help to refine the theoretical foundation on which child life practice is built, including child life educational curricula. By bringing attention to the various ways in which people’s lives can be shaped by contextual factors, I propose that relational sociological and nursing scholarship, including the sociology of childhood and relational inquiry (Doane & Varcoe, 2021), can promote alternative ways of knowing in child life practice (Koller, 2019). These relational approaches can challenge the premise of developmental theories that underlie child life practice in favour of more critical understandings, models and (sociological) scholarship on childhood and children’s rights outlined in Sections 7.2.1 and 7.2.2.

The practical ways in which relational inquiry outlines “how to pay attention” in health care contexts (Doane & Varcoe, 2021, p. 76) can respond to a call for a new theoretical vision for child life pedagogy (Koller & Wheelwright, 2020) that involves “teaching students *how* to think rather than just *what* to think” (Koller, 2019, p. 11). While being mindful of “which aspects of developmental theory are worth keeping” (Koller, 2019, p. 13), a new theoretical vision that attends to contextual factors in shaping children’s lives can promote more “contemporary views of what it means to be a child in today’s world and offers greater applicability in complex care environments than standardized theories of development” (Koller, 2019, p. 13). This relational approach to practice moves beyond the dominant focus on children’s decision-making developmental ‘abilities’ (Gabriel, 2021) in favour of an understanding of children’s participation in the context of “what’s possible given people’s life context” (Doane & Varcoe, 2021, p. 113).

7.3 Key Recommendations for Policies, Practices and Education

In this section, I discuss the key recommendations for pediatric health care policy developments, practices, and (child life) educational curricula that are based on the findings of this research.

7.3.1 Recommendations for Pediatric Health Care Policy Development

For pediatric health care policy developments, I recommend that:

1. Children's participation is conceptualized as relational and complex in 'shared' decision-making processes, and structurally embedded in health care institutions and practices and reflected in policies, guidelines, and documents (e.g., in institutional policies and/or guidelines on child- and family-centered care practices or in children's advisory council guidelines).
2. Decision-makers devote attention to children's (relational) rights in hospital policies, documents, and guidelines, including how such documents can be made more accessible to health care providers and visible across hospital units and practices. For example, the European Association for Children in Hospital (EACH)⁹⁷ provides clear guidelines on how children's rights can be applied to health care practices. This multi-page document could be made more accessible by being reformatted into a single-page, poster-sized document. In turn, this poster-sized document could be displayed on hospital units.
3. Hospital policies, guidelines and documents uphold the participation rights of all children regardless of their age by articulating that health care providers can assess children's (and their caregivers) preferences on an individual basis to recognize that children's (fluctuating)

⁹⁷ EACH provides several key overviews and/or guidelines on varying ways of understanding children's rights according to the UNCRC, Council of Europe, and 'other sources' such as the European Children's Hospital Organization (ECHO). These documents can be found at: <https://each-for-sick-children.org/rights>.

involvements in decisions may take different forms in different contexts according to their own needs, motivations, and preferences (rather than solely being based on children's age).

4. Decision-makers/managers of children's advisory councils revisit the degree to which children's involvements in councils may be structured by adult-driven processes and (re)assess how children can be informed of the outcomes and impacts of their council involvements (the checklist in Appendix L displays concrete questions to evaluate children's decision-making processes).
5. Decision-makers/managers of children's advisory councils consider how the recruitment of children with personal experience/expertise in specific health conditions can inform hospital-wide decision-making regarding specific topics (e.g., improving quality of care for children with cancer) in a more nuanced and applicable manner.
6. Children and their caregivers are provided with an opportunity to provide feedback on their experiences with hospitalization and being involved in decision-making to inform future decision-making regarding pediatric health care practices (e.g., in the form of writing letters to chief executives and/or 'experience monitors'⁹⁸ – see Schalkers (2016) for specific format suggestions).
7. Children's views are sought and implemented in all (re)developments initiatives related to hospital design and décor (e.g., children can be involved in research studies (e.g., Lambert et al., 2014) or children's advisory councils to provide their views on ideal physical design features for hospitals).

⁹⁸ As noted in Chapter Two, an 'experience monitor' is a digital instrument that allows children and caregivers to share their experiences of hospital care in the Netherlands (Kind & Ziekenhuis, 2020).

7.3.2 Recommendations for Pediatric Health Care Practices

Based on the study findings, I recommend that pediatric health care providers, including CLSs:

1. Adopt a relational approach to children’s participation informed by relational inquiry (Doane & Varcoe, 2021) and Lundy’s (2007) model of participation to recognize adults’ inherent role and power in shaping children’s rights to decision-making and how individual preferences, values and beliefs can shape children’s decision-making processes.
2. Involve children and their caregiver(s) in conversations regarding decision-making on an individualized basis to establish their preferred level of involvement and comfort in making decisions that pertain to the child’s care (including ‘minor’ and ‘major’ decisions).
Considering CLSs’ prominent role in preparing children for medical procedures, CLSs may also use documents such as a ‘hospital passport’ (referenced in Section 6.2.2) or a ‘Preparation sheet’⁹⁹ to involve children in decision-making.
3. Engage in collaborative information-sharing and (weekly) opportunities for discussion regarding clinical cases in which children’s participation in decision-making was particularly challenging (e.g., when perspectives and preferences collide, or participation is refused) during team meetings, for example. A guiding question could include: “What have we done to advance children’s rights today/this week?”
4. Familiarize themselves with local legal guidelines concerning children’s consent to medical treatments and how these guidelines may enable or constrain their abilities to involve children in decision-making, including how standardized guidelines to consent can shape decision-making opportunities for children with disabilities.

⁹⁹ The ‘iSupport’ (International collaborative standards to support pediatric patients during procedures, reducing harm and establishing trust) Preparation Sheet can be obtained from: <https://www.edgehill.ac.uk/wp-content/uploads/documents/ISupport-preparation-sheet-1.pdf>

5. Engage in training and professional education opportunities on children’s participation in decision-making that also attend to frameworks and guidelines on children’s rights.
6. Incorporate the use of ‘child-friendly’ resources, such as a storybook¹⁰⁰ for young children on the topic of decision-making (Appendix J) in their everyday practices (in addition to the checklists referenced in section 7.3). I developed this book as a response to: 1) research pointing to young children’s exclusion from health care decision-making, 2) CLSs’ prominent roles in facilitating young children’s involvements in ‘minor’ decision-making, the 3) the lack of clarity on *how* to facilitate children’s decision-making, and 4) the need for practical resources on children’s participation. Given CLS’ psychosocial responsibilities, they are seemingly well-positioned to take a leading role in using such resources in practice.

7.3.3 Recommendations for Child Life Educational Curricula

Based on the relational framing of children’s participation and further to the discussion offered in Section 7.2.3, I also propose specific recommendations for child life educational curricula. These recommendations may be relevant for individual child life educators and broader associations that govern the educational requirements of (certified) CLSs, such as the Association of Child Life Professionals (ACLP) in North America.

1. Integrate the sociological scholarship on childhood and relational inquiry (Doane & Varcoe, 2021) as alternative theoretical and conceptual frameworks to support the integration critical, contextual, and relational perspectives on children, childhood and their participation in child life practices. These frameworks can move beyond an over-reliance on

¹⁰⁰ This storybook can introduce children (and their caregivers) to the topic of decision-making and enhance their understanding of what ‘participation’ may entail in different scenarios (e.g., medical procedures). Given the psychosocial focus of this storybook, CLSs may be ideally positioned to distribute and collaboratively read the book with children and families.

developmental theories and convey the realities of children's (complex) life-worlds, experiences, and preferences.

2. Integrate conventions and guidelines on children's rights (e.g., UNCRC) in curricula and specify how they relate to child life practice. To emphasize children's right to participation, draw on Lundy's (2007) model of participation in curricula to support an understanding of the key factors that are necessary to realize children's rights to participation – particularly pertaining to how child-adult relations can shape children's rights to participation.

7.5 Future Research

The following recommendations are based on the lack of research focused on children's experiences of participation in decision-making (noted in Chapter Two) and the research limitations (noted in Chapter Five):

1. Regarding children's individual decision-making, incorporate interviews and observations to reveal nuances in triadic encounters between children, caregivers and providers and uncover contextual and interactional factors that may shape children's participation in specific contexts (e.g., oncology, palliative care) and over varying periods of time to explore how children's participation may differ over the course of a treatment trajectory.
2. Regarding children's collective decision-making, explore how children, families and decision-makers experience their involvements in children- and/or family-advisory councils to inform the integration of children's participation in hospital policies and guidelines.
3. Explore how different models, methods and approaches towards participation can shape children's diverse participation in health services at an individual and collective level of decision-making.

4. Assess the feasibility and efficacy of institutional guidelines and policies on children's participation in decision-making with the involvement of children, families, care providers, administrators, and policy-makers.
5. Based on the research limitation noted in Section 5.11, conduct critically oriented research that explicitly decentres Whiteness and examine how children's participation in health care can be differentially experienced by structurally marginalized and equity-seeking populations. This could be done by; (1) recruiting children, families, and health care providers with diverse identities and social locations, and (2) employing decolonizing research methodologies and methods that do not rest on Eurocentric, colonialist, and White ideologies (Thambinathan, 2021).

7.4 Conclusion

Overall, the knowledge generated by this study can contribute to our understandings of how children's participation rights have been conceptualized and implemented in the context of two pediatric hospitals in the Netherlands. The research findings provide evidence of the role that CLSs and directors can play in shaping children's participation in decision-making processes, including their use of practical tools and strategies used to facilitate participation (e.g., a hospital passport) and their individual beliefs and attitudes towards children's participation. The study also illustrates how contextual considerations, including acuity of a child's health status and hospital policies can shape children's participation in the legislative, political, and socio-cultural context of the Netherlands. In this manner, this study highlights the interdependency between power-laden individual and contextual (e.g., institutional) structures in influencing how children's participation in different contexts (Ocloo et al., 2020). This inherently complex and relational understanding of children's participation provides insights into the gap between how children's (idealized) decisions

ought to be made (e.g., as outlined in the UNCRC) and how they *are* made in the ‘real world’ (Sabatello et al., 2018).

This context-specific knowledge may be relevant for a wide variety of professionals who interact and practice with children and families in various contexts. In addition to CLSs, this knowledge may be relevant to other health care providers, including physicians, nurses, psychologists, occupational therapists, physical therapists, speech language pathologists, and social workers. Care providers who practice with children and families in community settings (e.g., child and youth workers) may also find value in applying the recommendations that have arisen from this study to their practice setting (e.g., child protection services).

In the context of health care, this study illustrates that significant uncertainty and ambiguity remains regarding how to include children in different forms of decision-making – despite children’s participation representing a fundamental human right. This study therefore echoes other scholars (e.g., Brady, 2017; Lundy, 2007) in calling for a rights-based approach to children’s complex and relational decision-making processes, including practical guidance on how to implement a rights-based approach. Implementing this rights-based approach requires an understanding of how people conceptualise participation and children’s rights, and how these understandings may inform health care practices and cultures as ‘ways of working’ in health care (Brady, 2017). For child life practice, this study offers insights into the ways in which more nuanced and critical understandings of children’s participation can further the (developmentalist) theoretical foundations on which the field is built.

From a broader, relational perspective rooted in the (new) sociology of childhood and relational inquiry (Doane & Varcoe, 2021), this study also brings attention to how contextual factors can shape children’s abilities to exercise decision-making agency. Even in the context of the Netherlands, with widespread commitments to children’s universal rights supported by a strong

economy and progressive socio-cultural understandings and legislation on children's decision-making, this study accentuates that some children (e.g., children with disabilities, critical illnesses, young children) may be excluded from decision-making processes. When children's participation rights are repeatedly (implicitly and/or explicitly) disregarded in complex and evolving health care settings, practitioners and policy-makers must advocate for new ways of viewing children and childhoods to facilitate children's meaningful involvements in decision-making.

References

- Aarthun, A., & Akerjordet, K. (2014). Parent participation in decision-making in health-care services for children: An integrative review. *Journal of Nursing Management*, 22(2), 177–191. <https://doi.org/10.1111/j.1365-2834.2012.01457.x>
- Abrines-Jaume, N., Midgley, N., Hopkins, K., Hoffman, J., Martin, K., Law, D., & Wolpert, M. (2016). A qualitative analysis of implementing shared decision making in child and adolescent mental health services in the United Kingdom: Stages and facilitators. *Clinical Child Psychology and Psychiatry*, 21(1), 19–31. <https://doi.org/10.1177/1359104514547596>
- Alanen, L. (2011). Moving towards a relational sociology of childhood. In: Rita Braches-Chyrek, Röhner, C., Schaarschuch, A. & Sünger, H.: *Kindheiten. Gesellschaften - Interdisziplinäre Zugänge zur Kindheitsforschung Opladen*: Barbara Budrich Verlag, 21-44. Retrieved from: https://www.researchgate.net/publication/324482889_Moving_towards_a_relational_sociology_of_childhood
- Alanen, L. (2019). Generational order: Troubles with a ‘travelling concept.’ *Children’s Geographies*, 1–3. <https://doi.org/10.1080/14733285.2019.1630715>
- Alderson, P. (2007). Competent children? Minors’ consent to health care treatment and research. *Social Science & Medicine*, 65(11), 2272–2283. <https://doi.org/10.1016/j.socscimed.2007.08.005>
- Alderson, P., Killen, M., & Hawthorne, J. (2005). The participation rights of premature babies. *The International Journal of Children’s Rights*, 13(1–2), 31–50.
- American Academy of Pediatrics, Committee on Pediatric Emergency Medicine, American College of Emergency Physicians, & Pediatric Emergency Medicine Committee. (2006). Patient- and family-centered care and the role of the emergency physician providing care to a child

- in the emergency department. *Pediatrics*, *118*(5), 2242–2244.
<https://doi.org/10.1542/peds.2006-2588>
- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom videoconferencing for qualitative data collection: Perceptions and experiences of researchers and participants. *International Journal of Qualitative Methods*, *18*, 1609406919874596.
- Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L. (2001). *Handbook of Ethnography*. SAGE Publications Ltd. <https://doi.org/10.4135/9781848608337>
- Ba, S. (2021). The critique of sociology of childhood: Human capital as the concrete ‘social construction of childhood.’ *Power and Education*, *13*(2), 73–87.
<https://doi.org/10.1177/17577438211011637>
- Badarau, D. O., Ruhe, K., Kühne, T., De Clercq, E., Colita, A., Elger, B. S., & Wangmo, T. (2017). Decision making in pediatric oncology: Views of parents and physicians in two European countries. *AJOB Empirical Bioethics*, *8*(1), 21–31.
<https://doi.org/10.1080/23294515.2016.1234519>
- Baker, M. (2018). *In other words: A coursebook on translation*. Routledge.
- Balcom, S., Doucet, S., & Dubé, A. (2021). Observation and institutional ethnography: Helping us to see better. *Qualitative Health Research*, *31*(8), 1534–1541.
<https://doi.org/10.1177/10497323211015966>
- Baston, J. (2008). Healthcare decisions: A review of children’s involvement. *Paediatric Nursing*, *20*(3), 24–26. <https://doi.org/10.7748/paed2008.04.20.3.24.c6517>
- Baumann, H. (2008). Reconsidering relational autonomy. Personal autonomy for socially embedded and temporally extended selves. *Analyse & Kritik*, *30*(2), 445–468.
<https://doi.org/10.1515/auk-2008-0206>

- Bell, J. A. H., & Balneaves, L. G. (2015). Cancer patient decision making related to clinical trial participation: An integrative review with implications for patients' relational autonomy. *Supportive Care in Cancer*, 23(4), 1169–1196. <https://doi.org/10.1007/s00520-014-2581-9>
- Bettencourt, G. M. (2020). Embracing problems, processes, and contact zones: Using youth participatory action research to challenge adultism. *Action Research*, 18(2), 153–170. <https://doi.org/10.1177/1476750318789475>
- Birch, J., Curtis, P., & James, A. (2007, December 2). *Sense and sensibilities: In search of the child-friendly hospital*. Alexandrine Press. <https://doi.org/10.2148/benv.33.4.405>
- Bisogni, S., Aringhieri, C., McGreevy, K., Olivini, N., Lopez, J. R. G., Ciofi, D., Merlo, A. M., Mariotti, P., & Festini, F. (2015). Actual implementation of sick children's rights in Italian pediatric units: A descriptive study based on nurses' perceptions. *BMC Medical Ethics*, 16(1), 33. <https://doi.org/10.1186/s12910-015-0021-0>
- Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., Lawson, M. L., Davis, A., Yameogo, A., & Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: A systematic review. *Implementation Science*, 14(1), 7. <https://doi.org/10.1186/s13012-018-0851-5>
- Boles, J., Turner, J., Rights, J., & Lu, R. (2021). Empirical evolution of child life. *The Journal of Child Life: Psychosocial Theory and Practice*, 2(1), 4–14. <https://doi.org/10.55591/001c.22522>
- Bourgeault, I. L., & Mulvale, G. (2006). Collaborative health care teams in Canada and the USA: Confronting the structural embeddedness of medical dominance. *Health Sociology Review*, 15(5), 481–495. <https://doi.org/10.5172/hesr.2006.15.5.481>

- Bovenkamp, H. M. V. D., Trappenburg, M. J., & Grit, K. J. (2010). Patient participation in collective healthcare decision making: The Dutch model. *Health Expectations*, *13*(1), 73–85. <https://doi.org/10.1111/j.1369-7625.2009.00567.x>
- Brady, G., Lowe, P., & Olin Lauritzen, S. (2015). Connecting a sociology of childhood perspective with the study of child health, illness and wellbeing: Introduction. *Sociology of Health & Illness*, *37*(2), 173–183. <https://doi.org/10.1111/1467-9566.12260>
- Brady, L.-M. (2017). Rhetoric to reality: An inquiry into embedding young people’s participation in health services and research. Retrieved from: <https://uwe-repository.worktribe.com/output/888254/rhetoric-to-reality-an-inquiry-into-embedding-young-peoples-participation-in-health-services-and-research>
- Brady, L.-M. (Ed.). (2020). *Embedding young people’s participation in health services: New approaches*. Policy Press.
- Brakel, R. & Pickels, A. (2015). Evaluation of legislation, policy and practice on child participation in the European Union (EU). Retrieved from: <https://op.europa.eu/en/publication-detail/-/publication/a5b659d0-4463-4412-9fe3-d2e028fb542a/language-en/format-PDF/source-260482407>.
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Bray, L., Appleton, V., & Sharpe, A. (2019). ‘If I knew what was going to happen, it wouldn’t worry me so much’: Children’s, parents’ and health professionals’ perspectives on information for children undergoing a procedure. *Journal of Child Health Care*, *23*(4), 626–638.

- Bray, L., Callery, P., & Kirk, S. (2012). A qualitative study of the pre-operative preparation of children, young people and their parents' for planned continence surgery: experiences and expectations. *Journal of Clinical Nursing*, 21(13-14), 1964-1973.
- Bricher, G. (2000). *Children in the Hospital: Issues of Power and Vulnerability*.
<http://link.galegroup.com/apps/doc/A62802765/ITBC?sid=lms>
- Brinkmann, S., & Kvale, S. (2018). *Doing Interviews*. SAGE Publications Ltd.
<https://doi.org/10.4135/9781529716665>
- Brown, N. (2018). “Listen to your gut”: A reflexive approach to data analysis. *World Conference on Qualitative Research*, 2, 10-18.
- Burawoy, M. (2017). On Desmond: The limits of spontaneous sociology. *Theory and Society*, 46(4), 261–284. <https://doi.org/10.1007/s11186-017-9294-2>
- Byrne, B., & Lundy, L. (2015). Reconciling children's policy and children's rights: Barriers to effective government delivery. *Children & Society*, 29(4), 266–276.
<https://doi.org/10.1111/chso.12045>
- Canosa, A., & Graham, A. (2020). Tracing the contribution of childhood studies: Maintaining momentum while navigating tensions. *Childhood*, 27(1), 25–47.
<https://doi.org/10.1177/0907568219886619>
- Carnevale, F. A., Campbell, A., Collin-Vézina, D., & Macdonald, M. E. (2015). Interdisciplinary studies of childhood ethics: Developing a new field of inquiry. *Children & Society*, 29(6), 511–523. doi:10.1111/chso.12063
- Carnevale, F. A. (2020). A “thick” conception of children's voices: A hermeneutical framework for childhood research. *International Journal of Qualitative Methods*, 19, 1609406920933767.
<https://doi.org/10.1177/1609406920933767>

- Carnevale, F. A., Collin-Vézina, D., Macdonald, M. E., Ménard, J. F., Talwar, V., & Van Praagh, S. (2020). Childhood ethics: An ontological advancement for childhood studies. *Children & Society, 35*(1), 110-124.
- Carnevale, F. A., Teachman, G., & Bogossian, A. (2017). A relational ethics framework for advancing practice with children with complex health care needs and their parents. *Comprehensive Child and Adolescent Nursing, 40*(4), 268-284.
- Carroll, K. W., Mollen, C. J., Aldridge, S., Hexem, K. R., & Feudtner, C. (2012). Influences on Decision Making Identified by Parents of Children Receiving Pediatric Palliative Care. *AJOB Primary Research, 3*(1), 1–7. <https://doi.org/10.1080/21507716.2011.638019>
- Carter, B. (2002). Chronic pain in childhood and the medical encounter: professional ventriloquism and hidden voices. *Qualitative Health Research, 12*(1), 28–41. <https://doi.org/10.1177/104973230201200103>
- Carter, B., Bray, L., Dickinson, A., Edwards, M., & Ford, K. (2014). *Child-Centred Nursing: Promoting Critical Thinking*. SAGE.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545–547. <https://doi.org/10.1188/14.ONF.545-547>
- Castells, M. (2016). A sociology of power: My intellectual journey. *Annual Review of Sociology, 42*, 1–19.
- CBS (2021a). *Age distribution*. Retrieved from: <https://www.cbs.nl/en-gb/visualisations/dashboard-population/age/age-distribution>
- CBS (2021b). *Origin: How many residents of the Netherlands were born abroad?* Retrieved from: <https://www.cbs.nl/en-GB/visualisations/dashboard-population/origin>

- CBS (2021c). *Languages and dialects in the Netherlands*. Retrieved from: <https://www.cbs.nl/nl-nl/longread/statistische-trends/2021/talen-en-dialecten-in-nederland?onepage=true#:~:text=Leeftijd%20is%20sterker%20onderscheidend.,14%20en%207%20procent%20dat>.
- CBS (2021d). *Jaarrapport jeugdmonitor*. Retrieved from: <https://longreads.cbs.nl/jeugdmonitor-2021/kinderrechten-in-nederland/>
- CBS (2022a). *Population dashboard: Up-to-date figures on the Dutch population*. Retrieved from: <https://www.cbs.nl/en-gb/visualisations/dashboard-population>
- CBS(2022b). *Hoeveel mensen met een migratieachtergrond wonen in Nederland?* Retrieved from: <https://www.cbs.nl/nl-nl/dossier/dossier-asiel-migratie-en-integratie/hoeveel-mensen-met-een-migratieachtergrond-wonen-in-nederland-#:~:text=Eerste%20en%20tweede%20generatie,procent%20een%20niet%20Dwesterse%20migratieachtergrond>.
- Chapman, C. (2011). Resonance, intersectionality, and reflexivity in critical pedagogy (and research methodology). *Social Work Education*, 30(7), 723–744.
<https://doi.org/10.1080/02615479.2010.520120>
- Charles, A., & Haines, K. (2019). Engaging young people as partners for change: the ur community project. *International Journal of Children's Rights*, 27(1), 140–175.
<https://doi.org/10.1163/15718182-02701007>
- Chen, H. (2020). Parental Decision-Making Capacity in Pediatric Palliative Care. *Pediatrics*, 146(1_MeetingAbstract), 219. <https://doi.org/10.1542/peds.146.1MA3.219a>
- Claridge, A., Hajec, L., Montgomery, L., & Knapp, B. (2020). Child and Parent Psychosocial Experiences of Hospitalization: An Examination of the Role of Child Life Specialists. *The*

- Journal of Child Life: Psychosocial Theory and Practice*, 1(1), 3–14.
<https://doi.org/10.55591/001c.22518>
- Clark, P. A. (2016). *Bioethics: Medical, Ethical and Legal Perspectives*. BoD – Books on Demand.
- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, 26(2).
- Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology*, 12(3), 297–298. <https://doi.org/10.1080/17439760.2016.1262613>
- Cockburn, L. (2002). Children and young people living in changing worlds: The process of assessing and understanding the 'third culture kid'. *School Psychology International*, 23(4), 475–485.
- Coghlan, D., & Brydon-Miller, M. (2014). *The SAGE Encyclopedia of Action Research* (Vol. 1–2). <https://doi.org/10.4135/9781446294406>
- Cohen Konrad, S. (2020). *Child and family practice: A relational perspective* (Second). Oxford University Press. <https://go.exlibris.link/j95yb13z>
- Collins, P. H., & Bilge, S. (2020). *Intersectionality*. John Wiley & Sons.
- Collins, T. M., Jamieson, L., Wright, L. H. V., Rizzini, I., Mayhew, A., Narang, J., Tisdall, E. K. M., & Ruiz-Casares, M. (2020). Involving child and youth advisors in academic research about child participation: The Child and Youth Advisory Committees of the International and Canadian Child Rights Partnership. *Children and Youth Services Review*, 109, 104569. <https://doi.org/10.1016/j.childyouth.2019.104569>
- Cornwall, A. (2008). Unpacking 'participation': Models, meanings and practices. *Community Development Journal*, 43(3), 269–283. <https://doi.org/10.1093/cdj/bsn010>
- Corsaro, W. A. (2015). *The Sociology of Childhood* (Fourth Edition). <https://doi.org/10.4135/9781483399027>

- Coughlin, K. W. (2018). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics & Child Health, 23*(2), 138–146. <https://doi.org/10.1093/pch/pxx127>
- Coyne, I. (2006). Consultation with children in hospital: Children, parents' and nurses' perspectives. *Journal of Clinical Nursing, 15*(1), 61–71. <https://doi.org/10.1111/j.1365-2702.2005.01247.x>
- Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies, 45*(11), 1682–1689. <https://doi.org/10.1016/j.ijnurstu.2008.05.002>
- Coyne, I., Amory, A., Gibson, F., & Kiernan, G. (2016). Information-sharing between healthcare professionals, parents and children with cancer: More than a matter of information exchange. *European Journal of Cancer Care, 25*(1), 141–156. <https://doi.org/10.1111/ecc.12411>
- Coyne, I., Amory, A., Kiernan, G., & Gibson, F. (2014). Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences. *European Journal of Oncology Nursing, 18*(3), 273–280. <https://doi.org/10.1016/j.ejon.2014.01.006>
- Coyne, I., & Cowley, S. (2007). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies, 44*(6), 893–904. <https://doi.org/10.1016/j.ijnurstu.2006.03.002>
- Coyne, I., & Gallagher, P. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing, 20*(15–16), 2334–2343. <https://doi.org/10.1111/j.1365-2702.2010.03582.x>

- Coyne, I., Hallström, I., & Söderbäck, M. (2016). Reframing the focus from a family-centred to a child-centred care approach for children's healthcare. *Journal of Child Health Care*, 20(4), 494–502. <https://doi.org/10.1177/1367493516642744>
- Coyne, I., & Harder, M. (2011). Children's participation in decision-making: Balancing protection with shared decision-making using a situational perspective. *Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community*, 15(4), 312–319. <https://doi.org/10.1177/1367493511406570>
- Coyne, I., Holmström, I., & Söderbäck, M. (2018a). Centeredness in healthcare: A concept synthesis of family-centered care, person-centered care and child-centered care. *Journal of Pediatric Nursing*, 42, 45–56. <https://doi.org/10.1016/j.pedn.2018.07.001>
- Coyne, I., O'Mathúna, D. P., Gibson, F., Shields, L., Leclercq, E., & Sheaf, G. (2016). Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database of Systematic Reviews*, 2016(11). <https://doi.org/10.1002/14651858.cd008970.pub3>
- Crossley, N. (2010). *Towards Relational Sociology*. Routledge. <https://doi.org/10.4324/9780203887066>
- Crowley. (2015). *Is Anyone Listening? The Impact of Children's Participation on Public Policy in: The International Journal of Children's Rights Volume 23 Issue 3 (2015)*. https://brill-com.ezproxy.library.uvic.ca/view/journals/chil/23/3/article-p602_6.xml
- Cummins, F. (2014). Agency is distinct from autonomy. *AVANT. Pismo Awangardy Filozoficzno-Naukowej*, 2, 98–112.
- Cunningham, R., & Walton, M. K. (2016). Partnering With patients to improve care: The value of patient and family advisory councils. *JONA: The Journal of Nursing Administration*, 46(11), 549–551. <https://doi.org/10.1097/NNA.0000000000000401>

- Cylus, J., Papanicolas, I., & Smith, P. C. (2016). A framework for thinking about health system efficiency. In *Health system efficiency: How to make measurement matter for policy and management [Internet]*. European Observatory on Health Systems and Policies.
<http://www.ncbi.nlm.nih.gov/books/NBK436891/>
- Cyck, L.M. & Hammer, C.S. (2020). Beliefs, values, and practices of Mexican immigrant families towards language and learning in toddlerhood; Setting the foundation for early childhood: Setting the foundation for early childhood education. *Early Childhood Research*, 52, 25-37.
- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: Perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36(4), 253–263. <https://doi.org/10.1097/DCC.0000000000000253>
- DalGLISH, S. L., Khalid, H., & McMahon, S. A. (2020). Document analysis in health policy research: The READ approach. *Health Policy and Planning*, 35(10), 1424–1431.
- Darwin Holmes, A. G. (2020). Researcher positionality—A consideration of its influence and place in qualitative research—A new researcher guide. *Shanlax International Journal of Education*, 8(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>
- Davies, C. A. (2012). *Reflexive Ethnography: A Guide to Researching Selves and Others*. Routledge. <https://doi.org/10.4324/9780203069370>
- Davis, J., & Smith, M. (2012). Participation and multi-professional working. In *Working in Multi-Professional Contexts: A Practical Guide for Professionals in Children's Services* (pp. 36–61). SAGE Publications Ltd. <https://doi.org/10.4135/9781446250761>
- de Vries, M. C., Wit, J. M., Engberts, D. P., Kaspers, G. J. L., & van Leeuwen, E. (2010). Pediatric oncologists' attitudes towards involving adolescents in decision-making concerning research participation. *Pediatric Blood & Cancer*, 55(1), 123–128. <https://doi.org/10.1002/pbc.22510>

- Dedding, C. W. M. (2009). *Delen in macht en onmacht: kindparticipatie in de (alledaagse) diabeteszorg* (Doctoral dissertation, Universiteit van Amsterdam). Retrieved from: <https://dare.uva.nl/search?identifier=e33bca82-cc47-496f-bd85-ecc067717f37>
- Dedding, C., Reis, R., Wolf, B., & Hardon, A. (2015). Revealing the hidden agency of children in a clinical setting. *Health Expectations*, 18(6), 2121–2128. <https://doi.org/10.1111/hex.12180>
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: A balance of relationship and rigour. *Family Medicine and Community Health*, 7(2), e000057. <https://doi.org/10.1136/fmch-2018-000057>
- Denzin, N. K., & Lincoln, Y. S. (2008a). *Introduction: The discipline and practice of qualitative research*.
- Denzin, N. K., & Lincoln, Y. S. (2008b). Introduction: The discipline and practice of qualitative research. In *Strategies of qualitative inquiry, 3rd ed* (pp. 1–43). Sage Publications, Inc.
- Dépelteau, F. (Ed.). (2018a). *The Palgrave Handbook of Relational Sociology*. Springer International Publishing. <https://doi.org/10.1007/978-3-319-66005-9>
- Dépelteau, F. (2018b). *The Palgrave Handbook of Relational Sociology*. Springer.
- Dépelteau, F., & Powell, C. (Eds.). (2013). *Applying Relational Sociology*. Palgrave Macmillan US. <https://doi.org/10.1057/9781137407009>
- Dixon-Woods, M., Young, B., & Heney, D. (2002). Childhood cancer and users' views: A critical perspective. *European Journal of Cancer Care*, 11(3), 173–177. <https://doi.org/10.1046/j.1365-2354.2002.00335.x>
- Doane, G. H., 1954, & Varcoe, C., 1952. (2021). *How to nurse: Relational inquiry in action* (Second). Wolters Kluwer. <https://go.exlibris.link/qWYtGRHq>
- Dobson, R. (2015). Power, agency, relationality and welfare practice. *Journal of Social Policy*, 44(4), 687–705. <https://doi.org/10.1017/S0047279415000318>

- Donati, P. (1994). Sociology and theology confronting the future: A relational approach. *Religioni e Società*, 9(19), 98–120.
- Donnelly, M., & Kilkelly, U. (2011). Participation in Healthcare: The Views and Experiences of Children and Young People. *The International Journal of Children's Rights*, 19(1), 107–125. <https://doi.org/10.1163/157181810X522379>
- Dorscheidt, J. H. H. M., & Doek, J. E. (2018). *Children's Rights in Health Care*. BRILL.
- Dove, E. S., Kelly, S. E., Lucivero, F., Machirori, M., Dheensa, S., & Prainsack, B. (2017). Beyond individualism: Is there a place for relational autonomy in clinical practice and research? *Clinical Ethics*, 12(3), 150–165. <https://doi.org/10.1177/1477750917704156>
- Dreesens, D., Veul, L., Westermann, J., Wijnands, N., Kremer, L., van der Weijden, T., & Verhagen, E. (2019). The clinical practice guideline palliative care for children and other strategies to enhance shared decision-making in pediatric palliative care; pediatricians' critical reflections. *BMC Pediatrics*, 19(1), 467. <https://doi.org/10.1186/s12887-019-1849-0>
- Dura-Vila, G. & Hodes, M. (2020). Cultural and religious variation in attitudes to young people consenting to health interventions. *Journal of Religion and Health*, 59, 870-890.
- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54–63. <https://doi.org/10.1177/160940690900800105>
- Ehlers, L., & Frank, C. (2008). Child Participation in Africa. In *Children's Rights in Africa*. Routledge.
- Ehrich, J., Pettoello-Mantovani, M., Lenton, S., Damm, L., & Goldhagen, J. (2015). Participation of Children and Young People in Their Health Care: Understanding the Potential and Limitations. *The Journal of Pediatrics*, 167(3), 783–784. <https://doi.org/10.1016/j.jpeds.2015.05.001>

- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine*, 27(10), 1361–1367. <https://doi.org/10.1007/s11606-012-2077-6>
- Emirbayer, M. (1997). Manifesto for a relational sociology. *American Journal of Sociology*, 103(2), 281–317.
- Etherington, N., Rodrigues, I. B., Giangregorio, L., Graham, I. D., Hoens, A. M., Kasperavicius, D., Kelly, C., Moore, J. E., Ponzano, M., Presseau, J., Sibley, K. M., & Straus, S. (2020). Applying an intersectionality lens to the theoretical domains framework: A tool for thinking about how intersecting social identities and structures of power influence behaviour. *BMC Medical Research Methodology*, 20(1), 169. <https://doi.org/10.1186/s12874-020-01056-1>
- Eurochild (2022). UNCRF in the Netherlands: A review of child rights implementation. Retrieved from: <https://www.eurochild.org/news/uncrc-in-the-netherlands-a-review-of-child-rights-implementation/>
- Family Integrated Care (2020). About FICare. Retrieved from: <http://familyintegratedcare.com/about-ficare/>
- Feenstra, B., Boland, L., Lawson, M. L., Harrison, D., Kryworuchko, J., Leblanc, M., & Stacey, D. (2014). Interventions to support children’s engagement in health-related decisions: A systematic review. *BMC Pediatrics*, 14(1), 109. <https://doi.org/10.1186/1471-2431-14-109>
- Fernandes, J. (2016). *The Relational Turn in Sociology*. <https://calenda.org/385123>
- Fitzgerald, L., & Harvey, G. (2015). Translational networks in healthcare? Evidence on the design and initiation of organizational networks for knowledge mobilization. *Social Science & Medicine*, 138, 192-200.

- Flynn, K. E., Smith, M. A., & Vanness, D. (2006). A typology of preferences for participation in healthcare decision making. *Social Science & Medicine*, 63(5), 1158–1169.
<https://doi.org/10.1016/j.socscimed.2006.03.030>
- Fokala, E., & Rudman, A. (2020). Age or maturity? African children’s right to participate in medical decision-making processes. *African Human Rights Law Journal*, 20(2), 667–687.
<https://doi.org/10.17159/1996-2096/2020/v20n2a14>
- Frankel, S., & McNamee, S. (2020). *Bringing Children Back into the Family: Relationality, Connectedness and Home*. Emerald Publishing Limited.
<http://ebookcentral.proquest.com/lib/uvic/detail.action?docID=6348710>
- Franklin, A., & Sloper, P. (2009). Supporting the participation of disabled children and young people in decision-making. *Children & Society*, 23(1), 3–15. <https://doi.org/10.1111/j.1099-0860.2007.00131.x>
- Gabe, J., Olumide, G., & Bury, M. (2004). ‘It takes three to tango’: A framework for understanding patient partnership in paediatric clinics. *Social Science & Medicine*, 59(5), 1071–1079.
<https://doi.org/10.1016/j.socscimed.2003.09.035>
- Gabriel, N. (2014). Growing up beside you: A relational sociology of early childhood. *History of the Human Sciences*, 27(3), 116–135. <https://doi.org/10.1177/0952695114539802>
- Gabriel, N. (2017). *The Sociology of Early Childhood: Critical Perspectives*. SAGE.
- Gabriel, N. (2021). Beyond ‘developmentalism’: A relational and embodied approach to young children’s development. *Children & Society*, 35(1), 48–61.
<https://doi.org/10.1111/chso.12381>
- Gallagher, M. (2008). Foucault, power and participation. *The International Journal of Children’s Rights*, 16(3), 395–406. <https://doi.org/10.1163/157181808X311222>

- Gallagher, M., Smith, M., Hardy, M., & Wilkinson, H. (2012). Children and families' involvement in social work decision making. *Children & Society*, 26(1), 74–85.
<https://doi.org/10.1111/j.1099-0860.2011.00409.x>
- Gaminiesfahani, H., Lozanovska, M., & Tucker, R. (2020). A scoping review of the impact on children of the built environment design characteristics of healing spaces. *HERD: Health Environments Research & Design Journal*, 13(4), 98–114.
<https://doi.org/10.1177/1937586720903845>
- Gergen, K. J. (2015). *An invitation to social construction* (Third edition). Sage.
- Gerlach, A. J., Teachman, G., Laliberte-Rudman, D., Aldrich, R. M., & Huot, S. (2018). Expanding beyond individualism: Engaging critical perspectives on occupation. *Scandinavian Journal of Occupational Therapy*, 25(1), 35–43. <https://doi.org/10.1080/11038128.2017.1327616>
- Gerlach, A., & Varcoe, C. (2021). Orienting child- and family-centered care toward equity. *Journal of Child Health Care*, 25(3), 457–467. <https://doi.org/10.1177/1367493520953354>
- Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S., & Richardson, A. (2010). Children and young people's experiences of cancer care: A qualitative research study using participatory methods. *International Journal of Nursing Studies*, 47(11), 1397–1407.
<https://doi.org/10.1016/j.ijnurstu.2010.03.019>
- Gilljam, B.-M., Arvidsson, S., Nygren, J. M., & Svedberg, P. (2016). Promoting participation in healthcare situations for children with JIA: A grounded theory study. *International Journal of Qualitative Studies on Health and Well-Being*, 11. <https://doi.org/10.3402/qhw.v11.30518>
- Gómez-Vírveda, C., & Usanos, R. A. (2021). Relational autonomy: Lessons from COVID-19 and twentieth-century philosophy. *Medicine, Health Care and Philosophy*, 24(4), 493–505.
<https://doi.org/10.1007/s11019-021-10035-2>

- Government of the Netherlands (2020). National action plan on human rights. Retrieved from:
[https://National+Action+Plan+on+Human+Rights+2020+for+the+Netherlands%20\(3\).pdf](https://National+Action+Plan+on+Human+Rights+2020+for+the+Netherlands%20(3).pdf)
- Grad, R., Légaré, F., Bell, N. R., Dickinson, J. A., Singh, H., Moore, A. E., Kasperavicius, D., & Kretschmer, K. L. (2017). Shared decision making in preventive health care. *Canadian Family Physician*, 63(9), 682–684.
- Graham, M. (2011). Changing paradigms in conditions of childhood: Implications for the social professions and social work. *British Journal of Social Work*, 1(8), 1532-1547.
- Gray, L. M., Wong-Wylie, G., Rempel, G. R., & Cook, K. (2020). *Expanding Qualitative Research Interviewing Strategies: Zoom Video Communications*. 11.
- Groenewoud, A. S., Atsma, F., Arvin, M., Westert, G. P., & Boer, T. A. (2021). Euthanasia in the Netherlands: A claims data cross-sectional study of geographical variation. *BMJ Supportive & Palliative Care*. <https://doi.org/10.1136/bmjspcare-2020-002573>
- Guerreiro, A., & Fløtten, K. (2017). Article 12: The translation into practice of children’s right to participation in health care. *The United Nations Convention on the Rights of the Child*, 681–707. https://doi.org/10.1163/9789004295056_033
- Gumbis, J., Bacianskaite, V., & Randakeviciute, J. (2008). Do human rights guarantee autonomy? *Cuadernos Constitucionales de La Cátedra Fadrique Furió Ceriol*, 62, 77–93.
- Gutman, T., Hanson, C. S., Bernays, S., Craig, J. C., Sinha, A., Dart, A., Eddy, A. A., Gipson, D. S., Bockenbauer, D., Yap, H.-K., Groothoff, J., Zappitelli, M., Webb, N. J. A., Alexander, S. I., Goldstein, S. L., Furth, S., Samuel, S., Blydt-Hansen, T., Dionne, J., ... Tong, A. (2018). Child and parental perspectives on communication and decision making in pediatric CKD: A focus group study. *American Journal of Kidney Diseases*, 72(4), 547–559. <https://doi.org/10.1053/j.ajkd.2018.05.005>

- Hackett, P. M. W., & Hayre, C. M. (Eds.). (2020). *Handbook of Ethnography in Healthcare Research*. Routledge. <https://doi.org/10.4324/9780429320927>
- Hallström, I., & Elander, G. (2004). Decision-making during hospitalization: Parents' and children's involvement. *Journal of Clinical Nursing, 13*(3), 367–375.
- Halm, M. A., Sabo, J., & Rudiger, M. (2006). The patient-family advisory council keeping a pulse on our customers. *Critical Care Nurse, 26*(5), 58–67.
<https://doi.org/10.4037/ccn2006.26.5.58>
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3rd ed). Routledge.
- Hanson, K. (2016). Children's participation and agency when they don't 'do the right thing.' *Childhood, 23*(4), 471–475. <https://doi.org/10.1177/0907568216669222>
- Hart, R. A. (2008). Stepping back from 'the ladder': Reflections on a model of participatory work with children. In A. Reid, B. B. Jensen, J. Nickel, & V. Simovska (Eds.), *Participation and Learning: Perspectives on Education and the Environment, Health and Sustainability* (pp. 19–31). Springer Netherlands. https://doi.org/10.1007/978-1-4020-6416-6_2
- Hart, R. A. (2013). *Children's Participation: The Theory and Practice of Involving Young Citizens in Community Development and Environmental Care*. Routledge.
<https://doi.org/10.4324/9781315070728>
- Hart, R., & Schwab, M. (1997). Children's rights and the building of democracy: A dialogue on the international movement for children's participation. *Social Justice, 24*(3 (69)), 177–191.
- Harzer, C., & Weber, M. (2022). Region of Western Europe (Austria, Belgium, France, Germany, the Netherlands, and Switzerland). In *The International Handbook of Positive Psychology* (pp. 185-221). Springer, Cham.
- Heidenreich, K., Bremer, A., Materstvedt, L. J., Tidefelt, U., & Svantesson, M. (2018). Relational autonomy in the care of the vulnerable: Health care professionals' reasoning in Moral Case

- Deliberation (MCD). *Medicine, Health Care and Philosophy*, 21(4), 467–477.
<https://doi.org/10.1007/s11019-017-9818-6>
- Hein, I. M., Troost, P. W., Lindeboom, R., de Vries, M. C., Zwaan, C. M., & Lindauer, R. J. L. (2012). Assessing children's competence to consent in research by a standardized tool: A validity study. *BMC Pediatrics*, 12(1), 156. <https://doi.org/10.1186/1471-2431-12-156>
- Hesse-Biber, S. N., & Leavy, P. (2010). *Handbook of Emergent Methods*. Guilford Press.
- Higginbottom, G. M., Boadu, N. Y., & Pillay, J. J. (2013). *Guidance on performing focused ethnographies with an emphasis on healthcare research*.
- Hill, C., Knafl, K. A., & Santacroce, S. J. (2017). Family-centered care from the perspective of parents of children cared for in a pediatric intensive care unit: An integrative review. *Journal of Pediatric Nursing*, S0882-5963(17)30531-6.
<https://doi.org/10.1016/j.pedn.2017.11.007>
- Hinds, P. S., Oakes, L., Furman, W., Quargnenti, A., Olson, M. S., Foppiano, P., & Srivastava, D. K. (2001). End-of-life decision making by adolescents, parents, and healthcare providers in pediatric oncology: Research to evidence-based practice guidelines. *Cancer Nursing*, 24(2), 122–134. <https://doi.org/10.1097/00002820-200104000-00007>
- Ho, A. (2008). Relational autonomy or undue pressure? Family's role in medical decision-making. *Scandinavian Journal of Caring Sciences*, 22(1), 128–135. <https://doi.org/10.1111/j.1471-6712.2007.00561.x>
- Hollins, S. (2009). *Religions, Culture and Healthcare: A Practical Handbook for Use in Healthcare Environments, Second Edition*. CRC Press LLC.
<http://ebookcentral.proquest.com/lib/uvic/detail.action?docID=4711440>
- Holstein, J. A., & Gubrium, J. F. (2008). Constructionist impulses in ethnographic fieldwork. *Handbook of Constructionist Research*, 373–395.

- Horgan, D. (2017). Child participatory research methods: Attempts to go ‘deeper.’ *Childhood*, 24(2), 245–259.
- Horgan, D., & Kennan, D. (2021). Introduction. In *Child and Youth Participation in Policy, Practice and Research*. Routledge.
- Horgan, D., & Kennan, D. (2022). *Child and youth participation in policy, practice and research*. Routledge. <https://go.exlibris.link/WY8TzbL4>
- Horstman, M., & Bradding, A. (2002). Helping children speak up in the health service. *European Journal of Oncology Nursing*, 6(2), 75–84. <https://doi.org/10.1054/ejon.2002.0185>
- Howlett, M. (2022). Looking at the ‘field’ through a Zoom lens: Methodological reflections on conducting online research during a global pandemic. *Qualitative Research*, 22(3), 387–402. <https://doi.org/10.1177/1468794120985691>
- Hyland, E. J., D’Cruz, R., Harvey, J. G., Moir, J., Parkinson, C., & Holland, A. J. A. (2015). An assessment of early Child Life Therapy pain and anxiety management: A prospective randomised controlled trial. *Burns*, 41(8), 1642–1652. <https://doi.org/10.1016/j.burns.2015.05.017>
- Ijzendoorn, M. H. V., & Frankrijker, H. de. (2005). *Pedagogiek in beeld: Een inleiding in de pedagogische studie van opvoeding, onderwijs en hulpverlener*. Bohn Stafleu van Loghum.
- Index Mundi (2021). Netherlands demographics profile. Retrieved from: https://www.indexmundi.com/netherlands/demographics_profile.html
- Ingersgaard, M. V., Tulstrup, M., Schmiegelow, K., & Larsen, H. B. (2018). A qualitative study of decision-making on Phase III randomized clinical trial participation in paediatric oncology: Adolescents’ and parents’ perspectives and preferences. *Journal of Advanced Nursing*, 74(1), 110–118. <https://doi.org/10.1111/jan.13407>

- Iusmen, I. (2018). How are children's rights (mis)interpreted in practice? The European commission, children's rights and policy narratives. In R. A. W. Rhodes (Ed.), *Narrative Policy Analysis: Cases in Decentred Policy* (pp. 97–120). Springer International Publishing. https://doi.org/10.1007/978-3-319-76635-5_5
- James, A. (2001). Ethnography in the study of children and childhood. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland, & L. Lofland, *Handbook of Ethnography* (pp. 246–257). SAGE Publications Ltd. <https://doi.org/10.4135/9781848608337.n17>
- James, A., & Curtis, P. (2012). Constructing the sick child: The cultural politics of children's hospitals. *The Sociological Review*, 60(4), 754–772. <https://doi.org/10.1111/j.1467-954X.2012.02132.x>
- James, A., & James, A. L. (2004). *Constructing childhood: Theory, policy and practice* Palgrave Macmillan. Basingstoke.
- James, A. L. (2010). Competition or integration? The next step in childhood studies? *Childhood*, 17(4), 485–499. <https://doi.org/10.1177/0907568209350783>
- James, A., & Prout, A. (2003). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. Routledge.
- Jenks, C. (2005). *Childhood: Critical Concepts in Sociology*. Taylor & Francis.
- Jensen, R. (2020). Whiteness. In S. M. Calienda & D. C. McIlwain (Eds.), *The Routledge Companion to Race and Ethnicity* (pp. 25-32). Routledge.
- Jeremic, V., Sénécal, K., Borry, P., Chokoshvili, D., & Vears, D. F. (2016). Participation of children in medical decision-making: Challenges and potential solutions. *Journal of Bioethical Inquiry*, 13(4), 525–534. <https://doi.org/10.1007/s11673-016-9747-8>
- Jiang, S., Wan, B., Lam, M., Agarwal, A., & Chow, E. (2017). *A qualitative review of Patient and Family Advisory Councils in cancer care—ProQuest*.

<http://www.proquest.com/openview/9b3d972c1c5cf70db257bcc859e39c12/1?cbl=2034829&parentSessionId=Cm9zN7it7hsBAS2VT3iGGo%2F12y7y8VTmDkq3R7pv0NU%3D&pq-origsite=gscholar&accountid=14846>

Johnson, V., & West, A. (2018). *Children's Participation in Global Contexts: Going Beyond Voice*. Routledge. <https://doi.org/10.4324/9781315680941>

Kalaja, P., & Ruohotie-Lyhty, M. (2021). Autonomy and agency. In *The Routledge Handbook of the Psychology of Language Learning and Teaching*. Routledge.

Kars, M. C., Grypdonck, M. H. F., de Bock, L. C., & van Delden, J. J. M. (2015). The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase. *Health Psychology, 34*(4), 446–452. <https://doi.org/10.1037/hea0000166>

Katz, A. L., Webb, S. A., & Bioethics, C. O. (2016). Informed consent in decision-making in pediatric practice. *Pediatrics, 138*(2). <https://doi.org/10.1542/peds.2016-1485>

Kehily, M. J. (2008a). *Introduction to Childhood Studies*. McGraw-Hill Education. <http://ebookcentral.proquest.com/lib/uvic/detail.action?docID=409764>

Kehily, M. J. (2008b). *Introduction to Childhood Studies*. McGraw-Hill Education. <http://ebookcentral.proquest.com/lib/uvic/detail.action?docID=409764>

Keller, R. (2011). The sociology of knowledge approach to discourse (SKAD). *Human Studies, 34*(1), 43–65. <https://doi.org/10.1007/s10746-011-9175-z>

Kennan, D., Brady, B., & Forkan, C. (2018). Supporting children's participation in decision making: A systematic literature review exploring the effectiveness of participatory processes. *The British Journal of Social Work, 48*(7), 1985–2002. <https://doi.org/10.1093/bjsw/bcx142>

Kerstetter, K. (2012). *Insider, outsider, or somewhere in between: The impact of researchers' identities on the community-based research process*. 27, 20.

KidsRights Index (2021). The KidsRightsIndex 2021. Retrieved from:

<https://www.kidsrights.org/nl/onderzoek/kidsrights-index/>

Kilicarslan-Toruner, E., & Akgun-Citak, E. (2013). Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*, 17(2), 176–183. <https://doi.org/10.1016/j.ejon.2012.03.001>

Kim, L., D'Arrigo, J., ChenFeng, J., & Esmiol Wilson, E. (2021). Relationality as a way of being:

A pedagogy of classroom conversations. In A. Desai & H. N. Nguyen (Eds.), *Global Perspectives on Dialogue in the Classroom: Cultivating Inclusive, Intersectional, and Authentic Conversations* (pp. 151–161). Springer International Publishing.

https://doi.org/10.1007/978-3-030-89043-8_11

Kinderburgemeesters (2022). Nederlands genootschpa van kinderburgemeesters. Retrieved from:

<https://kinderburgemeesters.nl/>

Kinderombudsman (2022). The childrens ombudsman. Retrieved from:

<https://www.kinderombudsman.nl/the-childrens-ombudsman>

Kinderombudsman (2015). Kinderrechtenmonitor: 2015. Retrieved from:

<https://www.kinderrechtenmonitor2015-webversie.pdf>

Kinderombudsman (2021a). Jaarverslag 2021 Nationale Ombudsman, Kinderombudsman en de Veteranenombudsman. Retrieved from:

<https://www.kinderombudsman.nl/publicaties/jaarverslag-2021-nationale-ombudsman-de-kinderombudsman-en-de-veteranenombudsman>

Kind & Ziekenhuis (2021). Positief taalgebruik. Retrieved from: [https://kinderziekenhuis.nl/wp-](https://kinderziekenhuis.nl/wp-content/uploads/2022/04/FOLDER-HELPE-ND-TAALGEBRUIK-EN-ONLINE-310322.pdf)

[content/uploads/2022/04/FOLDER-HELPE-ND-TAALGEBRUIK-EN-ONLINE-310322.pdf](https://kinderziekenhuis.nl/wp-content/uploads/2022/04/FOLDER-HELPE-ND-TAALGEBRUIK-EN-ONLINE-310322.pdf)

- Kind & Ziekenhuis (n.d.). Oprichten kinderadviesraad: Do's and don'ts. Retrieved from:
https://kindenziekenhuis.nl/wp-content/uploads/2018/11/Oprichten-KAR-Dos-en-Donts_KZ_Amalia.pdf
- Kind & Ziekenhuis (2012). Kinderparticipatie in het ziekenhuis: Een praktische introductie. Retrieved from: <https://kindenziekenhuis.nl/wp-content/uploads/2019/05/Handboek-Kinderparticipatie-in-het-Ziekenhuis.pdf>
- Kind & Ziekenhuis (2018). Expertiseprofiel: Medisch pedagogisch medewerker. Retrieved from: <https://kindenziekenhuis.nl/wp-content/uploads/2018/11/Expertiseprofiel-Medisch-pedagogisch-Zorgverlener.pdf>
- Kind & Ziekenhuis (2022a). Welke kwaliteitschecks zijn er? Retrieved from: <https://kindenziekenhuis.nl/welke-smileys-zijn-er/>
- Kind & Ziekenhuis (2022b). Tarieventabel academy ervaringsprofs kindzorg Lidmaatschapsbijdrage. Retrieved from: https://kindenziekenhuis.nl/wp-content/uploads/2021/12/Academy-Tarieventabel_2022.pdf
- Kinderrechtencollectief (2021). Kinderrechten in Nederland. Report retrieved from: <https://www.unicef.nl/files/NGO%20rapportage-Kinderrechten-NL-Webversie.pdf>
- Kirby, P., Great Britain, Department for Education and Skills, National Children's Bureau, & PK Research Consultancy. (2003). *Building a culture of participation: Involving children and young people in policy, service planning, delivery and evaluation : research report*. DfES Publications.
- Kirk, S. (2008) Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health and Development*, 34, 5, 567–75.

- Kjørholt, A. T. (2004). Childhood as a social and symbolic space: Discourses on children as social participants in society. In 268. Fakultet for samfunnsvitenskap og teknologiledelse.
<https://ntnuopen.ntnu.no/ntnu-xmlui/handle/11250/264979>
- Koller, D., & McLaren, C. (2014). Children's emotional responses to a paediatric hospital atrium. *Children & Society*, 28(6), 451–464. <https://doi.org/10.1111/chso.12002>
- Koller, D. (2017). 'Kids need to talk too': Inclusive practices for children's healthcare education and participation. *Journal of Clinical Nursing*, 26(17–18), 2657–2668.
<https://doi.org/10.1111/jocn.1370>
- Koller, D., Pouesard, M. L., & Rummens, J. A. (2018). Defining social inclusion for children with disabilities: A critical literature review. *Children & Society*, 32(1), 1-13.
- Koller, D. (2019). New ways of thinking and doing: A theoretical vision for child life. *ACLP Bulletin*, 37(4).
- Koller, D. (2019). New ways of thinking and doing: A theoretical vision for child life. *ACLP Bulletin*, 37(4). Retrieved from: <https://www.childlife.org/membership/acpl-bulletin/fall-2019-table-of-contents/new-ways-of-thinking-and-doing-a-theoretical-vision-for-child-life/>
- Koller, D. & Wheelwright, D. (2020). Disrupting the status quo: A new theoretical vision for the child life profession. *The Journal of Child Life* 1(2), 27-32.
- Koller, D. (2021). The right of children to be heard. *BMJ Pediatrics Open*, 5, 1-2.
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, 24(1), 120–124.
<https://doi.org/10.1080/13814788.2017.1375092>
- Kranendonk, E. J., Hennekam, R. C., & Ploem, M. C. (2017). The Dutch legal approach regarding health care decisions involving minors in the NGS days. *European Journal of Human Genetics*, 25(2), 166–166. <https://doi.org/10.1038/ejhg.2016.159>

- Kuhn, K. J., Mickelsen, L. J., Morimoto, L. N., & Larson, D. B. (2016). The use of patient and family advisory councils to improve patient experience in radiology. *American Journal of Roentgenology*, 207(5), 965–970. <https://doi.org/10.2214/AJR.16.16604>
- Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, 16(2), 297–305. <https://doi.org/10.1007/s10995-011-0751-7>
- Kuther, T. L. (2003). Medical decision-making and minors: Issues of consent and assent. *Adolescence*, 38(150), 343–358.
- Lambert, V., Coad, J., Hicks, P., & Glacken, M. (2014). Social spaces for young children in hospital. *Child: Care, Health and Development*, 40(2), 195–204. <https://doi.org/10.1111/cch.12016>
- Lambert, V., Glacken, M., & McCarron, M. (2008). ‘Visible-ness’: The nature of communication for children admitted to a specialist children’s hospital in the Republic of Ireland. *Journal of Clinical Nursing*, 17(23), 3092–3102. <https://doi.org/10.1111/j.1365-2702.2008.02462.x>
- Lang, F., & Quill, T. (2004). Making Decisions with Families at the End of Life. *American Family Physician*, 70(4), 719–723.
- Lansdown, G. (2014). 25 years of UNCRC: Lessons learned in children’s participation. The *Canadian Journal of Children’s Rights*, 1(1). Retrieved from: <https://ojs.library.carleton.ca/index.php/cjcr/article/view/12>
- Lavis, V. (2010). Multiple researcher identities: Highlighting tensions and implications for ethical practice in qualitative interviewing. *Qualitative Research in Psychology*, 7(4), 316–331. <https://doi.org/10.1080/14780880902929506>

- Lavizzo-Mourey, R. J., Besser, R. E., & Williams, D. R. (2021). Understanding and mitigating health inequities—Past, current, and future directions. *New England Journal of Medicine*, 384(18), 1681-1684.
- Lawless, B., & Chen, Y.-W. (2019). Developing a method of critical thematic analysis for qualitative communication inquiry. *The Howard Journal of Communications*, 30(1), 92–106. <https://doi.org/10.1080/10646175.2018.1439423>
- Leonard, M. (2016). *The Sociology of Children, Childhood and Generation*. <https://doi.org/10.4135/9781529714494>
- Levin, B. (2008, May). Thinking about knowledge mobilization. In an invitational symposium sponsored by the Canadian Council on Learning and the Social Sciences and Humanities Research Council of Canada (pp. 15-18).
- Lincoln, G. S. C. Y. S. (2017). Deploying qualitative methods for critical social purposes. In *Qualitative inquiry and social justice* (pp. 53–72). Routledge.
- Lipstein, E. A., Brinkman, W. B., Fiks, A. G., Hendrix, K. S., Kryworuchko, J., Miller, V. A., Prosser, L. A., Ungar, W. J., & Fox, D. (2015). An emerging field of research: Challenges in pediatric decision making. *Medical Decision Making*, 35(3), 403–408. <https://doi.org/10.1177/0272989X14546901>
- Littlechild, B. (2000). *Children's rights to be heard in child protection processes—Law, policy and practice in England and Wales—Littlechild—2000—Child Abuse Review—Wiley Online Library*. [https://onlinelibrary-wiley-com.ezproxy.library.uvic.ca/doi/abs/10.1002/1099-0852\(200011/12\)9:6%3C403::AID-CAR659%3E3.0.CO;2-9](https://onlinelibrary-wiley-com.ezproxy.library.uvic.ca/doi/abs/10.1002/1099-0852(200011/12)9:6%3C403::AID-CAR659%3E3.0.CO;2-9)
- Lobe, B., Morgan, D., & Hoffman, K. A. (2020). Qualitative data collection in an era of social distancing. *International Journal of Qualitative Methods*, 19, 1609406920937875. <https://doi.org/10.1177/1609406920937875>

- Lokossou, Y. U., Tambe, A. B., Azandjeme, C. & Mbhenyane, X. (2021). Socio-cultural beliefs influence feeding practices of mothers and their children in Grand Popo, Benin. *Journal of Health, Population and Nutrition*, 40(33), 1-12.
- London, L. (2008). What is a human-rights based approach to health and does it matter? *Health and Human Rights*, 10(1), 65–80. <https://doi.org/10.2307/20460088>
- Lookabaugh, S., & Ballard, S. M. (2018). The scope and future direction of child life. *Journal of Child and Family Studies*, 27(6), 1721–1731. <https://doi.org/10.1007/s10826-018-1031-6>
- Lundy, L. (2007). ‘Voice’ is not enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, 33(6), 927–942. <https://doi.org/10.1080/01411920701657033>
- Mackenzie, C., & Stoljar, N. (2000). *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*. Oxford University Press.
- Mandal, P. C. (2018). Translation in qualitative studies: evaluation criteria and equivalence. *The Qualitative Report*, 23(10), 2529–2537.
- Mårtenson, E. K., & Fägerskiöld, A. M. (2008). A review of children’s decision-making competence in health care. *Journal of Clinical Nursing*, 17(23), 3131–3141. <https://doi.org/10.1111/j.1365-2702.2006.01920.x>
- Mattei, P., & Broeks, M. (2018). From multiculturalism to civic integration: Citizenship education and integration policies in the Netherlands and England since the 2000s. *Ethnicities*, 18(1), 23–42. <https://doi.org/10.1177/1468796816676845>
- May, S., & Mumby, D. K. (2004). *Engaging Organizational Communication Theory and Research: Multiple Perspectives*. SAGE.

- Mayall, B. (2015). Understanding inter-generational relations: The case of health maintenance by children. *Sociology of Health & Illness*, 37(2), 312–324. <https://doi.org/10.1111/1467-9566.12227>
- McAllister, B. P. (2021). *Respecting Relational Autonomy* [M.A., University of Nevada, Reno]. <http://www.proquest.com/docview/2563495283/abstract/8F82E92AD5AE4C08PQ/1>
- McLaughlin, J. (2020). Relational autonomy as a way to recognise and enhance children’s capacity and agency to be participatory research actors. *Ethics and Social Welfare*, 14(2), 204–219. <https://doi.org/10.1080/17496535.2020.1714689>
- McShane, K. E., Davey, C. J., Rouse, J., Usher, A. M., & Sullivan, S. (2015). Beyond ethical obligation to research dissemination: Conceptualizing debriefing as a form of knowledge transfer. *Canadian Psychology/Psychologie Canadienne*, 56(1), 80–87. <https://doi.org/10.1037/a0035473>
- Merriam, S. B., Johnson-Bailey, J., Lee, M.-Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, 20(5), 405–416. <https://doi.org/10.1080/02601370120490>
- Meyers, S. (2008). Take heed. How patient and family advisors can improve quality. *Trustee*, 61(4), 14–16, 21–22, 1.
- Middel, F., López López, M., Fluke, J., & Grietens, H. (2022). Racial/ethnic and gender disparities in child protection decision-making: What role do stereotypes play? *Child Abuse & Neglect*, 127, 105579. <https://doi.org/10.1016/j.chiabu.2022.105579>
- Mills, A., Durepos, G., & Wiebe, E. (2010). *Encyclopedia of Case Study Research*. SAGE Publications, Inc. <https://doi.org/10.4135/9781412957397>

- Mills, J., & Birks, M. (2014). *Qualitative Methodology: A Practical Guide*. SAGE Publications, Inc. <https://doi.org/10.4135/9781473920163>
- Mitchell, S., Spry, J. L., Hill, E., Coad, J., Dale, J., & Plunkett, A. (2019). Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: A qualitative interview study. *BMJ Open*, *9*(5), e028548. <https://doi.org/10.1136/bmjopen-2018-028548>
- Montà, C. C. (2021). The meanings of ‘child participation’ in international and European policies on children(’s rights): A content analysis. *European Educational Research Journal*, *14*(749041211034972). <https://doi.org/10.1177/14749041211034971>
- Moore, L., & Kirk, S. (2010). A literature review of children’s and young people’s participation in decisions relating to health care: Children’s and young people’s participation in decisions. *Journal of Clinical Nursing*, *19*(15–16), 2215–2225. <https://doi.org/10.1111/j.1365-2702.2009.03161.x>
- Morse, J. M. (2007). Ethics in Action: Ethical Principles for Doing Qualitative Health Research. *Qualitative Health Research*, *17*(8), 1003–1005. <https://doi.org/10.1177/1049732307308197>
- Mukherjee, U. (2020). Towards a Critical Sociology of Children’s Leisure. *International Journal of the Sociology of Leisure*, *3*(3), 219–239. <https://doi.org/10.1007/s41978-020-00060-5>
- Murgic, L., Hébert, P. C., Sovic, S., & Pavlekovic, G. (2015). Paternalism and autonomy: Views of patients and providers in a transitional (post-communist) country. *BMC Medical Ethics*, *16*, 65. <https://doi.org/10.1186/s12910-015-0059-z>
- Murphy, E., & Dingwall, R. (2017). *Qualitative Methods and Health Policy Research*. Routledge. <https://doi.org/10.4324/9781315127873>
- Murray, J. (2019). Hearing young children’s voices. *International Journal of Early Years Education*, *27*(1), 1–5. <https://doi.org/10.1080/09669760.2018.1563352>

- Naganathan, G., Srikanthan, S., Balachandran, A., Gladly, A., & Shanmuganathan, V. (2022). Collaborative zoom coding—A novel approach to qualitative analysis. *International Journal of Qualitative Methods*, *21*, 16094069221075862.
<https://doi.org/10.1177/16094069221075862>
- Nat, P. B. van der, Veghel, D. van, Daeter, E., Crijns, H. J., Koolen, J., Houterman, S., Soliman, M. A., Mol, B. A. de, & Group, M. B. S. (2020). Insights on value-based healthcare implementation from Dutch heart care. *International Journal of Healthcare Management*, *13*(3), 189–192. <https://doi.org/10.1080/20479700.2017.1397307>
- Nationaal Jeugd Instituut (2022). Wat is jeugdparticipatie? Retrieved from:
<https://www.nji.nl/ervaringskennis/wat-is-jeugdparticipatie>
- Newnham, E., Small, K., & Allen, J. (2021). Critical ethnography in maternity care research: Bridging creativity and rigour – a discussion paper. *Midwifery*, *99*, 103014.
<https://doi.org/10.1016/j.midw.2021.103014>
- Newton, B. J., Rothlingova, Z., Gutteridge, R., LeMarchand, K., & Raphael, J. H. (2012). No room for reflexivity? Critical reflections following a systematic review of qualitative research. *Journal of Health Psychology*, *17*(6), 866–885. <https://doi.org/10.1177/1359105311427615>
- Nicholas, D. B., Keilty, K., & Karmali, K. (2014). Paediatric patient-centred care: Evidence and evolution. In R. Zlotnik Shaul (Ed.), *Paediatric Patient and Family-Centred Care: Ethical and Legal Issues* (pp. 3–18). Springer. https://doi.org/10.1007/978-1-4939-0323-8_1
- Nimmon, L., & Stenfors-Hayes, T. (2016). The “Handling” of power in the physician-patient encounter: Perceptions from experienced physicians. *BMC Medical Education*, *16*(1), 114.
<https://doi.org/10.1186/s12909-016-0634-0>

- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1609406917733847. <https://doi.org/10.1177/1609406917733847>
- Noyes, J. (2000). Enabling young ‘ventilator-dependent’ people to express their views and experiences of their care in hospital. *Journal of Advanced Nursing*, 31(5), 1206–1215. <https://doi.org/10.1046/j.1365-2648.2000.01376.x>
- Nugus, P., Greenfield, D., Travaglia, J., Westbrook, J., & Braithwaite, J. (2010). How and where clinicians exercise power: Interprofessional relations in health care. *Social Science & Medicine*, 71(5), 898–909. <https://doi.org/10.1016/j.socscimed.2010.05.029>
- Nunes, J., & Lotta, G. (2019). Discretion, power and the reproduction of inequality in health policy implementation: Practices, discursive styles and classifications of Brazil’s community health workers. *Social Science & Medicine*, 242, 112551. <https://doi.org/10.1016/j.socscimed.2019.112551>
- O’Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for Reporting Qualitative Research: A Synthesis of Recommendations. *Academic Medicine*, 89(9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>
- Ocloo, J., Goodrich, J., Tanaka, H., Birchall-Searle, J., Dawson, D., & Farr, M. (2020). The importance of power, context and agency in improving patient experience through a patient and family centred care approach. *Health Research Policy and Systems*, 18(1), 10. <https://doi.org/10.1186/s12961-019-0487-1>
- O’Connor, D., Lynch, H., & Boyle, B. (2021a). A qualitative study of child participation in decision-making: Exploring rights-based approaches in pediatric occupational therapy. *PLOS ONE*, 16(12), e0260975. <https://doi.org/10.1371/journal.pone.0260975>

- O'Connor, D., Lynch, H., & Boyle, B. (2021b). A qualitative study of child participation in decision-making: Exploring rights-based approaches in pediatric occupational therapy. *PLOS ONE*, *16*(12), e0260975. <https://doi.org/10.1371/journal.pone.0260975>
- Odigwe, C. (2004). Children say they are not involved enough in their treatment. *BMJ*, *328*(7440), 600.3. <https://doi.org/10.1136/bmj.328.7440.600-b>
- O'Kane, C., Trapp, A., Stephenson, P., & Smith-Brake, J. (2021). Management and governance accountability to children: participation and representation in organisational decision making. *Journal of Youth Development*, *16*(2–3), 197–226. <https://doi.org/10.5195/jyd.2021.1045>
- Oliffe, J. L., Kelly, M. T., Gonzalez Montaner, G., & Yu Ko, W. F. (2021). Zoom Interviews: Benefits and Concessions. *International Journal of Qualitative Methods*, *20*, 16094069211053522. <https://doi.org/10.1177/16094069211053522>
- Olszewski, A. E., & Goldkind, S. F. (2018). The default position: Optimizing pediatric participation in medical decision making. *The American Journal of Bioethics*, *18*(3), 4–9. <https://doi.org/10.1080/15265161.2017.1418921>
- Percy-Smith, B., & Thomas, N. (2009). *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice*. Routledge. <http://ebookcentral.proquest.com/lib/uvic/detail.action?docID=446715>
- Pérez-Duarte Mendiola, P. (2022). How to communicate with children, according to Health Play Specialists in the United Kingdom: A qualitative study. *Journal of Child Health Care*, *13674935221109112*. <https://doi.org/10.1177/13674935221109113>
- Pietilä, A.-M., Nurmi, S.-M., Halkoaho, A., & Kyngäs, H. (2020). Qualitative research: Ethical considerations. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The Application of*

- Content Analysis in Nursing Science Research* (pp. 49–69). Springer International Publishing. https://doi.org/10.1007/978-3-030-30199-6_6
- Pope, N., Tallon, M., Leslie, G., & Wilson, S. (2017). Why we need to research with children, not on children. *JBI Database of Systematic Reviews and Implementation Reports*, 15(6), 1497–1498. <https://doi.org/10.11124/JBISRIR-2017-003458>
- Porter, P. M. E. (2006). *Redefining Health Care: Creating Value-Based Competition on Results*. Retrieved from: https://www.hbs.edu/ris/Publication%20Files/20060502%20NACDS%20-%20Final%2005012006%20for%20On%20Point_db5ede1d-3d06-41f0-85e3-c11658534a63.pdf
- Prout, A. (2011). Taking a step away from modernity: Reconsidering the new sociology of childhood. *Global Studies of Childhood*, 1(1), 4–14.
- Pyke-Grimm, K. A., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision making and information needs of parents of children with cancer: A pilot study. *Journal of Pediatric Oncology Nursing*, 16(1), 13–24. [https://doi.org/10.1016/S1043-4542\(99\)90003-6](https://doi.org/10.1016/S1043-4542(99)90003-6)
- Quaye, A. A., Coyne, I., Söderbäck, M., & Hallström, I. K. (2019). Children's active participation in decision-making processes during hospitalisation: An observational study. *Journal of Clinical Nursing*, 28(23–24), 4525–4537. <https://doi.org/10.1111/jocn.1504>.
- Okewumi, E. O. & Akanle, O. (2022). Children's participation in decision-making within the family context of Yoruba culture. *Child Indicators Research*, 15, 235-247.
- Quennerstedt, A., & Quennerstedt, M. (2014). Researching children's rights in education: Sociology of childhood encountering educational theory. *British Journal of Sociology of Education*, 35(1), 115–132. <https://doi.org/10.1080/01425692.2013.783962>

- Qvortrup, J. (Ed.). (2005). *Studies in modern childhood: Society, agency, culture*. Palgrave Macmillan. <http://www.palgraveconnect.com/doifinder/10.1057/9780230504929>
- Qvortrup, J., Corsaro, W. A., Honig, M.-S., & Valentine, G. (2009). *The Palgrave handbook of childhood studies*. Springer.
- Raittila, R., & Vuorisalo, M. (2021). Relational analysis and the ethnographic approach: Constructing preschool childhood. *Ethnography and Education, 16*(3), 358–372. <https://doi.org/10.1080/17457823.2021.1872396>
- Rap, S., Verkroost, D., & Bruning, M. (2019). Children’s participation in Dutch youth care practice: An exploratory study into the opportunities for child participation in youth care from professionals’ perspective. *Child Care in Practice, 25*(1), 37–50. <https://doi.org/10.1080/13575279.2018.1521382>
- Rashid, M., Hodgson, C. S., & Luig, T. (2019). Ten tips for conducting focused ethnography in medical education research. *Medical Education Online, 24*(1). <https://doi.org/10.1080/10872981.2019.1624133>
- Reñosa, M. D. C., Mwamba, C., Meghani, A., West, N. S., Hariyani, S., Ddaaki, W., Sharma, A., Beres, L. K., & McMahon, S. (2021). Selfie consents, remote rapport, and Zoom debriefings: Collecting qualitative data amid a pandemic in four resource-constrained settings. *BMJ Global Health, 6*(1), e004193. <https://doi.org/10.1136/bmjgh-2020-004193>
- Ritchie, J., Lewis, J., Lewis, P. of S. P. J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. SAGE.
- Roberts. (2009). Understanding ethnography. *British Journal of Midwifery, 17*(5), 291–294. <https://doi.org/10.12968/bjom.2009.17.5.42220>
- Roper, J. M., & Shapira, J. (2000). *Ethnography in nursing research* (Vol. 1). Sage.

- Rost, M., Wangmo, T., Niggli, F., Hartmann, K., Hengartner, H., Ansari, M., Brazzola, P., Rischewski, J., Beck-Popovic, M., Kühne, T., & Elger, B. S. (2017). Parents' and physicians' perceptions of children's participation in decision-making in paediatric oncology: a quantitative study. *Journal of Bioethical Inquiry*, *14*(4), 555–565. <https://doi.org/10.1007/s11673-017-9813-x>
- Rubin, H., & Rubin, I. (2005). *Qualitative Interviewing (2nd ed.): The Art of Hearing Data*. SAGE Publications, Inc. <https://doi.org/10.4135/9781452226651>
- Ruhe, K. M., Badarau, D. O., Brazzola, P., Hengartner, H., Elger, B. S., Wangmo, T., & Group (SPOG), for the S. P. O. (2016). Participation in pediatric oncology: Views of child and adolescent patients. *Psycho-Oncology*, *25*(9), 1036–1042. <https://doi.org/10.1002/pon.4053>
- Runeson, I., Enskär, K., Elander, G., & Hermerén, G. (2001). Professionals' perceptions of children's participation in decision making in healthcare. *Journal of Clinical Nursing*, *10*(1), 70–78. <https://doi.org/10.1046/j.1365-2702.2001.00433.x>
- Runeson, I., Hallström, I., Elander, G., & Hermerén, G. (2002a). Children's participation in the decision-making process during hospitalization: An observational study. *Nursing Ethics*, *9*(6), 583–598. <https://doi.org/10.1191/0969733002ne553oa>
- Sabatello, M., Janvier, A., Verhagen, E., Morrison, W., & Lantos, J. (2018). Pediatric participation in medical decision making: Optimized or personalized? *The American Journal of Bioethics*, *18*(3), 1–3. <https://doi.org/10.1080/15265161.2017.1418931>
- Salmela, M., Salanterä, S., Ruotsalainen, T., & Aronen, E. T. (2010). Coping strategies for hospital-related fears in pre-school-aged children: Coping and pre-school children. *Journal of Paediatrics and Child Health*, *46*(3), 108–114. <https://doi.org/10.1111/j.1440-1754.2009.01647.x>

- Santos, K. D. S., Ribeiro, M. C., Queiroga, D. E. U. D., Silva, I. A. P. D., & Ferreira, S. M. S. (2020). The use of multiple triangulations as a validation strategy in a qualitative study. *Ciencia & Saude Coletiva*, 25, 655-664.
- Sanyal Tudela, A. (2014). Discourses of experience: The disciplining of identities and practices in student teaching. *Australian Journal of Teacher Education*, 39(3).
<https://doi.org/10.14221/ajte.2014v39n3.8>
- Sarmiento, M. J., Marchi, R. & Trevisan, G. (2018). Beyond the modern norm of childhood: Children at the margins as a challenge for the sociology of childhood. *In Theorising Childhood*, p. 135-157. Palgrave MacMillan, Cham.
- Savvides, N., Al-Youssef, J., Colin, M., & Garrido, C. (2014). Journeys into inner/outer space: reflections on the methodological challenges of negotiating insider/outsider status in international educational research. *Research in Comparative and International Education*, 9(4), 412–425. <https://doi.org/10.2304/rcie.2014.9.4.412>
- Schalkers, I., Parsons, C. S., Bunders, J. F., & Dedding, C. (2016a). Health professionals' perspectives on children's and young people's participation in health care: A qualitative multihospital study. *Journal of Clinical Nursing*, 25(7–8), 1035–1044.
<https://doi.org/10.1111/jocn.13152>
- Schenker, Y., Fernandez, A., Sudore, R., & Schillinger, D. (2011). Interventions to improve patient comprehension in informed consent for medical and surgical procedures: A systematic review. *Medical Decision Making*, 31(1), 151–173.
<https://doi.org/10.1177/0272989X10364247>
- Schillinger, D. (2020). The intersections between social determinants of health, health literacy, and health disparities. *Studies in Health Technology and Informatics*, 269, 22–41.
<https://doi.org/10.3233/SHTI200020>

- Schroeter, F. (2004). Endorsement and autonomous agency. *Philosophy and Phenomenological Research*, 69(3), 633–659. <https://doi.org/10.1111/j.1933-1592.2004.tb00521.x>
- Shields, L., Pratt, J., Davis, L. M., & Hunter, J. (2007). Family-centred care for children in hospital. *The Cochrane Database of Systematic Reviews*, 1, CD004811.
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of Clinical Nursing*, 15(10), 1317–1323. <https://doi.org/10.1111/j.1365-2702.2006.01433.x>
- Siew Pien, L. (2018). *Children's participation in decisions regarding their nursing care: An ethnographic study of children, parents and nurses in the oncology setting*. Retrieved from: <https://era.ed.ac.uk/handle/1842/31008>
- Sim, J., & Sharp, K. (1998). A critical appraisal of the role of triangulation in nursing research. *International Journal of Nursing Studies*, 35(1), 23–31. [https://doi.org/10.1016/S0020-7489\(98\)00014-5](https://doi.org/10.1016/S0020-7489(98)00014-5)
- Sinclair, R. (2004). Participation in practice: Making it meaningful, effective and sustainable. *Children & Society*, 18(2), 106–118. <https://doi.org/10.1002/chi.817>
- Sjöberg, C., Amhliden, H., Nygren, J. M., Arvidsson, S., & Svedberg, P. (2015). The perspective of children on factors influencing their participation in perioperative care. *Journal of Clinical Nursing*, 24(19–20), 2945–2953. <https://doi.org/10.1111/jocn.12911>
- Skaljic, M., McGinnis, A., & Streicher, J. L. (2020). Comfort positioning during procedures in pediatric dermatology. *Pediatric Dermatology*, 37(2), 396–398. <https://doi.org/10.1111/pde.14089>
- Slife, B. D. (2004). Taking practice seriously. Toward a relational ontology. *Journal of Theoretical and Philosophical Psychology*, 24(2), 157–178.

- Smart, C. (2011). Relationality and socio-cultural theories of family life. In R. Jallinoja & E. D. Widmer (Eds.), *Families and Kinship in Contemporary Europe: Rules and Practices of Relatedness* (pp. 13–28). Palgrave Macmillan UK.
https://doi.org/10.1057/9780230307452_2
- Söderbäck, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care. *Journal of Child Health Care*, *15*(2), 99–106.
<https://doi.org/10.1177/1367493510397624>
- Sorbring, E., & Kuczynski, L. (2019). Children's agency in the family, in school and in society: Implications for health and well-being. *International Journal of Qualitative Studies on Health and Well-Being*, *13*(Suppl 1), 1634414.
<https://doi.org/10.1080/17482631.2019.1634414>
- Spinetta, J. J., Masera, G., Eden, T., Oppenheim, D., Martins, A. G., Dongen-Melman, J. van, Siegler, M., Eiser, C., Arush, M. W. B., Kosmidis, H. V., & Jankovic, M. (2002). Refusal, non-compliance, and abandonment of treatment in children and adolescents with cancer. A report of the siop working committee on psychosocial issues in pediatric oncology. *Medical and Pediatric Oncology*, *38*(2), 114–117. <https://doi.org/10.1002/mpo.1283>
- Stewart, J. L., Pyke-Grimm, K. A., & Kelly, K. P. (2005). Parental treatment decision making in pediatric oncology. *Seminars in Oncology Nursing*, *21*(2), 89–97.
<https://doi.org/10.1016/j.soncn.2004.12.003>
- Stiggelbout, A. M., Weijden, T. V. d., Wit, M. P. T. D., Frosch, D., Legare, F., Montori, V. M., Trevena, L., & Elwyn, G. (2012). Shared decision making: Really putting patients at the centre of healthcare. *BMJ*, *344*(jan27 1), e256–e256. <https://doi.org/10.1136/bmj.e256>

- Subramani, S. (2019). Practising reflexivity: Ethics, methodology and theory construction. *Methodological Innovations*, 12(2), 2059799119863276.
<https://doi.org/10.1177/2059799119863276>
- Sutterlüty, F., & Tisdall, E. K. M. (2019). Agency, autonomy and self-determination: Questioning key concepts of childhood studies. *Global Studies of Childhood*, 9(3), 183–187.
<https://doi.org/10.1177/2043610619860992>
- Thambinathan, V., & Kinsella, E. A. (2021). Decolonizing methodologies in qualitative research: Creating spaces for transformative praxis. *International Journal of Qualitative Methods*, 20, 16094069211014766.
- Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Schepp, K. (2010). Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Annals of Oncology*, 21(6), 1145–1151.
<https://doi.org/10.1093/annonc/mdp534>
- Tates, K., & Meeuwesen, L. (2001). Doctor–parent–child communication. A (re)view of the literature. *Social Science & Medicine*, 52(6), 839–851. [https://doi.org/10.1016/S0277-9536\(00\)00193-3](https://doi.org/10.1016/S0277-9536(00)00193-3)
- Teachman, G., McDonough, P., Macarthur, C., & Gibson, B. E. (2018). A critical dialogical methodology for conducting research with disabled youth who use augmentative and alternative communication. *Qualitative Inquiry*, 24(1), 35-44.
- Thompson, R. H. (2018). *The Handbook of Child Life: A Guide for Pediatric Psychosocial Care*. Charles C Thomas Publisher.
- Tisdall, E. K. M. (2015). Addressing the challenges of children and young people’s participation: considering time and space. In *International Perspectives and Empirical Findings on Child*

- Participation*. Oxford University Press.
<https://doi.org/10.1093/acprof:oso/9780199366989.003.0017>
- Tisdall, E. K. M., & Punch, S. (2012). Not so ‘new’? Looking critically at childhood studies. *Children’s Geographies*, 10(3), 249–264. <https://doi.org/10.1080/14733285.2012.693376>
- Tisdall, K. (2008). Is the honeymoon over? Children and young people’s participation in public decision-making. *The International Journal of Children’s Rights*, 16(3), 419–429.
<https://doi.org/10.1163/157181808X311240>
- Toros, K. (2021). A systematic review of children’s participation in child protection decision-making: Tokenistic presence or not? *Children & Society*, 35(3), 395–411.
<https://doi.org/10.1111/chso.12418>
- Tracy, S. J. (2010). Qualitative quality: eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837–851. <https://doi.org/10.1177/1077800410383121>
- Twum-Danso Imoh, A. (2016). From the singular to the plural: Exploring diversities in contemporary childhoods in sub-Saharan Africa. *Childhood*, 23(3), 455–468.
<https://doi.org/10.1177/0907568216648746>
- Underwood, K., Chan, C., Koller, D., & Valeo, A. (2015). Understanding young children’s capabilities: Approaches to interviews with young children experiencing disability. *Child Care in Practice*, 21(3), 220–237. <https://doi.org/10.1080/13575279.2015.1037249>
- Ungar, M., McGrath, P., Black, D., Sketris, I., Whitman, S., & Liebenberg, L. (2015). Contribution of participatory action research to knowledge mobilization in mental health services for children and families. *Qualitative Social Work*, 14(5), 599-615.
- UNICEF (2013). Child wellbeing in rich countries: Innocenti Report Card 11. Retrieved from:
https://www.unicef-irc.org/publications/pdf/rc11_eng.pdf

- Valles, S. (2020). Philosophy of biomedicine. In E. Zalta (Ed), *The Stanford Encyclopedia of Philosophy* (Summer 2020 ed.). Stanford University. Retrieved from:
<https://plato.stanford.edu/entries/biomedicine/>
- van Bijleveld, G. G., Dedding, C. W. M., & Bunders-Aelen, J. F. G. (2014). Seeing eye to eye or not? Young people's and child protection workers' perspectives on children's participation within the Dutch child protection and welfare services. *Children and Youth Services Review*, 47, 253–259. <https://doi.org/10.1016/j.chilyouth.2014.09.018>
- van der Geest, S., & Satalkar, P. (2021). Autonomy and dying: Notes about decision-making and “completed life” euthanasia in the Netherlands. *Death Studies*, 45(8), 613–622.
<https://doi.org/10.1080/07481187.2019.1671543>
- van der Weijden, T., Post, H., Brand, P. L. P., van Veenendaal, H., Drenthen, T., van Mierlo, L. A., Stalmeier, P., Damman, O. C., & Stiggelbout, A. (2017). Shared decision making, a buzzword in the Netherlands, the pace quickens towards nationwide implementation.... *Zeitschrift Für Evidenz, Fortbildung Und Qualität Im Gesundheitswesen*, 123–124, 69–74.
<https://doi.org/10.1016/j.zefq.2017.05.016>
- Vannini, P. (2018). *Doing Public Ethnography: How to Create and Disseminate Ethnographic and Qualitative Research to Wide Audiences*. Routledge.
<https://doi.org/10.4324/9781315111001>
- Van Staa, A., Jedeloo, S., & van der Stege, H. (2011). “What we want”: chronically ill adolescents' preferences and priorities for improving health care. *Patient Preference and Adherence*, 5, 291-305.
- Verhagen, E., & Sauer, P. J. J. (2005). The Groningen Protocol—Euthanasia in severely ill newborns. *New England Journal of Medicine*, 352(10), 959–962.
<https://doi.org/10.1056/NEJMp058026>

- Vis, S. A., & Fossum, S. (2015). Organizational factors and child participation in decision-making: Differences between two child welfare organizations. *Child & Family Social Work, 20*(3), 277–287. <https://doi.org/10.1111/cfs.12076>
- Vis, S. A., Holtan, A., & Thomas, N. (2012). Obstacles for child participation in care and protection cases—Why Norwegian social workers find it difficult. *Child Abuse Review, 21*(1), 7–23. <https://doi.org/10.1002/car.1155>
- Vis, S. A., Strandbu, A., Holtan, A., & Thomas, N. (2011). Participation and health: A research review of child participation in planning and decision-making. *Child & Family Social Work, 16*(3), 325–335. <https://doi.org/10.1111/j.1365-2206.2010.00743.x>
- Vizcarrondo, F. E. (2014). Neonatal euthanasia: The Groningen Protocol. *The Linacre Quarterly, 81*(4), 388–392. <https://doi.org/10.1179/0024363914Z.000000000086>
- Wahl-Jorgensen, K. (2021). The affordances of interview research on zoom: New intimacies and active listening. *Communication, Culture and Critique, 14*(2), 373–376. <https://doi.org/10.1093/ccc/tcab015>
- Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery, 22*(2), 108–119. <https://doi.org/10.1016/j.midw.2005.05.004>
- Walter, J. K., & Ross, L. F. (2014). Relational autonomy: Moving beyond the limits of isolated individualism. *Pediatrics (Evanston), 133*(Journal Article), S16–S23. <https://doi.org/10.1542/peds.2013-3608D>
- Wheeler, G. (2000). *Beyond Individualism: Toward a New Understanding of Self, Relationship, and Experience*. Gestalt Press. <https://doi.org/10.4324/9780203766958>
- White, J. (2007). Knowing, doing and being in context: A praxis-oriented approach to child and youth care. *Child & Youth Care Forum, 36*(5–6), 225–244. <https://doi.org/10.1007/s10566-007-9043-1>

- Wiederhold, A. (2015). Conducting fieldwork at and away from home: Shifting researcher positionality with mobile interviewing methods. *Qualitative Research, 15*(5), 600–615. <https://doi.org/10.1177/1468794114550440>
- Wildman, W. J. (2010). An introduction to relational ontology. In *Relationality in Physical Science and Theology*.
- Wijngaarde, R. O., Hein, I., Daams, J., Van Goudoever, J. B., & Ubbink, D. T. (2021). Chronically ill children's participation and health outcomes in shared decision-making: A scoping review. *European Journal of Pediatrics, 180*(8), 2345–2357. <https://doi.org/10.1007/s00431-021-04055-6>
- Willig, C., & Rogers, W. S. (2017). *The SAGE handbook of qualitative research in psychology*. Sage.
- Woermann, M., Human, O., & Preiser, R. (2018). General complexity: A philosophical and critical perspective. *Emergence: Complexity and Organization, 20*(2), 1A-1A.
- Woodhead, M. (2005). Early childhood development: A question of rights. *International Journal of Early Childhood, 37*(79), p. 79-98.
- Worldbank Data (2020). *Physicians per 1,000 people*. Retrieved from: <https://data.worldbank.org/indicator/SH.MED.PHYS.ZS>
- Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P., Wang, Z., Domecq Garces, J. P., Montori, V. M., & LeBlanc, A. (2015). Shared decision making in pediatrics: a systematic review and meta-analysis. *Academic Pediatrics, 15*(6), 573–583. <https://doi.org/10.1016/j.acap.2015.03.011>
- Wyness, M. (2009). Adult's involvement in children's participation: Juggling children's places and spaces. *Children & Society, 23*(6), 395–406. <https://doi.org/10.1111/j.1099-0860.2008.00181.x>

- Wynn, J. D. (2015). The transforming power of patient advisors. *North Carolina Medical Journal*, 76(3), 171–173. <https://doi.org/10.18043/ncm.76.3.171>
- Yazdani, N., Chartrand, J., & Stacey, D. (2022). Exploring parental decision making for a child with a life-limiting condition: An interpretive description study. *Journal of Hospice & Palliative Nursing*, 24(2), 140–146. <https://doi.org/10.1097/NJH.0000000000000839>
- Yigitbas, C., & Top, F. U. (2020). The implementation of child rights in healthcare services. *Nursing Ethics*, 27(7), 1517–1528. <https://doi.org/10.1177/0969733020922883>
- Young, B. (2003). Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *BMJ*, 326(7384), 305–305. <https://doi.org/10.1136/bmj.326.7384.305>
- Young, B., Moffett, J. K., Jackson, D., & McNulty, A. (2006). Decision-making in community-based paediatric physiotherapy: A qualitative study of children, parents and practitioners. *Health & Social Care in the Community*, 14(2), 116–124. <https://doi.org/10.1111/j.1365-2524.2006.00599.x>
- Youngner, S. J., & Kimsma, G. K. (Eds.). (2012). *Physician-Assisted Death in Perspective: Assessing the Dutch Experience*. Cambridge University Press. <https://doi.org/10.1017/CBO9780511843976>
- Yudin, B. G. (2008). Understanding human being. Constructivism versus naturalism. *Dialogue and Universalism*, 18(11/12), 101–113.
- Zwaanswijk, M., Tates, K., Dulmen, S. van, Hoogerbrugge, P. M., Kamps, W. A., Beishuizen, A., & Bensing, J. M. (2011). Communicating with child patients in pediatric oncology consultations: A vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology*, 20(3), 269–277. <https://doi.org/10.1002/pon.1721>

Zwaanswijk, M., Tates, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J. M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics*, 7(1), 35.
<https://doi.org/10.1186/1471-2431-7-35>

Appendices

Appendix A: Research Ethics Board Certificate(s) of Approval

Original:



Office of Research Services | Human Research Ethics Board
 Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
 T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

Certificate of Approval

<p>PRINCIPAL INVESTIGATOR Alison Gerlach (Supervisor)</p> <p>PRINCIPAL APPLICANT Amarens Matthiesen PhD student</p> <p>UVIC DEPARTMENT Child and Youth Care CHIL</p>	<p>ETHICS PROTOCOL NUMBER 20-0105 Expedited review - delegated</p> <p>ORIGINAL APPROVAL DATE 05-Oct-2020</p> <p>APPROVED ON 05-Oct-2020</p> <p>APPROVAL EXPIRY DATE 04-Oct-2021</p>
<p>PROJECT TITLE Exploring the role of child life specialists in children's participation in decision-making: A critical qualitative inquiry</p> <p>RESEARCH TEAM MEMBERS Amarens Matthiesen - ,</p> <p>DECLARED PROJECT FUNDING None</p> <p>DOCUMENTS INCLUDED IN THIS APPROVAL tcps2_core_certificate (1).pdf - 02-Sep-2020 Appendix A Proof applied to local REB.pdf - 15-Sep-2020 Appendix B Prinses Maxima Hospital Approval.pdf - 15-Sep-2020 Appendix [REDACTED] Sep-2020 Appendix [REDACTED] pdf - 15-Sep-2020 Appendix [REDACTED] -2020 Appendix J Interview guide DUTCH pdf.pdf - 15-Sep-2020 Appendix K Socio-Demo Form English.pdf - 15-Sep-2020 Appendix L Sociodemographic Dutch.pdf - 15-Sep-2020 Research Proposal - AmarensM pdf.pdf - 16-Sep-2020 Appendix F Email script 3rd party recruiters.pdf - 02-Oct-2020 Appendix E Recruitment CLS Email Script.pdf - 02-Oct-2020 Appendix H Recruitment Poster English 2.pdf - 02-Oct-2020 Appendix G Recruitment Poster Dutch 2.pdf - 02-Oct-2020 Appendix N Consent Form Dutch (toestemmingsformulier).pdf - 02-Oct-2020 Appendix M Participant Consent Form English PDF.pdf - 02-Oct-2020</p>	
CONDITIONS OF APPROVAL	
<p>This Certificate of Approval is valid for the above term provided there is no change in the protocol.</p> <p>Modifications To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p>Renewals Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.</p> <p>Project Closures When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.</p>	
Certification	

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.



Dr. Rachael Scarth
Associate VP Research Operations

Amendments:



Office of Research Services | Human Research Ethics Board
 Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
 T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

Certificate of Approval - Amendments

PRINCIPAL INVESTIGATOR	Alison Gerlach (Supervisor)	ETHICS PROTOCOL NUMBER	20-0105
PRINCIPAL APPLICANT	Amarens Matthiesen PhD student	Expedited review - delegated	
UVIC DEPARTMENT	Child and Youth Care CHIL	ORIGINAL APPROVAL DATE	05-Oct-2020
		APPROVED ON	26-Mar-2021
		APPROVAL EXPIRY DATE	04-Oct-2021

PROJECT TITLE Exploring the role of child life specialists in children's participation in decision-making: A critical qualitative inquiry

RESEARCH TEAM MEMBERS
Amarens Matthiesen - ,

DECLARED PROJECT FUNDING None

DOCUMENTS INCLUDED IN THIS APPROVAL

- tcps2_core_certificate (1).pdf - 02-Sep-2020
- Appendix A Proof applied to local REB.pdf - 15-Sep-2020
- Appendix C [redacted] Sep-2020
- Appendix D [redacted].pdf - 15-Sep-2020
- Appendix I [redacted]-2020
- Appendix J Interview guide DUTCH pdf.pdf - 15-Sep-2020
- Appendix K Socio-Demo Form English.pdf - 15-Sep-2020
- Appendix L Sociodemographic Dutch.pdf - 15-Sep-2020
- Research Proposal - AmarensM pdf.pdf - 16-Sep-2020
- Appendix F Email script 3rd party recruiters.pdf - 02-Oct-2020
- Appendix E Recruitment CLS Email Script.pdf - 02-Oct-2020
- Appendix H Recruitment Poster English 2.pdf - 02-Oct-2020
- Appendix G Recruitment Poster Dutch 2.pdf - 02-Oct-2020
- Appendix N Consent Form Dutch (toestemmingsformulier).pdf - 02-Oct-2020
- Appendix M Participant Consent Form English PDF.pdf - 02-Oct-2020
- Appendix S - E-mail script invitation to participate - Interview managers - Dutch pdf.pdf - 16-Mar-2021
- Appendix P - Participant Consent Form - Managers Interview ENG pdf.pdf - 16-Mar-2021
- Appendix Q - Consent Form Managers Interview - Dutch pdf.pdf - 16-Mar-2021
- Appendix T - Interview Managers ENG pdf.pdf - 16-Mar-2021
- Appendix U - Interview questions - Managers DUTCH pdf.pdf - 16-Mar-2021
- Appendix R - E-mail script invitation to participate - Manager Interviews - English pdf.pdf - 18-Mar-2021

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications

To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals

Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures

When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.



Dr. Rachael Scarth
 Associate VP Research Operations

Appendix B: Recruitment Poster (English and Dutch)

English:

CHILD LIFE SPECIALISTS ARE INVITED TO TAKE
PART IN A RESEARCH STUDY FOCUSING ON:



Children's participation in decision-making

WHAT

THIS RESEARCH STUDY FOCUSES ON THE ROLE OF CHILD LIFE SPECIALISTS IN CHILDREN'S PARTICIPATION IN DECISION-MAKING IN HEALTHCARE SETTINGS

WHO

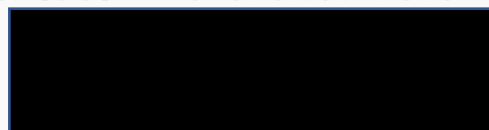
CHILD LIFE SPECIALISTS ARE INVITED TO COMPLETE AN INTERVIEW ON THE TOPIC OF CHILDREN'S PARTICIPATION IN DECISION-MAKING. THIS STUDY IS BEING CONDUCTED BY AMARENS MATTHIESEN, PHD STUDENT AT THE UNIVERSITY OF VICTORIA, AND IS BEING SUPERVISED BY DR. ALISON GERLACH.

WAAR

DUE TO COVID-19, INTERVIEWS WILL TAKE PLACE VIA VIDEO-CONFERENCING TECHNOLOGY (E.G., ZOOM, SKYPE)

Interested?

Please contact Amarens for more information:



Dutch:

PEDAGOGISCHE MEDEWERKERS
GEZOCHT VOOR DEELNAME AAN EEN ONDERZOEK
RONDOM HET THEMA:



kinderparticipatie in keuzes maken in de zorg

WAT

DIT ONDERZOEK RICHT ZICH OP HET THEMA KINDERPARTICIPATIE EN DE ROL VAN PEDAGOGISCHE MEDEWERKERS IN HET KINDERPARTICIPATIE PROCESS

WIE

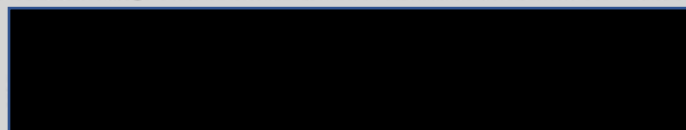
PEDAGOGISCHE MEDEWERKERS DIE WERKZAAM ZIJN IN EEN KINDERZIEKENHUIS IN NEDERLAND ZIJN UITGENODIGD OM DEEL TE NEMEN AAN EEN INTERVIEW

WAAR

ALS GEVOLG VAN HET CORONAVIRUS ZULLEN ALLE INTERVIEWS PLAATS VINDEN VIA VIDEOTECHNOLOGIE (E.G., ZOOM, SKYPE)

Geïnteresseerd?

Neem contact op met Amarens voor meer informatie:





Children’s Participation in Decision-Making: Exploring the Role of Child Life Specialists

You are invited to participate in a study named ‘Children’s Participation in Decision-Making: Exploring the Role of Child Life Specialists’ that is being conducted by Amarens Matthiesen.

Amarens Matthiesen is a doctoral student in the Faculty of Human and Social Development’s School of Child and Youth Care at the University of Victoria. As a graduate student, I am conducting research as part of the requirements for a doctorate in Child and Youth Care. It is being conducted under the supervision of Dr. Alison Gerlach. You may contact my supervisor at [REDACTED]

Purpose and Objectives

The purpose of this research project is to give you an opportunity to share your personal experiences regarding children’s participation in decision-making. I am particularly interested in hearing about how you define the concept ‘participation’, what ‘decisions’ mean to you and how your role as a child life specialist may play a role in shaping children’s participation in decision-making. Paying close attention to how you describe your experiences will help promote, shape, understand and shed light on the way in which children’s participation in decision-making can play a role in child life practice.

Importance of Research

First, this research will give child life specialists a better understanding of the way in which child life specialists experience children’s participation in decision-making in the context of multiple children’s hospitals in the Netherlands. No previous studies have explored children’s participation in decision-making in the context of child life practice. Thus, by paying close attention to the language used to describe child life specialists’ experiences, new light may be shed on the role of child life specialists can play a role in children’s participation decision-making processes. Second, this research examines the types of challenges and supports which can influence the abilities of child life specialists to promote children’s participation in decision-making. Third, by examining the sources from which child life specialists gather their knowledge about children’s participation, this study may contribute to the development of novel or pre-existing policies, guidelines and practices regarding providing children who have been hospitalized with opportunities for participation in decision-making.

Participant Selection

You are being asked to participate in this study because you are employed as child life specialist on a causal, part-time or full-time basis. I consider your opinions and perspectives as invaluable and thus would appreciate the opportunity to gain a deeper understanding of your experiences as a child life specialist in

relation to the topic of children's participation. Participants will be accepted into the study on a first-come basis. A waitlist will be created once 24 participants have been recruited, reaching the maximum number for participant recruitment. These waitlisted individuals will be contacted to participate if someone withdraws from the study.

What is Involved

If you consent to voluntarily participate in this research, your participation will include taking part in an interview with the researcher. You may also choose to participate in a follow-up interview, should your schedule allow. It is expected that one interview will take up between 20 minutes and 1 hour of your time. You are welcome to shorten or lengthen the time frame of the interview if you desire. With your permission, the interview will be audio-taped. Due to COVID-19, all interviews will take place remotely, via video-conferencing technology. You may therefore choose a quiet, comfortable and private location in which to conduct the interview. The interview questions will broadly revolve around gaining insight into your perspectives on the meaning of children's participation, your role in shaping children's participation, facilitators and barriers in children's participation, and your insights into recommendations for child life practice. In addition, there will be several questions that will focus on your socio-demographic background, in terms of your role as a child life specialist (e.g., in which area of the hospital you work, your employment status), how you identify your ethnicity and gender, as well as how many languages you speak.

Inconvenience

Should you choose to participate in this study, the time required for completing the consent forms and interview may cause you some inconvenience. The total time needed for this study will be a maximum of 1.5 hours. If you choose to participate in a follow-up interview, this study may take up an additional 1.5 hours of your time.

Risks

There are no known risks to you by participating in this research. I, the interviewer, will try to create a safe and supportive environment. There will be no pressure to continue in the research and you can withdraw at any time. You will also be welcomed to take breaks, get up and move around at any time during the interview if you feel the need to do so. In the unlikely event that you will experience stress, emotional discomfort or fatigue during the interview, I will offer you the opportunity to take a break and my assistance in accessing appropriate support services for you.

Benefits

There are potential benefits to your participation. First, by making a contribution to a gap in existing literature by sharing your personal experiences, your input has the potential to inform other child life specialists' knowledge and understandings of practices related to children's participation in decision-making in healthcare. Such understandings may extend to informing other healthcare providers' knowledge on children's participation. Second, your input may help society at large better understand the challenges child life specialists face in providing children with opportunities for participation in decision-making, and develop or tailor services that serve the needs of children who have been hospitalized in an optimal manner.

Voluntary Participation

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used and will be destroyed immediately.

Researcher's Relationship with Participants

It is possible that my dual role as a researcher and child life specialist could create conflicts and power imbalances that could affect your decision-making procedures. To prevent this relationship from influencing your decisions to participate, your participation or non-participation will not affect your current employment status at the hospital in which you are working, nor your relationship with the researcher.

Anonymity

Your anonymity will be protected before, during, and after your participation in this study. This will be achieved by removing identifying information (e.g., names and name of the hospital in which you practice) from the interview transcripts. Due to the nature of this study's topic, socio-demographic information (e.g., your cultural background, languages you speak) may be used in the reported findings of this study. However, participants will be referred to as participant 1, 2, 3 and etc. when analyzing transcripts, and reporting findings. This will help minimize the risk that anyone will be able to associate your data with you in the final reporting of this study. If you withdraw your choice to participate, your anonymity will still be protected.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by not using any identifying information in the data (e.g., personal names and name of the hospital in which you practice). All electronic data (i.e. audiotapes) will be kept on the researcher's password-protected laptop. Hard copies of the transcripts and paper records will be stored in a locked cabinet at the researcher's home office. Only the researcher (Amarens Matthiesen) will have access to the locked cabinet and the password-protected laptop. However, there are limits to confidentiality due to legal requirements. Confidentiality may be breached if there is a disclosure of child abuse or a disclosure of causing harm to the participant or others (i.e. disclosure of intent to self-harm). Despite my use of pseudonyms and removing specific identifiers from the interview transcripts, you may be faced with a risk of being identified. If you are not comfortable with doing the interview, you can withdraw from the research at any time.

Dissemination of Results

The data provided in your interview will be used in my doctoral dissertation in the completion of a doctorate in Child and Youth Care at the University of Victoria. The findings may also be published in journals and presented at workshops/scholarly meetings so that the important information found in this study can be passed along to other professionals working in a healthcare setting. A digital copy of my dissertation can be sent you at your request.

Disposal of Data

Data from this research will be disposed of once the criteria of degree completion have been met, anticipated to be no later than June 2022. After that time, files on the researcher's computer will be permanently deleted, paper records will be shredded, and audiotapes will be erased.

‘Kinderparticipatie in keuzes maken en de rol van pedagogische medewerkers’

U wordt uitgenodigd om deel te nemen aan een onderzoek dat zich richt op de potentiële rol van pedagogische medewerkers in het betrekken van kinderen in keuzes maken in de gezondheidszorg. Dit onderzoek wordt uitgevoerd door Amarens Matthiesen. Amarens Matthiesen is een (promotie)student aan de ‘School of Child and Youth Care’ (kind-en jeugd-studies) aan de Universiteit van Victoria in British Columbia, Canada. Dit onderzoek maakt deel uit van haar promotie-onderzoek en wordt begeleidt door Dr. Alison Gerlach.

Doelstellingen

Het doel van dit onderzoek is om u een kans te geven om uw persoonlijke ervaringen te delen over kinderparticipatie in keuzes maken. Ik ben vooral geïnteresseerd in hoe u het concept ‘participatie’ definieert, wat ‘keuzes’ voor u betekenen en hoe uw functie als pedagogisch medewerker een rol kan spelen in het kinderparticipatie proces. Door inzicht te krijgen in uw ervaringen rondom kinderparticipatie in de gezondheidszorg, kan er nieuw licht geworpen worden op de potentiële rol van pedagogische medewerkers in het bevorderen van kinderparticipatie in keuzes maken in verschillende kindziekenhuizen in Nederland.

Het belang van dit onderzoek

Weinig tot geen eerdere studies hebben het thema kinderparticipatie in keuzes maken exclusief gekoppeld aan de praktijk van pedagogische medewerkers. Dit onderzoek kan bijdragen aan nieuw inzicht in hoe pedagogische medewerkers een rol zouden kunnen spelen in het bevorderen van kinderparticipatie in keuzes maken door de nadruk te leggen op: (a) de ondersteuning die pedagogische medewerkers zouden kunnen helpen in het betrekken van kinderen in besluitvorming, (b) wat pedagogische medewerkers uitdagend vinden aan kinderparticipatie in keuzes maken, (c) de bronnen (zoals opleidingen, conferenties, workshops) die pedagogische medewerkers gebruiken om kennis op te doen over kinderparticipatie. Als gevolg kan deze studie bijdragen aan de ontwikkeling van nieuwe of reeds bestaande beleidslijnen, richtlijnen en praktijken om kinderen die in het ziekenhuis zijn opgenomen de gelegenheid te bieden om deel te nemen aan besluitvorming.

Selectie van deelnemers

U wordt gevraagd om deel te nemen aan dit onderzoek omdat u werkzaam bent als pedagogisch medewerker in Nederland. Ik zou de gelegenheid om u te kunnen spreken over u ervaringen met kinderparticipatie op prijs stellen om een dieper inzicht te krijgen over hoe pedagogische medewerkers in Nederland het thema kinderparticipatie ervaren. Deelnemers zullen worden geselecteerd op basis van wie zich het eerst aanmeldt. Zodra er 24 deelnemers zijn geworven (maximale aantal deelnemers), zal er een wachtlijst worden

aangemaakt. Als iemand zich terugtrekt uit het onderzoek, zullen de personen op de wachtlijst worden gecontacteerd om alsnog deel te nemen.

Wat houdt dit onderzoek in?

Als u toestemming geeft om vrijwillig deel te nemen aan dit onderzoek, dan wordt u gevraagd om deel te nemen aan een interview. Ook kunt u ervoor kiezen om deel te nemen aan een aanvullend interview die enige tijd na het eerste gesprek plaats kan vinden. Ik verwacht dat een interview tussen de 20 minuten en 1 uur zal duren. U kunt, als u wil, de tijd van het interview verkorten als dit nodig is. Met uw toestemming wordt het interview op geluidsband opgenomen. Vanwege COVID-19 zullen alle interviews op afstand plaatsvinden, via videoconferentietechnologie (zoals Zoom of Skype). U kunt daarom zelf een rustige en comfortabele locatie kiezen waarin het interview plaats kan vinden. De interview vragen richten zich op uw ervaringen met kinderparticipatie in de zorg, inclusief uw perspectieven op de betekenis van kinderparticipatie, uw rol in kinderparticipatie in keuzes maken, facilitatoren en belemmeringen omtrent kinderparticipatie, en uw aanbevelingen voor de psychosociale zorg in de praktijk.

Ongelegenheden

Mocht u ervoor kiezen om deel te nemen aan dit onderzoek, kan de tijd die nodig is voor het invullen van dit toestemmingsformulier en het interview enig ongemak voor u veroorzaken. De totale tijd die nodig is voor dit onderzoek is maximaal 1,5 uur. Als u ervoor kiest om deel te nemen aan een aanvullend interview, zal dit qua tijd nog ongeveer maximaal 1,5 uur in beslag nemen.

Risico's

Aan dit onderzoek zijn geen specifieke risico's verbonden. Ik, de interviewer, zal proberen om een vertrouwelijke en veilige sfeer te creëren tijdens de interviews. Er is geen druk om door te gaan met het onderzoek en u kunt op elk moment kiezen om niet door te gaan met het interview. U kunt ook op elk moment tijdens het gesprek een pauze nemen als u daar behoefte aan heeft. In het onwaarschijnlijke geval dat u tijdens het interview stress, emotioneel ongemak of vermoeidheid ervaart, zal ik u de gelegenheid bieden om een pauze te nemen en mijn hulp aanbieden bij het zoeken naar geschikte ondersteuning.

Voordelen

Deelname aan dit onderzoek is gebonden aan potentiële voordelen. Uw inbreng kan de samenleving als geheel helpen om de ervaringen van pedagogische medewerkers rondom kinderparticipatie beter te begrijpen en om beleiden en ondersteuning omtrent kinderparticipatie af te stemmen op de unieke capaciteiten en wensen van kinderen in het ziekenhuis. Het delen van uw persoonlijke ervaringen kan ook de kennis van andere professionals in de gezondheidszorg (zoals fysiotherapeuten, ergotherapeuten, verpleegsters) informeren omtrent het thema kinderparticipatie.

Vrijwillige deelname

Uw deelname aan dit onderzoek is geheel vrijwillig. Als u besluit deel te nemen, kunt u op elk moment kiezen om niet door te gaan met het interview, zonder enige consequenties of uitleg. Als u zich terugtrekt uit het onderzoek, worden uw gegevens onmiddellijk verwijderd.

Relatie tussen onderzoeker en deelnemers

Het is mogelijk dat mijn dubbele rol als onderzoeker en pedagogisch medewerker in Canada tot enige machtsongelijkheden kan leiden die uw besluitvorming in dit onderzoek kunnen beïnvloeden. Om te

voorkomen dat dit uw beslissingen om deel te nemen beïnvloedt, heeft uw deelname of niet-deelname geen invloed op uw huidige arbeidsstatus in het ziekenhuis waar u werkt, noch op uw relatie met de onderzoeker.

Anonimiteit

Uw anonimiteit zal worden beschermd voor, tijdens en na uw deelname aan dit onderzoek. Ik zal u enkele vragen stellen over uw socio-demografische achtergrond (zoals de talen die u spreekt, hoe u uw etniciteit identificeert). Alle deelnemers zullen echter worden geïdentificeerd als 1, 2, 3 etc. in het analyseren van transcripties en het rapporteren van bevindingen. Dit kan het risico verkleinen dat iemand uw persoonlijke identificaties (zoals de talen die u spreekt) aan u koppelt. Als u ervoor kiest om niet deel te nemen, zal uw anonimiteit worden beschermd door uw persoonlijke gegevens te verwijderen van mijn persoonlijke laptop.

Vertrouwelijkheid

Uw vertrouwelijkheid zal worden beschermd door geen identificerende informatie te gebruiken in de onderzoeksbevindingen. Alle elektronische gegevens (d.w.z. geluidsbanden en transcripties) zullen worden bewaard op (met paswoord beveiligde) laptop van de onderzoeker. Afgedrukte exemplaren van de transcripties en papieren documenten worden bewaard in een afgesloten kast op het thuishkantoor van de onderzoeker. Alleen de onderzoeker (Amarens Matthiesen) zal toegang krijgen tot de afgesloten kast en laptop. Ondanks mijn gebruik van pseudoniemen en het verwijderen van specifieke identificatiegegevens uit de interviewtranscripties, loopt u mogelijk het risico geïdentificeerd te worden door aspecten van uw social-demografische achtergrond te delen. Als u dit niet wenst, kan u kiezen om de social-demografische informatie niet uit te vullen en zich op elk moment terug te trekken uit het onderzoek.

Er zijn echter grenzen aan vertrouwelijkheid vanwege wettelijke vereisingen. De vertrouwelijkheid kan worden geschonden als er een melding wordt gemaakt van kindermishandeling of een melding die duidt op het veroorzaken van schade aan de deelnemer of anderen (zoals het onthullen van de intentie tot zelfbeschadiging).

Verspreiding van onderzoeksresultaten

De onderzoeksbevindingen zullen in mijn proefschrift worden gebruikt. Mijn proefschrift maakt deel uit van het behalen van een doctoraat in kinder- en jeugdzorg aan de Universiteit van Victoria. De bevindingen kunnen ook in academische tijdschriften worden gepubliceerd en gebruikt worden tijdens workshops en conferenties. Een digitale kopie van mijn proefschrift kan ook worden toegestuurd op uw verzoek.

Verwijdering van onderzoeksgegevens

De gegevens van dit onderzoek zullen worden verwijderd wanneer er aan de eisen van het diploma is voldaan (naar verwachting uiterlijk in juni 2022). Na die tijd worden bestanden op de computer van de onderzoeker definitief verwijderd, papieren dossiers versnipperd en geluidsbanden gewist.

Contactgegevens

Indien u vragen heeft over dit onderzoek mag u contact opnemen met de onderzoeker, Amarens Matthiesen via [REDACTED] (indien u via de telefoon belt: de onderzoeker bevindt zich in Canada met 8 uren tijdsverschil met Nederland) of de supervisor van de onderzoeker, Dr. Alison Gerlach via [REDACTED] (supervisor spreekt alleen Engels).

Bovendien kunt u de ethische goedkeuring van dit onderzoek verifiëren of eventuele zorgen over dit onderzoek kenbaar maken door contact op te nemen met het Human Research Ethics Office (ethische toetsingscommissie) aan de Universiteit van Victoria [REDACTED]

Door hieronder uw handtekening te plaatsen, geeft aan dat u de bovenstaande voorwaarden voor deelname aan dit onderzoek begrijpt, dat u de gelegenheid heeft gehad om uw vragen te laten beantwoorden door de onderzoekers en dat u instemt met uw deelname aan dit onderzoek.

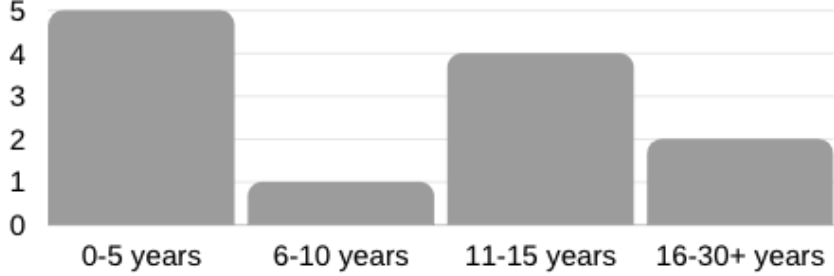
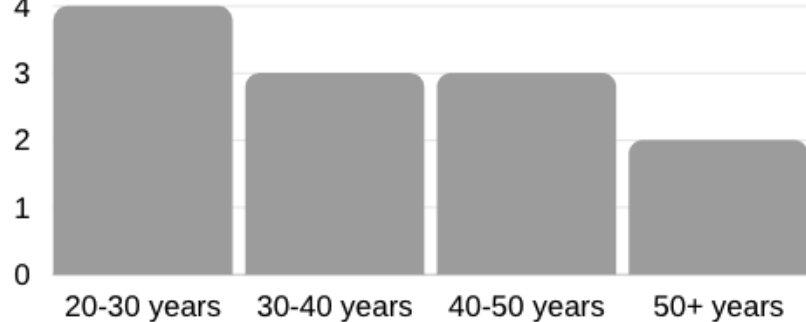
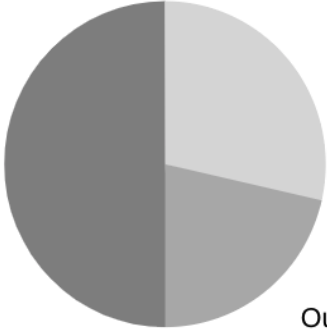
Name of Participant

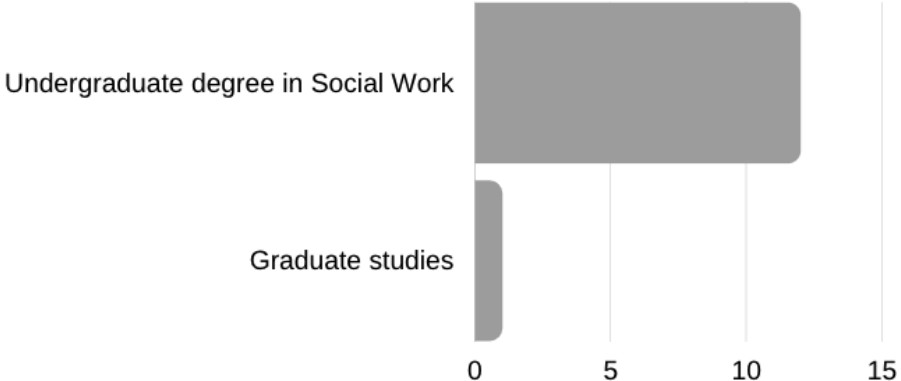
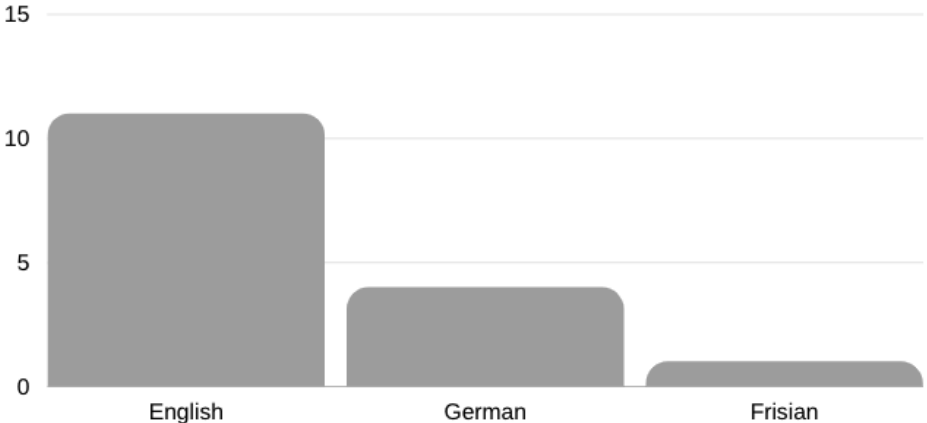
Signature

Date

U zal een kopie van dit formulier ontvangen en de onderzoeker zal een kopie behouden.

Appendix E: Participant Socio-demographic Information

Socio-demographic variable	Variable information										
<p>Length of time in practice as a CLS</p>	<p>Average: 12 years</p>  <table border="1"> <caption>Data for Length of time in practice as a CLS</caption> <thead> <tr> <th>Length of time in practice (years)</th> <th>Number of participants</th> </tr> </thead> <tbody> <tr> <td>0-5 years</td> <td>5</td> </tr> <tr> <td>6-10 years</td> <td>1</td> </tr> <tr> <td>11-15 years</td> <td>4</td> </tr> <tr> <td>16-30+ years</td> <td>2</td> </tr> </tbody> </table>	Length of time in practice (years)	Number of participants	0-5 years	5	6-10 years	1	11-15 years	4	16-30+ years	2
Length of time in practice (years)	Number of participants										
0-5 years	5										
6-10 years	1										
11-15 years	4										
16-30+ years	2										
<p>Participant age</p>	<p>Average: 39 years</p>  <table border="1"> <caption>Data for Participant age</caption> <thead> <tr> <th>Participant age (years)</th> <th>Number of participants</th> </tr> </thead> <tbody> <tr> <td>20-30 years</td> <td>4</td> </tr> <tr> <td>30-40 years</td> <td>3</td> </tr> <tr> <td>40-50 years</td> <td>3</td> </tr> <tr> <td>50+ years</td> <td>2</td> </tr> </tbody> </table>	Participant age (years)	Number of participants	20-30 years	4	30-40 years	3	40-50 years	3	50+ years	2
Participant age (years)	Number of participants										
20-30 years	4										
30-40 years	3										
40-50 years	3										
50+ years	2										
<p>Area of practice in hospital</p>	 <table border="1"> <caption>Data for Area of practice in hospital</caption> <thead> <tr> <th>Area of practice</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Inpatient care</td> <td>50%</td> </tr> <tr> <td>Acute care</td> <td>28.6%</td> </tr> <tr> <td>Outpatient care</td> <td>21.4%</td> </tr> </tbody> </table> <p>Inpatient care 50% <i>General surgery</i> <i>Psychiatry</i> <i>Oncology</i> <i>Neurology</i></p> <p>Acute care 28.6% <i>Emergency</i> <i>Intensive care</i> <i>Special care</i></p> <p>Outpatient care 21.4% <i>Day surgery & dialysis</i></p>	Area of practice	Percentage	Inpatient care	50%	Acute care	28.6%	Outpatient care	21.4%		
Area of practice	Percentage										
Inpatient care	50%										
Acute care	28.6%										
Outpatient care	21.4%										
<p>Gender</p>	<p>Female (n=12)</p>										
<p>Ethnicity</p>	<p>White (n=12)</p>										

<p>Level of education</p>	 <p>Undergraduate degree in Social Work</p> <p>Graduate studies</p> <p>0 5 10 15</p> <p>Undergraduate degree in Social Work/Pedagogiek¹⁰¹/SPH¹⁰² (n=11) Graduate studies¹⁰³ (n=2)</p>
<p>Language(s) spoken (in addition to Dutch)</p>	 <p>15</p> <p>10</p> <p>5</p> <p>0</p> <p>English German Frisian</p> <p>English (n = 11) German (n = 4) Frisian (n = 1)</p>

¹⁰¹ ‘Pedagogiek’ translates to ‘pedagogy’ which is a field of study that revolves around children’s upbringing, including children’s developmental stages, and the relationships between children and adults (parents, educators, teachers) and their environment.

¹⁰² ‘SPH’ stands for ‘Sociaal Pedagogische Hulpverlening’ or ‘Social Pedagogical Care Delivery’

¹⁰³ Post-graduate studies included a post-graduate diploma in ‘cognitive behavioural therapy’ (n=1) and a master’s degree in pedagogy (n=1).

Appendix F: Interview Guide (CLSs)

Socio-demographic information (English):

Interviews: Socio-Demographic Information Form

'Children's Participation in Decision-Making: Exploring the Role of Child Life Specialists in Dutch Children's Hospitals'

Note on confidentiality: All your personal information will be made anonymous. No personal identifying information will be included in any reports or communications about this study.

1) Information about your role as a child life specialist:

Length of time you have practiced as a child life specialist:

Length of time that you have been practicing at the hospital in which you currently work:

In which area(s) of the hospital do you currently work (e.g., inpatient, outpatient, ER):

Length of time you have practiced in your current specialty area:

Your employment status:

Full-time

Part-time

Casual

Other:

Do you currently hold any of the following that are specific to your role as a child life specialist:

Credentials

Type:

Name of institution/organization providing certification:

Certifications

Type:

Name of institution/organization providing certification:

Accreditations

Type:

Name of institution/organization providing certification:

Type of education completed:

University

College

Other:

Name of the educational program(s) completed:

Where did you complete your education?

City:

Country:

Additional locations:

Where did you complete your training to become a child life specialist?

City:

Country:

Additional locations:

In your role as a child life specialist, have you attended any of the following:

Conferences If yes, what was the location and name of the conference(s):

Professional development sessions If yes, what was the location and name of the session(s):

Other relevant training sessions:

2) Socio-demographic information:

How do you identify your culture and/or ethnicity?

How do you identify your gender?

Female

Male

Other:

In which year were you born?

Do you speak any languages other than Dutch?

If yes:

Socio-demographic information form (Dutch):

Interviews: Socio-demografisch informatieformulier

Opmerking over vertrouwelijkheid: al uw persoonlijke gegevens worden anoniem gemaakt. Er zal geen persoonlijk identificeerbare informatie worden opgenomen in rapporten of mededelingen over dit onderzoek.

1) Informatie over uw rol als pedagogisch medewerker:

Hoelang bent u al werkzaam als pedagogisch medewerker:

Hoelang werkt u in het ziekenhuis waar u momenteel werkt:

In welke afdeling(en) van het ziekenhuis werkt u momenteel (bijv. Spoed, poliklinisch):

Hoelang werk je al in deze afdeling(en):

Werkt u:

Full-time

Part-time

Anders, namelijk:

Heeft u certificaties die relevant zijn voor uw rol als pedagogisch medewerker?

Zo ja:

Wat voor soort certificatie?

Naam van instituut/organisatie die de certificering heeft verstrekt:

Wat voor opleiding volgt u of heeft u voltooid?

Master opleiding

Bachelor opleiding

Anders, namelijk:

Wat is de naam van het vak waarin u opleiding gevolgd heeft?

Waar heeft u/bent u momenteel uw opleiding voltooid/aan het voltooien?

Stad:

Land:

Aanvullende locaties:

Waar heeft u uw training om als pedagogische werker te kunnen werken voltooid?

Stad:

Land:

Aanvullende locaties:

In uw rol als pedagogisch medewerker, heeft u ooit een of meerdere van de volgende zaken bijgewoond:

Conferentie

Zo ja, wat was de locatie en naam van de conferentie(s)?

Training/professionele ontwikkelingsessie

Zo ja, wat was de locatie en naam van de sessie(s)?

Andere relevante evenementen/workshops:

2) Socio-demografische informatie:

Hoe identificeert u uw culturele ethniciteit?

Hoe identificeert u uw geslacht?

Vrouw

Man

Anders, namelijk:

Wat is uw geboortjaar?

Spreekt u andere talen (buiten Nederlands):

Zo ja, welke?

Main interview questions (English):

Interview Guide: Child Life Specialists (the Netherlands)

** Questions inside brackets [] are probing questions.*

Topic 1: The meaning of ‘participation’

- How would you describe children’s participation in decision-making?
- What do ‘decisions’ mean to you?
- Where and when did you learn about children’s participation in decision-making?

Topic 2: The role of child life specialists in shaping children’s participation

- How does children’s participation show up in your daily practice? *[When, where?]*
- Under which conditions are you involved/not involved in children’s participation in decision-making? *[e.g., distinguishing between ‘major’ treatment-related decisions or everyday ‘minor’ decisions]*
- How much importance do you pay to children’s participation in decision-making in your practice? *[Why do you believe that it is important/not important to consider children’s participation as a child life specialist?]*
- In your practice, who is typically involved in children’s decision-making processes? *[When (under which conditions) would you include/exclude children/parents in decision-making processes regarding children’s healthcare?]*

Topic 3: Barriers and facilitators in children’s participation

- Which challenge(s) do you experience regarding children’s participation in decision-making?
- What helps you support children’s participation in decision-making?

The influence of institutional spaces, policies and guidelines:

- How do hospital policies and guidelines play a role in shaping your involvement in children’s participation in decision-making? *[If so, how, when, where and in which ways?]*
- Do you use any supports provided by the hospital to help you involve children in decision-making? *[E.g., policies, documents, guidelines, workshops]*
- How do the physical spaces within the hospital play a role in shaping your involvement in children’s participation in decision-making? *[If so, how, when, where and in which ways?]*

The influence of social, political and cultural forces:

- What does 'childhood' mean to you? *[How do your views of children/childhood shape your perspective(s) on children's participation?]*
- What do children's rights mean to you? *[How do your views of children's rights shape your perspective(s) on children's participation?]*
- Do you refer to any frameworks, theories or concepts related to children's participation in your practice? *[If yes, how are they helpful or not in facilitating children's participation?]*

Topic 4: Recommendations for child life practice and the institution

- Which supports would you like the hospital to provide to help you include children in decision-making processes in the future? [E.g., materials, resources, policies, guidelines, training]
- Which supports could your professional discipline (i.e., child life department) provide to help you include children in decision-making processes in the future? [E.g., materials, resources, policies, guidelines, training]
- How could your education best prepare you for including children in decision-making processes?
- Is there anything else that you would like to share?

Main interview questions (Dutch):

Interview vragen: Pedagogische medewerkers

Vragen tussen haakjes [] zijn bedoeld om toevoegende informatie te verkrijgen

Onderwerp 1: De betekenis van "kinderparticipatie"

- Als ik het over kinderpaticipatie in keuzes maken heb, waar denk je dan aan?
- Aan wat voor soort 'keuzes' denk je dan? *[Verschillen tussen beslissingen die belangrijk zijn voor kinderen en volwassenen?]*
- Wat betekenen 'kinderen', 'de kindertijd' of 'jeugd' voor jou? *[Hoe hebben deze perspectieven invloed op hoe je over kinderpaticipatie nadenkt?]*
- Wat betekenen kinderrechten voor jou? *[Hoe beïnvloeden jou opvattingen over kinderrechten jou perspectieven op kinderpaticipatie?]*
- Hoe zou je het verschil/de verschillen beschrijven tussen de persoonlijke participatie van kinderen en de participatie van kinderen in de gemeenschap of het ziekenhuis?
- Kun je mij vertellen over hoe [en waar] je leert of blijft leren over de deelname van kinderen aan besluitvorming?

Onderwerp 2: De rol van pedagogische medewerkers in kinderpaticipatie

- Hoe komt de deelname van kinderen tot uiting in je dagelijks werk? *[Wanneer, waar en hoe ziet het eruit]*
- Hoeveel belang hecht je op een schaal van 1 tot 10 [10 is het hoogste niveau van belang] aan kinderpaticipatie in je dagelijks werk?
- Waarom is kinderpaticipatie in keuzes maken belangrijk voor jou? *[Wanneer is de deelname van kinderen aan besluitvorming niet belangrijk voor je?]*
- Kun je je een tijd voorstellen dat je betrokken was bij de deelname van een kind in keuzes maken en dat het heel goed ging? *[Waarom ging het goed? Wat is er gebeurd, wie waren erbij betrokken (gezinnen, andere zorgverleners) en op welke manieren?]*
- Kun je je een tijd voorstellen dat je betrokken was bij de deelname van een kind in keuzes maken en dat het niet heel goed ging? *[Waarom ging het niet goed? Wat is er gebeurd, wie waren erbij betrokken (gezinnen, andere zorgverleners) en op welke manieren?]*

- Kunt je mij vertellen wanneer je kinderen/ouders zou betrekken/uitsluiten bij besluitvormingsprocessen met betrekking tot de gezondheidszorg voor kinderen? *[onder welke voorwaarden]*

Onderwerp 3: Facilitatoren en belemmeringen bij de deelname van kinderen

- Wat helpt jou in de deelname van kinderen in keuzes maken te ondersteunen?
- Welke uitdaging(en) ervaar je met betrekking tot kinderp participatie in keuzes maken?
- Verwijs je naar kaders, theorieën of concepten die zich richten op kinderp participatie in je werk? *[Zo ja, hoe helpen ze al dan niet bij kinderp participatieprocesses?]*

De invloed van de ruimtes binnen het ziekenhuis, beleid en richtlijnen:

- Gebruik je ondersteuning die gegeven wordt door het ziekenhuis om kinderen te betrekken in keuzes maken? *[Bijv. Documenten, trainingen, workshops, conferenties]*
- Hoe spelen het beleid of richtlijnen binnen het ziekenhuis een rol bij het vormgeven van je betrokkenheid bij kinderp participatie? *[Zo ja, hoe, wanneer, waar, op welke manieren en specifiek(e) voorbeeld(en) van beleid]*
- Hoe spelen de fysieke ruimtes (d.w.z. het ontwerp van het gebouw, de kamers en het decor) in het ziekenhuis een rol bij het vormgeven van je betrokkenheid bij kinderp participatie? *[Hoe, wanneer, waar en op welke manieren?]*
- Welke ondersteuning zou het ziekenhuis je kunnen bieden om je te helpen in kinderen te betrekken bij besluitvormingsprocessen in de toekomst? *[Bijv. het ontwerp van fysieke ruimtes, materialen, middelen, beleid, richtlijnen, training]*

Onderwerp 4: Aanbevelingen voor de praktijk van het leven van kinderen

- Welke ondersteuning zou je professioneel vakgebied/vakgroep kunnen bieden om je te helpen in kinderen te betrekken bij besluitvormingsprocessen in de toekomst? *[Bijv. Materialen, bronnen, beleid, richtlijnen, training]*
- Hoe kan je opleiding jou het beste voorbereiden om kinderen bij besluitvormingsprocessen te betrekken? *[Wat mist er nog?]*
- Is er nog iets dat je met mij zou willen delen?

Appendix G: Interview Guide (Directors)

English:

Interview Guide - Directors

Topic 1: What is children's participation and where does it show up?

1. Could you tell me about your role/function in [organization]?
2. When you think of children's participation in decision-making, what comes to mind for you?
 - What does children's participation mean to you in the context of pediatric health care?
3. How is children's participation incorporated in [organization]?
4. Could you tell me about policies or initiatives that are relevant to children's participation/children's rights in decision-making at [organization]?
 - How are they supported/constrained?
5. Could you give me an example of a policy/initiative that you believe:
 - Works well/doesn't work well?
6. Are there quality assurance/accreditation standards related to children's participation at [organization] (e.g., Smiley quality standard)
 - If so:
 - i. When were they implemented?
 - ii. How are those standards operationalized (e.g., do they show up in employee job descriptions)?
 - If not, why do you think this might be the case?

Topic 2: Who is involved

7. Who do you think plays a role in ensuring children are provided with opportunities to participate in decision-making regarding their care at [organization]?
 - What is the role of health care professionals?
 - What is the role of policy makers/managers? (e.g., how is your role related to children's participation?)
 - What is the role of the [health care] institution?
8. Who sets/makes decisions regarding policies and guidelines on children's participation:
 - At [organization]?
 - In pediatric health care as a whole in the Netherlands?

Topic 3: Children's voices

9. Could you tell me about any ways (e.g., specific initiatives) that allow children to have a say in:
 - Their (health) care?
 - The development of policies/guidelines at [organization] (e.g., advisory councils)
 - What is the role of children's caregivers in such initiatives?

10. Do you think that children and families are aware of [aforementioned] initiatives, policies and guidelines related to children's participation at [organization]?

Topic 4: Recommendations for change/improvement

11. What changes do you think would be helpful in your organization regarding children's participation?

12. Is there anything that you believe you or [organization] needs to:

- Stop doing?
- Start doing?
- Continue doing?

13. Is there anything else that you would like to share with me?

Dutch:

Interview Vragenlijst

Onderwerp 1: Wat is de betekenis van kinderpaticipatie en waar komt het voor in het ziekenhuis?

1. Zou u mij meer kunnen vertellen over uw functie/rol in het ziekenhuis?
2. Wat betekent kinderpaticipatie voor u in de algemene zin en binnen het kader van het ziekenhuis?
 - - Wat voor beleid, richtlijnen of initiatieven bestaan er in het ziekenhuis die volgens u de participatie van kinderen ondersteunen?
 - - Wat voor uitdaging(en) ervaart u in het ondersteunen van kinderpaticipatie vanuit het perspectief van beleid/institutionele richtlijnen?
3. Zou u mij kunnen vertellen over kwaliteitsstandaarden en/of accreditatie binnen het ziekenhuis?
 - - Wanneer werden deze ingevoerd?
 - - Hoe en door wie werden deze standaarden ontwikkeld?
 - - Hoe worden deze standaarden ingevoerd in de zorg? (e.g., Staan ze in de beroepsomschrijvingen van medewerkers?)

Onderwerp 2: Wie speelt een rol in de participatie van kinderen in de zorg?

4. Wie speelt er volgens u een rol in het bieden van kansen aan kinderen om deel te nemen in keuzes maken?
 - - Wat is de rol van medewerkers?
 - - Wat is de rol van beleidsmakers/leidinggevenden?
 - - Wat is de rol van het ziekenhuis zelf?
5. Wie is er verantwoordelijk voor het ontwikkelen van beleid en richtlijnen die te maken hebben met kinderpaticipatie?
 - - In het ziekenhuis?
 - - In de algehele ziekenhuiszorg in Nederland?

Onderwerp 3: De stem van het kind

6. Zou u mij kunnen vertellen over manieren waarop kinderen iets te zeggen hebben over:
 - - Hun zorg
 - - De ontwikkeling van beleid/richtlijnen?
 - - Wat is de rol van ouders in zulke instanties?
7. Gelooft u dat kinderen en families zich bewust zijn van beleid, richtlijnen en andere initiatieven die zich richten op kinderpaticipatie in het ziekenhuis?

- Hoe worden kinderen/families hiervan op de hoogte gemaakt? ***Onderwerp 4: Aanbevelingen voor de praktijk***

8. Welke veranderingen denkt u dat behulpzaam zouden zijn in het ziekenhuis omtrent het thema kinderpaticipatie?
9. Is er iets wat het ziekenhuis volgens u:
 - - Mee zou moeten beginnen?
 - - Mee zou moeten stoppen?
 - - Mee zou door moeten gaan?

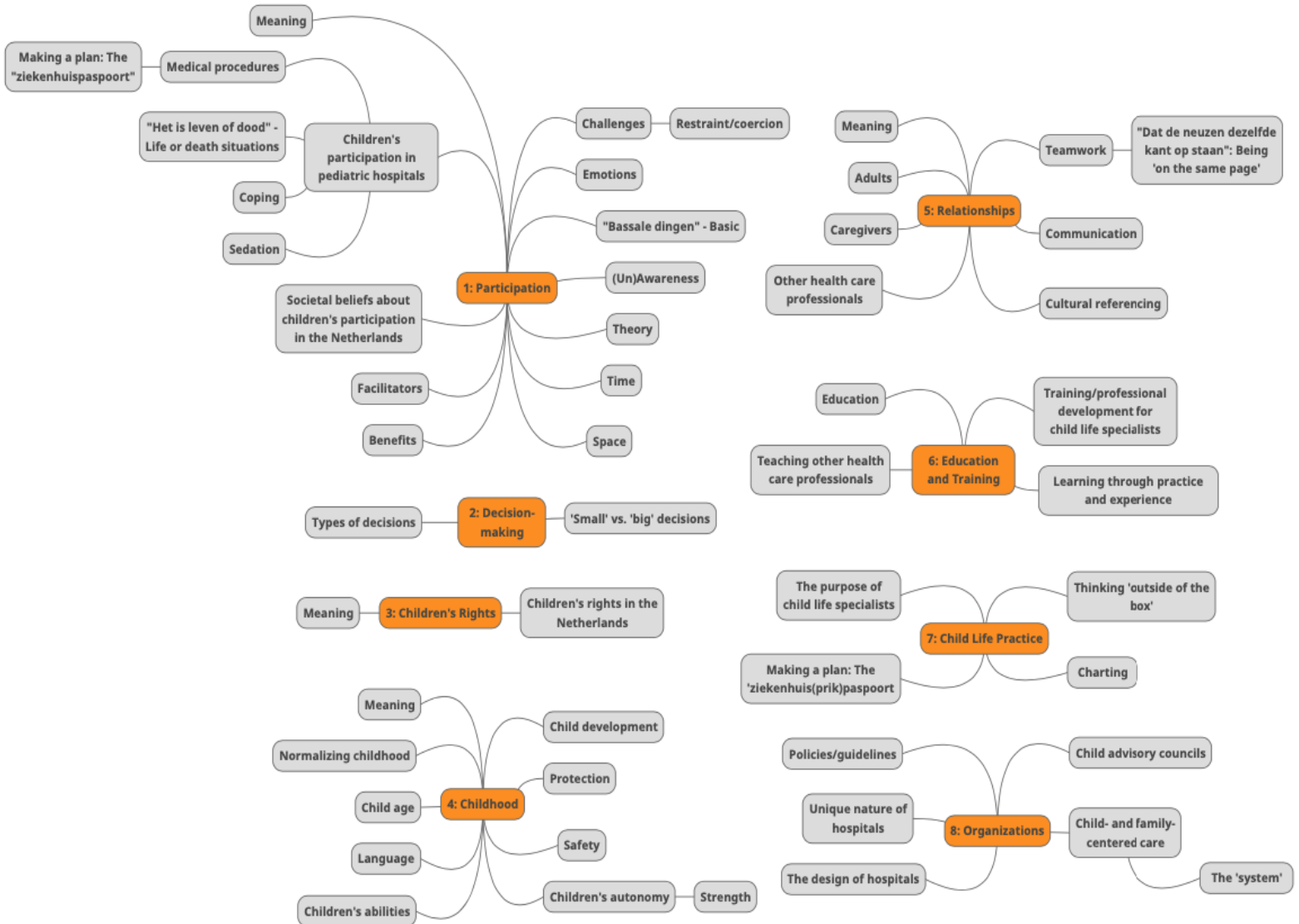
10. Is er nog iets wat u met mij zou willen delen?

Appendix H: Overview of Documents Included for Analysis

	Document Title	Author	Type	Digital/hard copy	Description
1.	'Emma goes to hospital' (Emma naar het ziekenhuis)	Emma Children's Hospital (Kinderziekenhuis AMC) (n.d.)	Booklet	Hard copy	Child-centred picture book aimed to help children prepare for hospitalization
2.	'Hospital passport' (Ziekenhuispaspoort)	Emma Children's Hospital (Kinderziekenhuis AMC) (n.d.)	Booklet	Digital	Document with pictures aimed to help children prepare for medical procedures by outlining their likes/dislikes/preferences, written in child-centred language
3.	Child- and family-centered criteria from the perspectives of children and families (Kind- en gezinsgerichte criteria vanuit het perspectief van kind en gezin)	Child & Hospital Foundation (Stichting Kind & Ziekenhuis) (2020)	Booklet	Digital	Document describes mission, pillars and themes of the organization's definition of 'optimal' child- and family-centered care.
4.	Experience monitor: A unique tool to elicit stories about the experiences of children, youth and parents (Ervaringsmonitor ©: Unieke tool voor het ophalen van ervaringsverhalen van kinderen, jongeren en ouders)	Child & Hospital Foundation (Stichting Kind & Ziekenhuis) (2020)	Booklet	Digital	Document reports on the goal, value and function of a PREM (patient reported experience measure) in pediatric health care titled the 'experience monitor'.
5.	'3 good questions' (3 goede vragen)	Child & Hospital Foundation (Stichting Kind & Ziekenhuis) and NVK (Nederlandse Vereniging van Kindergeneeskunde) (Dutch Association for Pediatric Health Care) (n.d.)	Poster	Digital	Poster displayed on a hospital unit encouraging children to ask '3 good questions' when visiting a doctor.
6.	'My rights as a sick child' (Mijn rechten als ziek kind)	Child & Hospital Foundation (Stichting Kind & Ziekenhuis) (2020)	Webpage	Digital	Webpage outlining children's rights in health care settings according to their age (<12 years, 12 – 15 years, >16 years).

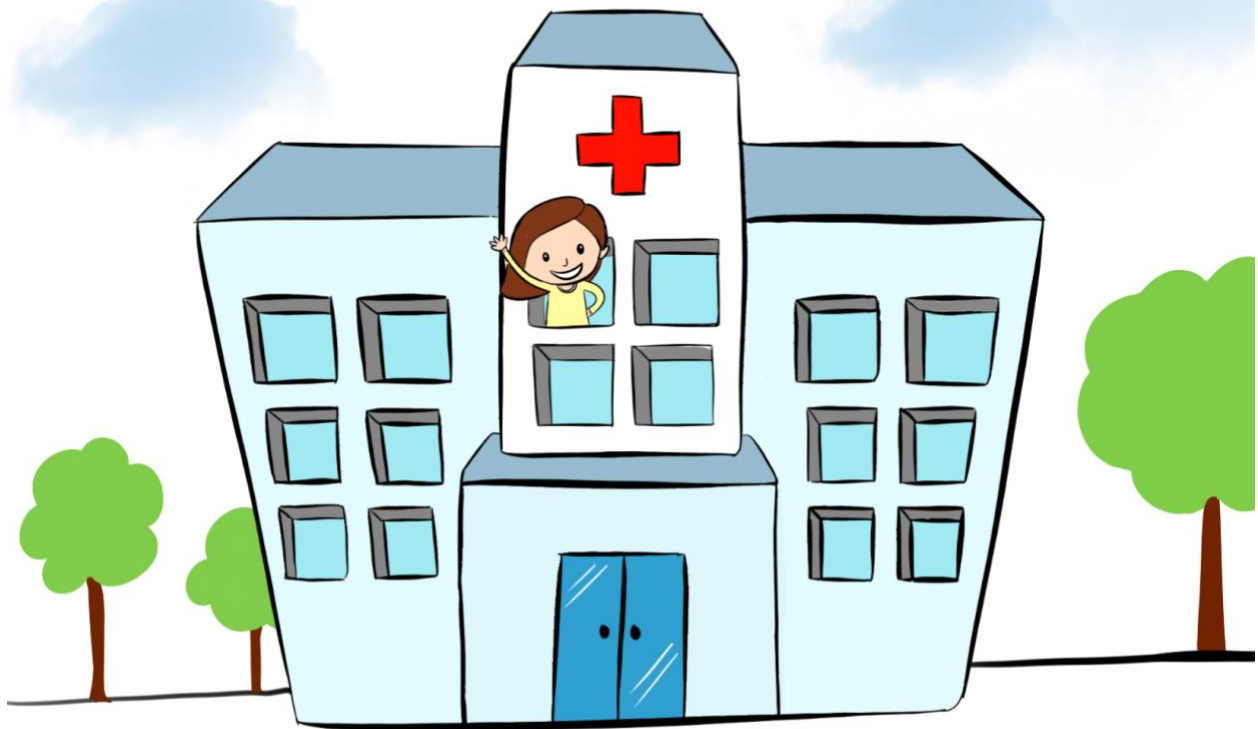
7.	Charter Child & Hospital (Handvest Kind & Ziekenhuis)	Child & Hospital Foundation (Stichting Kind & Ziekenhuis) (n.d.)	Booklet	Digital	Charter outlining children's rights in order to 'represent children's voice and therefore children's rights' including adult- and child-version
8.	Patient manifest – children (Patiëntmanifest – kinderen)	AMC Hospital (AMC) (n.d.)	Pamphlet	Hard copy	Document describing what children can expect with regards to: 1) the ER, 2) outpatient clinics, 3) medical procedures, 4) hospitalization and 5) discharge.
9.	Youth participation – 25 rules of thumb (Jeugdparticipatie – 25 vuistregels)	Alexander Foundation (Stichting Alexander) (2019)	Booklet	Hard copy	Booklet intended to shed light on the meaning and importance of youth participation in the Netherlands. Children and/or young people provided input into information contained in booklet.
10.	What are my rights and duties during a medical procedure? (Wat zijn mijn rechten en plichten bij een medische behandeling?)	Dutch Government (Nederlandse Rijksoverheid) (n.d.)	Webpage	Digital	Overview of legal rights and duties of individuals undergoing medical procedures in the Netherlands.
11.	Patient federation the Netherlands (Patiëntenfederatie Nederland)	Children, their parents and patient rights (Kinderen, hun ouders en patiëntenrechten) (n.d.)	Webpage	Digital	Overview of rights of children and caregivers categorized by age and including special attention devoted to rights in hospital settings.
12.	When your child cannot decide on their own (Als je kind niet zelf kan beslissen)	Schouders (ervaringskenniscentrum zorgkinderen), Handicap NL, and Emma Children's Hospital (Emma kindziekenhuis) (2019)	Booklet	Digital	Booklet written for parents, who have a child with an intellectual or complex disability, who are faced with making a medical decision(s) on behalf of their child.
13.	The rights of minors (Rechten minderjarigen)	Royal Dutch Medical Association (KNMG Artsenfederatie) (n.d.)	Webpage	Digital	Webpage outlining the rights of minors in the context of health care.
14.	Consent and information during treatment of minors (Toestemming en informatie bij behandeling van minderjarigen)	Royal Dutch Medical Association (KNMG Artsenfederatie) (2019)	Booklet	Digital	Booklet describing processes related to children's consent to medical treatment in the Netherlands.

Appendix I: 'Mind map' Depicting Main Themes and Sub-themes



Charlie Makes Choices

A Storybook about Decision-Making in Hospitals



Written and illustrated by
Amarens Matthiesen, MA, CCLS

A note from the author

A child's illness and hospitalization can be challenging, stressful and unpredictable for children and families. When children are hospitalized, they may feel fearful, apprehensive and confused about medical procedures and hospital routines over which children typically have little control.

This book is for children, parents and health care providers to explore the topic of decision-making in health care settings to help gain insight into what decision-making may look like for children and families in hospitals.

Children's decision-making is important because children's involvements in making decisions (big or small) can help children feel more confident and in control over their health care experience(s) in an often unfamiliar and unsettling environment.

© Amarens Matthiesen, 2022

Hi! I'm Charlie.
I will be staying at the hospital for 5 nights.
Let me show you around the hospital!



In the hospital, there are lots of things to see and do. You may see lots of doctors, nurses and other people around.

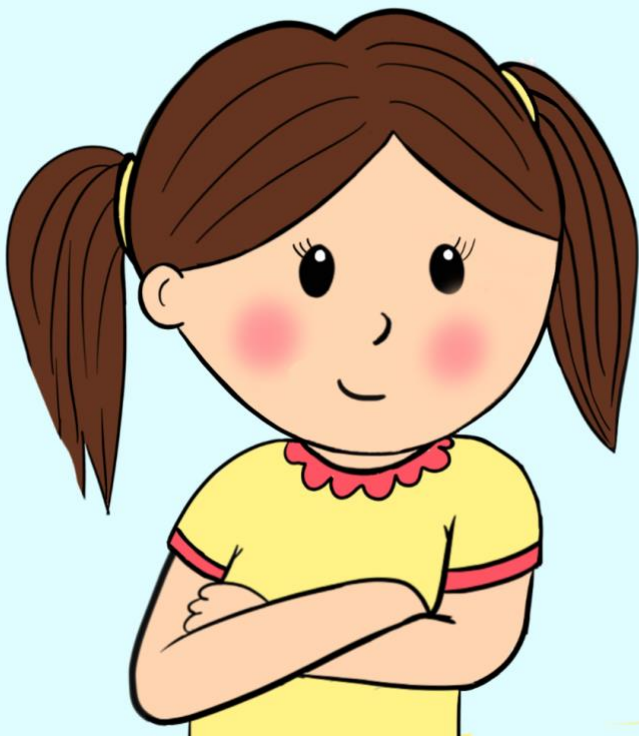
This is a hospital room. Can you see my friend, Thomas, and his doctor?



There may also be different places that you can go, like places to eat, a classroom, and even a playroom!



When I'm in the hospital, I talk to many different people who may ask me to do things like take my medicine and talk about how I am feeling.



These things are important because they help me feel better.

Sometimes, I can also make my own choices like:

What I want for breakfast

What I want to wear

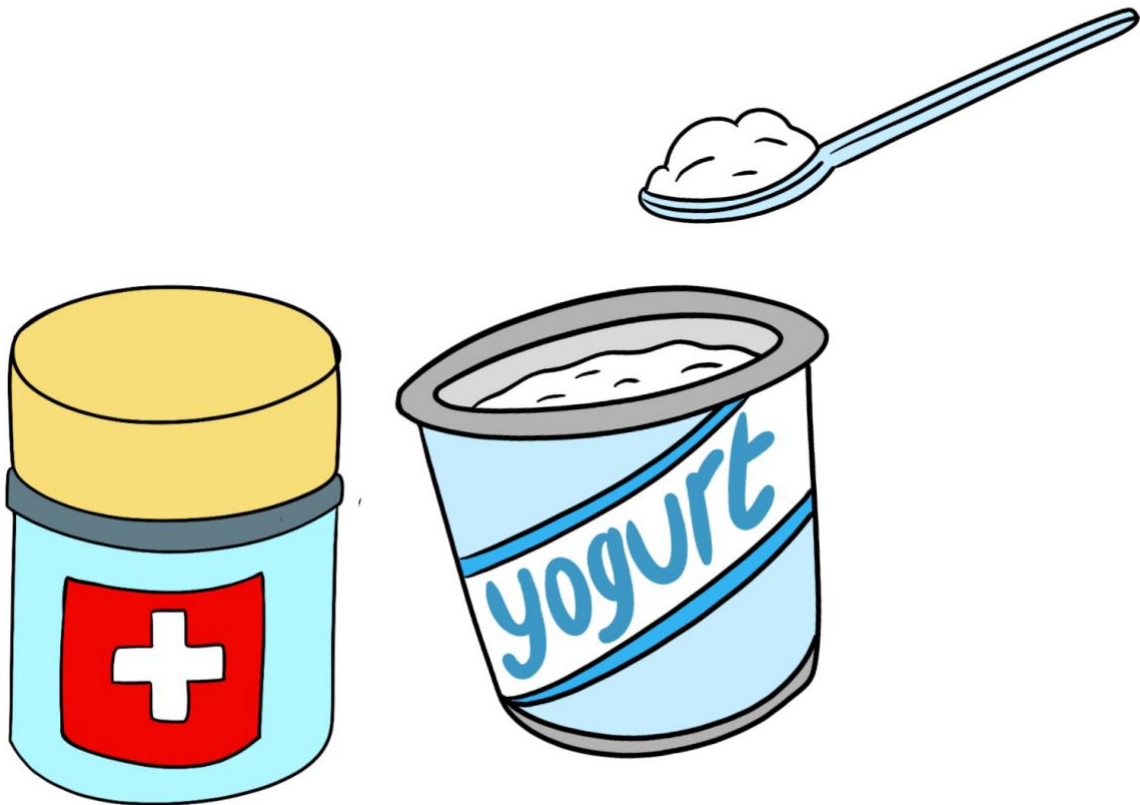


Sometimes, I also need to do things that are not so fun like getting a small poke in my arm.



But I still get to choose which arm the nurse uses, if I sit on mom's lap or not, or if we count to 3 or 5.

I also get to choose if I want to take my medicine with apple sauce or yoghurt!



Sometimes, when I lay in my bed before I go to sleep, I wonder about things like:

When will I go home?

Why do I need this medicine?

When will I see my friends?



When this happens, I write down the things
I am wondering about on a piece of paper
(or ask my parent to help me).



When I wake up the next morning, I can ask my doctor or nurse all my questions!



Sometimes, telling people what I want or don't want can be hard.

That is when I can always ask my parent for help.



Telling people what I am
thinking and feeling is
important and can help me
feel more comfortable!



Now, I get to go home. But before I go,
I would like to hear about you!

Can you answer the questions on the next page?



What is a choice that you made today?



What is something that you are wondering about?

