The experience of hope among parents of children with Neurodisabilities

Sacha Nicole Bailey

School of Social Work

McGill University, Montreal

January 2018

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Doctor of Philosophy

Table of Contents

List of Figures

List of Tables

List of Abbreviations

ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
CGT	Constructivist grounded theory
DD	Developmental Delay
GT	Grounded Theory (methodology)
HCP	Health Care Provider
ID	Intellectual Disability
ND	Neurodisability
MR	Mental Retardation
SI	Symbolic Interactionism

Dedication

This dissertation is dedicated to the eleven mothers and fathers who generously shared their time and their hopes with me. And to all the parents who have and continue to inspire me to do this work.

> "The light shines in the darkness, and the darkness has not overcome it." (John 1:5 ESV)

Acknowledgements

What a privilege and honor it is to be given the time and resources to collaborate, read, contemplate, interpret, and write! Although the doctoral journey can feel solitary at times, the truth is that many people contributed to this work and supported me in many ways. I can only attempt to thank them all. This dissertation would not have been possible without financial support from a number of sources: the McGill School of Social Work, the Fonds de Recherche du Québec - Société et Culture, the Centre for Research on Children and Families, and the Wolfe Chair in Scientific and Technological Literacy at McGill University.

I am so grateful to the many people who helped make this accomplishment a possibility. First, my mentor and doctoral supervisor, Lucy Lach. Lucy, I still remember sitting in your office during my MSW when you suggested I apply to the doctoral program. The thought had never crossed my mind. Your belief in me and your mentorship have carried me through all these years. Thank you for the countless opportunities to learn and grow. I can only hope to be a "Lucy" to someone else at some point in my career. To my doctoral committee members, Nicole Ives and David Nicholas, thank you for sticking with me all these years, for your supportive and thoughtful feedback, and even for your nit-picky edits. Nicole, thank you for inspiring in me a passion for qualitative research way back in that qualitative methods course. And for offering such a wonderful example of how faith and science can cohabitate.

I have had the immense privilege of being part of a vibrant community of great minds and big hearts at the Centre for Research on Children and Families. This group of students, trainees, faculty, and staff have always celebrated accomplishments and been there during times of struggle. I have benefitted from the mentorship and insights of those just ahead of me, and have had opportunities to support others in their learning. I am extremely grateful for the friendships and professional relationships I have developed during my time at CRCF. I am especially indebted to my two office-mates of many years who have accompanied me through many life transitions. I can't thank you enough for your friendship and deep love over the years. No "womb" will ever be the same without you. The School of Social Work at McGill has provided fertile ground for more learning in the last decade of my life than I ever imaged when I first walked through the doors of Wilson Hall. Thank you to the faculty, staff, and students who create a space for learning that is stimulating and supportive. Thank you especially to the faculty who have inspired me with their teaching, their research, and their passion for social work practice over the years. Thank you to the

faculty and students who make up the McGill Qualitative Health Research Group for your invaluable and constructive methodological feedback from the inception of this project to its completion.

To my cheerleaders near and far, my family and friends, thank you for knowing when the right time to ask "how the PhD is going", for rooting for me, and believing in me. To my peers in this doctoral journey, who have completed or are still running the marathon, I can't think of better people to have stumbled through this wilderness with.

I would like to acknowledge the work of the late Dr. Beverly Antle, who is said by her colleagues to have left a "legacy of hope" within the profession of social work. Her work inspired me as a master's student to pursue doctoral studies dedicated to the topic of hope. And, thank you, Lucy, for introducing me to her work.

And most importantly, to my loves, Eleanor and James. My little Peach, may you always have hope and know where to find it when yours is hard to find. Thank you for your silliness, your cuddles, and your amazing ability to warm my heart and bring me back to the present no matter how hard life gets. James, thank you for taking on more of everything so that I could have the space I needed to get this done. Here's to life beyond the PhD!

Abstract

The phenomenon of parenting children with Neurodisabilities (ND) has been widely researched, resulting in a spectrum of representations in both the scholarly literature and mainstream media. There has been a historic trend in the childhood disability literature to focus on the negative effects of caring for a person with extraordinary needs on the family. Another trend is one led by self-advocacy groups and researchers on positive aspects of parenting, and that calls for the examination of parenting from a more nuanced perspective. This shifting paradigm is highlighted in the examination, for example, of parenting a child with ND through the lens of "parental hope". This dissertation presents key frameworks used to understand and study parenting and hope and offers a critical discussion of their applicability to families of children with ND. This will set the stage for the main dissertation study – a qualitative constructivist grounded theory (CGT) study that situates hope for their child with ND as an aspect of the parenting experience.

The main goal of this study is to gain a meaningful understanding of parental hope experiences in order to develop a theory of the process of hope in relation to parenting a child with ND. The specific objectives are to 1) identify key elements and processes of hope; and 2) develop a conceptual understanding of the experience of hope for parents of children with ND. The secondary objective of this dissertation addresses the lack of reporting on methodological elements in published qualitative manuscripts. More specifically, the objectives are to offer a scholarly exemplar of applying CGT by: 1) demonstrating an in-depth understanding of the CGT methodological approach; 2) examining researcher reflexivity through a consideration of the impact of clinical experiences, personal values, interactions with participants, and the influence of audiences on the research process; and 3) presenting examples of decision making from a reflexive stance throughout the research process.

This manuscript-based dissertation includes two manuscripts in preparation for publication. The first offers a unique accounting through three aspects of taking up researcher reflexivity in the context of this dissertation research. The sections Knowing, Reflexing, and Doing each offer an elucidation of a novice researcher taking up a new-to-her approach to research by learning about the approach, exercising reflexivity, and conducting a study. The purpose of this paper is to generate discussion about what gets left out of published manuscripts, and to make explicit the methodological "gold nuggets" of research. The second presents the substantive theory, "Seeking

light at the end of the tunnel", generated by this empirical study, representing the accounts of eleven mothers and fathers of children aged 4 to 12 with a ND. This theory characterizes the process of seeking and maintaining hope amidst contextual constraints at multiple levels of influence. These distractors to hoping, operating at individual, family, social, and societal levels, serve as barriers to parental hope in the context of parenting children with ND. In order to maintain hope, parents draw on both personal and communal sources symbolizing the kindling to the fire of their hope, and employ strategies, some of which are innate, others which are mastered over time. Consequently to seeking light at the end of the tunnel, and in response to distractors, parents adjust the focus of their hopes - or find a new normal - and evolve and become different individuals and parents. Part of this evolution involves becoming a hope ambassador – sharing hope with others, and educating their communities about why hope matters.

A consideration of the contributions this thesis makes to the scholarship on childhood disability, parenting, and hope; recommendations for practice, policy, and social work education; and directions for future research are offered in the final chapter.

Résumé

Le phénomène du parentage des enfants atteints de troubles neurodéveloppementaux (TD) a fait l'objet de nombreuses recherches donnant lieu à un large éventail de représentations, dans la littérature savante et les médias grand public. En ce qui a trait à la littérature sur les déficiences chez l'enfant, on constate une tendance historique à mettre l'accent sur les répercussions négatives pour la famille des soins offerts à une personne ayant des besoins hors du commun. L'autre tendance, est l'accent mis par les groupes de défense des droits et les chercheurs sur les aspects positifs du parentage et l'invitation à examiner ce phénomène de façon plus nuancée. Ce changement de paradigme est mis en évidence notamment dans l'étude du parentage des enfants atteints de TD à travers le prisme de « l'espoir parental ». La présente thèse expose les principaux cadres utilisés pour comprendre et étudier le parentage et l'espoir, et comprend une analyse critique de leur applicabilité aux familles d'enfants atteints de TD. Ceci établira le cadre du mémoire principal — une étude qualitative axée sur l'approche constructiviste de la théorie ancrée (ACTA) — qui situe l'espoir entourant l'enfant atteint de TD comme un aspect de l'expérience de parentage.

L'objectif principal de cette étude est de bien comprendre les expériences d'espoir parental afin d'élaborer une théorie du processus de l'espoir en lien avec le parentage d'un enfant atteint de TD. Les objectifs spécifiques sont les suivants : 1) déterminer les principaux éléments et processus d'espoir; 2) développer une compréhension conceptuelle de l'expérience d'espoir des parents d'enfants atteints de TD. L'objectif secondaire de la thèse cible l'absence de présentation des éléments méthodologiques dans les manuscrits qualitatifs publiés. Plus précisément, les objectifs sont d'offrir un modèle scientifique d'application de l'ACTA : 1) en démontrant une compréhension approfondie de l'approche méthodologique de ladite théorie; 2) en examinant la réflexivité des chercheurs en tenant compte de l'impact des expériences cliniques, des valeurs personnelles, des interactions avec les participants, et de l'influence des différents publics sur le processus de recherche; 3) en présentant des exemples de prise de décision qui adoptent une position réflexive tout au long du processus de recherche.

Cette thèse basée sur des manuscrits inclut deux manuscrits en préparation de publication. Le premier présente trois aspects de l'intégration de la réflexivité du chercheur dans le cadre de la recherche. Les sections Connaître, Réfléchir et Agir offrent chacune une explication de la démarche d'un chercheur novice adoptant une nouvelle méthodologie de recherche en s'informant sur l'approche, en faisant preuve de réflexivité et en menant une étude. La thèse a pour but de susciter

une discussion sur ce qui est omis dans les manuscrits publiés et d'expliciter le « travail fastidieux » de la recherche. La deuxième présente la théorie substantielle, « la recherche de la lumière au bout du tunnel », généré par cette étude empirique, représentant les récits relatant l'expérience de onze parents d'enfants âgés de 4 à 12 ans atteints de TD. Cette théorie caractérise le processus de recherche et de maintien de l'espoir parmi les contraintes contextuelles à de multiples niveaux d'influence. Ces facteurs de distraction agissant aux niveaux individuel, familial, social, et sociétal, constituent des obstacles à l'espoir parental dans le cadre du parentage de l'enfant atteint de TD. Pour entretenir l'espoir, les parents doivent puiser à la fois dans les sources personnelles et communautaires — symbolisant l'oxygène qui attise la flamme de l'espoir — et utiliser des stratégies, dont certaines sont innées, d'autres maîtrisées au fil du temps. Lorsqu'ils cherchent la lumière au bout du tunnel, en réaction aux facteurs de distraction, les parents recentrent leurs espoirs — ou trouvent une nouvelle normalité —; ils évoluent et deviennent des individus et des parents différents. Une partie de cette évolution consiste à devenir un ambassadeur de l'espoir - à le transmettre aux autres et à éduquer la communauté quant aux raisons de son importance.

Enfin, le dernier chapitre examine les contributions de cette thèse à la recherche sur les déficiences des enfants, le rôle parental, et l'espoir. Il comprend des recommandations pour la pratique, les politiques, et l'enseignement en travail social, ainsi que des orientations pour la recherche future.

Preface and Contributions of Authors

I, Sacha Bailey, am the primary author of the chapters composing this thesis. I was the principal investigator for the study whose findings are presented here. I conceptualized the study, collected and analyzed the data, and interpreted and wrote the findings. The co-authors of the two manuscripts are members of my dissertation committee, Drs. Lucyna Lach, Nicole Ives, and David Nicholas. These authors provided methodological oversight and substantive expertise at the study proposal stage and throughout data collection and analysis. They also read various draft iterations of the entire dissertation and suggested revisions and edits.

The thesis study sample was recruited from a database of participants who completed the first part of a mixed method study, the Parenting Matters! clinical study. This study is part of a program of research entitled, *the CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada.* I served in the capacity of research coordinator for the Parenting Matters! program of research through my involvement with the Centre for Research on Children and Families at McGill University.

The material presented in this thesis has not been published elsewhere, except where specifically indicated, and is therefore considered original scholarship. The first manuscript entitled, Knowing, reflexing, and doing: Using CGT to study hope among parents of children with ND is currently being prepared to be submitted to one of two journals, Qualitative Health Research or Qualitative Social Work. The second mansucript, The light at the end of the tunnel: Experiences of seeking and maintaining hope among parents of children with ND, has been prepared for submission to one of the following journals: Qualitative Health Research, Child: Care, Health and Development, or Disability and Rehabilitation. The distinct contributions to knowledge are expounded in Chapter Six.

Chapter 1: Introduction

It was a statement made by a parent during a student placement that set this journey in motion: “there needs to be more hope in the system”. In the moment, this utterance came with frustration, anger, resentment, and sadness. This parent felt let down by a system she had thought would support her in her most challenging season of life to that point. After much advocacy and persistence, her child had been given a diagnosis of Autism. She assumed that following this diagnosis, he would be provided with the interventions he required to allow him to reach his potential. She quickly found out that this diagnosis was not the golden ticket to accessing services she expected it to be. She promptly found herself colliding with a series of barriers to the services she and her child desperately needed. Add to that an awareness that has trickled down from scientific findings into common knowledge, that early intervention is best for children like hers, it became a race against time to obtain the needed supports. As a neophyte social work intern, I sincerely wanted to comprehend what this parent had experienced that lead her to make such a comment, what it reflected about a system I was about to become part of, and how I might be able to help bring about change. Since that day, countless conversations and encounters have led me to the conclusion that hope is a critically important construct to understand for anyone in the position of supporting families of children who experience illness and disability.

The experience of parenting a child with a disability, much like the experience of parenting any child, is complex and idiosyncratic. For many decades, social scientists have sought to define and understand “parenting”. There are many models and frameworks seeking to characterize the determinants and outcomes of parenting. These theoretical understandings are continuously evolving as further empirical study lends support for some elements and disputes others. As a social work scholar interested in the study of parenting, it is essential to take a critical look at who is represented in empirical scholarship on parenting and to question whether the makeup of study samples reflects the diversity we see in modern-day families. Perhaps our theories of parenting are characteristic of some families, but not others. For instance, empirical research on parenting has historically left out the voices of fathers (Bogossian et al., 2017), caregivers of children with disabilities, and the most marginalized families in our society – those living in poverty, those of ethno-culturally diverse backgrounds (Ha, Greenberg, & Seltzer, 2011; Khanlou, Haque, Davidson, & Dastjerdi, 2016), First Nations families (Banks & Miller, 2005), and parents who themselves live with mental, physical, or developmental disabilities (Hassall, Rose, & McDonald, 2005). We must appreciate that our "conventional" wisdom about parenting is likely value-laden based on common representations, the particular community of scholars who built the scholarly body of knowledge on parenting, and our ideas about "good enough" mothering/parenting (Winnicott, 1958). This "science" of parenting borrows from the experience of some parents, but may very well exist outside the experiences of others. It would be unfair to judge or attempt to understand the lived experience of a subset of families, such as those parenting children with disabilities, based on biased and limited understandings of the breadth of the parenting experience.

The history of the ways in which parents of children with disabilities have been studied and represented is one that is marked by assumptions about the causes of disability. The damaging notion of the refrigerator mother causing Autism, for example, is one that took many decades to reverse (Farrugia, 2009). The idea that children born with impairments are cursed or a bad omen, leading to the abandonment, neglect, or isolation of some children is still evident in some non-Western cultures (Saetermoe, Scattone, & Kim, 2001). Other assumptions that appear in more contemporary clinical and empirical representations of these caregivers reflect ideas about family structure and parenting roles – the disengaged father who is absent during clinic visits or school meetings, the overinvolved or overprotective mother who hovers over her child, wanting to prevent injury or distress. Of course, there is great diversity in how disability is understood and experienced by families, reflective of personal and cultural values, constructions of disability, the particular ways in which the disability is manifested, and the related demands placed on family members. By and large, the spectrum of experiences is covered, although perhaps to an exaggerated extent, in both popular representations and in scholarly writing about the family experience of disability. More and more, TV shows, films, fiction and non-fiction novels, blogs, TED talks, and news stories include story lines, characters, and current events reflective of those with disabilities. Messages reflecting disability as tragedy clash with those illustrating disability as difference, or as cause for celebration. These divergent depictions reflect the reality that there is no one disability experience and attempts to oversimplify it will result in a loss of appreciation of the nuance.

It is incumbent upon childhood disability scholars, then, to consider how we situate parenting within a scholarship that has emerged from a context of assuming that all parenting is comparable, and which reflects a particular subset of families. We must appreciate the socio-cultural changes that have developed since the majority of early parenting scholars published their work.

Understandings of disability and of family have evolved and yet we often draw on conventional ideas as the foundations for our empirical work. This thesis will expound foundational understandings of parenting that form the basis of scholarship in the area in order to situate parental hope for their child as an aspect of "parenting as experienced" and "parenting as enacted"[1] (Bailey, Lach, & Byford-Richardson, 2012). These frameworks will then be critiqued from a childhood disability perspective and a discussion of their applicability to this population is offered.

In this dissertation, the subject of parenting intersects with that of hope in order to understand what comments such as the one presented at the start of this chapter connote. Going back to the Greek myth of Pandora's box (Hesiod, 2017), philosophers, poets, theologians, and writers have debated whether hope is inherently good or bad. When Pandora released all the blessings and curses into the world, but hope remained, we were left to interpret the meaning. Is hope being preserved because it is precious? Or, is hope being kept from us because it is evil? More recently, thanks to the positive psychology movement, psychologists have come to appreciate the importance of hope and other related aspects of resilience to key developmental outcomes of interest (Seligman, 2002). Hope has come to be known as a positive resource for individuals facing hardship.

Search for hope and you will find it. Browse any news site these days and amidst the many disheartening stories that often dominate the news cycle, you will come across stories of persistence, of medical miracles, of communities rallying for a cause. Like the one from November 14, 2017, entitled, "Surgeons repair spina bifida in fetus for 1st time in Canada, hospitals say" (Ireland, 2017). This article reports on a successfully performed pioneer in-utero surgery to repair a form of spina bifia on a fetus at 25 weeks gestation. The baby was born a few months later and a few months after that, the baby's parents spoke to a reporter about how hopeful they were about her future: "all of our prayers were answered. She's our little miracle" (Ireland, 2017). Stories like this offer hope to others whose children have been impacted by conditions that limit their capacity to fully participate in daily life activities, or which cause them to be reliant on life sustaining medications or medical equipment. Stories like these can incite others to think – if a miracle can happen for this family, why not mine? If you were to turn to blogs or biographies written by parents of children with disabilities, you would find that many of them reference hope. In her book, *The little dark spot: How I came to terms*

---

[1] See Chapter 2 for a definition of these terms.

with my baby's stroke, Helene Louise talks about the process of finding reasons to persevere in helping her daughter overcome the effects of her stroke (Louise, 2013). For her, finding examples of reasons to believe that good things are possible helped her to be hopeful about her daughter's future, which inspired her to keep looking for more reasons to hope. She likens this process to collecting fireflies – locating little flickers of hope, one at a time, and putting them in a jar. Perhaps this collection of littles hopes serves as a reminder in challenging times that there is always reason to hope.

Although most everyone can speak to the importance and meaning of hope in their lives, it is a tricky concept to define. Some definitions of hope describe it as a cognitive exercise, some appreciate that hoping is an affective experience as well as cerebral one. Others account for spirituality or faith-based beliefs that can form the foundation of one's hope. This dissertation will introduce the key frameworks used to understand and study hope and will offer a critical discussion of their applicability to families of children with disabilities. This will set the stage for the main dissertation study – a qualitative CGT study of the experience of hope among parents of children with ND. Although a particular definition of hope is not specifically drawn on throughout this study, the following definition, espoused by Groopman in his book, *The Anatomy of Hope*, offers a wide-ranging and pragmatic delineation of hope that seems most applicable to the experience of the participants in this study: "Hope is the elevating feeling we experience when we see – in the mind's eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion" (Groopman, 2004, p. xiv).

Research Problem and Significance

This dissertation addresses two key problems: 1) the lack of a meaningful understanding of the how hope is experienced by parents of children with ND in the current childhood disability and parenting scholarship; and 2) the dearth of reporting on the usage of researcher reflexivity in qualitative research. The first problem reflects concerns noted above about the limitations of applying generic parenting and hope theories to specific populations with which the theories were not developed or validated. By developing a grounded theory of parental hope for their child with a ND, this study generates a practical and useful framework from which to study hope among this population. A theory grounded in the experiences of individuals to whom it will be later applied is useful for future empirical study and for clinical practice, as will be discussed in the sixth chapter on the implications of the study findings.

The second problem addressed in this dissertation is that of the lack of reporting on methodological elements in published qualitative manuscripts. Specifically, empirical studies whose findings are published in peer reviewed journals are often limited in the amount of depth and detail provided about methodological decisions and processes. This is partly because of space limitations enforced by journals, but may also reflect a lack of methodological clarity in the scholarly community. A recent review of Canadian doctoral dissertations using GT published between 2001 and 2011 found that some key elements of GT were applied incorrectly or not at all (e.g., theoretical and data saturation, transparency/detailed description of the research process, and aspects of rigour) (Braganza, Akesson, & Rothwell, 2017). The authors of this review found that half of the dissertations' authors did not engage in a discussion of researcher reflexivity or offer a thoughtful examination of how their biases may have influenced the research process (Braganza et al., 2017). Many of the dissertations reviewed were categorized as using a CGT approach. This version of GT emphasizes the notion that meaning is socially constructed. As a result, the researcher's self is inherently imbedded in the interpretation and presentation of research findings. It follows that any empirical rendering drawing from CGT should include some level of discussion of researcher reflexivity. This is significant when we consider the importance of evaluating quality in qualitative research. These concerns are addressed in this dissertation by way of a manuscript that illustrates by example the usage of researcher reflexivity throughout the application of CGT to the study of hope among parents of children with disabilities.

Research Aims

The main goal of this study was to gain a meaningful understanding of parental hope experiences in order to develop a theory of the process of hope in relation to parenting a child with ND. In order to address the gaps in the literature relating to the experiences of hope for parents who care for a child with ND, the specific objectives of this project were to 1) identify key elements and processes of hope in mothers and fathers of children with ND; and 2) develop a conceptual understanding of the experience of hope for mothers and fathers of children with ND. The secondary objective of this dissertation was to offer a scholarly exemplar of applying CGT to a study about hope among parents of children with ND by: 1) demonstrating an in-depth understanding of the CGT methodological approach; 2) examining researcher reflexivity through a consideration of the impact of clinical experiences, personal values, interactions with participants, and the influence of audiences on the research process; and 3) presenting examples of decision making from a reflexive stance throughout the research process.

Organization of the Thesis

This manuscript-based dissertation is composed of six chapters, including two manuscripts in preparation for publication. Chapter 1, the Introduction, presents an introduction to the thesis topic, describes the research problem and its significance, sets forth the objectives of the research, and outlines the dissertation. Chapter 2, the Background, sets the study in the context of the theoretical scholarship on parenting and hope. In this chapter I present a brief history of the conceptualization and study of parenting, key theoretical models of parenting which guide empirical research in the area, and address key critiques of these frameworks including their applicability to the study of parenting and more specifically hope among children with ND. Thus, studies of hope are situation in the context of studies regarding parenting. I also present key theoretical frameworks informing research in the area of hope and critique these theories from the perspective of their utility in the study of hope among parents of children with ND.

Chapter 3, the Methods, presents the guiding paradigms informing this empirical work, including Symbolic Interactionism, Constructivism, and Pragmatism. This chapter also outlines methodological procedures undertaken in this study, including ethical considerations, sampling, data analysis, and integration of the scholarly literature. Here I also provide an in-depth consideration of evaluating the quality of this qualitative study. Aspects of the methodology are presented in three places in this dissertation – the Methods Chapter (Ch. 3), Manuscript 1 (Ch. 4), and Manuscript 2 (Ch. 5). Manuscript 2 offers a traditional presentation of the study methods as one would expect in a published paper, including a rationale for the fit between social work and CGT. In order to fulfill the dissertation requirements, more detail is provided in the manuscript than would be included in a published manuscript. Manuscript 1 elucidates the roots of the GT approach and the emergence of the constructivist version as expounded by Charmaz, which is drawn upon in this study. The Methods chapter bridges aspects of the methodology not presented in either manuscript, but that are required to be included in a dissertation. I see the methodological robustness of this study as one of its strengths and hope that my interpretation of CGT and representation of the process in these methodological chapters will be useful to other grounded theorists.

Chapter 4 presents the first Manuscript, which offers a unique accounting through three aspects of taking up researcher reflexivity in the context of this dissertation research. The sections Knowing, Reflexing, and Doing each offer an elucidation of a novice researcher taking up a new-to-her approach to research by learning about the approach, exercising reflexivity, and conducting a study. The manuscript offers examples of decision-making through a reflexive lens, taking into consideration the role of a clinician-student-researcher, and acknowledging bias, naiveté, and areas of expertise. The purpose of this paper is to generate discussion about what gets left out of published manuscripts, and to make explicit the methodological "gold nuggets" of research. The hope is that collectively as a scholarly community we can generate more examples of candid renderings of the ways in which our personal values, clinical experiences and expertise, interactions with participants, and exchanges with audiences influence each aspect of the research process, both in CGT, and across the methodological spectrum.

Chapter 5 presents the second Manuscript, the empirical study on the experiences of hope among parents of children with ND conducted as part of this dissertation. This manuscript is structured as a standard qualitative published report and is in preparation for submission to a peer-reviewed journal.

Chapter 6 offers a consideration of the contributions this thesis makes to the scholarship on childhood disability, parenting, and hope; recommendations for practice, policy, and social work education; directions for future research; and concludes the dissertation.

References

Bailey, S. N., Lach, L. M., & Byford-Richardson, K. (2012). Interpersonal interactions and relationships (D710-D799). In A. Majnemer (Ed.), *Measures for children with developmental disabilities* (pp. 381-403). London: Mac Keith Press.

Banks, S., & Miller, D. (2005). Empowering Indigenous families who have children with disabilities: An innovative outreach model. *Disability Studies Quarterly, 25*(2).

Bogossian, A., King, G., Lach, L. M., Currie, M., Nicholas, D., McNeill, T., & Saini, M. (2017). (Unpacking) father involvement in the context of childhood neurodisability research: a scoping review. *Disability and Rehabilitation*, 1-15. doi:10.1080/09638288.2017.1370497

Braganza, M., Akesson, B., & Rothwell, D. (2017). An Empirical Appraisal of Canadian Doctoral Dissertations Using Grounded Theory: Implications for Social Work Research and Teaching. *Journal of Teaching in Social Work, 37*(5), 528-548. doi:10.1080/08841233.2017.1386259

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness, 31*(7), 1011-1027. doi:10.1111/j.1467-9566.2009.01174.x

Groopman, J. (2004). *The anatomy of hope: How people prevail in teh face of illness*. New York: Random House Inc.

Ha, J.-H., Greenberg, J. S., & Seltzer, M. M. (2011). Parenting a child with a disability: The role of social support for African American parents. *Families in society : the journal of contemporary human services, 92*(4), 405-411. doi:10.1606/1044-3894.4150

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418. doi:10.1111/j.1365-2788.2005.00673.x

Hesiod. (2017). *The Poems of Hesiod: Theogony, Works and Days, and The Shield of Herakles*: University of California Press.

Ireland, N. (2017). Surgeons repair spina bifida in fetur for 1st time in Canada. *CBC News*. Retrieved from http://www.cbc.ca/news/health/spina-bifida-repaired-in-utero-canada-1.4400782

Khanlou, N., Haque, N., Davidson, D., & Dastjerdi, M. (2016). *Voice of immigrant mothers of children with disabilities: Availability and use of social support*. Retrieved from Toronto, Ontario:

Louise, H. (2013). *The little dark spot: How I came to terms with my baby's stroke*. Montreal, Canada: Micha Books.

Saetermoe, C. L., Scattone, D., & Kim, K. H. (2001). Ethnicity and the stigma of disabilities. *Psychology & Health, 16*(6), 699-713. doi:10.1080/08870440108405868

Seligman, M. E. P. (2002). *Authentic happiness: Using the new positive psychology to realize your potential for lasting fulfillment*. New York: The Free Press.

Winnicott, D. W. (1958). *Through paediatrics to psychoanalysis*. London: Hogarth.

Chapter 2: Background

The empirical focus of this dissertation is on the process of hoping among parents of children with ND. Parents can only speak to the ways in which they experience hope for their child's future by considering their connection to their child. They can only articulate their experiences through their parental lens. They cannot divorce themselves from this vantage point and speak about hope for their child's future as though they were not joined in such a profound way to their child. As such, in this dissertation hope is considered to be embedded in the experience of parenting. An argument is made in this chapter that hope be considered an element of "parenting as experienced" – the ways in which parents understand themselves and their role as a parent and the ways in which parents understand and experience their child and their interactions with their child, as well as an element of "parenting as enacted" – the things that parents do as parents, the ways in which parents interact with their child, the observable acts and patterns of parenting. In order to situate hope as an aspect of parenting one must consider the ways in which parenting has been described and theorized in the scholarship. This chapter will present the theoretical development of parenting and will set the stage for the study of parental hope which forms the core empirical work of this dissertation.

The Theoretical Development of Parenting

Parenting has been recognized as an important phenomenon in all historical periods and cultures. This is because it relates to the development of future generations. In fact, "parenting emerges as probably the most fundamental and universal concern of society" (Hoghughi, 2004, p. 6). We have all been parented in some way, shape, or form and many of us currently are, or will be parents. As a result, much of our knowledge about parenting is "embedded in conventional wisdom" (Patterson & Fisher, 2002, p. 60) and in our experiential knowledge of being parented or parenting our own children. Many of us have ideas about how we *will* parent, how we *do* parent, and how we *should* parent. How our ideas about parenting are formed and how they materialize in practice however, is not always apparent and has been a topic of research interest for the past several decades. The following is a review of the theoretical development of our understanding of "parenting", beginning in the twentieth century. This review will provide a foundation for understanding parental hope in the context of childhood neurodisability (ND).

Parenting became an important area of research beginning in the twentieth century. Key theorists in the disciplines of psychology, psychiatry, and child development helped to push the conceptualization of parenting forward. As parenting research advanced, there was increasing recognition of the changing landscape of family life: diverse family forms, increasing numbers of women in the work force, and a decrease in marriage and birth rates. Likewise, there was a "growing consensus about the increasing stress and complexity facing families" (Patterson & Fisher, 2002, p. 60). Taking these developments into account, the field of parenting transitioned to remain consistent with the realities of the family context. Families of children with disabilities come up against a number of challenges on a daily basis, above and beyond those of the typical parent. Thus, taking into account the increased level of complexity that these families face, benefits the study of parenting of children with disabilities. Although seeking to understand the lived experience of parenting a child with ND has not always been a high priority for parenting researchers, the consideration of complex realities facing parents to theoretical understandings of parenting has enhanced the applicability of traditional parenting theories to empirical research on parenting children with disabilities. The field of parenting research was pioneered by a number of seminal theorists. Here they will be presented briefly to offer a recent historical perspective of the emergence of our theoretical understanding of parenting and to set the stage for the study of parental hope.

In today's society, there is much interest in parenting and the effect of parenting on child outcomes (Brenner & Fox, 1999; Maccoby & Martin, 1983). In fact, the substantive area of parenting has been amply studied and conceptualized "ever since Freud drew formal attention to its critical significance for children's social, emotional, and intellectual functioning" (Grusec, Neil, & Paul, 2001, p. 11038). Because parenting is a complex phenomenon, however, there are many ways of conceptualizing and studying it and theoretical frameworks guiding the study of parenting are varied. There has also been a growing awareness among researchers who study the topic of parenting about the heterogeneity in the way "parenting practices" are defined and researched (Patterson & Fisher, 2002), in the way these constructs are measured, and in the way in which parenting practices are uniquely carried out in the context of the family (Hoghughi, 2004). There has been a call for a more unified definition which includes standardized measures and "a common set of parenting variables" (Patterson & Fisher, p. 60). In order to assess the relationship of parenting to child outcomes in an empirical way, we need a system of classifying parenting practices. A categorization such as this is important not only for the purposes of empirical research, but also for the purposes of assessment, intervention, and identifying at risk children (Brenner & Fox) - one of the key areas of social work practice. This insight has spurred empirical research in the domain of parenting. Questions such as: How does parenting impact child development? Are there mediating factors involved in this relationship? Is there a reciprocal interaction between child characteristics and parenting behaviours and cognitions? have been put forth and addressed empirically. Findings have guided the development of theoretical frameworks, which in turn have informed further empirical study in the area of parenting. Another rationale for taking a comprehensive look at the theoretical development of parenting in the context of this dissertation is that as a researcher, it is my obligation to base my work in the existing theoretical scholarship in my area of interest as well as to critically examine and extend this scholarship. Many studies in the domain of parenting and child development are not theoretically driven (Wallander, 1992). In fact, from a brief review of studies in the Journal of Pediatric Psychology, Wallander (1992) concluded that only 17% of studies were theory-driven. This finding suggests a need for parenting research to be grounded in theoretical frameworks in order to support or refute theories so that they can be adapted, strengthened, and built upon.

In this chapter I present a brief history of the conceptualization and study of parenting, key theoretical models of parenting which guide empirical research in the area, and address key critiques of these frameworks including their applicability to the study of parenting children with ND. I also present the key theoretical frameworks informing research in the area of hope and critique these theories from the perspective of their utility in the study of hope among parents of children with ND.

History of the conceptualization and study of parenting

While the act of parenting has existed ever since human beings have procreated, it was during the second quarter of the twentieth century that quantitative research on parenting and its impact on children began to emerge (Hoghughi, 2004). Around this time, developmental theorists drew attention to the significance of child development and our understanding of it. Erikson (1950) developed a model of childhood development, implying the importance of adaptive child functioning and growth over the lifespan. Bowlby (1951), a psychologist and psychiatrist interested in child development, studied children who were removed from their homes during World War II. Noticing the fundamental importance of early attachment throughout the life course, he focused on the parent-child interaction and attachment. This led to new areas of inquiry into parenting processes and outcomes (Hoghughi, 2004) and spurred a host of new research in the latter half of the twentieth century.

Donald Winnicott, a psychiatrist and sociologist, who began his career as a paediatrician, made lasting contributions to the field of psychoanalysis in the tradition of Object Relations Theory. In the late 1950s, Winnicott (1958) introduced the term "good enough mothering" as a desirable goal for parenting. The term "good enough mother" was used to refer to a mother who is "able to meet the needs of her infant at the beginning, and to meet these needs so well that the infant, as emergence from the matrix of the infant-mother relationship takes place, is able to have a brief experience of omnipotence" (Winnicott, 1965, p. 57). He also described the psychic space between the mother and the child as being a "holding environment" (Winnicott, 1965). It is this space that allows the child to develop adaptively and transition into an autonomous being. Failure to provide this holding environment (not-good-enough mothering) results in disorders in the child, according to Winnicott (1965). The conceptualization of "good enough mothering" puts forth the idea that parenting is not an activity to be perfected, but that there is a range of parenting that falls under what is generally considered adequate parenting; "realistically, the most and the best parents can do it to give [children] a core of unconditional love and reliable care, providing a safe setting for children's own resilience and developmental potential to unfold – as demonstrated by the larger part of humanity" (Hoghughi, 2004, p. 4). Adequate parenting, then, is that which promotes positive child outcomes. Ainsworth, a developmental psychologist, extended Bowlby's concept of attachment and described secure attachment as an outcome of good parenting practices (Ainsworth, Blehar, Waters, & Walls, 1998). Based on her research on parent-child relationships, she developed a typology of attachment styles: secure, anxious-resistant insecure, anxious-avoidant insecure, and later, disorganized/disoriented attachment. This research led to a general agreement that secure attachment is a "crucial outcome of good parenting, creating a lifelong protective shield for the developing child against adversity" (Hoghughi, 2004, p. 4). In this way, developmental theorists shaped our understanding of the centrality of parenting in shaping the child and promoting child outcomes. Winnicott, Bowlby, and Ainsworth's work has influenced the development of the relationship-based parenting program, Circle of Security.

Ecosystemic theorists broadened conceptualizations of parenting to include the systems within which the child and family are situated. Bronfenbrenner (1994) introduced the importance of the parenting context and its impact on parenting. This ecological systems perspective has influenced many contemporary parenting programs; for example, the Sure Start Program in the United Kingdom and Ontario's Early Years Plan. Building on the idea of the parenting context, Baumrind (1966, 1968, 1991) studied critical issues of child management in a social and developmental context. Based on her work focusing mainly on adolescents, she developed a parenting management styles typology: authoritarian, authoritative, and permissive, to which Maccoby and Martin (1983) later added neglectful parenting. These parenting styles were based on four elements: responsive versus unresponsive, and demanding versus undemanding parenting. Parental responsiveness refers to the degree to which parents respond to the needs of their child, and parental demandingness is the extent to which the parent expects mature, responsible behavior from their child (Baumrind, 1968). Baumrind hypothesized that "the key function of these parenting practices is to contribute differentially to the adolescents' identity formation and cognitive and moral development…some practices facilitate growth…though others do not" (Patterson & Fisher, 2002, p. 60). Since it is generally accepted that specific parenting behaviors are less predictive of child outcomes than the broad pattern of parenting (i.e., parenting style), this has been an extremely influential and often used classification system of parenting practices in the scholarship on parenting.

For the first half of the twentieth century, there was a heavy focus on the importance of parental attitudes toward childrearing (Holden & Buck, 2002). Parental attitudes were seen as determining parenting behaviors, which were assumed to be directly and unidirectionally related to child outcomes (Holden & Buck, 2002). However, starting in the 1950s, critiques regarding the emphasis on the importance of parenting attitudes stemmed from a lack of empirical evidence connecting parental attitudes to parenting behavior (Holden & Buck, 2002). In addition, methodological issues relating to the measurement of parenting attitudes were brought forth, such as insufficient sample sizes, inadequate measurement of behaviors, and limited assessment of global parenting attitudes (Holden & Buck, 2002).

Up to this point in time, much of the research assumed that parenting had a direct and unidirectional impact on child development, and more specifically, that bad mothering caused "bad children" – children with challenges, such as behavioral dysregulation or mental health concerns (Karraker & Coleman, 2005; Sameroff & MacKenzie, 2003). Research emerging in response to this assumption focused on relatively stable characteristics of children and the effect these have in shaping parenting practices, for example, child temperament, gender, age, and physical appearance (Karraker & Coleman, 2005). Work by Chess and Thomas (1999), as well as by Bell (1977) highlighted this interaction. For example, Bell demonstrated that many parent behaviors were actually influenced by child characteristics and behavior, and that parenting behavior was not simply a unidirectional influence toward the child. Based on research involving children with difficult temperaments, Thomas, Chess, and Birch (1968) found that these children stimulated maladaptive parenting, which later led to behavioral disturbances. In comparison, for children whose parents did not react in this way, there was no subsequent development of behavioral disturbances (Thomas et al., 1968). Building on this knowledge, Sameroff and Chandler (1975) pointed to the vital importance of transactional processes to child development. This led to the common understanding of parent-child relationships as being transactional in nature. Based on work with difficult and antisocial children, Patterson (1975) identified parameters and processes of parent-child interactions. Using social learning theory, he showed how processes can be altered by good intentions (Patterson, 1975).

Recognizing the challenging circumstances under which many children develop and thus under which many parents parent, Rutter (1985) described how vulnerability and resilience both affect outcomes and are affected by parenting practice. Given these findings, one may infer that the well-being of children, including those with disabilities, is determined by a host of factors, including parenting practices (i.e., styles, behaviors, and attitudes/cognitions), the parenting context (i.e., the immediate and extended family, and the social, economic, and cultural environment), and the child's inherent and acquired vulnerability and resilience. Likewise, determinants of parental hope may include child characteristics and behavior, and the parenting context.

This brief overview of the theoretical development of parenting underscores the importance of parenting: "parenting is *the* crucial process and transmission mechanism in shaping children's future" (Hoghughi, 2004, p. 5). Building on these developments and prompted by increasing public attention paid to child maltreatment and "outcomes of child development in the face of reduced mother-care and increased other-care" (Abidin, 1992, p. 407), the parenting scholarship pointed to the growing interest in the factors that influence parenting behavior. Some of these determinants of parenting will be visited below. But, first, we turn to a discussion of classifications of "parenting".

Defining "parenting"

As mentioned above, there remains in the parenting literature considerable heterogeneity in the way parenting practices and cognitions are defined and applied in the empirical research. Parenting has been defined broadly as "purposive activities aimed at ensuring the survival and development of children" (Hoghughi, 2004, p. 5). Despite the postulation that parenting is more concerned with "the activity of developing and educating than *who* does it" (Hoghughi, 2004, p. 5), it is important to recognize the complexities involved in conceptualizations of mothering and fathering and the social and cultural contexts in which they occur. Although an analysis of the theoretical scholarship on mothering and fathering is outside the scope of this dissertation, an awareness of the distinct ways in which mothers and fathers contribute to child development and the ways in which their roles have been societally shaped and studied in the parenting literature over time provide a lens through which to appreciate parenting literature.

The parenting scholarship has typically classified parenting into the broad categories: styles, practices, and cognitions.

Parenting style and practices

Parenting styles have been distinguished from parenting practices (Darling & Steinberg, 1993), although these two constructs have been shown to be related. Parenting style has been defined as "a stable set of complex attitudes and beliefs that form in the context in which parenting behavior occurs" (Brenner & Fox, 1999, p. 344). For example, an authoritarian father believes that children should obey his commands because children should respect their elders. Parenting practices are, "specific, goal-directed behaviors through which parents perform their parental duties" (Darling & Steinberg, 1993, p. 488). An example is spanking a child who does not comply with a parental request, or complimenting a child to enhance their self-esteem (Brenner & Fox, 1999). This distinction connotes differences in how each has an impact on child outcomes. Parenting practices directly affect child outcomes, and additionally, as described by Maccoby and Martin (1983), there is a reciprocal determinism, where parenting behaviors and child behaviors influence each other.

Research on the determinants of parenting has pointed to the importance of parenting behaviors. Determinants such as marital satisfaction, beliefs about discipline, parental abuse history, parental depression, level of spousal support, maternal age and education, and family economic stress have been identified as being correlated with parenting behavior, and thus can be used to predict it (Brenner & Fox, 1999). A number of these determinants are also known to be risk factors for child externalizing disorders. Because parenting practices have such a direct impact on child outcomes and behaviors, it is important that we have a system of classifying, and thus measuring, them.

Some scholars argue that parenting styles, in contrast to parenting practices, have indirect effects on child outcomes; they moderate the effects of parenting practices on child outcomes. However, others have maintained that Baumrind's typology has value in that parenting styles are related to specific child outcomes (Brenner & Fox, 1999). For example, authoritative parenting has been found to be correlated with a number of positive educational child outcomes, such as academic achievement, time spend on homework, positive school behavior, and completion of secondary school (Chao & Willms, 2002a). In comparison, children of authoritarian and permissive parents tend to show poorer educational outcomes (Chao & Willms, 2002a). Darling and Steinberg (1993) present a model which conceptualizes parenting style as a context that moderates the relationship of parenting practices on the child. An illustration of the relationship between parenting style and behavior materialized from a study by Brenner and colleagues (1999). In this study, four clusters of parenting practices were identified by way of a large-scale sampling of reported parenting behaviors from the Child Behavior Checklist's (CBCL) three dimensions: discipline, nurturing, and expectations. Three of these clusters corresponded to Baumrind's dimensions of parenting style (authoritative, permissive, and authoritarian) (Brenner & Fox, 1999).

Parenting cognitions

Parenting cognitions have been defined based on an understanding of general social cognitions, which include beliefs, attitudes, perceptions, attributions, and expectations (Bugental & Johnston, 2000; Okagaki & Bingham, 2005). Although at times, the parenting literature employs these concepts interchangeably, they will be delineated as clearly as possible here. The focus will be on beliefs and attitudes as these are the two most well-developed constructs in the literature.

There is a general consensus that parent attitudes and beliefs are of central importance with respect to directing parenting behavior. Much of the parenting research has focused on the link between how parents think about parenting and their children and child outcomes (Grusec et al., 2001). Parent beliefs are defined as "ideas or knowledge that parents consider to be factual or true"

(Okagaki & Bingham, 2005, p. 4). Examples include beliefs about childrearing strategies, child development, parent-child relationships, and what it means to be a good parent. Parental beliefs have been characterized as a parent's effectiveness in their parenting role. In other words, how the way a parent views themselves as a parent impacts on their parenting practices. These beliefs are of importance because "such cognitions are intrinsic to the exercising of parental responsibilities" (Sigel & McGillicuddy-De Lisi, 2002, p. 485). Research in this area often relies on Bandura's self-efficacy theory; "self-efficacy is applied to parent beliefs under the hypothesis that if parents feel competent they will behave in ways that are more effective with their children" (Sigel & McGillicuddy-De Lisi, 2002, p. 495). Some writers refer to this type of parenting belief as parent perceptions. Perceptions are seen as a type of belief and include "ideas about a particular person or social group" (Okagaki & Bingham, 2005, p. 4). For instance, parent perceptions of child characteristics, such as temperament, or parent perceptions of their own parenting ability (parenting self-efficacy). These perceptions are shaped by child characteristics (Okagaki & Bingham, 2005). Research with parents of children with disabilities, for example, has shown that "parents appear to adapt their childrearing strategies to account for their perceptions of their child's abilities or special needs (Okagaki & Bingham, 2005, p. 18).

Parental attributions build on perceptions in that they assign or infer cause or intention to a characteristic or action that is observed (Okagaki & Bingham, 2005). Parenting beliefs about parenting also have to do with beliefs as a source of parenting strategies and beliefs about the parenting role itself (Sigel & McGillicuddy-De Lisi, 2002). Parenting self-efficacy has been found to be related to parenting behaviors, which are then related to positive child outcomes. As well, parental beliefs in general have been shown to have an effect on children's cognitive development, especially in the areas of academic achievement, social development, and health and physical well-being (Sigel & McGillicuddy-De Lisi, 2002).

Attitudes build on beliefs, adding an evaluative component, which is a negative or positive evaluation to the ideas about the object (Sigel & McGillicuddy-De Lisi, 2002). Attitudes refer to a "tendency, internal state, or explicit evaluation of an 'attitude object'. This internal state biases or predisposes an individual toward reacting favorably or unfavorably to the entire entity or object" (Holden & Buck, 2002, p. 537). Others have defined attitudes as "beliefs or opinions, an evaluation of those beliefs, and an intention to act in accord with them" (Ajzen & Fishbein, as cited in Grusec, 2004, p. 11038). Attitudes, therefore, link cognitions and behavior and are closely related, but distinct from other aspects of social cognition (Holden & Buck, 2002). In the arena of parenting, attitudes may include such cognitions as parental attitudes toward breastfeeding, corporal punishment, and parent involvement in the child's education. As with other aspects of parenting, parental attitudes have been shown to be multiply determined (Holden & Buck, 2002). Cross-cultural studies have been especially popular, exploring cultural differences in childrearing attitudes among parents (e.g., Bornstein et al., 1998; Bornstein et al., 1996; Jones & Brayfield, 1997). Parent goals and expectations are outcomes that parents hope to achieve in the parenting context. For example, the type of person they would like their child to become, and daily accomplishments for the child, such as getting dressed in the morning (Okagaki & Bingham, 2005).

Many measures are in use that evaluate parental attitudes and beliefs. These have been used to attempt to clarify the relationships between parenting cognitions, behaviors, and child outcomes. Holden and Edwards (1989) note that it is important to recognize the assumptions inherent in this kind of measurement and that these assumptions are often violated, which may result in less robust findings. For example, it is assumed that parents have pre-existing attitudes toward child-rearing, when this might not always be the case; or that attitudes remain constant, when they can in fact be modified (Grusec, 2004). Attitudes are often measured by way of interviews or self-report questionnaires. Most of these measures ask about a parent's views about child-rearing practices, such as the quality of the parent-child relationship (e.g., warmth, acceptance, responsiveness, coldness, rejection, and hostility) and parental control of the child's behavior (e.g., permissiveness, firm control, punitiveness, and restrictiveness). A smaller number evaluate parents' views of children. The common critique of most research on parental attitudes, and parenting competence in general, is that it has been carried out on Anglo-European, middle-class mothers and their children, which may not be transferable to families of lower or higher economic groups or other cultural contexts (Grusec et al., 2001; Teti & Candelaria, 2002), or even to the parenting practices of fathers or non-heteronormative parenting contexts. A further critique of the measurement of parental cognitions is the difficulty of evaluating global attitudes. One proposed solution to this problem has been to focus on parental beliefs and attitudes in specific situations (Grusec et al., 2001). Finally, many of these measures have not been validated with parents of children with disabilities, which introduces limitations to their use in empirical studies with this population.

The ways in which disability has been understood at the societal and theoretical level has guided the development of research on parenting cognitions related to children with ND. The dichotomy of the social versus the medical perspective has been at least partly moderated by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) Framework (World Health Organization., 2007), which takes an integrative position, viewing disability as existing both as an individual impairment and as a social problem (Bugental, 2003). This dialogue has resulted in attention being drawn to the ways in which parents understand their child with a disability. Bugental (2003) emphasizes that parents have differing reactions to a child with a disability, which may be adaptive or maladaptive, and that these reactions impact on their parenting behavior. She notes that "parents who see a difficult caregiving experience as 'manageable' could be more likely to see such a child as a (positive) challenge rather than a 'threat' (Bugental, 2003, p. 28).

As mentioned, the literature has consistently demonstrated correlations between parental beliefs and behaviors. However, it is not always clear how these findings are to be interpreted. Parental beliefs and behaviors after often evaluated based on self-report measures, which may overestimate the relationship (Okagaki & Bingham, 2005). Additionally, since correlations between two measures are always stronger when reported by a single source, shared method variance may explain some of the relationship (Okagaki & Bingham, 2005). Another important consideration in the interpretation of this relationship is the "closeness of the match between the content of the beliefs and the type of behavior that is measured" (Okagaki & Bingham, 2005, p. 15). An example of this is the detection of differences in the strength of the correlation between self-reported beliefs and self-reported behaviors, and between self-reported beliefs and observed behaviors (Okagaki & Bingham, 2005).

Parental hope could be considered a key aspect of parenting cognition. Although not directly addressed in the parenting scholarship, parent goals and expectations as part of parenting cognition fit nicely with a consideration of how parents of children with ND experience hope for the future.

Theoretical frameworks of parenting

Seminal theories informing our understanding of parenting are presented, as well as the assumptions that are embedded in these theories and the extent to which we can generalize from these, based on culture, gender, and child ability. The following two models will primarily be discussed: Belsky's process model of the determinants of parenting, and Abidin's model of the theorized paths of influence regarding the determinants of parenting behaviour.

Belsky's model: A process model of the determinants of parenting

Writing in 1984, Belsky (1984) criticized the parenting literature for being unintegrated and underutilized, for neglecting the study of determinants of parenting, and for a lack of conceptual models that build on the existing literature. He felt that research being conducted in the area of child abuse could be applied to the study of the determinants of parenting; "in asking questions about the etiology of child abuse and neglect, clinicians and research scientists alike have been essentially inquiring into the determinants of parental functioning - or most precisely, parental dysfunction" (Belsky, p. 83). He sought to show that there is, in fact, a continuum of influence and that research on influences on parenting in the context of child abuse and neglect can be applied to determinants of parenting in general (Belsky). He believed, in essence, that "dysfunction can illuminate normal functioning" (Belsky, p. 92). This reflects a move away from a focus on global family variables that have an impact on parenting behaviour toward a consideration of personal, historical, sociological, behavioural and self-report variables. This model as well as Belsky's subsequent work has led to an increased focus in parenting theory on factors internal to the parent (Abidin, 1992).

The empirical literature on parental abuse and neglect had shown that parenting was influenced by three sources: parent factors (the parent's developmental history, personal resources and personality), child factors (child characteristics and individuality) and contextual sources of stress and support (Belsky, 1984). Based on this knowledge, Belsky sought to develop a model of the determinants of parenting (see Figure 1). His process model assumed that parenting impacts on child development. Parenting, in turn, is influenced by parent personality, child characteristics, and social environmental factors (marital relations, social network and occupational factors). Parent personality and general psychological well-being is influenced by the developmental history of the parent, marital relations, social network and occupational factors. This implies that these factors also indirectly affect parenting and therefore child development.

There is a significant amount of evidence for most of the links presented in the model. A few examples will be provided. In relation to parent factors impacting on parenting, three areas of empirical literature illuminate these linkages. Findings from the child abuse literature have demonstrated an association between experiences of maltreatment and the potential of abusing one's own child (Belsky, 1984). In addition, the depression literature has shown that experiencing a depressed parent as a child is correlated with a higher risk of developing depression and with more difficulties caring for a child (Belsky, 1984). However, these intergenerational transmissions are hardly inevitable (Belsky, 2005). And finally, on a more positive note, men who experience both high and low levels of father involvement growing up are likely to display high levels of involvement with their own child (Belsky, 1984). Personality characteristics of parenting (psychological attributes) are seen as shaping parenting by influencing the emotions parents experience and/or the attributions they make about the causes of child behaviour; these are influenced by developmental history (Belsky, 2005; Vondra, Sysko, & Belsky, 2005).

The transactional literature on the interactions between child temperament and parental functioning reveals that a child with a difficult temperament can undermine parental functioning (Belsky, 1984). Belsky suggests, however, that this relationship is almost certainly more complex than has been alluded to in the literature and that it is more about the goodness-of-fit between child temperament and parent characteristics than child temperament per se influencing parenting (Belsky). An ecological perspective leads to a consideration of contextual factors that influence parenting. Sources of stress and support are examples of these factors.

Social support is known to have a beneficial impact on parent psychological and physical health (Barakat & Linney, 1992; Belsky; Mitchell & Trickett, 1980). This finding is evidenced in the childhood disability literature. For example, among parents of children who required intensive care as neonates, the availability of social support predicted the extent to which they were stimulating[2] in their parenting approach (Pascoe, Losa, Jeffries, & Easp, 1981). In a study of mothers of children recently diagnosed with ASD, general social support had a significant negative association with individual, marital, and family burden and autism-specific social support was associated with decreased individual and family burden (Stuart & McGrew, 2009). To unearth the mechanisms through which social support influences parenting, both the functions and the sources of support need to be considered. Social support functions by providing emotional support, instrumental support, and social expectations (Belsky, 1984). Each of these functions can influence parenting both directly and indirectly (Belsky, 1984). Sources of stress and support that are likely to impact parenting include the marital relationship, social networks, and employment (Belsky, 1984). Belsky

---

[2] This study used a measure called Caldwell's Inventory of Home Stimulation to assess the cognitive stimulation and emotional tone in the home: "this inventory quantifies the caregiver's emotional and verbal responsiveness in providing her child with a safe, interesting home environment" (Pascoe, Losa, Jeffries, & Easp, 1981, p. 16).

hypothesized that these three sources of stress and support have a relative influence on parenting, but that the marital relationship has the strongest influence (Belsky, 1984). He and others have also noted that it is the *degree* of stress and support, more so than the mere presence of them, that has the greatest impact. Belsky (2005) later elaborated his argument stating that the biggest determinant of why parents parent the way they do is the accumulation of stressors and supports, or borrowing from developmental psychology terminology, risk and protective factors.

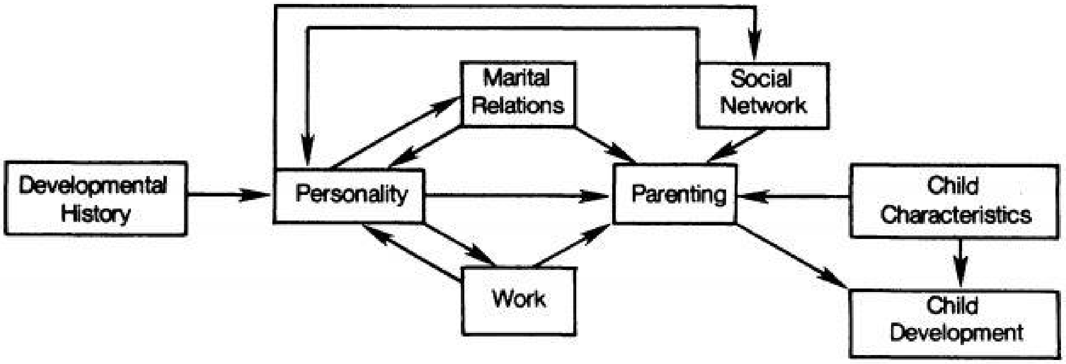

Figure 1. A process model of the determinants of parenting (Belsky, 1984)

A key assumption of this model is that the parenting system makes up for threats to its integrity by compensating in another area (Belsky, 1984). The parenting personality dimension of the model is considered to be the most influential to parent functioning. This means that when one or two other elements, such as marital relations or social networks, are weakened, "parental functioning is most protected when the personal resources subsystem still functions to promote sensitive involvement" (Belsky, p. 91). This assumption is supported by evidence from literature on high-risk and difficult infants (Belsky).

Belsky concludes that parenting is determined by multiple factors, that parenting is differentially influenced by characteristics of the parent, child and social context, and that parental developmental history and personality indirectly influence parenting by influencing the social context in which parent-child relationships are situated (Belsky, 1984; Sameroff & Chandler, 1975).

There are some important limitations to this model that should be mentioned. First, the process model inadequately addresses the additional sources of stress and support encountered by families of children with ND. For example, parents experience stress related to dealing with multiple services and health professionals, accessing needed supports, facing disability-related social stigma, and additional demands on their time, finances, and relationships. The scholarship on parenting children with disabilities has demonstrated that the psychosocial and physical impacts of a child's ND on parent-caregivers and the resources available to them are key determinants of parenting (e.g., Laskey & Cartwright-Hatton, 2009; Mitchell & Hauser-Cram, 2008; Osborne & Reed, 2010; Ventola, Lei, Paisley, Lebowitz, & Silverman, 2017). In this way, the present model is limited in its validity and applicability to parenting children with disabilities. And second, the limitations of the parenting research lessen the predictive ability of this model. For one, there is a reliance on correlational studies. Because of this, causal inferences cannot be made and the degree to which the model can be substantiated is limited by the designs of the existing empirical literature. A second major limitation is that studies tend to focus on one link at a time, rather than the entire model. Because of this, the process of connecting the various elements of the model into a cohesive whole has no empirical support (Belsky, 1984).

Abidin's model: Theorized paths of influence regarding the determinants of parenting behavior

Abidin critiqued the parenting research on a number of points. First, he argued that there is a gap in the theoretical literature on parenting addressing parental belief and motivation systems, noting that these are important variables to consider in relation to parenting and parent-child interactions (Abidin, 1992). Second, although some models, such as Patterson's model suggesting the determinants of antisocial and aggressive behaviour in children predict parenting behaviour, they do not account for why parenting behaviour occurs (Abidin). He maintains that "theories and models of parenting behaviour…need to be developed that go beyond the stimulus-response behavioural perspective and that integrate sociological and cognitive-psychological approaches with behavioural approaches" (Abidin, p. 408). And third, recognizing the contribution of Belsky's work to our understanding of parenting processes, Abidin criticized his model of the determinants of parenting, remarking that this framework fails to capture "the parent as a thinking, planning, goal-oriented individual" (Abidin, p. 410).

Researchers had begun to build models of the determinants of parenting, influenced by the identification of "some of the processes by which parent-child interactions are regulated by the beliefs and expectations of both parties during the child's infancy" (Abidin, 1992, p. 408). One example was Abidin's Parenting Stress Model (Abidin). This model emphasized stress as the central construct, which leads to dysfunctional parenting. Subsequent research, however, found that there was not a direct, linear relationship between stress and dysfunctional parenting; that the relationship is more complex than had previously been presumed. For instance, Abidin found that "very low levels of parenting stress also were associated with dysfunctional parenting due to the disengagement of the parent and the subsequent low level of vigilant parental behaviours" (p. 408).

Based on his own and others' previous work and a new appreciation for the complexity of parenting and its relationship to child outcomes, Abidin formulated a new model: Theorized paths of influence regarding the determinants of parenting (see Figure 2). This model, based on variables identified in the parenting literature as being the most predictive of parenting behaviour, identifies a number of variables which impact parenting behaviour and child adjustment, including sociological, environmental, behavioural, and developmental variables. These variables produce an impact on parenting through a "parenting role variable", which is essentially a parent's internal working model of themselves as a parent (Abidin, 1992). This variable represents "a set of beliefs and self-expectations serving as a moderator or buffer of more distal influences" (Abidin, p. 410). Therefore, parental cognitions and beliefs play an important role in this model. Abidin describes this variable as "self-as-parent", which is generated from the parent's attachment history and includes their individual goals and internalized expectations of others (Abidin). This acts as an appraisal moderator through which a parent assesses the harm or benefit facing them in their parenting role. This in turn, informs the level of stress experienced by the parent (Abidin). Interestingly, in this model parenting stress is seen as a motivational variable, "which energizes and encourages parents to utilize the resources available to them to support their parenting" (Abidin, p. 410). The impact of parenting stress on parenting behaviour is then moderated by resources available to the parent, such as social support, strength of the parenting alliance, parenting skills and competencies, material resources, and coping. This model is noticeably informed by Lazarus and Folkman's stress and coping model (Lazarus & Folkman, 1984). And in fact, Abidin describes his model as an explication of a specific application of the general stress and coping theory.

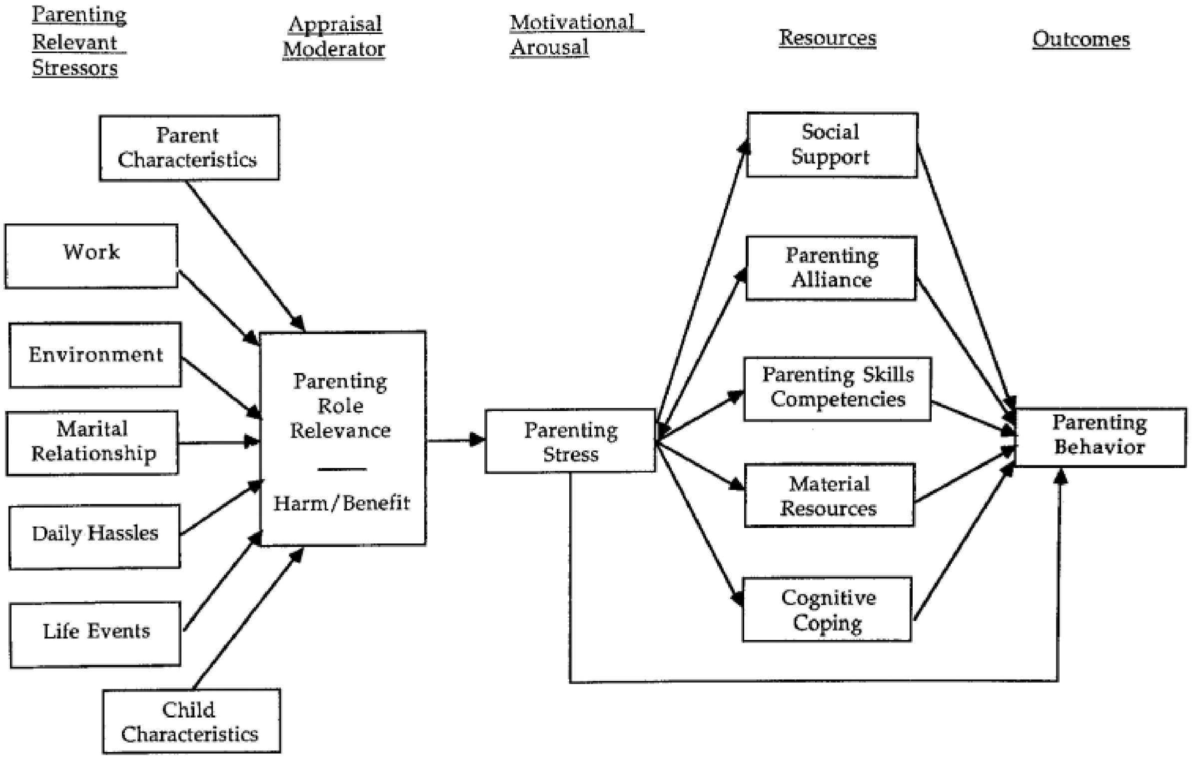

Figure 2. Abidin's model of the theorized paths of influence regarding the determinants of parenting (Abidin, 1992).

This model's biggest contribution to the scholarship on parenting is an understanding of parents as having a working model of himself or herself as a parent. This model has important applications to measurement. Abidin notes that "parental belief systems as measured by self-report have both direct and indirect influences on parenting behaviour and child outcomes" (Abidin, 1992, p. 411). Indirectly, the dyadic interaction between parent and child mediates the impact of parental beliefs on child outcomes. The direct influence of parental beliefs has to do with "the environment the parent creates or involves the child in and to the inferences the child makes about the parent's beliefs systems (expectations)" (Abidin, p. 411). The direct relationship can only by measured and observed over time in various contexts. He advocates for the use of self-report instruments to assess parental belief systems, rather than one-time observational tools. Due to the emphasis placed on parental cognitions and beliefs captured in the "parental role variable", this model may have stronger validity with respect to its application to parenting children with disabilities. Despite the fact that stress remains a central construct in the model, it is seen as a motivational variable. This conceptualization of stress fits with the reactions of many parents who experience psychosocial distress due to their child's additional needs and harness that energy into advocating for their child and other children.

Applications and limitations of parenting theory

The majority of theoretical frameworks informing our understanding of parenting have been developed outside the sphere of paediatric disability. For families with a child with a chronic condition such as a ND, their parenting realities are qualitatively different from those of other parents. Therefore, we must ask whether these conceptualizations of parenting are applicable here. As has been alluded to throughout the paper, some of the parenting models may not account for the challenges associated with caring for a child with a ND, such as additional reliance on sources of support or frequent interactions with the health and social care system. It would be unfitting, then, to indiscriminately apply frameworks of parenting to the study of parenting children with ND. Assumptions often made in the paediatric parenting literature relate to parenting stress and over-protection. These maladaptive parenting strategies are seen as having negative impacts on child outcomes. The notion of "paediatric parenting stress" insinuates that parents of children with ND will experience stress, and that without professional guidance, parents will engage in over-protective behaviour which will have maladaptive effects on their child (Thomasgard & Metz, 1997). However, this assumption may be unfounded, and as Abidin's model indicated, stress may actually be a motivating factor. Furthermore, although stress is certainly a significant part of parenting children with ND, the centrality of stress as the organizing principle in shaping the parental experience should be called into question.

One model that has demonstrated good applicability to parenting children with ND is Wallander et al.'s (1989) disability-stress-coping model. The model reflects a systemic framework and takes into account family life cycle stage (stage of development) by "view[ing] family members as an integrated whole, where a medical stressor or illness influencing the behaviour of one individual has implications for all family members" (Wallander et al., 1989, p. 185). The framework also takes into account the developmental phase of the child and the family as to the impact of the illness (or disability) on the family.

Early parenting theorists had privileged voices – most were European men – and so the field has been founded on perspectives that are likely not representative of the breadth of diversity among contemporary families. It must be recognized that important perspectives, such as those of women and people of color, and certainly Indigenous understandings of family and parenting, have been under-represented. This has allowed for assumptions about ethno-cultural and socioeconomic homogeneity in parenting to go unchecked.

Khanlou and colleagues, in their extensive program of research dedicated to the experiences of new arrivals to Canada who care for a child with disabilities found that in addition to challenges faced by most families of children with ND, immigrant families, encountered additional barriers to accessing needed services, such as discrimination, and language and cultural barriers (Khanlou, Haque, Davidson, & Dastjerdi, 2016). Literature on Indigenous families of children with disabilities has emphasized that these families "face unique additional challenges…such as difficulties in cross-cultural communication, historical and/or contemporary trauma experiences by families in schools, ongoing neglect of language, and lack of culturally rich curriculum for their children" (Banks & Miller, 2005).

Another limitation of the parenting frameworks presented is a lack of gender analysis. The frameworks seem to make the assumption that determinants of parenting and parenting practices are gender neutral, by nature. In fact, fathering has often been left out entirely of the dialogue about parenting; fathers have been the "forgotten contributors to child development" (Lamb, 1975, as cited in Parke et al., 2005, p. 245). Other writers, such as Chodorow (1978) and Lamb (1975; Lamb & Laumann-Billings, 1997) have written extensively on mothering and fathering respectively utilizing a gendered analysis. Although space prohibits a lengthy discussion of their work, one point to emphasize is that there are, in fact, differences in the determinants of parenting, which has been demonstrated by Lamb's (1975) work. He has highlighted some of the differences between determinants of mothering and fathering, such as biological (hormonal), social (attitudes, family level factors, marital relationship) and ecological (work, culture, and race/ethnicity) (Parke et al.) considerations. Furthermore, he has pointed to variations in how parents cope with a childhood illness or disability: "mothers and fathers rely on different strategies to support themselves when their children are affected by chronic illness" (Streisand & Tercyak, 2004, p. 186). Specifically, fathers use more "reasoning strategies", such as information seeking, whereas mothers use more "releasing" and "relating" strategies, such as exercising, crying, and communicating with others (Streisand & Tercyak). There has similarly been little emphasis on co-parenting and the negotiation processes involved in parenting a child with an ND.

A number of limitations of parenting research generally have already been mentioned, and will be summarized here. There has been a reliance on correlational studies when it comes to studying the impact of parenting practices on child outcomes and a lack of experimental studies, which water down findings (Belsky, 1984; Patterson & Fisher, 2002). Many have critiqued the wide usage of self-report measures of parenting practices and cognitions (e.g., Okagaki & Bingham, 2005), one reason being the pitfalls to creating good items and good, reliable, valid instruments (Okagaki & Bingham). In addition, we do not know how rating scales, reference periods, item format, and the context of the other items on the measure may influence parent responses (Okagaki & Bingham). However, Abidin (1992) advocates for the use of self-report instruments to assess parental beliefs systems, rather than one-time observational tools. This is because the direct relationship between parental beliefs and parenting behaviour and child outcomes can only be measured and observed over time and in various contexts (Abidin). As noted previously, empirical scholarship has failed to recognize the complexity of parents' social cognitions (Okagaki & Bingham). Namely, it has often not differentiated between parenting cognitions or recognized that social cognitions are not static (Okagaki & Bingham). The fact that the key models presented in this chapter were published over 20 and 30 years ago may reflect a lack of more current emphasis on this topic among scholars and may suggest that the models lack applicability to contemporary families.

A final limitation of the theoretical parenting scholarship is the lack of analysis of the impact of culture and socioeconomic status, which are also not static, on parenting practices. For example, there is an assumption held that one of the reasons children of poor parents tend to have poorer educational outcomes is because of parenting practices (Chao & Willms, 2002b). Analysis of Canadian national data has demonstrated that parents of lower socioeconomic classes are more likely to demonstrate authoritarian or permissive parenting styles (Chao & Willms). In response to this assumption, some have argued that parenting styles are conceptual categories and many parents may not fit easily into one of them. Culture and socioeconomic status are two factors which may amplify differences in parenting styles and, "relatively few studies have examined the relationship of parenting practice to particular aspects of socioeconomic status (SES), and research has not adequately determined the extent to which positive practices mediate the effects of SES on children's outcomes" (Chao & Willms, 2002b, p. 150). Other variables that may play a role in moderating or mediating the relationship between SES and parenting practices or child outcomes should be evaluated (e.g., Floyd & Saitzyk, 1992; Greenley, Holmbeck, & Rosie, 2006; Midouhas, Yogaratnam, Flouri, & Charman, 2013; Stabile & Allin, 2012). Parenting, then, needs to be understood in its social, cultural, economic and political context.

And finally, by calling for unified definitions and standardized measures of parenting in order to empirically evaluate the determinants of and correlates of parenting, certain types of understandings are advantaged over others. For instance, methodological approaches grounded in positivist scientific epistemologies lead to one type of understanding. Alternatively, approaches grounded in relativist or interpretivist epistemologies are minimized. In this way, we lose out on some of the complexities and nuance of parenting, for instance those that are arguably not captured reliably in a scale or questionnaire.

To summarize, theoretical frameworks informing our understanding of parenting are varied and numerous. Two of these models were presented here in detail as well as a discussion of the ways in which parenting practices, styles, and cognitions have been conceptualized to now. The limitations of the parenting scholarship were discussed in relation to its applicability to fathers, parents of children with ND, and families from diverse socioeconomic and cultural backgrounds. The parenting frameworks outlined here are useful when considering the experience of parental hope in that they situate various aspects of parenting (affect, cognition, style, behavior) within social, interpersonal, and intrapersonal contexts. They suggest that the various elements that make up "parenting" are multiply determined and multiple influenced. Hope, as an element of parenting, therefore, could be likewise be considered in these ways. Although it is conceivable that hope is conceptually integral to the parenting experience, there is no explicit consideration of hope in the parenting literature. We now turn to an examination of the ways in which the construct of hope has been conceptualized and studied empirically, leading to the argument to consider hope as an aspect of parenting in the context of this dissertation research.

The Conceptualization of Hope

In the last two decades, childhood disability scholars have begun to consider and study the positive aspects of parenting a child with a ND. The study of hope has been one of the results of this shift and the influence of hopefulness on well-being has become a topic of interest. In the fields of paediatric nursing, psychology, and medicine, hope is often thought of as an experience that is related to the end of life. That is, it is a concept that takes on a new relevance to families who are dealing with a terminal illness. In relation to its import among families who have a child with a chronic, but not necessarily progressive or terminal illness, there has been a focus on the absence or loss of hope, related to the losses that families of children with disabilities experience compared to those with typically developing children. The field of childhood disability has moved toward gaining a clearer picture of the determinants of hope among these families by drawing from theoretical frameworks of hope that have informed the development of scales that measure hope in a quantitative way. These theoretical frameworks are reviewed here, as well as the key scales resulting from them, and the limitations in terms of their applicability to the study of parenting children with ND.

Theoretical frameworks used in the study of hope

A consideration of the theoretical basis of hope is necessary in order to adequately appraise the ways in which hope has been studied empirically. The health and social sciences have historically been shaped by the medical model of disability, which views disability as intrinsic to the individual. The social model, in contrast, understands disability to be the result of environmental and social barriers, negative attitudes, and social exclusion. Recently, disability scholars have sought to reconcile these dichotomous perspectives of disability. For instance, the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) (2001) describes health and disability by taking into account the social and environmental contributions and also individual-level impairment. This framework has fostered a more holistic understanding of disability and has had an impact on the development of theoretical frameworks guiding the study of disability. In taking a bio-psychosocial approach to understanding the experience of parenting a child with a ND, frameworks of hope should be evaluated with a holistic and strengths-based lens in order to determine their applicability to the particular context of these families.

The major framework that has been used to study hope is Snyder's hope theory (Snyder, 2000). Other notable frameworks include Stotland's hope theory and Wong and colleagues' framework of "Vicarious Futurity", which includes "vicarious hope" and "vicarious despair" (Wong & Heriot, 2007; Wong, Heriot, Dossetor, & Nunn, in press). Snyder's hope theory is presented in detail due to its significance and wide usage in empirical study. This hope theory has also influenced the development of the Vicarious Futurity framework, which is presented because of its applicability to parenting children with ND. Other frameworks are explored in less detail.

In order to fully grasp the theoretical foundation of hope theories, we must consider the larger paradigm from which these theories emerge. Positive psychology provides the scaffolding for the emphasis on strengths and resilience in the field of psychology. For that reason, a presentation of the development of the seminal theories on hope emerging from a positive psychology paradigm follows.

Positive psychology

In the twentieth century, applied psychology tended to focus on deficits (Snyder & Lopez, 2007). However, there has been a shift from considering what is wrong with people to considering what is right about people (Snyder & Lopez). This is the question that is at the core of the field of positive psychology, which is "the scientific and applied approach to uncovering people's strengths and promoting their positive functioning" (Snyder & Lopez, p. 3). Positive psychology acknowledges weaknesses, while putting a strong emphasis on strengths, focusing on both stressors and resources in the environment. Martin Seligman, a pioneer of this paradigm, refers to the three missions of psychology prior to World War II as being: curing mental illness, making the lives of people more fulfilling, and identifying and nurturing talent (Snyder & Lopez). Since then, with the mental health industry burgeoning in both direct practice (psychotherapy) and research, two of the core missions of psychology have been neglected: increasing the quality of life of individuals and identifying and nurturing strengths and resilience. The field of psychology has been described as being a "victimology", where human beings are seen as passive, and psychologists view their role as being one of "repairing damaged habits, damaged drives, damaged childhoods, and damaged brains" (Seligman, 1998, p. 2). But, as Seligman reminds us, "psychology is not just the study of weakness and damage, it is also the study of strength and virtue. Treatment is not just fixing what is broken, it is nurturing what is best within ourselves" (Seligman, 1998, p. X). He points out that pathologizing has not advanced our understanding and prevention of mental disorders. In fact, the biggest advancements that have been made in the area of prevention have been based on a strengths-based and competency-building approach to the study of mental illness (Snyder & Lopez). Hope has been identified among a host of other human strengths, such as optimism, courage, and perseverance, as a buffer against mental illness. Seligman calls for a move away from a medical model framework based on personal weakness to a focus on human strengths and capacities. He believes that this reorientation to two of the neglected core missions of psychology will serve to increase the health of individuals and even to prevent many of the major psychological disorders (Snyder & Lopez).

The positive psychology movement has led to research focused on family resilience. This area of research seeks to address the question: why is it that some families who face adversity manage well and some do not? Resilience has been defined as "the capacity to rebound from adversity strengthened and more resourceful" (Walsh, 1998, p. 4). Grounded in this framework, Bayat (2007) studied specific resilience processes in families of children with Autism, such as making positive meaning of disability, mobilization of resources, family unity and closeness, appreciating life and other people, and gaining spiritual strength. His findings confirmed that parents of children with Autism demonstrate signs of resilience, "having become stronger as a result of disability in the family" (Bayat, p. 702).

Some of the major critiques of positive psychology are presented as well as replies from proponents of the framework. Positive psychology has been criticized for an overemphasis on positivity, a lack of appreciation of negativity (a negativity toward negativity), and a lack of use of scientific methods (Held, 2004; Rand & Snyder, 2003). Lazarus (2003, as cited in Rand & Snyder) characterizes positive psychology as "naïve, misleading, dogmatic, regressive, Pollyannish fad and fantasy" (p. 148). Held speaks of the "tyranny of the positive attitude" (p. 12) and the irony that this has resulted in people who are not able to be positive about their circumstances feeling even worse on account of our culture's emphasis on being positive. This criticism is in actuality about false hope, which will be addressed below in the section on Snyder's hope theory.

In response to this criticism, Seligman (2002) states that "positive psychology aims for the optimal balance between positive and negative thinking" (pp. 288-289), which offers a recognition of both positive and negative reactions. Further, Rand and Snyder (2003) maintain that positive psychology devotees are not under the illusion that it will locate a magic bullet cure for all concerns of mental health and that they are interested in much more than just emotions. Finally, positive psychology's adherents stress the importance of rigorous experimental methods; "the backbone of the initiative [positive psychology] should be good science" (Snyder & Lopez, 2007, p. 11). Key researchers operating within this paradigm, such as Snyder and Seligman, have prided themselves on their usage of rigorous scientific methods. Acknowledging the critique of positive psychology, we will turn to key theories of hope, which have developed from within this paradigm.

Stotland's hope theory

Stotland's theory of hope, operating from a social psychology framework of cognitive schemas, described hope as being "an expectation greater than zero of achieving a goal" (Stotland, 1969, p. 2). According to Stotland's definition, hopefulness reflects a greater "perceived probability of attaining a goal" (Stotland, p. 2). He differentiates between the expectation of achieving a goal and its desirability. He notes that the higher the probability of attaining a goal and the higher importance of that goal, the more positive the resulting emotions will be (Stotland). Anxiety is the result of chosen goals that are improbable yet important. There are inherent difficulties in the empirical evaluation of a concept such as hope since individuals have a hard time explaining how hopeful they are. We do not typically ask people about their expectations of goal achievement; we infer this from observations of an individual's reaction "to antecedent conditions in terms of subsequent behavioural outcomes" (Snyder, 1995, p. 355). People may be able to tell you how likely it is that they attain their goals, however, Stotland notes that these responses may be subject to biases such as social desirability. Applying this conceptualization to the study of hope among parents of children with ND suggests enquiring about a parent's goals and their expectations of achieving those goals. According to this framework, parents who set meaningful goals that are unlikely to be attained will experience anxiety.

Thus, Stotland uses hope as a concept in empirical research to refer to a mediating process which ties together antecedent and consequent events (Stotland). This theory, then, highlights the cognitive analysis of goal-related outcomes and sets a foundation for the development of Snyder's hope theory.

Snyder's hope theory

Snyder developed hope theory in the mid 1980s. Through conducting studies on performance, specifically, the excuses people make when they perform poorly, he learned from his participants that they were not only motivated to distance themselves from unattained goals, but were motivated to accomplish positive goals; something he had not been asking them about. He then looked at the existing literature on motivation from the previous 20 years and detected a theme: the desire to seek goals. Snyder felt, however, that something was missing from this conceptualization of the "hope motive" (Snyder, 2002, p. 249). At the same time, he was exploring the "cognitive revolution" literature, which emphasized the role of "pathways-thinking" in pursuing goals (Snyder). Snyder then interviewed people about their thought processes and found that people think in terms of goals and pathways to attaining their goals. Snyder was influenced in his conceptualizing of hope by Karl Menninger, a prominent psychiatrist in the area of mental health. Menninger helped lead Snyder to a focus on cognition, rather than affect in his thinking about hope; "hope…[is] primarily a way of thinking, with feelings playing an important, albeit contributory role" (Snyder, p. 249). Snyder initially regarded hopeful thinking as being both situational (state) and general (trait). State hope refers to situation-specific hope and is measured in a particular moment. Trait hope, on the other hand, is a stable dispositional characteristic that applies across situations in which an individual experiences hopeful thinking. Following his interviews with participants about their goals, he determined that people tend to have general thoughts about their capabilities in attaining goals, above and beyond those about specific goals. To date, however, the relationship between state and trait hope is not well understood.

In the early 1990s, Snyder and his colleagues put forth this definition of hope: "hope is a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (Snyder, Irving, & Anderson, 1991, p. 250). Snyder further defined hope as "goal-directed thinking in which the person utilizes pathways thinking (the perceived capacity to find routes to desired goals) and agency thinking (the requisite motivations to use those routes)" (Snyder & Lopez, 2007b, p. 189). And so, Snyder's theory builds on Stotland's conceptualization of hope by breaking the cognitive process of analyzing goal-related outcomes into two components: agency and pathways. We will take a more detailed look at each of the three core components of hope theory: goals, pathways and agency.

According to Snyder, "the goal is the cognitive component that anchors hope theory" (Snyder, 2002, p. 251). Goals must be of value to the individual and they can vary depending on a number of factors: specificity, temporality (short-term vs. long-term goals), approach-oriented goals (aimed at reaching a particular goal) versus preventative goals (aimed at averting an undesired event), and difficulty of attainment (easy versus difficult) (Snyder). Lazarus (1999) specified what constitutes a legitimate goal, suggesting that people hope for something only when there is a lack of that something in their life; in other words, when life circumstances are unsatisfactory. However, Snyder points out that Lazarus' definition precludes two categories of hope: "maintenance goals", which are the goals of daily living, and "enhancement goals", which build on what is currently thought of as satisfactory to arrive at even larger goals. These two types of goals fall into hope theory's definition of goals.

Pathways are the means by which a person reaches his or her goals; "for a high-hope person pursuing a specific goal, pathways thinking entails the production of one plausible route, with a concomitant sense of confidence in this route" (Snyder, 2002, p. 251). A person with high hope would thus be more certain about the pathways to reaching their goal than a person with low hope. A high hoper would also be skilled at finding alternate routes to his or her goals, as opposed to a low hoper who would be more easily dissuaded from goal attainment if one route were blocked.

Agency thinking is "the perceived capacity to use one's pathways to reach desired goals" (Snyder, 2002, p. 251). It is the motivational component of the model, where a person maintains their pursuit of a goal through all stages of the goal attainment process. High hopers tend to use positive self-talk, such as "I can do this" to get them through to their goals. This aspect of hope is especially relevant when blockages are faced.

Snyder differentiated between "high hopers" and "low hopers". He defined those with high hope as those who "have positive emotional sets and a sense of zest that stems from their histories of success in goal pursuits" (Snyder & Lopez, 2007b, p. 189). Comparatively, those with low hope, have "negative emotional sets and a sense of emotional flatness that stems from their histories of having failed in goal pursuits" (Snyder & Lopez, p. 189). Hope is therefore defined in this framework as a generally stable trait, which is developed over time as a result of positive goal attainment experiences, which produces positive emotions leading to an increased sense of agency and pathways thinking. The hope theory model elucidates the process by which hopeful thinking develops, goals are attained, and agency and pathway thinking is reinforced (see Figure 3).

The hope theory model

Children learn to hope from their parents (Snyder & Lopez, 2007). Snyder posits that hope is entirely learned and has no hereditary contributions; "the teaching of pathways and agency goal-directed thinking is an inherent part of parenting, and the components of hopeful thought are in place by age two" (Snyder & Lopez, 2007, p. 190). In contrast, some theorists have argued that the development of future-oriented cognitions, such as hope, require abstract thought and reasoning capacities, which typically develop around age four (Reading, 2004). Pathways thinking, which is acquired before agency thinking, consists of basic cause-and-effect learning. These are the lessons children learn over the course of development relating to correlation and causation (Snyder & Lopez). Agency thinking begins around the first year and represents the child's recognition that she is “the causal force in many of the cause-and-effect sequences in her surrounding environment” (Snyder & Lopez, p. 190). Snyder draws attention to the importance of early attachment in the development of hope (Snyder, 2000). This assertion has been supported empirically (Shorey, Snyder, Yang, & Lewin, 2003). He also notes that traumatic events experienced in childhood can lessen the level of hope that is developed across the life course. Further, adults may lose hope when they experience a loss, such as the death of a loved one (Snyder, 2002). This framework has implications for parents of children with ND. The actual and psychosocial losses experienced by these parents (Costantino, 2010; Olshansky, 1962; Riesz, 2004) can lead to a loss of hope. Over time, this loss of hope may have ramifications for the parents’ ability to maintain hope in the long term.

The hope theory model, which describes the process of hoping, starts with an iterative relationship between the pathways and agency components of hope, or hope thoughts. Pathways and agency thinking, a learned process beginning in childhood, are brought into situations of goal pursuits. Next are the emotional sets that are applied to specific goal pursuit activities. These include the emotions people have attached to the pursuit of a specific goal (state hope) or of goal attainment in general (trait hope). Next the values associated with specific goal pursuits are considered; there must be sufficient value tied to a given goal outcome in order for it to continue to be hoped for. Now the pathways and agency thoughts are applied to the goal. Emotions act as a feedback loop which either positively or negatively reinforce or inhibit the process. For example, if the process seems to be going well up to this point, the person will experience positive emotions, which will reinforce the continued pursuit of that goal. Emotions are seen as having a very functional role in this model; “emotions serve to establish our position vis-à-vis our environment, pulling us toward certain people, objects, actions, and ideas, and pushing us away from others” (Snyder, 2002, p. 254). Emotions may facilitate the pathways and agency processes if people find it helpful to process and express emotions; this will ease the progression of the goal attainment.

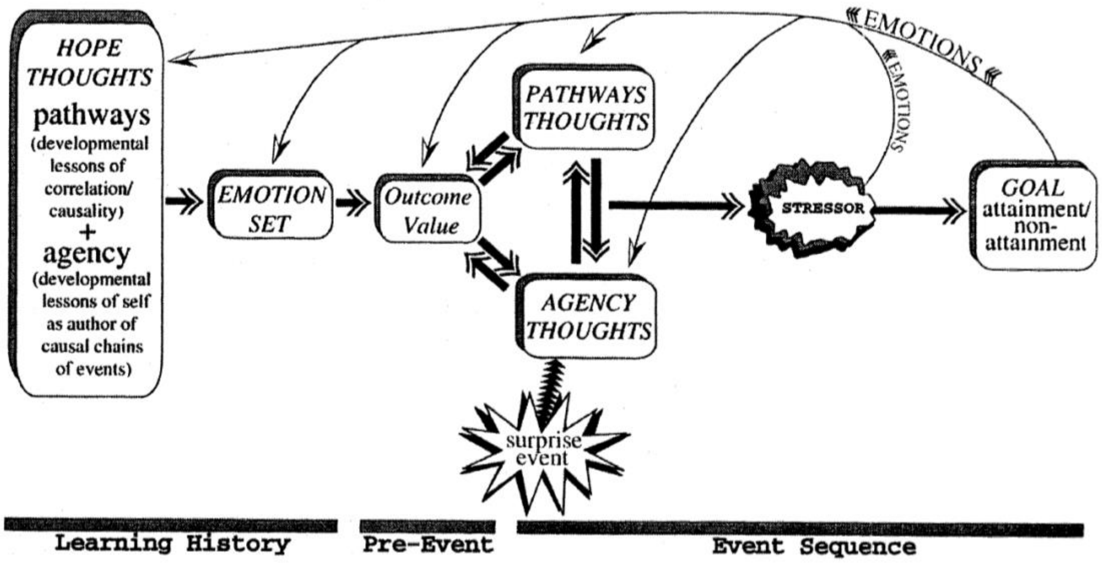

Figure 3. Snyder's hope theory model (Snyder, 2002).

Stressors are "any impediment of sufficient magnitude to jeopardize hopeful thought" (Snyder, 2002, p. 254). These barriers may block the attainment of a goal and result in a reduction of a person's agency. A person's appraisal of their ability to navigate a barrier and attain goals has an effect on emotions; "the successful pursuit of desired goals, especially when circumventing stressful impediments, results in positive emotions and continued goal pursuit efforts (i.e., positive reinforcements)" (Snyder & Lopez, 2007, p. 190). In contrast, when a person cannot navigate around the stressor and is therefore not successful in accomplishing a goal, negative emotions result. According to Lazarus and colleagues (1952), stress results from a person's appraisal that they cannot navigate around an obstacle; this appraisal will depend on their overall level of hope. High hopers, for example, who are used to successfully navigating challenges to goal attainment, typically have positive emotions, which helps them to see barriers (stressors) as challenges and are likely to explore alternative routes to goal attainment. This process is referred to as "coping" by Lazarus (1999). Whereas, low hopers, used to being obstructed from their goals, will show negative emotions and become stuck as a result of a blockage. This experience will in turn influence the person's state and trait level of hopefulness.

Continuing on the path to goal attainment in the hope theory model, once a person has successfully navigated around the stressor or if there was no stressor, agency and pathways thinking continue to influence one another as the person moves toward their goal. Emotions and cognitions about goal attainment “cycle back throughout the goal pursuit sequences” (Snyder, 2002, p. 255). Once a goal pursuit has been accomplished, emotions and cognitions about successful or unsuccessful goal attainment flow back to impact on the outcome value of the goal and on the agency and pathways thinking, both situationally and more generally. The hope model also accounts for surprise events, which can be of either positive or negative nature. These events elicit emotions because of the contrast they introduce into the person’s regular goal-pursuit process. Although they occur outside of the usual process, “these surprise emotions are quickly incorporated into the goal pursuit thought sequence” (Snyder, p. 255).

In applying the hope theory model to parenting, we might consider the birth or diagnosis of a child with a ND as a barrier to a parent’s goal attainment, or in Snyder’s terminology, a stressor. This barrier would impact the parent’s agency related to achieving their goals. Goals might include goals for the parent themselves (e.g., career and financial goals), for their child (e.g., independence, achievement goals) and for their family (e.g., family functioning, cohesion, participation in leisure activities). As the presence of a child with a ND places additional needs on the family system as a whole, goals at each of these levels might be thwarted and require re-consideration. Parents who are high hopers may be successful at finding alternate pathways to achieving their goals, or may modify their goals. For example, a parent who had a goal of independence for their child may resolve that independence for a child with ND entails being involved in daily decision-making relating to their quality of life, rather than independent living per se. Certainly, a consideration of cultural context is essential when attempting to understand one’s goals and pathways to achieving them. For example, diverse conceptualizations of disability and what children with disabilities are capable of compared to children with no disabilities (e.g., Gannotti, Handwerker, Groce, & Cruz, 2001) will undoubtedly influence a parent’s goal-setting. High hope parents may also decide that a previously held goal no longer holds the same value as it once did given their new circumstance and may decide that it is not worth pursuing. In comparison, low hope parents may have more difficulty with this process of maneuvering around barriers, which could result in negative emotions and in turn have an impact on the parent’s sense of hopefulness.

There are challenges inherent in applying the dichotomy of high versus low hope to parents of children with ND. Since Hope Theory has not been tested empirically amongst this population, it is impossible to conclude whether this categorization is a relevant and useful one. Perhaps parents experience varying levels of hope in various aspects of their lives. For example, a parent may have high hope in the domain of family functioning, but low hope for their child's future potential to attend university. Further, their hope may shift over the life course. Therefore, state hope rather than trait hope may be a more accurate way of understanding parental hope when caring for a child with a ND.

When a person judges that they are not able to successfully navigate their way around a barrier, the resultant level of stress will be a product of their general level of hope. It could be hypothesized, then, that parents with low levels of trait hope may experience more stress than parents with high hope in response to having a child with a ND. To date, the hope model framework has not been applied directly to parenting of children with ND and therefore this theory has yet to be tested empirically. What this theory does not account for is parents who maintain high levels of hope despite their reality of having a child with a ND *and* not achieving their goals. Although, as was mentioned previously, it is important to consider how these goals are constructed. The following questions ensue: are these parents living in denial? What can explain their high hope despite (or because of) their circumstances, which are seen by many as being extremely challenging? Is maintaining high hope in difficult circumstances indicative of maladaptive coping strategies that may be harmful to the parent and family system? We turn to a discussion of realistic and false hope for answers to some of these queries.

Realistic and false hope

A significant scholarship points to many advantages of having high levels of hope. However, some scholars have maintained that having high levels of hope may possibly be maladaptive (Snyder, 2002). Three arguments emerge in the scholarship endorsing this claim: 1) false hopes reflect expectations which are focused on illusions, 2) false hopes represent the pursuit of unsuitable goals, and 3) false hopes lead to poor goal attainment strategies (Snyder). These claims will each be examined from the perspective of hope theory, which disputes them.

Snyder (2002) argues that high hopers (potential false hopers) do not have "extreme biases" when it comes to being out of touch with reality. He also notes that they do not continue to maintain high hope despite feedback indicating that the goal may not be realistic; "high hopers appear to calibrate their goal expectancies according to the relevant boundary conditions" (Snyder, p. 264). He maintains that high hopers tend to be energized by barriers to goal attainment. Faced with such a barrier, they will put their energy into finding alternate pathways to achieving goals. A final argument against the contention that false hope is based on illusions is that a recent body of literature has found that high hopers, when faced with traumatic events, tend to find a sense of benefit and meaning in their circumstances. Additionally, this sense of benefit and meaning is related to general well-being and adjustment (Snyder). This has been evidenced in the literature on parents of children with disabilities and chronic health conditions (e.g., Cadell et al., 2014; Hartshorne, 2002; Hastings, 2016; Hastings & Taunt, 2002; King et al., 2006; MacDonald, Hastings, & Fitzsimons, 2010; McConnell & Savage, 2015), which suggests that some parents are able to make meaning out of their reality of having a child with high needs. One could argue that this, then, does not represent false hope.

The second argument states that false hopes are based on poorly chosen goals. These goals may be unattainable because they are too large, or may be negative goals in the sense that they are maladaptive for the individual or society at large. Snyder (2002) argues that people who set unreachable goals are, in fact, *low* in hope. He also points out that someone may set a lofty and unattainable goal for themselves with the understanding that it will not be met, but that an approximation of the goal is possible. The example he gives is of Christians who strive to emulate the perfection of Jesus Christ in their daily lives. These individuals are aware that being Jesus (God) is not a realistic and attainable goal, but that being *God-like* is. And this process of seeking to reflect such behaviour brings fulfillment to the Christian. The idea of pursuing seemingly unattainable goals is also relevant in the arena of terminal illness, where physicians may choose to offer hope to a patient despite the medical improbability of recovery or sustained life. Parents of children with ND may have goals for their children that seem to be unattainable, such as the child attending university. However, this line of thinking allows for flexibility in terms of how that goal is realized. Perhaps an adult child with a ND may complete an adult education program and become certified to perform a technical job. In this way, the parent cannot be said to have maintained false hope for their child because they recognize that their child may realistically only be able to attain an approximation of that goal.

The final argument is that false hopers choose inappropriate strategies for goal attainment. This argument runs counter to hope theory's concept of pathways thinking, which states that high hopers consistently choose successful pathways to their goals and low hopers do not. Therefore, "because pathways thought by definition is related to effective goal thinking, it is not possible in hope theory to find inappropriate pathways cognitions" (Snyder, 2002, p. 268). Direct empirical testing of the hypothesis that false hope leads to an inability to choose successful pathways to goal achievement has consistently found no support (Kwon, 2000).

Snyder's conclusion, based on the empirical and theoretical scholarship, is that the idea of false hope is not supported. To date, however, the idea of false hope has not been applied and studied in relation to parents of children with ND, who may have expectations about their child's future that are seen as unrealistic according to socially constructed norms of ability and independence. This is a pertinent concept in the context of parenting children with ND since parents are flooded with information and promises of recovery from a whole host of sources, resulting in a spectrum of hopefulness in relation to their child's future abilities, level of participation, and quality of life. It remains unclear whether the concept of false hope is applicable in this context and whether there is such a thing as a realistic amount of hope for parents who have children with ND. Additionally, the assumption that hope is only functional and "true", as opposed to "false", when based on reasonable and attainable goals should be examined. There may be value in hope that is in fact based on unrealistic outcomes, and yet brings comfort, strength, or a certain amount of peace to the parent. In other words, hope for hope's sake.

Empirical applications of Snyder's hope theory

Snyder and his colleagues have used hope theory to develop a number of self-report scales to measure hope: the Trait Hope Scale (Snyder et al., 1991), a 12-item trait measure of hope for adults; the State Hope Scale (SHS), a 6-item scale measuring here-and-now goal-directed thinking; and the Children's Hope Scale, a 6-item trait measure of hope for children age 8 to 15 years. These measures have all demonstrated good psychometric properties (Lopez, Ciarlelli, Coffman, Stone, & Wyatt, 2000). There is some evidence of validation of these instruments across different cultural groups (e.g., Chang & Banks, 2007; Marques, Pais-Ribeiro, & Lopez, 2009). Snyder, as well as many other researchers, have utilized these scales in the study of hope and have found that the predictors of hope remain even when other related but distinct constructs, such as optimism, self-efficacy, well-being and self-esteem, are taken into account (Magaletta & Oliver, 1999; Snyder, 2002). Hope Scale scores predict outcomes in various domains: academics, sports, physical health, adjustment, and psychotherapy (Snyder). For example, hope has been found to correlate highly with such academic results as tests of achievement in grade-school children (Snyder et al., 1997) and higher overall Grade Point Averages in both high school and college students (Snyder et al., 1991). Higher hope is also related to better overall psychological adjustment in both clinical (psychiatric) and normative populations (Cramer & Dyrkacz, 1998; Irving, Crenshaw, Snyder, Francis, & Gentry, 1990; Kwon, 2002). One explanation offered by Snyder for such findings is that high hopers tend to be better able to find alternate routes to goal achievement when there is a blockage of their goal pursuit. Because high hope is associated with better social adjustment, and more positive views about interpersonal relationships, these individuals are apt to call on social supports, such as friends and family, when they encounter stressors.

Other hope theories

Although this chapter has mainly highlighted Snyder's hope theory as the seminal framework to study hope, a number of other hope theories are important to mention. Mowrer (1960), a learning theorist, assumed that hope, along with the other primary emotion, fear, was learned by simple conditioning. Based on research with rats who he said experienced hope when they observed a stimulus that was linked with something pleasurable, he concluded that fear is the antithesis of hope (Mowrer, 1960). However, Mowrer's conceptualization of hope does not account for sustained hope in light of difficult circumstances. As described in this paper, Stotland explored the role of expectancies and cognitive schemas. He saw hope as involving important goals for which there is a reasonably high perceived probability of attainment. For Stotland, anxiety, and not fear, was the opposite of hope (Scioli & Biller, 2009). A Hope Scale was created based on Stotland's theory, which consists of 20 general and common goals, although this scale has not been put to wide empirical use (Snyder & Lopez). Gottschalk (1974) defined hope as "a measure of optimism that a favorable outcome is likely to occur, not only in one's personal earthly activities but also in cosmic phenomena and even in spiritual or imaginary events" (p. 779). Based on this definition of hope, Gottschalk developed a Hope Scale, which is applied to the content analysis of 5-minute speech samples. Gottschalk's Hope Scale has shown concurrent validity in terms of positive correlations with human relations and achievement and negative correlations with depression, anxiety, sleep disturbance, hostility, and social alienation in both normative and clinical samples (Gottschalk). Hope scores also predicted favorable outcomes, such as survival time and adherence to treatment recommendations in patients with terminal cancer, and degree of improvement in a number of areas of functioning for patients in emotional crises (Gottschalk). Gottschalk's definition of hope differed from Stotland's in that it considered the expectation of outside help as a contributor to an individual's hope (Scioli & Biller).

Abramson and colleagues (1989), building on the helplessness theory of depression, furthered the conceptualization of hope by proposing a subtype of depression, which they dubbed hopelessness depression. Abramson utilized the foundational idea of a hopeful mindset to develop her conceptualization of hope, which included an individual's positive outcome expectancies, as well as their perception of having the necessary resources to achieve this goal (Scioli & Biller). Snyder's hope theory is a further elaboration of this theorizing.

Breznitz (1999), a stress researcher, considered hoping to be both an emotional and a cognitive process involving expectations about the future. That is, a cognitive appraisal is involved in selecting positive outcomes out of many potential futures. He proposed five metaphors to capture the ways in which individuals hope in response to stressors such as a serious illness: hope as a protected area, a bridge, a vital principle, a skill, and an end in itself (Scioli & Biller, 2009). He cautioned, though, that hope might be an illusion akin to denial (Snyder & Lopez, 2007). Averill and colleagues (1990) put forth a definition of hope in affective terms; hope as an emotion with cognitive rules governing it. According to this theory, in order for the emotion of hope to be appropriate, the goal being pursued must be important, under some control, probable, and socially acceptable (Snyder & Lopez). Averill, like Breznitz, sought to capture the experience of hope in metaphors (Averill et al.).

Erikson (2000), a psychologist, defined hope as "the enduring belief in the attainability of fervent wishes" (p. 193). He saw hope as "the most fundamental human virtue" (Scioli & Biller, 2009, p. 25) and emphasized the role of environment in the development of hope. Staats (1989) proposed that hope is the "interaction between wishes and expectations" (p. 367). He developed a measure for tapping the affective and cognitive aspects of hope. Finally, building on some of the above-mentioned frameworks of hope, Scioli and Biller (2009) propose an integrative theory of hope where hope is defined as,

> A future-directed, four-channel emotion network, constructed from biological, psychological, and social resources. The four channels are the mastery, attachment, survival and spiritual subsystems. The hope network is designed to regulate these subsystems via both feed-forward (expansion) and feedback (maintenance) mechanisms, resulting in a greater perceived probability of power and presence as well as protection and liberation (p. 30).

A more recent conceptualization of hope is one put forth by Wong and colleagues (in press). They define Vicarious Futurity as "the hope and despair that a person has for another's future" (Wong et al., p. 3). The concept arose from the constructs of "personal futurity", which is the hope and despair that an individual has for their own future; hope; optimism; and self-efficacy (Wong et al.). These denote expectancies of a certain future outcome and have been shown to be positively correlated with many determinants of health and well-being and negatively correlated with risk factors, such as depression (Wong et al.). A measure of vicarious futurity, the Vicarious Futurity Scale (VFS; Dossetor, Santhanam, & Nunn, 1998) was developed based on a measure of personal futurity derived from Stotland's Hope Theory, the Hunter Opinions and Personal Expectations Scale (HOPES; Nunn, Lewin, Walton, & Carr, 1996). The VFS was developed and piloted with parents of typically developing children (Wong et al.), as well as children with autism and childhood dementia (Wong & Heriot, 2007). Eighty percent of parents of children with autism in the latter study were found to have low vicarious hope and high vicarious despair, compared to a normative sample of parents (Wong & Heriot). This points to the potential usefulness of this measure in studies of parenting children with ND. These findings also highlight the need to further explore the concepts of vicarious hope and despair and their relation to child and family outcomes. The notion of despair has been especially absent from studies of childhood disability; perhaps because of the assumption that parents are either not despairing or that they will not speak about it.

In contrast to the above-mentioned frameworks, which largely put forth an individualistic understanding of hope, some have conceptualized hope as a more collective experience. Collective hope is defined by Snyder as "the level of goal-directed thinking of a large group of people" (Snyder & Lopez, 2007, p. 194). This is evidenced, for example, when a group of people join forces to accomplish a goal that would have been impossible if tackled by one person alone. Given the adage "it takes a village" (to raise a child), the concept of collective hope may be applicable to the experience of caring for a child with a ND. Parents of children with disabilities and chronic health conditions often speak of "communities of care"; family, friends, and care providers who are united in their love and who pool their resources to care for a child. It is possible that at times when a parent lacks hope for the future, that others in their support networks may supplement that lack of hope with a collective sense of hopefulness. Marcel, a Christian existentialist, conceptualized hope as being the power to cope with helpless circumstances, based on the experiences of prisoners of war (Snyder & Lopez). He distinguished between fear and desire and despair and hope; the former relates specifically to an object, whereas the latter does not, the essence of is simply *to hope* or *to despair* (Marcel, 1973). The person who hopes, hopes only for deliverance from their current situation, and not in a particular solution. As with most philosophers and theologians who have put forth conceptualizations of hope, Marcel emphasized attachment and spiritual strivings. His famous quote: “I hope in thee for us” (Scioli & Biller, p. 27) demonstrates a focus on the communion of humanity in times of suffering and loss, rather than a concern for individual well-being. There can be no hope then that “does not constitute itself through a we and for a we” (Marcel, p. 143). Marcel’s “communal hope” (Scioli & Biller, p. 28) takes into consideration the way that hope impacts on one’s understanding and experience of time. He also distinguished between hope and refusing to accept reality (Scioli & Biller, 2009). Building on this existentialist understanding of hope, a number of other theorists and philosophers (e.g., Pruyser) described hope in more spiritual terms, underscoring spiritual factors, such as contact with a higher power, in the evolution of hope (Scioli & Biller). Reasonable hope was conceptualized as a variant of hope by Weingarten (2010). She suggests that this kind of hope softens the disparity between hope and despair; it is “sensible and moderate” (Weingarten, p. 7). Reasonable hope is about the actions one takes, rather than about the emotions one is able to muster (Weingarten). This definition of hope is along the same lines as Snyder’s collective hope and Marcel’s communal hope in that it may involve the actions of a group of people; it is relational at its core. This conceptualization differs from many of the other frameworks of hope in that it is not focused on the future; “reasonable hope’s objective is the process of making sense of what exists now in the belief that this prepares us to meet what lies ahead” (Weingarten, p. 7). Thus the emphasis is on the process, rather than on the end product (the goal). This hope allows for the co-existence of uncertainty, doubt and despair and sees hope as being co-created (Weingarten).

Application of Parenting and Hope Theories to the Current Study

The positive psychology framework and many of the hope theories acknowledge both strengths and weakness, resources and stressors. They likewise examine the question of why some families facing challenges seem to manage well, while others have a more difficult time. This makes them pertinent to the study of families of children with ND. However, the most prominent hope theories, such as Stotland’s (1969) and Snyder’s (Snyder, Rand, & Sigmon, 2002) suffer from some noteworthy shortcomings which may limit their usability in empirical research and clinical work with families of children with ND. First, they are goal-based, cognitively-focused theories which view emotions as being of secondary importance. Second, they were not generated or validated among families of children with ND. Third, Snyder's theory categorizes individuals as either high or low hopers, which may be an oversimplification of the complexity of a parent's hope for their child. They may have varying levels of hope or ways of approaching future goals and expectations for themselves versus for their child. Fourth, these theories do not account for parents who maintain a high level of hope for the future despite the reality of having a child with ND and not achieving previously set goals, as I have observed in my clinical and research work with families. And finally, I question whether the concept of false hope (in other words, being in denial or seeking unrealistic goals) is a valid or helpful one, given the context of caring for a child whose needs mean that many typical or standard life goals may require adjusting.

Some elements of other hope theories are drawn upon in this thesis, including the Vicarious Futurity framework (Wong & Heriot, 2007), which has guided the objectives of this dissertation research focused on the hope that a parent has for their child's future. The concept of collective hope is also one that is interesting and likely relevant to families of children with ND whose networks of formal and informal supports are central to their daily lives and functioning.

References

Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of clinical child psychology, 21*(4), 407-412.

Abramson, L. Y., Alloy, L. B., & Metalsky, G. I. (1989). Hopelessness depression: A theory-based subtype of depression. *Psychological Review, 96*(2), 358-372.

Averill, J. R., Catlin, G., & Chon, K. K. (1990). *Rules of hope*. New York: Springer-Verlag.

Banks, S., & Miller, D. (2005). Empowering Indigenous families who have children with disabilities: An innovative outreach model. *Disability Studies Quarterly, 25*(2).

Belsky, J. (1984). The determinants of parenting: A process model. *Child Development, 55*, 83-96.

Breznitz, S. (1999). The effect of hope on pain tolerance. *Social Research, 66*(2), 629-652.

Cadell, S., Hemsworth, D., Smit Quosai, T., Steele, R., Davies, E., Liben, S., . . . Siden, H. (2014). Posttraumatic growth in parents caring for a child with a life-limiting illness: A structural equation model. *AMerican Journal of Orthopsychiatry, 84*(2), 123-133. doi:10.1037/h0099384

Chang, E. C., & Banks, K. H. (2007). The color and texture of hope: Some preliminary findings and implications for hope theory and counseling among diverse racial/ethnic groups. *Cultural Diversity and Ethnic Minority Psychology, 13*(2), 94-103. doi:10.1037/1099-9809.13.2.94

Costantino, M. (2010). Parenting Children With Disabilities: Navigating Through the Storms. *Journal of Creativity in Mental Health, 5*(1), 87 - 92.

Cramer, K. M., & Dyrkacz, L. (1998). Differential prediction of maladjustment scores with the Snyder hoep subscales. *Psychological Reports, 83*, 1035-1041.

Dossetor, D. R., Santhanam, R., & Nunn, K. P. (1998). *Does vicarious futurity have a future? A measure to assess parent child relationships.* Paper presented at the Annual Conference of the Royal Autralian and New Zealand College of Psychiatrists, Sydney, Australia.

Erikson, E. H. (2000). *The Erik Erikson reader*. New York: Norton.

Floyd, F. J., & Saitzyk, A. R. (1992). Social class and parenting children with mild and moderate Mental Retardation. *Journal of Pediatric Psychology, 17*(5), 607-631. doi:10.1093/jpepsy/17.5.607

Gannotti, M. E., Handwerker, W. P., Groce, N. E., & Cruz, C. (2001). Sociocultural influences on disability status in Puerto Rican children. *Physical Therapy, 81*(9), 1512-1523.

Gottschalk, L. A. (1974). A hope scale applicable to verbal samples. *Archives of General Psychiatry, 30*, 779-785.

Greenley, R. N., Holmbeck, G. N., & Rosie, B. M. (2006). Predictors of parenting behavior trajectories among families of young adolescents with and without spina bifida. *Journal of Paediatric Psychology, 31*, 1057-1071.

Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *Journal of Individual Psychology, 58*(3), 263-278.

Hastings, R. P. (2016). Chapter Six - Do Children With Intellectual and Developmental Disabilities Have a Negative Impact on Other Family Members? The Case for Rejecting a Negative Narrativea. In R. M. Hodapp & D. J. Fidler (Eds.), *International Review of Research in Developmental Disabilities* (Vol. 50, pp. 165-194): Academic Press.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*(2), 116-127. doi:10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2

Hoghughi, M. (2004). Parenting: An introduction. In M. Hoghughi & N. Long (Eds.), *Handbook of parenting: Theory and research for practice*. London: Sage.

Irving, L. M., Crenshaw, W., Snyder, C. R., Francis, P., & Gentry, G. (1990). *Hope and its correlates in a psychiatric setting*. Paper presented at the Midwestern Psychological Association, Chicago.

Khanlou, N., Haque, N., Davidson, D., & Dastjerdi, M. (2016). *Voice of immigrant mothers of children with disabilities: Availability and use of social support.* Retrieved from Toronto, Ontario:

King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health & Development, 32*(3), 353-369.

Kwon, P. (2000). Hope and dysphoria: The moderating role of defense mechanisms. *Journal of personality, 68*(2), 199-223.

Kwon, P. (2002). Hope, defense mechanisms, and adjustment: Implications for false hope and defensive hopelessness. *Journal of personality, 70*, 207-231.

Laskey, B. J., & Cartwright-Hatton, S. (2009). Parental discipline behaviours and beliefs about their child: associations with child internalizing and mediation relationships. *Child: Care, Health & Development, 35*(5), 717-727.

Lazarus, R. S. (1999). Hope: An emotion and a vital coping resource against despair. *Social Research, 66*, 665-669.

Lazarus, R. S., Deese, J., & Osler, S. F. (1952). The effects of psychological stress upon performance. *Psychological Bulletin, 49*, 293-317.

Lopez, S. J., Ciarlelli, R., Coffman, L., Stone, M., & Wyatt, L. (2000). Diagnosing for strengths: On measuring hope building blocks. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications*. San Diego, CA: Academic Press.

MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological Acceptance Mediates the Impact of the Behaviour Problems of Children with Intellectual Disability on Fathers' Psychological Adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*(1), 27-37. doi:10.1111/j.1468-3148.2009.00546.x

Magaletta, P. R., & Oliver, J. M. (1999). The hope construct, will, and ways: Their relations with self-efficacy, optimism, and general well-being. *Journal of Clinical Psychology, 55*(5), 539-551. doi:10.1002/(sici)1097-4679(199905)55:5<539::aid-jclp2>3.0.co;2-g

Marcel, G. (1973). *Tragic wisdom and beyond* (S. Jolin & P. McCormick, Trans.). Evanston, IL: Northwestern University Press.

Marques, S. C., Pais-Ribeiro, J. L., & Lopez, S. J. (2009). Validation of a Portuguese version of the Children's Hope Scale. *School Psychology International, 30*(5), 538-551. doi:10.1177/0143034309107069

McConnell, D., & Savage, A. (2015). Stress and Resilience Among Families Caring for Children with Intellectual Disability: Expanding the Research Agenda. *Current Developmental Disorders Reports, 2*(2), 100-109. doi:10.1007/s40474-015-0040-z

Midouhas, E., Yogaratnam, A., Flouri, E., & Charman, T. (2013). Psychopathology Trajectories of Children With Autism Spectrum Disorder: The Role of Family Poverty and Parenting. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(10), 1057-1065.e1051. doi:http://dx.doi.org/10.1016/j.jaac.2013.07.011

Mitchell, D. B., & Hauser-Cram, P. (2008). The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care. *Research in Developmental Disabilities, 29*(2), 97-112.

Mowrer, O. H. (1960). *Learning theory and behavior*. New York: Wiley.

Nunn, K. P., Lewin, T. J., Walton, J. M., & Carr, V. J. (1996). The construction and characteristics of an instrument to measure personal hopefulness. *Psychological Medicine, 26*, 531-545.

Olshansky, S. (1962). Chronic Sorrow: A Response to Having a Mentally Defective Child. *Social Casework, 43*(4), 190-193.

Osborne, L. A., & Reed, P. (2010). Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders, 4*(3), 405-414.

Pascoe, J. M., Losa, F. A., Jeffries, V., & Easp, J. A. (1981). The association between mother's social support and provision of stimulation to their children. *Developmental and Behavioral Pediatrics, 2*, 15-19.

Reading, A. (2004). *Hope and despair: How perceptions of the future shape human behavior*. Baltimore: Johns Hopkins University Press.

Riesz, E. D. (2004). Loss and Transitions: A 30-Year Perspective on Life with a Child Who Has Down Syndrome. *Journal of Loss & Trauma, 9*(4), 371-382.

Scioli, A., & Biller, H. B. (2009). *Hope in the age of anxiety*. Oxford: Oxford University Press.

Shorey, H. S., Snyder, C., Yang, X., & Lewin, M. R. (2003). The role of hope as a mediator in recollected parenting, adult attachment, and mental health. *Journal of Social and Clinical Psychology, 22*(6), 685-715. doi:http://dx.doi.org/10.1521/jscp.22.6.685.22938

Snyder, C. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249-275. doi:http://dx.doi.org/10.1207/S15327965PLI1304_01

Snyder, C., Rand, K. L., & Sigmon, D. R. (2002). Hope theory: A member of the positive psychology family. *Handbook of positive psychology* (pp. 257-276). New York, NY: Oxford University Press.

Snyder, C. R. (2000). Genesis: The birth and growth of hope. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications* (pp. 25-38). San Diego, CA: Academic Press.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., . . . Harney, P. (1991). The will and the way: Development and validation of an individual-differences measure of hope. *J Pers Soc Psychol, 60*, 570-585.

Snyder, C. R., Hoza, B., Pelham, W. E., Rapoff, M., Ware, L., Danovsky, M., . . . Stahl, K. J. (1997). The development and validation of the Children's Hope Scale. *Journal of Pediatric Psychology, 22*, 399-421.

Snyder, C. R., & Lopez, S. J. (2007). Seeing our futures through self-efficacy, optimism and hope. In C. R. Snyder & S. J. Lopez (Eds.), *Positive psychology: The scientific and practical explorations of human strengths* (pp. 165-204). Thousand Oaks, CA: Sage Publications, Inc.

Staats, S. (1989). Hope: A comparison of two self-report measures for adults. *Journal of Personality Assessment, 53*(2), 366-375.

Stabile, M., & Allin, S. (2012). The economic costs of childhood disability. *Future Child, 22*(1), 65-96.

Stotland, E. (1969). *The psychology of hope: An integration of experimental, clinical, and social approaches*. San Francisco: Jossey-Bass Inc.

Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 3*(1), 86-97. doi:https://doi.org/10.1016/j.rasd.2008.04.006

Ventola, P., Lei, J., Paisley, C., Lebowitz, E., & Silverman, W. (2017). Parenting a Child with ASD: Comparison of Parenting Style Between ASD, Anxiety, and Typical Development. *Journal of Autism and Developmental Disorders, 47*(9), 2873-2884. doi:10.1007/s10803-017-3210-5

Weingarten, K. (2010). Reasonable Hope: Construct, Clinical Applications, and Supports. *Family Process, 49*(1), 5-25.

Wong, M. G., & Heriot, S. A. (2007). Vicarious Futurity in Autism and Childhood Dimentia. *Journal of Autism and Developmental Disorders, 37*, 1833-1841.

Wong, M. G., Heriot, S. A., Dossetor, D. R., & Nunn, K. P. (in press). Hope and Vicarious Futurity.

Linking Statement

The previous chapter set the groundwork for the study by presenting the theoretical scholarship on parenting and hope and offering a critique from the perspective of its applicability to the study of parenting children with ND. The following chapter presents the guiding paradigms informing this empirical study, including Symbolic Interactionism, Constructivism, and Pragmatism, outlines methodological procedures undertaken in this study, including ethical considerations, sampling, data analysis, and integration of the scholarly literature, and finally, provides an in-depth consideration of evaluating the quality of this qualitative study. Manuscripts 1 and 2 will provide more detail about the methodological approach and procedures.

Chapter 3: Methods

The current chapter introduces CGT, the methodological approach applied in this dissertation study of hope among parents of children with ND. The theoretical foundations of CGT are presented so as to situate the empirical study within these paradigms and to link with the next chapter, which offers further detail about CGT and elucidates methodological decisions taken during the course of the study.

Theoretical Foundations of Constructivist Grounded Theory

Symbolic interactionism (SI) and constructivism are paradigms guiding this study. SI, defined by Herbert Blumer and derived from pragmatism (George Herbert Mead), assumes that "society, reality, and self are constructed through interaction and thus rely on language and communication…[and] that interaction is inherently dynamic and interpretive and addresses how people create, enact and change meanings and actions" (Charmaz, 2006, p. 7). SI holds three basic premises:

> 1. Human beings act toward things on the basis of the meanings that things have for them;
> 2. the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows; and
> 3. these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, 1969, p. 3).

Charmaz (1980) adds the following three premises to build on and clarify Blumer's construct:

> 1. meanings are interpreted through shared language and communication;
> 2. the mediation of meaning in social interaction is distinguished by a continually emerging processual nature; and
> 3. the interpretive process becomes explicit when people's meanings and/or actions become problematic or their situations change (p. 25).

This perspective is useful to the study of hope. SI views interpretation and action as reciprocal processes (Charmaz, 2014). In relation to parenting, we know that parents act in relation to their children and their interpretations of their child's behavior. It follows that how parents interpret and make sense of their child's condition influences how they act. And in turn, their actions will shape how they view the future and their hope for their child's future. In other words, their subjective understandings of hope change over time as their experiences and actions change. I have observed that among parents of children with disabilities, hoping is an active process. Most of the parents I spoke with talked about hope in a way that suggested action; for them, hope necessarily led to doing. Viewing individuals as active agents in their lives, engaging in activities that impact the world, is in line with SI.

Mead's pragmatism declares that a good theory is one that is useful in solving social problems. Pragmatism is especially useful in social work research since it is consistent with key social work values of the pursuit of social justice, and service to humanity (Canadian Association of Social Workers, 2005a). The pragmatist emphasis on the practical application of empirical theories is well suited to using the findings to influence policies and practices impacting the populations studied. Pragmatism also views reality as open to multiple interpretations (Charmaz, 2014). Truth and reality are tested by way of their practical application. In line with this approach is constructivism, which begins an inquiry with the individual's experience and asks how the individual constructs it, why they constructed it, and what is constructed (Charmaz, 2006). Charmaz's CGT methodology views data and analysis as constructions, "created from shared experiences and relationships with participants and other sources of data" (p. 130). The constructivist paradigm reflects an epistemology and an ontology that recognizes multiple realities and the transactional and subjective nature of research findings. As such, grounded theorists take a reflexive stance to inquiry, recognizing what they bring to the research process and are as transparent as possible about this. Such reflection has been integrated in each step of the research process undertaken for this study and is discussed in great depth in Chapter 4/Manuscript 1 of this dissertation.

Further to sharing common roots in the foundational paradigms of pragmatism and constructivism (Oktay, 2012), GT methodology and the field of social work are a good fit for a number of reasons. Both emphasize the interaction between person and the environment -- commonly referred to as goodness-of-fit in social work. Both focus on the self or use of self, viewing individuals as active agents who develop their identity based on interactions with others in their social contexts, and on "meanings derived from the larger society" (Oktay, 2012, p. 12). GT methods can thus be used to test "practice wisdom" emerging from clinical settings, and to develop and expand existing theories and conceptual models that inform evidence-based social work practice. In line with the constant comparative model of GT, theoretical understandings of social and social psychological processes can in turn be taken up in practice settings and tested for their clinical usefulness. As a discipline that values theory- and evidence-informed interventions, it is imperative that social work practice draws from relevant and rigorous empirical research. For these reasons, CGT was deemed a fitting approach for the current study[3].

The aim of the study described in this dissertation was to gain a meaningful understanding of parental hope experiences in order to develop a theory of the process of hope in relation to parenting a child with ND. In order to address the gaps in the literature relating to the experiences of hope for parents who care for a child with ND, the goals of this project were to 1) identify key elements and processes of hope in mothers and fathers of children with ND; and 2) develop a conceptual understanding of the experience of hope for mothers and fathers of children with ND.

The following research questions guided the study:

1. How is hope expressed in the lives of parents of children with ND?
    a. How does hope emerge over time? How is it constructed?
    b. Where is hope found?
    c. What strategies are employed to maintain hope? What fosters or impedes ways of hoping?
    d. How does social context affect hope?
    e. What difference does hope make?

The methodological procedures described next provide details about ethical considerations taken into account during the planning and execution of the study and steps taken to ensure ethical guidelines in research were followed; sampling procedures; methods of data analysis including the integration of scholarly literature, and finally; a thorough discussion of evaluating the quality of a CGT study.

---

[3] A more in-depth accounting of CGT as the methodology of choice is presented in Chapters 4 and 5 of this dissertation.

Methodological Procedures

Ethical considerations

Ethics approval was received from the McGill University Research Ethics Board (REB) for this project. The research protocol for the Parenting Matters clinical study was approved by the REB of each of the recruitment sites, as well as by the academic institutions associated with each site (i.e., University of Toronto, McMaster University, McGill University, and the University of Calgary).

The data collection procedures were designed to take into account the need to collect the richest data possible, while at the same time limiting the data collection burden placed on participants. Study purposes and procedures were clearly articulated to participants at the start of the study and it was made clear that they may discontinue at any point. Participants each received a $20 gift card in recognition of their time. The only notable risk associated with this study was that by participating in the interviews, difficult struggles and life events relating to their child may have been brought up, which may have caused emotional discomfort. As per the approved ethics protocol, if, through the course of the interview, a participant became uncomfortable with the questions, they were asked if they would like to stop or take a break. They were also notified that they were not obligated to answer interview questions that made them uncomfortable. Through consideration of study aims and methods, it was determined that the benefits associated with this study of hope among parents of children with ND outweighed the minor risks posed. Study participants were informed prior to participation about the minor risks associated with participating. I was also prepared with referrals to local community resources should the need have presented itself, although these resources were not needed.

Study participants were made aware of confidentiality procedures and safeguards that were implemented throughout the study to protect their identity. This information was explained verbally as well as in the written consent form. Confidentiality was assured by assigning pseudonyms to participants for use in the data analysis. All raw data were kept secure by the researcher. Audio recordings of interviews were uploaded to a computer, saved in password-protected file, and transcribed verbatim. The recording of the interviews on the recording device were deleted. The transcripts of the interviews were kept on a password-protected computer in a password-protected file. All data and information relating to the study participants (i.e., audio files, transcriptions, consent forms, field notes, other relevant documents) were kept: 1) in a locked drawer at McGill University's Center for Research on Children and Families (CRCF); or 2) on the researcher's password-protected computer.

Sampling

An initial purposive sample of parents of children with a diagnosis of ND were selected to participate in the study. Participants were initially selected from a database of participants who had completed the first part (the quantitative portion) of a mixed method study entitled, *the CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada.* I had served in the capacity of research coordinator for the Parenting Matters! program of research through my involvement with the Centre for Research on Children and Families. Dr. Lucyna Lach, the co-Principal Investigator for the Parenting Matters! program of research and my doctoral supervisor, granted me access to the participant database for the purposes of my doctoral research. Although I served in a dual role as research coordinator for Parenting Matters! and principal investigator for the dissertation study, I had had no prior direct contact with the participants being recruited for the dissertation study and therefore did not believe there to be a conflict of interest at play or that participants might feel obligated to participate. The database consisted of parents of 263 children with ND. Parents who had completed the questionnaires (Part 1 of the Parenting Matters! study), had indicated that they were willing to participate in additional research projects by way of consent procedures, and lived in one of two jurisdictions – the Greater Toronto Area, and Montreal - served as the sampling frame. I contacted these parents to enquire about their interest in participating in an interview for the current study. Morse (2007) suggests selecting an initial sample that is homogeneous in terms of traditional demographic sampling criteria such as culture, age, and socioeconomic status. Once the researcher develops an initial sense of the experience, diversity should be sought out in order to access variations in meaning (Morse, 2007).

Sampling proceeded based on a small number of sample characteristics on which diversity was desired. For example, one assumption going into the research was that the child's level of function or the complexity of their neurological condition would make a difference to a parent's experience of hope. Another factor was a parent's sex. In the empirical scholarship on parenting, there has traditionally been an overrepresentation of the experiences of mothers. As a result, there is a bias both in the literature and in clinical practice toward understanding families of children with disabilities from the perspective of mothers. With the emergence of studies considering the differences between mothers and fathers, and more specifically, on the experiences of fathers (e.g., McNeill, 2004; Nicholas et al., 2009) there has been increasing recognition that mothers and fathers bring distinct perspectives to the parenting experience. For example, Ricci and Hodapp (2003) found that fathers appraise being the parent of a child with a disability differently than mothers, as was manifest in their divergent profiles of stress reactions. Another study found that fathers' pessimism about their child's prognosis and future was associated with dissatisfaction in their marriage, a relationship that did not hold for mothers (McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006). This approach to interviewing both mothers and fathers would allow for each to have a voice depicting their experiences and perspectives. This would also allow for the possibility of analyzing the data based on parent sex, if such an analysis emerged as theoretically relevant.

Initial sampling proceeded as described until theoretical categories began to develop through data analysis. This happened after the third interview was conducted and the transcript had undergone initial coding. At this point, sampling selection was guided by theoretical sampling based on emerging themes relating to the process of hoping (Charmaz, 1994, 2006, 2014). This approach to sampling guides the researcher to seek participants who have a sufficient understanding of the phenomenon of interest in order to maximize the richness of the data collected, as well as those whose experiences will further test emerging theoretical ideas. This sampling method is closely linked with the constant comparative method of analysis, where data collection is designed with strategies allowing for continual contrasts to be made to help bring the primary social processes into focus. As initial data are analyzed, the researcher develops initial tentative impressions, questions, and understandings about how the participants experience the phenomenon. Provisional conceptualizations are checked out by recruiting participants whom the researcher believes can further their understanding. This may mean that a particular subgroup of participants is sought out (e.g., rural families, bilingual and multilingual families, families of various cultural backgrounds). Theoretical sampling also occurs on site, where interview questions or observations are adapted toward emerging ideas (Strauss & Corbin, 1990b). Theoretical sampling can also mean going back to earlier data and sampling incidents for evidence of a tentative hypothesis. For example, based on the analysis of a first round of interviews with three participants, it became apparent that interview questions were focused solely on the experience of being hopeful and not asking explicitly about times when it felt like hope was hard to find. The interview guide was modified for the next round of interviews so that participants were directly asked to speak to the experience of hope-less-ness. As the core categories emerged through successive levels of data analysis, data collection became more directed by the emerging theory.

Theoretical sampling continued until theoretical saturation was reached (Charmaz, 2014). Charmaz (2014) defines saturation in GT as the point at which "the properties of your theoretical categories are 'saturated' with data" (p. 213). Thus, saturation is more than hearing the same or similar stories or experiences during subsequent interviews (Charmaz, 2014; Glaser, 2001). As long as participant narratives add meaningfully to the development of the conceptual understanding of the phenomenon, data collection should continue despite hearing similar stories. At the point of saturation, recurrent findings emerged, participant experiences were easily classified into existing categories, and additional data did not add meaningfully to the existing categories (Charmaz, 2014). Saturation was judged based on the following criteria, consistent with a GT approach: redundancy, feasibility, supervision, peer review, and methodological and substantive experts (dissertation committee members, colleagues, and National Research Advisory Group members).

The final sample size of eleven participants permitted descriptive analysis of the standardized data (e.g., demographic information, complexity of child's condition, parent health, financial stress) and allowed for sampling variation and heterogeneity among participants along a small number of factors which, based on the literature in the area of parenting children with disabilities, are known to make a difference to constructs related to hope, such as quality of life, and resilience. These factors included socioeconomic status, culture/language family constellation, geographic location, parent sex, child sex, and child functioning/diagnosis (Abbedutto et al., 2004; Green, 2007; Pelchat, Bisson, Bois, & Saucier, 2003; Thomasgard & Metz, 1997). Such sample diversity allowed for an appreciation of the phenomenon of interest in various forms and for the pursuit of zones of convergence and divergence in the data (Charmaz, 1994). In GT research, some contend that theoretical saturation and other considerations supersede sample size (Charmaz, 2014; Glaser, 1992, 2001; Stern, 2007). In fact, "sample adequacy" may be a more useful notion than sample size in GT studies, which seek to establish theoretical saturation through theoretical sampling: "sample size is important only as it relates to judging the extent to which issues of saturation have been carefully considered" (Bowen, 2008, p. 140). Studies with small samples such as this one may produce solid conceptual descriptions when rich data are engendered through targeted interview questions (Morse, 2007).

Data analysis

Analysis of interview data followed the CGT approach, involving a continual comparison and interplay between the data and emerging themes and working hypotheses (Charmaz, 2014). Constant comparative analysis is the "main intellectual activity that underlies all analysis in grounded theory" (Boeije, 2002, p. 392) and goes hand in hand with theoretical sampling (discussed above). Consequently, data analysis began at the very first interview and continued even as the grounded theory was being written up. Analysis, sampling, and theorizing continued in an iterative manner.

Each interview transcript was imported into Dedoose, a web-based data management and analysis application. Demographic information and some additional descriptive data collected by way of the Parenting Matters! study was imported into Dedoose as attributes (or "descriptors") of the sample. Attributes can be used in Dedoose to organize data by a particular descriptor. For example, data can be displayed based on parent sex, giving a sense of how often a mother or father endorsed a particular code or conceptual idea. As much as possible, as they were completed, interviews were transcribed and uploaded into Dedoose, where coding took place. This process is in line with the GT approach, which emphasizes the constant comparative method where early analytical ideas inform subsequent methodological decisions, such as interview questions, theoretical sampling, and hypothesis testing.

Once the first three interviews were coded, initial conceptual ideas began to form. These ideas led to the development of new interview questions that would test out some initial ideas about the process of hoping. In keeping with the constant comparative method, analysis of early interviews was reviewed as new codes were added. Throughout data collection and analysis, memos were written regarding methodological decision, analytic ideas, and reflexivity. Memo-writing is the key intermediate step between data collection and writing drafts of the grounded theory (Charmaz, 2014). This crucial step prompts grounded theorists to analyze early in the analytic process and to begin writing early on. Memos are used throughout data analysis to: record what is happening in the data, explore and fill out codes, describe how categories emerge and change, make comparisons, and formulate questions to guide further data collection and analysis (Charmaz, 2014). Making comparisons is a pivotal activity in GT analysis – comparisons are made between different people (their beliefs, situations, actions, experiences), between data from the same individuals at different points in time (if possible), between categories and other categories, sub-categories with categories, codes with categories, and the entire analysis with existing scholarship or sensitizing concepts. Memo-writing helps the researcher flesh out ideas and relationships between codes or concepts emerging in the data and provides the foundation for whole sections of the final written product.

Coding in CGT involves at least two phases: an initial phase and a focused (or selective) phase (Charmaz, 2014). The initial phase involves line-by-line or incident-by-incident coding, which remains very close to the data. The focused phase entails sorting, synthesizing, integrating, and organizing larger sections of data based on the most frequent and meaningful initial codes. As relationships among the codes become apparent, an overarching theoretical model began to emerge.

Initial coding

During initial coding, each transcript was read thoroughly and each segment (line or incident) of data was given one or more codes, that is, a label representing what that piece of text is about. Questions guiding the generation of codes include: "What is this data a study of?[4]" (Glaser, 1978, p. 57); "What do the data suggest? Pronounce? Leave unsaid?" (Charmaz, 2014, p. 116); What theoretical categories do these data indicate (Charmaz, 2014; Glaser, 1978). Gerunds, the noun form of verbs, are recommended in CGT to code for social and social psychological processes. For example, the code "recognizing that things could be worse" was assigned to incidents where parents explained that one way they maintained a hopeful perspective was reminding themselves that their child does have strengths and that other children have more limiting impairments. The use of gerunds allows for sticking closely to the data and reflects action in the data. Staying close to the data helps the researcher avoid applying preexisting categories to the data and promotes theoretical sensitivity (Charmaz, 2014), a characteristic of the researcher that comes from knowledge of the literature, and personal and professional experiences; "the attribute of having insight, the ability to give meaning to the data, the capacity to understand, and capability to separate the pertinent from that which isn't" (Strauss & Corbin, 1998, p. 42). Action codes also reflect the enacted social or social psychological process being studied. Initial codes are provisional since codes may get modified or subsumed under other codes as analysis proceeds and becomes increasingly abstract. The constant comparison of codes to existing data, codes to new data, and categories to codes is how analysis proceeds and forms the basis of the iterative process of GT analysis. New codes are created

---

[4] This question was an important one as it allowed for the possibility that this study might be a study of something other than parental hope. And, as a reflexive, and constructivist researcher, this was something that required consideration.

when an incident or piece of data is not easily categorized into an existing code. In vivo codes, or codes labeled using the specific language of a participant were used when they provided a creative or especially descriptive illustration of what is going on. For example, a number of participants spoke about hope as a "light at the end of the tunnel"; this became an in vivo code, as it was an expression used to reflect the image of hope being always present, and yet dimmer at times when it was harder to find or see.

Initial coding generates a large number of codes. In total, about 500 initial codes were constructed. Early on, I developed preliminary categories, based on initial impressions and hypotheses from the data. For example, participants spoke about how the focus of their hopes shifts over time – initially they hope for their child to survive, then for their child to achieve traditional milestones such as walking and talking; later, the focus turns to higher order, less concrete or discrete hopes for their child, such as being happy and being taken care of. These initial impressions helped me to begin to organize the codes into higher-level codes or categories as analysis progressed. I began to organize codes into categories and sub-categories and also cleaned up the list of initial codes. Some codes were easily eliminated either because they were redundant with another code or there was only one instance of a code and it could be subsumed under another similar code. In other instances, a new code was developed that better illustrated the data in two or more codes. Codes that were not directly related to the research question were categorized, but kept separate from codes directly related to the process of hoping. Participants often spoke about their parenting experiences more generally in response to having a child with a disability, for example. At this stage of the analytic process, I was unsure whether these codes were related to hope in some way. Codes related to parenting were kept separate and ended up in a grouping of codes that will be used in subsequent analyses but were not specifically integrated into the developing theoretical understanding.

Focused coding

Once the researcher has a tentative idea or category, she moves on to the focused coding stage of analysis. At this point, codes that seem to be the most important or relevant or frequent are promoted to the next level of coding. These codes are more directed, selective, and conceptual than initial codes, and they explain larger sections of data and help move the analysis in an interpretive, conceptual direction. At this stage, the researcher begins to conceptualize relationships among codes and categories. This stage can be seen as coding the initial codes (Charmaz, 2014). The activity of focused coding serves to raise the analytic level of the work and moves it toward a more holistic theoretical understanding of the process.

In order to move initial codes to the level of focused codes, I reviewed the initial codes and began to organize them into tentative categories if they seemed to be theoretically important. I went back to view the codes in the context of the interview transcripts to be sure that they represented the participant's words and that raising an initial code to the next conceptual level was appropriate. Initial codes were grouped together as analytic ideas about which conceptual categories were emerging from the data. A group of focused codes was identified that began to form the foundation of the grounded theory of hope. When a focused code was labeled, it was helpful to go back to the data to ensure that this higher-level code accurately represented a larger piece of text as well as the lower-level initial codes that were subsumed under it. New interviews were coded using the newly labeled focused codes as well as initial codes, as relevant. As described herein, the decisions made about which codes to push forward, group together, or put aside for later analysis was mine: "you interact with and act upon your data rather than passively read them. Through your actions, new threads for analysis become apparent" (Charmaz, 2014, p. 142). My own sense of which codes had the most "theoretical reach" influenced which ones were promoted and thus remained in the analysis versus those which did not receive such attention. This influence on the analysis was held in mind as analysis proceeded by way of memoing – I documented why certain codes were selected over others, why I felt that some concepts or categories were most relevant to the developing theoretical understanding than others. My own influence on the process was also held in check by way of checking out hunches by going back to previously collected data, by presenting ideas to new participants during interviews, and by seeking feedback from other parents and clinicians during clinical and research presentations of the study findings. The concept and application of reflexivity throughout the research process is documented in great detail in Chapter 4 of this dissertation.

Although Charmaz (2014) suggests that for many research projects, initial and focused coding will suffice to produce a rich grounded theory, elements of axial coding, as expounded by Strauss and Corbin (1990a), were found to be helpful in advancing the analysis. For instance, bringing the data into context and bringing together different aspects of the theory is a key aim of axial coding (Strauss & Corbin, 1990b). This level of coding helps place the categories and codes into context, and helps to reassemble the codes into a coherent whole (Charmaz, 2014, p. 147).

Strauss and Corbin (1990b) suggest an organizing scheme to aid the researcher in forming their theory, which consists of: conditions, actions/interactions, and consequences/outcomes. Rather than use the formal procedures spelled out by Strauss and Corbin, I opted to use some of these strategies while engaged in focused coding. I created categories and subcategories and compared these to other categories to develop a sense of how they worked together in time (process-oriented). I also sought to specify the properties and dimensions of the categories. For example, I found that for parents of children with ND, hope *emerged*, and it did so from both personal (from the parents themselves) and communal sources (from interactions with others). These categories of sources included a variety of examples, depending on the parent and the particular form that hope took for them. I also found it helpful to consider the conditions, interactions, and outcomes of hope/hoping for these parents. This led me to consider the individual, family, social, and cultural elements of one's life that may serve as a distractor to a parent's hopes for their child.

Integrating the Scholarly Literature

In the GT scholarship, there is animated debate about when and how to integrate the literature in a given study. Charmaz and other contemporary grounded theorists acknowledge that the early emphasis by Glaser to "ignore the literature of theory" (Glaser, 1978; Glaser & Strauss, 1967) is neither feasible nor necessarily helpful when attempting to further the theory in a particular area. Researchers who take this approach have been critiqued for re-inventing the wheel (Charmaz, 2014). Writers such as Morse (1989) suggest that researchers are capable of retaining scholarly ideas in mind while still remaining open to new and emerging notions coming from participants and so suggest that researchers review the literature, but "bracket" this knowledge while collecting and analyzing new data. In line with this idea, Dey (1999) remarked, "there is a difference between an open mind and an empty head" (p. 63). Researchers, especially graduate students, will typically have a cursory, if not an extensive, knowledge of the literature in their field of study. For graduate students, demonstrating their grasp of the scholarship is often a prerequisite to beginning their research projects. For both faculty and students, this is also a requirement of funding agencies when applying for grants. What Dey (1999) and others are saying is that it is possible to hold this knowledge in mind, while at the same time staying close to the data and striving to avoid the imposition of preconceived ideas on one's data. One strategy for "bracketing" suggested by grounded theorists is to exercise researcher reflexivity. As is discussed in the following Chapter (Manuscript 2), in the context of GT, reflexivity refers to the researcher acknowledging their prior and tacit knowledge and how that might be coming to bear on the way data are analyzed and interpreted. Constructivist researchers acknowledge that who they are and what they know necessarily impact the research process. Charmaz (2014) suggests taking a stance of "theoretical agnosticism" (Henwood & Pidgeon, 2003, p. 138), whereby the researcher treats extant concepts as "problematic and then look[s] for the extent to which their characteristics are lived and understood, not as given in the textbooks" (Charmaz, 2014, p. 306). Thornberg (2012) calls for "informed grounded theory", where the literature is used "as a possible source of inspiration, ideas, 'aha!' experiences, creative associations, critical reflections, and multiple lenses, very much in line with the logic of abduction[5]" (p. 7). Again, the important point being made is that literature should be utilized critically in the interpretation of data and that the product, the grounded theory, should first and foremost be a reflection of the empirical world – the scholarship can help interpret and understand that world at a more theoretical level.

An example from this study was the assumption that parents of children with disabilities experience chronic sorrow (Olshansky, 1962; Roos, 2002), deemed a natural response to the reality that children with intellectual impairments will continue to live, but will never be the hoped for or ideal child. Having quite an extensive knowledge on the literature in the area of non-bereavement loss among parents of children with disabilities, I expected to hear descriptions of loss from the participants in this study. Instead, this was not a theme that emerged during my analysis. Had I not been looking for it, this would not have been a surprise, but because I was primed to hear about experiences of loss, I was surprised when it was not raised during interviews or analysis. Of course, I acknowledge that the focus of the study being on hope and the fact that interview questions focused around parents' experience of hope may have directed participants away from sharing moments when they felt a sense of loss relating to their child. However, participants were also invited to speak about moments of difficulty, which easily came to mind for them. Still, a recurrent theme of loss did not emerge.

The final literature review for any study should be conducted based on the specific purpose and argument of the study and relevant literature should be woven throughout the final write up of the study (Charmaz, 2014). In Manuscript 2, focused on the findings of the study, the literature

---

[5] Abduction is a type of reasoning used in GT where the researcher observes something surprising or puzzling in the data that cannot be explained by extant theoretical understandings, forms hypotheses, and tests them until she arrives at the most plausible theoretical explanation for the data (Charmaz, 2014)

review was shaped by the particular direction taken during the study in terms of locating literature in the areas of paediatric oncology, adult psychology and psychiatry, theology, nursing and social work. The final grounded theory resulting from the analysis is presented in this paper. This theoretical rendering of the process of hope/hoping among parents of children with ND represents the integration of scholarly and other literature, codes and categories and the relationships among these, and memos into a cohesive whole.

Establishing Rigour

Evaluating quality in Grounded Theory research

This study takes into account current recommendations for rigour in qualitative methods and CGT more specifically (Beck, 1993; Charmaz, 1994, 2006, 2014; Chiovitti & Piran, 2003; Oktay, 2012) to ensure the quality, strength, and integrity of the findings and methodological approach. When discussing quality in qualitative research – also referred to as rigour, trustworthiness, and credibility - one must first reflect on some considerations that influence how an individual researcher approaches empirical work: the researcher's epistemological, ontological, and disciplinary positioning; the methodological approach selected for the study; and the particular aims of the study. Collectively, these considerations have been referred to as "vertical hierarchy", or the fit between ontology, epistemology, methodology, and method (Staller, 2013). These dynamics determine what aspects of rigour are meaningful in any given study.

There is no consensus about what constitutes rigour in qualitative research, or even what rigour means from a particular paradigmatic perspective, such as constructivism. As such, each researcher must set out early in the research process to determine which set(s) of criteria are relevant, and explicitly discuss how they will incorporate these elements. For instance, as a constructivist researcher, the belief that reality, and therefore research findings, are dynamically co-constructed by the researcher and her participants, inclined me to reject the notion that "member checking" – bringing the theory to study participants for confirmation – is necessary to demonstrate the credibility of study findings. If there are multiple realities that are co-constructed, then any given participant will not be able to corroborate a theory that has been abstracted from multiple others. The deeply conceptual nature of the emergent grounded theory may be indistinguishable to the participant, who is more immersed in their 'on the ground; experience of the phenomenon of inquiry. Drawing on the pragmatist underpinnings of the GT method, however, may lead me to value highly the usability and relatability of the resulting theory to those who either have participated in the study or are similar to them. Similarly, pragmatist researchers may find that some elements of rigour are more useful than others in determining the quality of a given empirical work and will choose to incorporate those elements. Since the usability of research findings is the key criteria by which empirical studies conducted from this philosophical orientation are judged (Glaser & Strauss, 1967), this should be one of the main criteria for evaluating rigour in such a study. Additionally, as a clinical social work researcher, I have an ethical responsibility to ensure that my conduct as a researcher is in line with social work values, and that participants are made aware of findings that are relevant to them (Canadian Association of Social Workers, 2005b). In the case of this substantive topic, as well as being sufficiently resonant and meaningful, a theoretical understanding of the experience of hope should be useful to parents who are similar to those who participated in the study, and also to those professionals who work with families similar to those in the study.

Some contend that GT studies should be evaluated according to two sets of criteria: those that consider the application of GT methods (the process of GT), and those that evaluate the resulting theory (the outcome of GT) (Glaser & Strauss, 1967; Oktay, 2012; Strauss & Corbin, 1998). Taking into account the "vertical hierarchy", I elected to define rigour in this way in the present study.

Evaluating the application of the Grounded Theory method

According to Oktay (2012), "[t]o Glaser and Strauss, the most important way to enhance credibility [is] for the researcher to adhere closely to the grounded theory method" (p. 107). Some refer to this criterion as *auditability*, which seeks to make clear the rationale for the study design and decisions made throughout the research process (Beck, 1993). Key criteria by which the quality of a GT study may be evaluated include: the use of the constant comparative method throughout the study, the use of theoretical sampling, and the development of a core category and other major categories. Strategies used in this study to enhance this aspect of rigour, as recommended by Glaser and Strauss in their seminal GT text (1967) include: immersion in the field, generation and testing of hypotheses in the field (and not before the start of data collection), the use of memoing, detailed description to support the theoretical understanding of the phenomena, and the pursuit of alternative explanations and negative cases. Each of these strategies is discussed in turn.

Immersion in the field or "prolonged engagement" (Padgett, 2008) transpired by staggering interviews over a period of 13 months, as well as having substantial clinical and substantive/research-based knowledge about the experience of parenting a child with ND. Despite bringing this knowledge into the research process, efforts were made to put aside previously generated hypotheses (by way of reflexive and analytical memoing) in order to *generate theoretical ideas and questions that were based on data collected for this study*. Hypotheses, interpretations of data and emerging categories, concepts, and part of the theory were tested by way of theoretical sampling of subsequently collected data. *Memoing* was used throughout the study by the primary researcher by way of reflexive, methodological, and analytical memos written in Dedoose. These memos could be linked to sections of data in Dedoose. Methodological memos offer a way of providing an "audit trail" of decisions made throughout the study. Reflexive memos are one way that researchers can keep their biases in check and ensure that prior substantive knowledge and clinical and/or personal experiences are explicitly being written about and incorporated into emerging theoretical ideas, and kept separate from the analysis[6]. A *detailed description* is offered in Manuscript 2 to support the theory of parental hope that is presented. Numerous participant quotes as well as a thorough account of the main categories, contextual factors, conditions, and consequences (Charmaz, 2014; Glaser, 1978; Oktay, 2012) are presented. *The pursuit of alternative explanations and negative cases* was done both during the collection of new data (during participant interviews), as well as by going back to previously collected data. For example, all participants in this study seemed to be quite hopeful when speaking about their child with ND. At a certain point in the analysis, I began to wonder whether there was something about the parents who had agreed to participate in the study that made it such that they were more hopeful than other parents. These were parents who had previously participated in the survey portion of a mixed method study involving the completion of over 20 questionnaires, and had agreed to participate in additional research studies. Perhaps these parents were in a better socioeconomic position than other parents, or had higher levels of well-being than other parents who had not agreed to participate. I was able to test out this theory, albeit in a limited way, by way of theoretical sampling, modifying the interview guide, and looking back on previously collected data. Although it was not possible to locate parents who had not previously participated in research (given that I was subsampling participants from a database of parents who had participated in a previous study), I did theoretically sample a few participants who had low scores on some of the

---

[6] For more on the reflexive process used in this study, see Manuscript 1/Chapter 4.

measures of well-being used in the Parenting Matters! study, indicating lower levels of psychological health (i.e., depression) and hope (as measured by the Vicarious Futurity Scale). The interview guide was modified to include questions about times when participants felt hopeless or "hope-little" about their child's future or their current circumstances. And finally, interviews that had been conducted earlier were analyzed with this hypothesis in mind, and were mined for instances when participants alluded to feeling like there was little or no hope.

Other strategies used to ensure a rigorous application of the CGT method include: *peer debriefing, immersion in the methodological literature,* and *training*. *Peer debriefing* occurred by consulting with the dissertation committee, through active participation in two methodological groups – one for GT (Grounded Theory Club at the University of Victoria) and one on applications of qualitative methods in health research (McGill Qualitative Health Research Group), and in engaging with doctoral program peers at a similar stage in their own data analysis. I met with three of my program peers on a regular basis to code each other's' raw participant data, discuss initial impressions, and conceptual ideas. This process helped reduce the impact of my personal biases on the developing analysis. *Immersion in the methodological literature* took place through extensive engagement with methodological writing on qualitative methods, GT, and CGT. *Training* on qualitative methods, GT, and CGT was acquired by way of required and elective doctoral coursework, as well as by participating in an experiential workshop facilitated by Kathy Charmaz, the pioneer of CGT.

Evaluating the theory produced in a Grounded Theory study

Given that the key aim of a GT study is to develop mid-range theory, any valuation of rigour in a GT study should include an appraisal of the outcome of the study – the substantive theory. For Glaser and Strauss (1967), the ultimate indicator of a quality GT is the application in a real-world setting. They describe four criteria that are necessary to determine applicability. The theory must: 1) fit with the substantive area; 2) be understandable to those working in the substantive/practice area; 3) be general enough to apply to a variety of situations (generality), and 4) allow for some control by the user in the setting; "the person who applies the theory must be enabled to understand and analyze ongoing situational realities, to produce and predict change in them, and to predict and control consequences both for the object of change and for other parts of the total situation that will be affected" (Glaser & Strauss, 1967, p. 245). From a constructivist perspective, Charmaz highlights criteria of credibility, originality, resonance, and usefulness, although she specifies that these are meant to "give you some ideas" (Charmaz, 2014, p. 337) rather than be a rigid set of indicators of quality. In CGT, the criteria of *credibility* emphasizes the researcher's role in the construction of the research findings and challenges us to be aware of the degree to which this is the case and to take steps to minimize this influence. *Originality* refers to the question of whether the theory offers new insights to the social or social psychological problem addressed in the research and advances our understanding and practice in the field. For example, does the theory, "challenge, extend, or refine current ideas, concepts, and practices?" (Charmaz, 2014, p. 337). *Resonance* signifies that the theory should portray and explain (a) the fullness of the experience (Charmaz, 2014), (b) meaning that includes implicit and hidden aspects of the experience that have been considered and attended to, and (c) participants' recognition that their experience is conveyed in the emergent theory. Being faithful to the method of constant comparison throughout data collection and analysis and ensuring that categories are saturated helps ensure that variation in the experiences of hope was captured by the theory. Last, *usefulness*, refers to the pragmatic aspects of the final product of the work. Is the analysis practical and functional to those who experience the phenomenon first-hand? Does it spark new ideas? (Charmaz, 2014). The above criteria were met by way of *member checking*[7], *peer debriefing*, and *triangulation*.

There is debate in the methodological literature about how and who to have evaluate the rendering of qualitative findings. For instance, discussions about member checking involve questions about the capability of participants to provide feedback about abstracted conceptual understandings of a phenomenon – the stated goal of GT research (Barbour, 2001; Thomas, 2017) and about the ethics of asking more work of participants (Barbour, 2001). Some authors question whether the level to which findings are abstracted makes it challenging for participants to relate to and confirm them: "the problem with member checks is that…study results have been synthesized, decontextualized, and abstracted from (and across) individual participants, so there is no reason for individuals to be able to recognize themselves or their particular experiences" (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 16). In other words, individual participants can speak to their individual experience of the phenomenon and, to a limited extent, the experiences of those whose

---

[7] What researchers may refer to as member checks, member checking, respondent validation, stakeholder involvement, etc (Thomas, 2017). Member checking was used in this study in reference to presenting study findings to groups of stakeholders – both parents and family members, and healthcare providers who work alongside families of children with ND. Rather, neither participant transcripts nor theoretical renderings of the findings were brought back to the actual study participants for verification or confirmation.

accounts they are familiar with, but are not positioned to speak to a collective experience of which they are but one part. That is, participants may be able to endorse part of the theory, but not the theory as a whole. On the other hand, from a pragmatist perspective, if the theory is not understandable, relatable, and usable from the point of view of participants and clinicians in the field, then there is a knowledge translation issue and a problem at the level of the vertical hierarchy. As a pragmatist and social work researcher, I hold the view that I have an ethical imperative to bring findings back to participants and to ensure that findings are relevant to and useful for them and those health and social care clinicians who work with them.

Based on my own paradigmatic, disciplinary, and methodological positioning, the criteria used to determine the applicability of the theory in a real-world setting as outlined by Glaser and Strauss (1967) and those described by Charmaz as described above (Charmaz, 2014) were drawn upon. *Member checking* was carried out by presenting the emerging theory at various stages in the analytic process to audiences who are knowledgeable about the phenomenon – meaning: 1) parents and other family members who have direct experience caring for a child with ND, 2) HCPs who have daily interactions with families, and 3) others who have observed the experience of parenting a child with ND and have reflected on it such as researchers in the field, policy makers, and managers in clinical settings. Nine presentations were given at different stages – from very preliminary categories to the fully formed theoretical rendering – to a total of an estimated 300 individuals (2 presentations to researchers in the field of paediatric disability and rehabilitation, healthcare, and/or child health and well-being; 2 presentations to parents of children with ND; 2 presentations to clinicians in the field of paediatric disability and/or paediatric healthcare; and 3 presentations to mixed groups). Feedback was often an enthusiastic endorsement of the findings and emerging theory. Beyond endorsing the theory, discussions with audiences at these presentations raised important critiques of the theory and valuable queries which were brought back to the existing and subsequently collected data to be investigated. For instance, during one presentation to a small interdisciplinary group of rehabilitation clinicians (occupational therapists, physiotherapists, social workers, psychologists), the issue of whose experience and/or voice was being represented in this theory was put forward. In the ensuing discussion, the clinicians and I contemplated some of the tensions they face between promoting hope and ensuring that their clients and their families have a "realistic" understanding of the range of possibilities that are on the table for a particular child. One of the outcomes of this discussion was a realization on my part that my theory is in fact a theory of *parental* hope for their child's future. Emphasizing the parent as the central figure in this theory is important as it highlights the vicarious nature of the hope; this hope is the hope that a parent has for their child, rather than a personal hope for themselves, or a child's hope for their own future. It also led to the addition of an important discussion point in the discussion of the findings. *Peer debriefing* was carried out with colleagues and mentors working in the field of paediatric disability during dissertation committee meetings, and through informal conversations; and with doctoral student peers by way of a data analysis support group where we shared raw data, coded each other's transcripts, and discussed early conceptual ideas. *Triangulation* informs the choice to use multiple methods of data collection: interviews, the demographic form, and literature on parental hope, from both academic and non-academic sources. In CGT studies, extant texts produced outside the confines of the research study may be used as sources of data and analyzed; they may also "provide evidence for your hunches" (Charmaz, 2006, p. 38).

The above discussion demonstrates the extent to which strategies that promote rigour or the quality of qualitative research were deliberately and explicitly considered and integrated through each stage of the research process.

Conclusion

This chapter outlined the paradigms upon which the study described in this dissertation were founded. An introduction to the methodological approach of CGT was offered by way of a discussion about ethical considerations and decisions implemented during the planning and execution of the study. A detailed accounting of the sampling and data analysis procedures were offered next, followed by an in-depth discussion of how the quality of a CGT study, and this study in particular, were conceptualized and put into practice. Further details about the CGT approach itself, its emergence, and its usage, as well as an accounting of considerations around reflexivity and how it was taken up in the study are offered in the following chapter (Manuscript 1). The chapter following that (Manuscript 2) presents a comprehensive description of the study methodology as per customary published manuscript standards.

References

Abbedutto, L., Seltzer, M. M., Shattuck, P., Wyngaarden Krauss, M., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with Autism, Down Syndrome, or Fragile X syndrome. *American Journal on Mental Retardation, 109*(3), 237-254.

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ : British Medical Journal, 322*(7294), 1115-1117.

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research, 15*, 263-266.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Boeije, H. (2002). A purposeful approach to the Constant Comparative Method in the analysis of qualitative interviews. *Quality & Quantity, 36*, 391-409.

Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research, 8*(1), 137-152.

Canadian Association of Social Workers. (2005a). *Code of Ethics of the Canadian Association of Social Workers*. Ottawa, Ontario: Canadian Association of Social Workers.

Canadian Association of Social Workers. (2005b). *Guidelines for ethical practice*. Ottawa, Ontario: Canadian Association of Social Workers Retrieved from http://www.casw-acts.ca/sites/default/files/attachements/casw_guidelines_for_ethical_practice_e.pdf.

Charmaz, K. (1980). *The social reality of death*. Reading, MA: Addison-Wesley.

Charmaz, K. (1994). Grounded theory in the 21st Century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 507-535). Thousand Oaks: Sage.

Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: Sage Publications.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). London: SAGE Publications.

Chiovitti, R. F., & Piran, N. (2003). Rigor and grounded theory research. *Journal of Advanced Nursing, 44*(4), 427-435.

Dey, I. (1999). *Grounding grounded theory*. San Diego, CA: Academic Press.

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the methodology of Grounded Theory*. San Francisco: Sociology Press.

Glaser, B. G. (1992). *Basics of Grounded Theory Analysis: Emergence vs. Forcing*. San Francisco: Sociology Press.

Glaser, B. G. (2001). *The Grounded Theory perspective: Conceptualization contrasted with description*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: AldineTransaction.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*, 150-163.

Henwood, K., & Pidgeon, N. (2003). Grounded theory in psychological research. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 131-155). Washington, DC: American Psychological Association.

McCarthy, A., Cuskelly, M., van Kraayenoord, C. E., & Cohen, J. (2006). Predictors of stress in mothers and fathers of children with Fragile X syndrome. *Research in Developmental Disabilities, 27*(6), 688-704.

McNeill, T. (2004). Fathers' Experience of Parenting a Child With Juvenile Rheumatoid Arthritis. *Qualitative Health Research, 14*(4), 526-545. doi:http://dx.doi.org/10.1177/1049732303262374

Morse, J. M. (2007). Sampling in Grounded Theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 229-244). London: SAGE Publications Ltd.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*, 13-22.

Nicholas, D. B., Gearing, R. E., McNeill, T., Fung, K., Lucchetta, S., & Selkirk, E. K. (2009). Experiences and Resistance Strategies Utilized by Fathers of Children with Cancer. *Social Work in Health Care, 48*(3), 260-275. doi:10.1080/00981380802591734

Oktay, J. S. (2012). *Grounded Theory*. New York, NY: Oxford University Press.

Olshansky, S. (1962). Chronic Sorrow: A Response to Having a Mentally Defective Child. *Social Casework, 43*(4), 190-193.

Padgett, D. (2008). *Qualitative Methods in Social Work Research* (2nd ed. Vol. 36). Thousand Oaks, CA: SAGE Publications, Inc.

Pelchat, D., Bisson, J., Bois, C., & Saucier, J. F. (2003). The effects of early relational antecedents and other factors on the parental sensitivity of motheres and fathers. *Infant and Child Development, 12*, 27-51.

Ricci, L. A., & Hodapp, R. M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: perceptions, stress and involvement. *Journal of Intellectual Disability Research, 47*(4-5), 273-284. doi:10.1046/j.1365-2788.2003.00489.x

Roos, S. (2002). What is chronic sorrow? *Chronic Sorrow: A living loss* (pp. 23-46). New York: Routledge.

Staller, K. M. (2013). Epistemological boot camp: The politics of science and what every qualitative researcher needs to know to survive in the academy. *Qualitative Social Work, 12*(4), 395-413. doi:doi:10.1177/1473325012450483

Stern, P. N. (2007). On solid ground: Essential properties for growing Grounded Theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 114-126). London: SAGE Publications LTD.

Strauss, A., & Corbin, J. (1990a). Introduction *Basics of qualitative research: Grounded Theory procedures and techniques* (pp. 17-32). Newbury Park, CA: Sage Publications.

Strauss, A., & Corbin, J. (1990b). Theoretical Sampling *Basics of qualitative research: Grounded Theory procedures and techniques* (pp. 176-193). Newbury Park, CA: Sage Publications.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks: Sage.

Thomas, D. R. (2017). Feedback from research participants: Are member checks useful in qualitative research. *Qualitative Research in Psychology, 14*(1), 23-41.

Thomasgard, M., & Metz, W. P. (1997). Parental overprotection and its relation to perceived child vulnerability. *AMerican Journal of Orthopsychiatry, 67*(2), 330-335.

Thornbeg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research, 55*(1), 1-17.

Linking Statement

The previous chapter reported on some key elements of the methodological process informing this study. The following chapter, the first manuscript, offers a unique accounting through three aspects of taking up researcher reflexivity in the context of this dissertation research. This chapter elucidates the roots of the GT approach and the emergence of the constructivist version as expounded by Charmaz, which is drawn upon in this study.

Chapter 4 - Knowing, Reflexing, and Doing: Using Constructivist Grounded Theory to Study Hope among Parents of Children with Neurodisabilities (Manuscript 1)

Bailey, S. N., Lach, L. M., Ives, N., & Nicholas, D.

*Target journal: Qualitative Health Research or Qualitative Social Work

Abstract

This paper offers both a reflexive and a practical discussion of applying CGT (Charmaz, 2014) to a study of hope among parents of children with Neurodisabilities (ND). The sections *Knowing*, *Reflexing*, and *Doing* each offer in-depth accounts which are often left out of published manuscripts due to space restrictions. *Knowing* provides a description of the emergence and roots of CGT in order to demonstrate that a thorough grasp of the approach is important to conducting rigorous qualitative research; *Reflexing* examines the role of researcher reflexivity and situates reflexivity in the context of CGT by offering an account of how clinical experiences and personal values, interactions with participants, and the influence of audiences impact the research process; and *Doing* presents two examples of how to apply reflexive decision-making consistent with a CGT approach as it relates to data collection and the presentation of findings, using as an example the first author's doctoral dissertation project. Unpacking and rendering explicit the role of the researcher in constructing grounded theories offer an example to other students and researchers of how to discuss and present what is typically only referred to briefly in published works.

Introduction

Students of Grounded Theory have traditionally learned to conduct research through a combination of mentorship and immersion in the field. Over the past half century, however, the methodological scholarship has expanded to include texts that describe the research process and offer students more direction. GT has customarily been one of the core qualitative approaches that has been seen as offering explicit instructions to guide the novice researcher, particularly in relation to data analysis. Although students can turn to methodological texts for help, when seeking examples methodological approaches relevant to disciplines or substantive topics, students may find it challenging to locate high quality examples in the published literature. Specifically, there is a need for more in-depth and reflexive accounts of the epistemological positioning of the researcher as well as explicit descriptions of decisions taken throughout the process of conducting a study. Although methodological texts emphasize the import of reflexivity in assessing the rigour of qualitative work (e.g., Creswell & Poth, 2018; Neuman & Robson, 2012; Padgett, 2008; Rubin & Babbie, 2013), few published studies include a thorough discussion of how the researcher's own biases, background, and knowledge influenced the work. The dearth of such explicit accounting is at least in part due to what Star calls "deleting the work" – when scientific journals force authors to erase the "grunt work" of research (Star, 2007, p. 80). The grunt work, the decisions made along the way and the intricacies of the research process, are the gold nuggets that students need to know as they learn to conduct their own research. More extensive methodological accounts would allow for these studies to be included and comprehensively appraised in systematic syntheses of qualitative research, which is increasingly becoming a widespread way to present a summary of the qualitative research on a particular substantive topic. To rigorously evaluate the quality of qualitative research, enough detail about what was done and how decisions were made must be offered. A methodological paper such as this one will enhance the scholarship and offer guidance to other doctoral students and researchers seeking to conduct high quality and thorough GT studies, but lacking the methodological acumen needed to produce such scholarship.

In a scoping review of 248 Canadian Social Work dissertations published between 2001 and 2011, Rothwell and colleagues found that the most common qualitative methods cited in dissertations were: qualitative description[8] (23%), GT (22%), and phenomenology (11%) (Rothwell et al., 2015). Over a quarter of dissertations (26%) did not fit into one of the authors' pre-determined categories and were therefore not categorized. This review demonstrates that a large proportion (49%) of doctoral scholarship relies on generic qualitative or unidentifiable methodologies. The authors of the scoping review caution that this latter group of studies do not uphold or advance our theoretical understandings of complex social issues (Rothwell et al., 2015) and this may leave social work scholarship trailing behind other practice disciplines who study similar topics but draw from methodological approaches that move theory forward or build theory from the ground up. GT is an approach that builds theory that is grounded in the data, thus moving our theoretical understandings to new levels and advancing our capacity to respond to important social problems, such as those encountered by disenfranchised populations who come into contact

---

[8] The authors categorized dissertations as "qualitative description" when they either explicitly self-identified as such or when they utilized generic content or thematic analysis (Rothwell, Lach, Blumenthal, & Akesson, 2015).

with social work services. Doctoral students and other researchers seeking to make progress in both our theoretical understanding of important social issues and our ability to address them can certainly benefit from applying an approach such as GT. However, the rigorous application of the methodology will determine how useful the product of the research will be.

GT has been taken up widely by social scientists in their study of social phenomenon. In fact, it is one of the most cited qualitative research methodologies in publications by social science researchers (Bryant & Charmaz, 2007a, 2007b; Titscher, Meyer, Wodak, & Vetter, 2000). Writers often reference key GT texts and terminology, however, upon close inspection, many studies fall short in their adherence to the GT methodology (O'Connor, Netting, & Thomas, 2008) as expressed by its originators (e.g., Charmaz, 2014; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). GT is often thought of as 1) an outcome – i.e., a substantive or theoretical interpretation of the phenomenon under study that is grounded in the data collected; or 2) a set of analytic guidelines to follow in analyzing qualitative data. In this vein, many researchers refer to "GT" as the framework that guides their coding and analysis of data, rather than as the overarching methodological approach informing each step in the research process. Hood (2007) elucidates the key distinctions between what he calls the Generic Inductive Qualitative Model (generic qualitative research) and GT; the essential tenets of GT are "1) theoretical sampling; 2) constant comparison of data to theoretical categories, and 3) focus on the development of theory via theoretical saturation of categories rather than substantive verifiable findings" (p. 163).

This paper offers an example of how social work researchers can conduct rigorous, high quality research, taking into account the disciplinary and paradigmatic positioning of the researcher, and how they can provide illustrations of the use of researcher reflexivity. Opening up the consideration of researcher reflexivity to include the influence of interactions with participants and audiences, in addition to the researcher's own values and experiences, encourages thorough and continuous reflexion[9] on the researcher's use of self in all aspects of the research process. This is accomplished in this paper though both a reflexive and a practical discussion of applying CGT to a study of hope among parents of children with ND. The sections *Knowing*, *Reflexing*, and *Doing* each offer in-depth accounts which are often left out of published manuscripts due to space restrictions. *Knowing* provides a description of the emergence and roots of CGT to demonstrate that a thorough

---

[9] See below section on "Reflexing" for a discussion of the terminology used in this manuscript.

grasp of the approach is important to conducting rigorous qualitative research; *Reflexing* examines the role of researcher reflexivity and situates reflexivity in the context of CGT by offering an account of how clinical experiences and personal values, interactions with participants, and the influence of audiences impact the research process; and *Doing* presents two examples of how to apply reflective decision-making consistent with a CGT approach as it relates to data collection and the presentation of research findings, using as an example the first author's doctoral dissertation project.

Knowing

Roots and emergence of Grounded Theory

Wide usage of Grounded Theory

GT has come to be used by researchers from a variety of disciplines, from the health sciences to social work to architecture, and a from diversity of philosophical backgrounds. It is used in a countless range of ways and is followed to greater or lesser extents. Some researchers utilize GT solely as a method of analyzing data due to its explicit guidelines for coding and data analysis. Others using a generic qualitative approach to their work refer to key ingredients of the traditional GT approach, such as the constant comparative method or theoretical sampling, without maintaining an allegiance to the overall methodological approach. Others refer to the product of inquiry as being a conceptual or theoretical understanding of a social phenomenon, which they refer to as "a GT". Some (methodological purists) argue that this picking and choosing invalidates the method, while others argue that it is a strategic move ("methods slurring"; Baker, Wuest, & Stern, 1992; Cutcliffe, 2000; Kahlke, 2014), which strengthens the research. In the same vein, those who write about GT do not agree on one definition. Some refer to it as a qualitative research method (e.g., Morse et al., 2009), others call it a "family of methods" (Bryant & Charmaz, 2007c). Morse (2009) defines GT as, "a way of thinking about data – processes of conceptualization – of theorizing from data, so that the end result is a theory that the scientist produces from data collected by interviewing and observing everyday life" (Morse, 2009, p. 18). Most would agree, however, as per Glaser and Strauss' (1967) initial description, that GT is a systematic, iterative, and comparative method of data analysis for the purpose of sociological theory construction.

Discovery of Grounded Theory

GT as a methodological approach was developed and expounded initially by Glaser and Strauss in the 1960s in response to what they saw as a lack of explicit techniques for the production of rigorous qualitative sociological studies. At the time of writing their seminal book, *The Discovery of Grounded Theory* (1967), the dominant paradigm in sociological research was positivism. The rise of increasingly sophisticated methods of statistical analysis meant that sociological research was dominated by quantitative methods, which were viewed as rigorous, objective, and exact, and which produced generalizable findings that were widely applicable.

Glaser and Strauss met at the University of California, San Francisco (UCSF) School of Nursing, each bringing their respective expertise and skillset to the study of patients dying in hospitals. Strauss had been influenced by Herbert Blumer, his advisor, and the symbolic interactionist perspective and also by pragmatism; "Strauss brought notions of human agency, emergent processes, social and subjective meanings, problem-solving practices, and the open-ended study of action to grounded theory" (Charmaz, 2014, p. 9). Glaser, on the other hand, brought a positivist approach to understanding sociological phenomena and sought to codify qualitative methods as had previously been done with quantitative methods; "he imbued the method with dispassionate empiricism, rigorous codified methods, emphasis on emergent discoveries, and its somewhat ambiguous specialized language that echoes quantitative methods" (Charmaz, 2014, p. 9).

Until that time, social science research had tended to take a deductive approach, meaning that the formulation of research questions was driven by theory. Theory informed research hypotheses, which were defined by way of operationalized variables that could be specifically measured. Hypotheses were tested through observation of social phenomenon and then either confirmed or not by way of the data. In contrast, Glaser and Strauss were interested in the inductive process, which reverses the order of the traditional scientific method. Using inductive logic, theory is built from the ground up – observations made in naturalistic research contexts lead the researcher to notice patterns in the data, which are extrapolated to tentative hypotheses that result in the development of theoretical explanations for the data. They were also interested in making the methods used to gather and analyze qualitative data more explicit. Students had tended to learn how to do qualitative research by immersing themselves in fieldwork and observing and learning from their mentors. Methods used in qualitative research were implicit and not well described at this point in time. Owing to the dominance of quantitative methods and the positivist paradigm, qualitative research was viewed by many as being unscientific, subjective, impressionistic, and anecdotal. Glaser and Strauss sought to elevate the quality of qualitative methods and raise their profile. They did so via their research on death and dying in hospitals. While conducting this work, they noticed that they had essentially developed a new way of doing qualitative research using inductive logic and successively building conceptual ideas from the data. They outlined their approach in their seminal work, published in 1967, the *Discovery of Grounded Theory* (Glaser & Strauss, 1967). This work focused on expounding clearly the strategies involved in conducting qualitative research, studying social processes, and generating middle range theory.

Fundamentals and divergence of Grounded Theory

The foundations of GT are generally agreed upon to include the following: the development of (midrange) theories or conceptual understandings of core social or social psychological processes on the basis of data; a continuous interplay of data collection, analysis, and reflexion (i.e., the constant comparative method); the use of theoretical sampling, which involves making early links between the empirical data being collected and initial theoretical ideas and checking these out; and engaging in analytic writing or memoing from the start of the research process (Bryant & Charmaz, 2007a; Hood, 2007). A completed GT should explain the properties of the theoretical categories, and often outline the causes and conditions under which the social/social psychological process emerges and varies, and delineate its consequences (Charmaz, 2014; Hood, 2007).

Over time, Glaser held to his positivist roots and what has come to be labelled "traditional" GT. Traditional GT reflects the epistemological backdrop of the 1960s and prevailing notions about the need to demonstrate validity and reliability of empirical findings and methodological processes. Strauss, on the other hand, aligned himself more closely with pragmatism, recognizing multiple perspectives and that these perspectives shape how individuals experience the world (Bryant & Charmaz, 2007b). During the 60s, 70s, and 80s, the paradigmatic landscape began to change in sociology, with the emergence of writings about taking a critical perspective of social structures, interactionism, and constructivism (Bryant & Charmaz, 2007b).

By the 1990s there were two distinct versions of GT: the one adhered to by Strauss and his students, including Juliet Corbin, who he would publish with in 1990, and the one held to by Glaser and those he mentored. These two camps have remained strong to the present, as some GT researchers aim to adhere faithfully to the approach as expounded by either Glaser or Strauss. Around the same time, a number of qualitative researchers and social scientists had begun challenging the positivist underpinnings of traditional GT. Some of these researchers advocated the position that there are multiple realities, rather than one reality that is knowable. Kathy Charmaz was one such scholar and she advanced a constructivist version of GT.

Constructivist Grounded Theory

With the appearance of CGT on the scene came an emphasis on the studied phenomenon rather than the methods used to study them: "constructivist grounded theory highlights the flexibility of the method and resists mechanical applications of it" (Charmaz, 2014, p. 13). CGT preserves many of the foundational principles of classic GT, while operating from a constructivist paradigm. This view, which challenges the objectivist bedrock of traditional GT, says that there are multiple realities and that knowledge is constructed, not discovered (Charmaz, 2014). What the researcher hears and observes in the field is influenced by their prior interpretive frames, biographies and interests, as well as the research context, relationships with participants, and methods of gathering and interpreting data (Charmaz, 2014). Constructivists acknowledge that conceptual understandings of phenomena are shaped by the researcher's interpretations of the data and what she and her participants bring to the research process; in other words, we construct our grounded theories (Charmaz, 2014). What follows is that CGT researchers take a reflexive stance toward interpreting and representing the empirical worlds they seek to understand. Charmaz purposely chose the term "constructivist" to differentiate her approach from other *constructionist* sociological approaches of the time and to emphasize, "social contexts, interaction, sharing viewpoints, and interpretive understandings" (Charmaz, 2014, p. 14). She viewed sociologists who allied with the constructionist perspective as portraying their analyses as accurate representations of the world, rather than recognizing them as social constructions (Charmaz, 2014). She also critiqued their work as not acknowledging the researcher's bias and subjectivity (Charmaz, 2014). In her most recent text, Charmaz (2014) grants that her constructivist position has come to align more closely with constructionism as it has evolved over time.

Theoretical foundations of Grounded Theory

It is often assumed that GT is inherently located in the symbolic interactionist (SI) paradigm; however, debates about the theoretical roots of GT abound. Some writers, including Glaser, argue fervently that GT is a-theoretical in the sense that it can be used to study phenomena from any theoretical perspective and using any type of data (Glaser, 2003). He acknowledges that many grounded theorists have taken up SI as the basis of their GT work and that many disciplines and schools have touted SI as the foundation from which GT must be carried out. However, he maintains that this was not the intention of the original GT approach and in fact refers to the "take over" of GT by SI. Other Glaserian grounded theorists are of the same mind. For example, Holton self-identifies as a classic grounded theorist and states that her work is grounded in the writings of Glaser (Holton, 2007). She argues that GT is a *general* methodology:

> Grounded Theory methodology, in the classic sense, does not fit within established research paradigms whether positivist, interpretivist, postmodern, or otherwise; rather, as a general methodology, classic grounded theory transcends the specific boundaries of established paradigms to accommodate any type of data sourced and expressed through any epistemological lens (Holton, 2007, p. 268).

Holton (2007) goes on to argue that grounded theorists should feel free to utilize whichever epistemological perspective is most suitable to the research question, the type of data being collected, and the ontological perspective of the researcher. Those aligning themselves with this perspective suggest that by limiting the lens to that of SI, the data collection, analysis, and interpretation become bound by one particular perspective which limits the researcher's creativity (Glaser, 2005; Holton, 2007).

In contrast, some argue that GT has deep roots in SI and that SI serves as the overall perspective from which the GT approach proceeds. Others recognize the considerable common ground between SI as a theory and GT as a methodological approach, for example, the emphases on agentic actor and process, and suggest that they can certainly be used as a theory/methods package (Bryant & Charmaz, 2007a).

Symbolic Interactionism, defined by Herbert Blumer and derived from pragmatism (à la George Herbert Mead), assumes that "society, reality, and self are constructed through interaction and thus rely on language and communication…[and] that interaction is inherently dynamic and interpretive and addresses how people create, enact and change meanings and actions" (Charmaz, 2006, p. 7). Symbolic Interactionism holds three basic premises:

> 1) Human beings act toward things on the basis of the meanings that things have for them;
> 2) the meanings of such things is derived from, or arises out of, the social interaction that one has with one's fellows; and
> 3) these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, 1969, p. 3).

Charmaz (1980) adds the following three premises to build on and clarify Blumer's:

> 1) Meanings are interpreted through shared language and communication;
> 2) the mediation of meaning in social interaction is distinguished by a continually emerging processual nature; and
> 3) the interpretive process becomes explicit when people's meanings and/or actions become problematic or their situations change (p. 25).

Mead's pragmatism declares that a good theory is one that is useful in solving social problems. Pragmatism also views reality as open to multiple interpretations (Charmaz, 2014). Truth and reality are tested by way of their practical application. In line with this approach is constructivism, which begins an inquiry with the individual's experience and asks how the individual constructs it, why they constructed it, and what is constructed (Charmaz, 2006). Charmaz's CGT methodology views data and analysis as constructions "created from shared experiences and relationships with participants and other sources of data" (p. 130). The constructivist paradigm reflects an epistemology and an ontology that recognizes multiple realities and the transactional and subjective nature of research findings. As such, constructivist grounded theorists take a reflexive stance to inquiry, recognizing what they bring to the research process and are as transparent as possible about this. Such reflexion should be integrated in each step of the research process. The following section offers an exposition of how such reflexivity was integrated into a doctoral research project on the experience of hope among parents of children with ND.

Reflexing

The terms reflexivity, reflection, and critical reflection have often been used interchangeably in social work practice and research scholarship. D'Cruz and colleagues (2007) have wrestled with these terms and have attempted to delineate the origins of each, define and differentiate the terms, and describe the consequences for social work practice, education, and research. Reflexivity[10] is used in the present paper in line with D'Cruz and colleagues' (2007) second and third variations of "reflexivity", as the focus is on the social work practitioner/researcher, rather than on the client (as in the first variation). In the second variation, reflexivity is defined as, "a critical approach to professional practice that questions how knowledge is generated and, further, how relations of power influence the processes of knowledge generation" (D'Cruz et al., 2007, p. 77). Of course, this manuscript is concerned with the use of researcher reflexivity and so I have operationalized this definition using the researcher as the subject, rather than the practitioner. The third variation, "is aligned to the second variation…[but adds] the acknowledgement of the dynamic relationship between thoughts and feelings: how thoughts can influence feelings and vice versa" (D'Cruz et al., 2007, p. 80). These two iterations reflect a process of looking both outward at the structures and interpersonal interactions that influence knowledge generation, and inward at the researcher's own reactions and experiences (or tacit knowledge) and incites us to consider the ways in which these impact the way we "make sense of the world" (D'Cruz et al., 2007, p. 78). In other words, knowledge claims are not accepted as is, but are subject to scrutiny and analysis. In this way, practice knowledge is valued alongside formal theory in the practice context, and, I would add, in the generation of new substantive theory.

Doucet (2008) uses the image of the gossamer wall to theorize three sets of reflexive relationships occurring throughout the research process. The walls "illustrate the thin and tenuous lines that exist in research relationships" (Doucet, p. 74) – those between researcher and self, between researcher and respondent, and between researcher and their audiences. Her conceptualization of researcher reflexivity as involving more than the researcher's own values, motivations, and history, and including the interactions and influences of research participants and audiences who consume the work is a move away from the dominant understandings of reflexivity as a "self-centred exercise" (Doucet, 2008, p. 74) and toward a more dynamic and multifaceted construal. Although she acknowledges that there are limitations to how much we can know about what influences our work, she nevertheless encourages researchers to be responsibly transparent throughout the research process about how our hidden motivations and experiences may come into play. Pulling together these two conceptualizations of reflexivity, the following sections of this paper

---

[10] The terms "reflexion", and "reflexing" are used in this manuscript to reflect an adherence to the definition of "reflexivity" as defined in the above paragraph and to differentiate them from the terms "reflection" and "reflecting".

serve as an example of how one researcher (first author) considered the influence of her own tacit knowledge, her interactions with participants, and the audiences who would consume the research on the process of knowledge generation.

The dissertation project is the result of a journey, both personal and communal, that I (first author) chose to embark on when I began graduate school, but also one that began long before my thoughts turned to conducting research in any tangible way. This section will focus on some of the key influences on my choosing to study this topic and on how my interactions with participants and audiences impacted how I viewed and interpreted the collected data.

Influences of clinical experiences and personal values

In line with the constructivist approach and D'Cruz and colleague's (2007) discussion of reflexivity as applied to social work, clinicians (and researchers) are encouraged to "identify their personal narratives (the stories they tell themselves) as this contributes to their understanding of how meaning is created (or constructed) in interactions with clients [and participants]" [p. 79]. In this vein, the 'self' of the researcher-clinician is an important contributor to the collected data, analysis, and presentation of research findings. The topic of hope emerged early on in my clinical career as a concept that mattered to families who have children with disabilities. I began my career working for a rehabilitation centre in Montreal. My role involved supervising and training adults who had a diagnosis of an intellectual and/or developmental disability, such as Autism Spectrum Disorder, although many of these individuals had co-morbid conditions, including other physical and mental health conditions. The clients were placed in a community setting where they were to learn social and vocational skills. For some, the goal was to eventually gain a level of vocational independence. For most, however, their professional lives would consist of attending a sheltered workshop on a daily basis. Other clients who had higher needs were placed in community settings called day programs, where the goal was less on professional skill development and more on providing a safe environment in which they were cared for, stimulated, and engaged in meaningful activity to the extent possible. This work was of course rewarding and meaningful, but also very challenging. I quite often felt conflicted about the conditions in which the clients worked, lived, and were engaged. I found it objectionable that companies were procuring what essentially amounted to free labour. Other times I wondered about our society's esteeming of production over allowing people with such limitations to choose enjoyable, life-giving activities. These concerns brought me to wonder about our values as a society. I was bothered by how most of these adults were shuttered away in warehouses rather than being included in settings that allowed for interactions with members of the community. Yet, I experienced the stigmatizing, fearful, and ignorant reactions of the general public to individuals with disabilities when I did accompany them in the community.

At times, I felt discouraged, perceiving that there was not much hope to effect change. I read Jean Vanier's (1998) writings about L'Arche communities of people with developmental disabilities who live together, with assistants (those without disabilities) who live with and support them in their daily activities. L'Arche has a beautiful mission of inclusion, compassion, and belonging. Those with disabilities are valued and treated with respect and tenderness. It sounded like an idealistic dream and Vanier managed to inspire this dream, making it a reality that now exists in thirty-five countries around the world, including almost 200 homes in Canada alone (L'Arche International., 2015). L'Arche members engage in productive work activities that are individually fulfilling and connected to the wider community – some create pottery that is sold locally; others participate in farming activities. Vanier's writing inspired and yet saddened me because these communities were not accessible to all – there simply were not enough of them and they had to set criteria as to how many and what types of people they accepted. Vanier's deep compassion and love for those with disabilities was inspired by his faith – he has spoken to this influence in his writings and in other public presentations (Vanier, 1998). His words touched me deeply and were an inspiration to do the work of listening to, being with, and allowing myself to be shaped by the lives of those impacted by disability.

My faith leads me to value those who are "poor in spirit" (Matthew 5:3, English Standard Version) and those who are on the margins of society; to love "the least of these" (Matthew 25:40). Spending my days with these men and women brought me to a deep respect and love for those whom many perceive as less valuable. I began to feel as if they had more to teach me than I them. Through this work, I truly did feel that I started to become human, as Jean Vanier has said (1998) – priorities shifted, values began to change, life goals were re-evaluated. One of the important ways that my faith influenced my perspective was that I began to view the people I worked with using a different lens. Instead of questioning what worth people with disabilities had if they were not able to contribute, I began to see that they offered something that was often lacking in our fast-paced consumer society. At a deeper level of human connection, I learned that these relationships were valuable because they required more or different effort than relationships based on what we can do for one another. I found hope in my encounters with individuals with disabilities because it seemed to me as though I was being granted a glimpse of a better world, where values were turned upside down, where worth was defined by one's humanness rather than by capacity to produce.

As a social work intern during my studies to earn my Masters degree, working with young children with disabilities and their families, I heard from parents about their frustrations, their fears, their encounters with helpful and not so helpful health and social care professionals, about the wait lists they faced in trying to get a diagnosis for their child, and then the wait lists again to gain access to services. Yet, the parents I met were hopeful in the midst of the hardships they faced. These were parents who started support groups for other parents, who blogged about their experiences and offered advice to others, who wrote letters to their political representatives advocating for more and better services, and who launched community programs for children with disabilities and their families. I was amazed at the resilience these families displayed, at the hopefulness they had for their children. It seemed like, despite everything, they hoped. They not only conveyed hope in their actions, they spoke about hope in a myriad of ways. One conversation that stuck with me was one that took place with a mother whose son had recently received an Autism diagnosis. She, like many parents, was shocked to discover that this diagnosis was not the golden ticket to accessing services that she had expected it to be. This mother tirelessly advocated to get her son assessed and secure the therapies he needed. She was a fighter. When I met with her to re-evaluate her needs for respite care and income support, we talked about her son – his development, his needs, his successes. Nearing the end of the home visit, I asked about how she was doing. She broke down and told me that it was the first time since she began her journey with her son's disability that anyone had asked how *she* was doing. She shared with me that she was struggling; she was exhausted and had moments of feeling depressed. It sounded like she was beaten down from constantly having to fight for what should be rightly available to her son. As I was leaving, she said, "There just needs to be more hope in the system." I was not sure exactly what she meant by that statement, but it caused me to contemplate the meaning of hope and it is one of the reasons why it became the topic to which I would devote the next six (or more) years of my life.

Personal values and beliefs about hope

Hope is an ineffable concept. It does not have an agreed-upon definition and gets used in so many contexts and in reference to so many objects that it seems almost impossible to narrowly define. When I ask myself about my own hope, my thoughts turn first and foremost to my faith. As a Christian, my faith allows me to believe that there is more to this life than what we can see, that there exists a future world that we call heaven, where pain and sorrow are no more, where true justice reigns, and where all has been made right. For me, there is no object more worthy of my hope than such a future and the God who desires this for us. When I experience or observe hardships, my prayers are focused on asking God for the courage to face them with grace and for peace in the face of uncertainty and not understanding. Of course, like most people, I also place my hope in worldly objects, outcomes, and people. My partner, my dearest companions, others I come into relationship with, can inspire and encourage hope; they can offer it when I am feeling like hope is hard to find. The objects of my desire, expectation, and hope are sometimes superficial and frivolous, sometimes more meaningful than that. As I am privileged in many ways, I thankfully do not have to hope for food, water, and shelter. I have hopes that may never be satisfied, but these will be higher-order desires, not essentials. Even earthly desires will ultimately only be fulfilled by God's provision. Coming from this perspective means that I have difficulty appreciating where others may find hope outside of a relationship with God. This has been a motivator too in my work, since many parents shared with me that they do not strictly have a faith or participate actively in spiritual practices. I had to work to try to get at what hope was for them. Other parents spoke about a faith of some kind that served as the source of their hopes. This was easier to relate to for me, although I could appreciate that their particular values and social and cultural contexts would make their experiences unique from mine.

As I spent time immersed in the words of participants, I had to be aware of these personal values and assumptions. Using a CGT approach to understand hope meant approaching the topic with openness and curiosity, while at the same time acknowledging that many influences came into play during data collection and analysis. The notion of allowing the theory to emerge from the data rather than imposing prior knowledge and assumptions was helpful as my own worldview threatened to direct my questions and analysis. The other idea key to CGT is that we *construct* our grounded theories rather than have them magically emerge from our data (Charmaz, 2014). This assertion was reassuring because it allowed me to move forward, while conceding that my grounded theory of hope would in fact belong to myself and my participants in a sense because *we* had co-constructed it. This theory thus would be shaped by my own history, values, worldview, and knowledge, just as it would by my participants and the particular time and context in which the research took place.

Influences of interactions with participants

Recognizing the life circumstances that separate me from my research participants has been at the forefront of my thoughts since I began this journey. At the start of my doctoral work, I was a single woman; I now find myself married with a baby on the way. These transitions – to married life, and now to becoming a parent, have altered the way I approach my participants and my data. I have always been particularly cognizant of my lack of parenting experience when speaking with parents (either as research participants, or as clients in clinical practice). I felt this as a limitation – that I somehow was unable to relate or identify with them, or worse, that they would feel that I was unable to be an effective social worker or researcher because I did not share their experience of parenting. Of course, now that I am about to be a parent, I recognize that parenting any child brings with it countless unknowns, uncertainties, challenges, and concerns. Had I been a parent when I interviewed my participants, I would have been aware of the differences between my child and theirs. If my child were neurotypical, would the parents feel that I could understand their experiences since our children were different? If my child did have a disability, would the parent either make assumptions about what I already knew about their experiences and leave out important details of their parenting narrative, or would they look to find the differences between our children, which surely would exist? These questions have been on my mind throughout this process and as I have entered new life stages. I do think that the imminence of becoming a mother has made me more attuned to the intricacies of preparing for and being a parent – both in my personal life and in my work. Oddly, until my contemporaries began to have children, my standard for child development had been the children I worked with. In that sense, I felt like I knew more about what it was like to parent a child with a disability than a typical child. These experiences and assumptions have most probably caused me to be both a better researcher of this topic and one who may make false assumptions about how well I can relate to and convey the narratives of my participants. In preparing interview questions and during interviews, I had to remain mindful of not presuming to know about their experiences based on the knowledge I had gained through my practice, my readings, and others interactions with parents of children with disabilities. I had to fight the tendency of a young, relatively inexperienced clinician and researcher to come across as expert and instead take a stance of curiosity and not-knowing, and ultimately of humility, that left plenty of room for participants to tell their stories. I also had to guard against the paralysis of assuming that being a parent (or a parent to a child with disabilities) would somehow make me a more effective researcher. These tensions – between allowing myself to hear surprising and new narratives from my participants, while recognizing that I do in fact bring a certain knowledge and expertise to the encounter – had to be kept in check throughout the research process. Memoing and debriefing with colleagues offered helpful outlets for acknowledging and working through these tensions.

And of course, I had to allow for the possibility that I would not find hope or that hope would manifest in a manner that was unlike my own expressions of hope. As a hopeful person, my assumption is that hope is always there, that there is always a reason to hope. However, as a reflective researcher, over the course of my interactions with participants, I had to remind myself to be aware that participants have distinct worldviews from my own and may not exude hope for their child, may express hope in very different ways, or may convey despair amidst their hoping.

As a CGT researcher, recognizing that the theoretical understandings generated within a particular study are, in fact, co-constructions is important. Researcher co-constructs with participant; participant co-constructs with the environment. I also recognize the limits to "knowing" the experience of parenting a child with a disability as a researcher and as an outsider. And so, instead of claiming to "know" my participants and their worlds, I have come to be at ease with the claim made by Doucet (2008) that all we can know is their narrated subjectivities: this is "as good as it gets for researchers striving to make bold knowledge claims about the messy, illusive and complex stories that emerge form people's everyday lives" (p. 84).

Influences of audiences

As a researcher, and particularly as a student researcher, my work is influenced in various implicit and explicit ways by the "theoretical and epistemological, or epistemic, communities" (Doucet, 2008, p. 80) in which I work and study. These dominant ways of knowing guide the types of inquiry researchers engage in, the approaches employed, and the evaluations our work is subject to (Doucet, 2008). It is important to recognize these influences and to position oneself theoretically and epistemologically as we present our knowledge claims. This positioning can help guard against research findings being taken up in unintended ways, although this cannot always be avoided. Researchers engaged in applied research fields, such as social work, are well positioned to consider how the multiple communities they are a part of have a bearing on their work and how it is presented in various contexts. Social work researchers are often located in academic institutions, yet conduct research in clinical or community settings. They also often engage in knowledge translation activities in a number of settings including clinical, academic, and community, where they may form their presentations to meet the interests of the varied audiences (e.g., clinicians, managers, policy makers, families, stakeholders, and researchers). A consideration of how these audiences may influence how research is presented and even conducted is a key part of a reflexive discussion in the context of clinical research.

The following section, "Doing", offers two examples of how reflexive, thoughtful, and rigorous decisions were made throughout the research process.

Doing

Context of the study

In the context of a doctoral dissertation, the first author sought to develop a theoretical understanding of the experience of hope among parents who have children with ND. The study utilized a CGT methodology (Charmaz, 2006, 2014) to build a theory of the process of hope based on the data generated[11]. The primary data source was in-depth, semi-structured interviews.

Collecting data from a reflexive stance

Situating oneself as a reflexive researcher means taking stock of how personal, professional, and paradigmatic positioning can influence each step of the research process. As a qualitative researcher, data collection through in-depth participant interviewing offers an opportunity to consider the impact of our interactions with participants from a reflexive stance. Social work researchers can struggle with the tensions between clinician and researcher as they often engage in research with populations similar to those with which they conduct clinical work. This may result in a pull to "switch hats" during interviewing and take on the role of helper when participants express distress or need while providing research data. This was certainly the case during data collection for the study on experiences of hope. Interviewing parents about their children is inherently very personal. In addition, an established field of scholarship has demonstrated the challenges of parenting children with ND, specifically the ways in which caregivers and other family members can

---

[11] For a detailed description of the study methodology, including detail about how methodological rigour was conceptualized and applied, refer to Chapters 3 and 5.

be impacted by the stress and daily struggles of meeting their child's needs. As is the case for many of the populations with whom social workers are in contact, parents of children with ND are often in need of various types of support. It is likely that these needs will arise in the context of an interview about their child and their family. As a clinician researcher knowledgeable about resources, there is a tension between sharing that information with participants and maintaining the primary focus of the meeting on data collection. Additionally, I have found that a topic like hope is one that promotes thoughtful reflection and taps into the emotional, psychological, and spiritual, all of which are intimate and potentially delicate areas. Throughout the interviews with parents about their experience of hope for their child, many became emotional while describing both challenges and successes in the life of their child and family. Some participants disclosed information that they indicated had not been shared with others, or only a very select few people – for example, a professional counselor, or religious leader. One mother disclosed that the child she was speaking with me about came to be conceived as the result of a rape. She revealed that she had not told many people about this – only a trusted community member and her parents. At the time, I was a very novice researcher – I had conducted a small number of participant interviews previously, and this was the first interview for my doctoral research. I was quite taken aback by her decision to share this information with me in the context of our first meeting, during the research interview. In the moment, I drew from my clinical training and allowed for some time and space to let us both sit with the disclosure. I offered an empathic one-word statement ("Okay") and tried to communicate non-verbally that this was a safe space, that what she had experienced was awful, and that I was worthy of her trust. The participant took in the silence – which felt like many minutes, but was closer to five seconds – and continued her narrative. At the end of the interview, I thanked her for her time and made extra effort to remind her about the confidentiality of the interview and anonymity of any data that would be shared publicly. When I left her, I found a place where I could sit and process my immediate reactions to the interview. I documented this as observational notes and as reflexive memos. Feeling like I needed more space to reflect on the disclosure, I called a colleague with whom I could process my reactions, and at a later date discussed this further with my doctoral dissertation committee.

Upon reflexion on my emotional reactions to the participant both during and after the interview, I asked myself some of the following questions – why did I react the way I did? What was influencing my reaction to the participant's disclosure – personal values, life experiences, clinical experiences? What did I think about my in-the-moment reaction to the disclosure? How did my role as researcher, as compared to that of social worker or caring other, impact my response? These questions stimulated thoughtful discussion and written reflections about both my emotional reactions to participant narratives and disclosures and about the clinician/researcher boundary. My immediate reaction during the interview was to offer emotional support to the person in front of me and pursue further her need to discuss the incident. As a clinician, my role is to explore "problems" and disclosures brought up by the client in so far as they relate to the issue as hand. If the client has shared an incident because she wishes it to be explored further in terms of its impact on her current functioning or the issue for which she is seeking help, it is important to acknowledge that and probe further. As a researcher, I likewise have a responsibility to probe areas that are important and related to the research question. The core differences between the two are: the research questions are pre-determined and constructed by me, rather than the participant, and the agreed-upon reason for us speaking with one another is for the participant to provide data to the research and not to receive help or support for a presenting problem. As a clinician-researcher, therefore, it is imperative to keep the context of the research always in mind, while at the same time allowing for empathy and seeking to understand the participant experience as best as one can. In this case, the disclosure of rape in the context of her story, ultimately provided some context for how the participant constructed and experienced hope in relation to her child. Neither the circumstances surrounding the incident, nor her emotional processing of it seemed relevant enough to my understanding of her experience of hope to necessitate probing further. In the moment, I created the space for participant decision making with regard to how much information she wanted to share and where to go from there.

Positioning myself as a constructivist in my approach to qualitative research has implications for how I view research outputs. One such implication is that findings are co-constructed by researcher and participants. I have offered one example here of a participant disclosure that prompted significant reflection on my part. My reactions and reflections became a source of data as per the GT methodology, where "all is data" (Glaser, 2001). Together with reflections from the other interviews conducted for this study and the raw data from participant interviews, these reflexive memos and field notes informed the theory of the experience of hope that was developed based on these sources. The co-construction is not only the interaction between the participant or their raw data and my own understanding of what that data says, but also includes my reactions, written and experienced, and all that I bring to the research context, which influence how I interpret, construct, and present findings in a CGT study. The interaction described here had a profound impact on my work as a social work researcher. It has impacted the way I think about collecting qualitative data, the manner in which I approach participants about sharing their narratives with me, and the way I prepare for and engage in eliciting data.

Presenting findings as a reflexive researcher

One of the primary goals of my work is for the findings and clinical recommendations to be meaningful and useful to parents of children with ND, their families, and the health and social care providers who journey alongside them. This objective has led me to focus my knowledge translation activities on gatherings where families and clinicians are present, if not make up the majority of the audience. Certainly, presenting my work to other scholars has provided me with valuable feedback in terms of the research process and the analysis of data. I have found, however, that the exchange of ideas that is generated as a result of presenting my ideas to parents and clinicians has been enlightening and rich and has brought me back to my analysis to push further and refine the conceptual model. To date, I have shared my findings in various forms to audiences at clinical conferences, clinical team rounds, and in informal conversations with parents and clinicians. During these presentations, I sought feedback about whether the conceptual understandings I had reached were recognizable to them. Hearing that they resonated for those who had first or second-hand experiences of parenting children with disabilities was a way to verify the rigour of my work. But, I not only sought to feel validated by these audiences; I also wanted to be challenged by them. They were able to express disagreement with ideas that did not fit for them or confusion when an idea needed more fleshing out or explanation. It is important to note that this sharing of data and the subsequent responses of the audiences were treated as feedback and not as equivalent data to the participant interviews which generated the research findings.

One of the biggest challenges about receiving feedback on the findings of my work relates to the philosophical question of whose truth the research represents. I found myself feeling the need to advocate for the parents I interviewed when presenting their stories to audiences of clinicians. This meant that I sometimes unintentionally overlooked the experiences of the people who work with families like the ones in my study. For example, parents suggested that the hopes they had for their children were grounded, realistic hopes. I wanted to emphasize this point since many parents have had the experience of being told in one way or another that if they displayed too much hope for their child, that they were in denial about their child's condition. I felt a duty to demonstrate that these parents were quite in tune with reality and were aware of their child's limitations, and yet persisted in their hope for their child's future. When I emphasized this during presentations in health care contexts, clinicians raised the very real tension they faced of setting goals with parents whose child they had determined would not be able to reach that goal because of their limitations. Clinicians agreed on the importance of allowing for hope in interactions with families, however, were concerned about encouraging a parent to hope for their child to walk when the child's particular level of functioning would prevent that. These tensions are real for health and social care clinicians, and yet the aim of my study was to represent experiences of parental hope. It was important to keep this perspective in mind as I reflected on the discussions generated during presentations and discussions.

Another tension arising from presenting the findings of a GT study relates to the resonance and usefulness of the research output. The intended result of a GT study is a mid-range substantive theory of the social or social psychological process under investigation. The theory should be abstracted to the point of being transferable to other similar populations and contexts, should, "[state] relationships between abstract concepts and may aim for either explanation or understanding" (Thornberg & Charmaz, 2012, p. 41). In other words, the conceptual rendering should be more than a descriptive collection of themes, or a "thematic survey" (Sandelowski & Barroso, 2003). This can pose challenges in the realm of ensuring rigour, or more specifically of evaluating the quality of the consequent grounded theory. "Member checking" is a common strategy used to assess rigour in qualitative research. Member checking can involve seeking feedback from participants (or those who have similar experiences with the phenomenon of interest) on either pieces or the whole theoretical rending. Establishing "resonance" means that the participants are able to locate their experience in the theory. As a CGT researcher, the criteria of usefulness and applicability, connected to the pragmatist underpinnings of the methodological approach, are also used to evaluate the quality of the conceptual understanding that results from the study. This means that the findings should be both relatable (resonance) and usable (applicability), while still maintaining a high enough level of abstraction to be considered a theoretical rendering rather than simply a thematic presentation.

As a reflexive researcher then, considering the impact of the various audiences before whom findings are presented requires a juggling act of sorts. On the one hand, those concerned with the methodological rigour of the work – often those located in academic contexts, some of whom have power over the success of the dissertation – need to be convinced of the strength of the study protocol and adherence to the core tenets of the methodological approach as per key writers. On the other hand, locating myself as a clinician researcher hoping to generate work that is both representative of the experiences of families and valuable and informative to various groups of stakeholders in the clinical realm, the focus on the quality and usability of the conceptual rendering is essential. These influences have implications for how findings are translated to audiences and require some thought to when and how concessions will be made on either side. For instance, some adherents to GT argue that the substantive theory should be abstracted to the level that the participants are not able to relate to and confirm them (Morse, Barrett, Mayan, Olson, & Spiers, 2002). A theory that satisfies this criterion may please some methodological purists (often academics, rather than parents or care providers), but may not be especially meaningful to other audiences, such as families and clinicians. Conversely, a theory that is presented as idiosyncratic and relatable, but has not been raised to a high enough level of abstraction to explain relationships between concepts in the theory and allow for some level of explanation, may not fulfill agreed upon standards within the epistemic and methodological communities, including the dissertation committee and/or examiners. I navigated this tension throughout my doctoral work – as a novice, seeking to adhere as faithfully as possible to the methodological approach, while as a more experienced researcher nearing the end of the doctoral program, finding a balance between the two. This was accomplished by appreciating that one can satisfy both criteria while accounting for the ways in which decisions made along the way were strategic and thoughtful and any concessions made were purposeful. As a good pragmatic-reflexive researcher, ultimately, the methodological choices made are those that make the most sense considering the researcher, the particular study, integrity in seeking coherence relative to methods and values, and allegiance to the context in which the research is being conducted. Those who situate themselves as pragmatic-reflexive researchers should consider their accountability to their participants and other stakeholders to the research. These communities – theoretical, epistemic, and I would add, practice-based – are partners in the journey of conducting empirical work and generating research outputs. Their influence should be considered not only at the dissemination and knowledge exchange stage, but from the outset at the study design phase.

Conclusion

This paper has offered methodological, reflexive, and pragmatic considerations for carrying out a CGT study. By tendering an explicit accounting of some of the “grunt work” (Star, 2007) of the research process which in actuality, arguable are the “golden nuggets” of the work, our hope is that this paper will be useful to both neophyte and veteran grounded theorists. This paper is not meant as a how-to, but rather as an example of how one researcher drew from a methodological knowledge base and sought to thoughtfully and critically integrate researcher reflexivity with a rigorous approach to research and integrity to who she is as a researcher. Beginning with a solid grounding in the history and fundamental theoretical and methodological principles of the approach, students and researchers can rigorously apply an approach such as CGT to the study of social problems. In emphasizing rigour in their application of methodology, social work researchers will contribute to the advancement of theoretical understandings of the social problems about which we seek to effect change. In doing so, policy and clinical advancements, reflecting recommendations put forward by way of our research findings, hopefully will have increasing weight. Students are taught about the importance of reflexivity in qualitative research (e.g., Creswell, 2007; Neuman & Robson, 2012; Padgett, 2008; Rubin & Babbie, 2013), but are rarely given opportunities to discuss the realities of how reflexivity gets integrated into the research process. Both qualitative research and reflexivity are messy and for novice researchers, it can be a challenge to make sense of methodological principles and instructions. It is the authors’ hope that the discussions put forward here will add to the methodological scholarship in the area of GT and offer students and researchers examples of what researcher reflexivity looks like and how it can be integrated into the various stages of the research process.

References

Baker, C., Wuest, J., & Stern, P. N. (1992). Method slurring: the grounded theory/phenomenology example. *Journal of Advanced Nursing, 17*(11), 1355-1360. doi:10.1111/j.1365-2648.1992.tb01859.x

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Bryant, A., & Charmaz, K. (2007a). Ground Theory research: Methods and practices. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 1-28). London: SAGE Publications Ltd.

Bryant, A., & Charmaz, K. (2007b). Grounded Theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 31-57). London: SAGE Publications Ltd.

Bryant, A., & Charmaz, K. (2007c). *The SAGE Handbook of Grounded Theory*. London: SAGE.

Charmaz, K. (1980). *The social reality of death*. Reading, MA: Addison-Wesley.

Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: Sage Publications.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). London: SAGE Publications.

Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five traditions* (2nd ed.). Thousand Oaks, CA: Sage Publications Inc.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Thousand Oaks, CA: SAGE.

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 31*(6), 1476-1484. doi:10.1046/j.1365-2648.2000.01430.x

D'Cruz, H., Gillingham, P., & Melendez, S. (2007). Reflexivity, its meanings and relevance for social work: A critical review of the literature. *The British Journal of Social Work, 37*(1), 73-90. doi:10.1093/bjsw/bcl001

Doucet, A. (2008). "From her side of the gossamer wall(s)": Reflexivity and relational knowing. *Qualitative Sociology, 31*, 73-87.

Glaser, B. G. (1978). *Theoretical Sensitivity: Advances in the methodology of Grounded Theory*. San Francisco: Sociology Press.

Glaser, B. G. (2001). *The Grounded Theory perspective: Conceptualization contrasted with description*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (2003). *The Grounded Theory perspective II: Description's remodeling of Grounded Theory methodology* (Vol. 2). Mill Valley, CA: Sociology Press.

Glaser, B. G. (2005). *The Grounded Theory perspective III: Theoretical coding*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Piscataway, NJ: AldineTransaction.

Holton, J. A. (2007). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 265-289). London: SAGE Publications Ltd.

Hood, J. C. (2007). Orthodoxy vs. power: The defining traits of Grounded Theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 151-164). London: SAGE Publications Ltd.

Kahlke, R. M. (2014). Generic qualitative approaches: Pitfalls and benefits of methodological mixology. *International Journal of Qualitative Methods, 13*, 37-52.

L'Arche International. (2015). L'Arche International. .

Morse, J. M. (2009). Tussels, tensions, and resolutions. In J. M. Morse, P. Noerager Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing Grounded Theory: The second generation* (pp. 13-22). Walnut Creek, CA: Left Coast Press, Inc.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*, 13-22.

Morse, J. M., Stern, P. N., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. E. (2009). *Developing Grounded Theory: The second generation* (Vol. 3). Walnut Creek, CA: Left Coast Press.

Neuman, W. L., & Robson, K. (2012). *Basics of social research: Qualitative and Quantitative Approaches* (2nd Canadian ed.). Toronto, Canada: Pearson Canada Inc.

O'Connor, M. K., Netting, F. E., & Thomas, M. L. (2008). Grounded Theory. *Qualitative Inquiry, 14*(1), 28-45. doi:doi:10.1177/1077800407308907

Padgett, D. (2008). *Qualitative Methods in Social Work Research* (2nd ed. Vol. 36). Thousand Oaks, CA: SAGE Publications, Inc.

Rothwell, D. W., Lach, L., Blumenthal, A., & Akesson, B. (2015). Patterns and trends of Canadian social work doctoral dissertations. *Journal of Teaching in Social Work, 35*, 46-64. doi:10.1080/08841233.2014.977988

Rubin, A., & Babbie, E. (2013). *Essential research methods for social work* (3rd ed.): Brooks/Cole Cengage Learning.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research, 13*(7), 905-923.

Star, S. L. (2007). Living Grounded Theory: Cognitive and emotional forms of pragmatism. In A. Bryant & K. Charmaz (Eds.), *The SAGE Handbook of Grounded Theory* (pp. 75-93). London: SAGE Publications.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks: Sage.

Thornberg, R., & Charmaz, K. (2012). Grounded Theory. In S. Lapan, M. Quartaroli, & F. Riemer (Eds.), *Qualitative research: An introduction to methods and designs* (pp. 41-67). San Francisco: Jossey-Bass.

Titscher, S., Meyer, M., Wodak, R., & Vetter, E. (2000). *Methods of text and discourse analysis*. London: SAGE.

Vanier, J. (1998). *Becoming Human*. Mahwah, New Jersey: Paulist Press.

Linking Statement

The previous chapter, Manuscript 1, offered an example of how researcher reflexivity can be integrated and reported on in a qualitative CGT study. The following chapter, the second manuscript, presents the empirical study on the experiences of hope among parents of children with ND conducted as part of this dissertation. This manuscript is structured as a standard qualitative published report and is in preparation for submission to a peer-reviewed journal.

Chapter 5 - The Light at the End of the Tunnel: Experiences of Seeking and Maintaining Hope among Parents of Children with Neurodisabilities

(Manuscript 2)

Bailey, S., N., Lach, L. M., Nicholas, D., & Ives, N.

*Potential target journals: Qualitative Health Research, Child: Care, Health and Development, Disability and Rehabilitation

Abstract

Background and objectives: The phenomenon of parenting children with Neurodisabilities (ND) has been widely researched, resulting in a spectrum of representations in both the scholarly literature and mainstream media about what this experience might be like. Renderings of this experience can be traced from pathological to strengths-based portrayals. There has been a historic trend in the literature to focus on the negative effects on the family of caring for a person with extraordinary needs. In contrast, this dissertation focuses on a trend, led by parent- and self-advocacy groups and researchers, to amplify positive aspects of parenting, and calls for spaces to examine parenting from a more nuanced perspective. This shifting paradigm is highlighted in the examination, for example, of parenting a child with ND through the lens of "parental hope". The main objective of this study is to gain a meaningful understanding of parental hope experiences in order to develop a theory of the process of hope in relation to parenting a child with ND.

Study design: This study employed a CGT approach (Charmaz, 2014), rooted in the foundational paradigms of pragmatism, constructivism, and Symbolic Interactionism to produce a grounded theory of the process of hope as experienced by parents of children with ND.

Study participants and setting: Participants were mothers and fathers (n=7 mothers, n=4 fathers; mean age=42.9 years) of a child with ND aged 4 to 12 years of age, living in one of two major metropolitan areas in Canada. Sample selection was based on a database of caregivers of 263 children with ND who participated in the first part of a study entitled *Parenting Matters!* Children represented a range of neurodevelopmental diagnoses and levels of functional impairment. Initial purposive sampling was followed by theoretical sampling as per CGT.

Materials and methods: The primary source of data for this study is parent narratives derived from intensive interviewing. Each participant was interviewed once at a convenient location. Interviews lasted between 40 and 120 minutes. All but one interview was face-to-face. The interview guide evolved over the course of the study, in line with CGT methodology. Observational notes were also taken and integrated into the analysis. Analysis was informed by the CGT approach, including initial coding, focused coding, and memo writing. Elements of rigour in qualitative research, and CGT specifically, were considered and enacted in the context of the "vertical hierarchy" (Staller, 2013).

Results: The resulting substantive theory, "seeking light at the end of the tunnel", characterizes the process of seeking and maintaining hope amidst contextual constraints at multiple levels of influence. The contextual constraints, or distractors to hoping, operating at the individual, family, social, and societal levels, serve as barriers to parental hope in the context of parenting their child with ND. In order to maintain hope, parents draw on both personal and communal sources symbolizing the kindling to the fire of their hope, and employ strategies, some of which are innate, others which are mastered over time. Consequent to seeking light at the end of the tunnel, and in response to distractors, parents adjust the focus of their hopes for the future - or find a new normal - and evolve and become different individuals and parents to their children. Part of this evolution involves becoming a hope ambassador – sharing hope with others, and educating their communities about why hope matters. Clinical implications and directions for future research are offered.

Background

The phenomenon of parenting children with ND has been widely researched, resulting in a spectrum of representations in both the scholarly literature and mainstream media about what this experience might be like. Renderings of the experiences of parents of a child with an ND can be traced from pathological to strengths-based representations. Over the course of history, parents have been portrayed as unsung heroes for their tireless efforts in providing physical care to severely disabled children (Singer, n.d.). Conversely, they have been portrayed as carriers of a tragic burden, or, as perpetrators of heinous crimes against innocent children they are no longer able to care for or whose care has become too overwhelming (R. v. Latimer, SCC 1, [2001] 1 S.C.R. 3, 2001). In the academic literature, two trends emerge most frequently; studies that investigate problematic parenting styles and behaviors, or those that report on the extent of parental caregiving burden or stress (Green, 2007; Webster, Majnemer, Platt, & Shevell, 2008). To be sure, there has been a historic trend in the literature on families of children with disabilities to focus on the negative effects of caring for a person with extraordinary needs on the family (e.g., Green, Darling, & Wilbers, 2016; Herring et al., 2006; Thomas, King, Mendelson, & Nelson-Gray, 2017; Webster et al., 2008). Another trend in the literature, that will be the focus of this paper, is a trend led by parent- and self-advocacy groups and researchers on positive aspects of parenting, and the calls to open up spaces to examine parenting from more nuanced perspectives.

This shifting paradigm is highlighted in the examination, for example, of parenting a child with a ND through the lens of "parental hope" and factors that influence this hope. Through this lens, scholars have found that parents may sometimes experience a lack of hope for their child and their family as a result of multiple psychosocial or economic losses experienced over the life course (Horton & Wallander, 2001; Olshansky, 1962; Wasow, Hatfield, & Wikler, 1981). However, while research has established that many parents of children with ND live with compromised physical and mental health (Lach et al., 2009) and psychological distress (Mednick et al., 2007) there is also considerable individual variation in terms of parental well-being among these parents (Horton & Wallander, 2001). For instance, in their study of mothers and children with intellectual disabilities, Hastings and colleagues (2004) found that mothers who reported higher levels of caregiving demand placed on them also reported experiencing more personal growth and maturity as a result of parenting their child with high care needs. These findings point to the importance of paying attention to the experiences of parenting as no simple, linear relationship exists between parenting a child with a disability, the complexity of a child's impairment, and parental well-being. Individual factors seem to come into play to determine parental well-being in the context of childhood disability such as personal flourishing, and experiencing the parenting role as one that could also lead to a more meaningful life. As a result of these latter understandings, it was deemed relevant to open up the concept of 'hope' toward a deeper understanding of how it operates among parents of children with ND.

Locating 'Hope' in the Field of Paediatric Neurodisability

Along with a shift in the social science literature toward the consideration of inherently positive constructs that are both indicators of parenting (e.g., nurturance) and are associated with parenting (e.g., hope), a movement has evolved to consider the experience of parenting a child with a disability from a strengths-based perspective. Yet, while researchers turn to exploring the positive aspects of the parenting experience in the context of childhood disability, such as family closeness, strength, and resiliency (e.g., Blacher & Baker, 2007), the concept of hope is one that remains poorly understood. Hope emerges an important concept in the domains of nursing, medicine, and psychology, mostly in the study of living with chronic health conditions, particularly in the context of living with cancer or having terminal illness (Miller, 2007).

The concept of hope has begun to receive attention as an important construct in the field of social work research, and more recently, in the area of childhood disability. Within the empirical paediatric disability literature, hope has been identified as a potential protective factor against adverse outcomes (Blacher & Baker, 2007), a mechanism for coping or making meaning out of difficult life events (King et al., 2006), and a factor related to increased health-related quality of life in children (Kirpalani et al., 2000). One study revealed that parents who seek out hope in varying forms and who have a positive outlook regarding their child's disability manage parenting better than those who do not (Horton & Wallander, 2001). In other work, higher levels of hope have been shown to be associated with less depression, anxiety (Cheavens, 2000) and distress (Mednick et al., 2007), which are commonly reported to be higher among parents who have children with disabilities compared to parents of neurotypical (NT) children. Mednick and colleagues (2006) found that hope protects against anxiety, even after controlling for diabetes regimen behavior and receiving caretaking help among mothers of children with Type 1 diabetes. King and colleagues (2006) found that raising a child with a disability can have a profound positive effect on a family's belief system, which can lead to an increased sense of coherence and capability, leading the authors to point to the importance of hope and of grasping future possibilities, and to call for further research to help measure such constructs as hope and beliefs systems of families. Kirpalani and colleagues recommend a future research focus on the examination of the determinants of hope: "hope is increasingly recognized as a disease modifier, although we are only beginning to understand how hope (and hopefulness) affect biological processes" (2000, p. 296). The sum of this small but important body of studies demonstrates the importance of examining the concept of hope and its relationship to the experience of parenting children with ND. To arrive at deeper understandings of this concept, and more specifically, before we can examine the determinants of "hope", we must first develop a conceptualization of the construct that is grounded in the experiences of those who care for their children with ND. Little is known about the role and meaning of hope and what difference hope makes when parenting a child with a ND. The current study begins here and seeks to generate, from the perspective of parents themselves, a theoretical articulation of parental hope.

For social workers and other professionals who support children with ND and their families, such as occupational therapists, physical therapists, developmental paediatricians, nurses, and educators, the topic of hope is one that arises in everyday interactions and discussions about a child's diagnosis, prognosis, progress, and future. Clinicians struggle with the tension between offering hope for the future and delivering news about a child's development that they fear may challenge a parent's hope for their child. Parents often mention hope in a variety of ways and speak to a loss of hope for themselves, their child, their family, and their future. Despite many challenges, however, parents often display incredible resilience and strength, which motivates this research on seeking to understand the role of hope in their lives[12].

This study contributes to knowledge in the area of parenting children with ND by exploring the role of hope in the context of parenting. Social work research in the health field takes into account not only the immediate context of the participants in the study, but also the broader systems within which people access services, come into contact with various health professionals, and the policies and practices guiding their interactions with these diverse systems. Thus, this study positions the experiences of parents of children with ND within the broader systems context to determine the process of hope.

Context of the Study

Terms such as "neurodisability" and "neurodevelopmental disorder/disability" have often been used interchangeably and with little consistency or specificity. This has been the case partly because, until very recently, there has been no international consensus about the definition of this group of conditions. A definition, was recently developed by a group of researchers in the UK, who, through the use of a Delphi survey, a consensus building research approach (Morris, Janssens, Tomlinson, Williams, & Logan, 2013) and with the collaboration of a diverse group of health professionals, allied health professionals and parents, arrived at a definition. In the current study, we will employ this definition for a number of reasons: 1) it was developed through a consensus-based process, thus inferring that a variety of priorities were solicited and weighed; 2) parents contributed to the definition suggesting that persons with lived experience contributed to its conceptualization; 3) a range of health care professionals participated in the consensus process suggesting a multi-perspective focus; 4) it is inclusive of children who have not received a diagnosis and yet still fall

---

[12] For more details about the motivation to study this topic, see Chapter 4 of this dissertation.

under the definition as stated; 5) it retains some of the conceptual terminology of the International Classification of Functioning (ICF), which is "the predominant conceptual framework for the human experience of health and disability" (Miller & Rosenbaum, 2016, p. 2); 6) as a non-categorical definition it allows for the promotion of non-categorical research, policies, and practices (Miller, Shen, & Masse, 2016), and 7) it has been taken up and promoted by key clinical researchers in the field of childhood disability (e.g., Miller & Rosenbaum, 2016). The definition put forward by Morris and colleagues (2013) is as follows:

> Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour (pp. 1105-1106).

Although we lack current, population-based data on children with ND in Canada (Dunn & Zwicker, 2017), we do know that children with ND make up 7-14% of all children in developed countries (Arim et al., 2012; Lach et al., 2007; Miller et al., 2016). The above definition is considered 'non-categorical' (as opposed to a diagnosis-based definition), and is inclusive of many specific diagnoses labels. Although historically, much of the research in the field of childhood disability has been diagnosis-specific, more recently, researchers have begun to find evidence supporting the notion that a child's functioning, or level of complexity, is a better determinant of many important health and social outcomes than the child's diagnosis (Miller et al., 2016; Ritzema, Lach, Rosenbaum, & Nicholas, 2016; Stein & Jessop, 1982, 1989). The inclusive nature of the study allows for comparisons to be made both within (level of functioning, complexity) and between conditions.

The current doctoral study was developed within the frame of a CIHR-funded Pan-Canadian program of research entitled *The CIHR Team in Parenting Matters! The Biopsychosocial Context of Parenting Children with Neurodevelopmental Disorders in Canada*. The Parenting Matters! program of research consists of four interrelated studies on parenting children with ND. The Parenting Matters! *clinical study,* from which the first author developed her own research study, is a mixed-method study about parenting children with ND for which parents were recruited from paediatric hospitals and rehabilitation centres across three provinces (Alberta, Ontario, and Quebec). The mixed method design of the larger study included a quantitative component in which parents were asked to complete a battery of measures (on parenting, about their child, their family, and their social environment) and a qualitative study using a mixed phenomenology/GT approach and in-depth interviews with parents. Participants for the current doctoral study were located from the Parenting Matters! clinical study database and represented parents who had provided consent to be contacted for further research opportunities. This research was carried out by the first author as part of her PhD work and was guided by her supervisor (LL) and doctoral committee members (DN and NI), who are the co-authors of this manuscript.

This study sought to gain a meaningful understanding of parental hope experiences to develop a theory of the process of hope in relation to parenting a child with ND. To address the gaps in the literature relating to the experiences of hope for parents who care for a child with ND, the goals of this project were to 1) identify key elements and processes of hope in mothers and fathers of children with ND; and 2) develop a conceptual understanding of the experience of hope for mothers and fathers of children with ND.

The following research questions guided the study:

- How is hope expressed in the lives of parents of children with ND?
    - How does hope emerge over time? How is it constructed?
    - Where is hope found?
    - What strategies are employed to maintain hope? What fosters or impedes ways of hoping?
    - How does social context affect hope?
    - What difference does hope make?

Methodological Approach

This study utilized a CGT methodology (Charmaz, 2006, 2014) to build a theory about the process of hope based on the data generated. GT methods are "a set of flexible analytic guidelines that enable researchers to focus their data collection and to build inductive middle-range theories through successive levels of data analysis and conceptual development" (Charmaz, 1994, p. 507). The end result of a GT study is an "analytic interpretation of participants' worlds and of the processes constituting how these worlds are constructed" (Charmaz, 1994, p. 508). As a methodological approach, CGT is a good fit for a study of parental hope for a number of reasons. For one, this methodology has been widely used in studies relating to paediatric health (e.g., Bally et al., 2013; Charmaz, 1990; Davis et al., 2010; Graungaard & Skov, 2007; MacKean, Thurston, & Scott, 2005; McNeill, 2004, 2007; Taanila, Jarvelin, & Kokkonen; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002). Furthermore, as Charmaz advocates (1994, 2006, 2014), CGT methods lend themselves to the study of phenomena which include issues of social justice, such as those facing families with a child with a chronic condition, such as a ND. Charmaz (1994) states that "social justice studies require looking at both realities and ideals" (p. 510). Some parents of children with disabilities may have to manage the tension of caring for a child who is not the child they envisaged (the 'ideal child'), they must renegotiate the sometimes-extraordinary caregiving needs of their child and they may also experience stigma, exclusion, inequality, and a lack access to services due to ableist social structures.

CGT[13] preserves many of the foundational principles of classic GT, while operating from a constructivist paradigm. This view, which challenges the objectivist underpinnings of traditional GT, holds that there are multiple realities and that knowledge is constructed, not discovered (Charmaz, 2014). What the researcher hears and observes in the field is influenced by their prior interpretive frames, biographies, and interests, as well as the research context, relationships with participants, and methods of gathering and interpreting data (Charmaz, 2014). Constructivists acknowledge that conceptual understandings of phenomena are shaped by the researcher's interpretations of the data and what she and her participants bring to the research process; in other words, we construct our grounded theories (Charmaz, 2014). What follows is that CGT researchers take a reflexive stance toward interpreting and representing the empirical worlds they seek to understand.

Symbolic interactionism (SI), pragmatism, and constructivism are the paradigms guiding this study[14]. Symbolic Interactionism, defined by Herbert Blumer and derived from pragmatism (George Herbert Mead), assumes that "society, reality, and self are constructed through interaction and thus

---

[13] Charmaz purposely chose the term "constructivist" to differentiate her approach from other *constructionist* sociological approaches and to emphasize, "social contexts, interaction, sharing viewpoints, and interpretive understandings" (Charmaz, 2014, p. 14). However, in her most recent text, Charmaz (2014) grants that her constructivist position has come to align closer with constructionism as it has evolved over time.

[14] See Chapter 3 of this dissertation for a more detailed rendering of the theoretical foundations of CGT.

rely on language and communication…[and] that interaction is inherently dynamic and interpretive and addresses how people create, enact and change meanings and actions" (Charmaz, 2006, p. 7). Pragmatism asserts that the mark of good theory is that it is suitable for solving social problems. This emphasis is well-aligned with the social work values of pursuing social justice and the focus on affecting change. The tenets of pragmatism and SI match well with constructivism – all of which recognize that reality is open to multiple interpretations.

Recruitment and sampling

Recruitment

Sample selection was based on a database of caregivers (n=198 mothers, n=52 fathers, n=13 other caregivers) of 263 children (n=91 female, n=147 male) between the ages of 3 and 13 years (M=8.18 years, SD=2.51) (Ritzema et al., 2016) who participated in the Parenting Matters! clinical study. Participants were recruited for the Parenting Matters! study between July 2011 and April 2014, by way of a familiar health care provider at a clinical paediatric centre where their child received services across three Canadian provinces (Alberta, Ontario, and Quebec). The clinician (e.g., social worker, nurse, physician, educator) determined whether a family fit the study inclusion criteria based on medical file data and/or their knowledge of the family. Parents were approached and informed of the study during an appointment with the healthcare provider (HCP). If interested, the parents were either: 1) referred to a local research assistant who was on site, or 2) asked to provide consent to have their contact information passed on to the local research assistant by the HCP. The research assistant provided interested parents with more detailed information about the study and if the parent agreed to participate, they were asked to read and sign the consent form, as per consent procedures approved by the respective Research Ethics Board of the associated institution. Part of the consent procedure involved participants having the option of agreeing to be contacted for future research opportunities. Participants who completed the quantitative portion (Part 1) of the Parenting Matters! study and who agreed to be contacted for future research were deemed eligible to participate in the current study.

Participants who fit the following criteria served as the sampling frame for the present study: 1) parent or caregiver of a child with a diagnosis of ND; 2) ND is the child's primary diagnosis; 3) the child is between 4 and 12 years of age; 4) a minimum of 6 months has passed since the child's diagnosis[15]; 5) parents are able to take part in an interview in English; and 6) the parent lives in one of two major metropolitan areas in Canada. Participants residing in one of the two aforementioned cities were chosen due to ease of access for the researcher to conduct in-person qualitative interviews. Upon receiving ethics approval from the University Research Ethics Board, participants were identified in the Parenting Matters! clinical study database and a list of potential initial participants was created. These participants were contacted by phone by the first author and asked whether they were interested in participating in an interview about their experiences of hope in relation to parenting a child with ND. All parents contacted were willing to take part in an interview. Interviews took place at a location of the participant's choosing – at their home, in a coffee shop, or at their office building. Interviews took place between November 2013 and December 2014.

Sampling

An initial purposive sample of three parents of children with a diagnosis of ND were selected to participate in the study. Sampling proceeded based on a small number of sample characteristics on which diversity was desired, for example, the child's primary diagnosis, the complexity of the child's functional impairments, family composition, language spoken in the home, and parent sex. Initial sampling continued until theoretical categories began to develop through data analysis, at which point, sampling selection was guided by theoretical sampling based on emerging themes relating to the process of hoping (Charmaz, 1994, 2006, 2014). Provisional conceptualizations were further examined by recruiting and interviewing participants whom the researcher believed could offer further depth to the developing theory. This meant that at times, a particular subgroup of participants was sought (e.g., rural families, parents with lower educational attainment, parents who had higher levels of financial stress, parents who reported higher levels of depression in the Parenting Matters! study, and parents who spoke languages other than English in the home). In line with CGT, theoretical sampling also occurred, whereby interview questions or observations were adapted toward emerging ideas and potential participants were selected based on emergent categories and questions (Strauss & Corbin, 1990b). Theoretical sampling also meant going back to earlier data and sampling incidents for evidence of a tentative hypothesis. As the core

---

[15] The rationale for requiring at least a 6-month time lapse between diagnosis and participation in the study is to avoid the effects of a new diagnosis. The assumption is that living with the condition has become somewhat entrenched in the lives of the families. This decision was made in the context of the Parenting Matters! study based on consultation with paediatric healthcare and allied health providers.

categories emerged through successive levels of data analysis, data collection became more directed by the emerging theory.

Theoretical sampling continued until theoretical saturation was reached (Charmaz, 2014). Charmaz (2014) defines saturation in GT as the point at which "the properties of your theoretical categories are 'saturated' with data" (p. 213). At the point of saturation, recurrent findings emerged, participant experiences were easily classified into existing categories, and additional data did not add meaningfully to the existing categories (Charmaz, 2014). Saturation was judged based on the following criteria, consistent with a GT approach: redundancy, feasibility, supervision, peer review, and methodological and substantive experts (dissertation committee members, colleagues, and National Research Advisory Group members).

The final sample size of eleven participants permitted descriptive analysis of the standardized data (e.g., demographic information, complexity of child's condition, parent health, financial stress) and allowed for sampling variation and heterogeneity among participants guided by a small number of factors which, based on the literature in the area of parenting children with disabilities, are known to make a difference to constructs related to hope, such as quality of life, and resilience, and therefore were assumed to potentially influence hope. These factors include: socioeconomic status, culture/language, family constellation, geographic location, parent sex, child sex, and child functioning/diagnosis (Abbedutto et al., 2004; Green, 2007; Pelchat, Bisson, Bois, & Saucier, 2003; Thomasgard & Metz, 1997). Such sample diversity allowed for an appreciation of the phenomenon of interest in various forms and for the pursuit of zones of convergence and divergence in the data (Charmaz, 1994).

Data collection

Interviews

The primary source of data for this study are parent narratives derived from intensive interviewing (Charmaz, 2014). Each participant was interviewed once, however participants were asked whether they were available to be contacted as the analysis progressed to clarify comments they made during interviews and/or to confirm whether emerging findings resonated with their experience. Although all participants agreed to be contacted in the future for clarification of interview data, it was not deemed necessary to do so during data analysis. Interviews took place at the convenience of the participant, in a location of their choosing. One interview (the last interview conducted) took place over Skype because the participant lived in a rural area. Interviews lasted between 40 minutes and 2 hours. Prior to commencing the interview, participants completed the informed consent form and were reminded that the interview would be audio recorded to facilitate the transcription of the interview and data analysis. Interviews were transcribed verbatim by the first author or a research assistant.

A preliminary interview guide developed for the study was used to elicit participant narratives about the meaning of hope[16] in relation to parenting their child, how hope was experienced, how hope developed over time, and the difference they felt that hope made to their lives. In line with a GT approach, the interview guide evolved as the conceptual categories emerged and became more specific in order to validate the emerging theory. The interviewer followed the participants' lead, allowing for deviation from the interview guide in the conversation.

Observational notes

Observational field notes were taken throughout the process of data collection. Immediately following each interview, the researcher logged her impressions and other pertinent details about the interview (Schreiber, 2001). Brief notes were also taken during each interview consisting of a salient word or short phrase/concept notation. These served as reminders of a particular thread to follow-up with the participant about, or a key word or phrase used by the participant to repeat back to them. Observations were also recorded in cases where the researcher was able to observe the participant interacting with their child and/or partner. In two cases, the participant's partner was present in the home and intermittently was present in the interview space. In a few instances, the partner spoke up to respond to a question or add details to responses provided by the participant. These responses were recorded, but not used as data per se, as the partners had not consented to participate in the study. Observational notes were taken, however, about interviewer impressions of the interactions between family members. These observations provided contextual information about how hope is expressed by the mother or father being interviewed. For example, how parents interacted with one another, how supportive they seemed to be, how they talked about their child(ren), the family climate, and so forth were found to add nuance and context relative to notions raised with regard to participants' experience of hope.

---

[16] Charmaz (1994) speaks about focusing on meaning and process; because meanings vary, we must "find the range of meanings and learn how people form them" (p. 522).

Data analysis

As they were completed, interviews were transcribed and uploaded into Dedoose, a web-based data management and analysis application. Demographic information and some additional descriptive data collected by way of the Parenting Matters! study was imported into Dedoose as attributes (or “descriptors”) of the sample. Analysis of interview data followed the CGT approach, involving a continual comparison and interplay between the data and emerging themes and working hypotheses (Charmaz, 2014). This constant comparison involved an iterative process of analysis, theoretical sampling, and theorizing. Analysis began during the first interview and continued even as the theory was being developed. Analysis in CGT involves at least two phases: an initial phase and a focused (or selective) phase (Charmaz, 2014).

The initial phase involved line-by-line or incident-by-incident coding, which remained very close to the data. Each segment (or incident) of data was given one or more codes. As much as possible, codes followed the recommended format of using gerunds (Charmaz, 2014), which help the researcher stay close to the data and code for social and social psychological processes by reflecting action in the data. New codes are created when a piece of data is not easily categorized into an existing code. Preliminary concepts or categories were developed early on, based on initial impressions and hypotheses. Initial codes were organized into higher order codes (concepts or categories) as analysis progressed and the list of initial codes was cleaned up by eliminating redundant codes or by collapsing similar codes. Analysis proceeded by coding new interviews as described and making comparisons – existing codes to existing data, existing codes to new data, and preliminary concepts and categories to codes.

The focused phase entailed sorting, synthesizing, integrating, and organizing larger sections of data based on the most frequent and meaningful initial codes. Initial codes and tentative categories that seemed to be the most theoretically important or relevant or that came up most frequently were promoted to focused codes. These codes were more conceptual, selective, and directed than initial codes, and moved the analysis in an interpretive, conceptual direction. A group of focused codes were generated that began to form the foundation of the grounded theory of hope. New interviews were coded using the new focused codes as well as initial codes, as relevant. Analysis of early interviews was reviewed as new codes were added. Relationships among codes and categories began to be formulated. As relationships among the codes become apparent, an overarching theoretical model began to emerge. This stage of coding raised the analytic level of the work and moved it toward a more holistic theoretical understanding of the process. Some elements of axial coding as expounded by Strauss and Corbin (1990a) were helpful in advancing the analysis. For example, putting the categories and codes in context by comparing them to other categories helped to develop a sense of how they worked together in time. The strategies of specifying the properties and dimensions of the categories and of considering the conditions, interactions, and outcomes of the process of hoping were also utilized and helped assemble the codes into a coherent whole (Charmaz, 2014).

Memo writing was utilized to document the analytic and decision-making process, to explore provisional ideas and relationships in the data, and to log researcher reactions, emotions, and reflections as the research advanced. The researcher's influence on the analytic process was held in check by way of a number of strategies: returning to prior data and checking out conceptual hunches, presenting ideas to new participants during interviews (theoretical sampling), and seeking feedback from other parents and clinicians by way of clinician, research, and community presentations of the study findings.

As analysis progressed, additional literature was sought and reviewed. This process of seeking out relevant scholarly work to help build, flesh out, or challenge emerging conceptual ideas is in line with the strategy outlined by Charmaz (2014) and other contemporary grounded theorists who suggest that extant theoretical understanding and substantive knowledge can be kept in mind without directing data collection and analysis. Researcher reflexivity and peer debriefing are strategies that were used to safeguard the emerging theory from being overly influenced by the researcher's prior knowledge of theory. In a similar vein, through memoing, potential connections to theory or substantive knowledge were tested. In this sense, this study represents an "informed grounded theory"; one where the literature is used "as a possible source of inspiration, ideas, 'aha!' experiences, creative associations, critical reflections, and multiple lenses" (Thornberg & Charmaz, 2012, p. 7).

Establishing rigour

Elements of rigour in this study were considered in the context of the fit between the researcher's and the study's ontology, epistemology, methodology, and method – or the "vertical hierarchy" (Staller, 2013). In doing so, current standards of quality in qualitative research and CGT in particular were considered (Beck, 1993; Charmaz, 1994, 2006, 2014; Chiovitti & Piran, 2003;

Oktay, 2012) to ensure the quality, strength, and integrity of the findings and methodological approach. Two sets of criteria were used: those pertaining to the application of the GT method, and those concerning the resulting theory – or the process and the outcome of GT respectively[17].

The application of the GT method was evaluated by way of the criteria of auditability (Glaser & Strauss, 1967; Oktay, 2012), which ensures that key components of the GT method are adhered to. These include the use of constant comparative methods, theoretical sampling, and the development of conceptual categories and/or a core category. Strategies used to enhance this aspect of rigour included those outlined by Glaser and Strauss in their seminal GT text:

> immersion in the field, generation and testing of hypotheses in the field (and not before the start of data collection), the use of memoing, detailed description to support the theoretical understanding of the phenomena, and the pursuit of alternative explanations and negative cases (Glaser & Strauss, 1967).

Additionally, the following strategies were employed: peer debriefing, immersion in the methodological literature, and methodological training.

The following criteria were used to evaluate the resulting substantive theory generated in the study: applicability (Glaser & Strauss, 1967), credibility, originality, resonance, and usefulness (Charmaz, 2014). Strategies used to meet the aforementioned criteria included: member checking, peer debriefing, and triangulation of data. Each of these strategies were deliberately and explicitly considered and integrated through each stage of the research process.

Findings

Participant demographic information is offered in Tables 1, 2 and 3.

Table 1. Demographic Characteristics of Parent Participants

Parent Characteristics (N=11)	
Parent age	Range=28-56 yrs; M=42.9 yrs
Parent sex	Female (7), Male (4)
Marital status	Married (7), Common law (2), Divorced (1), Single (1)
Family structure	Single-parent family (2), Two-parent family (9)
Highest level of education	Some high school (1), Some college (1), Completed college (3), Completed university (6)

---

[17] For a detailed consideration of rigour in this study, refer to Chapter 3 of this dissertation.

Household income	Range=10,000- >110,000
Main activity	Caring for family (4), F/T work (4), P/T work (2), Recovery illness/disability (1), School (1)

Table 2. Demographic Characteristics of Children of Parent Participants

Sample Characteristics: Child	
Child age	Range=4-12 yrs, M=8.5 yrs
Child sex	Female (5), Male (5)
Child diagnosis	ASD (2), CP (3), Epilepsy/Seizures (8), Genetic/chromosomal disorder (1), GDD (1), DD (1), ID (1), Down Syndrome (1)
School type	Preschool (1) Daycare (1) Regular school, regular program (4) Regular school, regular program, classroom assistance (3) Regular school, regular program, withdrawal assistance (1) Regular school, special ed (2) Special ed school (4) Community-based intensive rehab (1)
Complexity[18]: total number of concerns /26	Range=2-26, M=13.2
Complexity[18]: number of problem domains /9	Range=1-9, M=5.9
Complexity[18]: impact score /3	Range=0-2.8, M=1.8

---

[18] About my Child (Ritzema et al., 2016; Rosenbaum et al., 2008) is a tool for understanding the functional needs of children and the priorities of families regarding their children's needs. The 'complexity' of the child's health status is calculated by summing the number of concerns identified by parents (total number of concerns). The 26-item questionnaire allows parents to identify whether they have concerns about their child's function from seven categories: (a) physical function/mobility; (b) activities of daily living (eating, toileting, dressing, sleeping); (c) communication; (d) behavior; (e) mood; (f) cognitive function (thinking and learning); (g) social skills with children; (h) social skills with adults; and (i) participation in activities outside of school. A complexity score can also be generated by summing the total number of domains where a parent endorsed at least one item (number of problem domains). Parents are also asked to indicate the degree to which these items impact their child's ability to participate in everyday activities on a 4-point Likert-type scale (not at all, a little, somewhat, or a lot). The impact score is calculated as a mean of the impact responses over the 26 items. For the purposes of this study, the complexity scores provide the reader with a picture of the functional needs of the children parented by the study participants.

Table 3. Participant Summaries

Participant #	Parent Name[19]	Child Name[20]	Marital Status	Child Age	Child Diagnosis	Languages spoken in the home	Main Activity	Child complexity, total # concerns (# problem domains)[18]
1	Caroline	Parker	Single	7	Autism, Intractable Epilepsy	English	Attending school	14(7)
2	Kristina	Eve	Divorced	9	Quadriplegic CP (non-verbal, G-tube, poor head and trunk control)	English, Portuguese	Recovery from illness/disability	15(7)
3	Claire	Mark	Common law	11	ASD, DD, Seizures	English	Caring for family, full time work	26(9)
4	Gabriella	Manuel	Married	4	Epilepsy, ASD	English	Caring for family	14(7)
5	Abigail	Jamie	Married	10	Epilepsy	English	Full time work	2(1)
6	Richard	Ashley	Married	12	Chromosome 18 Disorder, bilateral hearing loss, seizures	English	Full time work	19(8)
7	Martine	Adèle	Common law	5	CP, anxiety, controlled seizures (suspected ADHD, ASD)	English, French	Caring for family	11(5)
8	Omar	Zara	Married	5	Epilepsy, moderate MR, GDD, speech delay	Arabic	Part time work	14(6)
9	Sam	Ladona	Married	10	Epilepsy	English	Part time work	9(3)
10	Carole	Remy	Married	8	Trisomy 21	French	Caring for family	14(6)
11	Jai	Navin	Married	12	CP	English, Hindi	Full time work	7(5)

ASD=Autism Spectrum Disorder, CP=Cerebral Palsy, DD=Developmental Delay, MR=Mental Retardation

---

[19] Pseudonym

[20] Pseudonym

Core process: Seeking light at the end of the tunnel

Seeking light

The core process of "seeking light at the end of the tunnel" emerged from the analysis of participant interviews with mothers and fathers of children with ND. The act of "seeking" was important, first in that it revealed an active process, second that it was something that parents saw as a good thing to pursue, and finally, that hoping involved choice - to a certain extent. Although many parents spoke about having made the choice to be hopeful in the face of challenge and uncertainty, at the same time they articulated that they had only one true choice and that was to seek hope for their child's future. A child born with significant medical concerns whose viability was uncertain, a child who relapsed or lost previously held skills following a surgery, the daily struggle to maintain consistent and patient parenting behaviors when trying to manage a child with behavioral dysregulation; parents who found themselves in these circumstances chose hope because the alternative was simply too bleak:

> *I think you don't have a choice as a parent, 'cause otherwise if, you know, if you're not sending those positive vibes out into the universe, then how's that gonna come back to you and your child? So then you're just setting yourself up for failure or a lack of progress and him up for lack of progress. (Claire[21])*

Caroline, a lone parent caring for a child with significant delays, said that if she had not been hopeful, she would have fallen apart and then there would have been no one to care for her son. Her child was her motivation to stay hopeful, and without hope, she did not believe she would have been capable of doing anything. This choice was sometimes made because it was easier than allowing oneself to dwell on what could have been, what should have been, or what might happen. So, it was and was not a true choice. In the words of one of the participants, *"there is only one way and that's forward" (Kristina).* The choice to be positive or hopeful about the future was not a once and for all decision, but a daily one; one that happened in the *"mess of life" (Kristina),* in the challenging moments when a child was crying at three o'clock in the morning for what seemed like endless periods of time. It was in the realization that *this* reality was what it meant to parent *this* child. It was the choice between, "I cannot cope, I give up", and "I will not give up on my child, I will move on.

---

[21] Pseudonyms are used for study participants and their children and partners/other family members to protect their privacy.

This too shall pass". Parents utilized strategies in their seeking of hope, including: using humour, locating and utilizing social supports, searching for information about their child's condition and effective interventions, advocating for change, contextualizing struggles, allowing for moments of hope-less-ness, and catering to the child's strengths and interests. These strategies allowed them to gain some perceived sense of control over their current and future circumstances. Through this "seeking", hope could be grasped, but could at times seemed out of reach.

Light at the end of the tunnel

> *the only way I sort of feel it is like, the beacon or a light, like, the you know, proverbial light at the end of the tunnel, kind of thing. And it's not, some days it's really faint and some days it's glowing [chuckling]. (Claire)*
>
> *I think that would be dark and bleak and depressing, because you have to look forward to something, you know. If you don't stay positive, that's not a way to live, you know. At least if you have hope for the future, then I guess it's kind of what keeps your flame alive, right? If you don't have any hope then you just give in to the darkness. So I think you have to try and stay positive, you have to, you know, keep your little light burning and say, 'Okay, he'll be able to do it, he can do it.' And then just keep working towards that end goal, you know. (Carole)*

The distinct image of light at the end of the tunnel materialized early on in the data collection and analysis process as one that parents used to explain their experience of hope in relation to parenting their child. The light was the object of pursuit in their hope journey. It was the ultimate goal. It represented the collective of hoped-for positive outcomes for their child. Hope was like a light in that it was indispensable to life; like breathing air, or having light to guide the way, hope was necessary and ever-present and was a requirement for moving forward. Parents described clinging to hope, searching for it, and relying on it to prevent them from *"falling into an abyss" (Claire).* Parents said, *"there is always hope"*, *"if you don't have hope, what is there?",* and expressed the belief that if they did not have hope they would fall apart.

The substance, strength, and focus of hope morphed over time. At times the light shone bright, at other times the darkness almost overcame it. And yet parents explained that the light was always there - having hope was the light that shone in the darkness. There were moments when parents felt especially hopeful about their child; moments when the light was markedly bright. These were moments when the child overcame an obstacle or succeeded at a goal they had been told they would never reach. These were moments of conquering, surmounting, and overcoming. Likewise, parents offered examples of moments when hope felt difficult to find, or when they felt hope-less or, more accurately, hope-little. The light was harder to see in a moment of crisis or when it became clear that their child was not going to achieve a goal or milestone that had been hoped for. In these moments, it felt like there was little hope, it was hard to see the light at the end of the tunnel; but this did not equate to having no hope. After all, the light was always there, it was simply hard to see through the darkness of *that* particular moment.

Parents expressed that in a time of crisis, hope may have to be suspended. Kristina shared about a time when her daughter was in the Neonatal Intensive Care Unit (NICU) soon after being born. She conveyed that in that moment she resisted hope: *"I don't know what hope looks like then, and sometimes you can't hope, you have to stop yourself from hoping because you don't know where you're gonna go…you don't know what you hope for even" (Kristina).* At times like these, the level of uncertainty was so high that parents were not able to anticipate or consider what the future looked like for their child. When the experts, upon whom parents were reliant to offer some idea of what to tether their hopes to, did not have the answers, it could mean that the light was very hard or impossible to grasp. In these moments, some parents used the strategy of suspending hope or allowing for moments of hope-less-ness until they were able to locate some answers to their questions and thus re-establish some sense of control over their family's future.

Hope was sparked by "kindling", which emerged from within the individual or from interactions with others. The characteristics of the light – its brightness or darkness – were influenced by a number of factors called "distractors" that will be discussed below.

Kindling hope

From the parents' descriptions, hope was ignited both from within individuals themselves and from interactions with others. As parents pursued the light at the end of the tunnel, these sources were like kindling that fostered and nurtured the fire of hope. Personal sources included: having a positive personality, having a worldview that involved believing things happen for a reason, that there is meaning to be found in difficult circumstances, and believing that there is always hope. Having an ability to put their own life circumstances into perspective was also a way for these parents to maintain hope for the future. When they recognized that yes, their child has a neurological condition, but that they also had many strengths and capacities, they allowed themselves to place their own and their child's challenges into a bigger picture:

> *Just also being cognizant of what other things are out there, what other things my child could be dealing with. He's been dealt with this hand, it's not a great hand, but there are other children out there and other parents out there who are dealing with far worse situations than what my husband and I are dealing with and what my son is dealing with. So knowing that there's always that hope things are going to be fine, and they are going to be fine. (Abigail)*

Many individuals had experienced challenging life circumstances in their families of origin – financial strain, maltreatment, family cutoff, mental health challenges – and this may have motivated them into hoping for something better for their own children and family.

Hope was more than an individual trait, however. Hope was found in interactions with others and even from the systems of care within with which families interacted. Children kindled hope in their caregivers. Carole described how her neurotypical daughter was a source of hope for her at times when she found it difficult to manage her son who has a diagnosis of Trisomy 21:

> *My daughter, she is wise and mature before her years….When I tell her, 'I don't know what to do with Remy [child with ND]' - because we talk a lot with her because she sees it, she's not stupid and she knows that he's different and that he's got Trisomy and what does that mean in general; she won't understand the whole chromosomes thing, but, she'll try and help me with him - and just sometimes the way that she'll look at things, and tell me, 'It's okay mommy, look he can do it! Look what he is doing!' So sometimes through her eyes, when I look at him through her little eyes, that helps too…She's my rock, that one. (Carole)*

Parents were also motivated in their hope by their interactions with their child with ND. When mothers and fathers felt connected with their child – emotionally, verbally, physically – hope for the future was sparked. Allowing for an element of surprise also might have kindled a parent's hope. For example, when children displayed a new skill or capacity, or demonstrated new learning they had previously had difficulty grasping, hope was sparked by the child.

Support from family and friends kindled hope. Support included both emotional and practical or instrumental support: having a partner who worked with the parent to manage and cope with challenges and encouraged the parent to see things in a positive light; feeling accepted by others; being offered a break in the form of offers of respite by family and friends who understood the special care needs of the child with ND. Kristina's family helped maintain her hope: *"my family really rallied around her and provided us with lots of comfort and support, and that was great, and it still happens today and it's just, it's definitely a source of hope" (Kristina).* When parents felt supported in both emotional and instrumental ways, they felt that they were *"not alone in this" (Martine)* and as a consequence, more hopeful. Parents in spousal/partnership arrangements offered examples of times when they leaned on their partner to give or receive hope for the future. Some parents in this study depicted their couple relationship such that one parent was the "hopeful one" whom the other relied on to pull them out of a dark place. But for others, parents described this dynamic as fluctuating depending on the situation. A common example was described as the moment when a diagnosis or prognosis was offered to families by a HCP. Parents experienced a range of reactions to being given "the news", and quite often, according to many of the parents in this study, one parent was more distraught or overwhelmed by the news than the other. In these moments, the partner who was having a hard time seeing the light at the end of the tunnel may have drawn hope from their partner in order to begin to integrate the diagnosis and appraise it in a positive light.

Some parents described care providers who advocated on behalf of their children, or who got creative with policies and mandates, pushing the limits of the system. One mother described an experience with an educator who continued to provide integration services for her son in a new daycare that was outside the catchment area of her agency. Clinicians also helped maintain hope by pointing out advances in the child's skill development. One mother described it this way: *"clinicians are able to provide an objective description, as opposed to a biased-mom-emotional perspective" (Claire).* It helped parents to maintain hope when the clinician pointed out gains. It seems as though seeing the clinician as an objective source of information increased the value of their evaluations for some parents.

For some, hope was enflamed by a faith in God or a higher power. Some parents found hope in the belief that God answers prayers, or performs miracles, while for others, faith was about believing that all things happen for a reason: *"we're not religious but I guess to justify it to myself, I always say that God gave him to me for a reason, you know, and obviously what doesn't kill you makes you stronger" (Carole).*

Hope was also portrayed as very much outside of the individual or collective; it could be drawn from something outside of the self and others with whom parents interacted. Societal norms and expectations, as well as the built environment could be more or less inclusive. Hope could be generated from experiences in the social world where parents felt that their child was accepted and integrated. This may have meant that adaptations had been made to the built environment to allow their child to participate in activities with their family and their peers. It could also have referred to interactions with people – family, friends, and strangers – that were perceived as welcoming, accepting, and non-judgmental.

The darkness of hopeless-ness was the result of the many ways that hope was challenged for parents of children with ND – these "distractors to hoping" existed at the individual, family, social, and societal levels and consisted of characteristics, beliefs, interactions, and structures that caused hope to fizzle. These distractors are discussed next. Although hope survived or endured despite these distractors, distractors could dampen hope momentarily or more permanently.

Distractors to hoping

Although hope was always present, there were distractors that could make hope momentarily hard to find. Distractors pulled parents away from hope; they made it hard to see that light at the end of the tunnel. Distractors were a crisis experienced by the parent or family related to the child, but more often than not, they were simply daily realities such as circumstances, bad news, interactions with others, and challenging scenarios. In other words, the context of life influenced what hope looked like and how it was experienced. Distractors existed at the individual, family, social/systemic, and societal levels.

Individual distractors

At the individual level, parent characteristics influenced what hope looked like and could distract from hoping. These characteristics included: personal worldviews, unmet needs or expectations, values, ways of coping, history of loss, previous experiences with disability, and family of origin experiences. For example, perpetually worrying about finances could wear parents down and made it difficult to be hopeful about the future. Persistently having unmet or expectations (e.g., financial, therapeutic, informational, social, sleep, self-care) may also have led to a lack of hope. A parent whose child was not able to communicate verbally in a way that demonstrated reciprocity of attachment described having unmet needs to guide their expectations about the future and had difficulty tailoring interactions in order to bond with their child. Parents described becoming frustrated at what they perceived to be unsuccessful attempts to deal with child behaviors. Children with behavioral dysregulation and/or communication challenges may have been limited in their ability to convey their needs and may not have responded to typical strategies used to calm or comfort a child. Parents who were inflexible in their approach to parenting found that they were discouraged by ineffective use of strategies to manage their child. This made it difficult to be hopeful about their interaction with their child.

Unmet needs or expectations may be unrelated to the child, however, they influenced how parents hoped for the future. One father, Omar, who had recently immigrated to Canada, described being unable to support his family financially to the extent he desired because he had been unable to obtain equivalency for his professional credentials. While undergoing re-training and studying for exams to demonstrate his competency, he had struggled to make ends meet financially for his family. Omar had been feeling discouraged as he had failed one of the exams three times and had been feeling desperate to pass. His sense of an inability to provide his child with the help she needed served to distract him from hoping for the future:

> *I work as a casual work and it is a lot of time…I want to work as a pharmacist, to be able to have money to spend for her in special, in private sector, like physiotherapy, even psycho-therapy. But I couldn't, so it's extend the time, every exam the difference between the two exams is six months, so six months plus six months plus six months, one year and half doing the same exam and I couldn't reach. (Omar)*

Many participants described unmet personal needs; they were living out the universal role of a parent, but in addition, had taken on the roles of nurse, therapist, case manager, teacher, and care-provider to a child who required more care, attention, and input than other children. As a result of this increased level of required input into the caregiving role, parents had a sense that their own need for self-care, for intimacy with a partner, for independence, was not met. Feeling like they were never enough and were stretched to capacity made it more difficult to maintain hope for themselves and their families for the future. Gabrielle described a time when Manuel was transitioning from daycare into Kindergarten. She had been urged by her doctor to take an Aquafit class to help with her sore knees. Since Manuel was to be in school full-time, she planned to take a class during the day over lunch:

> *So I had hoped that that time of the day was finally what I was claiming for myself. And within a month and a half, we realized, well it was a decision, actually, that he wasn't thriving with that lunchtime and that also his afternoon was getting really affected by that not having a break in the middle of the day. And so my*

> *hope for him to make him succeed at full day kindergarten completely crashed my hopes for having that venue of more time for myself and making sure that I took care of myself.*

Some participants who grew up with a sibling who had a disability or who had volunteer or work experiences with individuals with disabilities felt they a different perspective about disability and what the future holds than other parents. Richard explained that his wife, who grew up with a sibling with a disability, seemed to have a crystal ball about what the future held for their daughter. Because her sibling reached a plateau in terms of her development, this mom feared their daughter would similarly hit a developmental ceiling and would not get to live a fulfilling and happy life. Richard felt that this assumed foreknowledge about what was to come was blocking his wife's hope.

Participants described facing uncertainty about the future. From the moment they first recognized that their child was not developing typically, to the process of getting their child diagnosed, to questions about what their child's future would look like, parents were familiar with feelings of wondering what the future would hold: whether their child would attend college or university, find a fulfilling job, contribute to their community, or develop meaningful relationships. In their quest for answers, parents were often left with unsatisfying and vague responses from HCPs, which left them wondering how their child would progress, whether they would meet goals and milestones, and how this diagnosis would impact their child and their family over time. These uncertainties functioned as diversions to hoping. The more uncertainty a parent had about their child's developmental future, the harder it was for them to grab onto hope. Claire, mother to an 11-year-old boy with a diagnosis of ASD, developmental disability, and seizures, spoke about her uncertainty about the future, particularly related to the question of whether her son would be able to one day live independently – a concern that all parents in this sample indicated grappling with at one point or another:

> *The other thing is when you get to those big ones at the end, like, you know, what would happen if Jeremy [husband] and I weren't here and you can get mired in some scary stuff, so, trying to keep that away and and just do what you can, you know, some practical stuff that you can do for the will and everything but not sort of go into the hole, going down that pathway, cause it's, seems overwhelming. (Claire)*

Claire explained that there was a tension between wanting to ensure that her child would be cared for in the case where she and her husband were no longer able to, and knowing that there were significant barriers to accessing long-term care services, such as a 10-20 year wait list and the potentially prohibitive financial cost. Such barriers forced parents to put particular worries aside because there were too many unknowns. Claire explained that she compromised with herself – she tried to focus on practical tasks that seemed more achievable and less stressful, such as preparing a will to ensure that her child's needs were clearly spelled out and that provisions were made for his care. Locating these little threads of certainty, finding small ways to feel some sense of control over the future, was one way parents like Claire found to maintain hope for their child's future in the face of distractors.

Family distractors

At the level of the family, distractors included factors related to the child, the immediate family, and the extended family system. The complexity of the child's diagnosis, the presence of behavioral dysregulation, and failure to meet developmental milestones or show expected growth can diminish hope. At times when children undergo standardized testing or assessment to determine their readiness for academics, for example, parents may be surprised by reports of where their child scores compared to same age peers. Carole was asked about a time when she found that hope was especially hard to find:

> *I think that was my lowest of low. My God, I don't remember how old he was, I think he was three, maybe four. And before he gets ready for school you need to have psychological evaluations, and he needs to be evaluated to know on the spectrum how severe he is. And I remember, we did all the testing and we did the speech and the global, and he went through like, it took a while, and he had a few tests to do and I remember getting the report and I was reading it and I just felt - in my mind he was doing so well, and I was like, "God, he's awesome, you know, he's almost like his peers." - and then I'm reading this report and I'm crying because it says that he's got a severe disability and a two and half year to three year delay. And I'm like, I just felt like someone just made my bubble explode. And I just remember, I was reading it, I was in the kitchen and I just went on my knees and I started crying. I'm holding this report telling me that my child is has a severe intellectual delay, where in my own heart and in my own mind he was doing great, you know. I think that was, that was really the worst. (Carole)*

Some parents vocalized a desire to communicate with their child in some way. For some, this meant an ability to read their child's nonverbal cues to determine their desires and needs. For others, this was more about wishing that they would one day have a reciprocal conversation with their child the way they imagined they would. Based on knowledge of typical child development, experience with previous children, and exposure to the children of friends, family, and strangers, parents develop a sense of what developmental milestones look like over the life course. When children who have diagnoses of ND failed to meet such milestones or experienced setbacks in their development, many parents found it more difficult to see the light at the end of the tunnel. Similarly, high care needs of children were at times seen as rendering it more challenging for parents to hope. Parents whose children needed a lot of support with basic activities of daily living such as toileting, eating, and sleeping indicated that these functional issues had a notable impact on their ability to remain optimistic about the future. Sleep had been an especially trying area of challenge for Martine: *"With her sleep problems there's been periods where it was the hardest like, 'how am I going to get through this? I can't deal with this anymore'"* (Martine). On the other hand, for Gabriella, whose son, Manuel, has controlled focal seizures and a diagnosis of ASD, it was the cognitive delays that she found the most challenging:

> *I think with Manuel, in order for him to do really basic social things, it takes a lot of work, even though his body seems strong and growing and he's losing his first tooth, like he's just moving along… It's like so his body seems to be doing really well, but his development needs a lot of support." (Gabriella*)

Gabriella described her parenting journey as *"wonderfully challenging"* and explained that the most palpable challenge came with feeling like she was having a *"second life"* as a parent. By this she meant that instead of giving her son the tools he needs in life and *"sitting back"* to watch him use them, she had to give him the tools every day:

> *it's not like I'm witnessing him doing a craft, or I'm witnessing him being successful at playing soccer, or I'm witnessing him being relaxed um watching a TV show. I'm always actively participating in it. So I'm not just a mom witnessing his growth, I'm in it with him, doing the growing with him, and I think um it's hard because I'm a 38 year old person with other interests, but now my interest has become growing this child from 0 to 15 and making sure that he can function without me shadowing him all the time, so I think since he was being a baby, I've been shadowing him. (Gabriella)*

Richard, father to a daughter, aged 12, with a diagnosis of Chromosome 18q deletion syndrome, bilateral hearing loss, and seizures, was asked to think about his parenting journey over time, and whether hope was easier or harder to maintain. He said,

> *Oh, it's definitely harder because it's more years, you know…[Sigh] you see somebody that's a teenager, you just expect more, right? You just continually expect more than what you're getting, and you're saying, "Didn't I do this one already?" When I think about when I was at a swimming pool once, there's a special needs class and it had a unisex washroom and [the] door to this one change room was closed. And before the swim class, the mother's singing away to her child, "A, B, C, D [alphabet song]", and going through that. And when I saw the child, it was a late teens child. So it's that, "I've done this before, done it too long, I don't want to do it anymore" type of thing, as you get older…So if you haven't made those milestones, if you don't get over certain thresholds, or if you lose yardage you get pushed backwards, that's where your hope starts to go away. (Richard)*

Richard spoke about his daughter not meeting expected milestones, not showing expected growth, and his frustrations with these ongoing struggles. For him, it was becoming increasingly difficult to remain hopeful as the discrepancy between his daughter's development and that of other children grew wider. He also alluded to an individual distractor to his hope when he indicated that at that juncture in his parenting journey, he did not aspire to a life of extraordinary caregiving. That lack of desire for such an involved caregiving role was certainly related to his daughter's level of complexity, but may also reflect something in himself that served to pull him away from hope.

Other factors at the level of the family that distracted from hoping included having a partner or other children who were not coping well or were despairing, resulting in the parent not feeling supported by family. At times, one parent might be in a position to, or is otherwise rendered to, assume the majority of the childcare responsibilities. This may be because the other parent is obligated to spend more time working (for example, to provide financially for the family), has chosen to defer the majority of the care to the other parent, or, is unwilling to provide or share care. One mother described an instance where her husband expressed discouragement about not having the freedom to pursue desirable leisure activities due to the extra care needs of their child with ND. This resulted in her hope being dashed for a time as she found herself agreeing with her husband and longing for additional leisure time. Likewise, when parents did not feel supported emotionally and practically by their families, they may have begun to feel alone and burnt out, which in turn made it difficult to see the future in a positive and hopeful light. It may also be the case that one parent has a more difficult time managing the challenges associated with receiving a diagnosis of an ND. One mother who has since separated from the father of her child recounted the impact of the diagnosis on her marriage:

> *It's complicated because our family didn't last. I think being surrounded by people who are able to provide you with comfort in times of need is really important. And so, my extended family…has been great…People react differently to crisis. And so, Eve's dad had a really hard time dealing with all of this and the way that he dealt with it was immersing himself in work: working really hard, making lots of money, and being able to provide her with all of the things that she needed. And I went the other way…Because that's how I am, that's how he is, right? And so we took very different approaches to dealing with Eve. And unfortunately, our marriage didn't survive this. (Kristina)*

Kristina perceived herself and her ex-husband as having disparate reactions to their daughter receiving a diagnosis of a significant developmental delay at birth. She immersed herself in research on Eve's diagnosis, doing whatever she could to provide emotionally for Eve. Eve's father threw himself into work and providing financially for his family. These different reactions were irreconcilable for them and were part of the catalyst that led to the end of their marriage. For Kristina, feeling unsupported and missing the comfort from her spouse that she received from others distracted her from hoping. Kristina needed a life partner who felt equally positive about their daughter's future. She explained that during times when she felt less hopeful, it was her friends and family who encouraged her to keeping hoping. Her spouse had not been able to provide that kind of support, and, as a consequence, her hope was diluted.

Claire described a time when her son, Mark, experienced seizures for two years, a period coupled with a setback in his development that had begun to stabilize with the use of medication. However, a recent episode had brought on a series of seizures (up to 40 per day) that sent him back to the hospital. Claire and Mark spent an extended period of time in hospital as the treating team sought to understand what was going on and worked to stabilize the seizures. During this time, the rest of the siblings – 17- and 15-year-old girls, and a 10-year-old boy (with a diagnosis of Asperger Syndrome) had been at home with their father, who worked very long hours in construction:

> *It's more challenging when the rest of the family's not coping, which they were having a difficult time then because we'd been away so long already, so they were all maxed out, like you could just see them all, you know, they were barking at each other and barking at us and, you know, not feeling the love of Mark cause he was just an irritant at that point cause they were all, you know, on pins and needles for themselves, so if you're reading that other people aren't doing well, then it's hard to be hopeful. Because the hope, you know,*

> *the hope, well, as I said, the hope's for everybody, right? It's just different for each body, each person, but they're all there. (Claire)*

This narrative also demonstrates Claire's assumed role as the one who had a finger on the pulse of the emotional stability of the whole family. She paid attention to the dynamics of the rest of the children in the family and how they were coping with Mark's medical setbacks. And she noted that her hope was for every member of her family, not only for Mark. Being aware of these tensions meant that she could take action to address them, but it also meant that she had taken on even more emotional labour and felt the weight of wanting to take care of everyone else, even though she had little control over the situation.

Social and systemic distractors

In interactions with the health and social care system, parents frequently sought out the expertise and support of professionals whom they viewed as having answers to their questions about their child's health. Parents hunted for information and some sense of certainty as to what the future may look like for their child and their family. During times when HCPs were not able to provide these answers, hope may have been dashed. Parents were especially interested in knowing how their child would progress over time, what they would be capable of, and whether or not they would ultimately achieve some level of independence. In many cases, answers to these questions were simply not known and clinicians were not able to offer parents the reassurance they sought. Parents described how hard it was to maintain hope during these times: *"Because when you hear your own doctor saying, 'I don't know what else I can do for you' that's kind of discouraging"* (Martine).

> *At the beginning, it wasn't her body that we were worrying about, although it is now, it was really the damage to her brain. And they can take pictures of it, they can do MRIs, they can do all kinds of different tests, but they're not gonna give you the answers that you are looking for. And that's really hard, it's very hard as a parent because you, you want answers, you wanna know, is my kid gonna be able to cope?…And they can't, they can't tell you whether they're gonna walk or hear or see or swallow, they can't tell you anything, and it's very frustrating…*
>
> *She had her first MRI, she was about a few days old, and it was clear, it was clear, it was like eighty percent of her brain was damaged, we knew, this was gonna be a big, big deal…And I think, a lot of the medical profession, especially when babies are really little, it's always 'we don't know', 'brain is very elastic', 'you never know what's gonna happen'. The reality is, you know what's gonna happen, when eighty percent of your*

> *brain is damaged…[it's] bad. And so, we sought information. Everything with the doctors was very elusive, nobody wants to pin point it down, and so, it was comforting for us to know what could happen because then you can move forward, you know? Or, that's it, and at least you know that's it. (Kristina)*

Kristina sought out the information she needed in order to have some sense of what the future would hold for her daughter. She explained that accessing such content was the key to moving forward for her. Other parents, conversely, talked about information overload and the challenge of sifting through and determining the quality and validity of all the information they had access to. This was especially the case in relation to diagnostic, prognostic, and therapeutic information sought online.

Parents may become discouraged when they feel that their access to their child's healthcare team is limited or blocked. When a child is given a diagnosis, parents are often provided some information about the condition and where they can receive services. Many parents relayed that once they exited the clinic door, however, they felt lost. Once the reality of the diagnosis began to set in, they realized that they in fact have numerous questions and wished there was someone available to speak with as a follow-up to receiving the diagnosis. However, many parents found that they were left to fend for themselves to find answers to their questions and even to sort out how to navigate a complex health and social care system in order to procure services for their child. Similarly, when a child had an appointment with a specialist, the parent saw this as an opportunity for discussion and information gathering relating to the child's condition. Parents were surprised to realize that such appointments were often brief and to the point and did not allow for much checking in or discussion:

> *On the level with professionals, just give me a clue how to deal with her, psychologically…We go to the neurologist every six months, and it's very long again between the two visits, just two visits per year and each visit it's around five minutes: 'Everything is controlled?' 'How many times she got seizures?' 'The dose, increase the dose, decrease the dose'. That's it. And I ask him when we should decrease the medication, feel that the medications has a lot of side effects that may affect her psychologically, so I ask him several times, the level of seizures became better now, when we can decrease a little bit the dose of any medication? When we can stop one of the three medications? It is very hard, every day three times per day she take three doses of three medications, so just give me a clue. He refuse to speak with me on this issue; 'she is controlled, she is now better, okay, stay on this medication'. 'For how long?' There is no response. So I need…just a bit longer*

> *time; 10 minutes, not more than that. But try to speak with the parents…not to relief our pressure but to give us an idea about it. (Omar)*

These types of interactions with HCPs can leave parents feeling unsupported by their child's healthcare team. The lack of professional health care support can lead to feeling isolated and uncertain about the future, not having something to pin their hope to, which can contribute to hope being dashed. Some parents recounted other kinds of discouraging or unhelpful encounters with practitioners. For instance, when parents were left to spend their precious time and energy locating resources their child needed because their case coordinator or social worker was not familiar with the resources.

Parents know that having access to services will improve their child's chances of succeeding. Not being able to gain access to these services can frustrate a parent's hope:

> *I think the biggest part that challenges…my hope for his future is, not so much now because things are getting a lot better, but when we don't have services, when we don't have that support. It's hard to stay positive…it's hard to stay hopeful when you have to fight for all of these things that he's supposed to have, that's going to give him that edge and that extra little push that he needs to have a life as an adult. (Carole)*

Access may be an issue because of long wait lists in the public sector, and for financial reasons in the private sector. Some parents found that access became an issue when their child improved after having used a given service or therapy and then was no longer eligible to receive it because their level of functioning was now "too high". This was frustrating to parents who felt that their child was being punished for having improved. At the intervention level, when a particular approach to managing an aspect of the child's diagnosis failed to demonstrate success, especially when time, money, and energy had been dedicated, parents became discouraged, frustrated, and began to lose hope:

> *They [neurologists] examine her and everyone gave us a direction or a way of therapy and it failed. It was so depressing for us. Every couple of months a new medication, new dose, and there is no control. You know that for years you are moving from one physician to other and hoping that a new medication give her control and there is no. (Omar)*

Parents also talked about losing faith in the health care system. In this way, the system itself or HCPs who represent "the system" can distract from hoping. In some cases, a beneficial intervention was not provided in a timely manner. For example, Jai explained that Navin was to have a surgery that would increase the length of his hamstring muscles, which would allow him to stand straight. Navin was evaluated for surgery in the fall and was scheduled to have the surgery in the winter. His surgery date was delayed until the spring and when he went in for his pre-surgery examination, three weeks prior to his scheduled surgery, Navin's family was informed that the situation had changed:

> *[The physician said] 'Oh, I think in last six months situation is again gotten worse. So his muscles are so tight that only lengthening of muscles might not be enough'. So he might have to cut the bones, you know, and that means that that's for us it's so late, you know, it's so difficult to hear about it that fine, you're cutting bones now, you know like. It doesn't, it's not a good thing to hear, and it's so demoralizing and depressing. So, and why it happened, it happened because surgery was not done in time, okay, so that is cause. (Jai)*

Service gaps, and a lack of appropriate services in the public health and social service system to adequately fulfill the needs of one's child, may lead parents to seek services outside of the public-funded system. This may generate the unintended consequences of feelings of shame, frustration, or anger at having to resort to seeking charitable funding or paying out of pocket for supports and services that, in their mind, government-funded services should provide:

> *…when I had initially come here and I was, I was earning only $35/32,000 and somebody told me, okay, Navin is three-year-old now, Easter Seal gives out $900 to support parents diapers. And I was thinking, what? It's such a hopeless thing that why anybody else should buy diapers for my son? I should be able to support him, right? And, like I told you that generally I don't want to go to charity, right? So, I never went to them. Though I filled form initially, but I never posted, mailed that, I kept it with me. I thought that, I was feeling bad that I need to get, you know, diapers from somebody to support my child. Somehow, somewhere it reflected on me that, I'm going to take charity for diapers for my child. If I am chartered accountant from some other country or I am a CGA [Certified General Accountant] here, what kind of education I have, what kind of professional thing is this that I can't support by child? And for what? I can understand this for wheelchair and I can understand this for, you know, major expenses, medical expenses, right, because that is all built in the tax system. So, but for diapers, like, I am sure that those charities are doing good…Now my salary is more than double than what I was earning those days, but I still like feel like, now I am feeling more tight on money, right? And I really feel that system, I'm not saying that charity is*

> *bad, what the charity, Easter Seals is doing is great thing, right? $1,000 is a big amount for families. What I'm saying is that support should come from the government instead of from charity. (Jai)*

Some parents placed much hope in the possibility of medical advances that would benefit their child. This could be a positive thing if the advances materialized and their child was able to take advantage of them: *"Technology now is sort of our new hope, in a way, stem cell is sort of our new hope. We're not there yet, we might not be there for Eve's time…"* (Kristina). Jai was extremely optimistic about the potential therapeutic impact that new technology would have on his son's capacity to mobilize:

> *Lokomat is kind of robotic machine which has a few like, you know, hands kind of thing which snap on your legs and body and stimulates you to walk. So, it's like you are actually walking. And gradually what they do, initially it supports you like 100% and then it gradually stops, reduce supporting robotically and you start doing things independently. So I think one year before it was only in research phase, but yesterday only we got something, a pamphlet from some physiotherapy clinic that this is commercially done now. So now I'm thinking, oh fine, now I have to earn more money so that I can use those facilities. This is what I am very optimist about and, not only I am very, I am very optimist that something will happen, I don't know what can happen, Lokomat will help, surgery will help, more physiotherapist will help, you know, there will be something more, more professional or more that kind of people will come in our system, you know, and they will, we will be exposed to those people who are, who will be ready to walk that extra mile, you know, to go beyond normal things. (Jai)*

Such medical advances are typically slow to arrive or never occur, and parents can start to lose hope that technological and medical developments will be of assistance to their child. Although Jai had a lot of hope in the potential for Lokomat to help Navin walk, he had previously been let down by HCPs, and interventions and equipment he had been told would help Navin make progress in his mobility. Jai's hope was dashed momentarily by unsuccessful interventions in the past, however he continued to tie his hope to other promising medical advances.

Parents who lack a system of support or who at times perceive their support systems as unhelpful can begin to get discouraged. Many parents talked about the need for both formal and informal support systems – respite services and friends and family who can offer both emotional and practical support as needed. Parents relied on these supports to give them a break, either tangible or psychologically, from the constant caregiving that often accompanied having a child with ND. One mother described it this way:

> *I think that the best thing for families that have these struggles is a good support system. When I see parents that either their family is far away and they don't have anybody, you can see that it's harder for them. So a good support system either by the family or sometimes by some sort of respite care or something like that, needs to be more accessible or more available, it's a big part of having hope because if you don't have a good support system your hope can go down really fast I think, 'cause you just get discouraged and completely exhausted and when you're exhausted I mean it's kind of hard to see the light at the end of the tunnel…you just see darkness when you're really tired. So that's why I said a big part of my hope is when I can get help from family and friends just to give me a break and be able to recharge my batteries, it really helped a lot, and it's just like okay, I can keep doing this. (Martine)*

For Martine, support helped ease her strain and exhaustion, allowing her to gain encouragement and regain perspective, which in turn, amplified hope.

Parents recognized that there were limits to the capacity of public health services to provide the kinds of supports they needed. They understood that they would need to draw support from their communities of care (immediate and extended family, friends, and community members) in order to manage the extra demands on their time and energy. However, as a number of participant quotes have alluded to, the expectation was generally that communities of care would supplement government support, not replace it altogether.

Along the same lines, not feeling connected socially can detract from a parent's sense of hopefulness. As one mother put it: *"it's hard to be hopeful when you stand alone"* (Kristina). Some parents who were not connected to a community of fellow families of children with ND struggled with not feeling understood. Gabriella described feeling like she did not have anyone who could relate to her struggles about parenting her child. Her friends with typically developing children complained about what she saw as *"basic"* parenting issues, such as "*having too much laundry to do, or socks being left around the house"*. She found herself joining in those complaint sessions with her friends, but she would leave feeling that no one understood what it was like to manage a child like hers – *"the emotional exhaustion that you cope with every day" (Gabriella).* Keeping these struggles to herself resulted in feelings of disconnection and hopelessness. By the same token, many parents compare their child's development to that of the children around them. When parents socialized mostly with parents of typically developing children, or compared their child with ND to typical siblings, they sometimes became discouraged when they considered their child's challenges compared to the typically developing children around them, which could serve to deter them from having hope for their child's future.

Finally, local policies often have great impact on families of children with ND in terms of regulating what services are provided and how these services get rolled out. In Quebec, for example, language laws stipulate that children are to be educated in French unless their parents attended school in English. This policy has considerable consequences for children (from non-French-speaking families) with significant learning delays, such as those often-accompanying ND. Sam described frustration and difficulty due to these regulations: *"If they can't help my little girl [get into] an English school, they can't do nothing for [me]"*.

Societal and cultural distractors

Parent in this study expressed facing environmental, social, and political barriers to inclusion, which can mean a lack of participation in life activities, feelings of oppression, and experiencing the world as a frightening or dangerous place. As a caregiver to a child with ND, these obstacles can be encountered both first and second hand and can challenge a parent's hope for their child. Stigma can be experienced in various ways by parents and their children. Parents often revealed that they and their child experienced being stared at when in public spaces. Some parents reported experiencing negative or insensitive comments about their child, or even more seriously in some cases, harassment or threats. In considering her son's future, Caroline imagined and hoped for a world where he is accepted and integrated, rather than stigmatized for his differences:

> *I just really hope one day that he can be independent and then have a society that isn't so judgmental and that can actually accept him instead of shunning him and shaming him and pointing at him on the bus or laughing at him. (Caroline)*

For Caroline and other parents, these instances can lead to a lack of trust in society to do the right thing; to be kind and see through impairment to the child's strengths. The more parents experience encounters like these, the more they may start to think that the best strategy may be to protect their children from a frightening and hurtful world by keeping them in a protected circle of people who accept and understand them. Caroline expressed it this way: *"if I could just stay in a bubble with Parker and a few family and friends and just live like that, it would be amazing…it's like the more I see, the more terrified I become."* Experiencing the world this way can translate into a questioning of faith or belief system; wondering why a loving and perfect God would allow them to experience such difficulties, for example, or questioning how people can be so insensitive and ignorant about the disability experience. Some parents who hoped and prayed for miracles to happen – for their child to overcome their impairment or disability, or for society to become more accepting and integrated – over time could start to find that the strength of their hoping had been diminished by discouraging occurrences whereby hopes such as those became quashed by reminders that the culture or society does not value children with ND as much as they value their child or as much as they wish others would.

Barriers to participation can also result from the child's developmental level – some children were more comfortable interacting and playing with children (or adults) who were outside their peer group for a host of reasons:

> *Especially now where he is getting older, he's getting bigger, and I think now he's starting to realize that there is differences, whereas before he wasn't noticing it or realizing it. So, you know, the kids his age don't really play with him, he plays with you know the six, seven, eight year olds, kids that are a lot younger than him, because their games are less complex and they're more physical than intellectual. So, I'm just hoping that he doesn't have to go through that struggle and through that, those labels, that's what I want to try and avoid. (Carole)*

Carole noticed that, over time, her son Remy, aged 11, had taken to participating in activities with children at least three years his junior in order to be able to meaningfully engage. This strategy helped minimize developmental differences between Remy and his peers, although, as Carole pointed out, over time, this strategy may become less and less effective as the differences between Remy and his peers becomes more and more apparent.

Some families strategized to avoid facing societal stigma. For some this translated to avoiding those frequent and taken-for-granted conversations with friends and family about what their child was doing or not doing. Carole explained that for the first year of Remy's life, she did not share with her close circle of girlfriends, who were all starting their families around the same time as she was, that Remy had a diagnosis of Trisomy 21. Remy did not present with some of the visual characteristics many associate with Down Syndrome and so one of Carole's friends was surprised when she noticed some books about Down Syndrome on her bookshelf:

> *And she was like, "Why do you have those?" And I told her that Remy had, you know, Downs, and she was like, "Really? I didn't even notice!" So, see by kind of not pin pointing it, "Oh this is my son Remy, he's got Trisomy," you know, hopefully we're gonna stop those labels because he's very light, he doesn't look like a lot of typical people who have Downs. So hopefully, it's not to hide under the carpet, but it's just that's not who he [is]…it's not what defines him. (Carole)*

Other families wound up isolating themselves; avoiding social contact where they could come into contact with others whose children met typical milestones. For instance, Omar explained that he and his wife had a hard time socializing with their friends, none of whom had children with ND. He explained that his wife had a difficult time accepting their daughter's diagnosis of GDD, Intellectual Disability (ID), and epilepsy: *"it's hard for her. It's a matter of culture; she cannot accept the condition and see her daughter in comparison with other children in this situation. So we came to separate away from them, we live alone here."* (Omar). Despite strongly affiliating with a faith community, Omar's family stopped attending their local church for regular services because their daughter was unable to participate in the programmed activates, which were designed for typical children. Instead they engaged in spiritual practices on other days of the week, when there were fewer children present. This demonstrates the deliberate strategy some families developed of avoiding potentially stigmatizing encounters that could distract from their hope.

Those parents who had experienced living in different cultures with their child with ND were able to compare cultures in terms of how people with disabilities were treated and valued. These cultural values played out in the ways that individuals with disabilities were treated, in how policies shaped the services that were offered to the children and their families, and in the extent to which parents felt that their children were able to be participatory members of the society. For some parents, Canadian society offered more opportunities for their child to participate in daily life activities. For others, there was a sense that there was more stigma in Canada than in other countries. One father, whose family had immigrated to Canada from Egypt, remarked that individuals with disabilities are ignored in his country of origin, as evidenced by a lack of specialized services offered, whereas in Canada, his daughter attended specialized schools, camps, and other activities. He said that this change in societal acceptance caused him to have more hope: *"Really there is no clear picture about that [his daughter's future] but my hope it grows a little bit better in Canada especially in the atmosphere that there is special schools for these kind of children"* (Omar). This suggests that hope may be ignited when there is a comparator with less social acceptance or a commodity that is valued, that sheds a more positive light on the situation that the family is now facing. In this case, Omar suggested that relative to opportunities for people with disabilities in Egypt, life in Canada provided more possibilities, which led him to have more hope for his daughter's future.

Consequences of seeking hope

The consequences of seeking hope – either finding the light with the help of kindling or experiencing darkness because of distractors to hope – are twofold: adjusting the focus of hopes, and evolving and becoming.

Adjusting focus of hopes – Finding a new normal

At any given moment, parental hopes for their child were concentrated on either specific or general foci – often defined as either discrete measurable goals, or more enduring, long-term aspirations. The focus of their hope shifted over time and was adjusted based on experiences and contextual factors related to the individual, the family, the social context, and society or culture. When asked about her journey as a parent and what hope has looked like for her, Martine, the mother of Adéle, who is 7 years old with a diagnosis of CP, secondary anxiety, controlled seizures, and potential ADHD and ASD, spoke about shifting hopes – from survival, to walking, and now focusing on her daughter's emotional challenges. Over the course of these families' lives, hope increased and decreased, as she described, like a wave travelling through the water. It could might vary from one moment to the next, or could stay elevated for a particular season of life and then come down:

> *Yeah, well it's been kind of up and down. When she was born obviously we didn't know if she was going to pass the week, so that was kind of hard. And we had hope but the doctors didn't seem [as] hopeful as we were. After that when she passed through that, well we were really hopeful she was doing really well. The next step for us was: is she going to walk?; we weren't sure about that and when she passed through that struggle we were like, 'She can do anything she wants in life.' And, she was evolving superbly you know. And now her hurdle for now is her emotional problems, since we don't know exactly what's going on, we do have hope but at the same time we're like, what are going to be her limitations since we don't know exactly. But I'm sure she's so intelligent and so outgoing that I'm not too scared for her really. I'm still hopeful. (Martine)*

Martine also referred to the disparity between parental hopes and those of the HCPs who interacted with her child. Parents may have interpreted communications with HCPs through a lens of hope -

seeking slivers of hope in their words and ways of speaking about their child - and that may have influenced the way they adjusted their own hopes moving forward. As discussed in the section on distractors to hoping, interactions with HCPs and the system they represent can make it more difficult to remain hopeful if parents feel let down by these interactions. Parents look to physicians, nurses, and therapists to gauge the possibilities of what their child may achieve. When HCPs communicate either overtly or using nonverbal language that parents should taper their expectations and wishes, adjustments can be made taking these exchanges into account.

Specific hopes for their child's future are idiosyncratic, given that the child may not achieve the same expected developmental and social milestones as typically developing children. These hopes were often expressed in terms of measurable goals which the child may or may not achieve: feeding themselves, having a play date with a friend from school, communicating in such a way that they can be understood by others, etc. When children achieved the goals set out for them by their caregivers or family members, clinicians, or themselves, parents often felt a surge of optimism and encouragement. Meeting expectations and achieving a goal drove parents to reach for the next one and heartened them in their larger scale considerations of the future, as the quote above from Martine highlights. Likewise, children involved in ongoing rehabilitation and therapeutic intervention were motivated by the achievement of therapeutic goals. When children did not meet these specific goals, however, parents were faced with a dilemma – continue to pursue a goal for which there was little evidence of possible success, or revise the goal. This reworking of goals happened daily as the challenges of caring for a child who has developmental and behavioral needs often meant that things did not go as planned. A goal that was not met could be modified slightly or else the goal could be dispensed with and a new and different goal became the focus of parent efforts. Parents of children with mobility challenges, for example, were often focused on their child's potential to walk. They may have been told by HCPs that their child may not or will likely not be mobile in this way. Parents integrated this prognosis, processed it utilizing resources at their disposal, and determined a way forward taking these considerations into account. A parent who focused on their child being mobile in the traditional sense – walking unassisted – directed resources toward this goal. If it became clear that this goal was not attainable, parents shifted toward the child being mobile with assistance, for instance with the use of a mobility device. If it was likely that the child would achieve this goal, the focus now shifted toward attaining the needed equipment. How easy was it to locate the equipment? Was the family in a position to finance equipment, and if not, was there financial support that the family could access to put toward purchasing the device? Alongside this came a focus on working with the child in utilizing the device to maximize their mobility, and consequently, their ability to participate in life activities. Examples of this process surfaced in participant interviews. For example, Jai's ultimate goal for Navin to walk unassisted was thwarted by a number of medical and surgical setbacks. But, keeping this goal in mind, he set out to support Navin in achieving goals, such as stretching out tight muscles, and safely and comfortably walking with a walker, that would provide a scaffold for achieving the next goal and bring him closer to walking unassisted. In this way, as parents sought hope for their child and their future, they focused on specific goals which required adjusting as the child moved toward them or it became evident that a new or modified goal was needed.

The particular goals that parents focus on can re-emerge at different life stages, sometimes in different ways. For example, when a child was born with significant health complications and the experts were unsure about the viability of the child, parents hoped for their child to survive. Once the child survived, their hope became focused on minimizing neurodevelopmental losses caused by the early trauma to the brain. Once the parent had a sense of the child's condition and prognosis, the focus was on functional improvement and the achievement of milestones. At other stages, the goal of "surviving" may resurface: surviving toddlerhood, or adolescence, or a particularly difficult medical event (e.g., the onset or return of seizures). Over time, as parents became seasoned caregivers and benefitted from the knowledge and skills they had gained, they might have changed the way they set goals for their child. One of the ways that parents of infants and young children set goals is by comparing and contrasting their child's development to that of other children. Watching their child interact with similarly-aged peers at the park or within the immediate or extended family is an important source of knowledge on child development for parents. Parents may compare and begin to worry when noticeable differences emerge. The goal of *"closing the gap"* - between the child with ND and other typical children - is one that parents in this study consciously or not had on their radar, especially when children were young and there was much uncertainty about what skills and abilities the child possessed and what may emerge in response to rehabilitation interventions. Over time, though, as the family settled into the realities of the child's functional abilities and limitations, they became less concerned about *"closing the gap"* and focused instead on *"finding a new normal"*. The new normal did not equate to what life would look like had they not had the child with ND or had the child with ND been born a different child (one without disabilities); this new normal was life with the child whose milestones in life would look different from those of another child, who was not the child the parents had imagined necessarily, but who was now their child, a child who had been the catalyst for thinking differently about life goals and achievements. At this stage, parents understood that independence may take on many forms and does not have to look like an adult living in their own apartment or managing their income from a paid job, for example. Achieving milestones at this stage could mean developing meaningful reciprocal relationships, contributing to society in some way, or finding a life partner.

Participants in this study also had hopes that are universally-relatable, meaning hopes that any parent has for their child. And these hopes superseded the goal-oriented hopes which may or may not have be achieved, and which parents of typical children may not have experienced because their child, being developmentally typical, met the expected milestones. One parent referred to these universal hopes as *"airy fairy hopes"* – hoping for their child to maintain well-being and quality of life, happiness, fulfillment, independence, contentment, connectedness, and engagement in life activities:

> *P: …and then there's just sort of like the airy-fairy hope of positiveness and health and nothing tang-, like not the practical stuff but just, like a brightness of the future, if you know what I mean. So it's not something that I can put into a discrete set of jobs to do, but that there's, you know, the light at the end of the tunnel kind of thing, that there's something, happiness out there…*
>
> *SB: There's the practical, and then there's the, sort of bigger,*
>
> *P: Yeah, the bigger stuff that you can't, yet, like I'm sure, as you get closer to that, then those would become the practicals, right? Like, as we get closer to that age where he might go off to live somewhere else, then they become the practical, so they sort of start out as this cloud of stuff, but then the closer you get, then you wanna, or as you think that that is what he's able to, you know, focus on, then you start breaking it down to the practicalities and the physical stuff as much as you can. (Claire)*

> *In relation to Remy, when I think of hope, it's going to sound silly, it's nothing like huge ideas of grandeur, it's just really simple, that I hope that he'll be able to be integrated in life and be accepted, that's really what I want. I don't want to have to put him in a special home, you know, I want him to be able to be with other people and be accepted, that's my hope, that's all what I want for him. I don't want, he doesn't have to work,*

> *he doesn't have to do all of that, I just want him to be happy and love to do what he loves to do and not have to be judged or bullied by people. (Carole)*

These universal hopes were the non-negotiables for parents of children with ND. These goals were not alterable in the same way that the specific developmental milestone-type goals were. Parents were not willing to compromise on the goal of their child's happiness and well-being and would advocate and battle hard to keep these in sight. "Airy-fairy hopes" sometimes evolved over time into discrete aspirations that felt within reach, or could be broken down into smaller markers that were deemed more achievable than the more remote yearnings of higher order hopes. Parents talked about contributing to the *"end goal"* of happiness, or quality of life, or inclusion. They worked toward these end goals on a daily basis by dedicating themselves to showing love to their child, contributing to their learning and growth, and working toward distinct functional successes that they saw as connected to the overall health and happiness of their child. Ultimately, caregiving parents of children with ND lived one day at a time and followed the child's lead in their pursuit of goals:

> *So I think by lowering, I don't want to say lowering your expectations, but just making them in chunks, basically, right? Because my expectation is still the same: for him to be able to live on his own, to have a job, to have friends, go out, enjoy himself, to be a normal adult. That is still my end goal. But I'm not thinking that far, okay now I'm thinking let's get him to talk, let's get him to read, let's get him to write. The next thing, okay let's you know, get ready for high school, you know, and how is that going to work? Because that's something completely different now, high school. You know, and then we're going to start talking about puberty and then girls and then, you know, so I guess my advice to parents would be to don't think that far in the future, separate it in chucks and just deal with that little bit at a time because if you try to do it all and think that far ahead, it's just going to bring you down, it's too much. (Carole)*

Evolving and becoming

The consequences of seeking hope also included evolving and becoming. Evolving and becoming represents the ways in which parents are changed as a result of parenting their child with ND and seeking hope for the future. This "evolving and becoming" looked different for each parent and at different points in time over the life course. Parents' narratives highlighted these changes in the following ways: becoming a catalyst for social change, changing one's worldview, altering one's approach to the future, being a "hope missionary", developing a capacity to hope amidst challenge, and having confidence in one's family's capacity and strength.

Participants in this study often found themselves thrust into the role of advocate for their child. They felt they were required to continually advocate for services and supports that their child required to ensure the best quality of life. By embarking on this journey, their experiences and newly refined skills prepared them to enter into conversations about how to change systems of care and societal understandings of disability experiences with the end goal of making the world a better place for children like theirs. Witnessing stigmatizing experiences and negative societal messages about disability compelled and pushed these parents into action. They understood that they had a part to play in shaping societal attitudes about disability. Unintended consequences that emerged as a result of actions by mothers like Carole, who in the midst of fighting for the right for her son to attend summer camp like any other child, facilitated similar opportunities for other children while simultaneously advocating successfully for more services for her son, Remy:

> *Yeah, you know when we had to fight with the city two, three years ago because of a lack of day camp for him, you know, you call, you take out all your guns, you know, you call the [Government office dedicated to persons with disabilities], you call them, you call, you know, you have meeting with all these people, you write letters to your, you know, not to your congressmen, but your, the person who takes care of your regions in office and it was just, ugh [exhales] that was, that was awful. But I managed, I managed to get it for him and I managed to get it for the seven other kids who were in the same fight, so. I think that what drains you. All those fights that you have to do and you don't understand why because you pay taxes for these and it's just, I still don't understand why you know, but I get it, budget and what not. (Carole)*

A changing worldview or perspective often results from ongoing challenging circumstances. In some instances, parents became hardened, isolated, or discouraged by the many distractors to hoping they encountered. Some participants described things getting more difficult over time. As their child aged and the distance between their development and that of a typical child became more apparent, as parents become weary from seemingly repeated attempts to teach skills and positive behaviors and continually needing to advocate, many parents became worn down and found that the light at the end of the tunnel seemed further and further away. By far, though, the majority of parents in this sample, over time, embraced their family's status as "different" and began to evaluate, or re-evaluate, their values, assumptions about the world, and wishes for their children. Many parents spoke about celebrating the small things – successes they otherwise would have possibly not even considered worthy of celebration, but had become reasons to post a photo to social media for friends and family to see. The small things, which parents in this study acknowledged were taken for granted by other parents (saying, "I love you", holding a pencil, sleeping through the night), became the "big things", even milestones for these families. A changing worldview for some parents meant a shifting path, a new way of being in the world, either professionally or personally. Kristina is a great example of this:

> *Her birth changed the way that I see the world…I did not have a thought about disability before she was born, you know. I didn't feel as part of that circle or that community, I knew nothing about it, it caught me by surprise. And before Eve, you walk down the street, you see somebody in crutches or in a wheelchair or whatever and you, you avoid making eye contact, you don't wanna feel uncomfortable, you don't wanna make those people feel uncomfortable. But you're nice, you know, and you open the door, that kind of thing. That's the extent of my interaction with disability at that time. And suddenly Eve's born and, you know, in a in a moment, I am in the middle of that circle, you know, I'm the one who is getting the stares and the pity look, and I need somebody else's help, I'm the object of, um, you know… And so, that's changed – I was outside the circle, I'm in the, I'm in the centre of the circle now. And so, it was a big shift in realization for me…*
>
> *And so, I left my job and I dedicated myself to my daughter, and to my family full-time, full on. And it made me realize a lot of things. Having a kid with a disability makes you realize a lot of things about what's important in life and what you want for them. And, inevitably there are choices that you have to make. Either you let, sort of medicine and technology and other people take care of your child, or you do that yourself. And I decided that that's what I wanted to do; I wanted to know as much as possibly I could learn and apply it and make the best choices. And, you know, I've learned a lot in the process and I've become a better person for it. So, I left my IT job and I dedicated myself to working with children – I'm an Early Childhood Educator. So I went back to school after Eve was born, because of her disability. I did a postgraduate degree in [specialization in Special Needs]. And so I do work with children who have disabilities and their families and the community and stuff like that. And, I went back to [University] and I'm doing Disability Studies there, and so, I become sort of her advocate, not just for her, but for other children and other families as well. And so, ah, it's changed everything…It's changed my family, it's changed the way I see the world and the way I live my life. (Kristina)*

Kristina may be the most drastic example in this study of an altered path, but most parents experienced to a greater or lesser extent, a changed perspective on life since becoming the parent of a child with ND. Caroline, for example, described her parenting journey as having her eyes opened to the world. She was young when she had her son and did not have a lot of experience with medical complexity or disability: *"it's kinda like he burst that bubble and then I started seeing that there's so much more out there. And then, he just completely changed my whole outlook on everything."* Other parents described relaxing expectations for their child and themselves that they otherwise may have held onto more tightly:

> *P: When he was a baby, we thought about, you know, the name, the [family name] name is gonna pretty much end here because he's not going to have any kids. We're not going to have any more kids. So unless my daughter chooses to name her child [family name], then it ends here. And at one point I remember thinking that that was important, but it's not really important anymore.*
> *SB: It changes.*
> *P: It changes. It's just a name.*
> *SB: Yeah.*
> *P: Doesn't really matter. (Carole)*

For some, it meant simply appreciating that *"there are worse things that we [could] be dealing with" (Abigail).* And for others it meant a shifting in family structure or roles to make room for new ways of doing things. This readjustment or tweaking of priorities happened over time as parents fell in love with the child they have, released previously held desires, and embraced the future as a family who may not fit the "norm".

For parents in this study, as their caregiving journey unfolded, their relationship to the future also evolved. This relationship continued to change based on how the child progressed and how the parent imagined the future with their child. The majority of parents reported in some way that their approach to the future had shifted to taking things one day (or week, or month) at a time, rather than getting too focused on the big questions "the future" so often demands of them.

Being a hope ambassador means developing a desire to pass hope onto others; being a torch bearer for hope. Some parents described an innate drive to share their "light" – their insights and learnings - with other families. Once they discovered strategies for maintaining hope in the midst of challenge, they wanted to share these skills with others who may have a harder time locating the light. This calling to a collective sharing of hope played out in various ways in the different networks parents were connected with. For Abigail and her husband, it was expressed through their work in schools:

> *This whole thing with my son Jamie has helped my husband and I in the field of education greatly because we have a child with special needs, so it's very easy for the two of us to talk to other parents who have children with special needs, and provide them with that hope, that positive, 'Well, yes, this is what's happening, but look at what's going to happen now.'…So that, to me, is the silver lining. That out of this whole negative experience, I've been blessed with an amazing kid, but also we're able to talk to these parents and also talk to other educators and try to shed some light on, 'This is what happens to children with these types of exceptionalities; you have to look beyond it just being, you know, a kid who's in front of you.' So we've learned it as a, we've taken it as a learning opportunity and a teaching opportunity for both parents and other teachers. (Abigail)*

Developing a capacity to hope amidst the challenges is a survival skill for parents of children with ND. This proficiency takes time and is an ongoing learning process, but was conveyed as "keeping one's head above water" – or feeling grounded and positive about the future despite hurdles. At times, as discussed above, hope was drawn from sources other than the individual parents' reserves. And this capacity did not mean that parents at times did not feel discouraged about the future. But, it did mean that they found ways to celebrate small accomplishments, found a new normal for their family, and found happiness and joy in the midst of a parenting experience they had not planned for. In talking about her thoughts about the long-term future for her son, Manuel, Gabriella shared an experience she had at her local grocery store:

> *I always go to this grocery store, I was on my own, and I was unloading the cart and this older man came and he helps with the carts. I've always seen him, but we never really talked. And when he talked to me, I felt like I saw Manuel. He started telling me about the neighbourhood and his parents, and just the way that he was talking to me, I can see Manuel in it. And I couldn't stop crying when I got in the car. And I don't think it was because I don't think he [the man] has a fulfilled life. It was the realization that my hope [for Manuel] had plunged. Even if he was that guy in the grocery store, helping with the carts, I would be happy for him. So it was that moment that I was like, "Okay, so you need to make sure we get him here." And this is good enough for him…Because he was talking to me about his family, and family is so big for me… he talked to me about living with his aunt, and so I then I realized, "Okay, that's what I need," I need a strong supporting family around him that is going to carry him through.*

This quote demonstrates some of Gabriella's struggle with maintaining hope for Manuel. In the context of coming into contact with an adult with disabilities, she recognized that her hope for her son's future had dwindled. When faced with the man at the store's successful employment and supportive family, she realized that this "new normal", this alternate possible future was a worthwhile goal to pursue and work toward.

Finally, having confidence in one's family's capacity and strength means believing that one's family is able to handle whatever comes their way. For these parents, with time came a sense that their family was equipped (or had become equipped) to deal with whatever challenges arose. They learned that they were stronger and more capable than they might have imagined when the journey of parenting their child began. They no longer felt the need to cling to hope desperately as they did when they were new to the "world of disability", when they were still integrating the reality that their child would live a different path than the one they had imagined as they prepared to become parents. For these parents, goals continued to be set – goals to achieve certain milestones, goals for their child to live a fulfilling and quality life, goals for their child to be taken care of when they were no longer able to. And yet, these desires for their children felt less desperate than they once did. They had come to learn that as a family, they could handle what life threw at them, they felt secure in the knowledge that if one route did not pan out, that there were other alternative routes to try. In a sense, it seemed as though the relinquishment of a "desperate hope" at later stages in the parenting journey may have increased hope and led to a sense of contentment.

Discussion

The substantive theory, "seeking light at the end of the tunnel", represents a co-construction of the accounts of eleven mothers and fathers of children aged 4 to 12 with a ND. This theory characterizes the process of seeking and maintaining hope amidst contextual constraints at multiple levels of influence. The contextual constraints, or distractors to hoping, operating at the individual, family, social, and societal levels, serve as barriers to parental hope in the context of parenting their child with ND. In order to maintain hope, parents must draw on both personal and communal sources symbolizing the kindling to the fire of their hope and must employ strategies, some of which are innate, others which are mastered over time. As a consequence of seeking light at the end of the tunnel, and in response to distractors, parents adjust the focus of their hopes for the future - or find a new normal - and evolve and become different individuals and parents to their children. Part of this evolution involves becoming a hope missionary – proclaiming the "good news" of hope, sharing hope with others, and educating their communities about why hope matters.

“Seeking light” as an explanation of how parents of children with ND seek and maintain hope for the future supports other qualitative findings focused on parental hope. For instance, Barrera and colleagues (2013), in their prospective longitudinal study of parental hope for children with poor cancer prognoses, found that parental hope oscillated between the two poles of tenacity and tenuousness, influenced by individual and social contexts. Similarly, “seeking light” accounts for the ways in which parental hope can be both ignited by and tempered by personal and external influencers and consequently, how hopefulness and hope-little-ness are not mutually exclusive, but simultaneously experienced on a regular basis. Many elements of “seeking light at the end of the tunnel” resonate with the only other qualitative study which explicitly sought to describe hope among parents caring for children with ND. Kausar and colleagues (Kausar, Jevne, & Sobsey, 2003) interviewed parents of children with a range of NDs about their experience of hope. Eight emergent themes arose from interpretations of parent narratives, most of which can be seen in aspects of the grounded theory presented here. For example, parents explained that they and their families were changed by their experience of parenting their child with ND. They felt more care and compassion, and more value for life. They also felt that their family had become more cohesive and unified. Parents in Kausar’s study emphasized the importance of having a realistic understanding of their child’s disability. Likewise, in the current study, the focus of parental hopes was grounded in the realm of what parents saw as possible for their child. Kausar and colleagues also found that parents drew hope from their child, their faith or spirituality, and social resources including HCPs. However, the theory of “seeking light at the end of the tunnel” is original in considering factors from a range of levels of influence and the interaction between these factors. This notion is in line with ecosystems theory (Bronfenbrenner, 1979), an overriding framework informing social work practice. “Seeking light” also describes the strategies parents use to continue to pursue hope despite the distractors at each level.

Many of the distractors of hope emerging from this study align with outcomes from the paediatric disability literature, however, in the current study, each distractor is richly described and drawn from parents’ personal accounts. At an individual level, parents suggested that having a lack of control and certainty about the future is especially challenging. This is a pervasive experience when parenting a child with ND, as there is often little certainty yet vast amounts of information provided by health care professionals. Information overload about the diagnosis, treatments, and services can lead to confusion, stress, and feelings of being overwhelmed. Additionally, a sense of lack of control over child behaviors, how the child is progressing, how society responds to the child and the family, can make it more difficult to see light at the end of the tunnel.

Scholars have demonstrated that, at the level of the family, children who have difficulties self-managing with activities of daily living (Ello & Donovan, 2005) or who exhibit behavioral dysregulation (Blacher & Baker, 2017; Hastings & Brown, 2002; MacDonald, Hastings, & Fitzsimons, 2010), are more challenging to caregivers and negatively influence caregiver physical and mental health. For example, Padencheri and Russel (2002) concluded that parents of children with ID and multiple challenging behaviors reported lower levels of hope than parents whose children had ID, but no challenging behaviors. Also within the family system, supportive dyadic coping has been shown to be related to mothers' and fathers' relationship satisfaction and their adaptation (García-López, Sarriá, Pozo, & Recio, 2016), which may impact positively on their hope for the future. Other ways in which the organization of couple relationships may influence parental hope be related to the gendered nature of caregiving, often exacerbated among families of children with ND, wherein one parent, typically the child's mother, carries a larger caregiving load.

A child's ability to participate in leisure and other life activities (World Health Organization, 2007) predicts a number of salutogenic outcomes for the child and the family, for example, the child's Quality of Life (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012). Despite the positive impact of participation, children face a number of barriers, such as social attitudes and physical barriers to their participation (Imms, 2008). Specifically, aspects of the environment that may impact on a child's participation include: the physical environment (the built environment, equipment, physical distance, location, and accessibility), attitudes (stigma, bullying, segregation), social support (peers, teachers, family support), and policies and services (program design, institutional barriers, and information) (Heah, Case, McGuire, & Law, 2007; Imms, 2008). "Seeking light" reflects the way in which barriers to child participation in life activities can distract from parental hope for the future by limiting the child's and the family's opportunities to interact with others within the broader social context, which may lead to isolation and other adverse outcomes.

"Seeking light at the end of the tunnel" lends support for much of the published literature on the ways in which interactions with the health and social care system can at times be detrimental to a parent's sense of hope. Roscigno and colleagues (e.g., Roscigno, Grant, Savage, & Philipsen, 2013; Roscigno, Savage, Grant, & Philipsen, 2013; Roscigno et al., 2012) have produced a significant body of work on the interpersonal interactions between HCPs and families whose child is facing a future involving some level of disability. These studies have identified one of the mechanisms by which HCPs can be distractors to parental hope is by communicating their beliefs and values about disability through their interactions with families. By doing so in a negative or unresponsive way, families may conclude that the values of their HCPs are discordant with their own and may therefore dismiss prognostic information offered by these HCPs. In Roscigno's study on descriptions of hope following counseling of parents related to risk for having an extremely premature infant, some HCPs felt that it was their job to ensure that parents both understood what it meant to take home an infant with significant impairments and factored this understanding into the decision-making process (Roscigno et al., 2012). Parents indicated that they wish to hear the full range of information relating to prognosis and treatment options; "they wanted negative statistical information to be tempered with hope" (Roscigno et al., 2012, p. 1235). If parents felt they were not being given the full picture, they were apt to respond negatively to interactions with that HCP in the future and at times were likely to discount the information presented to them. On the other hand, "none of the parents discussed a negative impact from any HCP's expressions of hope, although several said they did not want to be given false hope" (Roscigno et al., 2012, p. 1236). Parent participants in this study similarly advocated for open, informative, and truthful interactions with HCPs. Parents have informational needs that can partially only be met by a professional expert who knows their child, their child's condition, and the evidence-based knowledge pertaining to that child's particular diagnosis. Informational needs are a key theme in the scholarship on parenting children with disabilities and chronic conditions (Gibson, Kaplan, & Vardell, 2017; Hall, Culler, & Frank-Webb, 2016; Nicholas, McNeill, Montgomery, Stapleford, & McClure, 2004; O'Neil, Ideishi, Nixon-Cave, & Kohrt, 2008; Roche & Skinner, 2009; Roscigno, Savage, et al., 2013) and were likewise reflected in the current study.

Studies about HCPs experience of giving news to parents whose child has a disability or life limiting illness reveal their uneasiness about providing a balanced picture of the future (Harnett, Tierney, & Guerin, 2009; Roscigno et al., 2012). HCPs report feeling hesitant to offer what they consider to be "false hope" by offering too rosy a picture of the child's future (Harnett et al., 2009). This uneasiness can partly be explained by concerns about future litigation leading them to present a worse-case-scenario (Harnett et al., 2009). But, more commonly, HCPs' comfort level, training, and the support available to them in communicating a diagnosis influences how they communicate hope to families (Harnett et al., 2009). The fear of offering false hope to families may also be grounded in a sense that if parents are hopeful (or too hopeful), that they have not heard and integrated the diagnostic or prognostic information provided by the HCP. HCPs, rightly, wish to ensure that families have understood the information presented about the child's condition. No evidence was found in the present study, however, that parents who are hopeful about their child's future are in denial about their child's condition (Roscigno et al., 2012). Parents have indicated that they wish for information to be presented in a realistic way that at the same time allows for hope (Harnett et al., 2009; Mulligan, MacCulloch, Good, & Nicholas, 2012) and have highlighted the importance of receiving a spectrum of possible outcomes (Roscigno et al., 2012). The findings from the present study lend support to these results. Parents who participated in this study indicated that diagnostic or prognostic information that did not allow room for hope was detrimental to their hope for the future. Importantly, these interactions stayed with parents over time, as evidenced in their retrospective accounts during participant interviews. It was obvious that parents had internalized these key messages rendering them quite meaningful in their parenting journey. Interestingly, we found no evidence in either the findings from this study nor from those of other empirical scholarship, that parents hold HCPs responsible when a child does not accomplish a milestone the HCP had proposed could be a possibility in their nascent prognostic discussions with the family.

"Seeking light at the end of the tunnel" addresses some of the limitations of other conceptualizations of hope documented in the paediatric scholarship to date. It also lends support to and builds on empirical findings from similar paediatric populations. The ways in which the grounded theory expounded in this dissertation addresses the strengths and limitations of previous research will be discussed in turn in this section. Existing theories of hope possess a number of limitations in their applicability to a population of parents of children with ND: they are individualistic by nature, they have questionable validity in this study population, there is an overemphasis on goal-directed behavior and a paucity of consideration of the multi-faceted-ness of hope, they often do not account for the connectedness of hoping, and they do not take into account the multiple systemic levels in which families of children with ND exist and which influence the process of hoping. "Seeking light" accounts for these limitations and offers a theoretical rendering of the process of hoping for the future for a child with ND from the perspective of parents.

One of the chief critiques of the dominant paradigm of hope, Snyder's Hope Theory (Snyder, 2002; Snyder, 2000), is that it is individualistic by nature. This assumption reflects a Western emphasis on individualism, grounded in dualistic thinking, whereby each one of us is conceptualized as a distinct self, separate from each other self. In comparison, collectivist notions of being in the world place more value on interdependence. Although, there is increasing acknowledgement in Western culture that connectedness and interdependence are valuable and worthwhile goals, "dualistic thinking is deeply embedded in the social consciousness" (Gibson, Carnevale, & King, 2012, p. 1895). This critique suggests that dominant hope theories may be less applicable to individuals and families with ethno-cultural backgrounds that are rooted in collectivist understandings of community and social life, which privilege the collective over individuality.

Further, drawing from scholarship and clinical experience with families of children with disabilities, the importance of connecting cannot be understated. And so, we suggest that a broader ecological approach would be useful in considering contextual and relational elements to the experience of hope among parents of children with ND. Historically, many disability frameworks and much of clinical practice have focused on the goal of independence and self-sufficiency (independent living, independence in activities of daily living). Gibson and colleagues (2012) explore the notion of in/dependence in the context of caring for a child who uses assistive technologies. These authors (Gibson, 2006; Gibson et al., 2012) suggest a shift from thinking about dependence (on technology, on other people, on medicine) toward considering "connectivities". Connectedness reflects an emphasis on acknowledging that individuals all have limits and areas of life in which inter/dependence could be beneficial. "Seeking light at the end of the tunnel" reflects notions of connectedness and interdependence in that it recognizes that pursuing hope has both individual and collective dimensions. It also considers the multiple and interacting contexts in which an individual parent is situated, which alone or in combination can distract from maintaining hope for the future. Our study findings revealed that there are times during the parenting journey when it becomes virtually impossible to see the light at the end of the tunnel. In these moments, in order to continue to hope, parents draw from their own reserves (of hopefulness) or, alternatively reach out to another to draw from theirs. This notion of drawing hope from others (a child, a partner, a helping professional, God) highlights the importance of interpersonal connections and interdependence, an important dimension missing from other theoretical and practice frameworks.

Many studies about hope among parents of children with complex needs have drawn upon quantitative methodologies, under the assumption that conceptualizations of hope and the operationalization of these constructs are valid for this population. Such studies regularly employ a conceptualization of hope based on Snyder's Hope Theory[22] (Snyder, Cheavens, & Michael, 2005) and use Snyder's Hope Scales (Snyder et al., 1991), which have predicted outcomes in various domains, such as academics, sports, physical health, adjustment, and psychotherapy in the general population (Snyder, 2002). Such studies have found that hope is salutogenic (i.e., promotes health and well-being) and is protective against known adverse effects on caregivers and family-level measures of health, such as anxiety (Lloyd & Hastings, 2009; Mednick et al., 2007), depressive symptoms (Faso, Neal-Beevers, & Carlson, 2013; Lloyd & Hastings, 2009), distress (Horton & Wallander, 2001), and worry (Ogston, Mackintosh, & Myers, 2011). In this body of thinking, hope is correlated with desired outcomes, such as subjective well-being (Shenaar-Golan, 2017), positive affect (Lloyd & Hastings, 2009), adaptation (Truitt, Biesecker, Capone, Bailey, & Erby, 2012), life satisfaction (Faso et al., 2013), parenting sense of competence (Carol, 2008), and psychological and family functioning indices including warm and nurturing parenting styles, cohesive and active family environment, and adaptive coping strategies (Kashdan et al., 2002). However, given that Snyder's Hope Scales were not inductively derived among caregiving parents of children with ND, the validity of the assumption that the construct of hope has been adequately and accurately operationalized for this population is questionable. In addition, the Hope Scales were intended to measure levels of state or trait hope. Moreover, they were designed to evaluate a parent's sense of hope for his or her own future. This brings into question their validity, particularly when being used to measure a parent's sense of hope for his or her child's future. In fact, Faso and colleagues (Faso et al., 2013) reported that parent-reported hope using Snyder's Hope Scale and vicarious futurity (a measure of a parent's hope and despair for their child's future) are largely independent constructs when measuring the well-being of parents of children with ASD. The present study, which sought to inductively and abductively derive a substantive theoretical understanding of parental hope for their child's future can serve as a foundation for the development of a robust and validated conceptualization of parental hope, which can be operationalized and used to generate a rigorous, sound measure of parental hope for a child's future.

Another aspect of the current literature in the area of parental hope in paediatrics that may limit its applicability to a population of parents of children with ND lies in the inherent differences between two sets of parenting experience – those of parents whose child has a life-limiting illness, and those of parents whose child has a neurodevelopmetanl condition that is lifelong, but not life-

---

[22] Snyder's Hope Theory is discussed in detail in Chapter 2 of this dissertation.

limiting. In line with other research in the area of paediatrics, parents in this study felt compelled to hope (e.g., Kylma & Juvakka, 2007; Reder & Serwint, 2009), and the focus and nature of their hopes varied over time (Granek et al., 2013; Reder & Serwint, 2009; Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013). In Reder and Serwint's study of bereaved parents and their HCPs, parents describe the "necessity of having hope as part of their role as a parent" (Reder & Serwint, 2009, p. 654). Although parents in the latter study were required to balance the tension of their child's life-threatening diagnosis with having hope, they were able to do so because their hopes were not pinned on waiting for a miracle or a cure, rather hope was directed at obtaining a positive outcome which could have been as simple as hoping for their child to be "alright" (Reder & Serwint, 2009). These findings point to the complexity of how hope operates and lend to understandings of the ability of people to hold two opposing states of being. In this study, two states – of acceptance of the inevitability of a situation *and* maintaining hope - could be tolerated and did not need to be pitted against each other. Despite similarities between the experience of hope for parents in that study and those in the current one, there are significant differences. Studies of parents who have either received an end of life prognosis for their child or are bereaved have found that their hopes are often tied to decision making around treatment options and prolonging life and hopes for successful interventions leading to a cure (e.g., Barrera et al., 2013; Granek et al., 2013; Reder & Serwint, 2009). Once a child has died, presumably hope for that child is no longer a daily focus for parents, since hope is generally understood as a future-orientation. Themes of hope commonly emerge or are directly sought in the literature on paediatric life limiting illness perhaps because death as a life event precipitates certain reactions and emotions, such as hope and considerations of spiritual values about the end of life and the afterlife (Copp, 1998; Eliott & Olver, 2009; Kübler-Ross, 2011). In the context of caring for a child with ND, the child continues to live, and yet caregivers are confronted with the task of parenting a child with unanticipated needs, who requires more care than a neurotypical child (Roos, 2002). Some scholars have suggested that this leads to an experience of chronic sorrow over the lifetime of the child (Roos, 2002). The findings of this study did not align with such a description necessarily, however, consistent with much of the scholarship on families' experience of a child with ND, participants relayed that they were required to adjust their expectations and hopes for the future for their child, and that this was an iterative process over time (Kausar et al., 2003; Shikako-Thomas et al., 2013).

“Seeking light at the end of the tunnel” shares some similarities with other conceptual frameworks of hope, such as Snyder’s Hope Theory (Snyder et al., 2005), Gottschalk’s definition of hope (Gottschalk, 1974), Averill and colleagues’ definition of hope (Averill, Catlin, & Chon, 1990) and the theory of Vicarious Futurity (Wong & Heriot, 2007). Unlike these models, however, seeking the light represents an iterative process, which reflects the way parents narrate their hope journeys. Hope is neither solely a set of cognitive goals to be reached and/or modified (Snyder, 2002), nor purely an emotional or spiritual experience (Breznitz, 1999; Scioli & Biller, 2009). It is not either/or - personal or communal - it is both/and. Moreover, the process is influenced at each level of contextual constraint, acting upon a given parent at any given moment in time. As in Snyder’s Hope Theory (Snyder, 2000), parents do speak of pursuing discrete goals set out for their child and the adjustment of these goals based on contextual constraints. However, the goal-setting and modification process does not provide a complete picture of the experience of hoping over time for a child with ND. This grounded theory adds to and builds on Snyder’s Hope Theory (Snyder, 2000) in that the goal-setting and adjusting is influenced by contextual factors and hope is kindled by both personal and communal sources. A key to setting good goals in Snyder’s Hope Theory is that the goals must be achievable. By contrast, setting goals for a child with ND is complicated by the context of uncertainty that often surrounds the diagnosis and prognosis of many children and by the lack of control parents have over the future for their child due to the unpredictability of their development and/or their condition. Often, parents have goals for their child that a HCP has told them the child will not achieve. Parents may continue to seek these goals, not because they are in denial about their child’s condition (or have false hope), but because they choose to believe that perhaps their child will meet that goal. Or, they continue to hope for that goal because they have previously experienced their child meeting a goal they had been told was unachievable. Parents may also set goals for their child without knowing whether or not they are reasonable goals; but they hope despite the uncertainty. These aspects to hoping are not accounted for in other theories of hope derived in the general population.

Further, in the hope seeking process for parents in this study, goals are not always discrete and measurable. For instance, the “airy-fairy hopes” of happiness and quality of life, cannot always be broken down into “goal-directed thinking in which the person utilizes pathways thinking (the perceived capacity to find routes to the desired goals) and agency thinking (the requisite motivations to use those routes)” (Snyder & Lopez, 2007a, p. 189). Hope Theory allows for short- and long-term goals, approach-oriented and preventative goals, and maintenance and enhancement goals (Snyder, 2002). Parents in this study differentiate between short- and long-term goals, however they suggest that some hopes (airy-fairy hopes) are not always definable or measurable. It may be that these sometimes-lofty goals do not always seem measurable in the moment, but rather feel as though they are in the clouds to a certain extent as the parent focuses on the day-to-day activities and challenges of family life. Some parents spoke about being able to break down the big "out there" desires, such as happiness, into smaller, more reachable goals, and about a capacity to then move toward these on a daily basis. But others, feeling the contextual constraints more keenly, describe setting aside these goals while they focus on more functional tasks that seem to them to be more accessible. What Snyder's Theory does not account for is the ways in which parents draw from both individual and communal sources to locate and maintain their hope for their child. Although Snyder and Lopez (2007a) account for collective hope, this notion refers to "the level of goal-directed thinking of a large group of people" (p. 194). Collective hope in this sense can be applied to parents of children with ND as a group – the collective hope for a more inclusive society, for example – however it does not account for the ways in which parents derive hope from others in their family and extended communities of care as was found in this study in other qualitative studies with families of children with ND and other health conditions (Barrera et al., 2013; Kausar et al., 2003; Kylma & Juvakka, 2007; Mulligan et al., 2012). By focusing on the multiple way in which parents are supported in their hoping and integrating contextual constraints at multiple levels of influence, "seeking light at the end of the tunnel" extends and enhances these previous conceptualizations of hope.

Another important element that this conceptual rendering of parental hope for the future adds to the scholarship is that there are influencing factors at multiple contextual levels impacting on a parent's capacity to maintain hope over time. These kindlers (facilitators) and distractors (barriers) to hoping reflect a bioecological systems approach to understanding individual development in context. The bioecological systems approach is a central framework in social work practice (Bronfenbrenner, 1979). In Bronfenbrenner's model, the individual is embedded in multiple environmental levels, from proximal to distal, that influence their development. The most proximal of those levels includes individual, biological factors and other personal characteristics. Moving further outward, the microsystem consists of the systems that directly impact on a person's development (school, work, family, peers). The mesosystem connects multiple microsystems. The macrosystem represents the culture and society in which a person exists, including attitudes and ideologies of the culture (Bronfenbrenner, 1979). The chronosystem integrates the notion of time and reflects an understanding that sociohistorical circumstances and the patterning of environmental events and transitions across the life course have an impact on individual development. This model suggests that a change or conflict in any one level will have ripple effects in other layers and on the individual. The grounded theory, "seeking light at the end of the tunnel", accounts for such a relationship between the multiple systems in which an individual is situated and the many multiple systems parents of children with ND find themselves interacting with on a daily basis. The substantive theory presented in this dissertation accounts for multiple influencing factors on a parent's hope for the future, including the ways that systems can interact to make it facilitative and/or challenging for parents to maintain hope over time.

Clinical Implications and Future Research

"Seeking light at the end of the tunnel" is a pragmatic substantive theory that can be taken up in various ways by health and social care providers working with families of children with ND[23]. Importantly, it is clear from the findings that hope matters to caregiving parents of children with ND. And, as a complex and multi-faceted construct, hope can present itself in any number of ways. One of the key messages emerging from these findings pertaining to what hope looks like is that hope can co-exist with other experiences, such as hope-less-ness, distress, and even despair, also identified by other hope researchers (Wong & Heriot, 2007). Clinicians would do well to not assume that because a parent is despairing about their child's condition and the future, that they are not hopeful; and conversely, that a parent who presents as hopeful may also at times find it difficult to maintain their hope.

Clinicians can be aware of the importance of hoping for the future and sensitive to the various influences on parental hope. HCPs have a role in encouraging and promoting hope in the children and families they see. They can also take part in advocating for resources and access to needed services, supporting families in seeking out informal and formal supports, and offering information in clear and realistic way that allows for hope. Clinicians should be willing to engage in conversations with families about what lies ahead. These are concerns that arise for families the moment they receive "the news" about their child's diagnosis. No HCP has the capacity to resolve

---

[23] Chapter 6 provides more detail about the implications of the study findings.

the uncertainty and lack of control parents experience; they can, however, notice these experiences and open the door to opportunities to speak about them. Participants in this study indicated that simply being offered the space and time to discuss their concerns with their child's HCPs would ease some of their distress related to the future. By opening up a dialogue with families about their hopes for the future, parents will feel listened to, respected, and supported. Routinely asking questions such as, "what do you hope for today? Tomorrow? The future?" or "What does hope look like for you? Your family?" with non-judgmental curiosity and sincerity will allow clinicians and families to examine each family members' thoughts about the future and can also allow room for clinicians to offer examples of hopes and goals when families are struggling to find them. Once clinicians have created an opening in the clinical encounter to discuss hopes for the future, these hopes can be integrated into the child's care plan. For example, different types of clinicians are accustomed to documenting clinical goals for the child as part of their assessment and evaluation of a child's progress in rehab. Responses to questions about hope can be used as a catalyst to setting long- and short-term goals. In doing so, rehab goals will reflect individualized wishes and desires that are of importance to children and parents.

Establishing a pattern of ongoing communication with parents and other family members involved in the care of the child allows parents opportunities to ask questions and voice concerns about their child's behaviors, reactions, and development. At diagnosis, parents can feel overwhelmed, with substantial and difficult information received while often also having little or no access to follow-up support. Parents require time to process the diagnostic and treatment information as well as their own emotional reactions to the information. Allowing parents and family members the opportunity to re-contact service providers as questions arise for them will contribute to a parents' sense of having a handle on the situation. It is also helpful for information to be given in manageable doses and when parents are ready for it. For example, parents often mention their desire for a repository they could access when in need of information or a service. Spending many hours searching for information online related to their child's diagnosis and services available in their area is a common experience for parents of children with ND. In fact, parents often become so knowledgeable about which services exist that they are more informed than their HCPs. Clinicians, like parents, are more often than not doing their best. By working together as a health and social care team they can build capacity to offer the family the best information available as well as the most effective treatment and other supports needed. A supportive HCP can make a difference to parental hope.

Recognizing that broaching the topic of hope with families may be challenging, some clinicians may benefit from “hope training”. By integrating research findings about the importance of hope into the curricula of health and social care programs, students will learn about what difference hope makes to families and why they should seek to integrate hopeful dialogue into their practice. Ongoing discussions with colleagues and keeping abreast of the latest published research will help clinicians feel confident in their ability to raise questions about what hope means to each family they encounter.

Limitations

As with any empirical study, there are limitations in this study. The limitations relate to the sample selected to participate, the data collection methods, and the interpretation and analysis of data. The study sample was drawn from two major Canadian urban centres. Although attempts were made to seek diversity in terms of geographical location (urban, rural/remote) within the sample, the sampling frame (the Parenting Matters! participant database) consisted of families who were receiving services from relatively large paediatric acute care and rehabilitation settings. The inherent geographical homogeneity of this sample presents limits to the diversity present in the sampling frame. As a result, families from rural and remote locations and those from other provinces and territories, let alone beyond Canada, are not represented. Provincial and territorial differences in how ministries structure and deliver health and social care to children with ND can lead to differing experiences of hope among families in various jurisdictions. This should be taken into account when considering the applicability of the findings. The parents who participated in this study might not be representative of the range of Canadian parents of a child with ND. First, generally speaking, it is important to consider who is generally represented in research. Those who are in a position to offer their time and share their personal parenting journey for the sake of research, are likely in a position of less marginalization compared to those parents who are distressed in various ways and/or who are not available or lack sufficient resources to participate in research. Further, the sample was drawn from a database of parents who had previously completed a series of over 20 standardized measures for one portion of the Parenting Matters! study. Completion of that study required a significant commitment of time and dedication. Thus, the subsample of parents who were interviewed for the current study are likely motivated parents who have a particular interest and desire to contribute to research.

Face-to-face interviews with parents were the primary method of data collection in this study. However, other methods could have been useful and may possibly have offered different perspectives or ways of considering the process of hope. For instance, observational methods could have been utilized to discover what hope looks like in the day-to-day lives of families of children with ND. Observations could have been made in a variety of settings where parents may be likely to either discover or draw hope, or in situations where distractors may be likely to be present, such as in interaction with the health and social care system, in public centres where barriers to participation may challenge social connection, or when families have to negotiate stressors within their family unity. It may also have been useful to triangulate parent interviews with interviews with others in the family or other networks – spouses, siblings, HCPs. However, since the focus of the study was on parental hope, it was determined that the most accurate accounting of that experience would come from the parent themselves and not from others reporting on that parent's experience of hope. A longitudinal study of parental hope might also have added a unique and temporal perspective to the elements and consequences of hoping.

Finally, I acknowledge that it is possible that the analysis and presentation of findings from collected data may be biased by my personal interest and focus on hope. This may mean that participants did not feel that they could bring up experiences related to their parenting that were not positive or optimistic or which might make them seem less hopeful. For instance, no parent in this study described having no hope at all. Efforts were made to counteract this bias by eliciting narratives about ways in which hope was hard to find or times when parents did not feel hopeful. All parents revealed that they experienced moments when they were less hopeful, when hope was hard to find, or when they felt hopeless. The range of time this sentiment lasted varied among parents. But despite experiencing "low" hope, parents inevitably were able to "see the light at the end of the tunnel". In retrospect, parents were able to describe the times of low hope and often were able to shed light on why they may have felt that way at the time – they could identify influencing factors, or distractors to hoping. Ultimately, all parents in this study said that hope was always there. Of course, not all parents of children with ND feel this way. There certainly are parents who constantly struggle with the loss of the hoped-for child. For these parents, time does not heal the wound of their sorrow and despair. Instead, they continue to grieve the loss of the child they imagined and do not find hope in the midst of the challenges of raising a child with ND. Because the parents in this study were recruited from a database of participants who had previously completed questionnaires about their health and mental health, parents could be theoretically sampled to participate in this study based on this information. Some parents were in fact recruited to participate based on their scores on measures of their mental health – for example, a high score on a depression scale (the CES-D; Radloff, 1977). Parents who report more depressive symptoms are less likely to report feeling hopeful (Cheavens, 2000), therefore it was assumed that those parents who had high depression scores may provide a different perspective about hope than those who had low depression scores. These parents were theoretically sampled for that reason. Yet the presence of this construct of hoe amidst this sample diversity appeared to remain constant.

Accordingly, although data from participants with high depression scores added other dimensions to the developing theory of hope, none of them described having no hope. There are two reasons why it might be the case that parents with no hope were not recruited for this study: 1) a recruitment bias, and 2) a self-selection bias. In the former, clinicians and research assistants who recruited the initial sample of participants may have been more likely to approach parents who are engaged, seem to be doing well overall, and are positive about their parenting experiences. Parents who are struggling with the diagnosis, having difficulty integrating, or are generally having a more challenging time, may not have been approached to participate, as HCPs assumed that they would either not be willing to, or that drawing out personal narratives about their experiences would be too much to ask. In the latter, parents who have more positive experiences of parenting their child and more optimistic views about disability may be more likely to respond to an advertisement to participate and may have different relationships with their child's HCPs, which may lead to them being approached more readily than other parents. An additional reason might be that hope is in fact a relatively constant experience among parents. As a reflexive scholar, these biases and thoughts were noted in memos throughout data collection and analysis, discussed at length, and integrated into this dissertation[24].

Conclusion

This manuscript describes a study conducted with the aim of describing the experience of hope for the future among parents of children with ND. The grounded theory that resulted from

---

[24] See Chapter 4.

interpretation of the participant data, Seeking the light at the end of the tunnel, teases apart the elements of hoping for the future. Specifically, hope as a light is expounded to help illuminate the importance of hope in the lives of these parents. The interacting ways that distractors at multiple contextual levels can take hope away and the ways in which personal and communal sources can spark hope are described. The strategies used by parents to continue seeking hope for their child despite distractors are brought forward. The substantive theory of "seeking light at the end of the tunnel" lends support for and builds on the limitations of previous scholarship on the topic of hope among caregivers of children with ND. It also offers a unique perspective that integrates eco-systemic thinking, constructivism, and pragmatism to produce a theory that is meaningful to families and HCPs and takes account of the various contexts in which families live.

References

Abbedutto, L., Seltzer, M. M., Shattuck, P., Wyngaarden Krauss, M., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with Autism, Down Syndrome, or Fragile X syndrome. *American Journal on Mental Retardation, 109*(3), 237-254.

Averill, J. R., Catlin, G., & Chon, K. K. (1990). *Rules of hope*. New York: Springer-Verlag.

Bally, J., Duggleby, W., Holtslander, L., Mpofu, C., Spurr, S., Thomas, R., & Wright, K. (2013). Keeping hope possible: A Grounded Theory study of the hope experience of parental caregivers who have children in treatment for cancer. *Cancer Nursing, 37*(5), 363-372. doi:doi: 10.1097/NCC.0b013e3182a453aa

Barrera, M., Granek, L., Shaheed, J., Nicholas, D., Beaune, L., D'Agostino, N. M., . . . Antle, B. (2013). The Tenacity and Tenuousness of Hope: Parental Experiences of Hope When Their Child Has a Poor Cancer Prognosis. *Cancer Nursing, 36*(5), 408-416. doi:10.1097/NCC.0b013e318291ba7d

Beck, C. T. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research, 15*, 263-266.

Blacher, J., & Baker, B. (2007). Positive impact of intellectual disability on families. *American Journal of Mental Retardation, 112*, 330-348.

Blacher, J., & Baker, B. L. (2017). Collateral Effects of Youth Disruptive Behavior Disorders on Mothers' Psychological Distress: Adolescents with Autism Spectrum Disorder, Intellectual Disability, or Typical Development. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-017-3347-2

Breznitz, S. (1999). The effect of hope on pain tolerance. *Social Research, 66*(2), 629-652.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Carol, M. L. (2008). *Well-being, spirituality, and hope as predictors of parenting sense of competence in mothers of children with autism*. Carol, Michele Lyn: Fordham U , US.

Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172.

Charmaz, K. (1994). Grounded theory in the 21st Century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 507-535). Thousand Oaks: Sage.

Charmaz, K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London: Sage Publications.

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). London: SAGE Publications.

Cheavens, J. (2000). Hope and depression: Light through the shadows. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications.* (pp. 321-340). San Diego: Academic.

Chiovitti, R. F., & Piran, N. (2003). Rigor and grounded theory research. *Journal of Advanced Nursing, 44*(4), 427-435.

Copp, G. (1998). A review of current theories of death and dying. *Journal of Advanced Nursing, 28*(2), 382-390. doi:10.1046/j.1365-2648.1998.00794.x

Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: a thematic analysis of the literature. *Quality of Life Research, 21*(3), 427-439. doi:10.1007/s11136-011-0063-9

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child: Care, Health and Development, 36*(1), 63-73. doi:10.1111/j.1365-2214.2009.00989.x

Eliott, J. A., & Olver, I. N. (2009). Hope, Life, and Death: A Qualitative Analysis of Dying Cancer Patients' Talk About Hope. *Death Studies, 33*(7), 609-638. doi:10.1080/07481180903011982

Ello, L. M., & Donovan, S. J. (2005). Assessment of the Relationship Between Parenting Stress and a Child's Ability to Functionally Communicate. *Research on Social Work Practice, 15*(6), 531-544. doi:10.1177/1049731505278928

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2013). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*(2), 288-297. doi:http://dx.doi.org/10.1016/j.rasd.2012.08.014

García-López, C., Sarriá, E., Pozo, P., & Recio, P. (2016). Supportive Dyadic Coping and Psychological Adaptation in Couples Parenting Children with Autism Spectrum Disorder: The Role of Relationship Satisfaction. *Journal of Autism and Developmental Disorders, 46*(11), 3434-3447. doi:10.1007/s10803-016-2883-5

Gibson, A. N., Kaplan, S., & Vardell, E. (2017). A Survey of Information Source Preferences of Parents of Individuals with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 47*(7), 2189-2204. doi:10.1007/s10803-017-3127-z

Gibson, B. E. (2006). Disability, Connectivity and Transgressing the Autonomous Body. *Journal of Medical Humanities, 27*(3), 187-196. doi:10.1007/s10912-006-9017-6

Gibson, B. E., Carnevale, F. A., & King, G. (2012). "This is my way": reimagining disability, in/dependence and interconnectedness of persons and assistive technologies. *Disability and Rehabilitation, 34*(22), 1894-1899. doi:10.3109/09638288.2012.670040

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: AldineTransaction.

Gottschalk, L. A. (1974). A hope scale applicable to verbal samples. *Archives of General Psychiatry, 30*, 779-785.

Granek, L., Barrera, M., Shaheed, J., Nicholas, D., Beaune, L., D'Agostino, N., . . . Antle, B. (2013). Trajectory of parental hope when a child has difficult-to-treat cancer: a prospective qualitative study. *Psycho-Oncology, 22*(11), 2436-2444. doi:10.1002/pon.3305

Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development, 33*(3), 296-307. doi:10.1111/j.1365-2214.2006.00666.x

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*, 150-163.

Green, S. E., Darling, R. B., & Wilbers, L. (2016). Struggles and joys: A review of research on the social experience of parenting disabled children. In S. E. Green & S. N. Barnartt (Eds.), *Sociology looking at disability: What did we know and when did we know it* (Vol. 9, pp. 261-285): Emerald Group Publishing.

Hall, C. M., Culler, E. D., & Frank-Webb, A. (2016). Online dissemination of resources and services for parents of children with Autism Spectrum Disorders (ASDs): A systematic review of evidence. *Review Journal of Autism and Developmental Disorders, 3*(4), 273-285. doi:10.1007/s40489-016-0083-z

Harnett, A., Tierney, E., & Guerin, S. (2009). Convention of hope: Communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities, 37*(4), 257-264.

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2004). Factors related to positive perception in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 269-275.

Hastings, R. P., & Brown, T. (2002). Behavior Problems of Children With Autism, Parental Self-Efficacy, and Mental Health. *American Journal on Mental Retardation, 107*(3), 222-232. doi:10.1352/0895-8017(2002)107<0222:bpocwa>2.0.co;2

Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful Participation: The Lived Experience among Children with Disabilities. *Canadian Journal of Occupational Therapy, 74*(1), 38-47. doi:10.2182/cjot.06.10

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*, 874-882.

Horton, T., & Wallander, J. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*(4), 382-399.

Horton, T. V., & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology, 46*(4), 382-399. doi:http://dx.doi.org/10.1037/0090-5550.46.4.382

Imms, C. (2008). Children with cerebral palsy participate: A review of the literature. *Disability and Rehabilitation, 30*(24), 1867-1884. doi:10.1080/09638280701673542

Kashdan, T. B., Pelham, W. E., Lang, A. R., Hoza, B., Jacob, R. G., Jennings, J., . . . Gnagy, E. M. (2002). Hope and optimism as human strengths in parents of children with externalizing disorders: Stress is in the eye of the beholder. *Journal of Social and Clinical Psychology, 21*(4), 441-468. doi:http://dx.doi.org/10.1521/jscp.21.4.441.22597

Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health & Development, 32*(3), 353-369.

Kirpalani, H. M., Parkin, P. C., Willan, A. R., Felings, D. L., Rosenbaum, P. L., King, D., & Van Nie, A. J. (2000). Quality of life in spina bifida: Importance of parental hope. *Archives of Disease in Childhood, 83*, 293-297.

Kübler-Ross, E. (2011). *On Death and Dying*: Scribner.

Kylma, J., & Juvakka, T. (2007). Hope in parents of adolescents with cancer--Factors endangering and engendering parental hope. *European Journal of Oncology Nursing, 11*(3), 262-271. doi:http://dx.doi.org/10.1016/j.ejon.2006.06.007

Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. (2007). Health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation, 31*(8), 607-618.

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957-968. doi:http://dx.doi.org/10.1111/j.1365-2788.2009.01206.x

MacDonald, E. E., Hastings, R. P., & Fitzsimons, E. (2010). Psychological Acceptance Mediates the Impact of the Behaviour Problems of Children with Intellectual Disability on Fathers' Psychological Adjustment. *Journal of Applied Research in Intellectual Disabilities, 23*(1), 27-37. doi:10.1111/j.1468-3148.2009.00546.x

MacKean, G. L., Thurston, W. E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family-centred care. *Health Expectations, 8*(1), 74-85. doi:10.1111/j.1369-7625.2005.00319.x

McNeill, T. (2004). Fathers' Experience of Parenting a Child With Juvenile Rheumatoid Arthritis. *Qualitative Health Research, 14*(4), 526-545. doi:http://dx.doi.org/10.1177/1049732303262374

McNeill, T. (2007). Fathers of children with a chronic health condition: Beyond gender stereotypes. *Men and Masculinities, 9*(4), 409-424. doi:http://dx.doi.org/10.1177/1097184X05284220

Mednick, L. (2006). *Stress, hope, and anxiety in parents of very young children with type 1 diabetes.* Mednick, Lauren: The George Washington U , US.

Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with Type 1 Diabetes. *Children's Healthcare, 36*(4), 385-396.

Miller, A., Shen, J., & Masse, L. C. (2016). Child functional characteristics explain child and family outcomes better than diagnosis: Population-based study of children with autism or other neurodevelopmental disorders/disabilities. *Health Rep, 27*(6), 9-18.

Miller, A. R., & Rosenbaum, P. (2016). Perspectives on "Disease" and "Disability" in child health: The case of childhood neurodisability. *Frontiers in Public Health, 4*(226). doi:http://dx.doi.org/10.3389/fpubh.2016.00226

Miller, J. F. (2007). Hope: A construct central to nursing. *Nurs Forum, 42*(1), 12-19.

Morris, C., Janssens, A., Tomlinson, R., Williams, J., & Logan, S. (2013). Towards a definition of neurodisability: a Delphi survey. *Developmental Medicine & Child Neurology, 55*(12), 1103-1108. doi:10.1111/dmcn.12218

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, Hope, and Empowerment: A Model for Partnering With Parents of a Child With Autism Spectrum Disorder at Diagnosis and Beyond. *Social Work in Mental Health, 10*(4), 311-330. doi:10.1080/15332985.2012.664487

Nicholas, D. B., McNeill, T., Montgomery, G., Stapleford, C., & McClure, M. (2004). Communication Features in an Online Group for Fathers of Children with Spina Bifida: Considerations for Group Development Among Men. *Social Work With Groups, 26*(2), 65 - 80.

O'Neil, M. E., Ideishi, R. I., Nixon-Cave, K., & Kohrt, A. (2008). Care coordination between medical and early intervention services: Family and provider perspectives. *Families, Systems, & Health, 26*(2), 119-134.

Ogston, P. L., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders, 5*(4), 1378-1384. doi:http://dx.doi.org/10.1016/j.rasd.2011.01.020

Oktay, J. S. (2012). *Grounded Theory.* New York, NY: Oxford University Press.

Olshansky, S. (1962). Chronic Sorrow: A Response to Having a Mentally Defective Child. *Social Casework, 43*(4), 190-193.

Padencheri, S., & Russell, P. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Learning Disabilities, 6*(3), 253-261. doi:http://dx.doi.org/10.1177/1469004702006003035

Pelchat, D., Bisson, J., Bois, C., & Saucier, J. F. (2003). The effects of early relational antecedents and other factors on the parental sensitivity of motheres and fathers. *Infant and Child Development, 12*, 27-51.

R. v. Latimer, SCC 1, [2001] 1 S.C.R. 3, (2001).

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.

Reder, E., & Serwint, J. R. (2009). Until the last breath: Exploring the concept of hope for parents and health care professionals during a child's serious illness. *Archives of Pediatrics & Adolescent Medicine, 163*(7), 653-657. doi:10.1001/archpediatrics.2009.87

Ritzema, A. M., Lach, L. M., Rosenbaum, P., & Nicholas, D. (2016). About my Child: Measuring 'complexity' in neurodisability. Evidence of reliability and validity. *Child: Care, Health & Development, 42*(3), 402-409. doi:doi:10.1111/cch.12326

Roche, M. I., & Skinner, D. (2009). How parents search, interpret, and evaluate genetic information obtained from the Internet. *Journal of Genetic Counseling, 18*(2), 119-129.

Roos, S. (2002). What is chronic sorrow? *Chronic Sorrow: A living loss* (pp. 23-46). New York: Routledge.

Roscigno, C. I., Grant, G., Savage, T. A., & Philipsen, G. (2013). Parent perceptions of early prognostic encounters following children's severe traumatic brain injury: 'locked up in this cage of absolute horror'. *Brain Inj, 27*(13-14), 1536-1548. doi:10.3109/02699052.2013.831122

Roscigno, C. I., Savage, T. A., Grant, G., & Philipsen, G. (2013). How healthcare provider talk with parents of children following severe traumatic brain injury is perceived in early acute care. *Soc Sci Med, 90*, 32-39. doi:10.1016/j.socscimed.2013.04.017

Roscigno, C. I., Savage, T. A., Kavanaugh, K., Moro, T. T., Kilpatrick, S. J., Strassner, H. T., . . . Kimura, R. E. (2012). Divergent views of hope influencing communications between parents and hospital providers. *Qual Health Res, 22*(9), 1232-1246. doi:10.1177/1049732312449210

Schreiber, R. S. (2001). The "how to" of grounded theory: Avoiding the pitfalls. In R. S. Schreiber & P. N. Stern (Eds.), *Using grounded theory in nursing*. New York: Springer Publishing Company.

Scioli, A., & Biller, H. B. (2009). *Hope in the age of anxiety*. Oxford: Oxford University Press.

Shenaar-Golan, V. (2017). Hope and subjective well-being among parents of children with special needs. *Child & Family Social Work, 22*(1), 306-316. doi:10.1111/cfs.12241

Shikako-Thomas, K., Bogossian, A., Lach, L. M., Shevell, M., & Majnemer, A. (2013). Parents' perspectives on the quality of life of adolescents with cerebral palsy: Trajectory, choices and hope. *Disability and Rehabilitation, 35*(25), 2113-2122. doi:10.3109/09638288.2013.770083

Singer, R. (Writer). (n.d.) [Television series], *Life's Little Miracles*. Canada: Canadian Broadcasting Corporation.

Snyder, C. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry, 13*(4), 249-275. doi:http://dx.doi.org/10.1207/S15327965PLI1304_01

Snyder, C., Cheavens, J. S., & Michael, S. T. (2005). Hope Theory: History and Elaborated Model. *Interdisciplinary perspectives on hope* (pp. 101-118). Hauppauge, NY: Nova Science Publishers.

Snyder, C. R. (2000). *Handbook of hope: Theory, measures, and applications*. San Diego, CA: Academic Press.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., . . . Harney, P. (1991). The will and the way: Development and validation of an individual-differences measure of hope. *J Pers Soc Psychol, 60*, 570-585.

Snyder, C. R., & Lopez, S. J. (2007a). *Positive psychology: The scientific and practical explorations of human strengths*. Thousand Oaks, CA: Sage Publications, Inc.

Snyder, C. R., & Lopez, S. J. (2007b). Welcome to positive psychology. In C. R. Snyder & S. J. Lopez (Eds.), *Positive psychology: The scientific and practical explorations of human strengths*. Thousand Oaks, CA: Sage Publications, Inc.

Staller, K. M. (2013). Epistemological boot camp: The politics of science and what every qualitative researcher needs to know to survive in the academy. *Qualitative Social Work, 12*(4), 395-413. doi:doi:10.1177/1473325012450483

Stein, R. E. K., & Jessop, D. J. (1982). A noncategorical approach to chronic childhood illness. *Public Health Reports, 97*, 354 - 362.

Stein, R. E. K., & Jessop, D. J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science & Medicine, 29*, 769 - 778.

Strauss, A., & Corbin, J. (1990a). Introduction *Basics of qualitative research: Grounded Theory procedures and techniques* (pp. 17-32). Newbury Park, CA: Sage Publications.

Strauss, A., & Corbin, J. (1990b). Theoretical Sampling *Basics of qualitative research: Grounded Theory procedures and techniques* (pp. 176-193). Newbury Park, CA: Sage Publications.

Taanila, A., Jarvelin, M., & Kokkonen, J. Cohesion and parents' social relations in families with a child with disability or chronic illness. *International Journal of Rehabilitation Research, 22*(2), 101-109.

Taanila, A., Syrjala, L., Kokkonen, J., & Jarvelin, M. R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development, 28*(1), 73-86.

Thomas, P. A., King, J. S., Mendelson, J. L., & Nelson-Gray, R. O. (2017). Parental psychopathology and expectations for the futures of children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a. doi:10.1111/jar.12337

Thomasgard, M., & Metz, W. P. (1997). Parental overprotection and its relation to perceived child vulnerability. *AMerican Journal of Orthopsychiatry, 67*(2), 330-335.

Thornberg, R., & Charmaz, K. (2012). Grounded Theory. In S. Lapan, M. Quartaroli, & F. Riemer (Eds.), *Qualitative research: An introduction to methods and designs* (pp. 41-67). San Francisco: Jossey-Bass.

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*(2), 233-238. doi:http://dx.doi.org/10.1016/j.pec.2011.08.015

Wasow, M., Hatfield, E., & Wikler, L. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *AMerican Journal of Orthopsychiatry, 51*(1), 63-70.

Webster, R., Majnemer, A., Platt, R., & Shevell, M. (2008). Child health and parental stress in school-age children with a preschool diagnosis of developmental delay. *Journal of Child Neurology, 23*, 32-38.

Wong, M. G., & Heriot, S. A. (2007). Vicarious Futurity in Autism and Childhood Dimentia. *Journal of Autism and Developmental Disorders, 37*, 1833-1841.

World Health Organization. (2007). *International Classification of Functioning, Disability, & Health - Children &Youth Version*. Geneva, Switzerland: WHO Press.

Chapter 6: Implications and General Conclusion

This dissertation is composed of two manuscripts and four chapters presenting theoretical foundations, methodological insights, and substantive findings from an empirical study which sought to capture how hope is expressed in the lives of parents of children with ND. In the concluding chapter, I summarize the contributions to the scholarship, present recommendations for practice, policy, and social work education, suggest directions for future research, and offer concluding remarks.

Contributions to the Scholarship

Manuscript 1 fills a gap in the methodological literature, specifically relating to the role of reflexivity in qualitative CGT research. Historically, Grounded Theory (GT) is a methodological approach that is accompanied by explicit guidelines for students and novice researchers. Students often rely on two sources of published work to guide them when learning a new methodology: textbooks, and exemplars of published manuscripts. Although students are taught about the importance of researcher reflexivity in GT and other qualitative approaches, the ways in which researchers integrate and report on their reflexivity practice is often absent from published manuscripts. Manuscript 1 offers a unique accounting through three aspects of taking up researcher reflexivity in the context of this dissertation research. The sections Knowing, Reflexing, and Doing each offer an elucidation of a novice researcher taking up a new-to-her approach to research by learning about the approach, exercising reflexivity, and conducting a study. The manuscript offers examples of decision-making through a reflexive lens, taking into consideration the role of a clinician-student-researcher, and acknowledging bias, naiveté, and areas of expertise. The purpose of this paper is to generate discussion about what gets left out of published manuscripts, and to make explicit the “grunt work” of research. The hope is that collectively as a scholarly community we can generate more examples of candid and comprehensive renderings of the ways in which our personal values, clinical experiences and expertise, interactions with participants, and exchanges with audiences influence each aspect of the research process, both in CGT, and across the methodological spectrum.

The Methods chapter bridges aspects of the methodology requiring more detail than could be offered in Manuscript 1. For instance, in this chapter, I situated the study within Symbolic Interactionism, Pragmatism, and Constructivism, the core paradigms informing CGT and provided a justification for the fit between social work research, childhood disability studies, and CGT. More detail was also provided about how sampling and data analysis proceeded from a CGT perspective. Other aspects of methodology were also discussed, such as how the scholarly literature was integrated in this empirical study, and finally, a substantial elucidation of how rigour was used and evaluated. I see the methodological robustness of this study as one of its strengths and hope that my interpretation of CGT and representation of the process in these two methodological chapters will be useful to other grounded theorists.

Manuscript 2 presents the empirical study on the experiences of hope among parents of children with ND conducted as part of this dissertation. The findings of this study contribute to the scholarship on parenting children with disabilities in a few ways. First, from a methodological perspective, efforts were made to counteract the bias in the parenting literature toward drawing conclusions about parenting based on the experiences of mothers alone. Fathers were sought out during theoretical sampling both to ensure the conceptualization of hope was representative of mothers and fathers, and to seek out theoretical saturation of the conceptual categories while keeping in mind the inherent gendered nature of caregiving and the ways in which mothers and fathers may differ in their experience of parenting their child. Second, this study applied a non-categorical approach to understanding the disability experience that takes into account the recognition that there are many more similarities than differences in several aspects of the family experience. In fact, emerging scholarship is demonstrating that child complexity or functional status is a better predictor of child and family health-related outcomes than the child's diagnosis (Miller, Shen, & Masse, 2016). Third, from a conceptual standpoint, through seeking to understand how hope is expressed, efforts were made to allow for expressions of despair. I inquired about and left room for participants to describe their experience of their child and of themselves as parents to their child in as real terms as they felt comfortable sharing. Efforts were made to elicit examples of times when hope was hard to find or did not feel accessible at all. As discussed in the Limitations section of Manuscript 2, I recognize that parents may not have felt at ease speaking about despair with a researcher who has selected the topic of hope as a doctoral research focus. And also, that my sample may have been biased by the fact that these eleven parents were motivated to participate in the first part of a study requiring a significant amount of time to complete a series of standardized measures within a specified time frame. Despite this potential bias, the resulting theory accounts for both hope and hope-little-ness by examining the ways in which hope is challenged and the strategies used by parents to continue to pursue a good life for their children.

Recommendations for Practice, Policy, and Social Work Education

Clinical implications relative to the study findings were offered in Chapter 5 (Manuscript 1). Further to that discussion, this section outlines additional recommendations for integrating hope into clinical practice generated by way of a consensus-building exercise conducted at a symposium of the Canadian Network of Children and Youth Rehabilitation (CN-CYR) and the Canadian Family Advisory Network (CFAN) at the 2014 annual meeting of the Canadian Association of Paediatric Health Centres (CAPHC)[25]. These recommendations take the study findings further relative to a broader application in clinical practice. The participants at this symposium included HCPs, parents, policy makers, managers/administrators, and researchers. A group of researchers from the Childhood Neurodisability Research Group at the Centre for Research on Children and Families (CRCF) presented selected findings from our work on the Parenting Matters! program of research. Participants were introduced to four "myths" related to parenting children with ND, followed by evidence from our work that counters the myth, and finally a discussion question was posed relating to how these findings might be integrated into clinical care. One of the myths presented was that parents who are hopeful are in denial. This myth is one that gets perpetuated in the clinical realm and is one that parents are acutely aware of and have been brought to my attention in various contexts. A preliminary version of the study findings was presented to the group in order to incite discussion of whether the myth about parents who are hopeful being in denial seemed grounded in empirical data and the experiences of the symposium participants. The question to the group was: how should hope be integrated into clinical care? After presenting a preliminary theoretical rendering of the research findings reported in this dissertation, participants were asked to convene in small groups of five or six. They were then asked to develop three priorities related to the discussion question and were given 10 minutes to do so. Each participant was then invited to select one of the three priorities that resonated for them and write it down on a small index card. Participants were then given 30 seconds to walk around the room and switch cards with each participant they saw.

---

[25] These are published in an infosheet: Bailey, S. N. (2016). Recommendations for hopeful clinical practice. Parenting Matters! Information Sheet. Retrieved from https://www.canchild.ca/system/tenon/assets/attachments/000/001/522/original/PM_Infosheet_Hopeful_Practice_Final_April_16_2016.pdf

When the facilitator told them to stop, participants were to read the recommendation on the card in their hand to the person in front of them. Together, the two participants were to rate each statement on each card on a scale of 1 (low priority) to 7 (high priority) and to write the number on the back of each card. The card exchange was repeated twice more so that at the end of the activity, each recommendation had three rankings on it, for a maximum score of 21. The cards were collected at the end of the activity and reviewed by the research team to identify the highest ranked recommendations and then analyzed thematically to determine the themes that appeared most frequently among them.

A total of 88 recommendations were collected for this activity from the participants at the workshop. From those who indicated their role, 5 were administrators or managers, 9 were parents of family members, 31 were service providers, and 2 indicated that they belonged to more than one of those groups. Five recommendations received perfect scores. These top five recommendations are listed in Table 4, below.

Table 4. Top Five Recommendations for Integrating Hope into Clinical Care

1. Ensure clinicians have the knowledge, skills, and attitudes to engage in conversations about hope (From a manager)
2. Integrate the importance of hope in care into the curriculum of healthcare students (From a clinician)
3. Make the question "what do you hope for today" (asked directly to the child or parent) a routine part of rounds or daily interactions – just Family-Centred Care! (From a clinician)
4. Clinicians should invite parents to share their immediate hopes for their child
5. Integrate hope by listening to parents without judgement and validate their feelings (From a clinician)

When the recommendations were analyzed thematically, three themes emerged as the most endorsed by participants:

1. Create opportunities for discussion about parent and child hopes where families feel listened to, respected, and supported (41 recommendations)
2. Offer hope training to clinicians (20 recommendations)
3. Align service provision with family goals, needs, and hopes (15 recommendations)

Create opportunities for discussion about parent and child hopes where families feel listened to, respected, and supported

The importance of integrating explicit conversations about hope into clinical care was widely endorsed by participants. By inviting parents to share their immediate and long-term goals, wishes, and hopes for their child, and listening with non-judgmental curiosity, clinicians can help parents explore their hopes and can offer examples of hopes and goals when parents are struggling to find them. One example of how to create these opportunities is to make hope questions a routine part of interactions with families. For example, asking the child and/or caregiver, "what do you hope for today? For tomorrow? For the future?", or, "what does hope look like for you?" The responses to such questions can form the basis of the formulation of care plans and goals.

Offer hope training to clinicians

In order to integrate conversations about hope into clinical encounters, clinicians may require training to feel confident in their ability to broach the topic of family hope and to explore family members' thoughts about the future. For example, clinicians may be preoccupied with wanting to support families in finding a balance of hope and realism in their goals for the future for their child. This requires having frank discussions about a child's level of complexity and potential to advance. Some clinicians may benefit from additional training about how to have these kinds of conversations with families. Participants suggested educating clinicians about the importance of hope, exploring myths related to hope (such as the one presented in the workshop), and training them to engage in hope-inspiring dialogue and conversations about hope with families. Participants noted that training and professional development should begin with integration into allied healthcare curricula and should be ongoing.

Align service provision with family goals, needs, and hopes

Once HCPs are comfortable exploring a family's hopes for the future, they can integrate them into the child's care plan. For example, parental hopes for their child and child hopes can be used as a springboard for short and long-term goal setting. In other words, clinical goals should be shaped toward family hopes for the child, rather than toward generic goals or goals that may not be important to the family. This may result in a tension for the clinician if the family-identified goals do not align with what they see as the priorities for the therapeutic work they will be doing together. They may not be "functional" goals, but may be focused more on quality of life, or meaningful participation in life activities – the “airy fairy” hopes parents indicated were overarching and non-negotiable. In this way, HCPs empower and facilitate the realization of family hopes.

The recommendations generated from this activity can be taken up in health and rehabilitation settings at both a systemic and an individual level to enhance the services provided to families of children with ND. They can be integrated into clinical guidelines in paediatric rehabilitation settings, both in acute and community rehabilitation, where health and allied health care professionals work across disciplines and in collaboration with children and their families from a family-centred perspective. As mentioned, there is room in the curricula of social work and other allied health and health care programs for teaching about the importance of hope, evidence for its impact on child and family outcomes, and for experiential learning opportunities around how to engage in hopeful communication with families. As an educator, I know that students seek opportunities to practice skills they will need when they are out in the field. Educators can offer students a safe space to do so and the chance to receive supportive critical feedback from their peers and instructors. Knowing how vital conversations about the future are to families, it becomes of utmost importance to engage students in the work of meaningful collaboration with families and of developing the interviewing and communication skills they need to ensure these encounters are helpful. Social workers are sometimes seen as bearers of hope and sometimes as bearers of bad news – for example, when a needed resource is not available in a timely way or not at all, or when a child is not eligible due to their diagnosis or level of function. Systemic barriers and the availability of resources may be determining factors in how a social worker is seen by a family. However, even in the context of fiscal and systemic constraints, social workers can engage in hopeful conversations about creatively using and accessing resources and in considering a future for their child in which they live a life of value. My hope is that these ideas might spark further discussion among professionals, trainees, and educators about how recommendations such as these might be taken up.

Directions for Future Research

The goal of a GT study is to produce a mid-range substantive theory. The conceptual model offered in this dissertation is one that can inform future research in a number of ways: first, a recognition that this theoretical conceptualization of hope is a starting point for future work. Any single grounded theory generated by any one study has the potential to be built on, expanded, and abstracted to a higher level. This is partly what makes GT research so exciting. And so, my hope is that this grounded theory will serve as a jumping off point for upcoming qualitative work about hope for the future among similar and different populations. For instance, do elements of this theory look different for new immigrants to Canada, for those living under extreme financial constraints, for same sex parent-led families, for foster families, or for children with other chronic or acute conditions? It would be interesting to pursue the ways in which this theory might be developed further with a more in-depth consideration of gender and the ways in which parenting roles are influenced by contemporary understandings of gender and caregiving roles within the family system and our society more broadly. Another way to extend this theory is to investigate hope over time. From a qualitative perspective, it would be fascinating to follow families through their journey, from the early stages of the diagnostic process, through key transitions, such as school entry and adolescence, and investigate how hope evolves over time. A longitudinal design could of course be utilized in a measurement-based study to examine the determinants and outcomes of hoping.

Second, the theory of the process of hoping – seeking the light at the end of the tunnel – can be drawn on to inform the operationalization of hope among parents of children with ND. The development of a measure of hope that has been conceptualized and validated for parents will support future quantitative studies about the predictors and determinants of hope. Such standardized measures could also be used to consider the outcomes of hoping. We might also consider how in the context of parenting, hope can be thought of as both an aspect of parent personality or "parenting as experienced" as well an aspect of "parenting as enacted" or the observable actions and patterns of behavior by parents toward their children (Bailey, Lach, & Byford-Richardson, 2012). Parents in this study described hope as cognitive, emotional, spritiual, but also as an experience that propelled them into action. And so, it may very well be that hope is both enacted and experienced. In Belsky's process model of the determinants of parenting (Belsky, 1984), parent personality is considered to be the most influential to parent functioning – it has both direct and indirect impacts through its influence on the social context of parenting (i.e., marital relations, social network, and work). Hope may also play a role in what Abidin refers to as the "parenting role variable" (Abidin, 1992) – a parent's internal working model of themself as a parent. This variable informs the level of stress experienced by a parent. Although I have critiqued the centrality of parenting stress in this model and its applicability to childhood disability[26], I suggest that there is value in considering how a hope variable might be included in eco-systemic models of parenting that

---

[26] See Chapter 2.

consider a parent's cognitions and beliefs about themselves and their child. Questions such as whether parental hope has an impact on parenting practices (e.g., parenting behaviors, parent sense of competence, parent sense of their effectiveness as a parent), child outcomes, or the parent-child relationship could be answered.

Finally, ongoing research on hope could consider the clinical impact of hope, not only on the family system, but on healthcare provision, and vice versa. We might ask questions such as: what clinical practices are related to hope among families? What system-level factors impact parental hope? What are the short and long-term outcomes of these influences on the child and the family? Toward the goal of providing training to clinicians about hope, future research using participatory methods could solicit the experiences and beliefs about encouraging and supporting hope among the families they work with. Integrating such findings with the findings of the current study could lead to the development of clinical guidelines relevant to paediatric HCPs in diverse settings.

Concluding Statement

The findings of this dissertation research point to hope as a complex and multiply-influenced process. Parents made it clear that hope is critical to their role as caregivers to their child with ND and to their own well-being. Although the brightness of this light at the end of the tunnel ebbs and flows, parents are cognizant that it is always there. Parents consciously or not have developed strategies to overcome moments of hopelessness in order to maintain a positive outlook on the future for their child. In doing so, families find a new normal as they review life goals and integrate the reality of their child's condition. Parents also find themselves changed in ways they did not expect as a consequence of seeking hope for their child. This dissertation has presented the scholarly context for understanding both parenting in general and in the context of disability, as well as the construct of hope. I have offered a unique illustration of the use of researcher reflexivity in the context of a CGT study. And finally, I have provided recommendations for how these empirical findings may be taken up in clinical, academic, and research contexts. I look forward to hope being granted a more prominent role in both research and practice in the world of childhood disability.

References

Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of clinical child psychology, 21*(4), 407-412.

Bailey, S. N., Lach, L. M., & Byford-Richardson, K. (2012). Interpersonal interactions and relationships (D710-D799). In A. Majnemer (Ed.), *Measures for children with developmental disabilities* (pp. 381-403). London: Mac Keith Press.

Belsky, J. (1984). The determinants of parenting: A process model. *Child Development, 55*, 83-96.

Miller, A., Shen, J., & Masse, L. C. (2016). Child functional characteristics explain child and family outcomes better than diagnosis: Population-based study of children with autism or other neurodevelopmental disorders/disabilities. *Health Rep, 27*(6), 9-18.

Appendices

Appendix 1: Interview Guide Iterations

Interview Guide
Draft Version: August 28, 2013

I am going to start with some questions about who your child is and gradually will start to enquire about your experience of hope and the role that it plays in your and your family's life.

1. What would you like to tell me about [child's name]?
    - Probe: name, age, school, diagnosis, disposition, challenges
2. Now I would like to talk with you about what it's been like to raise [child's name].
    - Probe: What has it been like for you as a mother/father?
    - Probe: What has it been like for you as a couple (if interviewing couple)?
    - Probe: What has it been like for you as a family?
3. When I say the word 'hope', what comes to mind?
    - Probe: What are you hopeful for?
4. When you think about your journey as a parent to [child's name], what has allowed you to remain positive or hopeful?
    - Follow-up: How has this evolved or changed over time?
    - Follow-up: What has challenged your ability to remain positive or hopeful?
    - Follow-up: What have been the sources of hope for you? Or, Where have you found hope?
    - Follow-up: How do you keep hope alive?
5. When you think about your child's future, what are some of your thoughts about that?
    - Probe: What role does hope play in your thoughts about the future?
    - Probe: What are your hopes? Or, What do you hope for, for your child, yourself, your family?
    - Follow-up: When you think about your family's future, what are your hopes?
6. Is there anything else you think I should know to better understand your experience of hope?

Interview Guide
Version: February 4, 2014

I am going to start with some questions about who your child is and gradually will start to enquire about your experience of hope and the role that it plays in yours and your family's life.

1. What would you like to tell me about [child's name]?
    - Probe: name, age, school, diagnosis, disposition, challenges, strengths, preferences.
2. Now I would like to talk with you about what it's been like to raise [child's name].
    - Probe: What has it been like for you as a mother/father?
    - Probe: What has it been like for you as a couple?
    - Probe: What has it been like for you as a family?

3. When I say the word ‘hope’, what comes to mind?
    - Probe: What are you hopeful for?
4. When you think about your journey as a parent to [child’s name], what has allowed you to remain positive or hopeful?
    - Follow-up: How has this evolved or changed over time?
    - Follow-up: What has challenged your ability to remain positive or hopeful?
    - Follow-up: What have been the sources of hope for you? Or, Where have you found hope?
    - Follow-up: How do you keep hope alive?
5. How would your hope be different if you didn’t have a child with a disability?
6. Are there times when hope is hard to find?
    - Probe: Are there times when you are not hopeful or when you are hopeless or when there is no hope?
7. Would you say that hope is the same as being positive? How is hope different from positivity or optimism?
8. How would you say hope has been different for each of you (you and your partner)?
    - Probe: How have you navigated hope together with your spouse?

Interview Guide
Version: July 6, 2014

I am going to start with some questions about who your child is and gradually will start to enquire about your experience of hope and the role that it plays in yours and your family’s life.

1. Can you tell me about [child’s name]?
    - Probe: name, age, school, diagnosis, disposition, challenges, strengths, preferences, etc.
2. Can you tell me a bit about what it’s been like to raise [child’s name]?
    - Probe: What has it been like for you as a mother/father? As a couple? As a family?
3. When I say the word ‘hope’, what comes to mind?
    - Probe: What are you hopeful for?
4. Consider a time or a moment when you felt especially hopeful. Can you describe that moment?
5. Consider a time or a moment when you felt especially hope-less or despairing. Can you tell me about that moment?
    - Follow-up: Can you tell me more about times when hope is hard to find?
6. When you think about your journey as a parent to [child’s name], what has allowed you to remain positive or hopeful?
    - Follow-up: How has this evolved or changed over time?
    - Follow-up: What has challenged your ability to remain positive or hopeful?
    - Follow-up: What have been the sources of hope for you? Or, Where have you found hope?
    - Follow-up: How do you keep hope alive?
    - Follow-up: What kinds of social interactions have helped or hindered your hope?
7. How would your hope be different if you didn’t have a child with a disability?

8. How would you say hope has been different for each of you (you and your partner)?
    - Probe: How have you navigated hope together with your spouse?
9. I'm interested to know, what would you like service providers to know about your experience that would improve their ability to provide relevant and good quality services to families such as yours?
10. Is there anything else you think I should know to better understand your experience of hope?

Interview Guide
Version: July 24, 2014

I am going to start with some questions about who your child is and gradually will start to enquire about your experience of hope and the role that it plays in yours and your family's life.

1. Can you tell me about [child's name]?
    - Probe: name, age, school, diagnosis, disposition, challenges, strengths, preferences, etc.
2. Can you tell me a bit about what it's been like to raise [child's name]?
    - Probe: What has it been like for you as a mother/father? As a couple? As a family?

Now, I want to talk with you about what hope is to you.

3. When I say the word 'hope', what comes to mind?
    - Probe: What are you hopeful for?
4. Consider a time or a moment when you felt especially hopeful. Can you describe that moment?
5. Consider a time or a moment when you felt especially hope-less or despairing. Can you tell me about that moment?
    - Follow-up: Can you tell me more about times when hope is hard to find?
6. When you think about your journey as a parent to [child's name], what has allowed you to remain positive or hopeful?
    - Follow-up: How has this evolved or changed over time?
    - Follow-up: What has challenged your ability to remain positive or hopeful?
    - Follow-up: What have been the sources of hope for you? Or, Where have you found hope?
    - Follow-up: How do you keep hope alive?
    - Follow-up: What kinds of social interactions have helped or hindered your hope?
7. What would it be like to have a child with [child's condition] if there was no hope?
8. How would your hope be different if you didn't have a child with a disability?
9. How would you say hope has been different for each of you (you and your partner)?
    - Probe: How have you navigated hope together with your spouse?
10. I'm interested to know, what would you like service providers to know about your experience that would improve their ability to provide relevant and good quality services to families such as yours?
11. Is there anything else you think I should know to better understand your experience of hope?

Interview Guide
Version: December 17, 2014

I am going to start by asking you a few questions about your child and your family and then will ask you about your experience of hope and the role that it plays in yours and your family's life.

1. Can you tell me about [child's name]?
    - Probe: name, age, school, diagnosis, disposition, challenges, strengths, preferences, etc.

Now, I want to talk with you about what hope is to you…

2. When I say the word 'hope', what comes to mind?
    - Probe: What are you hopeful for?
3. The parents that I have been speaking with so far seem to be telling me that there is always hope, but that at times it can be hard to find. Has that been your experience?
4. Consider a time or a moment when you felt especially hope-less or despairing. Can you tell me about that moment?
    - Follow-up: Can you tell me more about times when hope is hard to find?
5. I have been hearing that there are things that can distract parents from hoping – things that make it more difficult to be hopeful - and these "distractors" can come from various parts of life. For example, things about you and the way you think about the world and the way you experience the world; things about your family; about the social and health systems you interact with; and things about society. Does that resonate for you?
6. What have been the "distractors" to hoping in your life?
7. When you think about your journey as a parent to [child's name] – if you think back to when he/she was born, and what your hope looked like then, and then when you were given your child's diagnosis, and over time – how do you think your hopes for your child have changed?
8. What has allowed you to remain hopeful?
    - Probe: How have you been able to keep hope alive?
    - Follow-up: Where have you found hope?
    - Follow-up: Which social interactions have been the most helpful to you in maintaining hope?
9. What would it be like to have a child with [child's condition] if there was no hope?
10. How would your hope be different if you didn't have a child with a disability?
11. I'm interested to know, what would you like service providers to know about your experience that would improve their ability to provide relevant and good quality services to families such as yours?
12. Is there anything else you think I should know to better understand your experience of hope?

Appendix 2: Informed Consent Form

McGill

The Experience of Hope Among Parents of Children with Neurodevelopmental Disorders

Informed Consent Form

Principal Investigator:
Sacha Bailey, Master of Social Work (MSW), PhD Candidate
Centre for Research on Children and Families
McGill University, School of Social Work
3506 University St., Suite 106
Montreal, QC H3A 2A7
(514) 398-2107
sacha.bailey@mail.mcgill.ca

Faculty supervisor:
Lucyna Lach, MSW, PhD
McGill University, School of Social Work
Lucy.lach@mcgill.ca

Sponsor: This study is supported by funds from the Fonds de Recherche Société et Culture (FQRSC) and the Wolfe Chair in Scientific and Technological Literacy Graduate Fellowship

This Informed Consent form has 2 parts:

1. Information about your participation in the study
2. Consent (signature section if you agree to participate)

Introduction:

You are being asked to participate in a research project involving your experience as a parent of a child with a neurodevelopmental diagnosis (NDD). Before agreeing to participate in this project, please take the time to read and carefully consider the following information.

This consent form explains the aim of this study, the procedures, advantages, risks and inconveniences as well as persons to contact, if necessary.

This consent form may contain terms that you are not familiar with. I invite you to ask any question that you deem useful and ask me to explain any word or information that is not clear to you.

PART I: Information about your participation in the study

Purpose of the study:

This study seeks to better understand 'hope' among parent of children who have a neurodevelopmental diagnosis (NDD. About 15 parents of children with a range of diagnoses, both mothers and fathers, will be interviewed. The following questions will guide the interview: What does hope mean to you? Where do you find hope? How do you maintain hope? What difference does hope make to you? I am interested in developing a deeper understanding of how mothers and fathers experience hope and how hope differs between mothers and fathers.

Findings from the study will be relevant to practitioners who work with families of children with NDD in that they may guide assessments, interventions, and inform policies relating to how services are provided. The project will also generate further research questions that may be explored in future studies.

Description of the procedures:

In the recent past, you were approached by a familiar health professional and asked to participate in a study called Parenting Matters! Some of you completed a set of questionnaires and consented, at that time, to be contacted for future research projects. Others indicated an interest in participating in only this portion of the Parenting Matters! research. The results from this study will be used toward my doctoral dissertation about the experiences of hope among parents of children with NDD. Once the extent of your participation in this study has been explained to you, and if you agree to participate, you may complete this informed consent form.

Participation in this study involves one interview, and potentially a second, if it is deemed that a second interview would help in the analysis of the data. The interview will be about an hour in length and will take place at a time and location that is convenient for you (e.g., McGill, a work setting, a clinic where your child receives services, if possible, or your home). During the interview, I will ask you about your experience as a parent of a child with an NDD, and more specifically, I will seek to capture your experience of hope in relation to being the parent of your child. Interview questions will seek to elicit the meaning of hope, how hope is experienced, how hope develops, and what difference it makes to be hopeful. The interviews will be audio recorded to be sure that data collection is accurate. The audio recordings will be transcribed verbatim (typed word for word). As a thank you for your time, you will be given a $20 gift certificate to a local store of your choosing.

The data that was collected for the Parenting Matters! study by way of questionnaires (either in booklet form or online) may be useful to me as I make sense of the data that emerges from the interviews. I therefore ask permission from those who completed questionnaires to use this data in my study as well.

Potential Risks:

While the risks associated with taking part in this study are minor, there is a possibility that by participating in the interviews difficult struggles and life events may be brought up which may cause emotional discomfort. If you become uncomfortable with the interview questions, you can stop the interview or take a break at any time. At that time, I will remind you that you are not obligated to answer interview questions that make you uncomfortable. If as a result of the interview, you become distressed and indicate that you would like to speak with a professional for further support, I will provide a referral for this.

Potential Benefits:

Your family may not benefit directly from taking part in this study. However, many parents find it satisfying to share their personal experiences, in the hope that it will help others facing similar challenges. Additionally, the practical relevance of this study will be to help inform practitioners working in the area of paediatrics about the experience of families who have a child with an NDD. Knowing what hope is about for families will not only help these professionals have a better understanding of what parents experience, it will also change how they interact with parents and the kinds of conversations they have with them. Thus, families such as yours may experience a shift in the nature of their interactions with practitioners located in the various systems that deliver care to your child.

Confidentiality:

I will keep all information collected for this study confidential. The digital audio recordings of the interviews will be uploaded to a computer, saved in a password-protected file, and transcribed verbatim. All personal identifying information will be removed from the transcripts and the recording of the interview on the recording device will be deleted. The transcripts of the interviews will be kept on a password-protected computer in a password-protected file. Any reports or presentations of the research will not identify those who participated in the study. You will be given a fake name if quotations from your interviews are used in published reports or presentations. Any identifying information about you or your family will be altered in reporting the study results. Except as required by law, your child's identity and data related to this study will be kept confidential. In cases where a parent discloses current or planned acts of harm against themselves or their child, I am required to inform the appropriate authorities (youth protection/child protective services or law enforcement). The computer that will store results is located in the Centre for Research on Children and Families (CRCF), a McGill-based secure research centre. Once the dissertation is complete, the data will be wiped from that computer and stored in the Child Welfare Data Lab, a secure site located in the CRCF. Data will be stored for a period of seven years, after which it will be destroyed. Paper copies of consent forms will be stored in a locked filing cabinet at the CRCF. To help me make sense of the experiences you share with me and develop a well-grounded understanding of hope for parents of children who have a neurodevelopmental diagnosis, de-identified data may be shared with the researcher's thesis committee, composed of two faculty members from McGill University and one from the University of Calgary and colleagues working in the area of childhood disability.

Participation:

Participation in this study is voluntary. You are not obliged to answer any questions that you do not want to. Your refusal to participate will in no way impact on the quality of care that your child is receiving. You have the right to withdraw from the study at any time. If you wish to withdraw from the study after partaking in the interview, the audio file and transcription will be deleted and your interview will not be used in the analysis.

If you have any questions about this study, you may contact Sacha Bailey, at 514-398-2107 or sacha.bailey@mail.mcgill.ca. If you have any questions about your rights and recourse of your participation in this research study, you may contact Lynda McNeil, Research Ethics Officer at the McGill University Research Ethics Office, at 514-398-6831, or email Lynda.mcneil@mcgill.ca.

PART II: Consent

Consent:

I state that I have read this consent form. I acknowledge that this study, the nature and extent of my participation, as well as the benefits and risks/inconveniences to which I will be exposed have been explained to me in this form. I have been given the opportunity to ask questions concerning any aspects of the study and have received answers to my satisfaction.

I, the undersigned, voluntarily agree to take part in this study. I can withdraw from the study at any time without prejudice of any kind. I certify that I have had sufficient time to consider my decision to participate in this study. A copy of this consent form will be kept in a secure research office. A signed copy of this consent form will be given to me.

☐ I acknowledge that the procedures for this research study were explained to me. I understand that I have the right not to participate in this study. I also have the right to withdraw from the study at any time.

☐ I agree to be audio recorded during this study. These audio recordings will be used to ensure that the information that has been shared will be recorded and analyzed accurately and efficiently.

☐ I agree to have the researcher use audio clips from my interview(s) in research presentations.

☐ If applicable, I agree to have data collected via questionnaires for the Parenting Matters! study used by this researcher for her dissertation study.

By my signature below, I agree to participate in this study.

Name of Participant (print)	Signature of Participant	Date

Name of Researcher (print)	Signature of Researcher	Date