

FINDING BALANCE: IDENTIFYING WAYS TO IMPROVE THE DELIVERY OF  
SURGICAL CARE TO CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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TABLE OF CONTENTS

LIST OF TABLES ..... viii

LIST OF FIGURES ..... x

ABSTRACT ..... xi

LIST OF ABBREVIATIONS AND SYMBOLS USED ..... xii

CHAPTER 1. INTRODUCTION ..... 1

    High Needs for Healthcare Services ..... 2

    Children with Autism Experience Challenges In Accessing Healthcare  
    Services ..... 4

    Improving Healthcare Experiences ..... 5

    Participatory Action Approach To Improving The Delivery Of Surgical Care ..... 7

    Summary of Aims and Overview of Dissertation Content ..... 9

CHAPTER 2. MANUSCRIPT 1: A BALANCING ACT: AN INTERPRETIVE  
DESCRIPTION OF HEALTHCARE PROVIDERS’ AND FAMILIES’  
PERSPECTIVES ON THE SURGICAL EXPERIENCES OF CHILDREN WITH  
AUTISM SPECTRUM DISORDER ..... 12

    Abstract ..... 13

    Introduction ..... 14

    Method ..... 16

        Participants ..... 17

        Procedure ..... 18

        Interview Guides ..... 19

        Data Analysis ..... 20

    Results ..... 22

        Interpretation: The Experience is a Balancing Act ..... 22

        Theme 1: Finding Your Footing Through an Uncertain Journey - Individual

Factors.....	23
Subtheme: Individualized Care Helps Children Find their Balance .....	23
Subtheme: Parents Anticipate Losing Balance and Feel on Edge .....	25
Subtheme: HCPs’ Comfort in Maintaining Balance.....	26
Theme 2: Relationships can Help Keep Everyone Steady - Interpersonal Factors.....	28
Subtheme: Unsteadiness Affects Everyone; Empathy can be a Safety Net.....	28
Subtheme: Collaboration Stabilizes, but Dependency can Upset the balance .....	30
Subtheme: Coordination is Challenging but Essential to Maintain Balance.....	31
Theme 3: Systems Shape the Experience – Systemic Factors .....	32
Subtheme: Policies and Procedures Help but Must be Flexible... ..	33
Subtheme: An Open and Adaptable Culture is Important .....	33
Subtheme: Value of Autism-friendly spaces and resources .....	34
Discussion.....	36
Limitations and Future Directions .....	40
Conclusion .....	41
 CHAPTER 3. HOW QUALITATIVE STUDY FINDINGS INFORMED THE DIRECTION OF THE RESEARCH PROGRAM - OVERVIEW.....	 43
 CHAPTER 4. MANUSCRIPT 2: BUILDING BALANCE (BUILDING ALLIANCES FOR AUTISM NEEDS IN CLINICAL ENCOUNTERS): USING THE BEHAVIOUR CHANGE WHEEL TO DEVELOP AN INTERVENTION TO IMPROVE THE DELIVERY OF HEALTHCARE TO CHILDREN WITH AUTISM .....	 45
Abstract.....	46
Introduction.....	48

Applying the Behaviour Change Wheel to Address Implementation Gaps in the Healthcare of Children with Autism.....	50
Method .....	53
Aim 1: Developing the BALANCE Intervention .....	53
Overview of Behaviour Change Wheel Approach .....	53
Developing Behavioural Diagnosis .....	54
Selecting Behaviour Change Techniques .....	55
Selecting Mode of Delivery .....	56
Translating Behaviour Change Techniques into Intervention Content.....	56
Implementation of Intervention .....	56
Aim 2: Exploring Changes in Proposed Behavioural Determinants .....	57
Results.....	59
Aim 1: Developing the BALANCE intervention.....	59
Behavioural Diagnosis .....	59
Psychological Capability .....	59
Physical Opportunity .....	60
Social Opportunity .....	60
Reflective Motivation .....	60
Automatic Motivation.....	61
Selecting Behaviour Change Techniques .....	61
Selecting Mode of Delivery .....	61
Translating Behaviour Change Techniques into Intervention Content.....	62
Aim 2: Exploring Changes in Proposed Behavioural Determinants .....	63
Discussion.....	63

Strengths and Limitations .....	64
Reflections on Using the Behaviour Change Wheel to Develop Balance .....	68
Future Directions .....	69
Conclusions.....	70
CHAPTER 5. MANUSCRIPT 3: BUILDING ALLIANCES FOR AUTISM NEEDS IN CLINICAL ENCOUNTERS: FEASIBILITY, USABILITY, AND PRELIMINARY MIXED-METHODS PILOT EVALUATION OF A NOVEL INTERVENTION TO IMPROVE PERIOPERATIVE CARE FOR CHILDREN WITH AUTISM .....	102
Abstract.....	103
Introduction.....	105
Method .....	108
Participants.....	108
Procedure .....	109
Description of BALANCE.....	110
Measures .....	112
Demographics .....	112
Primary Aim 1: Feasibility.....	112
Primary Aim 2: Usability and Acceptability .....	112
Quantitative Ratings of Usability and Acceptability .....	112
Qualitative Feedback Pertaining to Usability and Acceptability.....	113
Secondary Aim: Exploratory Examination of Impact of BALANCE .....	113
Quantitative HCP Report: Partnering, Assessing Needs, Coordinating Care, and Expressing Empathic Care .....	113
Quantitative Caregiver Report: Family Perceptions of Care Delivery.....	115

Qualitative HCP Report .....	116
Data Analytic Plan .....	116
Primary Aim 1: Feasibility.....	117
Primary Aim 2: Acceptability and Usability .....	117
Secondary Aim: Exploratory Examination of Impact of BALANCE .....	117
Results.....	119
Demographics .....	119
Primary Aim 1: Feasibility.....	120
Primary Aim 2: Acceptability and Usability .....	120
Quantitative Ratings.....	120
Qualitative Feedback .....	121
Secondary Aim: Exploratory Examination of BALANCE Impact.....	122
Quantitative HCP’ Reports: PACE Care Questionnaire.....	122
Quantitative Caregivers’ Reports: FPCD Questionnaire .....	123
Qualitative HCP’ Reports of Impact.....	124
Learning .....	124
Intentions.....	125
Practice Change .....	125
Discussion.....	126
Conclusion .....	133
 CHAPTER 6. PRELIMINARY EXPLORATION OF WHETHER CHANGE IN DETERMINANTS IS ASSOCIATED WITH CHANGE IN FAMILY-CENTRED CARE .....	 152
Method.....	152

Participants.....	152
Procedure .....	152
Measures .....	152
Analysis.....	153
Results.....	153
Discussion.....	153
CHAPTER 7. GENERAL DISCUSSION .....	156
Reflections on Adopting a Participatory Action Approach .....	161
Limitations of Research Program .....	163
The Largely Exploratory Nature of this Research .....	163
Reliance on Subjective Reports and Author-made Measures.....	164
Need for Further Youth Engagement.....	165
Lack of Comparators and Controls.....	166
Additional Future Directions .....	166
Conclusion .....	168
REFERENCES .....	169
APPENDIX A.....	186
APPENDIX B.....	188
APPENDIX C.....	190
APPENDIX D.....	194
APPENDIX E .....	197
APPENDIX F.....	198
APPENDIX G.....	201

## LIST OF TABLES

Table 4.1 References and Brief Descriptions of Published Literature Included in Data Sources .....	72
Table 4.2 Brief Overview of Stakeholder Engagement Meetings Included as Data Sources .....	79
Table 4.3 Proposed Relationship Between Determinants and Selected Behaviour Change Techniques .....	80
Table 4.4 Examples of Links Between Behavioural Determinants, Behaviour Change Techniques, and Intervention Content .....	81
Table 4.5 Results from Linear Mixed Effects Models and Post-Hoc Comparisons Exploring Change from Baseline, to Post-BALANCE Implementation, and Follow-up in Capability, Opportunity, and Motivation Subscale Scores .....	82
Supplemental Table 4.1 Full Mapping of Targeted Aspects of Capability, Opportunity, and Motivation to Theoretical Domains, and Behaviour Change Techniques, via Proposed Intervention Functions .....	84
Supplemental Table 4.2 Detailed Overview of Intervention Content Labelled by Behaviour Change Techniques .....	93
Table 5.1 Healthcare Provider Demographics .....	134
Table 5.2 Caregiver and Child Sample Characteristics .....	135
Table 5.3 Overview of Intervention Components .....	136
Table 5.4 Summary of Healthcare Provider Responses to Open-ended Questions Soliciting Recommendations for Changes to Improve BALANCE .....	137
Table 5.5 Results from Linear Mixed Effects Models and Post Hoc Comparisons Exploring Change from Baseline to Post-BALANCE implementation, and Follow-up on Partnering, Assessing Needs, Coordinate Care, and Expressing Empathic Care Subscale Scores .....	139
Table 5.6 Results from Independent Samples T-tests Comparing Pre- and Post-BALANCE Caregiver Cohorts on Family Perception of Sale Delivery Subscale Scores and Associated Cohen’s <i>d</i> Values .....	140
Supplemental Table 5.1 BALANCE Learning Objectives Along with the Percentage of Responding Healthcare Providers who Agreed each Objective was Met .....	145



Supplemental Table 5.2 Healthcare Provider Acceptability and Usability Ratings for each Module.....	147
Supplemental Table 5.3 Additional Sample Responses to “What did You Learn or Confirm” .....	148
Supplemental Table 5.4 Additional Sample Responses to “What Changes are You Planning to Implement in Your Practice” .....	149
Supplemental Table 5.5 Additional Sample Responses to “How Have you Been Able to Put What You Learned into Practice” .....	150
Supplemental Table 5.6 Additional Sample Responses to Please Provide a Brief Example of a Situation to Which You Put What You Learned in the BALANCE Program into Practise .....	151
Table 6.1 Correlations Between Change in HCP Reports of Determinants (Baseline to Post-BALANCE Implementation) and change in HCP reports of Family-Centred Care (Baseline to Follow-up) .....	155

LIST OF FIGURES

Figure 2.1 Illustration of the Balancing Act Metaphor.....42

Figure 4.1 Estimated Marginal Mean Determinants Score at Baseline,  
Post-BALANCE Implementation, and Three-month Follow-up.....83

Figure 5.1 Flow of Participants Through the Study and BALANCE E-modules.....141

Figure 5.2 Schematic of Study Design .....142

Figure 5.3 Estimated Marginal Mean Total PACE Score at Baseline, Post-BALANCE  
Implementation, and Three-month Follow-up .....143

Figure 5.4 Mean FPCD Total Score for Pre- and Post- BALANCE Caregiver  
Cohorts.....144

## ABSTRACT

Children with autism spectrum disorder (hereafter, autism) interact with healthcare services more often than their peers, yet have poorer healthcare experiences and more unmet healthcare needs. Systematic research-based efforts are needed to improve the healthcare experiences of children with autism. This mixed-methods program of participatory action research was aimed at improving the surgical experiences of children with autism, their families, and healthcare providers (HCPs). Manuscript 1 details a qualitative study of the surgery-related experiences of children with autism. Interpretive description was used to explore the perspectives of parents and HCPs with direct experience caring for children with autism around the time of surgery. Findings provided a nuanced understanding of the experiential context within which efforts aimed at improving the surgery-related experiences of children with autism must be implemented, and shed light on potential intervention targets. Qualitative study findings enriched by stakeholder consultations led to the framing of the target for improvement as the delivery of high-quality family-centred care. Manuscript 2 describes how the Behaviour Change Wheel, a systematic and theory-driven process, was used with stakeholder engagement to develop an intervention aimed at improving the delivery of family-centred care to children with autism around the time of surgery (i.e., Building Alliances for Autism Needs in Clinical Encounters; BALANCE). Results described in Manuscript 2 also show that implementation of BALANCE in the perioperative service of a tertiary children's hospital was associated with positive changes in behavioural determinants (i.e., capability, opportunity, and motivation) hypothesized to underlie variations in family-centred care. Manuscript 3 describes evidence supporting the feasibility and acceptability of BALANCE implementation, and shows that BALANCE was associated with positive changes in families' and HCPs' reports of the delivery of family-centred care. Overall, this dissertation addresses research gaps concerning the surgical care of children with autism and interventions to improve the delivery of healthcare to these children. This dissertation also contributes to the literature on collaborative approaches to healthcare research, and methods for the development and design of interventions that aim to improve healthcare delivery.

## LIST OF ABBREVIATIONS USED

ASD	Autism Spectrum Disorder
BCT	Behaviour Change Technique
CI	Confidence Intervals
COM-B	Capability, Opportunity, and Motivation Model of Behaviour
<i>d</i>	Cohen's <i>d</i>
<i>df</i>	Degrees of Freedom
<i>ES</i>	Effect Size
<i>F</i>	Fisher's F Ratio
FCC	Family-Centred Care
FPCD	Family Perceptions of Care Delivery
HCP	Healthcare Provider
<i>IQR</i>	Inter-Quartile Range
<i>LME</i>	Linear Mixed Effects
<i>M</i>	Mean
<i>Mdn</i>	Median
<i>N</i>	Total Sample Size
<i>n</i>	Subsample Size
P	Parent
<i>p</i>	Probability
PACE	Partnering, Assessing Needs, Coordinating Care, And Expressing Empathic Care
PhD	Doctor of Philosophy
REDCAP	Research Electronic Data Capture
REML	Restricted Maximum Likelihood
<i>SD</i>	Standard Deviation
<i>SE</i>	Standard Error
SPSS	Statistical Package for Social Sciences

## Chapter 1. Introduction

Youth with autism spectrum disorder (hereafter, autism) have a high need for healthcare services (e.g., Tregnago & Cheak-Zamora, 2012), but they experience challenges in accessing healthcare (e.g., Bethell, Lindly, Kogan, & Zuckerman, 2014; Wilson & Peterson, 2018). There is a recognized need to improve healthcare experiences for children with autism, their families, and their healthcare providers (HCPs) (e.g., Johnson & Rodriguez, 2013; Karpur, Lello, Frazier, Dixon, & Shih, 2018; Muskat et al., 2015). Interventions aimed at increasing the capacity for healthcare systems to deliver high-quality healthcare to children with autism hold potential for meeting this need (Bethell et al., 2014; Bishop-Fitzpatrick & Kind, 2017; Johnson & Rodriguez, 2013; Wilson & Peterson, 2018). Such interventions should ideally be developed in collaboration with key stakeholders (e.g., healthcare providers, families of children with autism, children with autism; Colquhoun, Squires, Kolehmainen, Fraser, & Grimshaw, 2017; Curran, Bishop, Chorney, MacEachern, & Mackay, 2018; Greenhalgh, Robert, Macfarlane, & Kyriakidou, 2004; Minkler & Salvatore, 2012), and be guided by 1) a thorough understanding of existing gaps in the quality of care experiences, 2) systematic and comprehensive consideration of what needs to change to improve the quality of care delivery in a given context, and 3) theories and models of behaviour change (Colquhoun et al., 2017; Davies, Walker, & Grimshaw, 2010; French et al., 2012; Greenhalgh et al., 2004). My dissertation involved a mixed methods program of stakeholder-engaged research, wherein these key questions were considered and addressed in a series of projects that culminated in the development of an intervention that aimed to improve the delivery of healthcare to children with autism around the time of surgery. In the process,

my dissertation simultaneously addresses gaps in and contributes to the literature on the surgical care of children with autism and interventions to improve the delivery of healthcare to children with autism, as well as the broader literatures on collaborative approaches to healthcare research, and methods for the development and design of interventions that aim to improve healthcare delivery. In this introductory chapter, I provide background on the healthcare needs of children with autism, review the limited literature related to the delivery of healthcare to children with autism around the time of surgery, describe the rationale for adopting a stakeholder-engaged approach to this program of research, and conclude with a summary of aims and a brief overview of the structure and content of my dissertation.

### **High Needs for Healthcare Services**

Autism is a heterogeneous neurodevelopmental disorder that affects approximately 1 to 1.5% of the population (Baio et al., 2018; Elsabbagh et al., 2012; Public Health Agency of Canada, 2018). It is characterized by persistent core differences in social-communication skills, as well as the presence of repetitive and restricted behaviour or interests (American Psychiatric Association, 2013). These defining features of autism overlap and interact with a range of comorbidities that further complicate the individual clinical profile. Commonly identified concurrent challenges include higher rates of trait anxiety (MacNeil, Lopes, & Minnes, 2009; White, Oswald, Ollendick, & Scahill, 2009), and various health-related problems, including dental, gastrointestinal, feeding and voiding problems, sleep disturbances, epilepsy, and other developmental disorders (e.g., Fragile X, attention deficit hyperactivity disorder; Bauman, 2010; Celia, Freyestinson, & Frye, 2016; Kohane et al., 2012; Olivié, 2012; Scarpinato et al., 2010).

The complex and chronic health-related needs of children with autism may necessitate ongoing and frequent interactions with healthcare services. A recent systematic review concluded that, compared to various groups of their peers (e.g., healthy populations without autism, and children with special healthcare needs without autism) children with autism have increased rates of service utilization and associated costs (Tregnago & Cheak-Zamora, 2012). Available data examining trends across time convey that children with autism represent a growing proportion of healthcare service users with rising expenditures. For example, an analysis of hospitalization rates at a pediatric healthcare centre over a ten-year period detected an almost three-fold increase in rates of children with autism hospitalized in 2009 (n = 2400), compared with 1999 (n = 770) (Nayfack et al., 2014). In contrast, Nayfack and colleagues (2014) detected no significant change in rates of hospitalization of various groups of children without autism (e.g., general population, children with intellectual disabilities, children with Down syndrome, children with cerebral palsy) over the same ten-year period. Wang and Leslie (2010) provide another useful example. They conducted an analysis of healthcare expenditures of 2.5 million Medicaid-enrolled youth (i.e., patients  $\leq$  17 years old) with mental health diagnoses (i.e., autism, adjustment disorder, anxiety disorder, bipolar disorder, depression, hyperactivity, intellectual disability, conduct disorder, post-traumatic stress disorder, learning disorder, psychosis, and substance use) from across 42 states in the United States. Findings indicated that individuals with autism had the highest median healthcare expenses of all diagnostic groups. Wang and Leslie (2010) also identified a 32.8% increase in autism-related healthcare expenditures per 10,000 lives covered in the

four-year period spanning 2000 to 2003, which was the highest rate increase observed in any diagnostic group.

### **Children with Autism Experience Challenges in Accessing Healthcare Services**

In spite of high rates of service use, children with autism have disproportionately high rates of unmet healthcare needs (Bethell et al., 2014; Casagrande & Ingersoll, 2017; Chiri & Warfield, 2012; Karpur et al., 2018; Kogan et al., 2008; Tregnago & Cheak-Zamora, 2012; Zablotsky et al., 2015). For example, analysis based on a nationally representative survey of American children's health in 2016 estimated that children with autism were four times more likely than children without disabilities to have unmet needs, whereas children with non-autism related disabilities were only twice as likely as children without disabilities to have unmet needs (Karpur et al., 2018).

Apparent discrepancies in rates of service use and rates of unmet healthcare needs are likely in part attributable to disparities in the quality of healthcare experiences (Bishop-Fitzpatrick & Kind, 2017; Karpur et al., 2018; Solomon, Angell, Yin, & Lawlor, 2015; Wilson & Peterson, 2018). Comparative studies using various quantitative indicators of quality of healthcare (e.g., care coordination, shared decision making, access to family-centred care, discourse analysis of healthcare interactions) consistently identify critical deficits in the quality of care delivered to children with autism compared to their peers (Bethell et al., 2014; Karpur et al., 2018; Solomon, Heritage, Yin, Maynard, & Bauman, 2016; Tregnago & Cheak-Zamora, 2012; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014). Understandably, families of children with autism and HCPs alike have expressed dissatisfaction with the status quo (Brachlow, Ness, McPheeters, & Gurney, 2007; Bultas, 2012; Johnson & Rodriguez, 2013; Kogan et al., 2008; Lindberg, von Post,



& Eriksson, 2012; Minnes & Steiner, 2009; Muskat et al., 2015; Nicholas et al., 2016; Pratt, Baird, & Gringras, 2011; Strunk, Pickler, McCain, Ameringer, & Myers, 2014). Systematic research-based efforts are warranted to address apparent disparities in the quality of healthcare delivery, and ultimately improve healthcare experiences and outcomes for children with autism (Bethell et al., 2014; Bishop-Fitzpatrick & Kind, 2017; Karpur et al., 2018; Wilson & Peterson, 2018).

### **Improving Healthcare Experiences**

Best practices for improving the delivery of healthcare services suggest that improvement efforts should be 1) based on identified gaps in the quality of healthcare and on systematic and comprehensive consideration of what needs to change to bridge quality gaps, 2) guided by theories of behaviour change and conceptual models, and 3) sensitive to features of the context where change needs to take place (Colquhoun et al., 2017; Craig et al., 2008; Greenhalgh et al., 2004; Grol & Grimshaw, 2003; Michie & Johnston, 2012). Most published literature exploring gaps in the quality of healthcare experiences of children with autism has consisted of commentaries, editorials, and case studies (e.g., Johnson & Rodriguez, 2013). This literature documents HCPs' perspectives on the challenges associated with caring for children with autism in healthcare contexts, and draws on clinical experience and the broader autism literature to provide practical recommendations related to caring for children with autism. Discussions of challenges tend to focus on the vulnerability of children with autism to experiencing distress in healthcare contexts. Recommendations have emphasized child-directed strategies, on the presumption that the quality of healthcare experiences is determined by the presence or absence of children's distress. From this perspective, variations in the quality of

healthcare experiences are largely attributable to individual child factors (e.g., cognitive and behavioural differences, anxiety, procedural distress). However, emerging evidence from studies systematically exploring the healthcare experiences of individuals with autism (e.g., Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014; Muskat et al., 2015; Solomon et al., 2015), and the previously reviewed literature on disparities in healthcare delivery, paints a more complex picture of what high-quality healthcare experiences entail and what changes could address disparities in the quality of healthcare delivered to children with autism. In addition to child factors, family (e.g., care-related beliefs and emotions), HCP (e.g., knowledge, skills, self-efficacy), interpersonal (e.g., parent-HCP partnerships, HCP interactional style, HCP-HCP collaboration) and systemic (e.g., inflexible, unfamiliar, and unpredictable hospital environments) considerations have been implicated as influences on the quality of healthcare experiences of children with autism (Bultas, 2012; Casagrande & Ingersoll, 2017; Davignon et al., 2014; Muskat et al., 2015; Solomon et al., 2015; Wilson & Peterson, 2018; Zwaigenbaum et al., 2016). Although several single-site quality improvement and education initiatives have reported promising benefits (e.g., Broder-Fingert et al., 2016; Jensen et al., 2012; Lucarelli et al., 2018; McGonigle, Migyanka, et al., 2014; Thompson & Tielsch-Goddard, 2014), these have prioritized child-directed strategies in lieu of more complex interventions that comprehensively address the broad range of factors that recent research has implicated as influencing the quality of healthcare experiences of children with autism. In addition, theoretical and methodological considerations have limited the generalizability of findings from these initiatives. For example, the majority failed to consider theory in the development of interventions, or to clearly operationalize targets for change. Indeed, the

literature on improving the healthcare experiences of children with autism remains in its infancy. Better understanding of the complexity inherent in this clinical situation may be achieved by capitalizing on advances in implementation research.

### **Participatory Action Approach to Improving the Delivery of Surgical Care**

The program of research described in my dissertation focused on improving perioperative care (i.e., the care of youth immediately before and after surgery) because potential disparities in surgery-related experiences and the need to improve surgery-related experiences had been recognized in the published literature (Snow, Smith, Bird, Wright, & Chorney, 2016; Taghizadeh, Davidson, Williams, & Story, 2016), as well as anecdotally by clinicians in the day surgery unit at the pediatric tertiary care hospital where this research took place. Moreover, perioperative care is a good model for the types of healthcare interactions that may challenge children with autism (e.g., multiple fast-paced interactions, varied personnel, lack of predictability), and youth with autism also often require general anesthesia for otherwise routine interventions (e.g., dental procedures, MRI) resulting in exposure to surgical settings more often than their peers (e.g., Arnold et al., 2015; Loo, Graham, & Hughes, 2008). Not dissimilar to the broader healthcare literature, the perioperative literature that includes children with autism is critically limited (Snow et al., 2016; Taghizadeh et al., 2016). The extant literature in this area consists largely of case studies and commentaries (e.g., Bagshaw, 2011; Christiansen & Chambers, 2005; Mellado-Cairet, Harte, Séjourné, & Robel, 2018; Seid, Sherman, & Seid, 1997), a handful of retrospective medical chart audits (e.g., Arnold et al., 2015; Loo et al., 2008; van der Walt & Moran, 2001), three reports that describe the potential benefits of introducing standard procedures (e.g., preoperative assessment phone calls)

that facilitate the assessment of needs for each child with autism (Rainey & Van Der Walt, 1998; Swartz, Amos, Brindas, Girling, & Graham, 2017; Thompson & Tielsch-Goddard, 2014), and one study that gathered parents' perspectives on having a designated HCP liaison throughout their children's perioperative experiences (Lindberg et al., 2012). Recent reviews reinforce the need for systematic efforts to build a better understanding of the perioperative experiences of children with autism, their families, and HCPs as a first step to improvement efforts (Koski, Gabriels, & Beresford, 2016; Taghizadeh, Davidson, Williams, & Story, 2015; Vlassakova & Emmanouil, 2016).

My dissertation seeks to address such gaps in the perioperative literature, and the broader literature on healthcare delivery to children with autism through a mixed-methods program of participatory research wherein my colleagues and I 1) systematically gathered the perspectives of HCPs and families of children with autism to develop a more nuanced and inclusive understanding of the perioperative experiences of children with autism, 2) shared our developing understanding of the perioperative experiences of children with autism with families and HCPs to confirm our interpretation and inform efforts to improve their perioperative experiences, and 3) collaborated with HCPs, families, and children with autism to develop, implement and evaluate an intervention aimed at improving the capacity of a perioperative care unit to deliver high-quality care to children with autism. This participatory research framework was adopted for several reasons. First, a partnership emerged organically between my research team and frontline HCPs, who identified a local need to improve perioperative care and sought our assistance to address this need. In addition, the importance of engaging stakeholders with direct experience of the clinical problem being addressed is widely acknowledged in the

health research enterprise (Colquhoun et al., 2017; Curran et al., 2018; Greenhalgh et al., 2004; Minkler & Salvatore, 2012). Potential benefits of participatory approaches wherein researchers work together with stakeholders to understand and address identified needs include improving the relevance of research and interventions to the stakeholders who are most directly affected by an identified clinical problem, as well as improving the fit of research designs and interventions with the realities of the healthcare contexts targeted for change. In turn, this may increase the likelihood of successfully addressing clinical problems (Minkler & Salvatore, 2012). Moreover, engaging stakeholders has been identified as a key priority for autism research in particular (Pellicano & Stears, 2011; Pellicano et al., 2014a; Pellicano et al., 2014b; Fletcher-Watson et al., 2018), as historical exclusion of the perspectives of individuals with autism and their allies has contributed to distrust and negative perceptions of research amongst some members of the autism community. Although the broader healthcare literature has begun to incorporate perspectives of individuals with autism and their caregivers in efforts to improve care (e.g., Nicolaidis et al., 2016; Muskat et al., 2015; Carter et al., 2017), the perioperative literature shows little evidence of this trend.

### **Summary of Aims and Overview of Dissertation Content**

My dissertation describes a mixed-methods program of participatory action research aimed at improving the surgical experiences of children with autism, for the children themselves, their families, and their HCPs. My research colleagues and I worked in collaboration and consultation with stakeholders on a series of research projects that contributed to a better understanding of these surgical experiences, as well as the development, implementation, and preliminary evaluation of a theory-driven intervention

designed to improve the delivery of care to children with autism around the time of surgery.

The first manuscript (Chapter 2) describes a qualitative study that aimed to build an in-depth understanding of the surgery-related experiences of children with autism, from the perspectives of these children's parents and their HCPs, as a first step towards identifying ways to improve these surgery-related experiences. Semi-structured interviews were used to gather the perspectives of individuals directly involved in the surgical care of children with autism (i.e., parents/caregivers and HCPs). Parents and HCPs provided a nuanced understanding of individual, interpersonal, and systemic factors that positively and negatively influenced the surgical experiences of children with autism they supported around the time of surgery. In Chapter 3, I further describe how stakeholder engagement shaped the use of findings from the qualitative study to inform changes aimed at improving these surgical experiences, and provide details of the process by which the need for an intervention targeting care delivery to children with autism around the time of surgery was established. In the second manuscript (Chapter 4), I describe the theory-driven approach (i.e., the Behaviour Change Wheel; BCW) that guided the development of a complex intervention to improve healthcare delivery to children with autism around the time of surgery (i.e., Building Alliances for Autism Needs in Clinical Encounters; BALANCE). I also present an examination of whether intervention implementation was associated with changes in determinants of behaviour hypothesized to underlie variations in a complex set of operationalized target outcome behaviours that were conceptualized as the best-practice approach to care delivery for children with autism. The specific target outcome behaviour was family-centred care,

here operationalized as consisting of partnering with families, assessing and addressing individual needs, collaborating to coordinate care, and expressing empathy and warmth. In the third manuscript (Chapter 5), I describe an examination of the feasibility, usability, and acceptability of the BALANCE intervention, alongside preliminary qualitative and quantitative explorations of the impact of the BALANCE program. In Chapter 6, I present preliminary correlational analyses exploring associations between early change (baseline to post-BALANCE implementation) in determinants of behaviour hypothesized to underlie variation in the delivery of family-centred care and later change (baseline to three-month follow-up) in family-centred care. Finally, Chapter 7 constitutes a general discussion of findings, with commentary on how my dissertation research advances efforts to improve the healthcare experiences of children with autism. Furthermore, I reflect on the challenges and benefits of the participatory action approach used in my dissertation, identify limitations of my program of dissertation research, and consider directions for future research.

CHAPTER 2. MANUSCRIPT 1: A BALANCING ACT: AN INTERPRETIVE  
DESCRIPTION OF HEALTHCARE PROVIDERS' AND FAMILIES'  
PERSPECTIVES ON THE SURGICAL EXPERIENCES OF CHILDREN WITH  
AUTISM SPECTRUM DISORDER

Readers are advised that Stephanie Snow, with guidance from her co-supervisors, Drs. Jill Chorney and Isabel Smith, as well as her co-author and dissertation committee member, Dr. Margot Latimer, was responsible for all aspects of the planning and conduct of this study. Ms. Snow wrote the manuscript presented below, and revised it in accordance with suggestions from Drs. Chorney, Smith, and Latimer. With the support of Drs. Chorney, Smith, and Latimer, along with clinician collaborators involved in the broader program of participatory action research, Colleen D'Entremont (perioperative manager), Crista Martin (clinical leader for perioperative nursing), Dr. Stuart Wright (anesthesiologist), and Dr. Sally Bird (anesthesiologist), Ms. Snow also obtained competitive funding that supported the conduct of this study.



## Abstract

Children with autism spectrum (hereafter, autism) are vulnerable to negative perioperative experiences. This interpretive descriptive study sought to build insights that could inform changes to clinical care by gathering the perspectives of individuals with experience supporting children with autism through the perioperative period (i.e., 8 parents of children with autism and 15 healthcare providers, HCPs). Results yielded three main themes, and an overarching metaphor of these surgical experiences as a *balancing act*. The first theme, *Finding your footing through an uncertain journey* described individual factors (e.g., anticipatory anxiety) that set the foundation for surgery-related experiences; *Relationships can help to keep everyone steady* highlighted how interpersonal dynamics (e.g., collaboration and empathy) further influence the experience. Finally, *Systems shape the experience* captured the impact of systemic factors (e.g., hospital environment) on the *balancing act*. Overall, findings from this study provided a more in-depth, nuanced, and inclusive understanding of how individual, interpersonal, and systemic factors influence the perioperative experiences of children with autism, their families, and their HCPs. Findings and insights gained from this study can be used to inform the identification of targets for interventions aimed at improving these perioperative experiences.

## Introduction

Children with autism spectrum disorder (hereafter, autism) are susceptible to the full range of childhood medical conditions including those that necessitate surgical intervention (e.g., tonsillitis, ear infections, appendicitis). As a result of difficulty completing routine dental and medical care some children with autism also require general anesthesia for these procedures (e.g., blood work, MRI; van der Walt & Moran, 2001). Given these healthcare needs, the proportion of children with autism accessing surgical services may be greater than that expected based on autism prevalence rates (1 to 1.5% of children; Baio et al., 2018; Elsabbagh et al., 2012; Public Health Agency of Canada, 2018). For example, one study reported that children with autism made up 10% of consecutive perioperative cases of children who were administered general anesthesia for dental rehabilitation between 2006 and 2011 (Arnold et al., 2015). While the specific rates at which children with autism access surgical services will fluctuate based on institutional mandates and resources, healthcare providers (HCPs) involved in delivering pediatric surgical services will inevitably encounter children with autism.

Children with autism may be an especially vulnerable group for which to provide care around the time of surgery (for reviews see: Koski, Gabriels, & Beresford, 2016; Taghizadeh, Davidson, Williams, & Story, 2015). Given the core symptomatology of autism (e.g., social-communicative difficulties, sensory sensitivities, preferences for routine; American Psychiatric Association, 2013) and increased rates of trait anxiety (Sukhodolsky et al., 2008), the characteristics of the surgical process (e.g., fast-paced interactions, varied personnel, unpredictable setting, bright lights, novel sounds) may be especially challenging for this group of children. These children's distress and

corresponding behaviour (e.g., non-compliance, self-injury) can be difficult to prevent and manage, and may lead to the use of medical and/or physical restraint or costly last-minute decisions to forego surgery (Lewis, Burke, Voepel-Lewis, & Tait, 2007; Nelson & Amplo, 2009). Witnessing and managing these children's behavioural expressions of distress may also be upsetting for families and HCPs, and can pose safety risks for all those involved.

Published literature includes clinical commentaries (e.g., Nelson & Amplo, 2009) and a set of consensus-based guidelines (Gimbley Berglund, Huss, Enskär, Faresjö, Björkman, 2016; Gimbley Berglund, Björkman, Enskär, Faresjö, & Huus, 2017) with recommendations for caring for children with autism around the time of surgery (see Taghizadeh et al., 2015, for review). Common recommendations include consulting closely with parents to individualize care, environmental adaptations (e.g., limiting exposure to stimulation that might bother children with autism, such as lights, noises, and smells), using simple concrete language, minimizing the number of interactions in which children with autism are expected to engage, having a familiar person (e.g., parent or a healthcare provider who has been introduced prior to the day of surgery) designated to accompany the child throughout the surgery, and preparing the child for surgery (e.g., through familiarization by rehearsal with pictures of or experiences with the locations and / or steps involved, and using sedative medications where appropriate). While this literature offers an important starting point, recommendations rely almost exclusively on HCPs' perspectives and miss important contributions from the families receiving care. Moreover, the literature currently lacks a comprehensive understanding of the experiential context within which proposed recommendations are to be implemented.

Although commentaries hint that the perioperative experience is difficult for everyone involved, recommendations have focused largely on procedural strategies to mitigate children's distress without consideration of the importance of addressing the subjective experiences of HCPs and parents. Further, understanding the experiences of those involved in providing care may highlight novel areas in which to intervene or ways to ensure that recommendations and guidelines are translated into effective care.

The purpose of this study was to address these gaps in the literature by systematically exploring the perspectives of parents and HCPs with direct relevant experience to provide a fuller description of surgery-related experiences of children with autism. The research question was: What do HCPs and families experience when supporting children with autism through the surgical course, and what are their perspectives on factors that shape these experiences? Better understanding these experiences could provide information that can shift current care, advance the literature by identifying intervention targets important to HCPs and families, and shed light on potential barriers and facilitators to implementing existing clinical practice guidelines or other interventions.

### **Method**

This study reflects the first element of an ongoing program of participatory action research (Minkler & Salvatore, 2012), wherein psychology researchers with relevant experience (in autism and perioperative care) and stakeholders (including families) worked collaboratively to improve surgical experiences for children with autism, their families, and HCPs. As noted, this initial qualitative study explored the perspectives of

families and HCPs with direct experience supporting children with autism around the time of surgery.

This study employed Interpretive Description (Thorne, 2008), an approach to qualitative inquiry with the explicit goal of developing knowledge that informs and advances clinical care. This approach situates “knowledge” between objective fact and social construction. To achieve this knowledge, analyses go beyond simple description of data, to a level of interpretation that requires inductive reasoning, pattern recognition, and linking of concepts on the part of the researcher. As recommended by Thorne (2008), an interpretive description should pull together knowledge into a mental heuristic that allows a clinician to better understand, remember, and ideally act with this knowledge in mind. For example, Thorne (2008) points to Bakitas (2007), who used ‘background noise’ as a metaphor to convey the experiences of individuals with chemotherapy-induced peripheral neuropathy to exemplify an effective mental heuristic. Interpretive description is pragmatic, in that it has an applied goal of advancing clinical care, and draws on techniques from various qualitative methodologies (e.g., ethnography, grounded theory) as relevant to achieve this goal (Giacomini, 2010).

### **Participants**

Participants included English-speaking parents who had accompanied their 3- to 18-year-old children with autism on the day of ambulatory surgery at a Canadian pediatric tertiary care hospital (serving a population of 1,859,804) over a two-year period between 2012 and 2014. Parents were ineligible if their children had a co-morbid genetic syndrome (e.g., CHARGE syndrome, Fragile X). HCPs were eligible if they were a dentist, physician, or nurse working within the surgical service and in their current role

for at least one year, and who had cared for at least two children with autism. Twenty-three participants were interviewed: 8 mothers [age range 28 to 67 years ( $M = 42$ ,  $SD = 13$ )] of children with autism (3 females, 5 males, age range 4 to 16 years) and 15 HCPs [7 nurses, 5 pediatric physician specialists, and 3 pediatric dentists; 10 females, 5 males, age range 33 to 60 years ( $M = 45$  years,  $SD = 9$  years)]. Healthcare providers had worked in their professions for a median of 19 years (range = 2 to 37 years), and estimated having cared for 15 to 500 ( $Mdn = 75$ ) children with autism. Children's most recent surgical procedures were dental ( $n = 5$ ), orthopedic ( $n = 1$ ), urological ( $n = 1$ ), or otorhinolaryngological ( $n = 1$ ), and several had multiple procedures completed while under anesthesia (e.g., blood work, dental care). Four children had undergone anesthesia at least once before their most recent experience. Co-morbid medical conditions were reported for two children (acid reflux, sleep apnea). Rating how well their children handled previous medical visits, 4 parents endorsed *average*, 3 *poorly*, and 1 *very poorly*. This sample size ensured the desired breadth of perspectives within the sample (i.e., HCPs who interact with children at different perioperative stages, parents of children of different ages, parents of children with varying surgical experiences), and was deemed sufficient for conducting the qualitative analysis (Thorne, 2008).

## **Procedure**

Following research ethics board approval, recruitment was by study posters, word of mouth, presentation at staff meetings, and postal invitations to eligible families. Eligible families were identified by a member of the direct care team with approved access to lists of children with autism who recently had surgery. Approximately 40 invitation letters were sent in the summer of 2014 to the families of children with autism

who had most recently undergone day surgery. Sampling methods precluded an accurate count of how many potential HCP participants were approached. All 23 individuals who began the informed consent process opted to participate. Interviews were conducted in person by a PhD student in Clinical Psychology (author SS) over a 5-month period in 2014. Twenty-two interviews took place in private rooms in a pediatric hospital; one parent opted to be interviewed at home. Following written consent, participants completed brief demographic questionnaires. All interviews were audio-recorded and structured around interview guides. Field notes were used to capture non-verbal, tonal, and/or emotionally laden aspects of the interview. At the end of each interview, the interviewer shared a summary of key points and provided participants with an opportunity to elaborate and/or clarify. Interviews were transcribed verbatim by a professional transcriptionist and imported into NVivo 10 software (QSR International, 2012) for data management and organization.

### **Interview Guides**

Semi-structured interview guides tailored for parents and HCPs were developed based on literature review, clinical researchers' observations of children with autism undergoing ambulatory surgery, and consultations with experienced clinicians and qualitative researchers (see Appendices A and B). Questions aimed to elicit perspectives on a broad range of topics related to these surgical experiences, including (1) the presentation and nature of children's surgery-related distress, (2) what approaches were used to support children with autism around the time of surgery, and how they were perceived, (3) how these experiences could be improved, and (4) barriers and facilitators to potential improvements. Questions were open-ended, ranging from broad (e.g., "Can

you share with me your experience of having your child go through day surgery?") to specific (e.g. "What strategies for caring for children with autism and their families have you found helpful?"). Prompts (e.g., "Can you help me understand what you mean by...?") were used to encourage participants to elaborate and/or clarify responses. Interviews ranged from 17 to 76 minutes ( $M = 38$  minutes,  $SD = 16$  minutes).

### **Data Analysis**

Data collection and analysis were concurrent and iterative; early insights informed ideas to explore in later interviews (e.g., responses to interview questions about the impact of HCPs' and parents' anticipatory anxiety informed the interviewer's decision to encourage participants to elaborate further on their own thoughts and feelings related to these experiences). In line with the interpretive description approach (Thorne, 2000; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004), multiple processes and analytic techniques were drawn on to promote immersion in the data and facilitate inductive reasoning. Immersion was achieved by re-listening to audio-recorded interviews and re-reading each transcript multiple times throughout data collection and analysis. Broad non-categorical labels (e.g., stressed emotions, communication challenges, unpredictable responses, positive outcomes) were applied to potentially relevant pieces of data (i.e., that represented participants' experiences). Labels were not mutually exclusive or exhaustive; they were intended to gather pieces of data that appeared to share similarities so that data within these groupings could be compared and contrasted, exceptional or outlying cases could be identified and carefully considered, and patterns within and between data groupings could be explored. Through discussions within and beyond the research team (e.g., with clinicians and other researchers), and disciplined critical reflection (facilitated



by asking questions designed to challenge emerging patterns and themes; e.g., “What else might there be to see and how would I know that?”), the insights gained through the data analysis process were iteratively refined into the thematic summary presented here. In line with interpretive description, consideration was then given to relations among themes and how to convey these in a coherent interpretation.

Multiple verification and rigorous techniques were integrated throughout the study to enhance trustworthiness. Techniques included: source triangulation (i.e., sampling from parents and HCPs from various disciplines in order to provide multiple perspectives on the experience), analyst triangulation (i.e., the research team was composed of two PhD-level clinical psychologists with respective expertise in autism and perioperative care, a PhD-level nurse with expertise in qualitative research and procedural care, and a clinical psychology PhD student), peer debriefings (i.e., sharing, discussing, refining preliminary insights with colleagues), second readers (i.e., two readers not associated with the study audited the logic trail from the raw data to the preliminary results by randomly selecting six interviews and reviewing them alongside a preliminary summary of the results), prolonged engagement with context (i.e., the primary researcher, SS, maintained relationships with stakeholders and discussed reasoning and implications of interpretation throughout the project), and thick description (i.e., the results are grounded in verbatim accounts from the interview data). A meaningful part of prolonged engagement included sharing the metaphor and preliminary results with both participants and non-participating parents and HCPs. All 23 participants were emailed a written summary of the metaphor and results, and convenience samples of non-participants were presented with the same information in

stakeholder meetings. The 14 participants (61% of interviewees; 4 parents and 10 HCPs) and 23 non-participants (including child life specialists, pediatric specialist physicians, pediatric dentists, and parents) who chose to provide feedback indicated that the preliminary results conveyed by the metaphor reflected important aspects of their experiences.

## **Results**

### **Interpretation: The Experience is a Balancing Act**

The metaphor of a *balancing act* was the overarching heuristic designed to capture participants' experiences supporting children with autism through the perioperative course (see Figure 2.1 for visual depiction). Parents and HCPs shared that their goal was to support children to move from admission to discharge as *smoothly* as possible. That said, the process is a precarious one that can leave everyone involved feeling on "edge" (P 1 & HCP 7), with the possibility of the child experiencing distress looming large. Participants sensed that a single misstep could result in distress for the child with autism, and conveyed that supporting children with autism from admission to discharge was therefore a delicate *balancing act*. In presenting this metaphor at the beginning of our results section we aim to provide an overall context for the reader. Next we describe three themes and nine subthemes that describe individual, interpersonal, and systemic factors that participants identified as influencing this *balancing act*. The intention is not to suggest a one-to-one relationship between the metaphor and themes, but rather to build a mental heuristic that offers an organizing conceptual framework for the qualitative knowledge developed in this study (Thorne, 2008).

## **Theme 1: Finding Your Footing Through an Uncertain Journey - Individual Factors**

Participants conveyed that children, families, and HCPs have varying levels of comfort stepping into this balancing act and discussed child, family, and HCP factors that affected the ability to find their footing.

**Subtheme: Individualized Care Helps Children Find their Balance.** Most participants identified strategies to help children with autism find their footing on the day of surgery (e.g., preparation, active distraction, parental presence, sedation, and reducing sensory stimuli, non-essential interactions, and wait times). Participants acknowledged that not every strategy would help all children with autism. For example, in discussing approaches to care for children with autism, HCP 10 said, “It really depends on the kid. I find you have to tailor the stuff that you do for each child because not everything’s going to work”. Overall, participants acknowledged the importance of recognizing each child as unique and avoiding assumptions, as “there are variations in autism and looks are really deceiving” (P 2). A few participants suggested that the primary challenge is not knowledge of strategies but rather, responding to individual needs within a complex and fast-paced environment; as HCP 10 put it, “that’s where the work comes in, you have to find out what works for [each child]”.

Participants also conveyed that it is helpful to consider triggers that might cause *any* child to lose their footing and become distressed (e.g., introduction of medication or anesthetic mask, separation from parents), in addition to potential specific triggers for some children with autism, such as sensory (i.e., sights, sounds, smells, taste, and touch) or social stimuli (e.g., interactions with multiple unfamiliar people). For example, HCP 13 said, “when I know somebody has autism, I may ask the family directly, are there

certain things we need to know about your child? Are they okay if I approach them? Do loud noises bother them? Can I help by turning down the lights, or things like that?” In addition to finding out if “particular things ... are upsetting” (HCP 13), participants talked about how it is important to think about what kinds of things might be “particularly calming or useful” (HCP 13) to promote child coping. For example, HCP 15 commented that they try to find out, “what interests [a child has], what [they can] talk to [the child] about that will put them at ease”.

Participants explained that considering children’s communication styles and preferences can inform how to tailor care. At times, communication differences were easy to identify – some children had few words or used pictures to communicate – whereas other differences were subtle and easily overlooked. One mother (P 6) described her child’s needs: “although he speaks ... it’s not always for communication”. Elaborating, she stated she would want HCPs to know that “[if her son says] ‘yeah, okay’, it doesn’t always mean that. Sometimes he’s just saying that because he doesn’t want to answer your question.” Many HCPs readily recognized these communication differences, with some emphasizing the importance of HCPs figuring out how to communicate with children in spite of these differences; HCP 14 commented, “you have to learn how to communicate with these kids, because you have a job to do”. To identify “what works for each child” (HCP 4), it is also critical to understand and monitor children’s responses. Participants reported that children responded to the surgical experience differently; some find their footing and are calm, others are unsteady and feel anxious, and some lose their balance and experience distress and panic. Participants noted that distress could be an amplification of behaviour perceived to be characteristic of

autism (e.g., repetitive behaviour), but could also look the same as in children without autism (e.g., crying, screaming). Children's outward expressions of 'calm' and 'anxious' were more nuanced and idiosyncratic. For example, when describing her child's anxiety, one mother (P 3) said, "it's hard to explain ... it's more a change in his expression, a change in his movement. It's just something that you've learned over time to notice".

**Subtheme: Parents Anticipate Losing Balance and Feel on Edge.** Although families commonly experience some concern when children have medical procedures, families of children with autism may feel especially on edge. Speaking to this, HCP 7 said, "my sense is that people just sort of cope. They just keep their heads above water, and then something like [day surgery] tips them a bit over the edge". Parents' reports corroborated this observation. Only two of eight parents reported that their children became acutely distressed, yet most parents had trouble finding their footing, even when things went well. They conveyed a sense of foreboding, or anticipatory anxiety, in some cases long before the child's surgery. One parent commented, "any time [the upcoming surgery] would come to my mind that year, I would panic about it" (P 1). Previous challenging healthcare experiences and difficulty tolerating the uncertainty of the experience resulted in heightened parental anxiety. A mother (P 3) explained:

The anxiety is ... because ... you never really know how they're going to respond to something that's not on a regular basis familiar to them. He could always throw me a curveball ... it's that stress and that anxiety of how he's going to react, and whether I am going to be able to get him through the procedure or not

Parents have a dual focus: they worry about their children and about how the healthcare team will respond.

Some HCPs were attuned to this heightened parental anxiety. Several HCPs commented that parents will “be really worried about their child misbehaving, and that we, the healthcare providers, have to deal with it” (HCP 2). When things went smoothly, several parents were “bewildered to think how things could have gone” (P 1) and discussed specific moments or alternative approaches “that could have made things go completely wrong” (P 2). Parents who seemed more comfortable believed in their own and the HCP team’s abilities to negotiate this uncertain journey. Instead of worrying about what might go wrong, they could move steadily through the surgical experience, confident that they and the team possessed skills and resources to rely on if child distress arose.

**Subtheme: HCPs’ Comfort in Maintaining Balance.** Healthcare providers themselves have varying levels of comfort in caring for children with autism. Some shared experiences supporting children with autism that were mostly “positive” (HCP 2), and “it’s usually quite smooth for most of these kids” (HCP 7). Others discussed how some HCPs are “really scared to look after [children with autism]” (HCP 11) and are “just more comfortable going in and seeing somebody else [without autism]” (HCP 14). Some fear appeared to come from previous experiences; most HCPs vividly recalled instances when a child with autism had become so distressed that they felt overwhelmed, afraid, and helpless. One HCP (12) recalled, “the child was just kicking and biting, and would throw things. And I felt very afraid, and I was thinking, I can’t leave this child with somebody else over there ... so I stayed. And I felt afraid for the mother too. She’s had things thrown at her ... she’s had cuts and everything from this child. I felt very afraid. And the child was ... smaller than myself and I was still afraid”. HCP 7 shared, “I

remember in one case [an HCP] was visibly sort of distressed and flustered and just said, I'm not doing it". In some cases, memories of previous challenging experiences left people thinking "here we go again" (HCP 7), struggling to find their footing when facing a similar situation.

There was an interesting dissociation between HCPs' knowledge about autism and their comfort and self-efficacy in providing care. With rare exceptions, HCPs' reports suggested that they possessed enough knowledge and skills to provide high-quality care for children with autism. Specifically, all HCPs were able to comment on how symptoms associated with autism may influence the surgical course, discuss ways that distress might manifest in children with autism, and describe strategies that they use to support children with autism and their families around the time of surgery that were consistent with the extant clinical literature. However, knowledge, skills, and experience did not always ensure that HCPs felt *comfortable* caring for children with autism. When asked what to tell a new colleague about autism, HCP 2 emphatically exclaimed, "Wow. Not an expert on that", before elegantly articulating an understanding of autism and relevant associated features, such as sensory sensitivities. Despite knowing enough to provide high-quality care to children with autism, most HCPs seemed reluctant to take ownership of their knowledge, emphasizing that they "don't know as much as they would like to know" (HCP 14), and need more training and education.

On the other hand, HCPs who understood that "success is measured differently for each kid and each family" (HCP 8), and viewed a child's distress as a learning opportunity seemed to have found their footing and be more confident in their abilities., This seemed true especially for HCPs who had interacted with children with autism in

various contexts (e.g., caring for them in multiple contexts, personally knowing children with autism), though professional experiences alone did not seem to be reliably associated with HCP comfort.

## **Theme 2: Relationships Can Help Keep Everyone Steady – Interpersonal Factors**

Participants conveyed that the experiences of children with autism, their parents, and HCPs are inextricably linked -- empathy, collaboration, and coordination may keep everyone steady throughout the child's surgical experience.

### **Subtheme: Unsteadiness Affects Everyone; Empathy can be a Safety Net.**

Children with autism, their families, and HCPs may reflect each other's emotions on the day of surgery. As expressed by HCP 7, if "it's all very smooth from the child's perspective, I think it follows along with that that it's going to be an easier thing for the [HCP] at basically every step of the way; if the child is good, I'm good". The same provider noted that when things do not go smoothly, "you are feeling everybody's stress. Everybody is upset. Nobody wanted this to go this way" (HCP 7). Participants clearly communicated that the same processes are at play for families and children; that is, effects of each other's experiences are reciprocal. They touched on the value of the healthcare team also attending to parents' experiences on the day of surgery: "I felt like they were really good to us as parents too, which makes the whole experience better. Because if we're happy, the kids are happy, and if the kids are happy, we're happy, right?" (P 5). Children and families also react to how HCPs feel on the day of surgery; P 2 described how she could see that the healthcare team was "on edge to see how it would go".



Participants provided examples of how awareness of others' emotional states can be instrumental in guiding care. One mother (P 2) commented, "a nurse actually came in and ... you could see [the child with autism] had his shoulders up and he started chewing his tongue, but was still fixated on his Minecraft ... So the nurse was really good, and then she realized [that he was anxious], and she kind of started backing away ... It worked really, really well". However, participants also commonly provided examples of how awareness of and subsequent reactivity to others' psychological experiences could hinder care. Difficult feelings, particularly children's distress, amplified the discomfort experienced by families and HCPs. Regarding an experience in which a child with autism became very upset, HCP 6 said, "you could see, it made everybody so much more nervous and frustrated because his behaviour was escalating". Participants expressed that seeing a child in distress can be quite "disheartening"; they conveyed a feeling of helplessness by commenting that for some children, "there's nothing you can do" (HCP 13).

Despite some participants understandably feeling stuck or paralyzed in the face of children's distress, participants conveyed that empathic HCPs could turn otherwise challenging moments into opportunities to strengthen relationships among HCPs, children with autism, and their families. As P 1 put it, "I can't tell you how immediately reassuring ... [it was to] know that [the HCP] knew that [my child] was really anxious; it just lifted all of the weight off my shoulders because I was so – (exasperated laugh) – but it makes a difference when the person that's looking after your [child with autism] knows that [the child with autism is] anxious".

**Subtheme: Collaboration Stabilizes, but Dependency can Upset the Balance.**

Parents and HCPs emphasized the importance of strong collaborative relationships. HCPs told us that it is especially important to adopt an approach that draws heavily on parents' expertise when caring for children with autism. Sharing insight gained from working with many children with autism, HCP 6 said, "if anything I've ever learned, these parents know their kids. They know exactly what their kids need and what their kids don't need". In addition to facilitating effective tailoring of care, participants expressed that collaboration comforts parents by providing an opportunity to share their expertise on their children. When family knowledge is harnessed to inform the child's care it may also increase families' trust in the healthcare team. One mother (P 2) commented, "[the healthcare team] respected the parents' point of view, and that was the first time I think I really kind of felt like we belonged, and they understood". Other examples illustrated how effective parent-provider collaborations help to buffer the negative impact of challenging experiences. Regarding her daughter's significant distress, P 7 said:

I felt so helpless for her ... and I think the nurses were [stressed] too, because I think the nurses didn't know what to do either ... but they were excellent ...

Because when we [gave a suggestion] they were like ... let's do it. And they were there to help us go through it.

The relationship between HCPs and parents is nuanced. An important distinction was made between collaborative relationships, which are essential and valued, and dependent relationships, which can leave families and HCPs "floundering" (HCP 9). Several HCPs talked about depending on families more than they would for a child without autism. For example, HCP 14 commented, "I rely more on the family than I

would – like if I went in and [saw] a child that wasn't autistic then I would be more the one in charge". Although many parents valued the opportunity to be actively involved in their children's care, participants commented that some families may be too stressed, need to focus all their energy on their child, or simply may not yet have had enough opportunities to learn how to care for their child in a healthcare context. One HCP (13) spoke to this: "you kind of expect you're relying on [the family to share] 'what can we do that helps, what works?'" And when they're like, I don't know, I find that hard".

Participants conveyed the importance of avoiding dependent parent-provider relationships, in favour of true collaborative relationships; an ideal articulated by HCP 9: "as much as we lean on [families], for them to lean on us, and that they feel comfortable that we're okay". Parents were more readily supported by HCPs who conveyed an understanding of autism. Even simple things such as asking parents how to best adjust the physical and social environment indicated an HCP's 'autism awareness'.

**Subtheme: Coordination is Challenging but Essential to Maintain Balance.**

Children with autism, their families, and their HCPs benefit from a coordinated and consistent approach to care. Reaching this ideal necessitates effective communication and strong working alliances among all HCPs involved on the day of surgery. Participants reflected that "consistency is always a good thing" (HCP 14); several expressed a desire to have everybody "on the same page" to better collaborate and coordinate care with families. Healthcare providers commented that inconsistent approaches to care could undermine efforts to keep parents steady: "we can't ever say don't worry, we can't reassure ... because we can't speak on behalf of [other team members]" (HCP 12).

Parents' reports echoed the benefits of well-coordinated approaches to care and the consequences of encountering unexpected approaches, and discussed the potential pitfalls of inconsistent and uncoordinated care. As P 2 stated:

The only thing I would reiterate is that all staff are on board. I know the [HCP] didn't believe in [using a parent-suggested strategy], but they also didn't see my son before. They didn't know his needs and his cares, and I know by their attitude they were annoyed I was in the room and there. But for us as a family, [using the strategy] is what made it a success.

Participants conveyed that a coordinated approach is not easily achieved, as several professional groups (e.g., nursing, child life, surgery, anesthesiology) are involved. As HCP 7 reflected, "it would be interesting to have a bit more consensus ... I think right now everybody has their own idea". Healthcare providers conveyed a tension between their respect for colleagues' professional autonomy and their own desire for more coordinated approaches. For example, HCP 6 commented that colleagues "don't tell me how to [perform my role], so I try to advocate for families, but not step outside of my bounds". HCP 13 wanted to "reassure" parents, "if you think that's the best thing for your child, then one hundred percent, that's what we'll do ... But we can't so we ... tippy toe".

### **Theme 3: Systems Shape the Experience – Systemic Factors**

Surgery-related interactions among children with autism, their families, and HCPs occur within an established hospital system. Participants conveyed that flexible policies and procedures, open and adaptable organizational cultures, and 'autism friendly' spaces and resources facilitate this uncertain journey.

**Subtheme: Policies and Procedures Help but Must be Flexible.** Healthcare providers commented that organizational policies and clear procedural expectations help, although they emphasized the importance of enough flexibility to meet each child's needs. Overall, participants questioned which policies and procedures were essential, advocated for a more "streamlined" (HCP 6), "speed processing" (HCP 7) approach to caring for children with autism, suggesting that "the least ... going on is probably the best thing you can do" (HCP 10). For example, HCP 6 wondered:

... could they not come in a half hour before, and to their own room, and to not be bugged? Like if a nurse could take a parent out, so they just sit in their room for a half an hour barely, don't have to change into their jammies; unless they have kidney issues, do they have to get their blood pressure? Can they just be left alone?

**Subtheme: An Open and Adaptable Culture is Important.** Statements by HCPs suggested that an organizational culture that values the importance of individualizing care, characterized by openness, adaptability, and trust, makes it easier to see straight ahead. Touching on this, HCP 9 emphasized the importance of the team "being able to adapt...going with an open approach, and just doing things that you have to do versus doing the things that have always been done". Further, HCP 7 commented, "there aren't too many variables that can be modified, but you try to tip whatever ones you can in your favor to try to tip the whole thing towards success". In contrast, "old school" (HCP 9) ideas about how to approach care, preconceived notions about how care will unfold, resistance to change, and distrust or shame can all create obstacles. As HCP 10 stated, "the inability to evolve would be, I think, the biggest barrier". Participating HCPs

explained how preconceived ideas and expectations can interfere with team members' ability to see each child with autism as unique. For example, HCP 8 shared a story about an older adolescent boy with autism who was scheduled to undergo dental surgery. Before any information about the boy had been shared, another team member called the hospital security service to be on standby. Reflecting on this experience, HCP 8 commented, "trying to change some perceptions would be another thing I would like to achieve. Because I think a lot of time people apply labels, and there's less time in thinking and trying to understand". A culture of trust, in which HCPs are not "worried or ashamed [to] ask for help" (HCP 10) would provide opportunities for staff to be vulnerable and ask questions or be open to trying new things. Providing opportunities for team members to learn together about autism and be "trained in the same way" (HCP 12) might also promote a culture of openness, adaptability, and trust.

**Subtheme: Value of Autism-friendly Spaces and Resources.** Participants commented on the benefits of access to a physical environment that promotes children's coping, including appropriate distractors and spaces that afford families and healthcare control over sensory stimulation (e.g., lights and sounds). For example, "darkened rooms" (HCP 1), games or "videos on iPads" (P 2), "DVD players" (HCP 14), "headphones" (HCP 6), and "sensory items" (P 7) can promote coping during the wait to go to the operating room or as a distraction at induction of anesthesia. Patient rooms with doors, preferred by HCPs, were not always available.

Many HCPs discussed the value of being cued to a child's autism diagnosis before meeting the child and highlighted the potential utility of information and communication systems that would allow this. HCP 6 suggested that a "checklist" that

was “short and sweet and to the point” would allow the healthcare team to gather “the critical information that may impact that day’s treatment” efficiently, regardless of whether the autism diagnosis was flagged. In addition to facilitating individualized care plans, a checklist could help team members “pass that information on to everybody that needs to know” (HCP 11).

Finally, participants commented on the benefits of preparation resources and supports that facilitate families’ ability to prepare their children for surgery. For example, P 6, who felt that she did not have enough information to prepare her child said, “one thing I thought would have been great to have would be almost like a flip book that kind of shows the process”. Other parents commented on the benefits of having “received prior to the surgery a social story with pictures” (P 7), or “a little video, maybe with a cartoon or something of a kid going into surgery” (P 4). Many participants also commented on the value of drawing on pediatric health psychologists or child life specialists to support families’ and children’s learning about what to expect and how to prepare. Reflecting on the value of these services, P 1 said, “I just don’t know what I would have done had we not had [that support]. I just don’t even know where I would have started or how I would have ever managed”. Families are not always aware of whether such supports are available. For example, P 2 commented, “I think the thing that is frustrating across the board is that the information is not there freely...there should be some forum for people to know that they can go to certain things” (i.e., preparation resources / services). In addition, participants recognized that families may not understand what pediatric health psychologists and child life specialists can offer, and may therefore forego these services. It is hard to understand the value of support services

“until you go there and you see” (P 1). Accordingly, participants felt that there should be an effort to build awareness and understanding about existing resources and supports; the healthcare system needs to go “further” and “be more direct” so that families “know what the service is going to give them” (P 1).

## **Discussion**

This study aimed to build an in-depth understanding of surgery-related experiences surrounding children with autism. Parents’ and HCPs’ perspectives provided a nuanced understanding of individual, interpersonal, and systemic factors that influence the surgical experience. We have likened the experience to a balancing act; caring for children with autism around the time of surgery can leave everyone feeling on edge. Consistent with existing recommendations and guidelines (Gimbley Berglund et al., 2016; Gimbley Berglund et al., 2017; Koski et al., 2016; Thompson & Tielsch-Goddard, 2014) participants emphasized the need for HCPs to collaborate with families to identify how to individualize care for a given child with autism. Participants also highlighted the importance of ensuring that everyone involved in this ‘balancing act’ feels comfortable and confident enough to find their footing, avoiding dependency on families, conveying empathy (especially in challenging cases), and ensuring consistent care across the perioperative course.

This study advances the literature on caring for children with autism around the time of surgery by contributing a thorough understanding of the experiential context in which healthcare must be delivered. As previously described, the limited existing literature has largely been oriented towards describing recommendations that might help to mitigate the perceived vulnerability of children with autism to distress around the time



of surgery (see Taghizadeh et al., 2015). Perspectives from parents and HCPs in this study pertaining to helpful child-directed strategies corroborated existing care recommendations (e.g., provide access to a physical environment that is ‘autism friendly’, minimize the time children spend waiting, use distractions), including emphasizing the importance of HCPs collaborating with parents to develop an individualized care plan that considers the unique needs of each child with autism. However, findings from this study also suggested that it may be helpful to shift our focus away from children’s distress as the *sole* problem to a broader perspective that more fully considers the experiences of parents and of those providing care.

The precariousness of caring for children with autism around the time of surgery may bring up difficult feelings (e.g., anticipatory anxiety and fear) for HCPs and families (e.g., Lewis et al., 2017; Lindberg, von Post, Eriksson, 2012; Vlassakova & Emmanouil, 2016). Indeed, HCPs and families in this study described experiencing difficult feelings (e.g., anxiety, fear, disappointment, upset) that extended beyond the actual healthcare interactions involved in supporting children with autism around the time of surgery. This finding is not unique to our study. Other studies have noted that some HCP and families appear vulnerable to feelings of anxiety and stress in anticipation of and during healthcare interactions involving children with autism (e.g., Aston, Breau, & Macleod, 2014; Lindberg et al., 2012, Solomon, Angell, Yin, & Lawlor, 2015). For example, in one of the few perioperative studies to have included families’ perspectives, Lindberg et al. (2012) highlighted that families may experience feelings of hopelessness and suffering in association with the healthcare delivered around the time of their children with autism undergoing procedures that required anesthesia. Aston et al.’s (2014) qualitative

exploration of the hospital-based experiences of children with cognitive differences (including children with autism) indicated that HCPs reported fear associated with caring for children with various cognitive differences that stem from uncertainty regarding how smoothly the healthcare interaction will go. Difficult feelings may influence HCPs' or families' behaviour, including how they communicate and how they approach supporting the child through the interaction (Aston et al., 2014; Solomon et al., 2015). Consistent with the present findings, the broader healthcare literature has identified that collaboration, empathy, and understanding help to prevent and more efficiently resolve challenging emotions that HCPs and families might experience in the course of supporting children with autism throughout healthcare interactions (Aston et al., 2014; Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014; Lindberg et al., 2012; Muskat et al., 2015; Solomon et al., 2015). Rather than evaluating the outcomes of a perioperative experience based only on whether the child is deemed sufficiently cooperative or becomes distressed, a broader conceptualization that encompasses recognition of how family, HCP, and interpersonal factors influence the quality of healthcare experiences provides opportunities to judge experiences as successful if HCPs and parents feel more comfortable, parents are supported, and professionals collaborate effectively.

Whereas some interventions focus on the unique characteristics of children with autism and highlight differences in care approaches, it may be helpful to consider how focusing on such differences may contribute to HCPs' discomfort. Many of participants' suggestions are arguably relevant for all children. For example, individualizing care, partnering with families, providing empathy and coordinating care could be considered

best practices for perioperative care regardless of whether a child has autism (e.g., Chorney & Kain, 2010; Shields, 2007; Kain et al., 2007), and insofar as pediatric healthcare delivery entails HCPs working within systems, interpersonal and systemic factors necessarily influence all experiences. Despite these parallels, HCPs conveyed less comfort caring for children with autism, which has important implications for intervention. A strengths-based approach (e.g., Gottlieb, 2014; Richer, Ritchie, & Marchionni, 2010; Trajkovski, Schmied, Vickers, & Jackson, 2014) that supports and empowers HCPs may be more effective by conveying how the knowledge they already have can be applied in providing care for children with autism. Use of a strengths-based approach does not preclude specifying prerequisite knowledge and skills for individualizing care effectively for this population. For example, it is important that HCPs know that it is relevant to ask how best to communicate with the child or what potential triggers of distress the family can identify. That said, knowledge alone may not suffice to shift care (McGonigle, Migyanka, et al., 2014; Michie, Atkins, & West, 2014). Healthcare providers in our study knew enough about autism to care for this group, yet still conveyed relative discomfort with providing that care. This finding is consistent with previous research that has highlighted discrepancies in knowledge about autism and comfort caring for children with autism across HCPs working in varied roles and contexts (e.g., general practitioners, emergency personnel; e.g., Unigwe, Buckley, Crane, Kenny, Remington, & Pellicano, 2017; Wachob & Pesci, 2017; Zerbo, Massolo, Qian, & Croen, 2015). Healthcare providers need the psychological capability, motivation, and resources to engage in appropriate care behaviour (Michie et al., 2014). They must manage their

own emotions, have access to resources (e.g., visual schedules), and value partnership with and empathy and compassion for families.

### **Limitations and Future Directions**

We described participant demographics, care contexts, and study procedures to facilitate readers' assessment of the transferability of findings to their own contexts. That said, given the qualitative nature of this study, we cannot conclude that the experiences of these HCPs and families represent the experiences of those who were not interviewed, nor others who care for children with autism elsewhere. In addition, while we feel that our decision to interview HCPs and families on the same issues using qualitative methods was a key strength of this study, we acknowledge that the perspectives of children with autism were not directly gathered. Consistent with priorities that have been identified in the broader field of autism research (e.g., Harrington, Foster, Rodger, & Ashburn, 2014; Fayette & Bond, 2018, Pellicano et al., 2014a), additional studies addressing this important limitation are warranted.

The metaphor we developed resonated with our participants and other stakeholders, lending credibility to the notion that drawing results together in a heuristic can assist understanding. In turn, this understanding may help HCPs to recall and act in accordance with the expanded awareness that this heuristic brings. These assertions are supported by a broader literature on the function and power of metaphors within and beyond the field of healthcare (e.g., Hodgkins, 1985; Reisfield & Wilson, 2004; Lakoff & Johnson, 2008; Ortony, 1975). Metaphors bring coherence to complex experiences, assist in building shared understanding, help to reframe existing ideas and encourage remembering (Lakoff & Johnson, 2008; Ortony, 1975). Further research is needed to

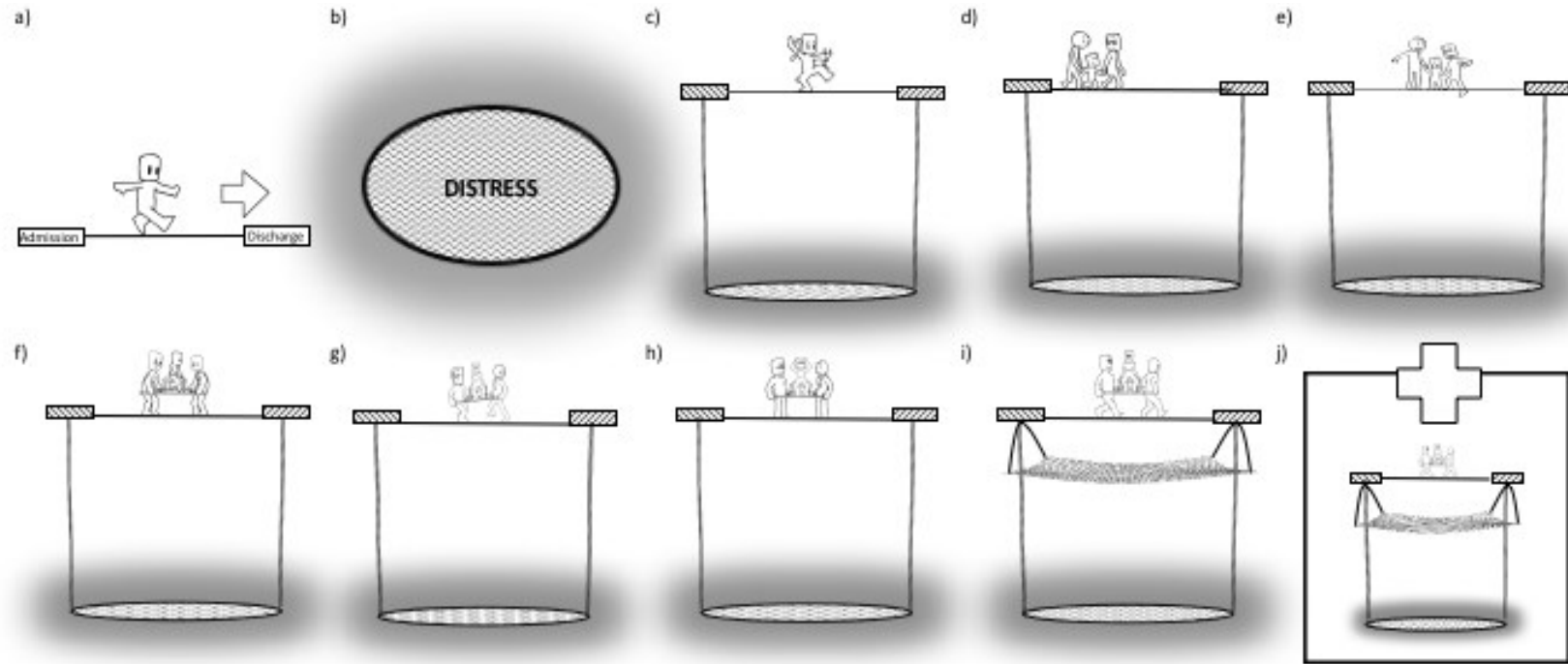
examine relationships amongst individual, interpersonal, and systemic factors proposed to influence this balancing act, and to begin exploring questions of generalizability.

Findings from this study could be used to inform the development and implementation of interventions to improve clinical practice (Alderfer & Sood, 2016).

Care processes influenced by complex factors offer many potential avenues for intervention – the experiential knowledge gained in this study could be used to guide the development of system-, HCP-, family-, or child-directed interventions.

### **Conclusion**

Despite calls for improvements in care, and clinical recommendations for the surgical care of children with ASD (see Koski et al., 2016, for review), little attention has been paid to understanding the experiences of children, families, and HCPs comprehensively. This study addresses this gap and sheds new light on the experiential context within which existing care recommendations or interventions aimed at improving care experiences must be implemented.



*Figure 2.1* Illustration of the Balancing Act Metaphor. Parents and healthcare providers (HCPs) conveyed: a) they shared the goal of children with autism moving smoothly from admission to discharge; b) but, the possibility of surgery-related distress loomed large; c) there was the sense that supporting children with autism through surgery is like a balancing act and that a single miss-step would send children with autism over the edge; d) everyone involved needs to find their footing, and whereas some are comfortable doing so; e) others are less steady and seem pre-occupied with worries about distress; f) well-coordinated HCPs work smoothly together and collaborate with parents to build a stabilizing sense of trust and steady foundation that is responsive to each child's unique needs; g) everyone's experience is connected, so relationships can be harnessed to keep each other steady; h) sometimes children do become distressed which can cause everyone to feel overwhelmed and stuck; i) if HCPs convey empathy they can weave a safety net of support to soften the impact of losing balance; and j) all of this happens within a system of hospital policies, culture, and resources that can help or hinder the balance.

### CHAPTER 3. HOW QUALITATIVE STUDY FINDINGS INFORMED THE DIRECTION OF THE RESEARCH PROGRAM - OVERVIEW

This brief chapter provides an overview of how the findings from the initial qualitative study, alongside stakeholder engagements, led to the decision to develop an intervention aimed at improving the capacity of HCPs to deliver high-quality care to children with autism.

Given the participatory nature of this research, an a priori decision was made to use the findings from the qualitative study to inform the direction of further efforts to improve the perioperative experiences of children with autism, their parents, and HCPs. We began the qualitative study with expectations that came from the experiences of our HCP stakeholders and the research literature. That is, we assumed that children's distress would be the most important target for intervention. Thus, we started with a goal of better understanding the presentation of child distress, and the factors that could influence distress. We thought this would likely set the stage for a cohort study that would contribute to measurement of children's distress and potentially the design of child-directed interventions to reduce such distress.

As described in Chapter 2, the qualitative study findings highlighted the complexity of the perioperative experience. First, the results demonstrated that positive perioperative experiences were determined by more than simply the absence of child distress; HCPs' worries and family experiences were also important. Second, the results demonstrated that individual, interpersonal, and systemic factors combined to influence perioperative experiences. Based on these results, we had to reconsider our presumed direction of focusing on children's distress and child-focused interventions.

In light of our qualitative study results, and in order to plan the next steps of this research, the findings and potential paths forward were discussed with 27 HCP stakeholders (including representatives from anesthesiology, child life, nursing, dentistry, administration, and psychology; 4 who of whom had participated in the qualitative study) across 10 engagement meetings. Child- and family- directed behavioural interventions (e.g., parent-mediated preparation programs, pre-operative phone calls) were ruled out due to concerns about feasibility (e.g., currently no reliable way to identify children with autism well in advance of surgery), sustainability (e.g., if such programs proved efficacious, who would be responsible for delivering them?), and the potential added burden that such programs might place on families. Child-directed sedation protocols were also ruled out, due to concerns related to the lack of evidence upon which to make recommendations (such as how to determine which children with autism might benefit from sedation). Ultimately, we identified the development of an intervention that increased the capacity of HCPs to consistently deliver high-quality care to children with autism as the priority for this program of research. Although the majority of our stakeholder engagement at this stage focused on HCPs, as we developed this intervention we engaged in additional informal consultations (e.g., brief “hallway discussions,” email correspondence) with HCPs, parents / caregivers, and youth with autism. Throughout these consultations, our decision to focus on an HCP-directed intervention with family-centred care as the target outcome was also validated by the families with whom we worked to develop this intervention. The next chapter describes the development of our intervention.



CHAPTER 4. MANUSCRIPT 2: BUILDING BALANCE (**BUILDING ALLIANCES FOR AUTISM NEEDS IN CLINICAL ENCOUNTERS**): USING THE BEHAVIOUR CHANGE WHEEL TO DEVELOP AN INTERVENTION TO IMPROVE THE DELIVERY OF HEALTHCARE TO CHILDREN WITH AUTISM

Readers are advised that Stephanie Snow, under the supervision of Drs. Jill Chorney and Isabel Smith, was primarily responsible for the conceptual and empirical work described in this manuscript. As described in the manuscript, stakeholders (i.e., HCPs, children with autism, and their families) were engaged in the development of the intervention described herein. Ms. Snow wrote the manuscript and revised it in accordance with suggestions from her co-supervisors. Ms. Snow completed this research in consultation with her dissertation committee members, Drs. Margot Latimer and Sherry Stewart, who provided guidance on data analyses and editorial feedback.

## ABSTRACT

Background: Interventions aimed at increasing the capacity of healthcare systems to deliver high-quality care to children with autism spectrum disorder (autism) are needed. We applied a systematic theory-driven method to develop a complex intervention to improve surgical care for children with autism. We employed an empirical approach to test aspects of the theory used to develop the intervention. Method: Following Behaviour Change Wheel guidance, we drew iteratively on three sources of data (published literature, findings from a qualitative needs assessment, and ongoing stakeholder engagement with HCPs, families, and children with autism) to identify and operationalize the target outcome behaviour, and to consider systematically determinants underlying variation in the target outcome behaviour. The resulting ‘behavioural diagnosis’ was used alongside stakeholder engagement activities to inform the mode of intervention delivery and selection of behaviour change techniques that were predicted to effect change in hypothesized determinants. Linear mixed-effects models and post hoc comparisons were used to explore whether implementation of the intervention was associated with changes in the hypothesized determinants of behaviour. Results: A complex and reflexive set of actions (comprising ‘family-centred care’) was operationalized as the target behaviour. Determinants of behaviour proposed to underlie variations in the delivery of family-centred care included psychological capability, physical opportunity, social opportunity, as well as reflective and automatic motivation. Thirty behaviour change techniques predicted to influence the proposed determinants were translated into the ‘Building Alliances for Autism Needs in Clinical Encounters’ (BALANCE) intervention. BALANCE was delivered primarily via e-modules targeted to individual HCPs and a

toolkit of resources introduced on the healthcare unit. Implementation of BALANCE on a tertiary pediatric perioperative unit was associated with positive shifts in HCPs' self-reports of proposed determinants of family-centred care delivery from baseline to post-implementation, which were sustained at three-month follow-up. Conclusions: We applied the Behaviour Change Wheel to a new context and population, advancing the literature on healthcare interventions for children with autism. This paper further builds on previous applications by describing how engagement with key stakeholders was incorporated, demonstrating use of the Behaviour Change Wheel in developing an intervention targeting a complex and reflexive target behaviour. Finally, we describe an approach to testing aspects of the Behaviour Change Wheel model.

## Introduction

Implementation research is dedicated to the study of methods to promote the uptake of research findings and improve the quality of healthcare (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005; Nilsen, 2015). This includes methods for designing complex interventions that aim to enhance the quality of care delivery by targeting behavioural changes at the level of individual HCPs, the healthcare teams within which they function, and the organizational systems in which teams are embedded (Eccles et al., 2005). In 2008, the Medical Research Council (MRC) in the United Kingdom published guidelines that advocated the use of theory in the development and evaluation of complex interventions (Craig et al., 2008). Specifically, the MRC and others have suggested that using theory could advance implementation research (and, in turn, healthcare delivery) by helping to improve the effectiveness, generalizability and replicability of complex interventions (Craig et al., 2008; Eccles et al., 2005; Michie, Fixsen, Grimshaw, & Eccles, 2009; Rycroft-Malone & Bucknall, 2010). Using theory could also allow for a cumulative body of evidence to clarify what (i.e., through what intervention components and techniques) and how (i.e., through what determinants) complex interventions influence behaviours that are targeted for change.

In the decade since the publication of the MRC guidelines, use of theory to guide implementation research has been accepted as best practice, but recent reviews have concluded that theory continues to be under-used or applied unsystematically (Davies, Walker, & Grimshaw, 2010; Prestwich et al., 2014). Indeed, the MRC guidelines have been criticized for providing little pragmatic instruction for how to use theory (Michie et al., 2009), and other models and frameworks have been deemed inadequate for

representing the complexity of the processes involved in applying theory to intervention design (Michie, van Stralen, & West, 2011; Rycroft-Malone & Bucknall, 2010).

The Behaviour Change Wheel approach (Michie, Atkins, & West, 2014; Michie et al., 2011) was developed to meet the need for a coherent and comprehensive theoretical framework for developing complex interventions. In addition to proposing a model to identify what determinants likely contribute to the target behavior, the Behaviour Change Wheel also provides pragmatic guidance on how this identification can be used to inform the selection and specification of intervention components. The Behaviour Change Wheel has been used to inform the development of interventions in numerous areas, including HCPs' smoking cessation care for Indigenous pregnant women (Gould et al., 2017), enhancing pharmacists' roles in mental healthcare (Murphy, Gardner, Kutcher, & Martin-Misener, 2014), enhancing nurses' efforts to increase patients' physical activity (Westland et al., 2017), and improving care of stroke patients (Craig et al., 2017).

Despite the Behaviour Change Wheel and MRC guidelines contributing to significant advances in implementation research, there is still room for growth. First, there is a need to better understand how (i.e., through what behavioral determinants) complex interventions work. With few exceptions (French et al., 2013; Shrubsole, Worrall, Power, & O'Connor, 2018), the effects of interventions on hypothesized behavioral determinants are rarely examined. Second, the match between intervention targets and measured outcomes requires attention. For example, studies often measure patient outcomes when an intervention is designed to target HCPs' behaviour. Third, clearly operationalizing and targeting complex behaviours is also an area in need of systematic attention (Michie & Johnston, 2012). Behavioral targets for interventions may

involve relatively concrete single-step actions (e.g., swallow a medication), multi-step actions (e.g., wash hands using a specific set of steps, follow the steps of care path), or a more complex and reflexive set of behaviours (e.g., assess a situation, and use that assessment to inform subsequent actions). To date, limited attention has been paid to how the Behaviour Change Wheel can be applied to behaviour that is complex and reflexive. Finally, although growing attention has been paid to the importance of engaging stakeholders (e.g., patients, HCPs; Cargo & Mercer, 2008; Carman et al., 2013; Colquhoun et al., 2017; Curran et al., 2018; Domecq et al., 2014; Greenhalgh, Robert, Macfarlane, & Kyriakidou, 2004; Minkler & Salvatore, 2012; Shen et al., 2017; Shippee et al., 2015), the degree and nature of stakeholder engagement and partnership in intervention development is seldom clear. More detailed descriptions are needed of how various stakeholder groups can be engaged throughout the process of developing complex interventions, to help clarify the contribution and value of such engagement. Thus, although the Behaviour Change Wheel and MRC guidelines have led to significant advances, room remains to continue advancing applications of this framework.

### **Applying the Behaviour Change Wheel to Address Implementation Gaps in the Healthcare of Children with Autism**

Over the past five years, our research team has been engaged in a collaborative program of research aimed at improving healthcare experiences for children with autism spectrum disorder (hereafter, ‘autism’). In addition to core developmental differences in social communicative behaviour and restricted and repetitive interests, children with autism experience high rates of co-morbid health-related problems (Celia, Freysteinson, & Frye, 2016; Jones et al., 2016; Kohane et al., 2012). Unfortunately, despite high rates

of healthcare service utilization (Chiri & Warfield, 2012; Zablotsky et al., 2015), children with autism are more likely than their peers to have unmet healthcare needs (Chiri & Warfield, 2012; Cummings et al., 2015), and to experience poor-quality healthcare (Vohra, Madhavan, Sambamoorthi, & St Peter, 2014; Zablotsky et al., 2015; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014). To date, our work has focused on surgery-related healthcare experiences as it grew from a local need for clinically feasible and evidence-informed ways to improve the surgery-related experiences of children with autism. Moreover, surgical care is a good model for the healthcare experiences that challenge children with autism (e.g., multiple fast-paced interactions, varied personnel, lack of predictability, sensory stimulating environment; Snow, Smith, Bird, Wright, & Chorney, 2016).

Limitations in existing interventions aimed at improving the delivery of healthcare to children with autism mirror challenges described in the broader implementation literature. Although several quality improvement initiatives and educational programs have been described (Broder-Fingert et al., 2016; Carter et al., 2017; Cermak et al., 2015; Chebuhar, McCarthy, Bosch, & Baker, 2013; Giarelli, Ruttenberg, & Segal, 2011; Jensen et al., 2012; Johnson, Lashley, Stonek, & Bonjour, 2012; McGonigle et al., 2014a; Swartz, Amos, Brindas, Girling, & Graham, 2017), few explicitly use theory or a systematic development process. None appeared to consider possible determinants underlying variations in the quality of care delivery, to link intervention components to possible determinants, or to operationalize outcome behaviours consistent with high-quality care delivery. Consequently, questions remain unanswered that are critical to building a cumulative and generalizable understanding of

what types of interventions are associated with changes in what aspects of care delivery and through what determinants. Further, whereas the autism literature (Fletcher-Watson et al., 2018; Pellicano, Dinsmore, & Charman, 2014a; Pellicano & Stears, 2011) and the broader literature on addressing disparities in the delivery of healthcare (Cargo & Mercer, 2008; Carman et al., 2013; Curran et al., 2018; Minkler & Salvatore, 2012) provide compelling arguments in favour of engaging individuals with autism and their families in efforts to improve the quality of healthcare, few studies have done so (Bultas, Johnson, Burkett, & Reinhold, 2016; Nicolaidis et al., 2016; Swartz et al., 2017). This historical privileging of HCPs' perspectives comes at the expense of building a more nuanced and inclusive understanding of how gaps in the quality of healthcare delivery to children with autism can be understood and addressed.

To address these limitations, a qualitative needs assessment was conducted (see Chapter 2), wherein HCPs and families of children who had received surgical care were interviewed to allow better understanding of the factors that shaped these experiences. Findings conveyed the complexities associated with these healthcare experiences, and pointed to individual child, caregiver, HCP, as well as interpersonal and systemic factors that could be targeted by improvement efforts. We discussed these results with HCPs who identified that they were a key contributor to, and well situated to improve the healthcare experiences of children with autism. Thus, the consensus was to develop an intervention that would target HCPs' behaviour as a way to enhance delivery of care. In this paper, we describe how we applied the Behaviour Change Wheel within our program of collaborative research. Doing so enabled us to develop the Building Alliances for Autism Needs in Clinical Encounters (BALANCE) intervention. We describe the



application of the Behaviour Change Wheel to a new context and population, advancing the literature on interventions to improve healthcare for children with autism whilst contributing to the growing body of literature on use of the Behaviour Change Wheel in developing complex interventions. We build on previous research using the Behaviour Change Wheel by describing our approach to collaborating with HCPs, families, and children with autism throughout the development of BALANCE, and detailing how we operationalized and targeted a complex behavioural outcome. Notably, we also present our approach to testing aspects of the model of behaviour proposed in the behaviour change wheel, by examining whether implementation of BALANCE contributed to changes in proposed determinants.

### **Method**

My study aims were 1) to use the Behaviour Change Wheel to develop a complex intervention to enhance HCPs approach to delivering care to children with autism around the time of surgery, and 2) to explore whether implementation of the intervention was associated with changes in determinants proposed to underlie variability in the target outcome behaviour (i.e., HCP's delivery of care).

#### **Aim 1: Developing the BALANCE Intervention**

**Overview of Behaviour Change Wheel Approach.** The process of developing the intervention using the Behavior Change Wheel began with creating a 'behavioural diagnosis' (Michie et al., 2014). This involved systematically (a) identifying and operationalizing the target outcome behaviour, and (b) considering the determinants that might underlie variations in this outcome behaviour. The capability, opportunity, motivation model of behaviour (COM-B; Michie et al., 2014; Michie et al., 2011)

proposed in the Behaviour Change Wheel served as the theoretical framework for the ‘behavioural diagnosis’. The next stage in the process was to identify and select from amongst the full range of intervention options that could theoretically lead to desired changes in the determinants and target behaviour. Next, consistent with this approach we considered the mode of delivery, as well as issues of feasibility and practicality to determine the characteristics of the intervention.

**Developing the Behavioral Diagnosis.** A clinical psychology PhD student (SS), and two psychology clinician-scientists, one with 30 years of experience in autism research (IS), and one with 15 years of experience in the field of health psychology and procedural care (JC), were primarily responsible for the conceptual application of the Behaviour Change Wheel. Three main data sources iteratively informed this behavioural diagnosis: published literature (commentaries, editorials, and empirical research) on improving healthcare for children with autism (see Table 4.1 for references), findings from our qualitative needs assessment that included families’ and HCPs’ perspectives (see Chapter 2), and ongoing collaboration and consultation with key stakeholders (HCPs and families of children with autism) via meetings (see Chapter 3 and Table 4.2 for details), informal conversations, and email correspondence. We drew on these sources iteratively as we identified a set of complex behaviours and determinants that could influence these behaviours. As recommended (Michie et al., 2014), we considered the following questions: “Who needs to do what, when, where, how often, and with whom” (p. 55) to improve the delivery of healthcare to children with autism around the time of surgery? Do HCPs have the necessary knowledge and skills to perform the target behaviours (capability)? Are there any social or physical barriers to be addressed to

facilitate the target behaviours (opportunity)? Are HCPs driven (consciously or automatically) towards or away from the target behaviours (motivation)?

**Selecting Behaviour Change Techniques.** Following intervention mapping processes described in the Behaviour Change Wheel (Michie, Johnston, Francis, Hardeman, & Eccles, 2008), we selected behaviour change techniques (i.e., “observable, replicable and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour”; Michie et al., 2013, p. 4) predicted to effect change in the capability, opportunity and motivation determinants that we conceptualized as underlying variations in our set of target behaviours (i.e., in our ‘behavioural diagnosis’)<sup>1</sup>. We labelled the list of behaviour change techniques that we included using

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<sup>1</sup> Within the Behaviour Change Wheel approach, there are two alternative processes through which the COM-B diagnosis can guide the systematic selection of behaviour change techniques. First, the COM-B has been linked to general intervention functions (e.g., education, persuasion, modelling). Second, more specific theoretical domains (e.g., knowledge, behaviour regulation, social role/identity) have been linked to specific behavior change techniques. In the absence of clear guidance from the Behaviour Change Wheel on how to choose between these alternatives, we used both processes and triangulated our selection of behaviour change techniques accordingly. Our approach is consistent with past applications of the Behaviour Change Wheel (e.g., Gould et al., 2017; McSharry, Murphy, & Byrne, 2016). For brevity, we present only the resulting links between our proposed determinants of behavior (COM) and selected behaviour change techniques. Further description of how our COM-B diagnosis and selected

the Behaviour Change Taxonomy (Michie et al., 2013). Definitions of selected behaviour change techniques are included in Supplemental Table 4.1.

**Selecting Mode of Delivery.** The behavioural diagnosis and consultations with administrators and frontline HCPs (through presentations and soliciting feedback at team meetings and informal one-on-one discussions) informed the selection of the mode of delivery for the intervention (see Chapter 3).

**Translating Behaviour Change Techniques into Intervention Content.**

Collaborations with HCP, children with autism, and their families informed the translation of selected behaviour change techniques into intervention content amenable to the selected modes of intervention delivery. Collaboration occurred through informal one-on-one discussions, email correspondence, and co-creation of video materials.

**Implementation of Intervention.** We implemented our intervention in a perioperative day surgery unit at a tertiary care pediatric hospital that regularly delivers care to children with autism. Detailed procedural information pertaining to the implementation of BALANCE and an examination of changes in the target outcome (HCP behaviour) and families' perceptions of care delivery from baseline to post-intervention are reported in another manuscript (see Chapter 5). Feedback from HCPs on the feasibility and acceptability of BALANCE is also presented elsewhere (see Chapter 5).

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behaviour change techniques were related to intervention functions and theoretical domains is presented in Supplemental Table 4.1.

## **Aim 2: Exploring Changes in Proposed Behavioural Determinants**

We used the COM-B model of behaviour (Michie et al., 2014) and our ‘behavioural diagnosis’ to inform the development of a questionnaire to measure proposed determinants of the target outcome behaviour (i.e., ‘determinants’ questionnaire; Appendix C). The questionnaire consists of 60 items assessing HCPs’ capability, opportunity, and motivation to deliver the target outcome behaviour. Of these, 19 items assess HCPs’ capability (e.g., *I know the current recommendations for delivering care to children with ASD and their families*), 12 items assess HCPs’ opportunity (e.g., *I have access to the resources I need to tailor my approach*), and 29 items assess HCPs’ motivation (e.g., *I am uneasy when I cannot predict how a child with ASD will cope*). Healthcare providers responded using an 8-point scale (1 = *Very much disagree*, 2 = *Generally disagree*, 3 = *Tend to disagree*, 4 = *Slightly disagree*, 5 = *Slightly agree*, 6 = *Tend to agree*, 7 = *Generally agree*, 8 = *Very much agree*). A mean overall scale score, and mean subscale scores for items assessing capability, opportunity, and motivation, were used in the current analysis. Eighteen negatively phrased items were reverse-scored (15 items on the motivation subscale, and 3 items on the opportunity subscale), and higher scores indicated higher levels of perceived capability, opportunity, and motivation to deliver the target behaviour. Internal consistency was good to excellent (Cronbach’s  $\alpha \geq 0.89$ ) for the overall scale score across all three measurement occasions (baseline  $\alpha = 0.90$ , post-implementation  $\alpha = 0.89$ , and follow-up  $\alpha = 0.92$ ). Internal consistency was acceptable to good (Cronbach’s  $\alpha \geq 0.70$ ) across all three measurement occasions for subscales of capability (baseline  $\alpha = 0.87$ , post-implementation  $\alpha = 0.83$ , and follow-up  $\alpha = 0.86$ ), opportunity (baseline  $\alpha = 0.72$ , post-

implementation  $\alpha = 0.81$ , and follow-up  $\alpha = 0.81$ ), and motivation (baseline  $\alpha = 0.70$ , post-implementation  $\alpha = 0.77$ , and follow-up  $\alpha = 0.84$ ).

We used this questionnaire to examine changes in HCPs' ratings of proposed determinants in the context of a pilot implementation trial (see Chapter 5). Sample size was determined pragmatically, based on the number of HCPs working in the day surgery unit. Sixty-six HCPs completed our baseline 'determinants' questionnaire, 53 were exposed to the intervention, 48 completed the post-implementation 'determinants' questionnaire, and 40 completed the follow-up 'determinants' questionnaire. We used descriptive statistics to summarize demographic information, and calculated Cronbach's alphas for the overall scale and subscale reliability. We used exploratory linear mixed-effects models to assess changes in estimated marginal mean ratings by HCPs across three measurement time points. The primary analysis examined changes in overall determinants scores; additional exploratory analysis examined changes in subscale scores (i.e., Capability, Opportunity, Motivation). Linear mixed-effects models were chosen as they are ideally suited to research designs with missing data, non-independent observations, and unequal measurement intervals (Hayat & Hedlin, 2012; Hayes, 2006; McCulloch, 2005). Post hoc analyses compared estimated marginal means from the LME model across adjacent time points, using Bonferroni correction. Effect sizes (ES) for post hoc comparisons were calculated as a ratio of the mean difference between estimated marginal means at each measurement occasion over the estimated standard deviation of the sample at baseline (Cohen, 1992; E. Duku, personal communication, February 19<sup>th</sup>, 2019; Taylor, 2014). Cohen's (1992) descriptors were used to interpret the magnitude of the ES (i.e., .20 = small effect, .50 = medium effect, .80 = large effect).

## Results

### **Aim 1: Developing the BALANCE Intervention**

**Behavioral Diagnosis.** Based on the multiple sources of data reviewed, the answer to “who needs to do what differently?” was determined to be a complex and reflexive set of actions that should ideally be adopted by all HCPs during any healthcare interaction with children with autism and their families. These actions broadly fell under the heading of family-centred care, which was further operationalized as 1) partnering with families, 2) assessing the needs of each child and tailoring care accordingly, 3) coordinating care through inter-professional collaboration, and 4) expressing empathy and warmth.

Using the COM-B model to guide our systematic consideration of determinants based on our multiple sources of data, we identified psychological capability, physical and social opportunities, as well as reflective and automatic motivation as potentially important targets for intervention.

**Psychological Capability.** We identified the need to: 1) increase knowledge about autism-specific needs, 2) increase awareness that existing evidence points to family-centred care as the most appropriate approach to healthcare delivery, 3) increase awareness of factors that might influence the delivery of family-centred care (i.e., child, family, HCP, and systemic factors), 4) strengthen procedural skills related to assessing and addressing autism-specific needs, 5) strengthen interpersonal skills necessary for partnering with families and collaborating with colleagues, 6) enhance coping skills for dealing with feelings of discomfort that interfere with the delivery of family-centred care,

and 7) increase behavioural regulation skills in order to facilitate the successful prioritization of family-centred care in the face of competing demands.

***Physical Opportunity.*** We identified the need to: 1) provide access to education and training that supports the development of relevant knowledge and skills, 2) provide prompts and tools that facilitate efficient assessment and interprofessional communication of each child's individual needs, and 3) provide resources to support HCPs efforts to address the needs of children with autism (e.g., ways of reducing sensory stimulation that bothers some children with autism, resources to support communication with children who use little or no speech).

***Social Opportunity.*** We identified the need to: 1) establish a shared understanding amongst the healthcare team about what family-centred care entails, 2) enhance social influences amongst the healthcare team that reinforce the use of family-centred care, and 3) challenge social norms operating within the context of the healthcare team that limit the degree to which disagreements and conflicts related to the delivery of family-centred care are discussed and resolved.

***Reflective Motivation.*** We identified the need to: 1) reframe beliefs that have the potential to interfere with the delivery of family-centred care (i.e., shift the perception that HCPs lack any relevant expertise, training, and skills; resolve ambivalence about whether HCPs and family-centred care exert positive influences on the healthcare experiences of children with autism, and challenge HCPs' perceptions that their successes are predicated on the presence or absence of children's distress and that others are more able to care for children with autism), 2) affirm HCPs' professional responsibility to deliver family-centred care to children with autism, 3) foster intentions to deliver family-



centred care, and (4) enhance HCPs' self-efficacy related to delivering healthcare to children with autism.

***Automatic Motivation.*** We identified the need to: 1) address and mitigate challenging emotional experiences (e.g., anticipatory anxiety, fear, intolerance of uncertainty, frustration, guilt, and self/other-oriented blame) that have the potential to interfere with the delivery of family-centred care to children with autism without HCPs' conscious awareness, and 2) enhance motivations to deliver family-centred care.

**Selecting Behavior Change Techniques.** Table 4.3 depicts proposed relationships between behavioral determinants and the thirty behaviour-change techniques that were included in the final version of BALANCE. For example, the determinant of reflective motivation was proposed to be targeted by 14 behaviour change techniques that include 1.1 Goal setting and 13.2 Framing/reframing, amongst others.

**Selecting Mode of Delivery.** Stakeholders identified that a predominantly online mode of delivery would provide flexibility that would make BALANCE more feasible for their group of inter-disciplinary HCPs than face-to-face modes (e.g., workshop format). The behavioural diagnosis also pointed to the importance of restructuring the physical and social environment to facilitate family-centred care. Thus, BALANCE was developed as a multi-level intervention. Specifically, 25 behaviour change techniques were delivered via seven 15- to 30-minute online learning modules (e-modules), 2 behaviour change techniques were delivered via the introduction of a toolkit of resources, 2 behaviour change techniques were delivered via posters and emails shared with all staff on the perioperative unit, and 2 behaviour change techniques were delivered as incentives available to HCPs who completed the modules (i.e., the opportunity to obtain

professional development credits, certificate of completion, and provision of an ‘autism-friendly’ pin).

**Translating Behaviour Change Techniques into Intervention Content.** Table 4.4 provides selected examples of how behaviour change techniques were translated into intervention content; Supplemental Table 4.2 provides a full description. The e-modules included a combination of narrated written content, videos featuring key stakeholders (e.g., HCPs, children with autism, parents), and applied learning activities. The first author (SS) could be contacted through the e-module platform to address questions, and the e-modules identified local champions whom HCPs could consult for support. Healthcare providers who completed the e-modules received an ‘autism-friendly’ pin and a certificate that could be used towards discipline-specific continuing education credits. Healthcare providers who completed the modules were also given written individualized strengths-based feedback on their responses to two case studies in the final e-module.

The resource toolkit contained: 1) a tool developed with stakeholder feedback, designed to guide HCPs’ assessment of the sensory, emotional, and communication needs of each child with autism (“Take a SEC” tool), 2) a magnetized symbol (check mark) to place on patient room doors, cueing HCPs that the assessment was completed and should be reviewed to facilitate care coordination, 3) items to facilitate adjustments to care (i.e., a pictorial communication aid, ear muffers, sunglasses, autism-friendly toys for distraction), 4) a pain assessment tool, and 5) an article about pain management. Staff-wide communications (emails and posters) informed staff members that the toolkits were available. Lastly, positive feedback gathered from families of children with autism in the 6-12 weeks following the intervention was shared with HCPs via posters in the unit.

## **Aim 2: Exploring Changes in Proposed Behavioural Determinants**

Changes in proposed determinants of family-centred care, as identified by the Behaviour Change Wheel including capability, opportunity, and motivation, were examined with linear mixed-effects models and post hoc comparisons. The linear mixed-effects models showed a main effect of time on HCPs' responses to the 'Determinants of Behavior' questionnaire ( $F(2, 91.370) = 44.37, p < 0.001$ ; see Figure 4.1). Post hoc comparisons and ES calculations suggested large increases ( $d = 0.82, p < 0.001$ ) from baseline ( $M = 5.36, SE = 0.06$ ) to post-BALANCE ( $M = 5.78, SE = .07$ ), a negligible change ( $d = .18; p = 0.43$ ) from post-BALANCE to follow-up ( $M = 5.87, SE = 0.07$ ), and a large change overall (baseline to follow-up  $d = 1.00; p < 0.001$ ). Results of linear mixed-effects models and associated post hoc comparisons and ES calculations exploring change in Capability, Opportunity, and Motivation subscale scores are presented in detail in Table 4.5. Results suggested that there was a large increase in Capability subscale scores alongside a medium increase in Opportunity subscale scores from baseline to post-BALANCE, with changes on both subscales sustained from post-BALANCE to follow-up. There was a medium increase in Motivation subscale scores from baseline to post-BALANCE, with another small change in Motivation subscale scores from post-BALANCE to follow-up, resulting in a large overall change in Motivation subscale scores (i.e., from baseline to follow-up).

## **Discussion**

The purpose of this paper was to describe how the Behaviour Change Wheel (Michie et al., 2014) was used within a program of collaborative research to develop BALANCE, an intervention aimed at improving HCPs' delivery of family-centred care to

children with autism around the time of surgery. This paper advances efforts to address gaps in the quality of healthcare delivered to children with autism by transparently describing the systematic, theory-driven, and stakeholder-engaged processes that informed the development of BALANCE. In so doing, this paper also contributes to the emerging literature on applications of the Behaviour Change Wheel. In addition to meeting the need for examples of applications of the Behavior Change Wheel in different patient populations and contexts (McSharry et al., 2016), we build on previous research (e.g., Craig et al., 2017; Gould et al., 2017; Westland et al., 2017) by describing how key stakeholders were engaged and by detailing how a complex and reflexive outcome behaviour (family-centred care) was operationalized and targeted with systematically selected behaviour change techniques. Lastly, this research provides preliminary support for the utility of the Behaviour Change Wheel, by demonstrating that implementation of BALANCE was associated with changes in proposed determinants of capability, opportunity and motivation.

### **Strengths and Limitations**

In this study, we integrated multiple sources of data to determine the target behaviour and proposed determinants. Specifically, we used relevant literature, perspectives of multiple stakeholders gathered through consultations, and results from a formal qualitative needs-assessment study (See Chapter 2). Stakeholder perspectives contributed to an in-depth, nuanced, and holistic understanding to inform our ‘behavioural diagnosis.’ For example, whereas clinical practice guidelines recommend developing individualized care plans, stakeholders helped us to appreciate the importance

of *how* HCPs approach these interactions. Thus, we included *how* (i.e., with empathy and warmth) in our operationalization of family-centred care.

Although our engagement with stakeholders was a strength of this study, we acknowledge that there was room for more engagement of children with autism and their families. While we did engage youth with autism in developing BALANCE content, and included in our data sources studies (e.g., Muskat et al., 2015) that have gathered perspectives of individuals with autism on their healthcare experiences, perspectives from youth with autism were not formally gathered in the qualitative study (Chapter 2). In addition, families were not explicitly involved in the stakeholder meetings that informed the decision to focus on developing an intervention to increase the capacity of the healthcare system to deliver high-quality care to children with autism (Chapter 3). Families that participated in the qualitative study raised the possibility of intervening at the level of HCPs and the healthcare system as a possible future direction, and families consulted throughout the development of BALANCE validated the decision that was made to focus our initial efforts on developing an intervention. That being said, it remains possible that had families and children been more explicitly and consistently engaged in the decision-making processes that followed the initial qualitative study (Chapter 2), they might have identified different priorities, taking this program of research in a different direction. Future research should continue to consider how to best engage children and families throughout all phases of a research program, and give careful consideration to how youth perspectives might contribute to a better understanding of what high-quality healthcare experiences entail.

Despite resulting in a thorough behavioural diagnosis, our use of multiple sources of data differed from approaches used in other studies in potentially consequential ways. The choice to focus on HCPs was made following our needs assessment (Chapter 2) and associated stakeholder consultations (Chapter 3); thus, we applied the COM-B as a post hoc framework for existing data and consultations, rather than developing a questionnaire or interview guide prior to gathering the data (e.g., Gould et al., 2017; McSharry, Murphy, & Byrne, 2016; Sinnott et al., 2015). In so doing, we may have missed determinants about which we did not explicitly ask. That said, our approach demonstrates that the Behavior Change Wheel can be applied in an iterative, flexible way. The relative strengths and weaknesses of different approaches to gathering data to inform a ‘behavioural diagnosis’ remain to be fully articulated.

A specific strength of this study was that we measured the determinants that we hypothesized would change as a result of our intervention. Our ‘behavioural diagnosis’ provided the conceptual foundation for the development of questionnaires assessing HCPs’ capabilities, opportunities, and motivations for delivering family-centred care. We demonstrated large changes in these determinants collectively from baseline to post-BALANCE that were maintained at 3-month follow-up. We also demonstrated changes in each individual determinant of interest. We observed immediate (i.e., change from baseline to post-BALANCE) changes in HCPs’ reports of their capability and opportunity to deliver family-centred care, and both immediate and delayed (i.e., post-BALANCE to follow-up) changes in HCPs’ reports of their motivation to deliver family-centred care. Specifically, we identified large changes in HCPs’ reports of their capability to deliver family-centred care from baseline to post-BALANCE that were maintained at 3

month follow-up, medium changes in HCPs' reports of their opportunity from baseline to post-BALANCE that were sustained at 3-month follow-up, and medium changes in HCPs' reports of their motivation from baseline to post-BALANCE, with large changes observed from baseline to 3-month follow-up. Taken together, these findings provide some compelling initial support for our theoretically guided selection of behaviour change techniques.

The promising exploratory findings demonstrated in this study need to be considered with the weaknesses and limitations of this study in mind. Examining changes in determinants is a strength of this study; however, we acknowledge that our measure (although it demonstrated internal consistency for the overall score and subscales) requires validation. Given that this study was a single-site pilot implementation trial rather than a controlled trial, it is also not possible to attribute the observed changes in determinants directly to the implementation of BALANCE. Alternative possibilities include that the observed changes in determinants reflect the passage of time or a placebo effect. Further, as a result of BALANCE being a complex intervention (multiple behavior-change techniques and intervention components), it is difficult to determine which components of the BALANCE intervention are necessary and sufficient. Another limitation of this study is that we have only presented an examination of the association between BALANCE implementation and changes in proposed determinants. Additional preliminary analyses examining the association between BALANCE implementation and the desired outcome of family-centred care, as well as the degree to which early changes in determinants were associated with overall changes in family-centred care, are presented elsewhere (see Chapters 5 and 6). However, these analyses are also limited by

the lack of a ‘no intervention’ comparison group in this pilot implementation trial.

Definitive controlled trials are needed to clarify the effectiveness of BALANCE, as well as the degree to which changes in proposed determinants account for changes in family-centred care.

### **Reflections on Using the Behaviour Change Wheel to Develop BALANCE**

The Behaviour Change Wheel advanced our understanding of what could facilitate HCPs’ provision of high-quality healthcare to children with autism, and prompted us to provide the most comprehensive and detailed analysis of the full range of internal (i.e., motivation and capability) and external (i.e., opportunity) determinants to date. The COM-B model of behaviour was helpful in guiding this analysis and allowed us to distinguish potential determinants from the identified target behaviours.

As previously identified, applying the Behavior Change Wheel is a time- and resource-intensive process. In our experience, the most conceptually and pragmatically challenging aspect was selecting behaviour change techniques based on the COM-B behavioural diagnosis and translating these techniques into intervention content. Although this process appears systematic in published descriptions, our application was more iterative and reliant on clinical judgment. For example, we used triangulation to navigate alternative processes for how the behavioural diagnosis could guide the selection of behaviour change techniques (e.g., through intervention functions or theoretical domains). We also moved back and forth amongst the steps of selecting behaviour change techniques, selecting modes of delivery, and translating to intervention content. For example, while co-producing videos with stakeholders we sometimes found



that we addressed more behaviour change techniques than anticipated. This led to the incorporation of many behaviour change techniques in BALANCE.

### **Future Directions**

As reported briefly here and described in detail elsewhere (see Chapter 5), the implementation of an intervention called BALANCE on a perioperative unit was associated with measurable changes in HCPs' reports of determinants. These findings provide preliminary empirical support for the notion that the Behaviour Change Wheel can guide the development of an intervention to achieve desired changes in relevant determinants. Definitive multi-site trials are needed to evaluate the effect of BALANCE implementation on the delivery of family-centred care, and to explore further the relationships among HCPs' capability, opportunity, and motivation and the delivery of family-centred care. In addition, although systematic and theory-driven methods are considered best practice in developing interventions and have compelling face value, few empirical data are available supporting the superiority of interventions developed using systematic and theory-driven approaches (Mittman, 2012). Comparisons of BALANCE to existing interventions could begin to help clarify the relative merits of using the systematic and theory-driven Behaviour Change Wheel approach to develop interventions aimed at improving the delivery of healthcare to children with autism. For example, it would be interesting to contrast the impact of BALANCE with the impact of interventions that have focused on relatively simple and concrete behaviours [e.g., use of a questionnaire to assess autism-specific needs (Broder-Fingert et al., 2016), use of a picture schedule during healthcare interaction (Chebuhar et al., 2013), provision of a 'sensory-adapted' environment (Cermak et al., 2015)]. In addition, it would be interesting

to explore differences between the impact of BALANCE and interventions that appear to focus on determinants of behaviour (e.g., aspects of HCPs' capability and motivation) without explicit consideration of what target behaviours HCPs need to change to improve the delivery of healthcare to children with autism (e.g., Giarelli et al., 2012; McGonigle et al., 2014). Lastly, to establish what BALANCE content is necessary and/or sufficient, dismantling studies will be important (Papa & Follete, 2015).

The 'behavioural diagnosis' presented here may be applicable to improving the delivery of family-centred care in a broader range of healthcare contexts beyond pediatric surgery. Indeed, gaps in the delivery of family-centred care and deficits in HCPs' capability, opportunity, and motivations related to caring for children with autism have been noted across healthcare contexts (e.g., Heidgerken, Geffken, Modi, & Frakey, 2005; Hubner, Feldman, & Huffman, 2016; Kuo, Frick, & Minkovitz, 2011; Muskat et al., 2015; Nicholas et al., 2016; Zuckerman et al., 2014). Emerging research continues to identify improvement of the capacity of healthcare systems to deliver family-centred care as a potential solution to addressing disparities (e.g., reducing rates of unmet healthcare needs) and improving the quality of healthcare delivered to children with autism (Casagrande & Ingersoll, 2017; Karpur, Lello, Frazier, Dixon, & Shih, 2018).

## **Conclusions**

Interventions aimed at increasing HCPs' and healthcare systems' capacity to deliver high-quality healthcare to children with autism have the potential to address critical gaps (Bishop-Fitzpatrick & Kind, 2017; Wilson & Peterson, 2018) and to improve healthcare experiences for children with autism and their families. Emerging evidence converges to suggest that high-quality healthcare delivery can be operationalized broadly

as family-centred care, wherein HCPs consistently partner with parents, assess and address the individual needs of each child, collaborate with inter-professional colleagues to coordinate care, and express empathy and warmth. A complex array of individual, interpersonal, and systemic factors has been implicated as determinants underlying variations in the delivery of high-quality healthcare to children with autism. The Behaviour Change Wheel was critical to guiding our systematic consideration of evidence-practice gaps, as well as to prompting our efforts to clearly operationalize family-centred care and to comprehensively consider the full range of determinants that could underlie variations in care delivery. In turn, this theory-driven process, alongside collaborations with key stakeholders informed the selection of behaviour change techniques and translation of behaviour change techniques into BALANCE, an intervention aimed at enhancing the delivery of family-centred care to children with autism around the time of surgery. Implementation of BALANCE was associated with increases in HCPs' reports of determinants that our 'behavioural diagnosis' proposed should promote the delivery of family-centred care

Table 4.1

*References and Brief Descriptions of Published Literature Included in Data Sources*

Reference	Article Description
Broder-Fingert, S., Shui, A., Ferrone, C., Iannuzzi, D., Cheng, E. R., Giaque, A., ... Kuhlthau, K. (2016). A pilot study of autism-specific care plans during hospital admission. <i>Pediatrics</i> , 137(Supplement 2), S196–S204. doi:10.1542/peds.2015-2851R	Report on quality improvement initiative that involved developing and implementing 'autism-specific' care plans in a tertiary care hospital
Cermak, S. A., Stein Duker, L. I., Williams, M. E., Dawson, M. E., Lane, C. J., & Polido, J. C. (2015). Sensory adapted dental environments to enhance oral care for children with autism spectrum disorders: a randomized controlled pilot study, <i>Journal of Autism and Developmental Disorders</i> , 45(9), 2876–2888.. doi:10.1007/s10803-015-2450-5	Randomized controlled crossover pilot trial of 'sensory adapted dental environments' for children with autism undergoing routine dental care
Chebuhar, A., McCarthy, A. M., Bosch, J., & Baker, S. (2013). Using picture schedules in medical settings for patients with an autism spectrum disorder. <i>Journal of Pediatric Nursing</i> , 28(2), 125–134. doi:10.1016/j.pedn.2012.05.004	Descriptive feasibility study examining the use of 'picture schedules' for children with autism in a tertiary care hospital
Davignon, M. N., Friedlaender, E., Cronholm, P. F., Paciotti, B., & Levy, S. E. (2014). Parent and provider perspectives on procedural care for children with autism spectrum disorder. <i>Journal of Developmental and Behavioral Pediatrics</i> , 35(3), 207–215. doi:10.1097/DBP.0000000000000036	Qualitative study exploring 20 parent and 20 HCP perspectives on barriers and facilitators to improving procedural care of children with autism
Drake, J., Johnson, N., Stoneck, A. V, Martinez, D. M., & Massey, M. (2012). Evaluation of a coping kit for children with challenging behaviors in a pediatric hospital. <i>Pediatric Nursing</i> , 38(4), 215–21. Retrieved from <a href="http://www.pediatricnursing.net/">http://www.pediatricnursing.net/</a>	Descriptive study evaluating nurses' perceptions of the utility of a 'coping kit' for meeting the needs of children with developmental disabilities, including autism, in hospital settings.

Reference	Article Description
Giarelli, E., Ruttenberg, J., & Segal, A. (2011). Continuing education for nurses in the clinical management of autism spectrum disorders: results of a pilot evaluation. <i>Journal of Continuing Education in Nursing</i> , 43(4), 169–176. doi:10.3928/00220124-20111115-01	Pilot evaluation of a two-day nurse-directed continuing education workshop focused on autism.
Jensen, C. C., Lydersen, T., Johnson, P. R., Weiss, S. R., Marconi, M. R., Cleave, M. L., & Weber, P. (2012). Choosing staff members reduces time in mechanical restraint due to self-injurious behaviour and requesting restraint. <i>Journal of Applied Research in Intellectual Disabilities</i> , 25(3), 282–7. doi:10.1111/j.1468-3148.2011.00664.x	Case study describing how reductions in self-injurious behaviour and mechanical restrains were realized when a hospitalized 28-year old woman with autism and addition comorbid psychiatric and medical diagnoses to choose her staff members
Johnson, N. L., Lashley, J., Stonek, A. V., & Bonjour, A. (2012). Children with developmental disabilities at a pediatric hospital: staff education to prevent and manage challenging behaviors. <i>Journal of Pediatric Nursing</i> , 27(6), 742–749. doi:10.1016/j.pedn.2012.02.009	Report of quality improvement initiative that involved piloting a hospital wide staff education program aimed at preventing and managing challenging behaviours of children with autism and other developmental disabilities.
Johnson, N. L., & Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: a systematic review of the literature. <i>Pediatric Nursing</i> , 39(3), 131–141. Retrieved from <a href="http://www.pediatricnursing.net/">http://www.pediatricnursing.net/</a>	Systematic review of 34 studies aimed at describing the behaviours of hospitalized children with autism that HCP find challenging, and proposing strategies for preventing or managing 'challenging behaviour'
Jolly, A. A. (2015). Handle with care: Top ten tips a nurse should know before caring for a hospitalized child with autism spectrum disorder. <i>Pediatric Nursing</i> , 41(1), 11–12. Retrieved from <a href="http://www.pediatricnursing.net/">http://www.pediatricnursing.net/</a>	Clinical commentary describing recommendations for nurses caring for hospitalized children with autism.

Reference	Article Description
<p>Koski, S., Gabriels, R. L., &amp; Beresford, C. (2016). Interventions for paediatric surgery patients with comorbid autism spectrum disorder : a systematic literature review. <i>Archives of Disease in Childhood, 101</i>, 1090–1094. doi:10.1136/archdischild-2016-310814</p>	<p>Systematic review of 11 studies with the aim of identifying management practices for children with autism receiving care in perioperative settings</p>
<p>Lindberg, S., von Post, I., &amp; Eriksson, K. (2012). The experiences of parents of children with severe autism in connection with their children's anaesthetics, in the presence and absence of the perioperative dialogue: a hermeneutic study. <i>Scandinavian Journal of Caring Sciences, 26</i>(4), 627–34. doi:10.1111/j.1471-6712.2012.00971.x</p>	<p>Qualitative study exploring the perspectives of 12 parents of children with autism whose children had undergone procedures requiring anesthesia, in the presence and absence of a 'perioperative dialogue'</p>
<p>MacKenzie, J. G., Abraham, G., &amp; Goebel, S. M. (2013). Management of pediatric patients with autistic spectrum disorders in the emergency department. <i>Clinical Pediatric Emergency Medicine, 14</i>(1), 56–59. doi:10.1016/j.cpem.2013.01.010</p>	<p>Clinical commentary on the management of children with autism in the emergency department</p>
<p>McGonigle, J. J., Migyanka, J. M., Glor-Scheib, S. J., Cramer, R., Fratangeli, J. J., Hegde, G. G., ... Venkat, A. (2014). Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients with autism spectrum disorder. <i>Journal of Autism and Developmental Disorders, 44</i>(5), 1252–1259. doi:10.1007/s10803-013-1962-0</p>	<p>Report of quality improvement initiative that involved developing and implementing an educational program for HCPs working in emergency medical services and emergency departments about how to care for patients with autism.</p>
<p>McGonigle, J. J., Venkat, A., Beresford, C., Campbell, T. P., &amp; Gabriels, R. L. (2014). Management of agitation in individuals with autism spectrum disorders in the emergency department. <i>Child and Adolescent Psychiatric Clinics of North America, 23</i>(1), 83–95. doi:10.1016/j.chc.2013.08.003</p>	<p>Clinical commentary on the management of 'agitation' in individuals with autism presenting to the emergency department</p>

Reference	Article Description
Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. <i>Child: Care, Health and Development</i> , 35(2), 250–256. doi:10.1111/j.1365-2214.2008.00931.x	Qualitative study exploring parent perspectives on improving the quality of healthcare services in Ontario, Canada for children with developmental disorders, including 3 parents of children with autism
Muskat, B., Burnham Riosa, P., Nicholas, D. B., Roberts, W., Stoddart, K. P., & Zwaigenbaum, L. (2015). Autism comes to the hospital: the experiences of patients with autism spectrum disorder, their parents and health-care providers at two Canadian paediatric hospitals. <i>Autism</i> , 19(4), 482–490. doi:10.1177/1362361314531341	Qualitative study exploring the perspectives of 6 youth with autism, 22 parents of children with autism, and 14 HCPs related to 20 distinct healthcare interactions that took place at one of two pediatric hospitals in Canada
Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., ... Boisclair, W. C. (2015). “Respect the way I need to communicate”: healthcare experiences of adults on the autism spectrum. <i>Autism</i> , 19(7), 824–31. doi:10.1177/1362361315576221	Qualitative study exploring the healthcare related experiences of adults with autism by gathering perspectives from 39 adults with autism and 16 individuals with experience supporting adults with autism in healthcare settings.
Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., ... Baggs, A. (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their primary care providers. <i>Journal of International General Medicine</i> , 31(10), 1180–1189. doi:10.1007/s11606-016-3763-6	Report on the development and preliminary evaluation of an online toolkit for adults with autism and their primary care providers aimed at reducing barriers adults with autism face in healthcare interactions
Pratt, K., Baird, G., & Gringras, P. (2011). Ensuring successful admission to hospital for young people with learning difficulties, autism and challenging behaviour: a continuous quality improvement and change management programme. <i>Child: Care, Health and Development</i> , 38(6), 789–797. doi:10.1111/j.1365-2214.2011.01335.x	Report on hospital based quality improvement initiative that involved developing and implementing a checklist assessing aspects of behaviour and communication to facilitate pre-admission planning for youth with autism.

Reference	Article Description
<p>Rainey, L., &amp; Van Der Walt, J. H. (1998). The anaesthetic management of autistic children. <i>Anaesthesia and Intensive Care</i>, 26, 682–686. Retrieved from <a href="https://www.aaic.net.au/">https://www.aaic.net.au/</a></p>	<p>Description of five case studies, accompanied by clinical commentary on approaches to managing children with autism undergoing procedures that require anesthesia.</p>
<p>Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., &amp; Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. <i>Journal for Specialists in Pediatric Nursing</i>, 15(3), 244–254. doi:10.1111/j.1744-6155.2010.00244.x</p>	<p>Clinical commentary exploring challenges of caring for children with autism in acute healthcare settings, accompanied by discussion of practice implications, including recommended care strategies.</p>
<p>Seid, M., Sherman, M., &amp; Seid, A. B. (1997). Perioperative psychosocial interventions for autistic children undergoing ENT surgery. <i>International Journal of Pediatric Otorhinolaryngology</i>, 40(2–3), 107–13. doi:10.1016/S0165-5876(97)01507-3</p>	<p>Clinical commentary accompanied by case studies highlighting behavioural strategies proposed to enhance the perioperative experiences of children with autism undergoing ear, nose, and throat surgeries.</p>
<p>Solomon, O., Angell, A., Yin, L., &amp; Lawlor, M. (2015). “You can turn off the light if you’d like”: pediatric health care visits for children with autism spectrum disorder as an interactional achievement. <i>Medical Anthropology Quarterly</i>, 29(4), 531–555. doi:10.1111/maq.12237</p>	<p>Discourse analysis of interactions that occur between HCP, parents, and children with autism during pediatric health care visits</p>
<p>Solomon, O., Heritage, J., Yin, L., Maynard, D., &amp; Bauman, M. (2016). “What brings him here today?”: medical problem presentation involving children with autism spectrum disorders and typically developing children. <i>Journal of Autism and Developmental Disorders</i>, 46(2), 378–393. doi:10.1007/s10803-015-2550-2</p>	<p>Conversation and discourse analyses used to facilitate comparison of healthcare visits involving children with autism to visits involving children without autism.</p>



Reference	Article Description
Strunk, J. A., Pickler, R., McCain, N., Ameringer, S., & Myers, B. (2014). Managing the healthcare needs of adolescents with autism spectrum disorder: the parents' experience. <i>Families, Systems, and Health</i> , 32(3), 328–337. doi:10.1037/a0037180	Qualitative study exploring the perspectives of 12 parents of children with autism whose children had undergone procedures requiring anesthesia, in the presence and absence of a 'perioperative dialogue'
Taghizadeh, N., Davidson, A., Williams, K., & Story, D. (2015). Autism spectrum disorder (ASD) and its perioperative management. <i>Pediatric Anesthesia</i> , 25(11), 1076–1084. doi:10.1111/pan.12732	Narrative review of literature on autism and the perioperative management of individuals with autism
Thompson, D. G., & Tielsch-Goddard, A. (2014). Improving management of patients with autism spectrum disorder having scheduled surgery: optimizing practice. <i>Journal of Pediatric Health Care</i> , 28(5), 394–403. doi:10.1016/j.pedhc.2013.09.007	Report of quality improvement initiative that involved the development and preliminary evaluation of the implementation of a pre-surgical telephone survey tool that gathered information from parents of children with autism scheduled for surgery on the individual needs of their child. The information gathered through the tool was in turn printed and placed on the child's chart to facilitate coordination of care on the day of the child's scheduled procedure.
van der Walt, J. H., & Moran, C. (2001). An audit of perioperative management of autistic children. <i>Paediatric Anaesthesia</i> , 11(4), 401–408. doi:10.1046/j.1460-9592.2001.00688.x	Retrospective chart audit of the perioperative management of children with autism
Vlassakova, B. G., & Emmanouil, D. E. (2016). Perioperative considerations in children with autism spectrum disorder. <i>Current Opinion in Anaesthesiology</i> , 29(3), 359–366. doi:10.1097/ACO.0000000000000325	Narrative review summarizing literature that informs perioperative considerations related to caring for children with autism

Reference	Article Description
<p>Zwaigenbaum, L., Nicholas, D. B., Muskat, B., Kilmer, C., Newton, A. S., Craig, W. R., ... Sharon, R. (2016). Perspectives of health care providers regarding emergency department care of children and youth with autism spectrum disorder. <i>Journal of Autism and Developmental Disorders</i>, 46(5), 1725–1736. doi:10.1007/s10803-016-2703-y</p>	<p>Qualitative study exploring 22 HCP perspectives on strategies for improving the experiences of youth with autism presenting to emergency departments.</p>
<p><i>Note.</i> HCP = healthcare provider</p>	

Table 4.2  
*Brief Overview of Stakeholder Engagement Meetings Included as Data Sources*

Time frame	Individuals	Focus of meeting
Spring, Summer, Fall 2015	27 individuals, including representatives from anesthesiology, psychology, child life, nursing, dentistry, administration (4 of whom had participated in initial qualitative study these individuals also participated in the interviews)	Ten meetings with various subgroups of stakeholders focused on presentation of findings from the, discussion of 'where to go next', initial discussions about what an intervention aimed at increasing the capacity of HCP to deliver high-quality surgery related care to children with autism might entail
Spring 2016	31 individuals, including representatives from the autism community (parents and advocates), anesthesiology, dentistry, child life, nursing, and hospital administration	Eleven meetings held with various subgroups of stakeholders focused on introducing initial ideas for the intervention, discussing and developing content, and discussing the most appropriate mode for intervention delivery
Spring, Summer 2016	20 individuals, including children with autism, parents of children with autism, autism advocates, psychologists (JC and IS), nurses, anesthesiologists, and a pediatric dentist	Sixteen filming sessions, that involved consulting with stakeholders in the videos to refine and then film intervention content.

*Note.* Informal meetings (e.g., hallway conversations) and email communications with stakeholders where in addition to formal meetings described in this table. HCP = healthcare provider.

Table 4.3

*Proposed Relationships Between Determinants and Selected Behaviour Change Techniques*

Behaviour Change Techniques	Psychological Capability	Social Opportunity	Physical Opportunity	Reflective Motivation	Automatic Motivation
1.1 Goal setting				■	
1.2 Problem solving	■				
2.2 Feedback on behaviour	■				■
2.7 Feedback on outcomes(s) of behaviour	■			■	
3.1 Social support (unspecified)		■			■
3.2 Social support (practical)	■	■			
3.3 Social support (emotional)		■			
4.1 Instruction on how to perform behaviour	■		■		
4.3 Re-attribution					■
5.2 Salience of consequences	■			■	
5.3 Information about social and environmental consequences	■			■	
5.5 Anticipated regret				■	
5.6 Information about emotional consequences	■			■	
6.1 Demonstration of behaviour	■				
6.2 Social Comparison		■		■	
6.3 Information about others' approval		■		■	
7.1 Prompts/cues		■	■		
8.1 Behavioural practice/rehearsal	■			■	■
9.1 Credible source		■		■	■
10.3 Non-specific reward					■
10.4 Social reward					■
10.6 Non-specific incentive					■
11.2 Reduce negative emotions	■				
11.3 Conserving mental resources	■				
12.5 Adding objects to the environment			■		
13.2 Framing/reframing				■	■
15.1 Verbal persuasion about capability				■	■
16.1 Imaginary punishment				■	
16.2 Imaginary reward					■
16.3 Vicarious consequences				■	

*Note.* Behaviour Change Techniques are from Michie et al., 2013. Mapping process was informed by guidance in Michie et al., 2014.

Table 4.4

*Examples of Links Between Behavioural Determinants, Behaviour Change Techniques, and Intervention Content*

Determinant	Sample Linked BCTs	Sample intervention content
Psychological Capability	Demonstration of behaviour	E-modules include training videos that demonstrate how HCP can deliver FCC and use the toolkit of resources to facilitate the same.
	Behavioural rehearsal	E-modules train and enable HCP delivery of FCC through the provision of case studies that facilitate rehearsal of FCC.
	Reduce negative emotions	E-modules provide education on coping strategies HCP can use to manage thoughts and feelings that interfere with the delivery of FCC
Social opportunity	Information about others' approval	E-modules include videos of children with ASD and families persuasively advocating the importance of FCC
Physical opportunity	Adding objects to the environment	A toolkit of resources introduced to unit to enable HCP to deliver FCC
Reflective motivation	Information about social and environmental consequences	E-modules include videos, written, and verbal information to educate HCP about the consequences of FCC
	Credible source	E-module content is delivered by individuals with relevant experience (e.g., HCP, children with ASD, families)
	Goal Setting (behaviour)	E-modules include activities that enable HCP to set goals for enhancing their use of FCC
Automatic motivation	Non-specific reward	Provision of 'autism-friendly' pin to HCP who complete e-modules
	Framing/reframing	E-module content persuading HCP to adopt the perspective that they are well-equipped for and are critical to the delivery of FCC, and that HCP delivering FCC is valuable regardless of child and family responses or outcomes.

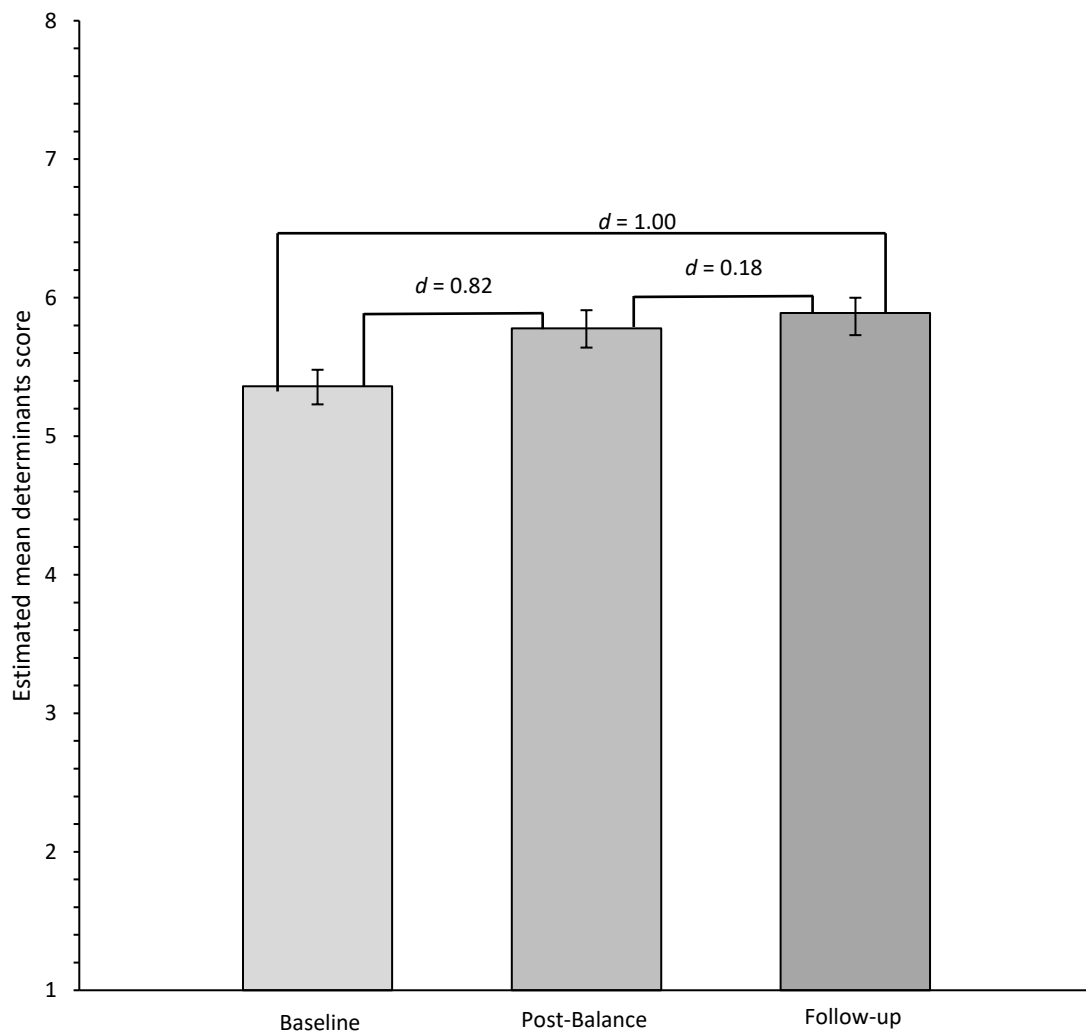
*Note:* Behaviour Change Techniques are from Michie et al. (2013). BCTs = behaviour change techniques; FCC = family-centred care; HCP = healthcare providers; ASD = autism spectrum disorder

Table 4.5

*Results from Linear Mixed-Effects Models and Post-Hoc Comparisons Exploring Change from Baseline, to Post-BALANCE Implementation, and Follow-up in Capability, Opportunity, and Motivation Subscale Scores*

	Fixed effect of time						Post-hoc comparisons		
	<i>M (SE)</i>			<i>df</i>	<i>F</i>	<i>p-value</i>	<i>d (p-value)</i>		
	<b>Baseline</b>	<b>Post</b>	<b>Follow-up</b>				<b>Baseline to Post</b>	<b>Post to Follow-up</b>	<b>Baseline to Follow-up</b>
<b>Capability</b>	5.74 (0.08)	6.40 (0.09)	6.42 (0.10)	(2, 91.97)	43.182	< 0.001	0.99(<0.001)	0.14(1.00)	1.02(< 0.001)
<b>Opportunity</b>	5.72 (0.08)	6.05 (0.09)	6.14 (0.09)	(2, 95.54)	15.19	< 0.001	0.52(< 0.001)	0.15(0.82)	0.68(< 0.001)
<b>Motivation</b>	4.95 (0.07)	5.26 (0.08)	5.40 (0.08)	(2, 92.05)	26.54	< 0.001	0.55(< 0.001)	0.25(0.12)	0.80(< 0.001)

*Note.* Mean values reflect estimated marginal means, and thus may not reflect the true mean values. Post hoc comparisons adjusted using Bonferroni corrections.



*Figure 4.1* Estimated Marginal Mean Determinants Score at Baseline, Post-BALANCE Implementation, and Three-month Follow-up. Error bars represent 95% Confidence Intervals, and  $d$  represents estimated Cohen's effect size for difference between time points.

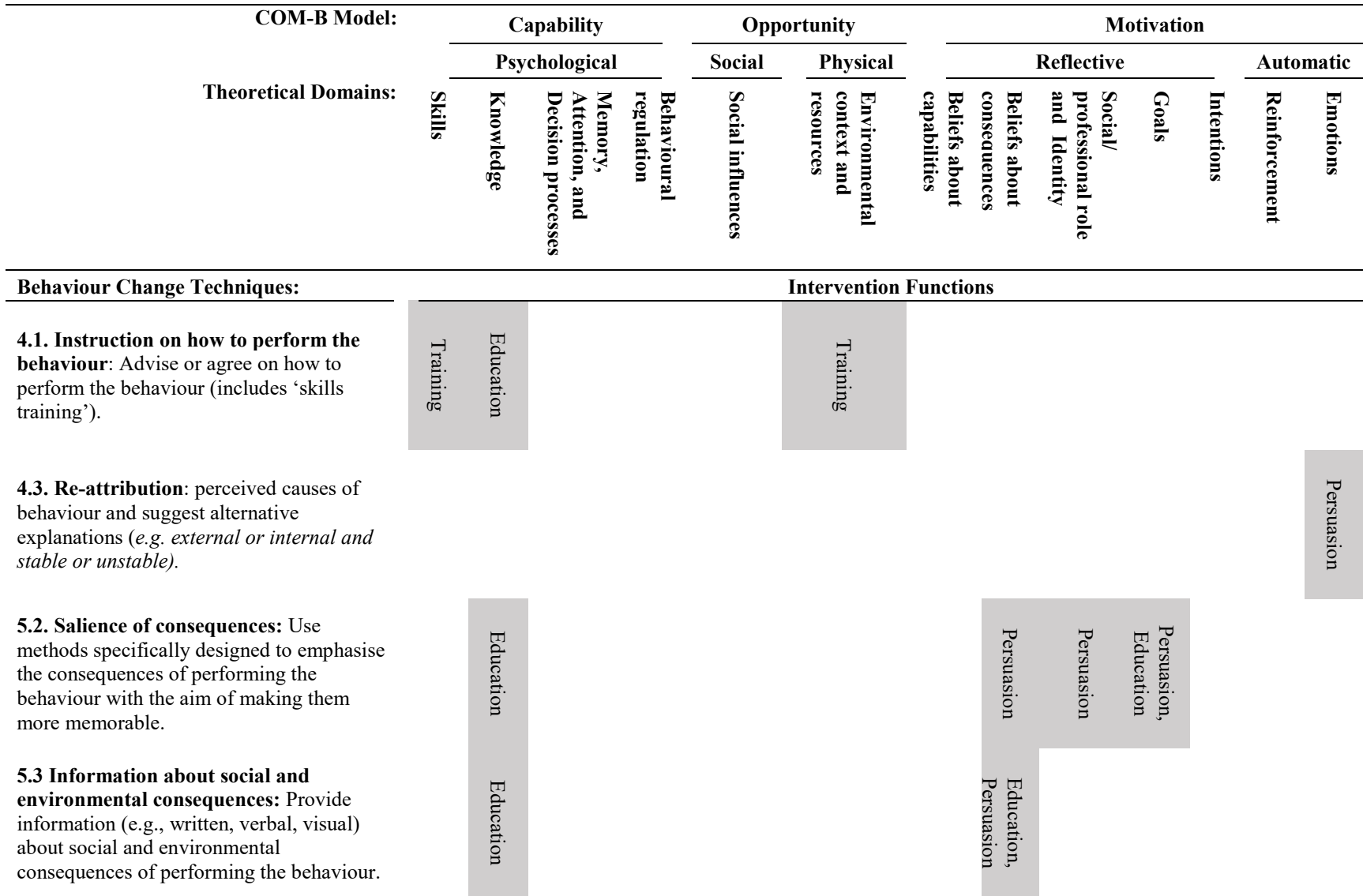
Supplemental Table 4.1

Full Mapping of Targeted Aspects of Capability, Opportunity, and Motivation to Theoretical Domains, and Behaviour Change Techniques, via Proposed Intervention Functions

COM-B Model:		Capability		Opportunity		Motivation						
Theoretical Domains:		Psychological		Social	Physical	Reflective		Automatic				
Skills		Knowledge	Memory, Attention, and Decision processes	Behavioural regulation	Social influences	Environmental context and resources	Beliefs about consequences	Beliefs about professional role and Identity	Goals	Intentions	Reinforcement	Emotions
Behaviour Change Techniques:		Intervention Functions										
<p><b>1.1. Goal setting (behaviour):</b> Set or agree a goal defined in terms of the behaviour to be achieved.</p>		<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> </div>										
<p><b>1.2. Problem solving:</b> Analyse, or prompt the person to analyse, factors influencing the behaviour and generate or select strategies that include overcoming barriers and/or increasing facilitators (includes ‘relapse prevention’ and ‘coping planning’).</p>		<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> </div>										
<p><b>2.2. Feedback on behaviour:</b> Monitor and provide informative or evaluative feedback on performance of the behaviour (e.g., form, frequency, duration, intensity).<sup>a</sup></p>		<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> <div style="width: 10%;"></div> </div>										







COM-B Model:	Capability			Opportunity		Motivation					
	Psychological			Social	Physical	Reflective			Automatic		
	Skills	Knowledge	Memory, Attention, and Decision processes	Social influences	Environmental context and resources	Beliefs about consequences	Beliefs about capabilities	Social/ professional role and Identity	Goals	Intentions	Reinforcement

Theoretical Domains:

**Behaviour Change Techniques:**

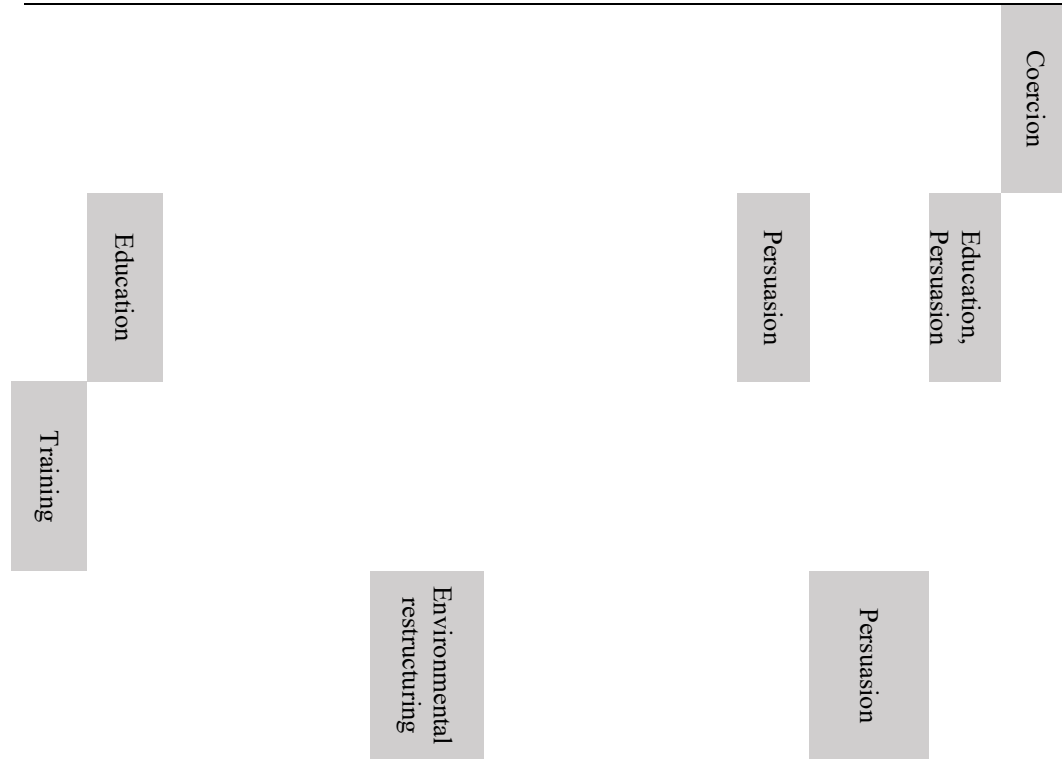
**Intervention Functions**

**5.5 Anticipated regret:** Induce or raise awareness of expectations of future regret about performance of the unwanted behaviour.

**5.6 Information about emotional consequences:** Provide information (e.g., written, verbal, visual) about emotional consequences of performing the behaviour.

**6.1 Demonstration of behaviour:** Provide an observable sample of the performance of the behaviour, directly in person or indirectly (e.g., via film or pictures for the person to aspire to or imitate), includes 'modelling'.

**6.2 Social comparison:** Draw attention to others' performance to allow comparison with the person's own performance.



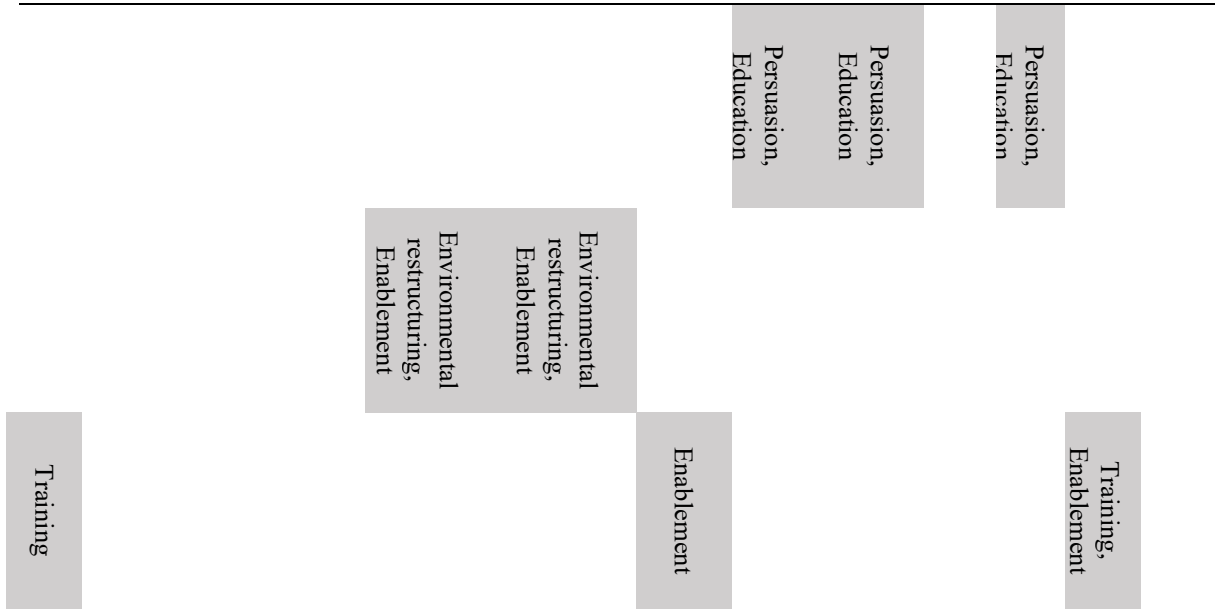
COM-B Model:	Capability		Opportunity		Motivation		
	Psychological		Social	Physical	Reflective		Automatic
	Theoretical Domains:	Skills	Knowledge	Social influences	Environmental context and resources	Beliefs about consequences	Beliefs about professional role and Identity
		Memory, Attention, and Decision processes				Goals	Reinforcement
		Behavioural regulation				Intentions	

**Behaviour Change Techniques: Intervention Functions**

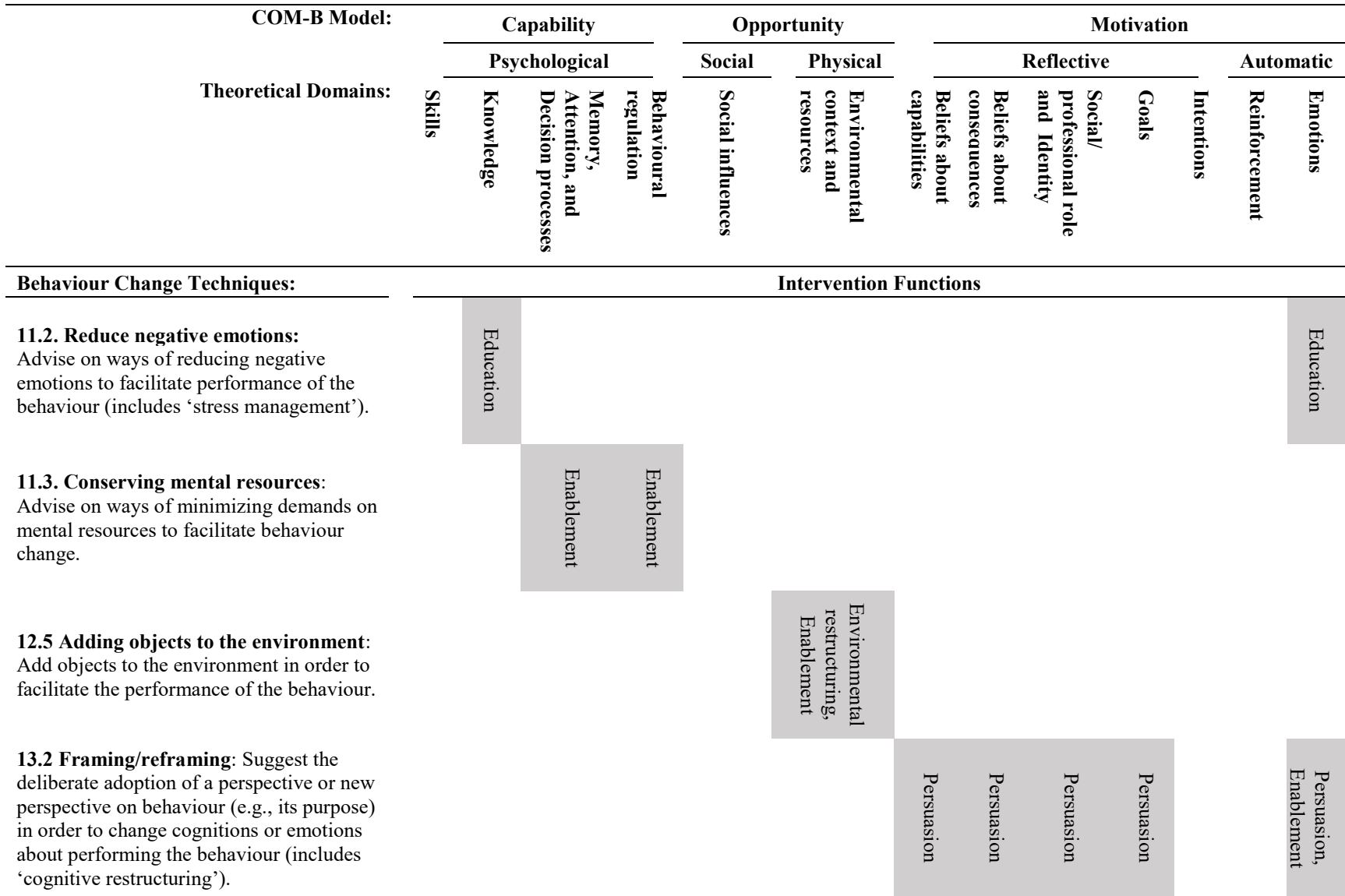
**6.3 Information about others' approval:**  
 Provide information about what other people think about the behaviour. The information clarifies whether others will like, approve or disapprove of what the person is doing or will do.

**7.1 Prompts/cues:** Introduce or define an environmental or social stimulus with the purpose of prompting or cueing the behavior. The prompt or cue would normally occur at the time or place of performance.

**8.1 Behavioural practice/rehearsal:**  
 Prompt practice or rehearsal of the performance of the behaviour one or more times in a context or at a time when the performance may not be necessary, in order to increase habit and skill.



COM-B Model:	Capability		Opportunity		Motivation						
	Psychological		Social	Physical	Reflective			Automatic			
	Skills	Knowledge	Social influences	Environmental context and resources	Beliefs about consequences	Beliefs about capabilities	Social/professional role and Identity	Goals	Intentions	Reinforcement	Emotions
<b>Theoretical Domains:</b>											
<b>Behaviour Change Techniques:</b>	<b>Intervention Functions</b>										
<p><b>9.1 Credible source.</b> Present verbal or visual communication from a credible source in favour of or against the behaviour.</p> <p><b>10.3 Non-specific reward:</b> Arrange delivery of a reward if and only if there has been effort and/or progress in performing the behaviour (includes ‘positive reinforcement’).</p> <p><b>10.4 Social reward:</b> Arrange verbal or non-verbal reward if and only if there has been effort and/or progress in performing the behaviour (includes ‘positive reinforcement’).</p> <p><b>10.6. Non-specific incentive:</b> Inform that a reward will be delivered if and only if there has been effort and/or progress in performing the behaviour (includes ‘positive reinforcement’).</p>			Modelling, Environmental Restructuring			Modelling, Persuasion	Persuasion	Persuasion	Persuasion	Persuasion	
											Incentivization
											Incentivization
											Incentivization



COM-B Model:	Capability		Opportunity		Motivation					
	Psychological		Social	Physical	Reflective		Automatic			
	Skills	Knowledge	Social influences	Environmental context and resources	Beliefs about consequences	Beliefs about capabilities	Goals	Intentions	Reinforcement	Emotions
Theoretical Domains:	Behavioural regulation	Memory, Attention, and Decision processes			Social/ professional role and Identity					

**Behaviour Change Techniques:**

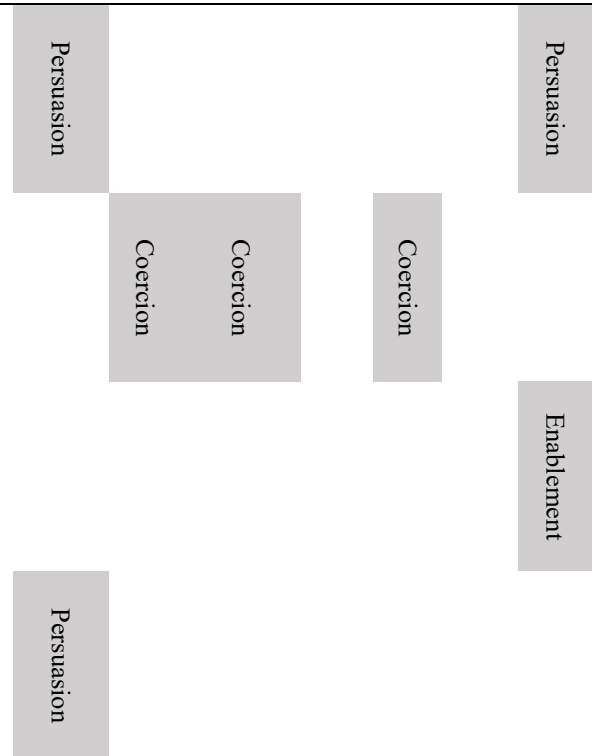
**Intervention Functions**

**15.1 Verbal persuasion about capability:** Tell the person that they can successfully perform the wanted behaviour, arguing against self-doubts and asserting that they can and will succeed.

**16.1 Imaginary punishment:** Advise to imagine performing the unwanted behaviour in a real-life situation followed by imagining an unpleasant consequence.

**16.2 Imaginary reward:** Advise to imagine performing the wanted behaviour in a real-life situation followed by imagining a pleasant consequence.

**16.3 Vicarious consequences:** Prompt observation of the consequences (including rewards and punishments) for others when they perform the behaviour.



*Note.* Behaviour Change Techniques and their definitions are from Michie et al., 2013. Michie et al. (2011) define intervention functions as follows: Enablement = Increasing means/reducing barriers to increase capability or opportunity; Training = Imparting skills; Education = Increasing knowledge or understanding; Persuasion = Using communication to induce positive or negative feelings or stimulate action; Environmental restructuring = Changing the physical or social context; Coercion = Creating expectation of punishment or cost; Modelling = Providing an example for people to aspire to or imitate; Incentivisation = Creating expectation of reward.

<sup>a,b</sup> Feedback delivered in relation to rehearsal of behaviour as prompted by case studies and activities, not on healthcare providers' direct use of the behaviour in vivo in a clinical context.



Supplemental Table 4.2

*Detailed Overview of Intervention Content Labelled by Behaviour Change Techniques*

Description of Intervention Content:	Behaviour Change Technique(s):
<b><u>Module 1</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	
Broad problem description (disparities in care for children with ASD)	
Description of how the intervention was developed	9.1 Credible source
93 Animation highlighting the experience of families, children, and HCPs around the time of surgery	
Discussion of the importance of engaging with program content	9.1 Credible source 15.1 Verbal persuasion about capability
<b><u>Module 2</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	
Video of anesthesiologist discussing best practices with explicit references to clinical experience and research literature, and providing information on how to deliver FCC	4.1 Instruction on how to perform the behaviour 9.1 Credible source 13.2 Framing/reframing
Video of families discussing the importance and power of FCC	5.3 Information and social and environmental consequences 5.6 Information about emotional consequences 9.1 Credible source 13.2 Framing/ reframing

<b>Description of Intervention Content:</b>	<b>Behaviour Change Technique(s):</b>
Review, including written instruction on how to perform the behaviour	4.1 Instruction on how to perform the behaviour 6.3 Information about other's approval
Watching video clips and identifying FCC behaviours, including prompts to consider outcomes of various behaviours, and feedback about ideal responses	2.2 Feedback on behaviour <sup>a</sup> 2.7 Feedback on outcome of behaviour <sup>b</sup> 6.1 Demonstration of the behaviour 16.3 Vicarious consequences 9.1 Credible source
Goal setting activity, including identifying goal behaviour, and potential barriers and facilitators to care	1.1 Goal setting (behaviour) 1.2 Problem solving 16.2 Imaginary reward
Written encouragement suggesting HCPs recognize and praise colleagues if they notice them engaging in any of the FCC behaviours	3.1 Social support (unspecified)
<b><u>Module 3</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	
Provision of information about ASD	
Videos of children with ASD providing information about how to assess and address their social, emotional, and communication needs, with prompts to rehearse how knowledge informs practice, followed by written summaries of the key information provided in videos	4.1 Instruction on how to perform the behaviour 5.3 Information about social and environmental consequences 5.6 Information about emotional responses 6.3 Information about others' approval 8.1 Behavioural practice/rehearsal 9.1 Credible source
Prompt for HCPs to identify a time when they made assumptions about a child with ASD that were not based on an individual assessment of needs, and discussion of potential consequences	5.2 Salience of consequences 16.1 Imaginary punishment

<b>Description of Intervention Content:</b>	<b>Behaviour Change Technique(s):</b>
Video providing overview of toolkit introduced to unit	4.1 Instruction on how to perform the behaviour 9.1 Credible source
Discussion of potential utility of the toolkit	11.3 Conserving mental resources
Video of HCP demonstrating how to use toolkit with family	4.1 Instruction on how to perform the behaviour 6.1 Demonstration of the behaviour 9.1 Credible source
Prompt for HCP to set goals about using toolkit	1.1 Goal setting (behaviour)
Prompt reflection on goals around increasing FCC	1.5 Review behaviour goals
Provision of links to additional resources and information about ASD	
<b><u>Module 4</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	
Video clips of families talking about challenges they experience in the healthcare system, followed by prompts asking HCPs to identify thoughts and feelings that were expressed in the videos	5.6 Information about emotional consequences 8.1 Behavioural practice/rehearsal 9.1 Credible source
Video clips of families providing information about what HCPs can do to help, with prompts asking HCPs to identify FCC discussed by families, followed by written summary	4.1 Instruction on how to perform behaviour 6.3 Information about other's approval 8.1 Behavioural practice/rehearsal 9.1 Credible source
Video clip of HCP modelling how to partner with families despite not being able/willing to do exactly what they hoped, accompanied by written statement clarifying that partnering with families doesn't always mean doing what they ask	4.1 Instruction on how to perform behaviour 6.1 Demonstration of behaviour 9.1 Credible source

<b>Description of Intervention Content:</b>	<b>Behaviour Change Technique(s):</b>
Video clip of mother speaking to the relief she experiences when she trusts that she can hand over some of the responsibility to HCPs, accompanied with a written statement clarifying that it is critical for HCPs to think about how to collaborate with families without over-relying on them	4.1 Instruction on how to perform behaviour 5.6 Information on emotional consequences of behaviour 6.3 Information about other's approval 9.1 Credible source
Animation describing empathy, what it is, what it is not, and what steps are involved in expressing it, followed by a written summary of key points	4.1 Instruction on how to perform behaviour 5.3 Information about the social and environmental consequences 5.5 Anticipated regret 5.6 Information about emotional consequences 6.1 Demonstration of the behaviour
Video clip of mother describing challenging experienced faced accompanied by activity prompting HCPs to reflect on how they would express empathy, followed by another clip of the mother expressing what she might have liked to have heard, and a prompt for HCPs to consider how the absence of empathy in challenging situations might impact family's relationships with healthcare systems.	5.2 Salience of consequences 6.3 Information about other's approval 8.1 Behavioural practice/rehearsal 9.1 Credible source
Video clips of families discussing the positive impact of HCPs partnering with them and expressing empathy	5.3 Information about the social and environmental consequences 5.6 Information about emotional consequences 6.3 Information about other's approval 9.1 Credible source 13.2 Framing/reframing
<b><u>Module 5</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	

Description of Intervention Content:	Behaviour Change Technique(s):
Provision of didactic/written information on the critical role of HCPs, statement that HCPs thoughts and feelings impact their ability to engage in their role, and acknowledgement of reasons why HCPs may feel less comfortable caring for children with ASD	3.1 Social support (unspecified) 5.3 Information about social and environmental consequences 5.6 Information about emotional consequences 13.2 Framing/reframing 15.1 Verbal persuasion about capability
Video clips of HCPs discussing experiences caring for children with ASD, followed by prompt for HCPs to consider whether they relate to the experiences	5.3 Information about social and environmental consequences 5.6 Information about emotional consequences 6.2 Social comparison 9.1 Credible source
Activity prompting HCPs to reflect on thoughts and feelings they have experienced when caring for children with ASD.	1.2 Problem solving 5.6 Information about emotional consequences 8.1 Behavioural practice/rehearsal
Written discussion of relationship between HCPs thoughts and feelings and their practice.	4.1 Instructions on how to perform behaviour 13.2 Framing/reframing
Videos of HCPs reflecting on how their own thoughts and feelings have impacted their practice	5.3 Information about social and environmental consequences 5.6 Information about emotional consequences 6.2 Social comparison 9.1 Credible source
Activity prompting HCPs to reflect on and identify positive and negative ways that thoughts and feelings have impacted their practice, accompanied by discussion emphasizing that thoughts and feelings can be helpful or unhelpful	8.1 Behavioural practice/rehearsal 13.2 Framing/reframing
Video of HCP normalizing the experience of having difficult thoughts and feelings interfere with the delivery of care to children with ASD	3.1 Social support (unspecified) 9.1 Credible source

Description of Intervention Content:	Behaviour Change Technique(s):
<p>Provision of information about coping strategies HCPs can use to manage challenging thoughts and feelings, followed by a reflection activity that asks HCPs to identify which coping strategies they feel will be most helpful for them</p> <p>Additional resources providing HCPs with information about supports available to them if they are experiencing chronic and persistent levels of stress (regardless of whether it relates to the delivery of FCC to children with ASD)</p>	<p>1.2 Problem solving 11.2 Reduce negative emotions 13.2 framing/reframing</p>
<b><u>Module 6</u></b>	
Introduction to people featured in modules	9.1 Credible source
Learning objectives	
Video clip of HCP providing an example of how systemic challenges to interprofessional care coordination negatively impact children and families experience	<p>5.3 Information about social and environmental consequences 5.6 Information about emotional consequences 9.1 Credible source</p>
Goal setting activity, including identifying goals for how to contribute to systems level changes, and reminder of goals set in module 3 and 4	1.1 Goal setting
Video clip of HCP reflecting on how inter-professional collaboration would have facilitated improved coordination of care	9.1 Credible source
Video clip of HCP acknowledging that disagreements occur between HCP's with regards to how to best care for the child, accompanied by a prompt for HCP to list two reasons why others might have a different approach than they would, which is then followed by a list of possible alternative explanations	<p>4.3 Re-attribution 9.1 Credible source 13.2 Framing/reframing</p>
Blame' animation, that discusses blame, how common it is, what blame offers, and how it impacts relationships	<p>5.3 Information about social consequences 5.5 Anticipated regret 5.6 Information about emotional consequences</p>

Description of Intervention Content:	Behaviour Change Technique(s):
Video clip of HCP acknowledging having 'blamed' colleagues when things did not go well, accompanied by prompt for HCPs to consider whether they can relate to this experience, and written information normalizing this experience	6.2 Social comparison 9.1 Credible source
Video clip of HCP reflecting on how 'blame' impacted their ability to collaborate with their colleagues, accompanied by prompt for HCP to identify what they noticed about how the HCP in the video's frustration and blame impacted their relationship with their team, followed by a written summary	9.1 Credible source 16.3 Vicarious consequences
Video clip of HCP discussing how they could have collaborated with their colleague to understand their perspective, and what the impact of that might have been, followed by a written statement acknowledging that collaboration is hard particularly when HCPs disagree, and a prompt for HCPs to reflect on a time when they disagreed with their colleague but chose not to discuss it and identify reasons for that choice (e.g., I was too busy, I was too frustrated)	1.2 Problem solving 9.1 Credible source 16.3 Vicarious consequences
Written suggestions about how to approach collaboration in the face of disagreements	4.1 Instruction on how to perform the behaviour
<b><u>Module 7</u></b>	
Learning objectives	
Review of key program ideas	
Case study activity, two case studies followed by questions to facilitate HCPs consideration of how to apply knowledge gained from practice to each case	8.1 Behavioural practice/rehearsal

<b>Description of Intervention Content:</b>	<b>Behaviour Change Technique(s):</b>
Congratulatory message, followed by video of families, children, and HCPs that participated in the program content development expressing appreciation and gratitude for HCPs taking the time to complete the program	6.3 Information about other's approval 10.4 Social reward
Detailed written feedback on case studies	2.2 Feedback on behaviour <sup>a</sup> 2.7 Feedback on outcome(s) of behaviour <sup>b</sup> 10.4 Social reward
<b><u>Intervention components external to the e-modules</u></b>	
Access to champions	1.2 Problem solving 3.1 Social support (unspecified) 3.2 Social support (practical) 3.3 Social support (emotional)
White boards	7.1 Prompts/cues 12.5 Adding objects to the environment
Provision of 'autism-friendly' pin at program completion	10.3 Non-specific reward
Toolkits	7.1 Prompts/cues 12.5 Adding objects to the environment
Detailed written feedback on case studies	2.2 Feedback on behaviour <sup>a</sup> 2.7 Feedback on outcome(s) of behaviour <sup>b</sup> 10.4 Social reward
Posters to communicate purpose of cues to HCPs not participating in the program	7.1 Prompts/cues
Emails praising progress in completing the program	10.4 Social reward
Feedback from families	10.4 Social reward
Opportunity to obtain professional development credits	10.6 Non-specific incentives



*Note.* Behaviour Change Techniques are from Michie et al. (2013). All of the intervention content is described in this table, however based on the definitions of Behaviour Change Techniques provided by Michie et al. (2013) not all of the content intervention content could be coded. This applied to all intervention content where the second column appears blank in the table (e.g., Learning Objectives). HCP = Healthcare Provider; FCC = family-centred care; ASD = autism spectrum disorder.

<sup>a,b</sup> Feedback delivered in relation to rehearsal of behaviour as prompted by case studies and activities, not on HCPs' direct use of the behaviour in vivo in a clinical context.

CHAPTER 5. MANUSCRIPT 3: BUILDING ALLIANCES FOR AUTISM NEEDS IN CLINICAL ENCOUNTERS: FEASIBILITY, USABILITY, AND MIXED-METHODS PILOT EVALUATION OF A NOVEL INTERVENTION TO IMPROVE PERIOPERATIVE CARE FOR CHILDREN WITH AUTISM

Readers are advised that Ms. Stephanie Snow, under the supervision of Drs. Jill Chorney and Isabel Smith, was primarily responsible for the planning and conduct of the pilot evaluation described in this manuscript. Ms. Snow trained and supervised research staff involved in this study, completed and oversaw data collection, processed the data and completed the statistical analyses, wrote the manuscript, and revised it in accordance with suggestions from her co-supervisors (Drs. Chorney and Smith). Key stakeholders engaged in the development of the intervention piloted in this study (i.e., Dr. Sally Bird, Carolyn Doucet, Dr. Heather Dymant, Leigh-Anne Marshall, Jenny Tyler, Nancy Walker, and Dr. Stuart Wright), as well as stakeholders instrumental to the organization and running of this pilot (i.e., Dr. Sally Bird, Carolyn Doucet, Dr. Heather Dymant, Dr. Stuart Wright, Leigh-Anne Marshall, and Drs. Sally Bird) will be invited to contribute feedback and be included as co-authors prior to this manuscript being submitted for peer review. Ms. Snow completed the research described in this manuscript in consultation with her dissertation committee members, Drs. Margot Latimer and Sherry Stewart, who provided guidance on data analyses and editorial feedback.

## ABSTRACT

**Background:** Building ALiances for Autism Needs in Clinical Encounters (BALANCE) is an intervention designed to improve the delivery of family-centred care to children with autism. BALANCE consists of seven online learning modules for healthcare providers, a toolkit of resources, and communications regarding these resources. This study assessed the feasibility of implementing BALANCE on a pediatric day surgery unit, evaluated the usability and acceptability of the BALANCE modules, and explored whether implementation was associated with positive shifts in healthcare providers' (HCPs') or caregivers' ratings of healthcare delivered to children with autism.

**Method:** Participants included HCPs working in the pediatric day surgery unit and caregivers (i.e., parents and guardians) of children with autism undergoing day surgery in the 3-month periods before and after BALANCE implementation. Descriptive statistics were used to summarize tracking data and HCPs' reports related to the feasibility of BALANCE implementation. Descriptive statistics, qualitative analyses, and linear mixed-effects models were used to analyze quantitative and qualitative reports by HCPs of the usability and acceptability of the BALANCE modules, as well as the delivery of care to children with autism. The quality of care delivered to children with autism was compared based on reports by caregivers who participated before and after BALANCE implementation. **Results:** Seventy multidisciplinary HCPs (nursing, anesthesiology, pediatric dentistry, surgery) consented to participate (66% of eligible staff). Of these, 62 started BALANCE and 53 completed all modules. Healthcare providers agreed that learning objectives were met, and engaged with most interactive questions / activities embedded throughout the program. Quantitative ratings by HCPs reflected that the

BALANCE program was usable and acceptable, and qualitative feedback highlighted how BALANCE helped them to consider how to enhance their approach to care.

Caregivers and HCPs both identified positive shifts in the delivery of family-centred care to children with autism associated with BALANCE implementation. **Conclusions:** This study provides preliminary support for the feasibility, usability, and acceptability of BALANCE. Initial qualitative and quantitative support was indicated for BALANCE's potential to improve the approach to delivering care to children with autism. Definitive trials will be needed to determine the effectiveness of BALANCE.

## Introduction

The complex and chronic healthcare needs of individuals with autism spectrum disorder (hereafter, autism) necessitate ongoing and frequent interactions with healthcare services (Bethell, Lindly, Kogan, & Zuckerman, 2014). Literature examining the healthcare experiences of individuals with autism, their families, and healthcare providers (HCPs) highlight difficulties when accessing services (Bethell et al., 2014; Kogan et al., 2008). For example, despite increased rates of service use and expenditures, children with autism have more unmet healthcare needs (Casagrande & Ingersoll, 2017; Chiri & Warfield, 2012; Zablotzky et al., 2015). Caregivers have expressed feelings of frustration and helplessness in the face of healthcare systems that seem to fail their children by design (Bultas, 2012; Lindberg, von Post, & Eriksson, 2012; Muskat et al., 2015) and have expressed dissatisfaction with quality of care delivered to their children (Brachlow, Ness, McPheeters, & Gurney, 2007; Kogan et al., 2008). Healthcare providers also report a lack of confidence in their own and their system's ability to care for children with autism (Bultas, McMillin, & Zand, 2016; Johnson & Rodriguez, 2013; Will, Barnfather, & Lesley, 2013). Understandably, some children with autism become overwhelmed and distressed by the fast paced, sensory stimulating, and often unpredictable healthcare context. This may have a cascading impact on caregivers and HCPs, leading to worry, tension, stress, and potential loss of trust (Mitchell & Hauser-Cram, 2008; Pratt, Baird, & Gringas, 2011).

Recognition that healthcare systems could do more to improve experiences for this growing population of service users has led to increased and varied efforts. Editorials, commentaries, reviews, consensus-driven guidelines, qualitative research, and

quality improvement studies point to the central importance of ensuring that care is informed by, and responsive to, individual needs (e.g., Gimpler Berglund, Björkman, Enskär, Faresjö, & Huus, 2017; Johnson & Rodriguez, 2013; Muskat et al., 2015; Taghizadeh, Davidson, Williams, & Story, 2015). For example, the implementation of individualized care plans has been associated with improvements in caregiver ratings of hospital experiences (Broder-Fingert et al., 2016). Coordination of care among HCPs has also been stressed as an important part of best-practice recommendations, as communication and coordination gaps have been implicated in increasing the stress and burden of the healthcare experience (Muskat et al., 2015; Nicholas et al., 2016; Chapter two). Research conducted by our team (see Chapter 2) and others also highlights the importance of interpersonal aspects of care delivery including empathic and compassionate HCP-caregiver partnerships (Casagrande & Ingersoll, 2017; Solomon, Angell, Yin, & Lawlor, 2015; Solomon, Heritage, Yin, Maynard, & Bauman, 2016). Consolidating research to date, the best-practice approach to delivering healthcare for youth with autism can be operationalized as family-centred care that involves 1) partnering with families, 2) assessing the needs of each child and tailoring care accordingly, 3) coordinating care through inter-professional collaboration, and 4) expressing empathy and warmth.

In partnership with key stakeholders (HCPs, parents/caregivers, and children with autism), we developed an intervention targeting HCPs and the system within which they work. The intervention, Building ALLiances for Autism Needs in Clinical Encounters (BALANCE) aims to improve the delivery of family-centred care to children with autism and their families. In brief, BALANCE is delivered through seven online learning

modules (e-modules), a toolkit of resources, and verbal communications regarding newly available resources. Although previous efforts have been made to increase broad-based knowledge about autism (Giarelli, Ruttenberg, & Segal, 2011; Mazurek, Brown, Curran, & Sohl, 2017) and train HCPs to manage children's challenging behaviour (Johnson, Lashley, Stonek, & Bonjour, 2012), to our knowledge, BALANCE is the first program that explicitly intervenes to enhance all aspects that characterize high-quality family-centred care. BALANCE is designed to be systematically implemented within a healthcare unit to address inter-professional and systemic barriers that may otherwise interfere with efforts by individual HCPs to deliver high-quality family-centred care (see Chapter 4 for full description). The initial version of BALANCE focused on perioperative care (i.e., the care of youth immediately before and after surgery), as it was developed in collaboration with HCPs who worked in this area. Moreover, perioperative care is a good model for healthcare interactions (e.g., multiple fast-paced interactions, varied personnel, lack of predictability), and youth with autism also often require general anesthesia for otherwise routine care (e.g., dental procedures, MRI; Arnold et al., 2015; Loo, Graham, & Hughes, 2009; Taghizadeh et al., 2015), which may result in them being exposed to surgical settings more often than their typically developing peers.

The primary aims of the current study were 1) To assess the feasibility of implementing BALANCE on the Day Surgery Unit at a pediatric hospital, and 2) To evaluate usability and acceptability of the BALANCE e-modules. Our secondary aim was to conduct an exploratory examination of the impact of BALANCE implementation. Specifically, we examined whether BALANCE implementation was associated with positive shifts in HCPs' and caregivers' ratings of the quality of care delivered to children

with autism. We also used qualitative analyses to examine HCPs' reports of learning, intention to change their practice, and care delivery following BALANCE.

## **Method**

### **Participants**

Participants in this study included HCPs and caregivers (i.e., parents and guardians) of children with autism. All participants were recruited through the Day Surgery Unit at a Canadian pediatric tertiary care hospital. All HCPs working within the unit were eligible; no exclusion criteria were applied. Given that this was a feasibility study, sample size for HCP participants was determined by pragmatic considerations: we aimed to recruit as many as possible of the approximately 106 eligible HCP affiliated with the Day Surgery Unit. Based on discussions with the unit manager and previous research participation rates, we anticipated recruiting at least 25-30 HCPs. Pertinent to the feasibility of BALANCE, information on the flow of HCPs through BALANCE and the research study is presented in the Results and Figure 5.1.

We also recruited a convenience sample of caregivers (i.e., parents or guardians) of children with autism who underwent day surgery in the same hospital. English-speaking caregivers of children who were identified on the day surgery list or by their families as having autism (i.e., any term denoting an autism spectrum disorder) were eligible. Additional inclusion criteria were that caregivers had accompanied their children to surgery, could complete the survey within a week, and had access to a telephone. We aimed to collect data from two separate cohorts of 25-30 caregivers each, one before and one after BALANCE. In total, 80 (40 pre- and 40 post- BALANCE) caregivers returned



leaflets on the day of their children's surgeries expressing willingness to be contacted by the study team. Of these, 15 could not be reached within seven days, 7 declined to participate, and 3 did not meet diagnostic eligibility criteria. The remaining 55 caregivers participated in the study (30 pre- and 25 post- BALANCE). Data from one caregiver were ultimately excluded based on further information clarifying that the child did not have a diagnosis of autism. Another caregiver was inadvertently recruited twice and reported on two distinct surgical experiences; only the first report was retained for analysis. The final sample consisted of 54 caregivers (30 pre- and 24 post- BALANCE).

### **Procedure**

All study procedures were approved by the hospital research ethics board (see Figure 5.2 for a schematic of the study design). Healthcare providers were informed of this study via emails sent by their manager and profession chiefs, announcements at staff meetings/rounds, and posted flyers. Healthcare provider participants gave informed consent before initiating study procedures. After completing baseline questionnaires, participants were provided with a unique login and password for accessing the BALANCE e-modules. Healthcare providers who finished the BALANCE e-modules were immediately invited to complete a post-program questionnaire, and approximately three months later, a follow-up questionnaire. Baseline, post-program, and follow-up questionnaires were completed via the secure, web-based application REDCap (Research Electronic Data Capture; Harris et al., 2009).

Caregivers were recruited over the 3 months preceding and following BALANCE implementation. Caregivers were informed of this study on the day of their children's surgery via leaflets from HCPs or by reading copies posted throughout the unit.

Caregivers were told that the study was about improving care for children with autism but were blind to the implementation of the study intervention, BALANCE. Interested caregivers filled in their contact information on the leaflet. A research team member who was not involved in BALANCE implementation contacted interested caregivers to conduct the informed consent process and to administer measures two days after surgery. Attempts to contact caregiver participants continued for up to one week. Questionnaires were administered verbally by a research assistant in telephone calls.

### **Description of BALANCE**

BALANCE is an intervention designed to improve the delivery of family-centred care to children with autism. The intervention was informed by a review of the existing literature on recommendations for improving care experiences, a qualitative needs assessment (see Chapter 2), stakeholder engagement, and relevant theories of behaviour change (Behaviour Change Wheel and Theoretical Domains Framework; Michie, Johnston, Francis, Hardeman, & Eccles, 2008; Michie, van Stralen, & West, 2011). Key steps in the design and development process included 1) operationalizing family-centred care as the target set of behaviours, 2) clarifying individual, inter-personal, and systemic barriers to family-centred care, 3) identifying behaviour change techniques with the potential to address barriers and to change the delivery of family-centred care, 4) consulting with stakeholders to select a feasible mode of delivery, and 5) translating behaviour-change techniques into the intervention components. Further detailed information on theoretical underpinnings, the design and development process, as well as the impact of BALANCE implementation on barriers to family-centred care is reported elsewhere (see Chapter 4).

Table 3 provides an overview of BALANCE intervention components that were delivered to individual HCPs via seven interactive e-modules, as well as through minor restructuring of the Day Surgery environment (e.g., introduction of a toolkit of resources). Stakeholders participated in the development of content for all e-modules, and are featured in videos providing information (e.g., children with autism describing characteristics of autism), demonstrating skills (e.g., nurses demonstrating how to assess individual needs), or using persuasive communication (e.g., parents talking about their experiences of children's healthcare).

The e-modules were released systematically over four weeks; Modules 1 and 2 were released at the beginning of the first week, followed by Module 3 and release of the physical toolkits in the second week, Modules 4 and 5 in the third week, and Modules 6 and 7 in the fourth week. Healthcare providers were emailed notifications when modules were released that provided encouragement and summarized their e-module progress. Healthcare providers were permitted to enroll at any point during the roll-out period and were given approximately six weeks from the release of Module 1 to complete all seven modules at their own pace. We anticipated that completing all modules would require about 2 to 2.5 hours, divided over multiple login occasions. The Day Surgery unit manager endorsed BALANCE at staff meetings and via emails and allowed HCPs to complete the e-modules during work hours. Headsets and instructions for accessing and logging into the BALANCE e-modules were placed at computers accessible to HCPs during work hours. Clinical champions (a clinical nurse educator, an anesthesiologist, a child life specialist, and a researcher) shared their experiences of BALANCE with colleagues and were available for consultation regarding implementation throughout the

e-module roll-out period. After participants completed all e-modules, they received individualized feedback on their responses to two case studies that were included in the final module (see Appendix D for sample individualized feedback, which was provided by author SS), an ‘autism friendly’ pin, and a certificate as proof of completion for learning credits. Positive feedback obtained from post-BALANCE families in the 6- and 12-week periods following BALANCE implementation was shared via emails and posters placed throughout the Day Surgery unit (see Appendix E for sample poster).

## **Measures**

**Demographics.** Healthcare providers provided information on their age, sex, education, and professional experience, including past participation in autism-focused learning. Caregivers completed items on their ages, highest level of education, estimated annual income, relationship status, current living situation, relationship with the child with autism, the child’s age, surgery, as well as some key information about the child’s diagnostic and medical history.

**Primary Aim 1: Feasibility.** Feasibility was assessed by tracking HCP enrollment, retention, and rate of progress through e-modules. Engagement with content was also assessed by calculating the proportion of HCP responses to questions/activities that were embedded within the BALANCE e-modules.

### **Primary Aim 2: Usability and Acceptability.**

***Quantitative Ratings of Usability and Acceptability.*** Feedback was solicited at the end of each module on whether HCPs agreed (*yes/no*) that learning objectives had been addressed (e.g., *this module [two] included activities and questions to encourage thinking about the delivery of family-centred care*; see Supplemental Table 5.1 for all

learning objectives). Feedback was also collected at the end of each module using an author-made set of six items informed by the ‘user experience honeycomb,’ a model of critical qualities to consider in web design (Morville & Sullenger, 2010). Items assessed whether the module was useful (*this module was helpful*), usable (*this module was easy to navigate*), desirable (*the presentation of the content in this module contributed to a positive user experience*), valuable (*this module contained valuable information*), accessible (*I felt comfortable working through this module and understood the information presented to me*), and credible (*I trusted the information in this module*). Healthcare providers were asked to respond to each item with a *yes* or *no*, and to suggest *no changes*, *minor changes*, or *major changes*. Upon completion of the BALANCE e-modules, HCPs were asked to respond (*yes*, *no*, or *maybe*) to ten items that assessed their perceptions of the usability of and their satisfaction with BALANCE (e.g., *I was satisfied with the program*, *the time required to complete the intervention was reasonable*, *the program helped me to think about how to enhance my practice*).

***Qualitative Feedback Pertaining to Usability and Acceptability.*** Healthcare providers who indicated that changes were needed in response to the end of module usability and acceptability questions were asked to elaborate. Upon completion of the BALANCE e-modules, HCPs were also invited to respond to the following open-ended questions: *Are there any other changes that would improve this program?* and *Who would benefit most from this program?*

**Secondary Aim: Exploratory Examination of BALANCE Impact.**

***Quantitative HCP Report: Partnering, Assessing Needs, Coordinating Care, and Expressing Empathic Care (PACE).*** The PACE is a 35-item author-made HCP-

report measure of behaviours identified as important for high-quality family-centred care for children with autism (see Appendix F). There were 8 items assessing HCPs' use of behaviours to form partnerships with parents (e.g., *Ask families how they can tell how their children feel*), 6 items assessing HCPs' use of behaviours to assess and address individual children's needs (e.g., *Adapt how I interact with the child based on his or her communication needs*), 11 items assessing HCPs' use of behaviours to coordinate care (e.g., *Communicate with my colleagues about changes to the care plan*), and 10 items assessing HCPs' use of behaviours to express empathy to families (e.g., *Tell families that what they are feeling makes sense*). Item content was informed by a review of existing measures of related constructs (e.g., Four habits coding scheme, Stein, Frankel, & Krupat, 2005; Measure of Processes of Care, King, King, & Rosenbaum, 2004; Individualized Care Scale, Suhonen, Leino-Kilpi, & Valimaki, 2005; and Perceptions of Family-Centred Care tool, Shields & Tanner, 2004). Healthcare providers responded using an 8-point scale (1 = *Almost Never*; 2 = *Rarely*; 3 = *Infrequently*; 4 = *Sometimes*; 5 = *Pretty often*; 6 = *Frequently*; 7 = *Most of the time*; 8 = *Almost Always*). One negatively phrased item on the Empathy subscale was reverse-scored. Estimated marginal mean frequencies for the overall scale score, as well as Partner, Assess and address, Coordinate, and Empathy subscale scores are reported, with higher scores indicating more frequent use of PACE-consistent behaviours. Internal consistency was good to excellent (all Cronbach's  $\alpha \geq 0.89$ ) for the overall scale score across all three measurement occasions (baseline  $\alpha = 0.89$ , post-implementation  $\alpha = 0.89$ , and follow-up  $\alpha = 0.95$ ). Internal consistency was acceptable to excellent (Cronbach's  $\alpha \geq 0.70$  for scales including more than ten items and  $\alpha \geq 0.60$  for scales with fewer than ten items;

Loewenthal, 1996) across all three measurement occasions for subscales of Partner (baseline  $\alpha = 0.76$ , post-implementation  $\alpha = 0.73$ , and follow-up  $\alpha = 0.83$ ), Assess and address (baseline  $\alpha = 0.77$ , post-implementation  $\alpha = 0.83$ , and follow-up  $\alpha = 0.91$ ), Coordinate (baseline  $\alpha = 0.77$ , post-implementation  $\alpha = 0.80$ , and follow-up  $\alpha = 0.87$ ), and Empathy (baseline  $\alpha = 0.62$ , post-implementation  $\alpha = 0.70$ , and follow-up  $\alpha = 0.79$ ) subscale scores.

***Quantitative Caregiver Report: Family Perceptions of Care Delivery (FPCD).***

The FPCD is a 26-item author-made questionnaire designed to measure caregivers' perspectives on the care delivered to their children with autism (see Appendix G). It consists of 6 items that assessed caregivers' perspectives on whether HCPs partnered with families (e.g., *Healthcare providers asked questions to try and learn from my expertise as a parent*), 6 items that assessed caregivers' perspectives on whether HCPs assessed and addressed their children's individual needs (e.g., *Healthcare providers appeared to have difficulty adjusting their approach to care to meet my child's needs*), 4 items that assessed caregivers' perspectives on whether HCPs collaborated to coordinate their children's care (e.g., *It frustrated me that many of the healthcare providers that we interacted with asked us the same questions*), 8 items that assessed caregivers' perspectives on whether HCPs approached the interaction with empathy and warmth (e.g., *Healthcare providers communicated that they understood our concerns*). The measure also includes 3 items that assessed caregivers' overall impressions of the care provided (e.g., *In a general overall sense, I was satisfied with the care provided by the healthcare providers that we interacted with*). Caregivers were asked to rate each item on a 5-point scale (1 = *Strongly disagree*, 2 = *Disagree*, 3 = *Neither agree nor disagree*, 4 =

*agree, 5 = Strongly agree*). A mean overall scale score, and mean subscale scores for items assessing caregivers' perceptions on whether HCPs 'Partnered', 'Assessed and addressed', 'Coordinated', and 'Empathized', and caregivers' 'General Satisfaction' with care provided were used in the current analysis. Eight negatively phrased items were reverse-scored (1 item on the Partnered subscale, 2 items on the Assessed and addressed subscale, 2 items on the Coordination subscale, 2 items on the Empathy subscale, and 1 item on the General Satisfaction subscale), and higher scores indicated more favourable ratings of care delivery. Internal consistency based on all available family data was excellent (Cronbach's  $\alpha = 0.91$ ) for the overall scale score, and acceptable to good (Cronbach's  $\alpha \geq .70 \leq 0.89$ ) for all subscale scores (Partnered  $\alpha = 0.79$ , Assessed  $\alpha = 0.73$ , Coordinated  $\alpha = 0.75$ , Empathized  $\alpha = 0.77$ , General Satisfaction  $\alpha = 0.85$ ).

***Qualitative HCP Report.*** Healthcare providers were asked open-ended questions about the impact of the BALANCE e-modules on their learning, intentions, and practice. Specifically, at BALANCE e-module completion they were asked, *What did you learn or confirm? (Learning)* and *What changes are you planning to implement into your practice? (Intentions)*, and at follow-up they were asked, *How have you been able to put what you learned into practice over the past two months?* and to *Provide a brief example of a situation in which you put what you learned in the BALANCE program into practice (Practice Change)*.

### **Data Analytic Plan**

Descriptive statistics were used to summarize demographic data. Potential group differences were examined between demographic and descriptive characteristics of HCPs who completed the BALANCE e-modules (i.e., BALANCE completers), and HCP who



began but did not finish the modules (i.e., BALANCE non-completers), as well as between HCPs who completed all study components (i.e., completed BALANCE e-modules and all questionnaires; study completers) versus study non-completers. Potential group differences were also examined and between the pre- and post-BALANCE family cohorts. Chi-square tests, Fisher's exact tests, Likelihood ratios, independent samples t-tests, and Mann Whitney U tests were used as appropriate.

**Primary Aim 1: Feasibility.** Descriptive statistics were used to summarize quantitative data related to the feasibility of BALANCE implementation.

**Primary Aim 2: Acceptability and Usability.** Descriptive statistics were used to summarize HCP quantitative ratings related to the acceptability and usability of BALANCE. Healthcare providers' responses to the open-ended questions about recommended changes at the end of each module and the end of the program, and who would benefit from BALANCE were summarized using a general inductive approach for analyzing qualitative evaluation data (Thomas, 2006). Responses were broken into individual units of analysis, each reflecting a single idea. Codes were derived inductively from the data and were then applied to each unit of analysis. The numbers of HCPs endorsing each code in response to prompts to indicate recommendations and who would benefit from BALANCE were then tabulated.

**Secondary Aim: Exploratory Examination of BALANCE Impact.** An exploratory linear mixed-effect (LME) model conducted using the SPSS mixed procedure (SPSS, 2005) was used to explore potential shifts in HCP ratings on the PACE care questionnaire across time (baseline, post-intervention, 3-month follow-up). The primary analysis examined changes in overall scores across time, and additional exploratory

analyses were conducted to examine changes in subscale scores across time. Linear mixed-effect models are ideally suited to research designs with missing data, non-independent observations, and unequal measurement intervals (Hayat & Hedlin, 2012; Hayes, 2006; McCulloch, 2005). All available data were used to calculate outcomes; restricted maximum likelihood (REML) was used to estimate model parameters. Time was nested within HCPs, using random intercepts and fixed linear slopes. Post hoc analyses compared estimated marginal means from the LME model across adjacent time points, using Bonferroni correction. Effect sizes for post hoc comparisons were calculated as a ratio of the mean difference between estimated marginal means at each measurement occasion over the estimated standard deviation of the sample at baseline (Cohen, 1992; E. Duku, personal communication, February 19<sup>th</sup>, 2019; Taylor, 2014). Cohen's (1992) descriptors were used to interpret the magnitude of ES from all analyses (i.e., .20 = small effect, .50 = medium effect, .80 = large effect).

Differences in mean FPCD scores of caregivers who participated before and after BALANCE implementation were examined using an exploratory independent samples *t*-test and Cohen's *d* ES were calculated and interpreted using Cohen's (1992) descriptors as detailed above. Mean imputation was used to address missing item-level data (0.21%). Imputed values were based on the mean of the item across all remaining participants.

Healthcare providers' responses to open-ended questions on learning, intention and practice were analyzed using a general inductive approach for analyzing qualitative evaluation data (Thomas, 2006). A separate analysis was conducted for each question. Results are summarized descriptively alongside representative quotes.

## Results

### Demographics

Healthcare provider participants included nurses ( $n = 43$ ), anesthesiologists ( $n = 6$ ), surgeons ( $n = 8$ ), pediatric dentists ( $n = 3$ ), child life specialists ( $n = 3$ ), dental residents ( $n = 1$ ), and ward clerks ( $n = 2$ ), between the ages of 26 and 63 years ( $M = 42.95$ ,  $SD = 10.09$ ). Additional HCP demographic information for the full sample ( $N = 66$ ) is summarized in Table 5.1. Sixty-two HCPs began the BALANCE e-modules. Compared to BALANCE e-module completers ( $n = 52$ ), non-completers ( $n = 10$ ) had significantly more years of experience working in their current profession ( $Mdn = 25.00$  vs.  $Mdn = 17.00$ ;  $U = 155.00$ ,  $p = 0.04$ ), and in a pediatric perioperative setting ( $Mdn = 20.25$  vs.  $Mdn = 6.5$ ;  $U = 123.00$ ,  $p = 0.01$ ). In addition, BALANCE non-completers were significantly ( $p < 0.05$ ) slower to complete the baseline questionnaires, and to progress through the modules that they did complete. There were no other differences between BALANCE completers and non-completers, and none between study completers ( $n = 34$ ) and non-completers ( $n = 32$ ).

Overall, caregivers ( $N = 54$ ) ranged in age from 23 to 57 years ( $M = 40.07$ ,  $SD = 8.86$ ) and were primarily mothers (80.0% mothers, 13.3% fathers, 6.7% other guardians) who completed the study an average of three days ( $SD = 1.67$ ) after their children's day surgery. Children ranged in age from 3 to 16 years ( $M = 8.61$ ,  $SD = 3.41$ ) and 81.5% were male. Based on caregiver recollection, the children were on average 3.56 years old ( $SD = 1.54$ ) at the time of autism diagnosis, which 28 children received from the same pediatric hospitals' autism team, and 24 received from a psychologist or physician external to the hospital. The profession of the child's diagnostic provider could not be

determined for two children. Most children underwent day surgery for a dental procedure (75.9%) and had prior day surgical experiences (79.2%). Additional demographic and descriptive information for caregiver participants and their children is reported in Table 5.2. No group differences between pre-BALANCE and post-BALANCE cohorts were identified based on any of these sample characteristics.

### **Primary Aim 1: Feasibility**

Figure 5.1 provides an overview of the flow of HCPs through all BALANCE and study procedures. Overall, 66% ( $n = 70$ ) of the estimated 106 eligible Day Surgery unit staff expressed interest in the study by completing consent procedures, 58% of eligible staff completed parts of the BALANCE e-modules, 50% of eligible staff completed the e-modules in full, and 32% of eligible staff completed all study questionnaires. The retention rate for the BALANCE e-modules was 85%, whereas overall study retention (i.e., completing all modules and study questionnaires) was 49%. Median timeframe to completion from Module 1 release to Module 7 completion was 31 days (inter-quartile range (IQR) = 29.0 – 33.5). Healthcare providers who began the BALANCE e-modules completed 93% of the 22 forced-choice questions ( $Mdn = 20$ , (IQR) = 19.0 – 21.0), and 72% of the 18 open-ended questions ( $Mdn = 16$ , IQR = 14.0 – 17.0).

### **Primary Aim 2: Acceptability and Usability**

**Quantitative Ratings.** More than 90% of HCPs agreed that all 39 identified learning objectives were addressed by the e-modules (see Supplemental Table 5.1). Overall, HCPs rated each BALANCE e-module and the overall program as acceptable and usable. Of the 50 HCPs who provided ratings at the end of the program, 100% agreed with the statements, *the program was useful for me*, *the program would be useful for*

*others, the program contained valuable information, I felt comfortable working through the program, and I was satisfied with the program; 98% agreed (2% ‘maybe’) with the statements, the program was easy to navigate, I trusted the information in the program, and the program helped me to think about how to enhance my practice; and 96% agreed (4% ‘maybe’) that, the presentation of the content contributed to a positive user experience.* Responses to the statement, *the time required to complete the intervention was reasonable* were more varied, with 76% of HCPs agreeing, 22% ‘maybe’, and 2% ‘no’. Healthcare provider ratings for each module are reported in Supplemental Table 5.2.

**Qualitative Feedback.** Of the 62 HCPs who completed at least one module, 47 responded to the open-ended prompts for changes at the end of each module. Overall the comments provided positive feedback about the usefulness and suggestions for better functionality. Ten responded with positive feedback (e.g., “this was a powerful module [4]” [HCP 4], “I enjoyed the personal stories that were presented [Module 5] ... it makes you feel as though you aren’t as alone as you may feel” [HCP 22]), two commented that no changes were needed, and 46 recommended changes. Of the 50 HCPs who began the post-program questionnaire, 47 responded to the open-ended question, *Are there any other changes that would improve this program?* (Note: HCPs could provide more than one response, so response frequency may sum to more than 47). Twenty-two HCPs commented that no changes were needed, 10 provided positive feedback (e.g., “I was pleasantly surprised at how useful the program was” [HCP 40]), 4 suggested that BALANCE should be implemented more broadly (e.g., “make accessible to other areas of healthcare” [HCP 49]), and 27 recommended changes.

Recommendations by HCPs, which were similar whether reported at the end of a module or the entire program, were coded as follows: *improve audio-quality*, *shorten*, *request additional content* (i.e., add new substantive activity or information), *request additional functionality* (i.e., add new technical feature), *suggestions for presentation of content* (i.e., change presentation of an existing feature or activity), *suggestions for speakers*, *address inadvertently repeated video*, *other non-replicable technological problems*, and *suggestions related to roll-out*. Numbers of HCPs who made each type of recommendation at any point, and exemplary quotes, are provided in Table 5.4.

All 50 HCPs who began the post-program questionnaire responded to the open-ended question “Who would benefit most from this program?” (Note: HCPs could provide more than one response, so response frequency may sum to more than 50). Seven HCPs specifically referenced HCPs and staff involved in delivering surgical care (e.g., “All peri-op personnel” [HCP 39]), 46 indicated that BALANCE could be beneficial for a wider array of HCPs, staff, and volunteers working throughout the healthcare system (e.g., “All clinical areas could/would benefit. My current role is new and I kept thinking about how this would benefit me in other areas where I've worked” [HCP 37]), and several ( $n = 3$ ) noted that BALANCE could also inform how to approach caring for children with non-autism-related needs (e.g., “Anyone who would work with children, not only children with autism” [HCP 46]). None indicated that BALANCE would not be beneficial.

### **Secondary Aim: Exploratory Examination of BALANCE Impact**

**Quantitative HCP’ Reports: PACE Care Questionnaire.** There was a main effect of time on PACE total scores ( $F(2, 87.96) = 6.16, p = 0.003$ ; see Figure 5.3). Post

hoc comparisons and ES calculations suggested a negligible change ( $d = 0.16, p = 0.55$ ) from baseline ( $M = 6.63, SE = 0.08$ ) to post-BALANCE ( $M = 6.74, SE = 0.09$ ), a small change ( $d = 0.28; p = 0.11$ ) from post-BALANCE to follow-up ( $M = 6.92, SE = 0.10$ ), and a small change overall (i.e., baseline to follow-up;  $d = 0.45; p = 0.002$ ). Results of linear mixed-effects models exploring change in PACE subscale scores are presented in Table 5.5. From baseline to post-BALANCE negligible positive changes were observed on the Partner and Assess subscales, alongside negligible negative changes on the Empathy subscale. From post-BALANCE to follow-up, small positive changes were observed on the Empathy and Assess subscales, alongside negligible positive changes on the Partner subscale. These changes resulted in small positive changes across all three subscales from baseline to follow-up, with relatively larger increases observed on the Assess subscale compared to the Partner and Empathy subscales. There was a small increase in the Coordination subscale from baseline to post-BALANCE, with another small change from post-BALANCE to follow-up, resulting in a medium increase in the Coordination subscale overall (i.e., from baseline to follow-up).

**Quantitative Caregiver' Reports: FPCD Questionnaire.** A significant difference was observed between pre- and post-BALANCE caregiver cohorts on the overall mean FPCD score  $t(52) = 2.40, p = 0.02, 95\% \text{ CIs } [-0.58, -0.05]$ ; see Figure 5.4), with a medium ES ( $d = 0.68$ ). Caregivers in the post-BALANCE group reported more favourable perceptions of the care delivered to their children with autism ( $M = 4.58, SD = 0.36$ ) than did caregivers in the pre-BALANCE group, although these ratings were also positive ( $M = 4.26, SD = 0.56$ ). Results for t-tests comparing pre- and post-BALANCE caregiver cohorts on FPCD subscale scores are presented in Table 5.6. Consistent with

the overall analyses, post-BALANCE caregivers rated all subscales more favourably than pre-BALANCE caregivers. Specifically, medium differences were observed on the Assessed and Partnered subscales, alongside small differences on the Coordinated, Empathized, and General Satisfaction subscale. Scores on the Coordinated and Empathized subscales were larger than scores on the General Satisfaction subscale. However, a ceiling effect was observed for two of the three items contributing to the General Satisfaction subscale score, constraining the range of possible differences.

**Qualitative HCP' Reports of Impact.** Healthcare providers' responses to open-ended questions about their learning, intentions, and practice change are summarized descriptively here along with select sample quotes. Supplemental Tables 5.3-5.7 contain additional examples of HCPs' responses to these open-ended questions.

**Learning.** All 50 HCPs who began the post-program questionnaire responded to the question about what they learned from BALANCE. Overall, HCPs' responses indicated that BALANCE clarified the value and importance of family-centred care: partnering with families (e.g., "that I need to be open to asking parents to help me out with key info, I don't have all the answers and it's okay" [HCP 29]), assessing the needs of each child and tailoring care accordingly (e.g., "highlighted even more for me that each child with autism is so different and really requires and deserves individual support" HCP 29), coordinating care through inter-professional collaboration (e.g., "teamwork / communication is the best approach to providing the best possible care" [HCP 49]), and expressing empathy and warmth (e.g., "having patience and understanding and empathy will help" [HCP 31]).



In response to this question, HCPs also reflected on how BALANCE helped them to feel more confident in their approach to caring for children with autism by providing evidence-based reassurance that family-centred care is the appropriate approach (e.g., “I confirmed that the approach to children and families should be individualized; however, these approaches are based upon sound principles” [HCP 39]) and introduced techniques and tools support the delivery of the same (e.g., “taught me new techniques” [HCP 40]).

***Intentions.*** Forty-nine HCPs responded to the question about changes that they planned to implement in their practice. HCPs stated their intentions to change their practice by increased use of behaviour consistent with the delivery of family-centred care. For example, common HCPs’ intentions included increasing efforts to partner with parents (e.g., “better communicate with families” [HCP 5]), shifting the manner in which they collaborate with their colleagues (e.g., “learn to be a better communicator of my thoughts and feelings with my fellow team members” [HCP 45]), expressing more empathy (e.g., “avoid attempts to reassure with don’t worry [and instead] label and normalize behaviours observed” [HCP 15]), and making concerted efforts to assess and tailor care to individual needs (e.g., “be more conscious of the special needs of each child” [HCP 33]). Half of the HCPs (n = 25) specifically expressed their intention to incorporate the toolkit of resources into their approach to caring for children with autism (e.g., “use the... toolkit” [HCP 14]).

***Practice Change.*** Of the 40 HCPs who responded to open-ended questions at follow-up, 28 reported that they had put what they learned in BALANCE into practice, and 26 provided further such examples. Overall, HCPs reported having engaged in behaviours that were in line with the types of intentions HCPs described in the post-

program questionnaire. For example, one HCP described how the modules yielded “a better understanding of the condition and more empathy for the patients and their caregivers, [which] translated into more patience in [their] approach to care [HCP 18]”, and another talked about using the checklist, noting that it “is extremely helpful, it prevents me from asking the families the same questions, and gives me instant insight into how to best provide family-centred care” (HCP 17). Healthcare providers who gave specific examples often described scenarios in which they had drawn on the toolkit of resources when delivering care to children with autism (e.g., “I utilized the toolkit [resources] to create a *first-then then*<sup>2</sup> story for a child who communicates regularly this way” [HCP 17]).

## Discussion

The primary aims of this study were to assess the feasibility, usability, and acceptability of BALANCE, a novel multi-level intervention developed in partnership with key stakeholders with the aim of improving the delivery of care to children with autism around the time of surgery. Results suggested that implementing BALANCE within a busy day surgery unit of a tertiary pediatric hospital was feasible and that HCPs found BALANCE to be useful and relevant. The secondary aim of this study was to conduct a preliminary mixed-methods evaluation of the impact of BALANCE

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<sup>2</sup> A first-then-then story is a child-directed strategy for managing behaviour and expectations that involves explicitly stating what will happen first (e.g., First I will check your weight), and what that will be followed by (e.g., then I will listen to your heartbeat, and then you can play with your iPad)

implementation. Quantitative and qualitative data gathered from HCPs and caregivers suggested that BALANCE implementation was associated with positive shifts in the delivery of healthcare care to children with autism in the perioperative setting.

We speculate that our methodical process of stakeholder consultation and subsequent multi-pronged mode of delivery enhanced the feasibility and possibly the impact of BALANCE implementation (see Chapter 4). We consulted and collaborated with HCPs to identify as convenient and accessible a mode of intervention delivery as possible, while simultaneously intervening at the individual HCP level and within their work environment. These processes led to the decision that most content would be delivered through systematically released e-modules, with corresponding minor unit-level changes to ensure that HCPs had access to resources needed to deliver care in the manner advocated within the modules. In addition, unit-wide communications informed all staff members about these changes and provided information about the purpose of the resources introduced.

The opportunity for HCPs to complete the BALANCE e-modules was offered without obligation, in expectation that HCPs seeking support in caring for individuals with autism (or at least receptive to such support) would try to adjust their approach to care based on what they learned in the e-modules. Approximately 50% of all eligible HCPs completed the BALANCE e-modules. This was double the expected number based on consultations with the Day Surgery unit manager and prior research experience on the same unit, indicating widespread interest in the intervention. Healthcare providers who began but did not complete the BALANCE e-modules ( $n = 10$ ) were generally more experienced in their current roles. Comparisons between BALANCE completers and non-

completers should be interpreted with caution, due to the lower number of non-completers. Nonetheless, in the future it might be helpful to engage more experienced HCPs before implementation to explore what might motivate them to complete the e-modules. One possibility -- assuming their current practices are in line with BALANCE -- might be to foster their motivation to complete the modules by emphasizing the formal and informal leadership roles experienced HCPs could play in enhancing the uptake of the tools and approaches introduced in the BALANCE e-modules.

All HCPs agreed that the BALANCE learning objectives were met and engaged with most interactive questions embedded throughout the program. Moreover, feedback by HCPs at the end of each module, as well as at the end of the program, was overwhelmingly positive and reflected their assessments that the BALANCE program was usable, useful, desirable, accessible, valuable, and credible. They also endorsed that BALANCE helped them to think about how to enhance their approach to care and conveyed their expectation that BALANCE would be beneficial for all HCPs who care for children with autism, with several expressing their desire for BALANCE to have been mandatory for all HCPs on the unit. Quantitative and qualitative responses by HCPs also shed light on changes that could help to improve BALANCE, with the need to improve audio quality and the potential benefit of shortening some aspects of the program emerging as two clear issues to consider.

Both HCPs and caregivers identified potential positive shifts in the delivery of family-centred care to children with autism in association with BALANCE implementation. We observed a small-to-medium increase in HCPs' overall reports of the delivery of family-centred care from baseline to follow-up, alongside moderate

improvements in caregivers' overall perceptions of the care delivered to their children. Findings from subscale analyses identified that the relative pattern of changes differed for HCPs and caregivers. HCPs identified larger small-to-moderate increases on the Assess and Coordinate subscales, alongside smaller increases on the Partner and Empathy subscales. In contrast, caregivers identified relatively large moderate increases on the Partnered and Assessed subscales, alongside small increases on the Coordinated and Empathized subscales. In contrast to changes observed on subscales assessing aspects of family-centred care, smaller positive increases were observed on the subscale assessing caregivers' General Satisfaction. Caution is warranted in interpreting this discrepancy as ceiling effects restricted the change that could be observed on this subscale.

Given the exploratory nature of this study, it is difficult to draw conclusions from these findings. At first glance, results of analyses of HCP reports on the PACE questionnaire subscales may suggest that BALANCE yields most change in behaviours measured by the Assess and Coordinate subscales. However, this interpretation is challenged by the caregiver reports on the FPCD questionnaire subscales that in addition to revealing comparable changes on the Assessed subscale, revealed changes of similar or greater magnitude on the Partnered and Empathized subscales. It has been previously demonstrated that HCPs' and caregivers' perspectives do not always align even when both are favourable (e.g., Gill et al., 2013), but the reasons for such differences are unclear. Such interpretations are further hampered in the current study, given that the PACE and FPCD questionnaire assess related constructs but do not map precisely onto one another. Additional research is needed to clarify the implications of this pattern of findings from the subscale analyses.

In addition, although a full exploration of changes in the behavioural determinants proposed to underlie variations in the delivery of family-centred care (i.e., HCP capability, opportunity, and motivation) is beyond the scope of this study (see Chapter 4), it is noteworthy that moderate improvements in HCPs' reports of behavioural determinants from baseline to post-implementation *preceded* the observed changes in their reports of the delivery of family-centred care from post-implementation to follow-up (see Chapter 4). This pattern of changes is consistent with expectations based on the theories of behaviour change that informed the development of BALANCE, providing a measure of confidence that BALANCE works as designed. Future studies designed and powered for empirical examinations of mechanisms of action, are needed to establish whether changes in determinants mediate changes in family-centred care.

Responses by HCPs to open-ended questions underscored the potential for BALANCE to have positive effects on HCPs' learning, intentions, and practice. Moreover, HCPs' qualitative responses helped to characterize more fully the potential clinical impact of the small and moderate changes detected on measures of family-centred care based on HCPs' and caregivers' responses. Healthcare providers' responses to open-ended questions conveyed that HCPs who completed the e-modules had learned and appreciated the value of an evidence-informed family-centred approach to caring for children with autism. Healthcare providers' responses also suggested the intention to change aspects of their behaviour to be more consistent with the family-centred approach advocated. By follow-up, according to their reports many HCPs had shifted their approaches to care to incorporate what they had learned. Caregivers' informal reports corroborated that HCPs had incorporated into practice aspects of what they learned

through the e-modules. For example, although use of the BALANCE toolkit of resources was not prescribed as necessary to the delivery of family-centred care (and thus was not formally monitored), 83% of caregivers in the post-implementation group reported that HCPs had used a toolkit resource while caring for their children with autism. In general, HCPs enthusiastically endorsed the potential clinical impact of BALANCE, with the majority using the opportunity provided by an open-ended question querying who would benefit from the program to advocate that BALANCE should be available to anyone involved in delivering healthcare for children with autism. Research exploring the appropriateness of BALANCE for other healthcare contexts is needed.

Notwithstanding the importance of feasibility studies as an essential initial step in the evaluation of novel and complex interventions (Craig et al., 2008) or the promising preliminary support for the potential impact of BALANCE, these findings must be interpreted with caution. Best-practice reporting and interpretation guidelines emphasize that ES tend to be more variable for feasibility studies (Arain, Campbell, Cooper, & Lancaster, 2010). Our reported effects may over- or under-estimate changes in HCP reports across time, as well as differences between pre- and post-BALANCE caregiver reports. Moreover, although the complementary nature of the findings from HCPs and caregivers in this study is encouraging, the lack of a no-intervention comparison group hampers our interpretation. For example, it is not possible to determine whether the apparent positive changes in indices of the delivery of family-centred care reflect effects of the intervention, the passage of time, a placebo effect, or some unidentified sampling or response bias. Definitive evaluative trials are needed to address the effectiveness of BALANCE. Such trials ideally should involve randomization at the system level, given

that BALANCE targets both individual and system-level change. Such trials would also facilitate further exploration of potential spillover effects of BALANCE on service use (e.g., cost effectiveness) or health-related (e.g., procedural distress, post-procedural adjustment) outcomes. Given that HCP attrition rates for completion of evaluative components were relatively high (50%), future BALANCE trials should consider additional strategies for enhancing HCPs' motivation and willingness to complete evaluation measures (e.g., additional incentives, persuasive communication about the importance of the evaluation, timing of measures).

Additional limitations worth noting include the reliance on study-specific measures of the best-practice approach to delivering care to individuals with autism. Consolidating research to date, we conceptualized that best practices entail (1) partnering with families, (2) assessing the needs of each child and tailoring care accordingly, (3) coordinating care through inter-professional collaboration, and (4) expressing empathy and warmth. We operationalized these four key behavioural components as reflecting family-centred care, a term familiar to HCPs at the pediatric hospital where this study took place. Existing measures of family-centred care have been criticized as assessing vague and broad constructs (Franck & Callery, 2004; Trute, Hiebert-Murphy, & Wright, 2008), and we considered these inadequate for measuring our operationalization of family-centred care. Thus, we followed recommendations (Trute et al., 2008) to generate outcome measures that specifically assessed the behavioural components that we targeted for change. Additional efforts to validate measures will be necessary. Further, comparison of HCP and caregiver reports with data gathered through direct observations of care delivery would be valuable. However, in the absence of validated measures and



the impracticality of direct observations in the Day Surgery unit, we bolstered the credibility of our assessment of the delivery of family-centred care through our mixed-method and multi-informant approach.

## **Conclusion**

The need to improve the delivery of care to individuals with autism has been clearly articulated. BALANCE is a novel theory-driven intervention designed by clinician-researchers working with families and HCPs to address this need by intervening at the level of HCP and the care environment to enhance the delivery of family-centred care to this vulnerable group. This study provided preliminary support for the feasibility, usability, and acceptability of the BALANCE e-modules. Secondly, it provided promising initial qualitative and quantitative support for BALANCE's potential to improve the approach to delivering care to children with autism. These preliminary findings are encouraging, and will inform modifications to fine-tune and enhance BALANCE. Definitive evaluation trials will be needed to determine the effectiveness of BALANCE.

Table 5.1  
*Healthcare Provider Demographics*

Characteristic	<i>N</i> = 66
Sex (% female)	83.3
Age ( <i>M</i> <sub>years</sub> , <i>SD</i> )	43.0 (10)*
Educational Background (%)	
Diploma	33.3
Undergraduate degree	65.2
Post graduate degree	22.7
Residency	19.7
Fellowship	22.7
Specialist training in pediatric care	53.0
Years of experience in current profession (%)	
< 5	15.2
5-9	22.7
10-19	15.2
20-29	24.2
30+	22.7
Years of experience working in pediatric perioperative setting (%)	
< 5	39.4
5-9	19.7
10-19	24.2
20-29	10.6
30+	6.1
Participation in activities to learn about autism spectrum disorder (%)	
Lectures during your schooling	42.5
Workshops lasting two hours or more	4.5
Presentations or public lectures	53.0
Self-directed learning	60.6

*Note.* \* Age estimates are based on *n* = 65; one HCP misreported age as 0 years

Table 5.2  
*Caregiver and Child Sample Characteristics*

	<b>Group</b>		<b>Overall</b>
	<b><u>Pre-BALANCE</u></b> <i>n</i> = 30	<b><u>Post-BALANCE</u></b> <i>n</i> = 24	<i>N</i> = 54
<b><u>Caregiver</u></b>			
Age ( <i>M</i> <sub>years</sub> , <i>SD</i> )	38.5 (8.69)	42.0 (8.88)	40.1 (8.86)
Relationship to Child (%)			
Mother	80.0	83.3	81.5
Father	13.3	8.3	11.1
Other Guardian	6.7	8.3	7.4
Relationship Status (%)			
Married/Common Law	76.7	79.2	77.8
Other	13.0	20.9	22.3
Highest Level of Education (%)			
High School	36.7	25.0	31.5
College or Diploma Program	36.7	37.5	37.0
University Degree	26.7	37.5	31.5
Estimated Household Income (%)			
Less than \$20,000	10.0	4.2	7.4
\$21,000 - \$40,000	13.3	12.5	13.0
\$41,000 - \$60,000	6.7	16.7	11.1
\$61,000 - \$80,000	13.3	25.0	18.5
\$81,000 - \$100,000	16.7	8.3	13.0
More than 100,000	30.0	16.7	24.1
Prefer not to answer	10.0	16.7	13.0
<b><u>Child with autism</u></b>			
Comorbid Medical Conditions (% yes) (e.g., asthma, seizures, diabetes, neurodevelopmental conditions)	36.7	50.0	42.6
How child handles medical visits (%)			
With little difficulty	40.0	25.0	33.3
With some difficulty	40.0	54.2	46.3
With great difficulty	20.0	20.8	20.4
Level of support needed for medical visits (%)			
Little need for support	16.7	12.5	14.8
Some need for support	33.3	41.7	37.0
Lots of need for support	50.0	45.8	48.1
Current Surgery Type (%)			
Dental	80.0	70.8	75.9
Ophthalmological	6.7	12.5	9.3
Gastroscopy	10.0	8.3	9.3
Orthopedic	3.3	8.3	5.6
Otolaryngological	6.7	4.2	5.6
Urological	3.3	4.2	5.6
Other	3.3	8.3	5.6
Pre-operative sedation (% yes)	70.0	58.3	64.8

Table 5.3  
*Overview of Intervention Components*

<b>Key Intervention Components</b>
<b><u>E-modules</u></b>
Information about autism and family-centred care
Persuasive communication highlighting the importance of family-centred care for children with autism
Videos to demonstrate family-centred care delivery, facilitate perspective taking, and reflection on aspects of family-centred care
Activity to facilitate recognition of own thoughts, feelings, and behaviours, and identify potentially helpful coping skills
Activities to aid goal setting and behaviour action plans for adjusting approach to care
Vignettes and case studies to facilitate rehearsal
Individualized feedback on case studies
<b><u>Rewards and incentives for completion of e-modules</u></b>
Provision of ‘autism friendly’ pin
Professional learning credits
<b><u>Environmental restructuring</u></b>
Toolkits with resources to prompt and facilitate family-centred care:
‘Take a SEC’ Tool to facilitate assessment and tailoring of care to individual needs
Magnet to prompt HCP that assessment tool was completed and should be reviewed to ensure coordination of individualized care
Pain assessment tool
Pain education resource for families
Visual support/communication aid (First, Then, Then tool)
Sound-attenuating earphones
Sunglasses
Sensory toys: prisms, bubbles, squishy balls, pinwheels
Installation of magnetic white-boards to be used for ‘cues’
Posters and emails to communicate purpose of toolkits to all HCP
Headphones stationed at computers to facilitate completion of e-modules during clinical down-times
Access to clinical champions
Posters and emails to communicate positive feedback from families of children with autism

Table 5.4  
*Summary of Healthcare Provider Responses to Open-ended Questions Soliciting Recommendations for Changes to Improve BALANCE*

Code	Number of HCP	Sample quotes
Improve audio-quality	28	“the audio was at different levels for different component” (HCP 18) “improve the balance of sound level between videos” (HCP 14)
Shorten	13	“try to make it shorter” (HCP 30) “[module 1] could be more brief” (HCP 6)
Request additional content	12	“a refresher or summary module for a month or two down the road” (HCP 4) “It would be fun to have a page with the toolkit and its contents where you could drag particular items out of the box...that would be most helpful with the cases” (HCP 51)
Suggestions for presentation of content	8	“link for drop down thoughts should be easier to see... perhaps a different colour to indicate this?” (HCP 38) “would be helpful to have the dialogue at the bottom of the screen” (HCP 36)
Suggestions for speakers	5	“it’s distracting when the speaker consistently looks aside to read” (HCP 34) “the children were all in the older age group and fairly well developmentally advanced, not typical of [children we see when there are challenges]” (HCP 56)
Address inadvertently repeated video <sup>a</sup>	5	“the last video was a repeat from the earlier module” (HCP 14)
Other non-replicable technological issues <sup>b</sup>	5	“iPad... won’t recognize click here” (HCP 4) “I was unable to access two links” (HCP 31)
Request additional functionality	3	“how about a keypoints downloadable for my phone so I can refer to them at will” (HCP 56) “provide us a means to keep our list of resolutions...a print or save button” (HCP 56)
Suggestions related to roll-out	3	“update staff with current practice changes” <sup>c</sup> (HCP 47) “I wish I had more time from session to session of the program” (HCP 31)

*Note.* HCP= healthcare provider

<sup>a</sup> This issue was addressed during BALANCE implementation by notifying HCP of the error and providing them with a link to watch the intended video. <sup>b</sup> These issues were

presumed to be anomalous and likely related to the interface the HCPs used to access the BALANCE e-modules as they could not be replicated by the study team and were noted by such a small fraction of HCP in relation to seemingly random buttons. <sup>c</sup> Email and poster-based communications were distributed to update staff who chose not to complete the e-modules, about how BALANCE might affect their practice

Table 5.5

*Results from Linear Mixed-Effects Models and Post Hoc Comparisons Exploring Change from Baseline to Post-BALANCE implementation, and Follow-up on Partnering, Assessing Needs, Coordinate Care, and Expressing Empathic Care Subscale Scores*

	Fixed effects of time						Post hoc comparisons		
	<i>M (SE)</i>			<i>df</i>	<i>F</i>	<i>p-value</i>	<i>d (p-value)</i>		
	Baseline	Post	Follow-up				Baseline to Post	Post to Follow-up	Baseline to Follow-up
<b>Partner</b>	7.01(0.09)	7.10(0.11)	7.21(0.11)	(2, 85.03)	2.14	0.12	0.12(1.00)	0.15(0.83)	0.26(0.13)
<b>Assess</b>	6.76(0.12)	6.93(0.13)	7.18(0.14)	(2, 89.14)	5.35	0.006	0.18(0.55)	0.28(0.19)	0.46(0.01)
<b>Coordinate</b>	6.22(0.11)	6.44(0.12)	6.66(0.13)	(2, 89.13)	6.87	0.002	0.26(0.18)	0.26(0.24)	0.52(0.001)
<b>Empathy</b>	6.32 (0.09)	6.23 (0.10)	6.46 (0.11)	(2, 88.58)	2.73	0.07	-0.11(1.00)	0.31(0.07)	0.20(0.37)

*Note.* Mean values reflect estimated marginal means, and thus may not reflect the true mean values. Post hoc comparisons adjusted using Bonferroni corrections.

Table 5.6

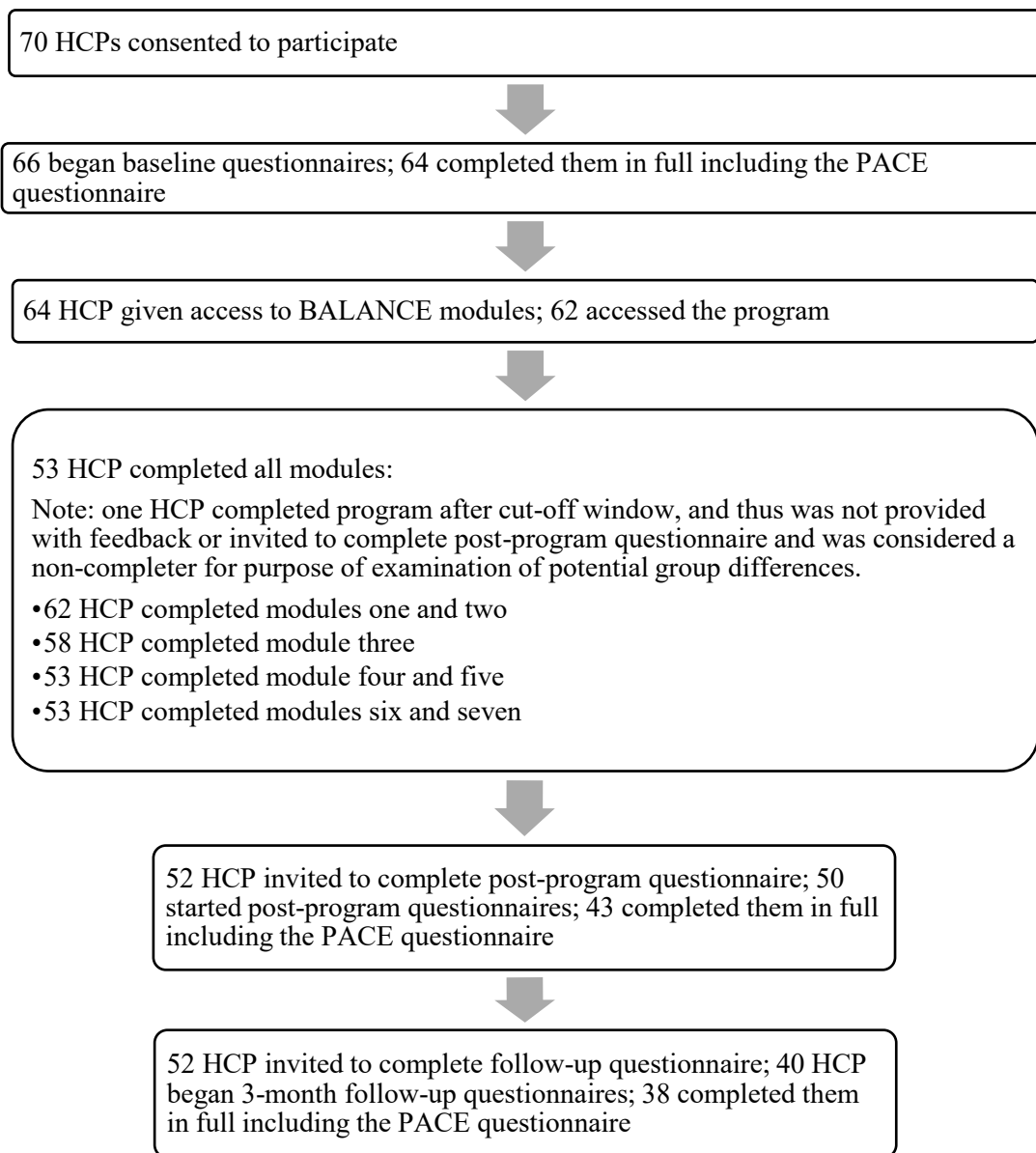
*Results from Independent Samples T-tests Comparing Pre- and Post-BALANCE Caregiver Cohorts on Family Perception of Scale Delivery Subscale Scores and Associated Cohen's d Values*

	<i>M(SD)</i>		<i>df</i>	<i>t</i>	<i>p-value</i>	<b>95% CI</b>	<b>Cohen's <i>d</i></b>
	<b>Pre-BALANCE</b>	<b>Post-BALANCE</b>					
<b>Partnered</b>	4.31(0.67)	4.67(0.34)	52	2.17	0.04	[-0.60, -0.02]	0.68
<b>Assessed<sup>a</sup></b>	3.86(0.87)	4.39(0.55)	49.4	2.74	0.01 <sup>b</sup>	[-0.92, -0.14]	0.73
<b>Coordinated</b>	4.19(0.76)	4.46(0.67)	52	1.40	0.17	[-0.67, 0.12]	0.35
<b>Empathized</b>	4.36(0.58)	4.60(0.41)	52	1.71	0.09	[-0.52, 0.04]	0.48
<b>General Satisfaction</b>	4.72(0.57)	4.85(0.29)	52	0.98	0.33	[-0.38, 0.13]	0.29

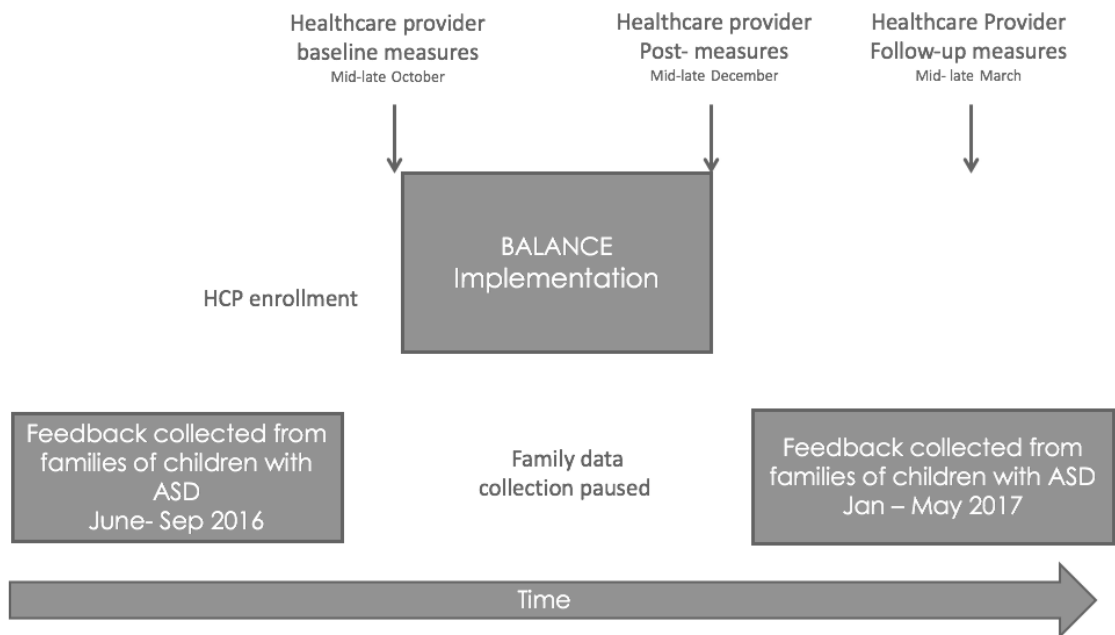
*Note.* CI = confident interval. Presented *p*-values are unadjusted. The Bonferroni adjusted *p*-value is 0.01.

<sup>a</sup>Levene's Test for Equality of Variances was significant (0.008) for the Assessed subscale, thus *t*-test comparing pre-BALANCE and post-BALANCE scores on the Assessed subscale did not assume equal variances. <sup>b</sup>Comparison significant at the level of the Bonferroni corrected *p*-value (0.01).

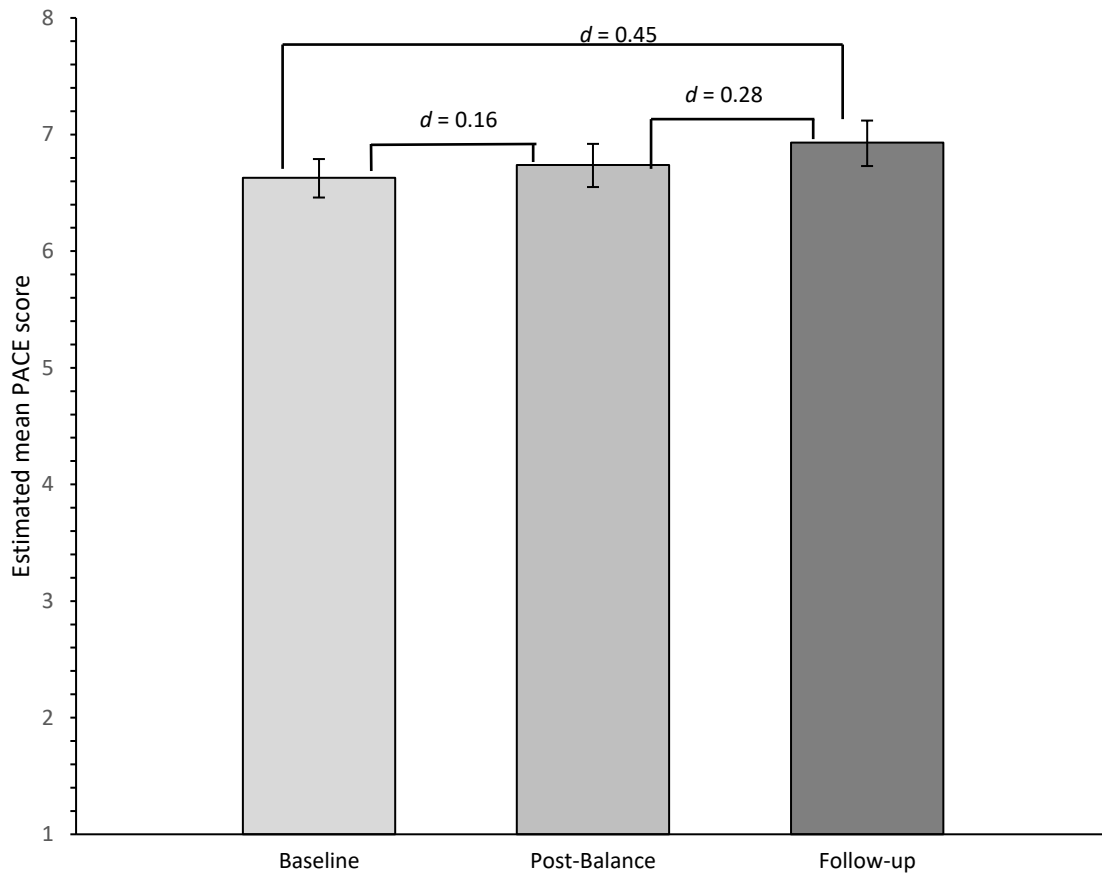




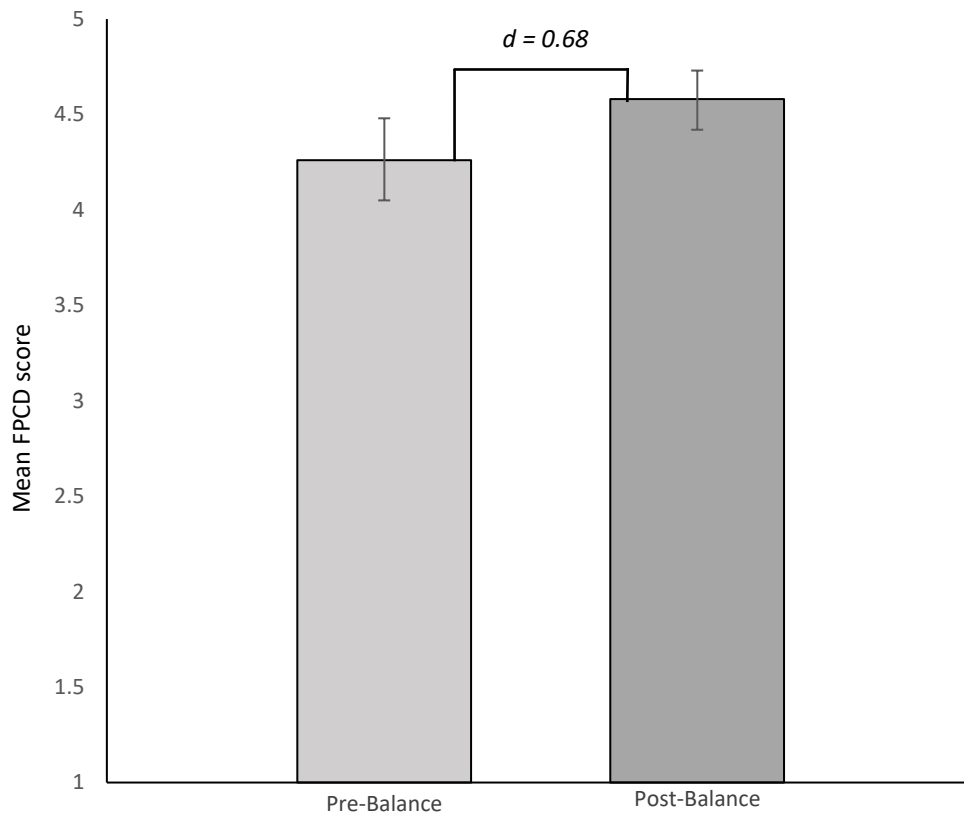
*Figure 5.1* Flow of Participants Through the Study and BALANCE E-modules. HCP = healthcare provider; PACE = Partnership, Assessing Needs, Coordinating Care, and Expressing Empathic Care questionnaire



*Figure 5.2* Schematic of Study Design. ASD = autism spectrum disorder, HCP = Healthcare provider



*Figure 5.3* Estimated Marginal Mean Total PACE Score at Baseline, Post-BALANCE Implementation, and Three-month Follow-up. Error bars represent 95% Confidence Intervals, and  $d$  represents estimated Cohen's effect size for difference between time points. PACE = Partnership, Assessing Needs, Coordinating Care, and Expressing Empathic Care questionnaire.



*Figure 5.4* Mean FPCD Total Score for Pre- and Post-BALANCE Caregiver Cohorts. Error bars represent 95% Confidence Intervals, and  $d$  represents Cohen's effect size for difference between groups. FPCD = Family Perceptions of Care Delivery questionnaire.

Supplemental Table 5.1

*BALANCE Learning Objectives Along with the Percentage of Responding Healthcare Providers Who Agreed each Objective was Met*

<b>Learning Objectives</b>	<b>% yes</b>	<b><i>n</i></b>
<b>Module 1 (Introduction to the BALANCE program)...</b>		
Identified why this program is important	100	62
Identified important factors to consider (child, family, provider, system) when thinking about providing surgical care for children with autism	98.4	61
Introduced how child, family, healthcare provider, and systemic factors interact to influence the surgical experiences of children with autism	98.4	61
Provided an overview of the format and major topic areas covered by the BALANCE program	96.7	60
Emphasized the importance of engaging with the interactive components of the program	96.6	58
<b>Module 2 (Focus on Family-centred Care)...</b>		
Addressed why family-centred care should be considered best practise for children with autism undergoing surgery	100	60
Introduced how the BALANCE program defines family-centred care	100	59
Included activities and questions to encourage thinking about the delivery of family-centred care	100	59
Asked me to set a goal related to enhancing my use of strategies that promote family-centred care	100	59
Provided an opportunity to think about things that might get in the way of my goal	98.3	57
Provided an opportunity to think about what might help me follow through on my goal	100	59
Provided an opportunity to think about why my goal is important	100	59
<b>Module 3 (Focus on the Child)...</b>		
Identified autism-related features that might make children with autism more vulnerable during healthcare experiences	100	58
Showed the importance of treating each child with autism as an individual with their own unique needs	98.3	58
Presented information on how the sensory differences experienced by some children with autism might impact the surgical experience	100	58
Presented information on ways that children with autism experience, express, and process emotions	100	56
Presented information on how communication differences experienced by children with autism may impact the surgical experience	100	57
Showed how healthcare providers can use the 'Take a SEC' checklist and tool kit to facilitate the delivery of coordinated family-centred care	98.2	57
<b>Module 4 (Focus on the Family)...</b>		
Presented information on what might be stressful for families on the day of their child's surgery	100	57
Provided opportunities to think about how healthcare providers might reduce families' stress on the day of surgery	100	56
Presented specific information about the power of empathy	100	57

<b>Learning Objectives</b>	<b>% yes</b>	<b>n</b>
Provided an opportunity to practice skills related to expressing empathy	93	57
Touched on the difference between collaborating with and depending too much on families	94.6	56
Emphasized that collaborating with families is preferable to depending on families	98.2	57
Highlighted that families view healthcare providers (no matter the situation or how brief) as representatives of the healthcare system	100	56
Provided opportunities to reflect on how challenging experiences on the day of surgery might have a negative impact on families' future relationships with the healthcare system	96.5	57
Emphasized that a healthcare provider's response to a child's distress is often more important to families than whether or not their children experience distress	100	57
Highlighted that families can have positive experiences, even if their child becomes distressed on the day of surgery	98.2	56
Provided opportunities to reflect on how moments of distress can create opportunities to express empathy and strengthen relationships	100	57
<b>Module 5 (Focus on the Healthcare Provider)...</b>		
Emphasized the important role that healthcare providers play in shaping the surgical experiences of children with autism and their families	98.2	55
Provided opportunities to reflect on my own feelings, thoughts, and/or behaviours about caring for children with autism	100	54
Provided information about simple coping strategies for managing challenging thoughts or feelings while providing care	100	55
<b>Module 6 (Focus on the System) ...</b>		
Got me to think about how to contribute to systems level changes	98.1	53
Discussed the idea that being on the same page does not necessarily mean that healthcare providers will always agree on the best way to care for a particular child	100	53
Talked about the fact that people can have different perspectives on the best way to care for a particular child	100	53
Provided opportunities to reflect on situations when frustration or blame could get in the way of providing care or relationships with colleagues	100	53
Provided information on how healthcare providers might discuss different perspectives regarding the best way to individualize care for each child and family	100	53
<b>Module 7 (Putting BALANCE into practice)...</b>		
Provided a review of key topics and ideas presented throughout the BALANCE program	100	53
The cases [two included in the module] helped me to think about how to apply what I learned	100	53

Supplemental Table 5.2

*Healthcare Provider Acceptability and Usability Ratings for each Module*

<b>E-module number:</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
<b>Item</b>				<b>% yes (n)</b>			
This module was helpful	100 (58)	98.3 (59)	100 (56)	100 (57)	100 (55)	100 (53)	100 (53)
This module was easy to navigate	100 (57)	100 (53)	98.1 (54)	100 (56)	100 (54)	98 (51)	100 (53)
The presentation of the content in this module contributed to a positive user experience	100 (57)	96.4 (56)	100 (56)	98.2 (56)	100 (54)	100 (52)	98.1 (53)
This module contained valuable information	100 (56)	98.2 (56)	100 (55)	100 (56)	100 (54)	100 (52)	98.1 (52)
I felt comfortable working through this module and understood the information it presented	100 (57)	100 (55)	100 (56)	100 (56)	100 (54)	100 (52)	100 (53)
I trusted the information in this module	100 (57)	100 (55)	100 (56)	100 (55)	100 (54)	*	100 (52)

\*Item inadvertently omitted at the end of Module 6.

### Supplemental Table 5.3

#### *Additional Sample Responses to “What did You Learn or Confirm?”*

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##### Sample Healthcare Provider Responses

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“That kids are kids who cope in their own unique ways. That we all need to collaborate better with families and peers to get the best end result.” (HCP 3)

“Listening to families and respecting their opinions to create positive experiences. The need to support families as healthcare experiences for families with children with Autism Spectrum Disorder are often stressful for everyone involved. Resources available. How to better collaborate with the team and an approach to resolve disagreements.”(HCP 5)

“The value in minimizing repetitive interactions and a coordinated approach between health care providers.” (HCP 7)

“I knew most of the information, but it gave me more confidence in dealing with families with more direct communication to improve the care for their child.” (HCP 9)

“I learned that autistic children can communicate, but just in a different way.” (HCP 10)

“I was able to confirm that a lot of what I was already doing was helpful, however i was able to build on that base of skills to provide even better care for this population and their families.” (HCP 13)

“The importance of empathy was reinforced and to be flexible and patient with planning the care of patients and their families with autism.” (HCP 14)

“We need to communicate as a team and try to stay together versus apart through challenging situations as they arise. We need to listen to families and prioritize/respect their knowledge of their child and insight into the best possible solutions.” (HCP 15)

“I learned so much from this program - including ways to help families [be] more comfortable, and coping mechanisms for me and the team I'm working with.” (HCP 21)

“I learned that I needed to show more empathy, spend more time with these children and their families. Also to include the parents and child more in the decision making for plan of care.” (HCP 25)

“Through completing this program it has highlighted even more for me that each child with autism is SO different and really requires and deserves individual support.” (HCP 29)

“I learned that we as health care professionals, don't have to have all the answers on how to help a child with Autism and their family have the best experience during the pre and post op experience, Having patience and understanding and empathy will help.” (HCP 31)

“Many interventions that I can use. That others feel the way I do about feeling ill prepared and uneasy around these families. Just acknowledging that was huge.” (HCP 36)

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*Note.* HCP = healthcare provider



#### Supplemental Table 5.4

#### *Additional Sample Responses to “What Changes are You Planning to Implement in Your Practice?”*

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##### Sample Healthcare Provider Responses

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“Use the Take a Sec checklist whenever I can. Try my best to tailor my approach to the individual needs of the child and family. Better communicate with families and try to acknowledge how they may be feeling. Better communicate with the team to avoid asking the same questions over and over. Advocate for children and families” (HCP 5)

“Including the parents more in the plan, doing take a sec, using the toolkit and expressing empathy.” (HCP 9)

“To ensure all the health care professionals, patient and family are ok with the plan of care”. (HCP 12)

“Label and normalize behaviours observed. Avoid attempts to reassure with "don't worry" messages but perhaps consider the point above instead!” (HCP 15)

“Definitely I will implement the Take A Sec assessment tool into my practice with the goal of becoming a more empathetic and effective communicator. I hope to be able to facilitate a positive experience for everyone involved in the perioperative experience of an autistic child and their family.” (HCP 17)

“I have spent most of my time in recovery during the program and have only learned about the bins in theory. I can't wait to actually use a checklist for the first time and use the rest of the products in the bins. Also...I've learned to let the family and the patient with autism guide me through their post op experience....I'm on their timetable....vs the patient being on mine.” (HCP 31)

“Using the kit with all autistic children & their families.” (HCP 34)

“Be more aware of the environment we are creating (dim lights, soft noise).” (HCP 38)

“Taking the extra time to learn what may be helpful and not helpful, rather than feeling rushed by other team members.” (HCP 42)

“Be more self-aware and critically think and evaluate more about the patient and family situation before interacting with them.” (HCP 46)

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*Note.* HCP = healthcare provider

### Supplemental Table 5.5

#### *Additional Sample Responses to “How Have You Been Able to Put What You Learned into Practice Over the Past Two Months?”*

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##### Sample Healthcare Provider Responses

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“Completing the [Take a SEC tool] with the parent ...Helping new staff with completing this form. Help other healthcare providers come on board with the plan.” (HCP 1)

“I have a better understanding of the condition and more empathy for the patients and their caregivers. This has translated into more patience in my approach to their care.” (HCP 18)

“Overall, the program made me feel more confident in discussing plans with the team and family. I feel that everyone communicates more clearly now that we have a shared knowledge base.” (HCP 44)

“Remembering that each child is unique and care plan should be tailored to them as individuals. We are not always aware that the child we are going to sign in to the [Day Surgery Unit] has autism. Therefore, I always make a point to look for the Take a SEC tool sheet and read it completely to see if there is any adjustments to [operating room] setting needed ie. dimming lights, reducing noise and informing team members.” (HCP 16)

“I found that I'm less task oriented when I enter a patient's room now and focus more on what the family and patient need...Before, I was in the mode of I have this, this and this to do and then the patient can go home....I find we as healthcare professionals are now more open to collaboration with child life and each other on how to best care for children with autism and their families....In the last few months, I have relied on child life so much more than I did before the program. It takes a village...” (HCP 31)

“Yes. There seems to be much better coordination between teams as well.” (HCP 19)

“I've not done many “take a sec” [tools] because of my schedule and working mostly in recovery room. But I have had a chance to read the info and use for the children I've cared for” (HCP 27)

“Yes. The Take SEC checklist on patient charts is extremely helpful. It prevents me from asking the families the same questions, and gives me instant insight into how to best provide family-centred care.” (HCP 17)

“I have a heightened awareness of the needs of all parties (families, healthcare providers) and appreciate the preparation required to accommodate these needs” (HCP 50)

“I have been better able to identify the needs of both patients and families. I have been given tools to support my interventions. The patient and family stories have helped increase motivation to ensure these patients are given excellent care. I have been able to recommend the tools to other healthcare professionals, therefore spreading the knowledge and education pieces.” (HCP 29)

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*Note.* HCP = healthcare provider

## Supplemental Table 5.6

### *Additional Sample Responses to “Please Provide a Brief Example of a Situation in Which You Put What You Learned in the BALANCE Program into Practice”*

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#### Sample Healthcare Provider Responses

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“Last week I did some surgery on a little boy who has been diagnosed with autism. He was verbal and pretty in tune with his feelings, and just needed time and opportunity to express himself. When this was provided, he got through the process without a problem.” (HCP 18)

“On one occasion, there was not a take a SEC tool sheet immediately available for me to review prior to seeing family. The child was non-verbal and had been to the operating room on several occasions. Some experiences had not been positive in the past. I asked mom how she knows what her daughter is feeling and what we could do to make the experience as positive for her as possible.” (HCP 16)

“A discrepancy between what different members of the team saw as part of the post op plan. Rather than blaming or throwing our hands up work together calmly towards the best resolution for everyone” (HCP 7)

“With the most recent patient, I collaborated with the team to provide a supportive environment. Noise was identified as a stressor. We tried our best to avoid this trigger and even requested that the construction noise stop during while patient was in the area. I didn't meet this particular patient but know my role from a distance was supportive. I would've been an additional new person and that interaction was unnecessary as per nursing assessment. I helped provide sensory items and collaborate with the team to provide a supportive environment. This was a great role to have. I am thankful that the nurse felt comfortable and confident to care for this patient and communicate to the team for support as needed!” (HCP 20)

“I find I am communicating more to the anesthesia staff about what I know based on previous interactions with the child in clinic. I think our notes about behaviour and some of the [Take a SEC tool] components can be a useful start to the conversation about the best way to manage a patient perioperatively.” (HCP 15)

“I was caring for a patient ASD and the nurses had used the Take a SEC tool. [checklist from toolkit]. I was able to use that as a discussion starting point with the patient's mom to ask more questions and learn more about her child. I took a few minutes to really chat with her about what she thought would work for her child - I don't believe I was so intentional about this before. Afterward, the operating room nurse I was working with let me know that she thought I did a really wonderful job communicating with that family. Which was lovely, and it was because of the BALANCE program that I had been more intentional during this interaction.” (HCP 35)

“Signing in a patient from day surgery, spoke with mom, reviewed checklist, called operating room to pass along preferences (speak slowly, warm room, no touching, one person to speak at a time).” (HCP 10)

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*Note.* HCP = healthcare provider

## CHAPTER 6. PRELIMINARY EXPLORATION OF WHETHER CHANGE IN DETERMINANTS IS ASSOCIATED WITH CHANGE IN FAMILY-CENTRED CARE

As discussed in Chapter 5, studies designed and powered for empirical examinations of mechanisms of action are needed to establish whether changes in determinants (i.e., capability, opportunity, and motivation) account for changes in family-centred care. Although the sample size of this study does not allow for formal mediation analysis, the longitudinal design allowed me to conduct a preliminary exploration of whether early change in proposed determinants was associated with later change in family-centred care. Given their preliminary nature, I chose to present results of these analyses in a brief chapter rather than a full manuscript.

### **Method**

#### **Participants**

Healthcare provider participants as described in Chapters 4 and 5 were included who had data available from which to derive the change scores used in the analyses. This subset of HCPs ( $N = 36$ ) did not differ from the subset of HCPs ( $N = 30$ ) that did not have enough data available for analyses of demographic characteristics, or responses to the baseline determinants and PACE questionnaires.

#### **Procedure**

Data are from HCPs' reports at baseline, post-BALANCE and follow-up. See Chapters 4 and 5 for details of the procedure.

#### **Measures**

Data were employed from HCPs' reports on measures of their psychological capability, social and physical opportunity, and reflective and automatic motivation (Capability, Opportunity, Motivation; Determinants questionnaire) and behaviour

*(Partnering, Assessing Needs, Coordinating Care, and Expressing Empathic Care; PACE questionnaire).*

### **Analysis**

Change scores from baseline to post-BALANCE implementation were calculated for the Determinants questionnaire total score and subscale scores. Change scores from baseline to follow-up were calculated for the total score and subscale scores of the PACE questionnaire. Pearson correlations were used to examine associations between early change (i.e., pre- to post-BALANCE) in total and subscale Determinant scores and later change in total and subscale PACE scores (i.e., pre-BALANCE to follow-up). Cohen's (1992) descriptors were used to interpret the magnitude of the correlations (i.e., .10 = small ES, .30 = medium ES, .50 = large ES).

### **Results**

Correlations are presented in Table 6.1. A large correlation was observed between early changes in the total Determinants score and later changes in the total PACE score. At the subscale level, change in the Capability subscale score was most highly correlated across all PACE subscales, with correlations ranging from medium to large in magnitude. Changes in the Motivation and Opportunity subscales were moderately associated with changes in the Coordination and Empathy subscales; however, the magnitude of the association was smaller than for the change in Capability.

### **Discussion**

Results of these correlational analyses indicated a strong association between changes in overall reports of Determinants from baseline to post-BALANCE and changes in overall reports of PACE from baseline to follow-up. Although very preliminary, these

results do provide some initial support for the assertion that early changes in proposed determinants are related to later changes in behaviour. The pattern of findings across subscales is also interesting, particularly with regard to change in the Capability subscale score being most strongly related to changes in all PACE subscale scores. These results may suggest that changes in HCPs' capabilities are a primary driver of change in the desired aspects of family-centred care.

Caution is warranted in interpreting these findings. Analyses were conducted using data from the relatively small number of HCPs that had provided enough responses for calculation of change scores. However, no differences were detected between these participants and the group of HCPs that did not have enough baseline data available for these analyses. These results may also be driven by shared method and reporter variance. Further research incorporating multiple methods and powered for multiple regression analyses that can control for intercorrelations among determinants would be needed to clarify how change in individual determinants accounts for change in desired outcome. Available guidelines suggest that such analyses would require data from a minimum sample of 74 participants (VanVoorhis & Morgan, 2007).

Table 6.1

*Correlations Between Change in HCP Reports of Determinants (Baseline to Post-BALANCE Implementation) and Change in HCP Reports of Family-Centred Care (Baseline to Follow-up)*

<b>Determinants</b>	<b>Outcome</b>				
	<b>Overall</b>	<b>Partner</b>	<b>Assess</b>	<b>Coordinate</b>	<b>Empathy</b>
<b>Overall</b>	0.56**	0.40*	0.47**	0.55**	0.58**
<b>Capability</b>	0.58**	0.47**	0.59**	0.53**	0.62**
<b>Opportunity</b>	0.41*	0.26	0.24	0.47**	0.33*
<b>Motivation</b>	0.36*	0.23	0.25	0.35*	0.40*

Note.  $N = 36$  for all correlations. \*\* Correlation is significant at the 0.01 level (2-tailed).

\*Correlation is significant at the 0.05 level (2-tailed).

## CHAPTER 7. GENERAL DISCUSSION

This dissertation describes a mixed-methods program of participatory action research aimed at improving the surgical experiences of children with autism, their families, and their HCPs. Researchers worked in collaboration and consultation with stakeholders on a series of research projects that contributed to a better understanding of the surgical experiences, as well as the development, implementation, and preliminary evaluation of a theory-driven intervention (i.e., BALANCE) aimed at enhancing HCPs' ability to delivery family-centred care to children with autism. This chapter briefly reviews the key research activities and decision points that shaped this dissertation, strengths and weaknesses of this program of research, how these findings are situated in the current literature, and directions for further research.

The first manuscript (Chapter 2) described a qualitative inquiry into the perioperative experiences of families of children with autism. The objective of this initial qualitative study was to address gaps in the extant perioperative literature related to children with autism (for reviews see: Koski et al., 2016; Taghizadeh et al., 2015) by building an in-depth, nuanced, and inclusive understanding of these perioperative experiences that could inform potential targets for clinically feasible interventions or changes to service provision. Consistent with the participatory approach of the broader program of research, an a priori decision was made that the findings would inform the direction and design of subsequent efforts, to ensure that researchers were privileging the questions and needs that key stakeholders (i.e., families and HCPs) identified. Face-to-face semi-structured interviews were used to gather the perspectives of HCPs and parents who had direct experience supporting children with autism around the time of surgery.



Interpretive description (Thorne, 2008) guided the analysis and identification of three main themes (*Finding your footing through an uncertain journey, relationships can help to keep everyone steady, systems shape the experience*), and the development of a heuristic (i.e., the ‘balancing act’ metaphor) that aimed to provide an organizing conceptual framework for the experiential knowledge gathered in this study. The credibility and trustworthiness of the data analysis and interpretation was established using rigorous qualitative methods (e.g., thick description, negative case analysis, peer debriefing, second readers). Notably, preliminary results including the metaphor were shared with a sample of participants and non-participant HCPs and parents. All who chose to provide feedback indicated that the results and metaphor captured important aspects of their experience.

As discussed in Chapter 3, based on the available literature (for reviews see: Koski et al., 2016; Taghizadeh et al., 2015) and anecdotal reports from HCPs, the initial expectation was that children’s distress would be the most important target for intervention. Consistent with emerging evidence from qualitative studies that systematically explore the healthcare experiences of individuals with autism, their families (e.g., Davignon et al., 2014; Muskat et al., 2015; Solomon et al., 2015) and recent quantitative research on disparities in healthcare delivery (e.g., Casagrande & Ingersoll, 2017), findings from the qualitative study identified a complex array of individual (child, parent, and HCP), interpersonal (child-HCP, parent-HCP, parent-child, HCP-HCP), and systemic (organizational and environmental) factors that could be leveraged in attempts to improve the perioperative experiences of children with autism. Interventions directed at children, families, HCPs, and the healthcare system were

considered. Stakeholder perspectives, as well as ethical and pragmatic considerations, informed the choice to prioritize the development of an intervention aimed at enhancing HCPs' abilities to deliver high-quality care to children with autism as the next step in this program of research.

The second manuscript (Chapter 4) describes how the Behaviour Change Wheel approach (Michie, Atkins, & West, 2014) informed the systematic and theory-driven development of Building Alliances for Autism Needs in Clinical Encounters (BALANCE, an homage to the metaphor described in Chapter 2). As alluded to in the introduction (Chapter 1) and the second manuscript (Chapter 3), in so doing the second manuscript advances the literature on interventions to improve the quality of care to children with autism (e.g., Broder-Fingert et al., 2016; Carter et al., 2017; Cermak et al., 2015; Chebuhar, McCarthy, Bosch, & Baker, 2013), whilst simultaneously contributing to the broader literature on intervention development (e.g., Gould et al., 2017; Westland et al., 2017; Craig et al., 2017). Multiple sources of data (i.e., published literature, stakeholder engagements, and the initial qualitative study) were reviewed to inform a better understanding of what aspects of HCPs' behaviour needed to change to improve the quality of healthcare delivered to children with autism, as well as considerations of which behavioural determinants proposed in the capability, opportunity, and motivation model of behaviour could be targeted to achieve desired changes in HCP behaviour. Family-centred care was selected and operationalized as the target behaviour. Behaviour change techniques were selected based on their potential to address proposed deficits in HCPs' capability, opportunity, and motivation to deliver family-centred care. Stakeholders were engaged to identify an appropriate mode of intervention delivery and

assist with translating behaviour change techniques into intervention content. Healthcare providers reported positive changes in their capabilities, opportunities, and motivation to deliver family-centred care from baseline to post-BALANCE implementation. Positive changes in HCPs' reported capability and opportunity to deliver family-centred care were sustained at three-month follow-up, and reports of motivation increased again from post-BALANCE to follow-up. These findings provided preliminary support for the notion that BALANCE has the potential to achieve changes in proposed behavioural determinants of family-centred care.

The final manuscript (Chapter 5) described an examination of the feasibility, usability, and acceptability of BALANCE, alongside an exploratory mixed-method examination of the impact of BALANCE implementation on healthcare from the perspectives of both HCPs and caregivers. Overall, this study provided initial qualitative and quantitative support for the BALANCE intervention's potential to improve the delivery of healthcare to children with ASD. Findings indicated that BALANCE was feasible to implement within a perioperative day surgery unit at a tertiary pediatric hospital. Fifty percent of HCPs working on the unit completed BALANCE and toolkits were introduced to the unit without problems. Healthcare providers overwhelmingly rated BALANCE as usable and acceptable. Healthcare providers' responses to open-ended questions pointed to changes that could be made to fine-tune and enhance BALANCE, and highlighted how BALANCE had affected HCPs' learning, intentions, and practices. Exploratory quantitative analyses indicated that implementation of BALANCE was associated with positive changes in HCP reports of the delivery of family-centred care from baseline to three-month follow-up. Examination of individual subscale scores

demonstrated the greatest change in areas of assessing and addressing individual needs and collaboration to coordinate care, rather than partnering with families and expressing empathy. Families whose children with autism had surgery following BALANCE implementation also reported more favourable perceptions of the care delivered to their children than families whose children with autism had surgery before BALANCE implementation (even though those reports were also positive). Examination of subscale scores identified that compared to pre-BALANCE caregivers, post-BALANCE caregivers noted the greatest positive differences in HCPs' efforts in the areas of partnering with families and assessing and addressing individual needs.

The final brief chapter (Chapter 6), capitalized on data available from the pilot implementation trial discussed in Chapters 4 and 5 to conduct a preliminary exploration of whether early change (i.e., baseline to post- BALANCE) in proposed determinants (i.e., capability, opportunity, and motivation) was associated with later change (i.e., baseline to three-month follow-up) in the target behaviour of family-centred care (as measured by the PACE questionnaire). As discussed in Chapter 6, findings based on these preliminary analyses suggested that shifts in HCPs' psychological capability (having the knowledge, skills, memory, attention, and decision making, as well as the ability to engage in family-centred care in the face of competing demands) from baseline to post-BALANCE may be a primary driver of change across all targeted aspects of family-centred care. Baseline to post-BALANCE change in HCPs' reports of their opportunity (having social influences and access to a physical environment that facilitated the delivery of family-centred care) and motivation (reflective and automatic motivational processes, such as beliefs about capabilities, intentions, and automatic

emotions) were also moderately associated with baseline to follow-up change in HCPs' reports of their efforts to express empathy and collaborate to coordinate care. In contrast, only small correlations were observed between baseline to post-BALANCE change in HCP's reports of their opportunity and motivation to delivery family-centred care, and baseline to follow-up change in HCPs' reports of their efforts to partner with families and assess and address individual child needs.

### **Reflections on Adopting a Participatory Action Approach**

This research program adopted a participatory approach that involved researchers working with key stakeholders (i.e., HCPs, families, children with autism) towards the shared goal of improving the perioperative experiences of children with autism. The rationale for adopting this approach was discussed in Chapter 1, but further reflection on the benefits and challenges of the participatory approach seems warranted.

Adopting a participatory action approach was not without its challenges and limitations. For example, building and maintaining relationships with stakeholders throughout this program of research required a substantial investment of time and energy. Engaging stakeholders also required contending with 1) staffing changes that affected which stakeholders were engaged with the project over time, 2) the challenges involved in engaging stakeholders who have limited availability and flexibility in their schedules, 3) managing expectations related to the timelines involved in research, and 4) negotiating amongst different stakeholders' perspectives to reach consensus for research priorities and immediate objectives. In order to avoid tokenism, it was essential to allow stakeholder perspectives to truly influence the direction and scope of the research, which inevitably meant navigating challenges associated with relinquishing elements of

research control. For example, given that the a priori decision was made to allow the initial qualitative study's findings to influence next steps, it was not possible to specify fully the scope of the dissertation from the outset. Instead, research methods were selected pragmatically at each phase of the research program based on the questions and priorities identified through stakeholder engagements. This compelled methodological pluralism as well as the development of questionnaires appropriate for measuring outcomes identified as relevant. Overall, the challenges noted in this program of research were consistent with published critical reflections on participatory action approaches (e.g., see Israel, Schulz, Parker, & Becker, 1998; Minkler & Salvatore, 2012).

Despite these challenges, the choice to adopt a participatory action approach strengthened this research. In particular, stakeholder perspectives gathered through the initial qualitative study provided an inclusive and nuanced understanding of factors that influence the perioperative experiences of children with autism and their families. As described in Chapter 3, this understanding influenced the direction of the research program in a manner that likely enhanced the relevance and uptake of improvement efforts that followed. Engaging HCP, children with autism, and their families in the development of the intervention content may have also enhanced the appeal, credibility, utility, and impact of BALANCE. Moreover, engagement with and uptake of BALANCE was much higher than expected, and HCPs often commented on how they valued the opportunity to hear directly from the children with autism and families featured in BALANCE. Anecdotal reports from HCPs and families also suggested that the participatory action approach helped to overcome some research-related distrust and cynicism. For example, in expressing appreciation that their perspectives and priorities

were respected and used to inform improvement efforts with direct clinical relevance, stakeholders often commented on frustrations associated with past participation in research that they perceived as academic exercises with little applied benefit. In sum, many potential benefits of participatory approaches appeared to be realized through this dissertation research program (e.g., see Israel et al., 1998; Minkler & Salvatore, 2012).

### **Limitations of the Research Program**

Chapters 2, 4, and, 5 addressed several manuscript-specific limitations. Three key limitations of the broader program of dissertation research are elaborated here.

**The Largely Exploratory Nature of this Research.** Historically, the field of autism research has been focused on etiology, assessment, and treatment of core symptoms and associated mental health disorders. Only in recent years has the field begun attending to the health-related needs of children with autism and the challenges that they face in accessing healthcare services. Although applied health-related research has been identified as a priority (e.g., Frazier et al., 2018; Pellicano et al., 2014b), research funding for health services research has been relatively limited (e.g., Krahn & Fenton, 2012) and there is scant relevant high-quality research addressing stakeholder priorities.

An exploratory approach was deemed appropriate and necessary to addressing gaps in the literature and examining the feasibility, usability, and acceptability of BALANCE. Nevertheless, the largely exploratory approach constrains conclusions that can be drawn based on this program of research. Specifically, based on the studies in this dissertation it is not possible to determine whether changes observed in HCPs' reports of

determinants and family-centred care, and caregiver reports of family-centred care can attributed directly to the implementation of BALANCE.

**Reliance on Subjective Reports and Author-made Measures.** Subjective reports from HCPs and families were the primary sources of data gathered throughout this dissertation. The reliance on subjective reports introduces questions about the role of social desirability biases. This would best be addressed by future research that incorporates researcher-driven observations of healthcare experiences. The merits and potential advantages of including researcher-driven observations of the interactions among HCPs, families, and children with autism around the time of surgery were considered. However, they were deemed impractical for these research purposes. For example, conducting such observations would only be feasible if all HCPs involved in delivering care around the time of surgery consented to being observed. In addition, even if all consented, there were concerns that having an observer present during healthcare interactions would add unnecessary stress to the day of surgery. Unfortunately, no means were available to record interactions in a less obtrusive manner, which would have allowed for later observation and coding. Further, the subjective reports were gathered through author-made and purpose-driven measures. Available guidance on measure development (e.g., Streiner & Norman, 2008) was followed, and reliability statistics (Cronbach's alpha) were reported for questionnaire data. Nonetheless, the validity of these measures remains to be established. It is also important to note that measures used to evaluate BALANCE were limited to HCPs and caregivers. It is important that future research also considers youths' perspectives on their care.



**Need for Further Youth Engagement.** Throughout this research program, efforts were made to engage important stakeholders in both participating and contributing to the research. Youth were featured in the development of BALANCE, but I acknowledge that the perspectives of youth were less integrated into the overall project than were the perspectives of their caregivers and HCPs. The decision to focus on HCPs' and families' perspectives in the initial qualitative study was influenced by the paucity of guidance in the literature about how to gather perspectives of individuals with autism on their lived experiences. This was particularly concerning in light of the core difficulties that children with autism display in terms of social communication (American Psychiatric Association, 2013), as well as research identifying potential weakness in episodic memory in children with autism (e.g., Bruck, London, Landa, & Goodman, 2007; Lind, 2010). However, more recent research has demonstrated that with appropriate supports and methods children with autism can recall and share information about their lived experiences with as much accuracy as their non-autistic peers (e.g., Almeida, Lamb, & Weisblatt, 2018). In addition, increasing recognition of the importance of incorporating the perspectives of individuals with autism in matters that affect them has yielded recent advancements in interview methods (e.g., computer- or picture-assisted, or activity-oriented; e.g., Barrow & Hannah, 2012; Winstone, Huntington, Goldsack, Kyrou, & Millward, 2013) and best practices for interviewing children with autism have begun to be articulated (Tesfaye et al., in press). Studies are warranted that draw on these recent methodological recommendations to explore the perspectives of children with autism on their healthcare experiences.

**Lack of Comparators and Controls.** Part of the impetus for engaging in research-based efforts to improve the perioperative care of children with autism stems from assertions in commentaries and editorials and by HCPs that children with autism are more vulnerable than their peers to negative experiences around the time of surgery. The first systematic comparison of perioperative experiences of children with and without autism (Arnold et al., 2015) was published following the completion of our qualitative study (Chapter 2). Arnold et al.'s retrospective study relied on comparing data from the charts of children with and without autism undergoing general anesthesia related to dental rehabilitation and found few discernable differences. Although this study was limited in several ways (see Snow et al., 2016), it nevertheless called into question whether the perioperative experiences of children with autism really differ from those of children without autism. The inclusion of a comparison group of families of children without autism in the initial qualitative study could have shed further light on this question. In addition, given that BALANCE simultaneously targets systemic and individual-level factors, it was not possible to use HCPs working within the same unit as controls for one another in the preliminary evaluation of the intervention (Chapter 5). Although not possible within the scope of this program of participatory research, the inclusion of a second perioperative unit as a control would have strengthened interpretations about the feasibility and impact of the BALANCE implementation pilot trial (Chapter 5).

### **Additional Future Directions**

Additional exploratory and confirmatory (i.e., hypothesis driven) research that builds on this set of studies by addressing noted limitations would help to further advance relevant literatures. For example, exploratory studies are already underway to clarify the

applicability of BALANCE to other pediatric hospital contexts (e.g., emergency room, inpatient health units). Exploratory studies may also be needed to further inform the researcher-driven observation tools that could be incorporated into future studies.

Hypothesis-driven research is needed to establish 1) whether individual, interpersonal, and systemic factors interact to influence the surgical experiences of children with autism as proposed in the initial qualitative study (Chapter 2), 2) whether interventions developed on the basis of systematic and theory-driven methods are superior to non-theory-driven interventions (Chapter 4), 3) whether behavioural determinants proposed to underlie variations in family-centred care in the perioperative context are relevant across healthcare contexts, and 3) the efficacy of BALANCE in changing HCPs' behaviour.

Addressing these questions will require additional survey or interview research as well as controlled multi-site studies. These studies should and will necessarily involve investigations that extend beyond a single healthcare centre, which will allow questions of replicability and generalizability to be addressed. It will also be important to explore whether the implementation of BALANCE, and the delivery of family-centred care are associated with changes in relevant proximal (e.g., children's procedural distress, health outcomes, and behavioural adjustment following the care experience) and distal outcomes (e.g., reductions in unmet healthcare needs, rates of service utilization, healthcare costs). Psychometric studies that establish the validity and reliability of measures designed for this dissertation (e.g., behavioural determinants, and family-centred care), as well as measures of other outcomes of interest that have not been established for use with children with autism (e.g., children's procedural distress,

behavioural adjustment), will also be important for strengthening conclusions to be drawn from any future confirmatory research.

## **Conclusion**

My dissertation involved a program of participatory action research wherein researchers worked in consultation and collaboration with HCPs, children with autism, and the families of children with autism throughout a series of research projects aimed at improving the surgical experiences of children with autism. Consistent with the participatory action approach, stakeholders' perspectives and priorities strongly influenced the direction of this research program. By adopting a systematic approach to gathering experiential knowledge about the perioperative experiences of children with autism, and by following established best practices to inform the development of BALANCE, my dissertation addressed notable gaps in relevant bodies of literature whilst simultaneously addressing a clinical need. In so doing, this research strengthened the foundation of literature informing efforts aimed at improving the quality of healthcare delivered to children with autism.

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## APPENDIX A

### Interview Guide: Parent Participants

**Note:** Parents will be prompted to think back to their experience of having their child undergo day surgery at the IWK. If multiple surgeries have occurred, parents will be prompted to think back to their most recent surgical experience and then prompted to think of whether or not all of their surgical experiences were relatively consistent. To this end, the examiner will add the prompt *how does this differ or relate to your child's previous surgical experiences* where relevant.

**Preamble:** Thank you for taking the time to speak with me today, I am very grateful to have the opportunity to learn from your experiences. So just to reiterate I'm interested in gaining a better understanding of the surgery-related experiences of children with autism spectrum disorders (ASD). One way that I thought I could do that is to draw on your expertise as a parent who has witnessed their child receiving surgery at the IWK Health Centre. So I have designed a series of questions aimed at helping me to gain insight into your child's [most] recent surgical experience.

[If applicable: where your child has had more than one surgical experience, I would ask that when I ask the questions you respond by first thinking about your child's most recent experience. When you are finished, I will ask you to compare your child's most recent experience to their previous experiences so that we can be sure to capture as much information as possible.]

The specific questions/sub questions and clarifying probes (in brackets) that parents will be asked include:

- 1) Can you share with me your experience of having your child go through the Day Surgery at the IWK?**
  - a) What was this experience like for your child?
  - b) What was this experience like for you? Your family?
  - c) What kind of surgery was your child receiving? For what purpose?
  
- 2) How did you and your child prepare to come to the IWK for their surgery?**
  - a) What happened before you came to the hospital?
    - i) How did you learn about your child's surgery?
    - ii) What was the communication before surgery? (From your family doctor?; From the IWK surgery department? Nurses? Were you mailed or sent any information? Did you receive a phone-call? Were you provided with any online resources?)
      - (1) With your child?
        - (a) When did you inform your child that they would be coming to the IWK?
    - iii) Did you spend time preparing your child for their visit to the IWK? Did you believe you had enough resources to prepare your child?

- (1) If yes, what did this preparation consist of? Did you find this preparation helpful?
- 3) Once you arrived at the IWK, how did you and your child cope before surgery while you were together in the waiting room? (Were you comfortable with the process or the way things went while waiting to go into the OR?)**
- a) How would you describe you and your child's emotional state at that time? Calm, anxious, frustrated, content?
  - b) Do you remember speaking to healthcare providers during this period of time? If you can remember, who did you speak to? What kinds of information did they provide you with?
  - c) Did anything occur during before surgery time that made the waiting period more or less challenging?
    - i) Was your child given any medication or provided with any other resources?
- 4) What was the experience like when...**
- a) Your child was separated from you to go to the OR?
  - b) When you were allowed to go see them after surgery?
  - c) When you returned home? (How comfortable did you feel with discharge instructions? What was your child's behaviour like when they got home?)
- 5) Imagine for a moment that you were returning to the IWK and your child was undergoing another Day Surgery. What would you want your child's healthcare providers to know?**
- a) Are there particular strategies that you think would help your child have the best experience possible? What about strategies that you think would help ensure that you had the best experience possible?
  - b) What would you change? What would you keep the same?
- 6) Is there anything more you would like to share with me about your child's experience in the IWK Day Surgery Service?**

## APPENDIX B

### Interview Guide: Healthcare Provider Participants

#### Study Title: Perspectives on the Perioperative Experience of Children with Autism Spectrum Disorders

**Preamble:** Thank you for taking the time to speak with me today, I am very grateful to have the opportunity to learn from your experiences. So just to reiterate I'm interested in gaining a better understanding of the perioperative experiences of children with autism spectrum disorders (ASD). One way that I thought I could do that is to draw on your expertise as a member of the perioperative staff that has direct experience providing perioperative care for children with ASD. So ,I have designed a series of questions aimed at helping me to gain insight into your observations and experiences of working with children with ASD and their families within the perioperative context.

The specific questions/sub questions that healthcare providers will be asked include:

- 1) **Can you share with me your typical experience of working with a family who has a child with ASD?**
  - a. What is this experience like for you?
  - b. If you came in to work and found out that you were going to be caring for a family who have a child with ASD how would you prepare yourself? Do you do anything different?
  - c. Can you describe your best experience of working with a child with ASD within the Day Surgery setting?
  - d. Can you describe your most challenging experience working with a child with ASD within the Day Surgery setting?
  
- 2) **If a new colleague came to you looking for support around how to best care for a family/child with ASD during the surgical course, what would you tell them?**
  - a. What would you tell them about autism spectrum disorders in general? How would you explain to them what it was?
  - b. Are there specific coping strategies the families and child use during the surgical course?
  - c. What might they expect to see from a child with ASD and [his/her] family across the surgical course? What about their families?
    - i. Before surgery?
    - ii. At induction?
    - iii. After surgery?
  - d. What information or strategies for caring for children with ASD and their families have you found helpful?
  - e. Are their comments or remarks that parents of children with ASD commonly make? Have these informed your approach?
  
- 3) **From your perspective, if resources weren't an issue, what supports would you have in place to ensure that children with ASD and their families**



**received the best clinical care possible during their time on the Day Surgery unit?**

- a. What would you change or keep the same?
- b. What do you think would get in the way of having these supports in place?  
What barriers to change could you foresee?

**4) Is there anything more you would like to share with me about your experience of managing children with ASD undergoing day surgery at the IWK?**

## APPENDIX C

### Determinants Questionnaire

**Instructions:** These questions all relate to things that might influence the care you provide to children with autism and their families. Please *think specifically about children with autism and their families* when answering.

Please note that we have used ‘autism’ to refer to autism spectrum disorder (including the historical ‘pervasive developmental disorder’, ‘Asperger syndrome’). ‘Colleagues’ includes all of the healthcare providers from different disciplines involved in working with children with autism and their families on the day of surgery (e.g., nurses, surgeons, anesthetists, child life specialists, pediatric dentists, administrators).

For the purposes of this study family-centred care is defined as: collaborative, supportive, and respectful interactions with the family and child. Family-centred care also includes effective collaboration between members of the healthcare team that results in coordinated care, meeting the individual emotional, sensory, and socio-communicative needs of each child with autism.

**Response set:**

Very much disagree	General disagree	Tend to disagree	Slightly disagree	Slightly agree	Tend to agree	Generally agree	Very much agree
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***Remember, please think specifically about providing healthcare for children with autism and their families when rating the following statements....***

- 1) My colleagues notice and acknowledge when I provide family-centred care (Motivation)
- 2) I can assess the emotional needs of children with autism and their families (Capability)
- 3) I have access to the resources I need to tailor my approach (e.g., visual supports, toys, assessment tools) (Opportunity)
- 4) All of my colleagues feel prepared to care for children with autism and their families (Motivation)
- 5) I have the skills needed to deliver family-centred care to children with autism and their families (Capability)
- 6) My priority is that no child experiences distress while in my care \* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 7) My colleagues take into account each other’s ideas about the best approach to care (Opportunity)
- 8) My interactions with families on the day of surgery don’t matter in the long run \* (Motivation)

- 9) I see myself as an expert in providing family-centred care to children with autism and their families (Motivation)
- 10) I know the current recommendations for delivering care to children with autism and their families. (Capability)
- 11) My colleagues support me when I run into challenges providing care (Opportunity)
- 12) I worry about the child's safety \* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 13) I can prioritize the needs of children and families, even when I am faced with competing demands (Motivation)
- 14) In the event of a change in the care plan, healthcare providers understand the reasons for change (Opportunity)
- 15) My colleagues share information about families' needs (Opportunity)
- 16) My team has control over whether families receive family-centred care (Motivation)
- 17) Being assigned a patient with autism makes me nervous \* (Motivation)
- 18) Challenging experiences give me a chance to build stronger relationships with families (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 19) I am aware of how child characteristics (e.g., sensory characteristics, communication characteristics) influence children's experiences in day surgery (Capability)
- 20) Delivering family-centred care is my responsibility as a healthcare provider (Motivation)
- 21) Individualized approaches to care are hampered by health center policies, guidelines, and procedures \* (Opportunity)
- 22) I can assess the sensory needs of children with autism and their families (Capability)
- 23) My colleagues think that family-centred care is important (Opportunity)
- 24) I am less confident in my ability to care for children with autism and their families, compared with other children \* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 25) I can effectively communicate with families about their care (Capability)
- 26) Challenging situations really stick with me emotionally \* (Motivation)
- 27) My colleagues communicate about their approaches to care (Opportunity)
- 28) How I respond to challenging situations is more important to families than whether the child experiences distress (Motivation)
- 29) Families notice and let me know when I provide family-centred care (Motivation)
- 30) I worry about making a plan with the family that my colleagues may not follow through on \* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 31) I worry about my own safety \* (Motivation)
- 32) I can effectively communicate with other healthcare professionals to provide coordinated care (Capability)
- 33) I can assess the communication needs of children with autism and their families (Capability)

- 34) My goal is to deliver family-centred care, regardless of how the child and family cope (Capability)
- 35) I am aware of how family characteristics (e.g., parent worry) influence children's experiences in day surgery (Capability)
- 36) When things do not go well, I think about the things other team members could have done differently\* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 37) When things do not go well, I think about the things I could have done differently \* (Motivation)
- 38) I can effectively communicate with other healthcare professionals when we disagree about an approach to care (Capability)
- 39) My relationships with my colleagues are strained when children and families are distressed \* (Motivation)
- 40) I know enough about the characteristics of autism to tailor my approach to care (Capability)
- 41) I know that children with autism and their families are less likely to receive family-centred care (Capability)
- 42) Distress in children with autism is especially difficult to manage \* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 43) My colleagues are better able than I am to care for children with autism and their families \* (Motivation)
- 44) I can still make a family's experience positive, even if their child is very distressed (Motivation)
- 45) Delivering family-centred care makes a positive difference for children with autism and their families (Motivation)
- 46) I am uneasy when I cannot predict how a child with autism will cope \* (Motivation)
- 47) I have influence over whether families receive family-centred care (Capability)
- 48) I can adjust my approach to care to meet the needs of children with autism and their families (Capability)

***Thinking about providing healthcare for children with autism and their families....***

- 49) When confronted by a child or family who struggles to cope with the surgical experience, my colleagues discuss how to handle the situation (Opportunity)
- 50) My colleagues and I have different views on what is meant by family-centred care \* (Opportunity)
- 51) I am aware of how system factors (e.g., hospital policies, team dynamics) influence children's experiences in day surgery (Capability)
- 52) If a challenging situation upsets me, I can handle it and still provide effective care (Capability)
- 53) I am aware of how healthcare provider characteristics (e.g., healthcare provider distress) influence children's experiences in day surgery (Capability)
- 54) I feel like I have failed in my role if a child becomes distressed\* (Motivation)

***Thinking about providing healthcare for children with autism and their families....***

- 55) In my work delivering family-centred care to children with autism and their families, I know exactly what is expected of me (Motivation)
- 56) Challenging experiences give me a chance to build stronger relationships with colleagues (Motivation)
- 57) I have a clear plan for how I can enhance family-centred care (Capability)
- 58) I have access to training about how to tailor my approach to care (Opportunity)
- 59) I intend to prioritize family-centred care (Motivation)
- 60) My colleagues keep differences of opinions about care to themselves \* (Opportunity)

Notes: \* denotes items that are reverse scored. The subscale (i.e., Capability, Opportunity, Motivation) that each item was included on is indicated in the brackets following each item. This bracketed information was not presented to participants.

## APPENDIX D

### Example of individualized feedback provided to healthcare providers who completed BALANCE e-modules

Dear Healthcare Provider,

For each case I have gone through and looked at your answers. I broke my feedback down by case, though in some cases some of the feedback might be relevant for both. I also provide a few general overall comments. My aim is to provide supportive feedback and also pose questions or make comments that ‘stretch’ your thinking even further. These ‘stretches’ are not meant to be critical, they are simply meant to stimulate further ideas and engagement. My hope is that this will be helpful and of interest to you!

Please do not hesitate to reach out if you have any questions or comments about this feedback or the program more generally.

**Case 1:** Great job! The priorities that you selected are the three most logical choices in this case. I asked for priorities to encourage thinking about how to make *informed and selective choices* about what to tick under the approach column of the ‘Take a SEC checklist.’ Ideally, the things ticked in the approach column would logically fit with the things ticked in the assessment column (i.e., just as the choices you have made here fit with the case information)

My guess is that making these kinds of selective choices is harder to do in reality - your time is likely more limited and families may provide you with a lot more information than I did! While I really like the idea of working through the Take a SEC checklist with families, I also worry that families might be inclined to tick most of the things in the approach column if they seem them. This is not necessarily a problem, I am just cognizant that seeing a list where everything is ticked might be a bit overwhelming for other team members (on the other hand, maybe some people will find it helpful because they will just know to do everything on the list). I wonder whether families would feel just as much a part of the team, if the team member administering the checklist reviews the approach options on their own and uses their clinical judgement to select a few key approach options that fit with what they learned from completing the assessment column that they can then offer to and discuss with the family. There are no right/wrong ways to use the checklist, these are just the kinds of questions that pop into my head when I think about how to balance making the Take a SEC checklist work best for families, healthcare providers, and the team.

In terms of the family and team pieces, your ideas were insightful and entirely appropriate. You picked up on the fact that mom is likely to be concerned about the day and the separation, that their previous negative experiences at the hospital are likely playing into her expectations and had great ideas about how you could communicate to Jaquelin your understanding of her thoughts and feelings. I would expect that doing what you described would help you to build a strong relationship with Jaquelin and help her to feel more comfortable and at ease. You also talked about the importance of making sure all team members were aware of what would be helpful for Sarah and her mom Jaquelin, and mentioned the possibility of doing a debriefing, which included information about how the family felt it went. I think that is a wonderful idea. I have heard through my research that the team doesn’t always get the opportunity to hear the family’s perspective on their experience, and how helpful this could be. I wonder how it would work- would you think about someone on the team sending an email to all involved?

It was also great to see that you would be thinking that you could handle the situation. You also mentioned that you might be thinking that it was going to take more time. As discussed in module 5 thoughts and feelings are not problems unless you find they are getting your way. If you ever did start to notice that you were getting worried by the thought that it was going to take longer, and that was getting in your way of your goal of focusing on the family without being too distracted, I would encourage you to try out the grounding strategy you identified as being potentially helpful in module 5. It seems so simple, but in times when our mind is getting carried away with itself, noticing our surroundings can really help to bring us back to the present moment and interaction.

**Case 2:** Again, I completely agree with your response to question one (provide sensory items and use simple first, then instructions). While turning the lights down, using the parent as the ‘interpreter’, and sedation can be helpful in many cases they are not the clear priorities here.

Your responses to the family-related questions were also bang on. The uncertainty of it all has been a huge piece for many of the families that I talked to. While this is always a challenge, I think that it is especially difficult for families of young children who may have recently gotten a diagnosis- or those kids that I know you guys see that do not have a diagnosis but leave you wondering whether they might get one in the future. These families are often still trying to work out what to expect, what is going to trigger their child, and what is the best way to approach them. It is by no means a rule, but I think it is important to be mindful that these families may have a harder time supporting the healthcare team to figure out what is going to work best for their child – I wouldn’t be surprised if you got a lot more ‘I’m not sure’ or ‘I don’t know’ with these families when you try to assess what might be helpful for their kiddos.

I loved how you picked up on that they may also be feeling hopeful. This is not something that I had thought about myself, but I think it is an incredibly important point! What is clear to me is that there is no ‘single interaction’ with the healthcare system for these families. Every interaction with the healthcare system plays into their overall perception and ideas about how the next one is going to go. I loved how you decided to focus on the strengths and the positives, while still acknowledging their feelings of uncertainty and letting them know your goal is to try and figure out what things are going to work well. I wonder if in some cases you may also include explicitly labelling the feelings that you have picked up on. For example, you might actually say something like “I’m wondering if you are feeling a little bit uncomfortable or unsure of how today is going to go.” If they say ‘yes’ then you can jump into validating that it makes sense that they would feel that way and offer your reassurance that you are going to do your best. If they say no, it gives you some more information, and hopefully opens the door to them letting you know more about what they are experiencing and provides you an opportunity to validate that instead.

It is awesome that you would be thinking that you were ready to handle this case! In module 5 you mentioned that there are times where you might feel that there are others that will do a better job than you. It is totally natural to feel this way – particularly when others might have more experiences supporting children with autism. If this were a case similar to the ones you were reflecting on in module 5, and instead of thinking *I can handle this* you were thinking *someone else could do a better job for this child and family than me* what do you think would happen if you chose to take the case despite feeling the urge to pass it on? What would it cost you? What would you gain? What impact would your choice have on the family, your team, and the system. Personally, there have certainly been cases where I bowed out and relied on others. I try not to beat myself up about that, I am still learning and sometimes it is the most appropriate choice. Other times though, I decide to take on a case in spite of thinking, feeling, and sometimes even knowing that someone else can do a better job, in the service of building my skills and in turn

building the system's capacity to provide high quality care for the next child and the child after that.

I also love that you are thinking about using the Take A SEC checklist to help make sure all members of the team are aware of the child's needs. I think that it has the potential to do exactly what you described- the ongoing challenge is going to be figuring out the best way make sure that the whole care team knows when the Take A SEC checklist has been completed, and that everyone feels comfortable referring to it to inform their approach. I know that we have briefly chatted about a few of these challenges – for example, that sometimes if you are in phase 1 recovery you may not know that it has been completed. How do we address this gap in the communication link- can we flag it better somehow or should it be said verbally by someone who brings the child to recovery? I hope that the team keeps engaging in these kinds of discussions to figure out how to best make the Take a SEC checklist and toolkits work for everyone!

**Final thoughts:** I have had the chance to go through and check that all your responses have been saved throughout the program. I want to thank you for your engagement and commitment to the completing the BALANCE program. Your thoughtful responses illustrated for me how 'Autism Friendly' and well qualified you are to provide high quality care for these children and families. I hope that it has been helpful for you and helped you feel confident in your own skills and abilities!



APPENDIX E


Example of poster used to communicate positive feedback from families of children with autism

# BALANCE: Family Feedback

\* The comments below were shared by families of children with autism who had surgery since 53 Healthcare Providers working within the Day Surgery Unit completed the BALANCE program (Building Alliances for Autism Needs in Clinical Encounters).

Comments or Questions? Contact: [Stephanie.Snow@wk.nhealth.ca](mailto:Stephanie.Snow@wk.nhealth.ca)


<p>"Everything went well. The approach was very oriented to his needs. This was the first time we were asked questions about his needs. They really cared about him having autism."</p>	<p>"It was just wonderful. The staff is amazing. I don't know where you find your people. Amazing people"</p>
<p>"They really, really tried. I was almost surprised how they tried to augment the care because he was on the spectrum. It was unexpected, but very nice at the same time."</p>	<p>"I really appreciated that everything they were telling me, they told him too. Even though it didn't appear like he was listening, he was. I just really appreciated that respect."</p>
<p>"It's just obvious that the staff has either received training or that they are really serious about adapting their care to make kids more comfortable."</p>	<p>"The checklist that they went over was very helpful...Having that expanded to other areas for other children that need it for issues that they have would be awesome as well. Maybe not just for day surgery."</p>
<p>"I think it is an improvement from last time."</p>	<p>"They offered us everything we wanted."</p>



**PREP**  
Providing Research in Pediatric Care

**Thank You!**

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February, 2017

APPENDIX F

Family-centred Care: Partnering, Assessing Needs, Coordinating Care, and Expressing Empathic Care (PACE) Questionnaire

**Instructions:** These questions relate to what healthcare providers might do when interacting with children with autism and their families, and colleagues on the day of surgery. Please *think specifically about children with autism and their families* when answering.

Please note that we have used ‘autism’ to refer to autism spectrum disorder (including the historical ‘pervasive developmental disorder’, ‘Asperger syndrome’). ‘Colleagues’ includes all of the healthcare providers from different disciplines involved in working with children with autism and their families on the day of surgery (e.g., nurses, surgeons, anesthetists, child life specialists, pediatric dentists, administrators).

**Response set options:**

i) ***When providing care for children with autism and their families, I:***

Almost Never	Rarely	Infrequently	Sometimes	Pretty often	Frequently	Most of the time	Almost always
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ii) ***This behaviour is:***

Not at all important	Low importance	Slightly important	Moderately important	Very important	Extremely important
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***When providing care for children with autism and their families, I:***

1. Ask or refer to information about child’s sensory sensitivities/needs (Assess and address)
2. Assess what families already know about the procedure (Partner)
3. Listen to families’ concerns or worries (Empathy)
4. Encourage families to let me know when I should adjust my approach to care for their children (Partner)
5. Share information about the care plan (Partner)
6. Adapt how I interact with the child based on his or her emotional needs (e.g., consider pre-medication, provide distractions) (Assess and address)

***When providing care for children with autism and their families, I:***

7. Ask families how they can tell how their children feel (Partner)
8. Provide choices for families to make about their children’s care (Partner)
9. Collaborate with my colleagues to develop a care plan (Coordinate)
10. Tell families that they don’t need to be worried or scared (e.g., “don’t worry, she’ll be fine”)\*(Empathy)
11. Ask my colleagues for input when I’m unsure (Coordinate)
12. Adapt how I interact with the child based on his or her communication needs (e.g., use visual supports) (Assess and address)

***When providing care for children with autism and their families, I:***

13. Ask or refer to information about the best way to communicate with the child (Assess and address)
14. Ask or refer to information about things that might upset the child (Assess and address)
15. Debrief about challenging cases with colleagues who were involved (Coordinate)
16. Ask families if there is anything that they want to know more about (Partner)
17. Explain medical terms (Empathy)
18. Tell families that what they are feeling makes sense (e.g., “lots of kids feel worried”) (Empathy)

***When providing care for children with autism and their families, I:***

19. Acknowledge to families when I need to confirm something that has been asked already (Empathy)
20. Find out what my colleagues have already explained to families about the care plan (Coordinate)
21. Express concern for my colleagues when they encounter child and family distress (Coordinate)
22. Take into account my colleagues’ ideas about the care plan (Coordinate)
23. Appear relaxed (e.g., speak and move slowly, be gentle, don’t rush) (Empathy)
24. Name what I think the parent or child is feeling (e.g., “seems like you might be feeling a bit nervous”) (Empathy)

***When providing care for children with autism and their families, I:***

25. Adapt how I interact with the child based on his or her sensory needs (e.g., turn down lights) (Assess and address)
26. Use simple language (Partner)
27. Focus on the child and family without distraction (e.g., be “in the moment”) (Empathy)
28. Talk to my colleagues when we disagree on the care plan (Coordinate)
29. Talk to my colleagues about how to handle child and family distress (Coordinate)
30. Communicate with my colleagues about changes to the care plan (Coordinate)

***When providing care for children with autism and their families, I:***

31. Try not to repeat questions that my colleagues have already asked (Coordinate)
32. Share information I gather with the rest of the team (Coordinate)
33. Ask families if they have any questions (Partnership)
34. Acknowledge that the family is an important part of the team (Partner)
35. Communicate that I understand families’ concerns (e.g., “I can see why you’d feel that way”) (Empathy)

Notes: \* denotes items that are reverse scored. Information in Brackets following each item indicates which subscale each item was included on and was not presented to participants. Partner = partnering with families, Assess and address = assessing the needs

of each child and tailoring care accordingly, Coordination = coordinating care through inter-professional collaboration, and Empathy = expressing empathy and warmth.

APPENDIX G

Family Perceptions of Care Delivery (FPCD) Questionnaire

Instructions: Please indicate the extent to which you agree or disagree with the following statements. The response options are strongly disagree, disagree, neither agree or disagree, agree, and strongly agree. We are interested in your honest opinions, positive or negative.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
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- 1) Healthcare providers met my child’s needs (Assessed and addressed)
- 2) Healthcare providers did not meet my needs\* (Partnered)
- 3) Healthcare providers communicated in a way that was appropriate for me and my child (Partnered)
- 4) Healthcare providers asked about and addressed our concerns (Partnered)
- 5) Interacting with healthcare providers reduced my stress and worry (Partnered)
- 6) Interacting with healthcare increased my child’s stress and worry\* (Assessed and addressed)
- 7) Healthcare providers communicated that they understood our concerns (Empathized)
- 8) Healthcare providers appeared to be listening during interactions with me and my child (Empathized)
- 9) Healthcare providers appeared distracted during interactions with me and my child\* (Empathized)
- 10) Healthcare providers seemed at ease when interacting with me and my child (Empathized)
- 11) Healthcare providers were generally warm and friendly during interactions with me and my child (Empathized)
- 12) Healthcare providers appeared to have difficulty adjusting their approach to care to meet my child’s needs\* (Assessed and addressed)
- 13) Healthcare providers asked questions to try and learn from my expertise as a parent (Partnered)
- 14) Healthcare providers asked about my child’s sensory needs (Assessed and addressed)
- 15) Healthcare providers asked about my child’s emotional needs (Assessed and addressed)
- 16) Healthcare providers asked about my child’s communication needs (Assessed and addressed)
- 17) Healthcare providers used the information I provided to inform their approach (Partnered)
- 18) Healthcare providers that interacted with me and my child appeared to be working as a unified team (Coordinated)
- 19) Healthcare providers that interacted with me and my child did not all seem to be on the same page\* (Coordinated)

- 20) Healthcare providers seemed to communicate the information they asked me for to their colleagues (Coordinated)
- 21) It frustrated me that many of the healthcare providers that we interacted with asked us the same questions\* (Coordinated)
- 22) Healthcare providers we did not directly interact with seemed comfortable around my child (Empathized)
- 23) Healthcare providers we did not directly interact with sometimes looked uneasy, as if they were worried how my child would behave\* (Empathized)
- 24) In a general overall sense, I was satisfied with the care provided by the healthcare providers that we interacted with (General Satisfaction)
- 25) If my child needed surgery again, I would happily work with the same healthcare providers (General Satisfaction)
- 26) I would not recommend the healthcare providers that we worked with to other families with children with autism\* (General Satisfaction)

Notes: \* denotes items that are reverse scored. Information in Brackets following each item indicates which subscale each item was included on and was not presented to participants. Partnered = partnering with families, Assessed and addressed = assessing the needs of each child and tailoring care accordingly, Coordinated = coordinating care through inter-professional collaboration, and Empathized = expressing empathy and warmth.