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Coping and Stress Related to Support Needs: Assessing Needs in Parent and Caregivers of Children with Down syndrome

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Abstract

The present study aims to better understand support needs among parents/caregivers of children with Down syndrome, and its relationship to parental stress and coping strategies. 122 parents and caregivers of children with Down syndrome of various age groups completed an online survey including demographics information, Family Needs Survey - Revised, Questionnaire on Resources and Stress – Friedrich Version, and the Family Crisis Oriented Personal Scales. Descriptive statistics characterize the sample and determine which items are important and met as needs. Relationship between the important unmet needs (IUN), coping and stress were explored using Pearson correlations across the three measures. The most important needs domains were Information and Community Services. Findings support our hypotheses that greater stress is correlated with IUN, and more effective coping strategies are correlated with less stress and less IUN. With greater understanding of these relationships, support programs and interventions could be designed to target specific needs.

Keywords

Down syndrome, needs assessment, stress and coping, unmet needs

Summary for Lay Audience

This study aims to better understand support needs in parents and caregivers of children with Down syndrome. Despite Down syndrome (DS) being the most prevalent chromosomal cause of intellectual disability, research including individuals with DS often groups the population with other etiologies of developmental or intellectual disabilities or considers the population a control group in studies of autism spectrum disorder. Individuals with DS have a unique profile of strengths and vulnerabilities, which means that parents will also present with unique needs and require supports to meet their own mental health concerns. For parents of children with DS, support received was the main factor that helped parents manage all types of stress. Furthermore, perceived helpfulness of informal support and coping patterns made independent contributions to predicting healthy adaptation, suggesting the importance of exploring coping strategies and support needs in order to yield healthy family adaptation.

Therefore, we want to conduct a needs assessment that would inform the development of a support group, which reflects the voices of the parents and caregivers. The purpose of my study is to better understand parental stress and coping strategies among parents and caregivers of children with DS, and how these factors may predict support needs. The study will contribute to the knowledge in the field of developmental disabilities, as no studies to date have examined the needs and the accessibility of services in the DS population especially in the Canada. Furthermore, knowledge translation of the outcome of this research will be distributed to support agencies and organizations for DS in Ontario.

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Chapter 1

1 Introduction

Down syndrome (DS) is the most prevalent chromosomal cause of intellectual disability, occurring in 1 out of every 700-1000 births. Individuals with DS present with a unique phenotypic profile of strengths and weaknesses in areas such as linguistic and cognitive functioning (Dykens, 2005). For example, children with DS generally exhibit a typical developmental sequence in cognitive abilities, and early language milestones emerge similarly to typically developing children (Chapman & Hesketh, 2000). They have relative strengths in visual memory and vocabulary comprehension, and relative weaknesses in verbal short-term memory. They show slower rates of development in expressive language and show impairments in nonverbal communicative behaviours, such as requesting (Chapman & Hesketh, 2000). Having this unique profile means that the parents of these children will present with a unique set of needs as well.

A model used to understand family adaptation to caring for a child with a disability is the double ABCX model (Hill, 1949; McCubbin & Patterson, 1981). Modified from the original Hill (1949) model, the model conceptualizes family adaptation over time, where adaptation (X) is a function of a given stressful event or condition along with the difficult background conditions (aA), combined with resources (bB) and the perception of the stressful event, and coping strategies (cC; Bristol, 1987; Dabrowska & Pisula, 2010; Wang & Singer, 2016). When applied to families of children with DS, the initial stressor relates to caring for a child with characteristics related to DS, including challenging behaviors. Pile-up of stressors (aA) refer to additional demands placed on the family such as financial strain, stigma from others, and any other stressors which may occur (Paynter, Riley, Beamish, Davies, & Milford, 2013). Resources (bB) refer to both internal attributes such as self-efficacy and personality, and external supports such as social networks. The double ABCX model has been found to be an effective way of conceptualizing family adaptation to having a child with a disability, because it recognizes the social and contextual nature of adaptation over time; assesses not only the risk factors/stressors, but the perception of the stressor and active coping strategies; and most importantly, recognizes that a family could respond to stress to yield healthy adaptation rather than pathology (Bristol, 1987). Different factors may be related to these outcomes, as coping variables were significant predictors of positive adaptation, whereas family financial hardship, a stressor, was a predictor of parental distress (Minnes, Perry & Weiss, 2015).

Parents of children with developmental disabilities are repeatedly reported to have higher stress levels than parents of typically developing children (Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016; Richman, Belmont, Kim, Slavin, & Hayner, 2009; Siklos & Kerns, 2006), which partly depend on the child's behavioural characteristics associated with specific disorders (Richman et al., 2009). However, the DS population is often studied looking at developmental or intellectual disabilities in general, or as a control group compared to autism spectrum disorder (ASD). The family's reaction to a child's diagnosis partially depend on the characteristics of the child, hence making it essential to study DS on its own, as the needs may not be similar to other etiologies of developmental disabilities or mixed-etiology samples (Hodapp, 2007; Phillips, Conners, & Curtner-Smith, 2017).

Studies using the double ABCX model to predict adaptation in families with children with other developmental disabilities, such as ASD, found that parents' social support, the perception of child's diagnosis, and coping strategies explained more than half of variance in family adaptation to the diagnosis of autism (Bristol, 1987; Pakenham, Samios & Sofronoff, 2005). Furthermore, coping patterns predicted healthy adaptation along with perceived helpfulness of informal support, suggesting the importance of coping strategies for parents to manage the stressors (Bristol, 1987). Coping strategies are influenced by the two components of the model – the external resources available and the perception of the stressor (bB and cC; Cuzzocrea et al., 2016). In particular, the model has been helpful in identifying internal and external resources for better or worse coping strategies (Hodapp, 2007). For parents of children with DS, it was found that coping strategies were relevant to parent distress, however, could function both as a risk factor and a protective factor (Cuzzocrea et al., 2016). Thus, it is important to ask which coping strategies are effective and which ones are not. Just as how resources targeting the wrong needs are ineffective, coping styles that are dysfunctional cause more harm than benefit to healthy family adaptation (Cuzzocrea et al., 2016; van der Veek, Kraaij, & Garnefski, 2009). Consequently, social and parental factors must be considered as factors that contribute to family stress and satisfaction, and it would be important to see how these factors could inform and predict the support needs in these parents. Therefore, the purpose of the current study is to assess the support needs in parents of children with DS and the relationship of their needs to the parental stress and coping strategies. This study will provide evidence to better understand the factors that may predict support needs, and how interventions could address these specific needs.

Chapter 2

2 Literature Review

2.1 Levels of Stress in Parents of Children with DS: aA

Caring for a child with DS can impact the wellbeing of families, as there is the added challenge of the child's characteristics associated with specific disorders (Hodapp, 2007; Richman et al., 2009). Fortunately, research on the effects of caregiving for a child with a disability has shifted away from the "tragedy assumption", where the caregiving of a child with a disability is constituted as a stressor to be overcome and not an inevitable tragedy to be pitied. (Hodapp, Ricci, Ly & Fidler, 2003; Sloper, Knussen, Turner, & Cunningham, 1991; Wang & Singer, 2016). The "tragedy assumption" led to the misinterpretation and even an oversimplification of the challenges faced by these families, which in consequence brought forth unnecessary support groups with limited goals that failed to address the high levels of stress in these parents (Wang & Singer, 2016).

Parental stress can have either positive or negative effects depending on various parent, family, or child factors, and has several components (Hodapp et al., 2003). Studies have generally found lower parental stress levels in parents of children with DS compared to parents of children with ASD (Cuzzocrea et al., 2016; Hodapp et al., 2003; Philips et al., 2017). This is often attributed to the fact that children with DS often show more positive, socially oriented personalities and lower rates of maladaptive behaviour, also known as the "Down syndrome advantage" (Hodapp et al., 2003). Specifically, mothers of children with DS report lower levels of child-related stress, which concerns child qualities that make it difficult for parents to be parents, compared to mothers of children with other intellectual disabilities. However, they do not significantly differ in total parent-related stress levels, which concerns the parents' functioning, such as parental competence, isolation, relationship with spouse, health, role restriction, and attachment to child (Hodapp et al., 2003). Therefore, although parents of children with DS react favourably when their child displays more "stereotypical Down-syndrome like" personalities, parents still face challenges with etiology-related child behaviours, and degree of communicative impairment (Hodapp et al., 2003). This finding highlights the importance of exploring the sources of stress that may be unique to the parents and caregivers of children with DS.

2.2 Coping Strategies: bB and cC

Key processes that influence one's ability to manage stress and their adaption is the way they perceive the situation (cognitive appraisal) and the use of effective coping strategies (McCubbin & Patterson, 1981; Lazarus & Folkman, 1987). Lazarus and Folkman (1987) describe two functions of coping: (1) to change the troubled person-environment relationship (adaptation), which is known as problem-focused coping and (2) to regulate emotional distress, which is known as emotion-focused, or cognitive coping. Studies exploring the relationship between coping strategies and stress in parents of children with various developmental disabilities find that helpful coping strategies predict reduced parental stress (Cuzzocrea et al., 2016; Glidden, Billings, & Jobe., 2006; Kiami & Goodgold, 2017; van der Veek et al, 2009). Coping strategies were a stronger predictor than child characteristics and financial hardship for parents of children with DD, supporting the role of coping strategies in abating parental stress and promoting healthy family adaptation (Minnes et al., 2014).

A previous study exploring the relationship between coping strategies and parenting stress in families with a child with ASD found that the percentage of helpful coping strategies predicted maternal stress (Kiami & Goodgold, 2017). Among families of children with DS, studies also found coping strategies relevant to parental distress, however, was also a risk factor depending on the types of coping strategies used (Cuzzocrea et al., 2016). This may be because the coping strategies endorsed by DS parents were found to be unhelpful in managing their stress. In fact, rather than reducing the parental stress, these coping strategies seemed to increase it (Cuzzocrea et al., 2016).

As introduced by Folkman & Lazaraus (1987), there are two modes of coping: problem-focused coping and emotion-focused or cognitive coping. When comparing two types of cognitive coping, avoidance and approach strategies, Roth and Cohen (1986) argue that avoidance is effective for brief, uncontrollable stressors for individuals, whereas approach diminishes long-term, controllable stressors for which the stressor is inescapable (as cited in Atkinson, Scott, Tarn, & Goldberg, 1995). However, with child-rearing stressors these dimensions are not univocal: while the stress is long term and thus may not benefit from avoidance, the stress also fluctuates with the developmental stages and environmental challenges, especially when disability is concerned. Thus, depending on the sources and the nature of the stressors, the definition of what constitutes as functional versus dysfunctional coping strategies may also be unique for the parents and caregivers of children with DS.

Supporting the double ABCX model, strategies that helped with positive perception of the stressor such as reframing, positive reappraisal, and cognitive restricting are considered positive or functional coping strategies by researchers (Minnes et al., 2015). However, van der Veek and colleagues (2009) revealed an unexpected finding that having a “positive attitude” was maladaptive for parents of children with DS. This may reflect an avoidant coping style, which is associated with high levels of stress and mental health problems in both mothers and fathers, and is viewed as a dysfunctional coping strategy (Cuzzocrea et al., 2016; Hastings, Beck & Hill, 2005). The avoidant coping style includes acceptance, rumination, positive refocusing, refocus on planning and catastrophizing (van der Veek et al., 2009). Parents of DS children reported using “positive attitude” the most in problematic situations, and even when controlling for stressful events that occurred, these coping strategies consistently predicted higher levels of parental stress (Cuzzocrea et al., 2016; van der Veek et al., 2009). These strategies may be evidence of passive acceptance or even “giving up”, which was previously found to be related to more depressive symptoms (van der Veek et al., 2009). Thus, it may not just be the positive perception alone, but the rational and problem-focused strategy that is followed by an actual behaviour that leads to adaptation. Rational and problem-focused coping was related to feelings of reward, allowing the parents to perceive the benefits in parenting the child and the benefits that the child was bringing to their family (Burke, Fisher & Hodapp, 2012).

Cuzzocrea and colleagues (2016) compared coping strategies across parents of children with high functioning autism, low functioning autism, DS and typically developing children, and “problem solving” was the most functional strategy used by all parents. When parents engage in “problem solving” strategies, they may experience family empowerment, focusing on parenting self-efficacy, parent confidence and competence, knowledge related to the child, and the ability to find information and access assistance when needed, which are all predictors of both greater positive gain and lower parental stress (Minnes et al., 2015). This further supports that maintaining a positive attitude in conjunction with functional coping strategies -related to seeking social support and drawing on inner personal strengths- contributes to healthy adaptation (Cless, Goff, & Durtschi, 2017). As a result, it appears to be important for DS parents to engage in both internal and external coping strategies (McCubbin & Patterson, 1981), and the availability of social support as an external strategy would be an important potential resource for parents (Cuzzocrea et al., 2016).

2.3 Needs in Parents of Children with DS: bB

Understanding the sources of stress and providing parents with the appropriate support is a crucial way to meet the functional needs of these parents of children with DS. Few studies have looked at the self-reported needs of caregivers of children with DS. Often, caregivers of children with DS act as control groups in studies exploring the needs of caregivers of children with other disabilities, commonly ASD. In one study comparing the important and unmet needs of parents of children with ASD and DS, the two groups did not differ in the number of important needs, and both groups reported that more than half of the important needs remained unmet (Kiami & Goodgold, 2017; Siklos & Kerns, 2006). Interestingly, the most reported important unmet needs differed for the two groups and even within groups. Whereas parents of children with ASD rated formal supports (e.g. professionals working with their child) as most important, parents of children with DS endorsed items more related to social support, such as community programming and friendship opportunities for their child (Siklos & Kerns, 2006).This highlights the importance of understanding not only the unique needs of various disability populations, but also a needs assessment for each unique family’s important unmet needs (Kiami & Goodgold, 2017).

A small number of studies have looked at the support needs of caregivers of children with DS. Marshall and colleagues (2014) identified four major areas of key issues from a focus group of caregivers and service providers of children with DS, from pregnancy through child's school-age years: diagnosis and prenatal care, services, care co-ordination, and social and community support. With regards to social and community support, they found that parents had difficulties dealing with a full schedule of care and services, with a lack of accessibility to services and support being a preventative factor as well (Marshall, Tanner, Kozyr, & Kirby, 2014).

The availability and perception of social support have been found to be very important resources for parents, especially those of children with intellectual disabilities (Cuzzocrea et al., 2016). High levels of informal support from friends and family, and perceptions of helpfulness of social support is associated with lower parental stress, greater feelings of empowerment, and higher levels of marital satisfaction. For parents of children with DS in particular, support received from family and friends was the main factor that helped parents manage all types of stress including: total stress perceived, significant influence on parent distress, on parent-child dysfunctional distress, and on stress caused by children's difficulties (Canary, 2008; Cuzzocrea et al., 2016). Thus, the relationship between support needs and stress needs to be explored.

Despite the positive findings regarding support, parents still faced barriers and challenges related to receiving necessary support, including inaccessibility of reliable information about DS and available services, lack of sensitivity, knowledge, and care co-ordination among providers, and a scarcity of formal and informal support systems (Marshall et al., 2014). Furthermore, low-income families have less informational support about disability issues, consequently limiting access to professional support services and inconsistent available supports (Canary, 2008). Parents with higher coping abilities are more likely to be involved in early intervention programs, as coping was found to mediate the relationship between program involvement and family functioning. As a result, ways that promote and develop positive support systems should be explored, with an emphasis on positive coping strategies, and interventions that do not just lower distress, but cultivate beneficial outcomes for these families (Canary, 2008). As previous studies did not look specifically into DS needs, this study aims to explore important needs reported by parents and caregivers, and delineate between met versus unmet needs. Looking at the important needs that are reported to have been addressed or discussed before compared to those that have not been could provide insight into the strengths and gaps of the current services (Hodgetts et al., 2015).

2.4 Present Study

Studies on accessing support and coping strategies have been conducted with families of children with autism and developmental disabilities in general, but not much work has been done with the DS population. There is a need for this line of research for the DS population, as studies that compared the needs in parents of children with autism versus DS reported the same number of important unmet needs, especially those of social support (Cuzzocrea et al., 2016; Siklos & Kern, 2006). Thus, the purpose of this study is to better understand parental stress and coping strategies among parents of children with DS, and how these factors may be related to support needs. The research questions we will explore are: (1) What are the services and topics of need in families? (2) What is the relationship between stress, coping, and needs? We hypothesize:

1) Increased important unmet needs will be related to increased parental stress
2) Parents with more effective coping strategies will report lower levels of stress, as well as lower levels of important unmet support needs.

With greater understanding of the relationship among stress factors, unmet needs, and coping strategies, support groups and interventions could be designed to target specific needs, whether it be providing key resources or information of better coping strategies.

Chapter 3

3 Methodology

3.1 Participants

A convenience sample of parents or caregivers of children with DS was recruited through community DS organizations across Ontario. Respondents for this study met the following criteria: (a) a parent or caregiver of a child/children diagnosed with Down Syndrome by a regulated health professional, regardless of age; (b) English speaking and (c) residents of Ontario. Participant inclusion criteria was confirmed via the online survey, and participants who did not meet these criteria were thanked and taken to an exit screen. In total, 224 parents or caregivers of children with DS across Canada responded to the online survey. Of these respondents, 59 respondents were excluded because they were not residents of Ontario, and 43 respondents who were residents of Ontario were excluded because their surveys were incomplete. Thus, data from 122 respondents who met the inclusion criteria and completed the survey were analysed in the current study. The sample size was calculated using a correlation power analysis. Given an estimated effect size of 0.1 with an alpha level of 0.05 and 3 predictor variables, the recommended sample size was 112 participants to achieve a power of 0.8. The effect size of 0.1 was chosen because a small effect size is used to identify a real effect that is difficult to detect (Cohen, 1988).

Frequencies for the demographic variables of the respondents can be seen in Table 1.

Table 1.

Demographic characteristics of the sample (n = 122)

Child Characteristics	n (%)
Gender	
Male	69 (56.6)
Female	49 (40.2)
Age	

0-3	17 (13.9)
4-5	13 (10.7)
6-12	33 (27.0)
13-18	20 (16.4)
19-35	31 (25.4)
35+	8 (6.6)
Diagnosed with Intellectual Disability	
Yes	104 (85.2)
No	17 (13.9)
Parent/Caregiver Characteristics	
Role	
Mother	106 (86.9)
Father	13 (10.7)
Caregiver/Guardian	3 (2.5)
Age	
<24	0 (0)
25-35	12 (9.8)
36-45	38 (31.1)
46-55	36 (29.5)
55-64	24 (19.7)
65-74	11 (9.0)
>75	1 (0.8)
Marital Status	
Married	102 (83.6)
Separated	3 (2.5)
Never Married	4 (3.3)
Divorced	8 (6.6)
Widowed	5 (4.1)
Ethnic Background	
White	107 (87.7)
South Asian	5 (4.1)
Hispanic/Latin American	4 (3.3)
Aboriginal	1 (0.8)
Black	1 (0.8)
Multi-racial	1 (0.8)
Southeast Asian	1 (0.8)
Other	2 (1.6)
Education	
Graduate/Professional Degree	27 (22.1)
University Degree	40 (32.8)
College Diploma	43 (35.2)
High School Diploma or equivalent	11 (9.0)
Some High School	1 (0.8)
Total Household Income	

<$15,000	4 (3.3)
$15,000-$24,999	4 (3.3)
$25,000-$34,999	2 (1.6)
$35,000-$49,999	2 (1.6)
$50,000-$74,999	17 (13.9)
$75,000-$99,999	23 (18.9)
$100,000-$149,999	35 (28.7)
>$150,000	30 (24.6)
Total Number of Children in the House	
1	32 (26.2)
2	46 (37.7)
3	23 (18.9)
4	11 (9.0)
5 or more	7 (5.7)
Geographical Location of Residence within Ontario	
Southwestern Ontario	44 (36.1)
Greater Toronto Area	36 (29.5)
Eastern Ontario	18 (14.8)
Central Ontario	16 (13.1)
Northern Ontario	8 (6.6)

3.2 Measures

3.2.1 Demographics (aA factor)

An 11-item demographics questionnaire assessed information about the respondent and their child. Respondents were asked to choose a categorical rating for the following: respondent role (parent or caregiver/guardian), marital status, ethnic background, education, total household income, total number of children in the house, geographical location of residence, and previously/currently used services. Questions regarding their child included: age, gender, and the presence of a comorbid intellectual disability (see Appendix B).

3.2.2 Family Needs Survey (bB factor)

The Family Needs Survey (FNS) is a 35-item survey assessing needs in seven domains: Information, Family and Social Support, Financial, Explaining to Others, Childcare, Professional Support and Community Services (Bailey & Simmeonsson, 1990). The scale was developed to assess functional needs of parents with young children with disability, initially used with 34, two-parent families with infants with a wide range of disabilities.

The original instrument asked, “Would you like to discuss this topic with a staff person from our program?” using a three-point Likert scale. The authors amended the question to ask, “Is this topic important to be discussed/addressed?” and kept the three response options of (1) “No”, (2) Not Sure” and (3) “Yes”. Additionally, the authors added a second question, asking if the item had been addressed/discussed before, which respondents could answer either “yes” or “no” (see Appendix B). It has been suggested that support needs questionnaires that elucidate both the importance of the need and whether or not the need is met or unmet increases methodological strength (Kiami & Goodgold, 2017). Furthermore, the original version has two open ended items, asking for (a) other topics that parents may find helpful and (b) if there is a person parents would like to talk with. The addition of the open-ended response format allowed families to clarify responses to the standard items and provide information about needs in addition to the ones that were listed (Bailey & Simmeonsson, 1990). The author revised the second question to ask: (b) What are some other services you would like to have to support yourself and your child?

In previous studies, the test-retest reliability of the FNS after 6 months was .67 for mothers and .81 for fathers, with some subscales showing more stability than others (Bailey & Simmeonsson, 1990). The FNS has been used to assess needs in families of children with disabilities, including ASD, cerebral palsy, and other intellectual disabilities (Hodgetts, Zwaigenbaum, & Nicholas, 2015; Sexton, Burrell, & Thompson, 1992; Trute & Hiebert-murphy, 2005). A study looking at the measurement integrity of the FNS on mothers of children with disabilities reported internal consistency for FNS total score to be .91, and the alpha coefficients for the subscales to range from .65 to .86. Consequently, the results of the FNS was reported to afford considerable credence, with possible benefits for early interventions by looking at the most frequently identified service need (Sexton et al., 1992).

3.2.3 Questionnaire on Resources and Stress – Friedrich Version (aA factor)

The Questionnaire on Resources and Stress-Friedrich version (QRS-F; Friedrich, Greenberg & Crnic, 1983) is a short version of the original 285-item questionnaire that assesses the impact of having a child with disability on the family. The QRS-F contains 52-items and asks parents to answer “true” or “false” to items regarding family stress and yields a total stress score (ranging from 0 to 52) along with four factor scores: Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation. The Parent and Family Problems subscale consists of 20 items that assesses the perception of problems themselves, other family members, or the family unit. Pessimism subscale consists of 11 items that captures the pessimistic outlook about the child’s prospects of achieving self-sufficiency. The Child Characteristics subscale consists of 15 items, which assesses the respondent’s perception of the specific behavioural or personality difficulties of the child. Lastly, the Physical Incapacitation subscale measures the respondent’s perceptions of the limitations of the child’s physical abilities and self-help skills (Friedrich et al., 1983)

The QRS-F has been well validated, and thus is the most commonly used short form of the QRS in published research (Hayes & Watson, 2013). Honey and colleagues (2005) assessed the reliability and construct validity of the QRS-F with parents of young children with autism. The study reported good internal consistency (0.93 for mothers and 0.88 in fathers) and evidence to support convergent validity; specifically, negative correaltions between total stress score, social support and coping scales, and parents’ adaptation to their child (Honey, Hastings, & McConachie, 2005).

3.2.4 Family Crisis Oriented Personal Scales (cC factor)

The Family Crisis Oriented Personal Scales (F-COPES) is a 30-item survey to measure coping strategies used by an individual when faced with problems or crises (McCubbin, Olson, & Larsen, 1981). The measure integrates the family resources and meaning perception factors that are identified by the family stress theory into coping strategies. The items are rated on a five-point Likert scale, with 1 being “Strongly Disagree” and 5, “Strongly Agree”. The scale measures five areas of coping strategies: Acquiring Social support, Reframing, Seeking Spiritual Support, Mobilizing Family Support and Passive Appraisal. Internal consistency for the subscales ranges from .63 to .83, and .86 for the total scale (McCubbin et al, 1981). Cless, Nelson, Goff and Durtschi (2017) used the F-COPES to measure coping strategies in mothers of children with DS and found through exploratory factor analyses that the F-COPES was representative of a single factor. Thus, higher scores on measure indicate higher use of coping behaviours. The Cronbach's alpha for the subscales ranged from .73 to .87 (Barnett, Hall, & Bramlett, 1990; McCubbin et al., 1981).

3.3 Procedure

The Research Ethics Board at the authors' academic institution reviewed and approved this study prior to participant recruitment. Respondents were recruited through local and national Down syndrome and parent organizations. The researcher contacted organizations through phone and email; participating organizations were provided with a flyer that included an anonymous link to the survey on Qualtrics to distribute via email, organization websites, or social media platforms. Once the link was opened, respondents were provided with instructions and consent to participate was implied upon completing the survey. Respondents could complete the survey wherever they had access to a computer with Wi-Fi, and the survey took 15 – 20 minutes to complete. Upon completion of the survey, respondents were given the option to provide an email and/or phone number to be contacted to participate in a subsequent interview for a different study. In addition, they were invited to be entered into a lottery for draw of one in five $50 e-gift cards as an honorarium for participating in the study. Participants completed the online survey in the span of four months from April to July 2019.

Chapter 4

4 Results

4.1 Statistical Analysis

Data was extracted from Qualtrics and analysed using the Statistical Package for the Social Sciences (IBM SPSS Statistic 26). Descriptive statistics were used to describe participants' demographics (Table 1) and scores on the FNS, QRS and F-COPES. To answer the research questions, Pearson correlations were run using the mean scores of the FNS, QRS and F-COPES. One-way ANOVAs were conducted to determine whether scores on the FNS, QRS and F-COPES varied across demographic groups.

4.2 Research Question 1: What are the services used by families, and what are their needs?

4.2.1 Services

Table 2 provides the frequencies of services used or currently in use by parents/caregivers. Services previously used or currently in use by more than 50% of the respondents include speech therapist, physiotherapist, parent support groups, paediatrician, occupational therapist, family doctor, and audiologist (Table 2).

Table 2.

Services used or currently in use by parents/caregivers.

Service	n (%)
Family Doctor	94 (77.0%)
Paediatrician	94 (77.0%)
Speech therapist	93 (76.2%)
Audiologist	82 (67.2%)
Occupational therapist	78 (63.9%)
Physiotherapist	75 (61.5%)
Parent support groups	65 (53.3%)
Early intervention program	44 (36.1%)
Social worker	35 (28.7%)
Other (Please specify)	33 (27.0%)
Case manager	31 (25.4%)
Behaviour management program	16 (13.1%)

Social readiness program	8 (6.6%)
Intensive behavioural intervention program	5 (4.1%)
Other Services Used:	
Hospital/Community organizations (15)	
Cardiologist (4)	
ENT Doctor (4)	
Optometrist/ Eye specialist (4)	

4.2.2 Family Needs Survey

Participants reported an average of 25.7 (*SD* = 8.46) of the 35 items as “important”. All of the need statements except for two were endorsed as “important” by at least half of the respondents; the needs least frequently rated as important were: “Getting appropriate care of my child in a church or synagogue during religious services” (40%; 46/114 respondents) and “Meeting with a minister, priest, or rabbi” (26%; 30/114 respondents). The five needs most frequently identified as being important were: (1) Information about services that are presently available for my child (96%; 115/120 respondents), (2) Information about the services my child might receive in the future (96%; 115/120 respondents), (3) How to teach my child (93%; 109/117 respondents), (4) Information about any condition or disability my child might have (92%; 108/117 respondents), and (5) Paying for therapy, day care, or other services my child needs (91%; 108/119 respondents). For each subscale, the proportion of people reporting the domains as important and as being met are as follows: Information (Important = 91%, Met = 62%); Family and Social Support (Important = 75%, Met = 33%); Financial (Important = 76%, Met = 44%); Explaining to Others (Important = 71%, Met = 31%); Child Care (Important = 69%, Met = 33%); Professional Support (Important = 58%, 35%) and Community Services (Important = 86%, Met = 60%).

Table 3 presents proportions of self-reported “important met needs” and “important unmet needs” for each need statement. Important unmet needs (IUN) was calculated using a crosstab analysis. Proportions of people rating needs as important and unmet range from a high of 65% and a low of 11%. Nine out of 35 need statements identified as important were also reported as unmet by at least half of the respondents, which included: (1) Helping our family support each other during difficult times (65%; 66/102 respondents); (2) Information about the services my child might receive in the future

(58%; 64/111 respondents); (3) Explaining my child's condition to other children (56%; 61/102 respondents); (4) Finding more time for myself (62/108 respondents); (5) Knowing how to respond when friends, neighbours, or strangers ask questions about my child (57%; 56/100 respondents); (6) Helping our family discuss problems and reach solutions (56%; 58/104 respondents); (7) Locating babysitters or respite care providers who are willing and able to care for my child (55%; 57/103 respondents); (8) How to handle my child's behaviour (51%; 54/106 respondents); and (9) Paying for expenses such as food, housing, medical care, clothing, or transportation (50%; 52/105 respondents). Three of these nine are from the Family & Social Support domain. Important needs that were reported as being met by at least half of the respondents included: (1) Information about any condition or disability my child might have (79%, 82/104 respondents); (2) How to play or talk with my child (73%; 78/107 respondents); (3) How children grow and develop (70%, n = 109); (4) Information about services that are presently available for my child (63%, n = 108); (5) Paying for babysitting or respite care (57%, n = 105); (6) How to teach my child (55%, n = 107); (7) Paying for therapy, day care, or other services my child needs (55%, n = 104); and (8) Getting any special equipment my child needs (54%, n = 105).

Table 3.

Proportion of respondents reporting each item as important and unmet/met.

Domain	Item	Important and unmet needs n (%)	Important and met n (%)	n*
Information	How children grow and develop	21 (19%)	76 (70%)	109
	How to play or talk with my child	12 (11%)	78 (73%)	107
	How to teach my child	43 (40%)	59 (55%)	107
	How to handle my child's behaviour	54 (51%)	42 (40%)	106
	Information about any condition or disability my child might have	16 (15%)	82 (79%)	104

	Information about services that are presently available for my child	36 (33%)	68 (63%)	108
	Information about the services my child might receive in the future	64 (58%)	42 (38%)	111
Family and Social Support	Talking with someone in my family about concerns	46 (44%)	38 (37%)	104
	Having friends to talk to	50 (46%)	44 (41%)	108
	Finding more time for myself	62 (57%)	30 (28%)	108
	Helping my spouse accept any condition our child might have	46 (46%)	31 (31%)	101
	Helping our family discuss problems and reach solutions	58 (56%)	29 (28%)	104
	Helping our family support each other during difficult times	66 (65%)	23 (23%)	102
	Deciding who will do household chores, child care, and other family tasks	47 (46%)	26 (25%)	103
	Deciding on and doing family recreational activities	45 (43%)	31 (30%)	104
Financial	Paying for expenses such as food, housing, medical care, clothing, or transportation	52 (50%)	37 (35%)	105
	Getting any special equipment my child needs	38 (36%)	57 (54%)	105
	Paying for therapy, day care, or other services my child needs	47 (45%)	57 (55%)	104
	Counselling or help in getting a job	41 (42%)	20 (20%)	98
	Paying for babysitting or respite care	32 (30%)	60 (57%)	105
	Paying for toys that my child needs	40 (42%)	22 (23%)	96
Explaining to Others	Explaining my child's condition to my parents or my spouse's parents	41 (42%)	22 (22%)	98
	Explaining my child's condition to his or her siblings	46 (47%)	32 (33%)	98
	Knowing how to respond when friends, neighbours, or strangers ask questions about my child	56 (56%)	22 (22%)	100
	Explaining my child's condition to other children	61 (60%)	21 (21%)	102

	Finding reading material about other families who have a child like mine	46 (44%)	43 (41%)	104
Child Care	Locating babysitters or respite care providers who are willing and able to care for my child	57 (55%)	37 (36%)	103
	Locating a day care program or preschool for my child	41 (41%)	45 (45%)	100
	Getting appropriate care for my child in a church or synagogue during religious services	34 (39%)	9 (10%)	87
Professional Support	Meeting with a minister, priest, or rabbi	19 (23%)	9 (11%)	83
	Meeting with a counsellor (psychologist, social worker, psychiatrist)	36 (38%)	34 (36%)	94
	More time to talk to my child's teacher or therapist	38 (39%)	46 (47%)	98
Community Services	Meeting & talking with other parents who have a child like mine	31 (30%)	64 (62%)	103
	Locating a doctor who understands me and my child's needs	39 (38%)	56 (55%)	102
	Locating a dentist who will see my child	33 (32%)	55 (53%)	103

*Note. The n for each of the items vary because some items were left blank by some respondents. The unreported proportions are from the unimportant needs.

Statements generated from the two open-ended questions of the FNS were used to explore other topics and other services that parents and caregivers felt were important to be addressed (Refer to Table 4). The author grouped the statements into themes for each question. The first question regarding other topics were grouped into the following themes: (1) Funding, (2) School programs, (3) Information/Advocacy, (4) Access/Navigating Services, (5) Services for Adults with DS, (6) Child Development and (7) Caregiver Support. The themes with most responses involved services: (3) Information/Advocacy, which included statements such as, "…education on why it is important not to choose abortion as an option…", "As my child ages, questions about sexuality", and "how to promote and support spaces for self-advocacy for people with DS…"; (4) Access/Navigating Services, which included statements such as "…family counseling, estate planning, public education", "learning how to navigate the public systems…”; “…I would like to see information on DS friendly audiologists, dentists, doctors and how and when to contact them…”and (5) Services for adults with DS, which included statements such as “connecting with information concerning older children…”, “finding inclusive social activities for my 22 year old daughter…”, and “planning for supported independent living in the community, helping my child find work, friends…”.

Table 4 a.

Responses to question: What are some other services you would like to have to support yourself and your child? (open-ended question; n = 77)

Theme	Examples of Contributing Data	Responses (%)
Caregiver Support	“Psychological support at time of diagnosis” “Would be nice to interact more with other parents dealing with similar issues.”	10
Financial Support	“Not so much services as the funding to support those services so that they can continue and aren't cut off by the government”	8
Community Services	“Respite and community services that accept our son.” “Direct therapy instead of directional therapy and more often, playgroups for children with Down syndrome and other disabilities, support for newly diagnosed children, assistance with coping strategies for families” “More support to help our daughter successfully obtain and keep volunteer or paid jobs.”	22
Access/ Navigation	“Connections to respite, more continuity between all care providers to ensure we are all balancing and focusing on the same process not independent goals” “Help working the system to access all available funding and supports” “Navigate financial paperwork or other paperwork that needs to be done at certain ages of the down syndrome child”	18
Education	“More speech and language therapy should be made available through the education system” “School support services”	16
Adult Services	“More affordable or subsidized day programs for our DS dependents after graduating school” “Transitions to school to high school and into life after school, housing, employment opportunities, recreational opportunities” “Planning for our future - Where will Maddie live, who will be her people, what will she do for fun? How will we make sure she is happy and has friends?”	26

The second question regarding other services were grouped into the following themes: (1) Caregiver, (2) Financial, (3) Community, (4) Access/Navigation, (5) Education, and (6) Adult. The themes with most responses involved the services for adults, and services available through the community. The services for (6) Adults included statements such as, “Transitions to school …into life after school, housing, employment opportunities, recreational opportunities”, “transition from school to independent living …to meaningful employment…” and “There are so few services for +18 children (adults) it is not funny. There are waiting lists everywhere. how to find permanent accommodation for your child would be great for those of us who are aging quickly”. The services through (3) Community, which included statements such as, “More support to help our daughter successfully obtain and keep volunteer or paid jobs”, “Respite and community services that accept our son”, and “…access to a library focused appropriate books and therapeutic tools to aid parents arm themselves with tools and knowledge to address some of their child's needs…”.

Table 4 b.

Responses to what other topics that parents may find helpful (open-ended question; n = 57)

Theme	Examples of Contributing Data	Responses (%)
Services for Adults	“Navigating puberty, planning for life after high school, financial planning for my family and long-term care of my child with disability, etc.” “Unfortunately you seem to be focussing on families with young children. In my experience there are reasonable services until the age of 21. Once you leave the school system it is like falling off a cliff into the unknown…” “A lot of the question relate to younger person with Down Syndrome and don't apply to an older adult.”	33
Caregiver Support	“…the biggest overlooked topic, is self care for the care giver…” “I wish I could connect with parents with a child who has DS, RDSP, All transitions, death in the family, making friends, medical issues, medical tech.support for siblings, any thing fun!! something social.....”	9
Service Navigation/ Access	“Learning how to navigate the public systems (especially therapy) and how/when to access private therapy; funding for private therapy”	21

	“Finding a psychologist, social worker, psychiatrist to meet her mental health needs has been a struggle.” “I feel that our providers have provided information about other resources but only after I really pushed and asked for referrals”	
Information/ Advocacy	“The strengths that a child with Down Syndrome posses such as a huge heart, caring, polite, affectionate and the norms a child with Down Syndrome such as stubbornness.” “Providing the medical community with current research and data to help them make informed choices for people with DS.” “Multiple complex issues i.e. autism, g-tube feeding, incontinent, using wheelchair for mobility” “Sexuality, marriage, parenting”	14
School Programs	“Help with school IEP process” “Behaviour management in the school system”	18
Funding	“…With adequate funding, a more fluid, healthy, working lifestyle can be achieved for both the child and the parents. There are many resources available, you just need to be able to pay for them, especially as your child gets older and school is no longer a support for them” “… stable reliable funding that is not changed with every change of government.”	5

4.3 Research Question 2: What is the relationship between stress, coping and important unmet needs?

4.3.1 Hypothesis 1: Increased important unmet needs will be related to increased parental stress.

Total and subscales scores for the QRS are presented in Table 5. Higher scores on the measure indicate higher levels of stress in the respondents. The five statements most reported to be true (at least 90% of the respondents) were: (1) I worry what will happen to ___ when he/she gets older, (2) ___ accepts himself/herself as a person, (3) I worry what will happen to ___ when I can no longer take care of him/her, (4) Our family agrees on important matters, and (5) I often worry what will happen to ___ when I can no longer take care of him/her. Three of these five statements are from the Pessimism subscale, indicating that the greatest source of stress for respondents is the pessimistic outlook about the child’s prospect of achieving self-sufficiency.

Table 4.

Means of Subscales on the QRS and F-COPES.

		Mean (SD)	Total Items (Possible Subscale Score)
QRS-F			
	Parent and Family Problems	7.57 (4.86)	20
	Pessimism	5.75 (2.33)	11
	Child Characteristics	6.63 (3.16)	15
	Physical Incapacitation	1.80 (1.63)	6
	Total Score	21.75 (9.09)	52
F-COPES			
	Acquiring Social Support	23.70 (6.78)	9 (45)
	Reframing	31.93 (4.68)	8 (40)
	Seeking Spiritual Support	9.77 (4.81)	4 (20)
	Mobilizing Family Support	14.34 (2.92)	4 (20)
	Passive Appraisal*	15.56 (2.74)	4 (20)
	Total Score	97.91 (14.08)	29 (145)

*The Passive Appraisal subscale is reverse scored. Thus, the higher score on this subscale indicates less use.
QRS: Questionnaire of Resources and Stress
F-COPES: Family Crisis Oriented Personal Scales

Table 6 summarizes results from the Pearson correlation analysis relating total scores on the QRS to important unmet needs. The QRS and IUN were significantly positively correlated, *r*(120) = .283, *p* =.01. Thus, higher stress levels as indicated on the QRS is associated with an increased number of IUN.

Table 5

Pearson correlation results for QRS, F-COPES, and IUN.

		QRS		IUN	
		r	p	r	p
F-COPES		$-.308^{**}$	.001	$-.304^{**}$	.006
	Acquiring Social Support	$-.251^{**}$	.005	$-.282^{*}$	.011
	Reframing	$-.381^{**}$	.000	$-.338^{**}$	.002
	Mobilizing Family Support	-.124	.174	$-.232^{*}$	.038
	Seeking Spiritual Support	.083	.362	.066	.560
	Passive Appraisal	$-.273^{**}$	.002	-.135	.230
IUN		$.283^{*}$	.010		

**Correlation is significant at the 0.01 level (2-tailed)
*Correlation is significant at the 0.05 level (2-tailed)
QRS: Questionnaire of Resources and Stress
F-COPES: Family Crisis Oriented Personal Scales
IUN: Important Unmet Needs

Note. The Passive Appraisal subscale is reverse scored. Thus, the higher score on this subscale indicates less use.

4.3.2 Hypothesis 2: More effective coping related to lower stress and lower IUN.

Total and subscales scores for the F-COPES are presented in Table 5. When looking at the comparative data provided by McCubbin and colleagues (1981), our sample means are lower for both male and female adults, falling in the 28th percentile for females. The Acquiring Social Support and Seeking Spiritual Support subscale means are also comparatively lower, falling in the 28th and 7th percentile respectively for females. Acquiring Social Support is a measurement of the respondent's ability to actively acquire support from relatives, friends, neighbours and extended family (McCubbin et al, 1981). Seeking Spiritual Support focuses on the family's ability to acquire spiritual support (McCubbin et al, 1981). Means for the Reframing and Mobilizing Family Support subscale was higher than the comparative data, at 70th and 80th percentile respectively. Reframing was the most used coping strategy by majority of the respondents, with the mean score of 31.93 (SD = 4.68). This subscale assesses the family's capability to redefine stressful events and circumstances in order to make them more manageable (McCubbin et al, 1981). Mobilizing Family Support measures the family's ability to seek out community resources and accept help from others (McCubbin et al, 1981). The Passive Appraisal subscale showed the greatest difference from the comparative data, at the 98th percentile. Passive Appraisal assess the family's ability to accept problematic issues in order to minimize reactivity (McCubbin et al, 1981). This subscale is reverse scored, meaning that parents and caregivers of children with DS engage less in passive coping than the comparative data.

Pearson correlations between the F-COPES total score, subscale scores, and total QRS score were run to determine the relationship between coping strategies and stress (Refer to Table 6 for summary of correlation analyses). There was an overall negative significant relationship between F-COPES and QRS, $r(120) = -.308$, $p = .001$. Thus, overall more positive coping strategies appear to be related to lower stress levels. The Passive Appraisal subscale showed a significant negative relationship with the QRS, $r(120) = -.273$, $p = .002$. As this subscale is reversed scored, this relationship indicates that less use of Passive Appraisal strategies, is related to lower stress levels as measured by the QRS.

Acquiring Social Support, *r*(120) = -.251, *p* = .005 and Reframing, *r*(120) = -.381, *p* > .001 showed a significant negative correlation with the QRS. Higher scores on these subscales, indicating greater use of these strategies, was related to lower stress levels as indicated by the QRS. Mobilizing Family Support also showed a negative relationship, however they were not significant. All three subscales - Acquiring Social Support, Reframing, and Mobilizing Family Support - showed a significant negative relationship with IUN (Refer to table 5). Thus, greater use of Acquiring Social Support, Reframing and Mobilizing Family Support strategies is associated with less IUN.

There was a significant negative correlation with the F-COPES and IUN, *r*(79) = -.304**, *p* = .006). Thus, higher overall coping strategy use is associated with less IUN.

4.3.3 Post Hoc Analyses

One-way ANOVAs were conducted to compare the ratings of stress, coping strategy use and the number of IUN as a function of demographic variables. The demographic variables were chosen based on previous literature that was suggested to be related to adaptation (parent age, child age, total number of children), and ones the authors hypothesized could influence service needs (geographical location). Levels of stress did not significantly vary as a function of parent age, *F*(4,116) = .426, *p* = .790; child age, *F*(5, 115) = 1.326, *p* = .258; total number of children in the home, *F*(4, 114) = .713, *p* = .585) and geographic location of respondents, *F*(4, 116) = .572, *p* = .683. Similarly, coping strategy use did not significantly vary as a function of parent age, *F*(4, 116) = 1.325, *p* = .265; child age, *F*(5, 155) = 2.042, *p* = .078; total number of children in the home, F(4, 114) = 2.118, *p* = .083; and geographic location of respondents, *F*(4, 116) = .540, *p* = .706. Lastly, the number of IUN also did not significantly vary as a function of parent age, *F*(4, 76) = 1.987, *p* = .105; child age, *F*(5, 75) = 2.274, *p* = .056; total number of children in the home, *F*(4,114) = .726, *p* = .577 and geographic location of respondents, *F*(4,76) = .551, *p* = .699. Thus, there were no significant relationships found.

Chapter 5

5 Discussion

The purpose of this study was to better understand support needs among parents and caregivers of children with DS and how these may be related to stress and coping strategies. This is the first study to explore the met and unmet needs and its relation to stress and coping in families of children with DS across different age groups in Canada. Previous studies did not look specifically into DS needs, nor delineate between met versus unmet needs. Looking at the important needs that are reported to have been addressed or discussed before compared to those that have not been could provide insight into the strengths and gaps of the current services (Hodgetts et al., 2015). When looking at the relationship between stress, coping and IUN, our hypotheses were supported: more effective coping strategies associated with less stress and less IUN.

All of the need statements except for two were rated as “important” by at least half of the respondents. The most important needs domain was Information, which includes items about information regarding services or child development and characteristics, and Community Services, which includes items about talking with other parents and finding other healthcare professionals. Specifically, the two most important needs reported were regarding services presently available (96%) and services in the future (96%). Results showed that respondents perceive present services to be well addressed (63%), however, not services for the future (38%).

Qualitative answers from the FNS supported this finding, with many frustrated caregivers voicing their concerns for the future and the lack of services and information for their older children. Some even commented on how the questionnaires were targeted towards younger children, leaving them “once again, feeling left out or insignificant”. Information on future-planning and services for older children with DS was the most prominent topic and need that parents and caregivers identified. This is consistent with the fact that DS can no longer be considered a pediatric condition to be addressed by pediatricians with the increases in life expectancy for individuals with DS (Burke, Wagner, Marolda, Quintana, & Maddux, 2017). With this shift, topics and needs that need to be addressed included limited job opportunities, sexual health education, adult-focused medical care and socialization opportunities.

Furthermore, the pessimistic outlook about the child's prospects of achieving self-sufficiency was the greatest source of stress for these families, as reported by the top three reported stressors on the QRS. This further emphasizes the need for services for the future, especially as caregivers and parents worry about when they are no longer alive or available to care for their growing children (33% of responses to other topics were regarding adult services). Although analyses showed no significant differences for older and younger children across the outcome variables, qualitatively it was reported. This might be explained by the measures' limitations in capturing the needs of older children. For example, the FNS does not include many items related to needs for older children. When designing measures, it can be a challenge to capture the complete spectrum of needs, as older children may be grouped with younger individuals due to the intellectual and adaptive behaviours and abilities resulting in some overlap of needs (Burke et al., 2017). The question remains on how services could meet the needs of an adult who also has some of the needs of a child. As Depape and Lindsay (2015) suggested, caregiver stress may not only be related to stressors of caring for a child with a disability, but on a systemic level, of getting the functional needs met attached to caring for a child with unique needs (as cited in Farkas et al., 2019).

The comparison between the areas that have been well-met versus unmet potentially address the question of whether it is the lack of available resources in the community, or the lack of funding or service navigation to access these services (Kiami & Goodgold, 2017). For our respondents, it appears that people are generally aware of the available services, however, are lacking the funds or the practical means to access and navigate the services. This is supported by the Information and Community Services domain being rated as important and also the most well-met. Qualitative responses also support this hypothesis; respondents expressed that there is "no lack of services, just lack of funding and access". Meanwhile, financial support for services remained an important domain to be addressed by majority of respondents, with only half of them reporting to have their financial needs met. Also reflected in the qualitative responses is the confusion by parents in accessing and navigating services (21% of respondents in response to other topics), asking for more “continuity between care providers to ensure we are all balancing and focusing on the same process not independent goals”, and “help working the system to access all available funding and supports”.

Our respondents indicated almost the same number of overall needs as parents of children with ASD using the FNS (Hodgetts et al., 2015). This reflects that parents of children with developmental disabilities feel that the service delivery system is not providing adequate support to their needs (Siklos & Kerns, 2006). Further, in comparison to other studies administering QRS to various populations, our mean ratings for Parent and Family Problems subscale was much higher than previously reported in the DS population and comparable to means reported among the ASD population (Fidler et al., 2010; Griffith, Hastings, Nash, & Hill, 2010). Unlike in studies of caregivers for children with ASD, information on services available was well met, with the exception of future services (reported unmet by 58% of respondents).

Results of the correlations showed that levels of stress and coping strategies are related to important unmet needs, supporting our hypotheses. Though our correlations (Table 6) were found to be significant, only the overall relationship between the F-COPES, QRS, and IUN and the Reframing subscale showed a moderate effect ($r > .30$), while the remaining correlations revealed weak effects ($r < .30$; Cohen, 1988). The lack of stronger associations may be due to the lack of variability in the sample, resulting in the small effect size yet significant results. However, the significance of the results could provide practical information with regards to support needs, specifically that they are related to the sources of stress and could be mitigated by effective coping strategies. The degree to which this may be the case may not be tremendous and vary depending on the individual, however, this alludes to the fact that services must be individualized, and at least, specific to the disability.

Looking into the implications of the relationship between stress, coping and needs, Acquiring Social Support was significantly associated with less stress and less IUN. This finding is in line with previous studies suggesting that family and social support is a huge contributor to decreasing stress and support needs for families with children with DS. In addition, families reported Explaining to Others and Family and Social Support as important needs, however, as being inadequately met (Canary, 2008; Cuzzocrea et al., 2016; Siklos & Kerns, 2006). For example, respondents reported the importance of getting help for their families to discuss problems and reach solutions (79%) and help for their family to support each other (82%), and yet these needs were met for less than 30%. As Bristol (1984) suggests, parents' beliefs about receiving adequate social support are very important for successful family adaptation, especially for DS parents. This may explain the greatest source of stress being the pessimistic outlook for their children's future, as they worry that when they are no longer around to take care of their children, the system will not be there to do so. This then becomes a vicious cycle for these families, where the families are able to cope by accepting their child with a positive reframe and working together as a family, until they exhaust their own internal resources and feel isolated or "insignificant" as their child ages.

As a result of the perceived inadequate support, families of children with DS may be turning inwards, relying on more of their internal coping abilities. Families frequently reported using Reframing strategies, reflecting a general acceptance of the difficulties and believing in the internal strength of the families in order to work towards a solution. It also shows the strength and resilience in these families, as a large proportion of the respondents believed in their own families' strengths and power to solve major problems (75% of respondents). However, Farkas and colleagues (2019) suggested that it is not enough for parents of DS to reframe, but to use problem-focused strategies to gain information and advocate for their children's unique needs. With negative experiences of parents of children with DS being themed around the interaction of others on or with the child, they may experience a unique type of stress where the challenges of navigating the world with their child with DS may never be totally ameliorated by emotion-focused, or internal coping strategies (Farkas et al., 2019). This was true for our sample, and parents and caregivers did not simply resort to having a "positive attitude". The respondents' Mobilizing Family Support strategy use was higher than instrument norms.

Although the Mobilizing Family Support strategy was correlated with less IUN, it was not significantly correlated with decreased levels of stress. Thus, even when families do seek out support, they may not necessarily be receiving services that adequately serve their needs. This finding supports the evidence that simply putting programs in place do not guarantee that families will receive supports they need nor that they will perceive them as beneficial (Canary, 2008; Cuzzocrea et al., 2016). The difference between having decreased IUN and yet no effect on levels of stress could be supported by the findings in social support research that negative social interactions and social support represent distinct constructs (Lakey, Tardiff, & Drew, 1994; Lincoln, 2000). In fact, negative social interactions can potentially be more harmful than the impact of social support being helpful (Lincoln, 2000). If it is the case that families reaching out to the community for help is met with negativity, fear, and stigma, as some of the qualitative responses demonstrate, it makes sense why seeking support for their family would only exacerbate stressors rather than ameliorate them. Furthermore, our respondents appear to rely on their families and their ability to seek resources a lot more than social support (respondents' mean score fell in the 27th percentile on the Acquiring Social Support subscale from instrument norms), which may not be enough to provide a positive "buffer" that social support is shown to build (Cuzzocrea et al., 2016; Kiami & Goodgold, 2017). One respondent expressed her journey from the "initial 12 week ultrasound and throughout pregnancy", how "the conversation from the initial phone call from your family doctor and then the discussion with your ob[stetrician] needs to be one of inclusion, positivity, support and not shrouded in fear.". Many respondents expressed the need for inclusive activities and supports, including social activities with "typical people", and information on "DS friendly audiologists, dentists, and doctors". Again, this reflects the systemic issue that goes beyond the internal coping of parents and caregivers of children with DS.

Surprisingly, our results in coping strategy use was contrary to findings in previous literature that parents of DS children tend to use "avoidance strategies" (Cuzzocrea et al., 2016; Hastings et al., 2005; van der Veek et al., 2009). Respondents significantly endorsed less Passive Appraisal coping strategies, even compared to the instrument norms. Rather, by greatly endorsing Reframing strategies, the families demonstrated the positive, yet the proactive attitude that they take to provide support for themselves. Unlike the suggestion that these strategies may be evidence of passive acceptance or even “giving up”, Reframing strategies for these parents and caregivers were adaptive, associated with less stress and less IUN. Rather than the worrying or rumination that could come with the passive acceptance of their child’s condition, the families demonstrated their internal strength of reframing, accompanied by mobilizing their families to get practical help.

Chapter 6

6 Limitations

This study provided important information on met and unmet needs of families of children with DS, but it presents with several limitations. First, the sample is biased despite good response rate compared to other studies. The sample was limited in ethnic diversity and socioeconomic status and education, which may not paint the whole picture of service needs of parents and caregivers even within Ontario. Especially given that a sample population of predominantly White, middle-upper SES, and higher education is associated with greater service use, the respondents in our study may already be accessing and aware of the service needs available than the average parent or caregiver (Pickard & Ingersoll, 2016). Unfortunately, the homogenous sample in DS studies is common, and it has been noted as a limitation and direction for future research (Burke et al., 2012; Cless et al., 2017; Phillips et al., 2017). This partially may be attributed to the fact of increased practical barriers to ethnic minority groups in general with regards to service seeking, such as low awareness of services and service availability (Canary, 2008; Greenwood, Habibi, Smith, & Manthorpe, 2015). This outcome also reflects the restriction of accessibility of online surveys, as authors acknowledge the limitation that not all parents and caregivers may easily access an online survey. One way this could have been mitigated is in-person recruitment or mailing paper copies to the DS organizations. Furthermore, because the main source of advertisement was through DS organizations and advocacy groups, participants may already be support-seeking and active in the DS community. This could be a contributing factor of why geographical location did not reveal a significant difference in IUN. It is the hope that the service needs indicated by this sample highlight the needs that still remain unmet despite all their efforts and knowledge, across the life span of a child with DS.

As the present study was exploratory in nature, the understanding of the relationship between effective coping strategies determined by level of stress may be too reductionistic. Glidden and colleagues (2006) pointed out how classifying stress and coping may not actually measure coping as a process. A comprehensive look at coping may include individual differences such as personality and other family characteristics

(Glidden et al., 2006). In addition, despite statistical significance of the correlations, they were weak correlations. Thus, although practical implications were discussed in the study, further analysis would be required to examine the strength and nature of these relationships. However, the main focus of this study was to explore the needs of the parents and caregivers. Furthermore, with the limitation of the time restraint on online surveys, the authors decided not to include extra measures, such as subjective well-being, hope scales, and quality of life. Future research could potentially look at family adaptation as a process, as suggested by the double ABCX model. Concurrent rather than prospective measurement of coping, stress and needs may provide a dynamic picture of the changes in the various needs of parents and caregivers.

Lastly, despite the diversity of the age of children in our sample, the measures may have been best suited for younger children with DS. In the qualitative responses for the FNS, couple of the respondents have noted that the items appear to target younger children. However, this limitation reflects the original purpose of the assessment tool, which was for early intervention (Hodgetts et al., 2014 reported the same limitation). This limitation brings recognition to the fact that even the assessment of service needs, along with service access and navigation varies across the lifespan.

Chapter 7

7 Conclusion

The results of this research highlight the importance of focusing on the specific needs of parents and caregivers of children with DS, as they present with unique strengths and struggles. According to double ABCX model, pile-up of stress can occur when there is a lack of any other components in the process of adaptation. For families of children with DS, if their coping strategy of seeking out resources is met with frustrating encounters, stress may be exacerbated and the adaptation process will spiral into a vicious cycle (Farkas et al., 2019). It is important to go beyond questions of whether support is associated with positive outcomes and explore questions of how support becomes associated with positive family outcomes for specific diagnoses (Canary, 2008). Further research should focus on what parents find helpful, in order to provide and maximize benefits from the intervention programs (Solomon et al., 2001). This is especially true for family and social support, as it could be a cost-effective, time-effective and particularly crucial for families of children with DS (Hodgetts et al., 2015). We hope that the outcomes of this research and further research will contribute to meeting the important unmet needs in response to the voices of parents and caregivers of children with DS.

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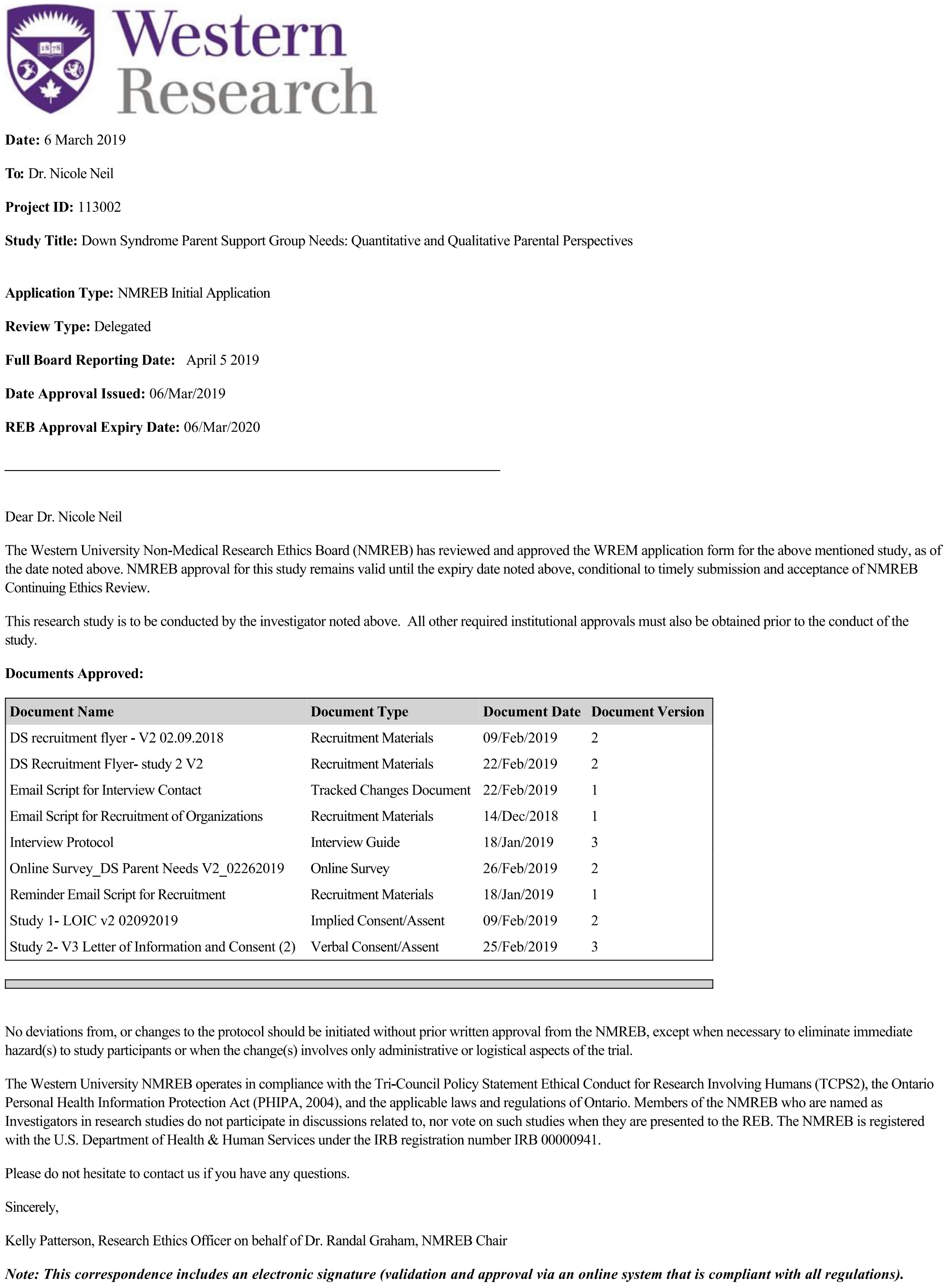
Appendices

Appendix A

Western Ethics Approval



Western Research

Date: 6 March 2019

To: Dr. Nicole Neil

Project ID: 113002

Study Title: Down Syndrome Parent Support Group Needs: Quantitative and Qualitative Parental Perspectives

Application Type: NMREB Initial Application

Review Type: Delegated

Full Board Reporting Date: April 5 2019

Date Approval Issued: 06/Mar/2019

REB Approval Expiry Date: 06/Mar/2020

Dear Dr. Nicole Neil

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
DS recruitment flyer - V2 02.09.2018	Recruitment Materials	09/Feb/2019	2
DS Recruitment Flyer- study 2 V2	Recruitment Materials	22/Feb/2019	2
Email Script for Interview Contact	Tracked Changes Document	22/Feb/2019	1
Email Script for Recruitment of Organizations	Recruitment Materials	14/Dec/2018	1
Interview Protocol	Interview Guide	18/Jan/2019	3
Online Survey_DS Parent Needs V2_02262019	Online Survey	26/Feb/2019	2
Reminder Email Script for Recruitment	Recruitment Materials	18/Jan/2019	1
Study 1- LOIC v2 02092019	Implied Consent/Assent	09/Feb/2019	2
Study 2- V3 Letter of Information and Consent (2)	Verbal Consent/Assent	25/Feb/2019	3

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Kelly Patterson, Research Ethics Officer on behalf of Dr. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B

Demographics Information

Please provide the following information for your child with Down syndrome:

Age in years:

Gender: Female Male

Comorbid Conditions:

Please provide the following information for yourself:

Parent Role: Mother Father Other (Please Specify): ___________

Race/Ethnicity: Caucasian Hispanic African Asian Native

Other (Please Specify): _________________

Education: Some High School High School Diploma College diploma

University Degree Graduate/Professional degree

Total Household Income:

< $15,000 $15,000 - $24,999 $25,000 - $34,000 $35,000 - $49,999

$50,000 - $74,999 $75,000 - $99,999 $100,000 – $149,000 > $150,000

Total number of children: 1 2 3 4 >5

Geographical location of residence within Ontario:

Is your family currently receiving support services? YES or NO

If YES, please list the services you are receiving

Appendix C

Family Needs Survey – Revised

	Is this an important topic to be discussed/addressed?			Has the topic been addressed by the services received?	
Topics	**No**	**Not Sure**	**Yes**	**No**	**Yes**
Information 1. How children grow and develop					
2. How to play or talk with my child					
3. How to teach my child					
4. How to handle my child's behavior					
5. Information about any condition or disability my child might have					
6. Information about services that are presently available for my child					
7. Information about the services my child might receive in the future					
Family & Social Support 1. Talking with someone in my family about concerns					
2. Having friends to talk to					
3. Finding more time for myself					
4. Helping my spouse accept any condition our child might have					
5. Helping our family discuss problems and reach solutions					
6. Helping our family support each other during difficult times					
7. Deciding who will do household chores, child care, and other family tasks					
8. Deciding on and doing family recreational activities					
Financial 1. Paying for expenses such as food, housing, medical care, clothing, or transportation					
2. Getting any special equipment my child needs					
3. Paying for therapy, day care, or other services my child needs					
4. Counseling or help in getting a job					
5. Paying for babysitting or respite care					
6. Paying for toys that my child needs					

	Is this an important topic to be discussed/addressed?			Has the topic been addressed by the services received?	
Topics	**No**	**Not Sure**	**Yes**	**No**	**Yes**
Explaining to Others 1. Explaining my child’s condition to my parents or my spouse’s parents					
2. Explaining my child’s condition to his or her siblings					
3. Knowing how to respond when friends, neighbors, or strangers ask questions about my child					
4. Explaining my child’s condition to other children					
5. Finding reading material about other families who have a child like mine					
Child Care 1. Locating babysitters or respite care providers who are willing and able to care for my child.					
2. Locating a day care program or preschool for my child					
3. Getting appropriate care for my child in a church or synagogue during religious services					
Professional Support 1. Meeting with a minister, priest, or rabbi					
2. Meeting with a counselor (psychologist, social worker, psychiatrist)					
3. More time to talk to my child’s teacher or therapist					
Community Services 1. Meeting & talking with other parents who have a child like mine					
2. Locating a doctor who understands me and my child’s needs					
3. Locating a dentist who will see my child					

Please list other topics or provide any other information that you would like to discuss.

____

____

What are some other services you would like to have to support yourself and your child?

____

____

Appendix D

Questionnaire on Resources and Stress

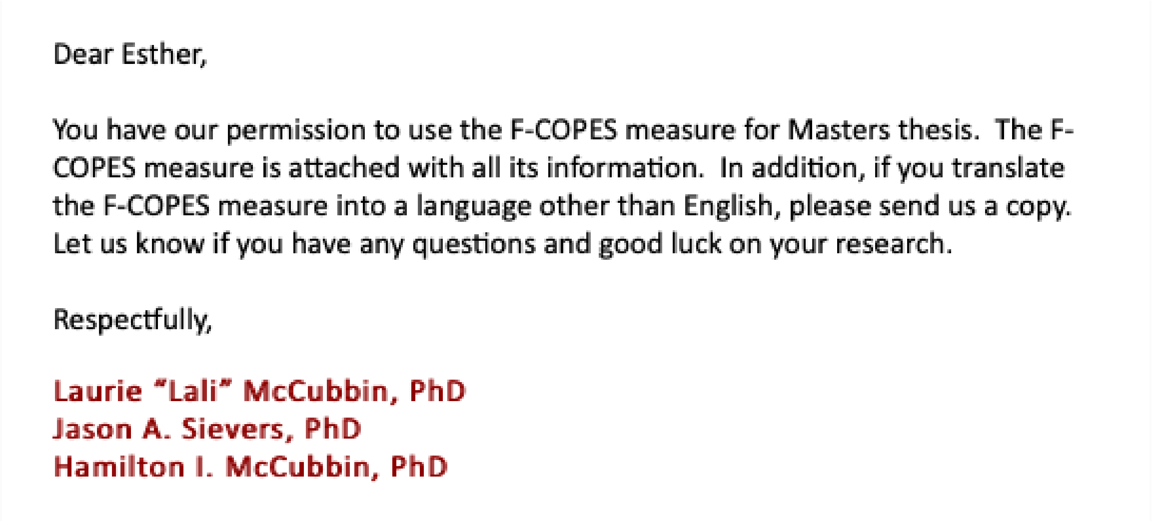
This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes, the questions refer to problems your family do not have. nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all of the questions.

1. ___ doesn't communicate with others of his/her age group
2. Other family members have to do without things because of ___
3. Our family agrees on important matters
4. I worry what will happen to ___ when I can no longer take care of him/her
5. Constant demands to care for ___ limit he growth and development of someone else in our family
6. ___ is limited in the kind of work he/she can do to make a living
7. I have accepted that ___ might have to live out his/her life in a special setting (e.g. Institution or group home)
8. ___ can feed himself/herself
9. I have given up things I really wanted to care for ___
10. ___ is able to fit into the family social group
11. Sometimes I avoid taking ___ out in public
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress
13. I bothers me that ___ will always be this way
14. I feel tense whenever I take ___ out in public
15. I can go to visit friends whenever I want
17. ___ knows his/her own address
18. The family does as many things together now as we ever did
19. ___ is aware of who he/she is
20. I get upset with the way my life is going
21. Sometimes I feel very embarrassed because of ___
22. ___ doesn't do as much as he/she should be able to do
23. It is difficult to communicate with ___ because he/she has difficulty understanding what is being said to him/her
24. There are many places we can enjoy ourselves as a family when ___ comes along
25. ___ is over-protected
26. ___ is able to take part in games or sports
27. ___ has too much time on his/her hands
28. I am disappointed that ___ does not lead a normal life
29. Time drags for ___, especially free time
30. ___ can't pay attention for very long
31. It is easy for me to relax
32. I worry what will happen to ___ when he/she gets older

33. I get almost too tired to enjoy myself
34. One of the things I appreciate about ___ is his/her confidence
35. There is a lot of anger and resentment in our family
36. ___ is able to go to the bathroom alone
37. ___ can't remember what he/she says from one moment to the next
38. ___ can ride on a bus
39. It is easy to communicate with ___
40. Constant demands to care for ___ limit my growth and development
41. ___ accepts himself/herself as a person
42. I feel sad when I think of ___
43. I often worry what will happen to ___ when I can no longer take care of him/her
44. People can't understand what ___ tries to say
45. Caring for ___ puts a strain on me
46. Member of our family get to do the same kinds of things that other families do
47. ___ will always be a problem to us
48. ___ is able to express his/her feelings to others
49. ___ has to use a bedpan or a nappy
50. I rarely feel blue
51. I am worried much of the time
52. ___ can walk without help.

Appendix E

Permission to Use the Family Crisis Oriented Personal Evaluation Scale



Dear Esther,

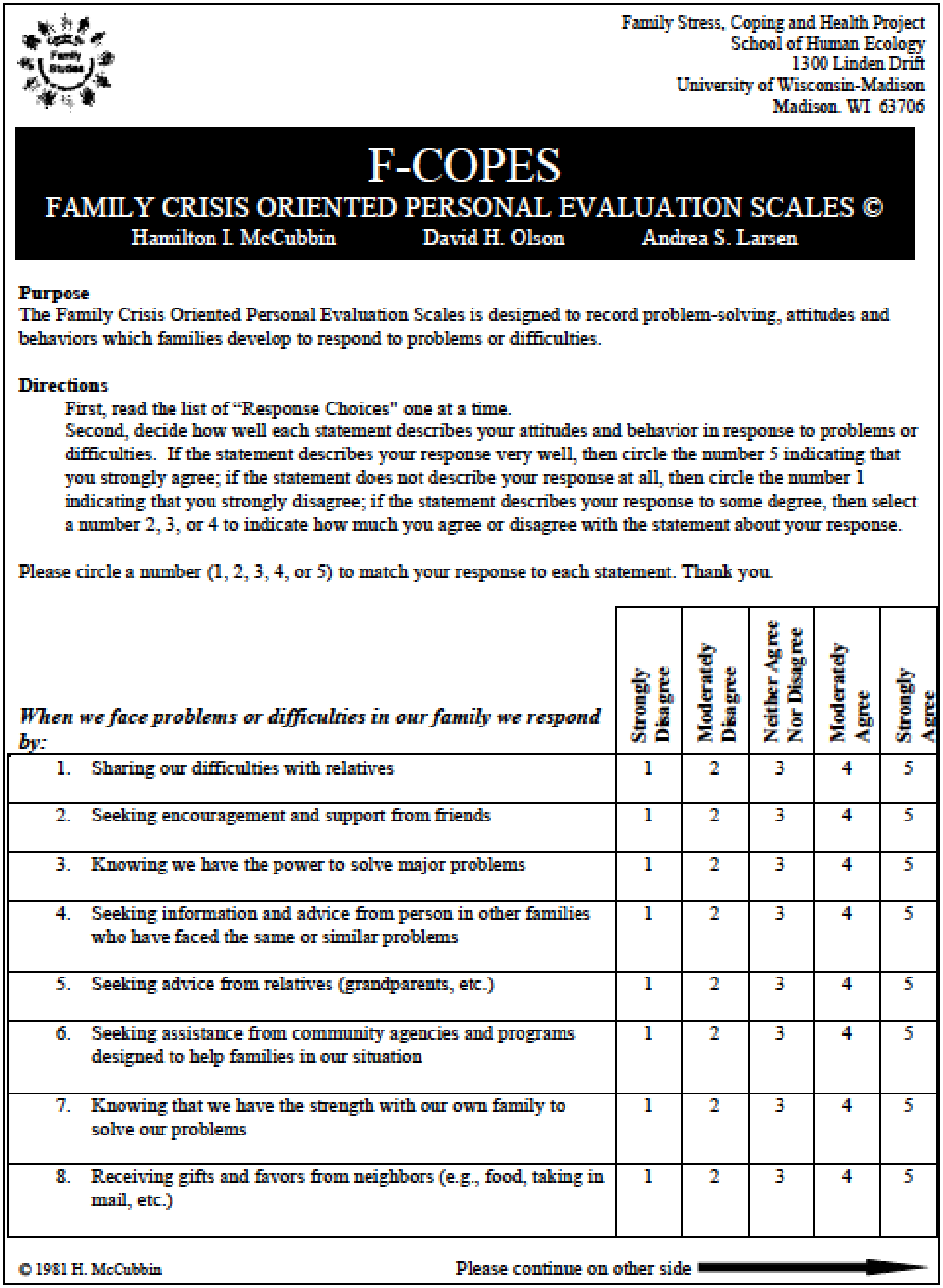
You have our permission to use the F-COPES measure for Masters thesis. The F-COPES measure is attached with all its information. In addition, if you translate the F-COPES measure into a language other than English, please send us a copy. Let us know if you have any questions and good luck on your research.

Respectfully,

Laurie "Lali" McCubbin, PhD
Jason A. Sievers, PhD
Hamilton I. McCubbin, PhD

Appendix F

Family Crisis Oriented Personal Evaluation Scale



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drift
University of Wisconsin-Madison
Madison, WI 63706

F-COPES

FAMILY CRISIS ORIENTED PERSONAL EVALUATION SCALES ©

Hamilton I. McCubbin **David H. Olson** **Andrea S. Larsen**

Purpose

The Family Crisis Oriented Personal Evaluation Scales is designed to record problem-solving, attitudes and behaviors which families develop to respond to problems or difficulties.

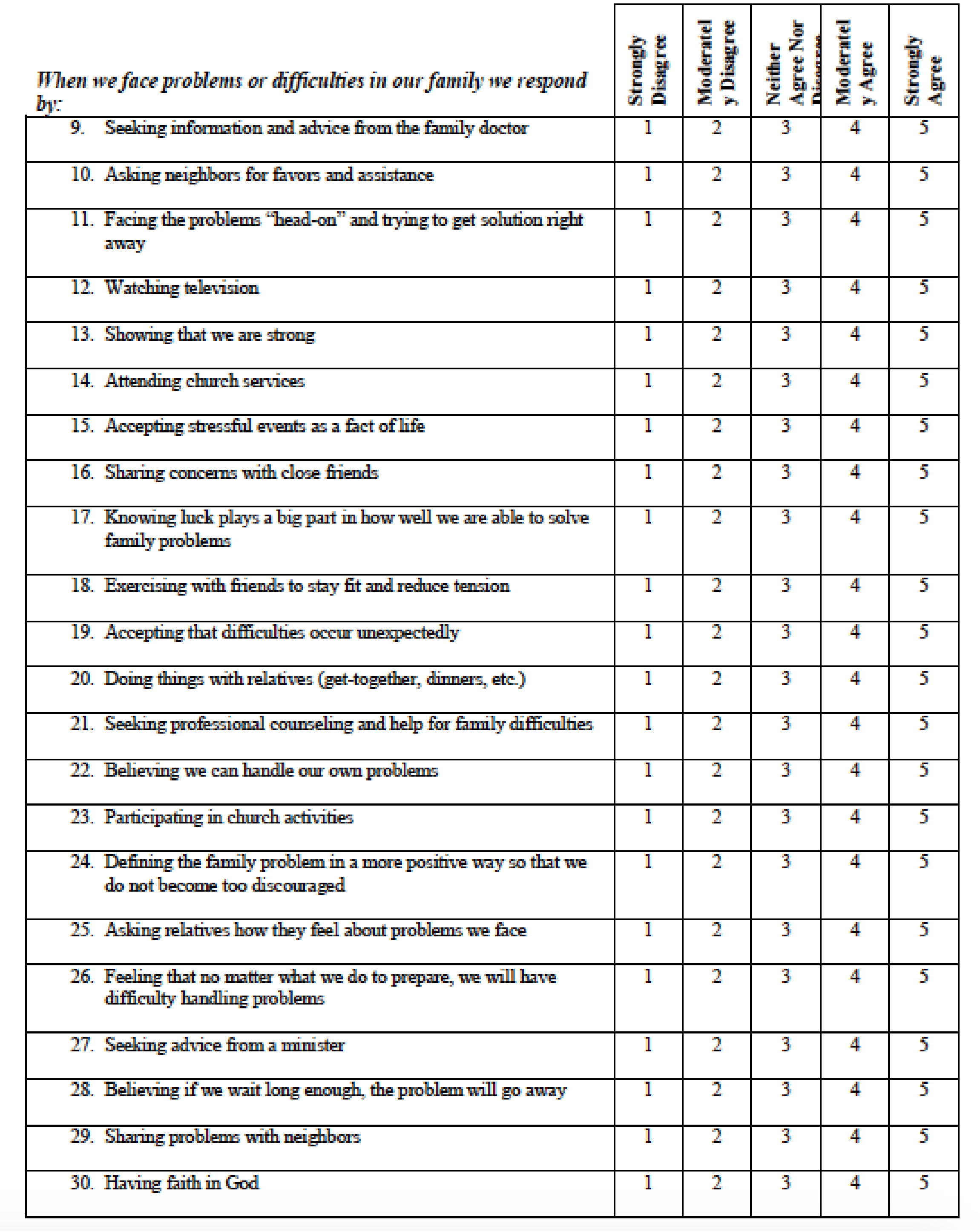
Directions

First, read the list of "Response Choices" one at a time.
Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response very well, then circle the number 5 indicating that you strongly agree; if the statement does not describe your response at all, then circle the number 1 indicating that you strongly disagree; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

Please circle a number (1, 2, 3, 4, or 5) to match your response to each statement. Thank you.

When we face problems or difficulties in our family we respond by:	**Strongly Disagree**	**Moderately Disagree**	**Neither Agree Nor Disagree**	**Moderately Agree**	**Strongly Agree**
1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friends	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from person in other families who have faced the same or similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength with our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favors from neighbors (e.g., food, taking in mail, etc.)	1	2	3	4	5

Please continue on other side



When we face problems or difficulties in our family we respond by:	Strongly Disagree	Moderately Disagree	Neither Agree Nor	Moderately Agree	Strongly Agree
9. Seeking information and advice from the family doctor	1	2	3	4	5
10. Asking neighbors for favors and assistance	1	2	3	4	5
11. Facing the problems “head-on” and trying to get solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5
14. Attending church services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-together, dinners, etc.)	1	2	3	4	5
21. Seeking professional counseling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in church activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbors	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

Curriculum Vitae

Name: Esther Yejin Lee

Post-secondary Education and Degrees:

Master of Arts in Counselling Psychology
September 2018 – Present, Graduating April 2020
Western University, London, ON

Honors Bachelor of Science, Specialist in Mental Health Studies
With High Distinction
September 2013 – August 2017
University of Toronto

Professional Experience:

Counselling Internship
September 2019 - Present
Vanier Children’s Services, London, ON

FASD Kid Group Co-Facilitator
September 2019 – Present
London Family Court Clinic, London, ON

Research Experience:

Graduate Research Assistant, Advisor: Dr. Nicole Neil
September 2018 – Present
Western University, London, ON

Research Assistant, Advisor: Dr. Nicolas Rule
February 2017 – June 2018
Social Perception and Cognition Lab, Toronto, ON

Research Student, Advisor: Dr. Brendan Andrade
June 2017 – April 2018
Centre for Mental Health and Addiction, Toronto, ON

Research Assistant, Advisor: Dr. Mark Schmuckler
September 2016 – August 2017
Music Cognition Lab, Toronto, ON

Research Assistant
January 2016 – May 2016
Ontario Shores Mental Health Centre, Whitby, ON

Honours and Awards:

Western University
MA Entrance Scholarship

Graduate Student Assistantship
September 2018 – Present

Ontario Association on Developmental Disabilities
Student Research Scholarship
2019

Natural Science and Engineering Research Council of Canada
NSERC Undergraduate Student Research Award
2017

University of Toronto
Dean’s List
2014 - 2017