

**Family Functioning and Health-Related Quality of Life in Parents of Children with Mental
Illness**

by

Madeline Reed

A thesis

presented to the University of Waterloo

in fulfillment of the

thesis requirement for the degree of

Master of Science

in

Public Health and Health Systems

Waterloo, Ontario, Canada, 2021

© Madeline Reed 2021

Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Background: When a child suffers from mental illness, their family, and particularly, their parents are adversely affected. Existing research suggests that parents of children with mental illness have significantly lower health-related quality of life (HRQoL) than parents of healthy children. Poor HRQoL of parents is associated with worse symptomology in their children, and decreased ability to care for their children. Previous research demonstrates that dysfunctional family functioning may be associated with lower HRQoL of parent caregivers.

Objectives: This project examined whether parent caregivers of children with mental illness have poorer health-related quality of life than Canadian population norms; modelled associations between family functioning and physical and mental HRQoL; and, investigated whether these associations were moderated by parent or child factors.

Methods: Cross-sectional data were collected from children receiving mental health care at a pediatric hospital and their parents. Physical and mental HRQoL of parents were measured using the Short Form 36 Health Survey (SF-36), and sample means were compared to weighted Canadian population norms using t-tests and effect sizes were calculated. Multiple regression was employed to evaluate associations between family functioning and parental physical and mental HRQoL, adjusting for child and parent demographic and clinical covariates. Proposed moderators, including child age, sex, and externalizing disorder, and parental psychological distress, were added as product-term interactions to the models.

Results: Parent caregivers had significantly poorer physical and mental HRQoL than adult Canadian norms in most domains of the SF-36, and in the physical and mental component summary scores ($d = 0.31$ to 1.47). Family functioning was not significantly associated with parental physical HRQoL, $\beta = 0.13$ (0.17), $p = .46$. Greater family dysfunction was related to poorer parental mental HRQoL, $\beta = 0.29$ (0.14), $p = .04$. No moderators significantly augmented the associations between family functioning and parental HRQoL.

Conclusion: These findings support the uptake of approaches that strive for collaboration among healthcare providers, children, and their families (i.e., family-centered care) in child psychiatry settings, to assist the health needs of all family members. Future research should assess potential mediators and moderators of these associations in longitudinal samples and examine the impact that family interventions may have on improving parent outcomes, and subsequently, child mental health.

Acknowledgements

Firstly, I would like to give a huge thank you to my supervisor, Dr. Mark Ferro. Your ongoing support, encouragement, advice, and wisdom have made working on this thesis such a pleasure. I have learned so much from you throughout this process and as a member of the ARCH lab, thank you for being a great mentor!

I would like to thank my committee members, Dr. Dillon Browne and Dr. Chris Perlman for your excellent feedback and encouragement that greatly supported this project. I want to thank my fellow ARCH lab members; your insights and advice have been much appreciated.

Thank you to my friends and colleagues within the SPHHS. I am inspired by your work and kindness, and I am grateful to have had the opportunity to be a part of this community.

Thank you to the Wednesday social group, I will never forget our calls throughout quarantine that kept me motivated. I would like to thank my fellow grad school friends who worked with me virtually, these work sessions were immensely helpful and appreciated. Thank you to my other friends who have supported me throughout my education.

A big thanks to my family for your support, encouragement, and words of wisdom.

And finally, I can never thank you enough, mom. Thank you for instilling in me the importance of education and hard work; I would not have made it this far in my educational journey without your continual support. I am grateful to have been with you throughout the lockdowns while completing this project. I dedicate this thesis to you.

Table of Contents

Author’s Declaration	ii
Abstract.....	iii
Acknowledgements.....	iv
List of Figures.....	viii
List of Tables	ix
List of Abbreviations	x
Introduction.....	1
1.1 Mental Illness in Children	1
1.2 Parents of Children with Mental Illness	2
1.2.1 Parental Stress	3
1.2.2 Effects of Stress on Parenting	4
1.2.3 Caregiver Burden and Family Burden	5
1.3 Functioning in Families with Children with Mental Illness.....	6
1.3.1 McMaster Model of Family Functioning.....	7
1.3.2 Impacts on Family Dyads	7
1.3.3 Family Functioning and Child Psychopathology	8
1.4 Health-Related Quality of Life.....	9
1.4.1 Family Functioning and HRQoL	11
1.5 Mental Health Services and Barriers to Care in Canada	12
1.5.1 Family-Centered Care	13
1.5.2 Family Psychoeducation	14
1.5.3 Support Groups	15
1.6 Theoretical Orientation.....	15
Study Rationale and Objectives.....	18
2.1 Study Rationale	18
2.2 Study Objectives and Hypotheses	18
2.2.1 Objective 1	19
2.2.2 Objective 2	19
2.2.3 Objective 3	19
Methods	22
3.1 Research Design and Sample	22
3.2 Procedure.....	22
3.3 Measures.....	23
3.3.1 Short Form 36 Health Survey (SF-36).....	23
3.3.2 McMaster Family Assessment Device (FAD).....	25

3.3.3 Parental Stress Scale (PSS)	25
3.3.4 State-Trait Anxiety Inventory (STAI).....	26
3.3.5 Center for Epidemiological Studies Depression Scale (CES-D)	26
3.3.6 Mini International Neuropsychiatric Interview (MINI).....	27
3.3.7 Demographic Characteristics	27
3.4 Analysis Plan.....	27
3.4.1 Objective 1	27
3.4.2 Objective 2	28
3.4.3 Objective 3	30
Results.....	31
4.1 Sample Characteristics	31
4.2 Prevalence of Mental Disorders	31
4.3 Objective 1	33
4.4 Objective 2	35
4.4.1 PCS.....	35
4.4.2 MCS	37
4.5 Objective 3	39
4.5.1 PCS.....	39
4.5.2 MCS	41
Discussion.....	44
5.1 Summary of Results	44
5.2 Objective 1	44
5.3 Objective 2	47
5.3.1 Association between Family Functioning and Parental Physical HRQoL	47
5.3.1.1 Parental Education Associated with Parental Physical HRQoL.....	48
5.3.1.2 Externalizing Disorder Related to Parental Physical HRQoL.....	50
5.3.1.3 Parental Psychological Distress Associated with Parental Physical HRQoL	51
5.3.2 Association between Family Functioning and Parental Mental HRQoL.....	52
5.3.2.1 Association between Parental Psychological Distress and Parental Mental HRQoL	55
5.4 Objective 3	56
5.5 Application to Theoretical Framework – Pearlin’s Stress Process Model.....	57
5.6 Implications for Public Health and Clinical Interventions	58
5.6.1 Family-Centered Care (FCC).....	58
5.6.2 Family Psychoeducation	59
5.6.3 Support Groups	60
5.6.4 Other Interventions	61

5.7 Strengths and Limitations.....	62
5.8 Future Directions.....	64
5.8.1 Other Family Members.....	64
5.8.2 COVID-19 Implications.....	64
5.8.3 Family-Centered Care.....	65
5.8.4 Variations between Disorders.....	65
5.8.5 Mediating Effects.....	66
Conclusion.....	67
References.....	68
Appendix A.....	105

List of Figures

Figure 1. Theoretical Model Based on Pearlin's Stress Process Model

List of Tables

Table 1. Characteristics of children in the sample (n = 97).

Table 2. Characteristics of parents in the sample (n = 97).

Table 3. T-tests comparing SF-36 scores between the sample and Canadian population norms.

Table 4. Hierarchical linear regression assessing the association between parent-reported family functioning and parental physical HRQoL.

Table 5. Hierarchical linear regression assessing the association between parent-reported family functioning and parental mental HRQoL.

Table 6. Moderated hierarchical linear regression assessing the association between family functioning and parental physical HRQoL.

Table 7. Moderated hierarchical linear regression assessing the association between family functioning and parental mental HRQoL.

List of Abbreviations

HRQoL	Health-related quality of life
SF-36	Short Form 36 Health Survey
ADHD	Attention-deficit hyperactivity disorder
QoL	Quality of life
FAD	McMaster Family Assessment Device
FCC	Family-centered care
CFCC	Child and family-centered care
MDD	Major depressive disorder
GAD	Generalized anxiety disorder
MINI	Mini International Neuropsychiatric Interview
PCS	Physical component summary score
MCS	Mental component summary score
PSS	Parental Stress Scale
STAI	State-Trait Anxiety Inventory
CES-D	Center for Epidemiological Studies Depression Scale
COVID-19	Coronavirus disease 2019

Introduction

1.1 Mental Illness in Children

Mental illness affects an unreasonably high number of children in Canada (Mental Health Commission of Canada, 2013). In 2011 it was estimated that 23% of Canadian children aged 9-19 were living with at least one mental illness (Mental Health Commission of Canada, 2013). Mental illnesses are conditions that impact cognition, emotion, and behaviour (Manderscheid et al., 2010). There is a large range of severity and level of impairment across various mental illnesses (Manderscheid et al., 2010). Experiencing mental illness without intervention can lead to further problems for children in areas of family, learning and development, school attendance, social functioning, health, and criminal behaviour (Sheehan, 2017; Child and Adolescent Mental Health Services, 2008).

Mental illnesses are frequently referred to as mental disorders (Cosgrove et al., 2011). Some mental disorders reflect internalizing symptoms, marked by directing one's distress inwards, and/or externalizing symptoms, characterized by outwardly expressing one's emotions (Cosgrove et al., 2011). Youth with a mental disorder have comorbid (i.e., multiple) disorders at rates highly exceeding that of chance, suggesting that shared processes may explain the occurrence of comorbidities (Oland & Shaw, 2005; Willner et al., 2016; Beauchaine & McNulty, 2013; Caron & Rutter, 1991). The most prevalent mental disorders among Canadian youth in 2011 included mood and anxiety disorders (12%) and substance use disorders (7%) (Mental Health Commission of Canada, 2013).

Due to the high prevalence of mental disorders in the Canadian population, there is also a large proportion of Canadians who care for a family member with a mental illness. It was

estimated in 2012 that 7.6% of the 4 million family caregivers in Canada were caring for a member of their family with a mental illness (Mental Health Commission of Canada, 2015). The negative impacts that caring can have on families, and particularly parents, is significant and is often overlooked in treatment and interventions (Mendenhall & Mount, 2011), despite best practice guidelines that advocate for child and family-centred approaches to care for children with mental illness (Mental Health Commission of Canada, 2010).

1.2 Parents of Children with Mental Illness

When a child or adolescent suffers from a mental illness, the whole family is often impacted. From a social ecological systems perspective, illness or stress in one family member inevitably affects the health of all family members (Witt & Deleire, 2009; Armstrong et al., 2005; Friedman et al., 2003). Parents have to adapt their existing roles (consistent standards of behaviour) and assume additional roles of caregivers, advocates, and case managers for their children (Mendenhall & Mount, 2011; Olasoji et al., 2017). As the role of a parent can already be stressful, the need to tackle new roles in the face of their child's mental illness creates substantial additional distress and can disrupt family functioning in several areas (Ross et al., 1998; Duchovic et al., 2009). The difficulty in finding appropriate treatment for their child due to lack of services or restricted communication with healthcare providers can also be very stressful (Mendenhall & Mount, 2011; Olasoji et al., 2017; Mackinaw-Koons & Fristad, 2004). Economic challenges can result from the need for additional treatments, or from disruptions to employment including schedule changes, additional distractions, absences, and impacts on productivity (Clark & Drake, 1994; Haley, 2003; Mendenhall & Mount, 2011). In addition, parents of children with mental illness often experience embarrassment and blame for their child's ongoing issues and

can experience strained or distant social relationships due to the stigma associated with their child's illness (Mackinaw-Koons & Fristad, 2004; Goldberg-Arnold et al., 1999; Corrigan & Miller, 2004). They also may have less time to interact with their friends and family due to caregiving strains (Mendenhall & Mount, 2011). The impacts of caring for a child with a mental illness can negatively affect parent mental health; these parents have higher rates of depression and anxiety in comparison to controls (Cussen et al., 2012; Tamplin et al., 1998; Biederman et al., 1987; Seltzer et al., 2004). The stress of caring for children with mental illness is also associated with poorer HRQoL of parents and worse physical health outcomes including increased somatic complaints (Hsiao, 2016; Huang et al., 2014; Suresky et al., 2008; Ha et al., 2008).

1.2.1 Parental Stress

Caring for a child with a mental illness can be extremely stressful, and this significant stress can exacerbate existing stressors that parents encountered before the onset of illness, as well as create additional strains. Parental stress can be defined as a parent's judgement that there is a shortcoming of available resources to meet their parenting demands and obligations (Hsiao, 2018; Abidin, 1997; Raphael et al., 2010). All parents experience some parental stress, although parents of children with mental illness generally experience substantially greater levels (Anastopoulos et al., 1992; Wingrove & Rickwood, 2019). Stress can also be related to other negative health outcomes for caregivers, as subjective distress was found to be a mediator of the association between child's internalizing problems and depressive symptoms in parents (Gerkensemeyer et al., 2008). Stress related to a family member's mental illness has demonstrated to adversely impact family functioning, which may lead to additional

psychological issues for parents and children (Friedmann et al., 1997; Gerkensemeyer et al., 2008; Chazan et al., 2011). Children of over-stressed parents have higher expenditures for use of support services, and parents with more parental stress use support services less often (Browne et al., 2010). These parents may be experiencing greater stress as they are not getting the support they need, or their heightened stress may be impeding their ability to seek out additional needed services (Browne et al., 2010). Greater behaviour or psychological problems in the child can further increase parental stress, leading to an ongoing cycle of strain within the family (Browne et al., 2010; Hsiao, 2018). Increased parental stress is also associated with worse parental HRQoL and greater levels of caregiver burden (Hsiao, 2016; Huang et al., 2014; Tung et al., 2014; Sales, 2003; Wingrove & Rickwood, 2019; Suresky et al., 2008).

1.2.2 Effects of Stress on Parenting

Parental stress can impact the way parents interact with and care for members of their family. Parents who experience significant amounts of stress may be less able to effectively care for their children, including being unable to acquire proper care and supports for their child, and reacting inappropriately to their child's behaviour (Zablotsky et al., 2013; Hsiao, 2018). Extensive parental stress can have indirect, through parenting behaviours and family mechanisms, and direct negative consequences for the child's physical and mental health (Hsiao, 2018; Mash & Johnston, 1990). Greater frequency of poor parenting strategies has been reported in parents of children with mental illness (Woodward et al., 1998). Higher rates of aggressive parenting strategies, including the use of physical punishment, and poorer parental coping strategies have been reported in parents of children with attention-deficit hyperactivity disorder (ADHD) in comparison to controls (Woodward et al., 1998). More parental rejection and

overprotection as well as reduced emotional warmth have been associated with higher levels of internalizing and externalizing symptoms in youth (Muris et al., 2003).

1.2.3 Caregiver Burden and Family Burden

A related yet distinct phenomenon to parental stress that parent caregivers can experience is caregiver burden. This includes the physical, psychological, social, and financial problems that family caregivers can endure as a result of caring for their ill child (George & Gwyther, 1986).

Caregiver burden is usually classified into objective and subjective burden, with objective burden including observable consequences to the family due to the illness, and subjective burden including the intangible sufferings experienced as a result of caregiving (Loukissa, 1994).

Objective burden includes differences in household routine and family roles, strains in family relationships, loss of social relations and support, disrupted leisure time and career development, worsening financial situation, and negative impacts on other children (Schene, 1990). Subjective burden can include adverse impacts on physical and mental health, and subjective distress such as experiencing negative feelings (Schene, 1990). Family burden, or informal caregiver burden, has also been described to include the physical, psychological, and social burdens that caring for a family member with mental illness has on the whole family (Zahid & Ohaeri, 2010; Awad & Vourganti, 2008; Ohaeri, 2003). Some researchers prefer the term “family caregiving consequences”, as some families experience positive emotions throughout caregiving (Zahid & Ohaeri, 2010).

The majority of previous research suggests that family caregivers of children with mental illness experience high levels of caregiver and family burden (Ohaeri, 2003; Liu et al., 2007).

Various studies have demonstrated that caregiver burden can be a predictor of HRQoL, quality of life (QoL), and overall well-being in caregivers (Sales, 2003; Chappel & Reid, 2002; Pearlin

et al., 1990; Hughes et al., 1999; Khanna et al., 2011). Higher rates of caregiver burden are also related to health outcomes in their children, including poorer recovery (Zahid & Ohaeri, 2010). When perceptions of caregiver burden and patient's depressive symptoms decreased due to an intervention, caregiver QoL improved (Las Hayas et al., 2014).

1.3 Functioning in Families with Children with Mental Illness

Living with a family member who has a mental illness can lead to continual adaptation and adjustment within the family as the illness unfolds (Saunders, 2003; Danielson et al., 1993). This ongoing adjustment can greatly disrupt families in areas of functioning including relations, communication (reciprocal sharing of information), and responsibilities, and can cause changes in roles (Friedman et al., 2003; Saunders, 2003; Miller et al., 1986; Marsh, 1992; Epstein et al., 1978). Family functioning has been defined as how the family operates, including communication and adaptation of the environment to problem solve (Mosby's, 2009; Holtom-Viesel & Allan, 2014). Family systems theory suggests that the family should be considered as a whole, and that family structure and organization impact how each family member behaves (Holtom-Viesel & Allan, 2014). This theory emphasizes that through repetition, family transactions become rigid patterns of behaviour (Minuchin, 1974; Browne et al., 2015). Functional families are able to achieve balance through creating and preserving strengths such as use of resources and coping strategies that can meet ongoingly shifting demands (Patterson & Garwick, 1994). Family dysfunction, including increased conflict among members, lower cohesion (poorer emotional bonding and reinforcement of boundaries), and difficulty balancing the needs of all family members, is common in families with children with mental illness (Cussen et al., 2012; Limbers et al., 2011; Wang et al., 2013; Keitner et al., 2009; Murphy & Flessner, 2015; Holtom-Viesel & Allan, 2014; Biederman et al., 1999). Dysfunction can be

fluctuational, as difficulties in family functioning in areas of problem solving (capability to settle problems), affective expression and responsiveness (appropriate emotional responses and expression), communication, and general functioning are associated with a family member experiencing an acute episode of a psychiatric illness (Friedmann et al., 1997; Epstein et al., 1978). Support received from family members and extended family may be less than expected, and this is associated with poorer mental health of caregivers (Johnson et al., 2011; Easter Seals, 2009). Poor family functioning is associated with worse health outcomes for parent caregivers, including greater depressive symptoms and lower HRQoL (Gerkensemeyer et al., 2008; Johnson et al., 2011; Chen et al., 2014). As family functioning consists of many various components, several models and measures have been developed to describe and assess families and family functioning (Hamilton & Carr, 2016; Browne et al., 2020).

1.3.1 McMaster Model of Family Functioning

The McMaster Model of Family Functioning is based on family systems theory, and aims to characterize the organization, transactions within, and structures of families (Epstein et al., 1978). This model considers domains including problem solving, communication, roles, affective responsiveness, affective involvement (level of interest and concern for one another), and behaviour control (how the family creates and reinforces rules) as important for clinical assessment (Epstein et al., 1978; Holtom-Viesel & Allan, 2014). This model was used to develop the McMaster Family Assessment Device (FAD) and its shorter version, the 12-item General Functioning subscale which was used in this study to assess overall family functioning.

1.3.2 Impacts on Family Dyads

Mental illness impacts all of an individual's relationships systems, and most notably, the family system (Bowen, 1978; Minuchin, 1974; Haley, 1987). Family systems perspectives also

suggest that each individual family member may have a different emotional reaction and behavioural response to a family member's mental illness (Trepal et al., 2006). Living with a family member with mental illness can impact family dyads, including parent-child, marital, and sibling dyads (Murphy & Flessner, 2015; Ma et al., 2017; Saunders, 2003). Increased marital and sibling strain and conflict have been reported in these families (Murphy & Flessner, 2015; Ma et al., 2017). Siblings of children with mental illness have demonstrated lower QoL, higher rates of their own mental health problems, and reported poorer family functioning than children from a community population study (Barnett & Hunter, 2012).

1.3.3 Family Functioning and Child Psychopathology

The association between child psychopathology and family functioning is inherently cyclical (Griffith et al., 1989). Following a family systems perspective, the onset of mental illness can partially be due to the family system one belongs to (Hughes & Gullone, 2008; Steinglass, 1987). Onset of anxiety in children has shown to be associated with overinvolved and overprotective parents, rejection from parents, and poor family functioning (Bögels & Brechman-Toussaint, 2006; Breinholst et al., 2012; Crawford & Manassis, 2001; Ginsburg et al., 2004).

In addition, clinical child outcomes can be influenced by poor family functioning. Adverse outcomes for ill children in dysfunctional families can include greater ongoing symptoms, poorer overall functioning, and worse response to treatment (Chazan et al., 2011; Johnston & Mash, 2001; Goodyer et al., 1997; Biederman et al., 1995). In families with children with an anxiety disorder, poor family functioning reported by mothers and fathers was associated with more symptoms of anxiety, worse overall functioning, and greater severity of anxiety disorder in children (Hughes et al., 2008). In adolescents with bipolar disorder, family cohesion,

adaptability and conflict were related to their depressive symptoms over time (Sullivan et al., 2012). Difficulties with family functioning can affect caregiver's quality of care, and as a result disrupt the progress of recovery of the ill family member (Lauber et al., 2005).

Family-centered interventions can improve family functioning and caregivers' abilities to provide appropriate care for their ill children, which can in turn impact child and family health. While participating in family-focused treatment, reductions in family conflict reported by parents was associated with reductions in adolescents' symptoms of mania (Sullivan et al., 2012). Patients whose caregivers received a family-focused intervention demonstrated less symptoms of depression and mania, and the decline in symptoms of depression was partially mediated by reductions in their caregiver's depressive symptoms (Perlick et al., 2010). Emotion-Focused Family Therapy can improve parental self-efficacy, decrease parental emotional blocks, and help resolve their child's symptoms over time (Foroughe et al., 2019). Family-centered practices are important to improve caregiver health, and subsequently support child and family well-being.

1.4 Health-Related Quality of Life

Health-related quality of life of parent caregivers of children with mental illness can be negatively affected by the challenges of caregiving and dysfunctional family functioning. The current study draws on the definition developed by Hays & Reeve (2008), which states that “[HRQoL] refers to how well a person functions in their life and his or her perceived well-being in physical, mental, and social domains of health” (p. 195). Functioning includes physical functioning, such as the ability to engage in activities of daily living such as dressing oneself and participating in physical exercise, and social functioning, including the ability to effectively communicate with family, friends, and other individuals (Hays & Reeve, 2008). Perceived well-being is one's personal perceptions of their levels of vitality, anxiety, depressive symptoms, pain,

and general health (Hays & Reeve, 2008). Measures of HRQoL have historically been used to compare individuals with a certain disease or condition, for population surveillance, and within clinical practice (Hays & Reeve, 2008; Berzon et al., 1993). Relatedly, quality of life is a broader concept including all variables that influence an individual's life, such as health, activities, participation, spirituality, levels of social support, personal satisfaction, resources, and life situations (Torrance, 1987; Karimi & Brazier, 2016; Diener & Suh, 1997).

Several studies have demonstrated impaired HRQoL in parent caregivers of individuals with severe mental illness in comparison to parents of healthy children or population norms (Zendjidjian et al., 2012; Dey et al., 2019; Cappe et al., 2017; Jeyagurunathan et al., 2017; Kim et al., 2014; Chen et al., 2014; Andrade et al., 2016). A study with family caregivers of individuals with mood disorders found that these caregivers had significantly lower QoL than demographic-matched controls, and were particularly affected in mental wellbeing, social functioning, and emotional role functioning (Zendjidjian et al., 2012). Previous studies with family caregivers have examined factors related to worse HRQoL including female sex, older age of caregiver, older age of offspring, lower socioeconomic status, chronic illness in caregiver, greater severity of symptoms in family member, increased levels of parental stress and caregiver burden, worse family functioning, and mental illness in caregiver (Hsiao, 2016; Johnson et al., 2011; Zendjidjian et al., 2012; Dey et al., 2019; Cappe et al., 2017; Jeyagurunathan et al., 2017; Chen et al., 2014; Xiang et al., 2009; Gutiérrez-Maldonado et al., 2005; Wong et al., 2012).

Poor HRQoL in family caregivers is related to other negative health impacts for themselves and their ill family member. Lower HRQoL is associated with higher rates of mental illness among parent carers, specifically depression and anxiety (Jeyagurunathan et al., 2017; Chen et al., 2014; Martín et al., 2013; Kousha et al., 2016). Impaired HRQoL in parents can

affect their ability to effectively care for their child, and in turn their child's symptoms (Chen et al., 2014; Lee et al., 2009). Family caregivers' QoL can have an indirect impact on their ill relative's QoL, mediated by severity of their relative's symptoms (Caqueo-Urizar et al., 2017).

1.4.1 Family Functioning and HRQoL

Mixed results have been examined on the association between family functioning and HRQoL in family caregivers. In family caregivers assisting a relative with daily life activities, an unadjusted association between family functioning and HRQoL has been demonstrated (Rodríguez-Sanchez et al., 2011). Poor family functioning in families caring for relatives with mood disorders was strongly correlated with poorer QoL in the domains of mental health, vitality, and general health perceptions (Heru et al., 2004). Disruption of family leisure and interaction due to a family member's mental illness has been associated with worse QoL of caregivers (Pereira & de Almeida, 1999). A large discrepancy between reality and expectations of family functioning and support has been related to poorer mental HRQoL in parents of children with autism spectrum disorder (Johnson et al., 2011). Perceived level of family support and communication was associated with QoL in mothers of children with ADHD after controlling for several variables (Chen et al., 2014). Alternatively, family functioning was not related to parental HRQoL after accounting for variables such as coping style in parents of children with autism spectrum disorder (Khanna et al., 2011). Similar results were demonstrated in family caregivers of individuals with schizophrenia; family functioning was not significantly associated with HRQoL in a multiple regression analysis (Ribé et al., 2018). Additionally, the directionality of this association is not well established, and it is likely that parental HRQoL also impacts family functioning, potentially through increased strain on relationships in the family, including marital, sibling, and parent-child relationships (Prime et al., 2020).

1.5 Mental Health Services and Barriers to Care in Canada

Mental healthcare in Canada is either provided in community or acute care settings (Canadian Institute for Health Information, 2019). Community-based care includes primary care clinics, social services, mental health and addictions service clinics, and residential services (Canadian Institute for Health Information, 2019). Access to primary care for mental health problems is poor in Canada, and care received is often low-quality (Centre for Addiction and Mental Health, 2016). Interventions for children in mental health clinics and other community-based centers usually include counselling or psychotherapy such as cognitive behavioural therapy (CMHA BC Division, 2014). Other interventions for youth include medication and support groups (CMHA BC Division, 2014). Acute care includes emergency department, inpatient, or psychiatric services (Canadian Institute for Health Information, 2019). The majority of current community-based and acute care interventions are centered around the patient and do not directly involve the patient's parents or family. Interventions that involve carers can increase their quality of life, decrease psychological distress, and improve the experience of caregiving (Skärsäter et al., 2018; Pharoah et al., 2010; Macleod et al., 2011; Sin & Norman, 2013; Yesufu-Udechuku et al., 2015).

There are many barriers to receiving appropriate care for children and youth with mental illness in Canada. Parents may not know where to begin to search for services or may be unaware that particular services exist (Owens et al., 2002). In a survey of Ontario families, 76% of parents stated that it was very or extremely difficult to know where to get help for their child (Parents for Children's Mental Health, 2013). Another barrier is long wait times; children and youth requiring long-term counselling in Ontario can wait for care for 3 months up to 1.5 years (Loebach & Ayobzadeh, 2017). This is partially due to lack of funding for community-based

care and poor coordination between services (Canadian Mental Health Association, 2018). Other common barriers to receiving care for children in Ontario include the services offered not meeting the needs of the child and no available services nearby (Ipsos, 2017). In addition, 40% Ontarian families surveyed did not receive or were still waiting for services their child required (Ipsos, 2017). Barriers to receiving needed care for their child can exacerbate parental stress and may in turn impact outcomes such as family functioning and parental HRQoL (Mendenhall & Mount, 2011; Olasoji et al., 2017; Mackinaw-Koons & Fristad, 2004).

1.5.1 Family-Centered Care

Recent best practice guidelines call for the uptake of family-centered care (FCC) or child and family-centered care (CFCC) in child psychiatry settings (Mental Health Commission of Canada, 2010). Family-centered care is defined as a way to plan, distribute, and assess health care that is rooted in partnerships among healthcare providers, children, and families that are reciprocally valuable to all stakeholders (Johnson, 2000; Regan et al., 2017). Core values of FCC and CFCC include dignity and respect, the sharing of information between stakeholders that is helpful, and participation and collaboration (Bell, 2013; Falkov, 2012). A family-centered approach views the patient and family as the experts who identify their own needs, while healthcare providers actively involve them in decision making regarding the patient's care (MacKean et al., 2012). Family-centered care aims to support children and families in identifying and enhancing their existing strengths and supports (MacKean et al., 2012). Several benefits of FCC have been demonstrated including increased child and family management skills, lower rates of re-hospitalization, faster recovery, lower levels of caregiver and family stress, and better health and well-being of the child and family (MacKean et al., 2012).

Various barriers have discouraged practitioners from implementing FCC and CFCC. There is a lack of education and training of healthcare professionals including nurses on how to collaborate with families or implement FCC which further discourages implementation (Skärsäter et al., 2018; MacKean et al., 2012). Mental health professionals often view FCC to be too time-consuming compared to individualized care, and as too complicated to navigate confidentiality concerns (Skundberg-Kletthagen et al., 2020; MacKean et al., 2012). The misinterpreted blame that may be placed on parents for their child's mental illness often discourages health professionals from involving families in interventions (Osher & Osher, 2002; MacKean et al., 2012).

1.5.2 Family Psychoeducation

Family psychoeducation is an intervention that provides information on an illness and its management, as well as emotional and practical support and problem-solving skills for family caregivers (Sin & Norman, 2013; Dixon et al., 2000). Several studies have demonstrated the benefits of psychoeducation to alleviate caregiver burden and improve other health outcomes for caregivers and patients with internalizing disorders and severe mental illnesses (Gutiérrez-Maldonado & Caqueo-Urizar, 2007; McDonnell et al., 2003; Caqueo-Urizar et al., 2015; Lucksted et al., 2012). Benefits of psychoeducation for caregivers of individuals with schizophrenia can include increased self-efficacy, social support, and satisfaction with caregiving, which are possibly mediated by favourable changes in caregivers' attitudes (Caqueo-Urizar et al., 2015). Psychoeducation is also associated with lower rates of readmission and better adherence to the patient's medication regime, and increased knowledge and coping strategies in caregivers (Caqueo-Urizar et al., 2015; Sin & Norman, 2013). A parental psychoeducation intervention significantly increased parent-reported child QoL over time, while the group receiving standard

treatment reported no significant increase (Kousha & Kakrodi, 2019). To improve long-term outcomes for patients and their families, it has been recommended that psychoeducation be practiced routinely in order to keep families in contact with health professionals and services (Caqueo-Urizar et al., 2015).

1.5.3 Support Groups

As family caregivers may have lower levels of social support (Leng et al., 2019), a possible intervention is support groups, where caregivers meet with other family caregivers to share stories, coping mechanisms, guidance, and awareness of services (Perron, 2002). Support groups for patients and families have demonstrated to be effective for improving knowledge of the illness, decreasing caregiver burden, and increasing coping strategies, abilities, and social support, although some studies reviewed lacked appropriate statistical control (Chien & Norman, 2009). As HRQoL has been related to availability of social support systems (Fung & Chien, 2002), it is possible that support groups may increase parental HRQoL. This has been previously observed, as well as improved experiences of caregiving and reduced psychological distress in caregivers, although more research is needed to validate these findings (Yesufu-Udechuku et al., 2015).

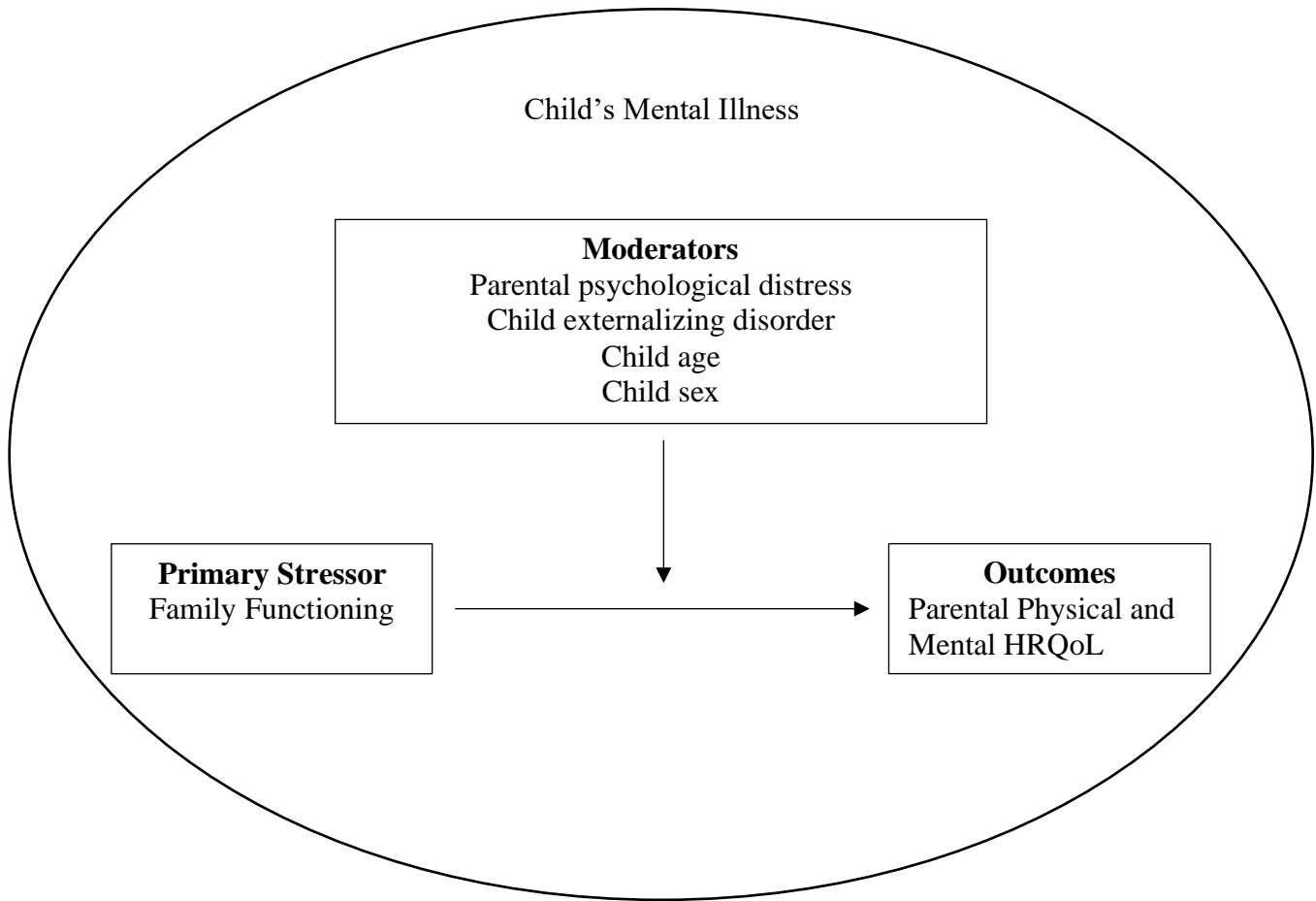
1.6 Theoretical Orientation

Pearlin's Stress Process Model informed the development of the objectives, selection of variables, statistical analysis, and guided the interpretation of findings (Pearlin et al., 1981; Pearlin et al., 1990; Ferro, 2015). The Stress Process Model applied to the caregiving context proposes that several variables including background and socioeconomic indicators, primary stressors, secondary role strains, and secondary intrapsychic strains influence the health outcomes of caregivers (Pearlin et al., 1990). Primary stressors include stressors that may result

from caregiving responsibilities, while secondary role strains include role stress in areas such as employment that do not develop directly from caregiving stressors (Pearlin et al., 1990; Goode et al., 1998). Family functioning is considered the primary stressor in the current study, in which family dysfunction was hypothesized to result from caregiving strains, as well as within the context of having a child with mental illness in the family. The primary outcomes are parental physical and mental HRQoL, that were hypothesized to be directly impacted by family functioning, as well as indirectly within the environment of having a child with mental illness in the family. Some versions of the Stress Process Model have proposed that stress moderators, such as individual stressful events, ongoing strains, and social characteristics, can augment associations between stressors and health outcomes (Ferro, 2015; Goode, 1998). Proposed moderators that were hypothesized to augment the associations between family functioning and parental physical and mental HRQoL include parental psychological distress, child externalizing disorder, child age, and child sex.

Figure 1

Theoretical Model Based on Pearlin's Stress Process Model



Note. Modified Stress Process Model to visualize the relationships among the context of having a child with mental illness, family functioning, and parental physical and mental HRQoL.

Study Rationale and Objectives

2.1 Study Rationale

There is limited research examining the HRQoL of parents of children with mental illness, particularly in a Canadian context (Cappe et al., 2018). As this area of research is mainly unexplored in Canada, it is hoped that this project will prompt and inform future research, as well as support recommendations for family-centered care. The majority of previous research has focused on parents of children with illnesses or disorders such as autism spectrum disorder and attention-deficit hyperactivity disorder; there is a dearth of research assessing parents of children with mental illnesses such as major depressive disorder (MDD), oppositional defiant disorder, or generalized anxiety disorder (GAD). Although previous research has examined poor HRQoL in parents of children with autism spectrum disorder and attention-deficit hyperactivity disorder, and in family caregivers of adults with various mental illnesses, it is unclear whether these results will generalize to parents of children with other internalizing and/or externalizing disorders (Dey et al., 2019; Zendjidjian et al., 2012). Most existing research has focused on parents of children with one specific mental illness, and little research has addressed parents of children with comorbidities (Xiang et al., 2009). The current study will address these gaps, as a sample of parents of children with various internalizing and/or externalizing mental illness and with or without comorbidities was used. Prior research has concentrated on non-modifiable risk factors for poor HRQoL of caregivers such as age of patient and caregiver, and sex of patient and caregiver. As the current study focused on family functioning as a modifiable risk factor, the results may support family-focused interventions that aim to improve family functioning, HRQoL of parents, and in turn child and family health.

2.2 Study Objectives and Hypotheses

The specific objectives of this thesis are to:

2.2.1 Objective 1: Compare SF-36 scores measuring physical and mental HRQoL between parents of children with mental illness and Canadian population norms.

It was hypothesized that parents of children with mental illness would demonstrate significantly poorer physical and mental HRQoL in comparison to Canadian population norms. This hypothesis was based on previous literature examining parents of children with severe mental illnesses or disorders, as well as family caregivers of adults with mental illnesses such as MDD.

2.2.2 Objective 2: Analyze the associations between family functioning and parental physical and mental HRQoL while adjusting for sociodemographic and clinical variables.

It was hypothesized that poorer family functioning would be associated with worse parental physical and mental HRQoL in the sample. This hypothesis was based on previous literature that has examined dysfunctional family functioning to be associated with lower parental HRQoL in multiple regression analyses utilizing similar clinical populations. The analyses adjusted for child age and sex, child externalizing disorder, parent age and sex, household income, parent education level, parental stress, and parental psychological distress. These variables were chosen based on literature detailing them to be confounders or correlates of parental HRQoL.

2.2.3 Objective 3: Investigate whether child and parental variables moderate the associations between family functioning and parental physical and mental HRQoL.

Applying Pearlin's Stress Process Model, stress moderators, including child age and sex, child externalizing disorder, and parental psychological distress, were proposed to augment the associations between family functioning and parental physical and mental HRQoL. As greater

child age and worse family functioning are correlated with poorer parental HRQoL, it was suspected that older child age would moderate the associations between family functioning and parental physical and mental HRQoL (Dey et al., 2019; Martín et al., 2013; Grover & Dutt, 2011; Johnson et al., 2011; Chen et al., 2014). As male child sex is associated with worse parental HRQoL (Aarti et al., 2019), it was hypothesized that male child sex would augment the relationships between dysfunctional family functioning and poor parental physical and mental HRQoL. Greater youth externalizing symptoms have been previously associated with poorer caregiver HRQoL (Wu et al., 2018) and dysfunctional family functioning (Esposito-Smythers et al., 2006), therefore it was suspected that child externalizing disorder would significantly moderate the relations between family functioning and parental physical and mental HRQoL. It was speculated that greater parental psychological distress would strengthen the association between family functioning and parental HRQoL, as increased psychiatric symptoms in family caregivers are related to poorer HRQoL (Jeyagurunathan et al., 2017; Kim et al., 2014).

Since higher HRQoL of parent caregivers is associated with more positive outcomes for their ill children, including better care received, enhanced response to treatment, and improved functioning (Cussen et al., 2012; Chazan et al., 2011; Chen et al., 2014; Lee et al., 2009; Agha et al., 2017), it is important to analyze whether parent caregivers are experiencing poor HRQoL in comparison to Canadian norms. If significantly lower HRQoL is found in this sample, it will provide the impetus that these individuals receive appropriate attention in the context of providing care for children with mental illness. Examining family functioning and parental HRQoL while adjusting for relevant sociodemographic and clinical factors will contribute a more accurate estimate of this association to the literature, as previous research is sparse, mixed, and inadequately controlled for error. As prior research has not tested potential moderating

effects in this subgroup, this study will inform future research, and may allow for supports to be better tailored. By conducting one of the first analyses of HRQoL of this subgroup in a Canadian context, it is conceivable that attention will be brought to this issue by relevant stakeholders who strive to improve the health of these families. Specifically, it is plausible that this research will support recommendations for child and family-centered care addressing the needs of ill children and their parents.

Methods

3.1 Research Design and Sample

This study is a secondary data analysis using data from a cross-sectional study which examined youth and parents of youth receiving tertiary mental healthcare in Ontario, Canada. Participants were recruited from the inpatient or outpatient mental health service at McMaster Children's Hospital. Inclusion criteria for children in the primary study were as follows: aged 4-17 years at enrolment; screened positive for at least one of generalized anxiety disorder, major depressive disorder, attention-deficit hyperactivity disorder, oppositional defiant disorder, conduct disorder, separation anxiety disorder, social phobia – generalized or non-generalized, or specific phobia based on parent's report of child's symptoms using the Mini International Neuropsychiatric Interview (MINI); had a parent/guardian who was the primary caregiver for at least three months preceding referral to the mental health program; and, both children and parents had sufficient proficiency in English to complete the study measures. Children who were restricted in their capacity to complete the MINI and the questionnaires due to their current state of mental health were excluded.

Initially, 259 children were found to be eligible per the inclusion criteria. There was an initial response of 144 child-parent pairs (56%) who provided consent. One hundred pairs (39%) were enrolled in the study. Of the 100 parents, 1 did not complete the questionnaires and 2 had incomplete data and were removed from the analysis, leading to a final sample of 97 parent and child pairs (37%).

3.2 Procedure

Children who were referred to outpatient treatment at McMaster Children's Hospital and their parents were contacted upon referral for potential involvement in research. The study

coordinator met with youth receiving inpatient care to describe the study and ask them for consent to contact their parent. Parents of outpatient and inpatient youth were then contacted and screened for inclusion criteria by the study coordinator via phone. Interviews with outpatient youth and parents were scheduled at the research center, and oral consent was obtained from the participants. Interviews with inpatient youth and parents were completed during hospital visits or after youth were discharged. Informed written consent/assent was obtained before data collection. Data was collected separately from youth and parents using laptops. The study received ethics approval from the Hamilton Integrated Research Ethics Board, and the current study obtained ethics clearance from the University of Waterloo Office of Research Ethics.

3.3 Measures

3.3.1 Short Form 36 Health Survey (SF-36)

The primary outcome, HRQoL, was measured in parents of children with mental illness using the Short Form 36 Health Survey. The SF-36 was developed in order to examine health status within the Medical Outcomes Study, which aimed to routinely assess various medical outcomes (Ware & Sherbourne, 1992; Tarlov et al., 1989). The developers included health concepts that are widely used in the Medical Outcomes Study scale and other established health surveys, and embedded concepts into eight subscales (Ware & Sherbourne, 1992). These subscales include physical functioning, role limitations due to physical problems (role-physical), general health perceptions (general health), social functioning, role limitations due to emotional problems (role-emotional), psychological distress and well-being (mental health), energy levels and fatigue (vitality), and bodily pain (Ware & Sherbourne, 1992). Another unscored item asks individuals how much their health status has changed over the past year (Ware & Sherbourne, 1992). The scale includes items with various response options (e.g., 1-5 Likert scale, yes and no

questions, etc.) (Ware et al., 1993). The SF-36 has been used extensively throughout the world and is considered the most widely validated measurement tool for measuring HRQoL (Contopoulos-Ioannidis et al., 2009). The construct validity of the full scale has been supported in various samples of patients, their caregivers, and the general population (McDowell, 2006; Keller et al., 1998; Machinick et al., 2009; Kwan et al., 2016; Loge et al., 1998). Test-retest reliability after two weeks has been shown to be greater than 0.80 for physical functioning, vitality, and general health perceptions, and exceeding or equal to 0.60 for the rest of the subscales (McDowell, 2006). The internal consistency of the full scale was estimated as $\alpha = 0.93$ in the current study.

Two separate groups of scores can be calculated from the SF-36: one including all eight subscale scores, and one including two summary scores, the physical component (PCS) and the mental component (MCS) summary scores (McDowell, 2006). The eight subscales are scored on a 0-100 scale, with higher scores signifying more favourable HRQoL (Ware et al., 1993; Aaronson et al., 1992). The subscale scores are calculated by scoring each item, and averaging the items corresponding to each subscale. Factor analyses of the eight subscales have demonstrated the physical functioning (10 items), role-physical (4 items), bodily pain (2 items), and general health perceptions (5 items) subscales to load onto one factor (physical health), while the social functioning (2 items), role-emotional (3 items), mental health (5 items), and energy/vitality (4 items) subscales to load onto another factor (mental health), affirming the distinction between physical and mental health dimensions (Farivar et al., 2007). The current study used factor coefficients from a two-factor (physical and mental health) oblique model that allowed the physical and mental health factors to correlate (Farivar et al., 2007). Factor coefficients for both the physical and mental health factors were separately multiplied by z-

scores for each of the eight subscales, which were calculated using the sample and normative data. The two sets of products were subsequently summed to create physical and mental health aggregate scores. The aggregate scores were transformed into T-scores with a mean of 50 and standard deviation of 10, creating the final physical and mental component summary scores.

3.3.2 McMaster Family Assessment Device (FAD)

The McMaster Family Assessment Device was developed from the McMaster Model of Family Functioning, which was designed to describe the structure of families and distinguish healthy from unhealthy families (Epstein et al., 1983). The 12-item General Functioning subscale within the FAD was completed by parents to measure overall family functioning which was considered the primary stressor in the theoretical model (Byles et al., 1988). The items strongly correlate with the other domains measured in the full FAD (Byles et al., 1988). Items are scored on a 4-point scale, and after six items are reversed coded, greater scores on the 0-36 scale indicate healthier family functioning. Internal consistency of the subscale was $\alpha = 0.83$. The construct validity of this subscale has been substantiated for measuring how a family generally perceives collective functioning on crucial tasks (Byles et al., 1988).

3.3.3 Parental Stress Scale (PSS)

The Parental Stress Scale (PSS) was used to assess parents' perceptions of stress specific to parenting (Berry & Jones, 1995). Items reflect possible losses of valued resources, as well as rewards of parenting, which are summarized into factors of rewards (6 items), stressors (6 items), lack of control (3 items), and satisfaction (3 items) (Berry & Jones, 1995). The measure employs a 5-point scale, with possible total scores ranging from 18-90, for which higher total scores demonstrate greater levels of parenting stress (Berry & Jones, 1995). The PSS has demonstrated to successfully distinguish parents of healthy children from parents of children with

developmental and behavioural problems (Berry & Jones, 1995). Test-retest reliability has shown to be adequate, at $r = 0.81$ over the course of 6 weeks (Berry & Jones, 1995).

Additionally, scores have significantly positively correlated with almost all subscale scores in the Parenting Stress Index, a previously established stress scale for parents, demonstrating strong convergent validity (Berry & Jones, 1995; Abidin, 1983). Internal consistency of the PSS in the current study was computed as $\alpha = 0.85$.

3.3.4 State-Trait Anxiety Inventory (STAI)

The State-Trait Anxiety Inventory (STAI) measures stable (trait) anxiety, and current (state) anxiety (Spielberger et al., 1971). In the context of this study, only 20 items measuring trait anxiety in parents were included. Individuals are asked how often they experience particular anxiety symptoms on a 4-point scale, and total scores can range from 20 to 80, with higher scores indicating greater levels of trait anxiety (Spielberger et al., 1971). Scores on the trait scale have demonstrated to be adequately constant over time, and unaffected by situation and time specific stressors (Spielberger et al., 1971). The internal consistency of the STAI in this study was $\alpha = 0.77$. In a content validity study, the STAI was observed to measure five out of eight criteria domains for generalized anxiety disorder based on the DSM-IV criteria (Okun et al., 1996).

3.3.5 Center for Epidemiological Studies Depression Scale (CES-D)

The Center for Epidemiology Studies Depression Scale (CES-D) was used to measure depressive symptoms in parents (Radloff, 1977). Items are scored on a 4-point scale and scale scores can range from 0-60, with higher scores specifying more symptoms of depression within the last week (Radloff, 1977). Scores equal to or greater than 16 suggest that the individual's symptoms are clinically relevant (Weissman et al., 1977). The scale displays sufficient test-retest

reliability (Radloff, 1977; Orme et al., 1986). Strong internal consistency for this scale was demonstrated in the current sample, as $\alpha = 0.86$. The criterion validity has been demonstrated through strong correlations with similar scales measuring symptoms of depression (Radloff, 1977).

3.3.6 Mini International Neuropsychiatric Interview (MINI)

The Mini International Neuropsychiatric Interview (MINI) is a structured interview that was developed to assess for presence of psychiatric illnesses following the DSM-IV and ICD-10 criteria (Sheehan et al., 1998). The interview was administered to parents and children and consisted of modules screening for each illness of interest with ‘yes’ or ‘no’ questions used to further assess the child’s symptoms (Högberg et al., 2019). The validity and reliability of the MINI are similar to established diagnostic interviews, and no significant differences in percent agreement of diagnoses between the child and parent version have been observed (Högberg et al., 2019; Sheehan et al., 2010). The parent report of the MINI was employed in the analysis. Test-retest reliability for the child version has demonstrated to be substantial for the majority of disorders evaluated (Sheehan et al., 2010).

3.3.7 Demographic Characteristics

Demographic information collected including age of the child and parent, sex of the child and parent, yearly household income, child externalizing disorder, and education level of parent was also used in the multiple regression analysis.

3.4 Analysis Plan

3.4.1 Objective 1: Compare SF-36 scores measuring physical and mental HRQoL between parents of children with mental illness and Canadian population norms.

The Canadian normative data, which includes mean age- and sex-standardized SF-36 scores for Canadian men and women, were used as the comparison group to analyze whether parents in the sample have significantly poorer HRQoL (Hopman et al., 2000). Two-sided Welch's t-tests were used to compare the sample mean scores in the eight subscales and two component summary scores to weighted scores in the Canadian normative data. Welch's t-tests are recommended when sample sizes are different, and Student's t-test can lead to biased conclusions when the homogeneity of variance assumption is not met (Delacre et al., 2017). In order to include all eligible parents in the sample, weighted scores were calculated for each subscale and summary scale for the Canadian population norms. The weighted scores were calculated by taking the mean score for the appropriate age and sex segments that matched the age and sex distribution of participants included in the sample and multiplying the mean score by the proportion of total individuals included in the normative data. Total weighted scores for each subscale and summary score of the normative data were then calculated by summing the weighted scores. The same procedure was conducted to calculate weighted SDs for the normative data.

3.4.2 Objective 2: Analyze the associations between family functioning and parental physical and mental HRQoL while adjusting for sociodemographic and clinical variables.

All regression analyses were conducted in SAS Studio, Version 9.04 (SAS Institute Inc., Cary, NC) using PROC REG and employed a significance level of $\alpha = 0.05$. Multiple regression analysis was utilized to examine the associations between family functioning and parental physical and mental HRQoL in the first set of models, while adjusting for other variables in subsequent models. Two sets of models were built with SF-36 physical and mental component summary scores as the dependent variables. Independent variables were added to the models in

blocks in a step format in an order based on previous literature. Adding predictors in blocks allowed the for estimation of the incremental variance of adding a block of predictors after other predictors have been accounted for. The final models contained all the independent variables. Adjusted R-squared estimates, change in Adjusted R-squared, and standardized coefficients were analyzed in each model.

Blocks of independent variables were added (in addition to the previous blocks) in steps based on previous literature (see Appendix A):

The first step added only family functioning to examine the primary associations between family functioning and parental physical and mental HRQoL.

The second step added a block including parent age (continuous), child age (continuous), parent sex (binary), child sex (binary), household income (binary), and education level of the parent (binary). These variables were added into the second model as previous literature suggests they can be correlates of or confounders in associations with parental HRQoL (Dey et al., 2019; Gutiérrez-Maldonado et al., 2005; Martín et al., 2013; Martín et al., 2015; Skundberg-Kletthagen et al., 2015; Cooper et al., 2006; Ho et al., 2009). For sex of parent, male sex was treated as the reference category as previous research demonstrates that mothers have poorer HRQoL (Gutiérrez-Maldonado et al., 2005; Morgan et al., 2013; Gudmundsson et al., 2002). For child sex, female sex was the reference category as caring for a male child is associated with worse parental HRQoL (Aarti et al., 2019). Household income was analyzed as a binary variable, with a cut-off of \$90,000. It is hypothesized that parents with household income < \$90,000 will have worse HRQoL (Leng et al., 2019; Xiang et al., 2009; Azazy et al., 2018). Education level of the parent was collapsed into whether the parent reported having completed college, university, or a greater level of education, or not. The reference category was parents who reported having

completed at least college or university education, as previous studies demonstrate that parents with lower educational attainment report inferior HRQoL (Jeyagurunathan et al., 2017; Chen et al., 2014; Wong et al., 2012).

The third step added child presence of externalizing disorder. Greater externalizing symptoms in youth have demonstrated to be related to worse caregiver HRQoL (Wu et al., 2018). No known previous studies have directly assessed the role of child externalizing disorder in relation to parental HRQoL.

The fourth step added a block of two continuous predictors: PSS score measuring parental stress, and a measure of parental psychological distress which summed the CES-D score measuring parental depressive symptoms and the STAI score measuring parental symptoms of anxiety. These variables were added in this block as previous research indicates that greater levels of parenting stress and psychological distress are related to poorer HRQoL (Hsiao, 2016; Huang et al., 2014; Suresky et al., 2008; Jeyagurunathan et al., 2017; Kim et al., 2014; Chen et al., 2014; Tung et al., 2014).

3.4.3 Objective 3: Investigate whether child and parental variables moderate the associations between family functioning and parental physical and mental HRQoL.

The hypothesized interactions were added in separate models as a fifth step to the existing final model to investigate whether the associations between family functioning and parental physical and mental HRQoL were significantly moderated by the proposed variables. The hypothesized effect modifiers of the associations between family functioning and parental physical and mental HRQoL were child age, child sex, child externalizing disorder, and parental psychological distress.

Results

4.1 Sample Characteristics

The characteristics of the children are presented in Table 1. Children had a mean age of 13.9 years ($SD = 3.1$), 37% were recruited from an inpatient setting, 71% were female, and 3% were immigrants. Characteristics of parents are shown in Table 2. Parents had a mean age of 45.3 years ($SD = 6.7$), 13% were immigrants, 60% were in a partnered relationship, 65% were a college or university graduate, and 38% reported a household income \geq \$90,000 per year.

4.2 Prevalence of Mental Disorders

The most prevalent mental disorders reported by children were major depressive disorder (70%), social phobia (58%), and generalized anxiety disorder (57%). The majority of children in the sample had 2 internalizing disorders (67%). The most common externalizing disorder was oppositional defiant disorder (38%), followed by attention-deficit hyperactivity disorder (36%), and 27% had 2 externalizing disorders. 41% of children had co-occurring internalizing and externalizing disorders.

Table 1. Characteristics of children in the sample (n = 97).

	M (SD)
Age (years)	13.9 (3.1)
Impairment level, WHODAS 2.0	2.4 (0.7)
	n (%)
Female	69 (71.1)
Immigrant	3 (3.1)
Mental Disorder	
Major depressive	62 (69.7)
Generalized anxiety	51 (57.3)
Separation anxiety	25 (28.1)
Specific phobia	27 (30.3)
Social phobia	52 (58.4)
Attention-deficit	32 (36.0)
hyperactivity	
Oppositional defiant	34 (38.2)
Conduct	15 (16.9)

Table 2. Characteristics of parents in the sample (n = 97).

	M (SD)
Age (years)	45.3 (6.7)
Psychological distress	64.5 (16.8)
Parental stress	51.5 (12.6)
Family functioning	20.7 (6.2)
	n (%)
Female	82 (84.5)
Immigrant	12 (12.5)
Partnered relationship	58 (59.8)
College/university graduate	63 (65.0)
Household income per year	
<\$30,000	15 (15.4)
\$30-\$59,000	23 (23.7)
\$60-\$89,000	22 (22.7)
\$90-\$119,000	18 (18.6)
\$120,000	19 (19.6)

4.3 Objective 1

Parents in the sample had significantly lower scores on the SF-36 than weighted Canadian population norms in all subscales and summary scales except for physical functioning (see Table 3). The effect sizes for the t-tests indicate that parent caregivers in the sample had the greatest disparities in scores compared to the weighted Canadian population norms in subscales

primarily representing mental HRQoL, such as Vitality, $d = 1.06$, Social Functioning, $d = 0.92$, Role-Emotional, $d = 1.10$, and Mental Health, $d = 1.00$.

Parents in the sample also had significantly lower scores in subscales more closely measuring physical HRQoL, including Bodily Pain, $d = 0.31$, General Health, $d = 0.61$, and Role-Physical, $d = 0.66$, indicating that potential impacts of caregiving on physical HRQoL should also be considered. Parent caregivers also had significantly reduced scores in both the PCS, $d = 0.86$, and the MCS, $d = 1.47$, demonstrating that they may be struggling with both their physical and mental HRQoL.

Table 3. T-tests comparing SF-36 scores between the sample and Canadian population norms.

SF-36 Subscale/Summary Scale	Sample (n = 97)	Canadian Normative Data (n = 5650)	t-value	p-value	Cohen's d
Subscales	M (SD)	M (SD)			
Physical Functioning	81.9 (22.9)	84.4 (18.1)	1.08	.282	.12
Role-Physical	56.7 (41.7)	81.6 (33.2)	5.86	< .001	.66
Bodily Pain	67.7 (24.3)	75.1 (23.4)	2.98	.004	.31
General Health	65.4 (16.2)	76.1 (18.7)	6.45	< .001	.61
Vitality	47.5 (18.3)	66.7 (17.9)	10.22	< .001	1.06
Social Functioning	64.8 (27.1)	86.7 (19.5)	7.89	< .001	.92
Role-Emotional	44.7 (42.2)	85.2 (30.4)	9.43	< .001	1.10
Mental Health	62.4 (16.2)	78.1 (15.1)	9.47	< .001	1.00
Summary Scales					
Physical Component	42.5 (10.0)	50.7 (9.0)	7.98	< .001	.86
Mental Component	38.6 (10.0)	52.4 (8.7)	13.53	< .001	1.47

4.4 Objective 2

4.4.1 PCS

Results from the hierarchical regression assessing the association between parent-reported family functioning and parental physical HRQoL using the PCS are reported in Table 4. In the unadjusted model, parent-reported family functioning was not significantly associated with parental physical HRQoL using the PCS ($\beta = 0.19, p = .27$). Family functioning accounted for

1% of the variance in parental physical HRQoL. In Model 2, while adjusting for parent age, child age, parent sex, child sex, household income, and parental education level, family functioning was not significantly associated with parental physical HRQoL ($\beta = 0.15, p = .39$). Model 2 explained an additional 2% of the total variance in parental physical HRQoL. In Model 3, presence of externalizing disorder was added to the existing model. Model 3 accounted for an additional 3% of the total variance in parental physical HRQoL. In Model 3, family functioning was not significantly associated with parental physical HRQoL ($\beta = 0.06, p = .73$). A higher level of education in parents was related to better parental physical HRQoL ($\beta = 5.51, p < .05$). In Model 4, parent clinical factors including parental stress and psychological distress were combined with the existing variables. As in the other models, family functioning was not related to parental physical HRQoL ($\beta = 0.13, p = .46$). In the full model, greater psychological distress was associated with poorer physical HRQoL in parents ($\beta = -0.28, p < .001$). Parental education level was also related to parental physical HRQoL in Model 4 ($\beta = 4.04, p < .05$). Child externalizing disorder was related to worse parental physical HRQoL in the full model ($\beta = -3.57, p < .05$). The final model explained an additional 30% of the total variance in parental physical HRQoL.

Table 4. Hierarchical linear regression assessing the association between parent-reported family functioning and parental physical HRQoL.

	Unadjusted	Model 2	Model 3	Model 4
Independent Variables	β (SE)	β (SE)	β (SE)	β (SE)
Family functioning	0.19 (0.17)	0.15 (0.18)	0.06 (0.18)	0.13 (0.17)
Child age		-0.37 (0.37)	-0.46 (0.37)	-0.15 (0.31)
Child sex, female		0.11 (2.30)	-0.81 (2.32)	-0.38 (1.93)
Parent age		0.02 (0.17)	0.03 (0.17)	-0.12 (0.14)
Parent sex, female		-4.83 (2.87)	-5.22 (2.84)	-3.33 (2.37)
Parental education		4.63 (2.43)	5.51 (2.44)*	4.04 (2.03)*
Household income		0.66 (2.34)	0.49 (2.31)	-0.30 (1.91)
Externalizing disorder			-4.05 (2.13)	-3.57 (1.79)*
Parental stress				-0.11 (0.09)
Parental psychological distress				-0.28 (0.06)***
Adjusted R^2	0.01	0.03	0.06	0.36
Change in Adjusted R^2		0.02	0.03	0.30

* $p < .05$, ** $p < .01$, *** $p < .001$

4.4.2 MCS

Results from the hierarchical regression analysis describing the association between family functioning and parental mental HRQoL employing the MCS are reported in Table 5. In the unadjusted model, there was no significant association between family functioning and parental mental HRQoL ($\beta = 0.26$, $p = .12$). Family functioning explained 2% of the total

variance in parents' mental HRQoL. Model 2 adjusted for parent age, child age, parent sex, child sex, household income, and parent's level of education, and did not explain any additional variance in parental mental HRQoL. Family functioning was not related to parental mental HRQoL while accounting for family sociodemographic factors ($\beta = 0.27, p = .14$). In Model 3, presence of externalizing disorder was added, which explained no additional variance in parental mental HRQoL. Family functioning was not significantly associated with parents' mental HRQoL in Model 3 ($\beta = 0.24, p = .20$). In Model 4, parent clinical variables including parental stress and psychological distress were added, which explained an additional 57% of the total variance in parental mental HRQoL. In the full model, after adjusting for all parent and child variables, family functioning was significantly associated with parental mental HRQoL ($\beta = 0.29, p < .05$). Parental psychological distress was the only covariate associated with their mental HRQoL in the full model ($\beta = -0.40, p < .001$).

Table 5. Hierarchical linear regression assessing the association between parent-reported family functioning and parental mental HRQoL.

	Unadjusted	Model 2	Model 3	Model 4
Independent Variables	β (SE)	β (SE)	β (SE)	β (SE)
Family functioning	0.26 (0.16)	0.27 (0.18)	0.24 (0.19)	0.29 (0.14)*
Child age		-0.63 (0.37)	-0.65 (0.37)	-0.22 (0.25)
Child sex, female		-0.62 (2.30)	-0.89 (2.36)	-0.21 (1.55)
Parent age		0.17 (0.17)	0.17 (0.18)	-0.03 (0.12)
Parent sex, female		-3.16 (2.87)	-3.27 (2.89)	-0.64 (1.89)
Parental education		2.32 (2.43)	2.58 (2.49)	0.58 (1.62)
Household income		1.43 (2.34)	1.38 (2.35)	0.31 (1.53)
Externalizing disorder			-1.18 (2.17)	-0.64 (1.43)
Parental stress				-0.11 (0.07)
Parental psychological distress				-0.40 (0.05)***
Adjusted R^2	0.02	0.02	0.02	0.59
Change in Adjusted R^2		0.00	0.00	0.57

* $p < .05$, ** $p < .01$, *** $p < .001$

4.5 Objective 3

4.5.1 PCS

Results from the moderation analyses performed to test potential effect modifiers of the association between family functioning and parental physical HRQoL are presented in Table 6.

The product-term interaction between child age and family functioning did not significantly

moderate this association ($\beta = 0.05, p = .33$). The child sex by family functioning product-term also did not significantly augment the relationship between family functioning and parental physical HRQoL ($\beta = 0.17, p = .54$). Parental psychological distress did not significantly moderate the association between family functioning and parents' physical HRQoL ($\beta = -0.01, p = .32$). Presence of a child externalizing disorder was not a significant moderator of the primary association ($\beta = 0.07, p = .81$). None of the interaction terms explained any additional variance in parental physical HRQoL.

Table 6. Moderated hierarchical linear regression assessing the association between family functioning and parental physical HRQoL.

	Model 4 + Family Functioning* Child Age	Model 4 + Family Functioning* Child Sex	Model 4 + Family Functioning* Parental Psychological Distress	Model 4 + Family Functioning* Child Externalizing Disorder
Independent Variables	β (SE)	β (SE)	β (SE)	β (SE)
Family functioning	0.14 (0.17)	0.16 (0.18)	0.12 (0.17)	0.12 (0.18)
Child age, years	-0.21 (0.31)	-0.16 (0.31)	-0.14 (0.31)	-0.13 (0.31)
Child sex, female	-0.61 (1.95)	-0.51 (1.95)	-0.25 (1.94)	-0.36 (1.95)
Parent age, years	-0.12 (0.14)	-0.12 (0.14)	-0.13 (0.14)	-0.12 (0.14)
Parent sex, female	-3.60 (2.38)	-3.34 (2.38)	-3.23 (2.37)	-3.27 (2.40)
Parental education	3.80 (2.05)	3.99 (2.04)	4.46 (2.08)*	3.99 (2.05)
Household income	-0.41 (1.92)	-0.17 (1.93)	-0.25 (1.91)	-0.27 (1.93)
Externalizing disorder	-3.91 (1.82)*	-3.58 (1.79)*	-3.49 (1.79)	-3.55 (1.80)
Parental stress	-0.11 (0.09)	-0.12 (0.09)	-0.10 (0.09)	-0.11 (0.09)
Parental psychological distress	-0.28 (0.06)***	-0.28 (0.06)***	-0.31 (0.07)***	-0.28 (0.06)***
Product term interaction	0.05 (0.05)	0.17 (0.28)	-0.01 (0.01)	-0.07 (0.28)
Adjusted R^2	0.36	0.35	0.36	0.35

* $p < .05$, ** $p < .01$, *** $p < .001$

4.5.2 MCS

The results of the moderation analyses testing potential effect modifiers in the association between family functioning and parental mental HRQoL, measured using the MCS, are presented in Table 7. The child age by family functioning product-term interaction was nonsignificant, ($\beta = 0.04, p = .32$), indicating that child age is not an effect modifier of the primary association. Child sex included in a product-term with family functioning did not significantly moderate the association between family functioning and parental mental HRQoL ($\beta = -0.25, p = .27$). The product-term interaction between parental psychological distress and family functioning was not significant in augmenting the association between family functioning and parental mental HRQoL ($\beta = -0.01, p = .19$). Presence of externalizing disorder by family functioning as an interaction term did not moderate the association between family functioning and parental mental HRQoL ($\beta = -0.02, p = .93$). None of the product-term interactions tested improved the fit of the existing full models.

Table 7. Moderated hierarchical linear regression assessing the association between family functioning and parental mental HRQoL.

	Model 4 + Family Functioning* Child Age	Model 4 + Family Functioning* Child Sex	Model 4 + Family Functioning* Parental Psychological Distress	Model 4 + Family Functioning* Child Externalizing Disorder
Independent Variables	β (SE)	β (SE)	β (SE)	β (SE)
Family functioning	0.30 (0.14)*	0.25 (0.14)	0.29 (0.14)*	0.29 (0.14)*
Child age, years	-0.27 (0.25)	-0.20 (0.25)	-0.21 (0.24)	-0.21 (0.25)
Child sex, female	-0.39 (1.56)	-0.02 (1.55)	-0.07 (1.54)	-0.20 (1.56)
Parent age, years	-0.03 (0.12)	-0.03 (0.11)	-0.04 (0.11)	-0.03 (0.12)
Parent sex, female	-0.86 (1.91)	-0.63 (1.89)	-0.53 (1.89)	-0.62 (1.92)
Parental education	0.38 (1.64)	0.64 (1.62)	1.03 (1.65)	0.56 (1.64)
Household income	0.22 (1.53)	0.12 (1.54)	0.36 (1.52)	0.32 (1.54)
Externalizing disorder	-0.92 (1.46)	-0.61 (1.43)	-0.56 (1.42)	-0.63 (1.44)
Parental stress	-0.11 (0.07)	-0.10 (0.07)	-0.10 (0.07)	-0.11 (0.08)
Parental psychological distress	-0.40 (0.05)***	-0.41 (0.05)***	-0.43 (0.05)***	-0.40 (0.05)***
Product term interaction	0.04 (0.04)	-0.25 (0.22)	-0.01 (0.01)	-0.02 (0.23)
Adjusted R^2	0.59	0.59	0.59	0.58

* $p < .05$, ** $p < .01$, *** $p < .001$

Discussion

5.1 Summary of Results

This study is the first to examine the associations between family functioning and physical and mental HRQoL in a clinical sample of parent caregivers of children with mental illness. As the majority of previous studies have included family functioning as a covariate and have focused on parents of children with one specific mental illness, this study filled gaps in the literature by examining family functioning and HRQoL of parents within a heterogeneous sample. Our findings demonstrate that physical and mental HRQoL in parents of children with mental illness were significantly poorer than Canadian norms, and that family functioning was associated with parental mental HRQoL after adjusting for relevant covariates. This suggests that family strain may be exacerbated by caring for a child with mental illness, which may negatively impact the mental HRQoL of parent caregivers. As family dysfunction and poor parent HRQoL can reduce their ability to effectively care for and parent their children (Chen et al., 2014; Lee et al., 2009), which can lead to poor clinical outcomes in their offspring (Caqueo-Urizar et al., 2017; van der Kolk et al., 2014), it is imperative that family dysfunction and low parental HRQoL are addressed in this population. These findings support the increased uptake of family-focused practices within child psychiatry, including family-centered care, support groups for parents, and family psychoeducation, that aim to improve health outcomes of all family members.

5.2 Objective 1

In this study, parent caregivers reported significantly poorer HRQoL for all domains (role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health) except physical functioning, and for both summary scales (PCS and MCS) of the

SF-36 in comparison to Canadian population norms. Caregiving and related stressors such as advocating for and finding treatment for their child, social and economic consequences, and family dysfunction can lower both the physical and mental HRQoL of parent caregivers. The significant and medium-to-large effect sizes indicate that parent caregivers are likely struggling with their HRQoL and demonstrate the importance of addressing this issue. This finding is consistent with similar previous studies; primary caregivers of individuals with MDD or bipolar disorder had significantly lower HRQoL compared to French matched controls in all domains except physical functioning (for MDD and bipolar disorder) and role-emotional (for bipolar disorder) (Zendjidjian et al., 2012). Female primary caregivers of children with autism had poorer HRQoL in all domains except physical functioning, and in the MCS but not the PCS in comparison to US norms (Khanna et al., 2011).

The greatest disparities between parents in our sample and Canadian population norms were in domains that more closely reflect mental HRQoL using the SF-36, including vitality, social functioning, role-emotional, and mental health, and in the MCS. This finding reflects previous studies that have found significant disparities between family caregivers and norms or controls in domains more similar to the MCS, but not the PCS. Family caregivers of patients with obsessive-compulsive disorder reported worse HRQoL in all domains of the SF-36 other than physical functioning, bodily pain, and general health in comparison to Italian norms (Albert et al., 2007). Mothers and fathers of adolescents with an eating disorder or a substance-related disorder had significantly lower scores on the MCS, although not on the PCS, than parents of healthy controls (Anastasiadou et al., 2016). Parents of children with ADHD perceived significantly poorer HRQoL than control families in domains of the SF-36 including mental health, bodily pain, general health, and vitality (Kandemir et al., 2014).

It is important to note that parent caregivers had significantly poorer HRQoL than Canadian norms in domains more indicative of physical HRQoL, including role-physical, bodily pain, and general health, and in the PCS. Higher rates of somatic symptoms such as backaches, sleep disturbances, and joint stiffness have been reported by parent caregivers in comparison to parents of healthy children (Ha et al., 2008). In addition, during the coronavirus disease 2019 (COVID-19) pandemic, long-term caregivers have reported more somatic symptoms including headaches, body aches, and abdominal discomfort than short-term caregivers and non-caregivers (S. S. Park, 2021). Physical outcomes are often more easily overlooked in family caregivers (Chang et al., 2010), therefore it is important to acknowledge that parent caregivers may also be struggling with their physical HRQoL. Physical health is also closely related to mental health, as higher rates of somatic symptoms have been related to a greater chance of having a mood disorder (Ohayon & Schatzberg, 2003). Therefore, it is important that healthcare professionals aim to monitor and address both physical and mental HRQoL of family caregivers.

It is possible that HRQoL of family caregivers is disorder-dependent, due to diverse care needs that reflect certain disorders, variations in severity of symptoms, or other mechanisms. Zendjidjian et al. (2012) found that caregivers of individuals with schizophrenia had worse HRQoL than caregivers of those with MDD or bipolar disorder. Discerning variations in HRQoL between parents of children with different disorders was not possible in this study due to small sample size. Future research should aim to explore possible deviations in domains of HRQoL between parent caregivers of children with different mental illnesses in broad clinical samples to better tailor interventions.

Poor HRQoL of parents can inhibit their ability to properly care for their ill child (Chen et al., 2014; Lee et al., 2009), which can in turn negatively impact child outcomes such as

severity of symptoms (Caqueo-Urizar et al., 2017) and HRQoL (Caqueo-Urizar et al., 2017; van der Kolk et al., 2014). Low HRQoL in parents is associated with higher rates of mental illness in themselves (Jeyagurunathan et al., 2017; Chen et al., 2014; Martin et al., 2013; Kousha et al., 2016), greater parental stress and caregiver burden (Huang et al., 2014; Sales, 2003; Khanna et al., 2011), and family dysfunction (Rodríguez-Sanchez et al., 2011; Grover & Dutt, 2011; Johnson et al., 2011; Chen et al., 2014), which can impact the health of the whole family. It is important that interventions involving children with mental illness also aim to improve the HRQoL of their parents, in order to support caregiving ability and parenting practices, and subsequently enhance the health of their ill child and the rest of the family. Appropriate interventions will be further discussed in Section 5.6.

5.3 Objective 2

5.3.1 Association between Family Functioning and Parental Physical HRQoL

There was no significant association between family functioning and parental physical HRQoL. This result does not align with our hypothesis and is in contrast with some previous research that suggests family dysfunction is related to poorer physical HRQoL in parent caregivers. In parents of children with autism, overall family functioning was significantly affiliated with physical QoL (Pisula & Porebowicz-Dorsmann, 2017). A low score in dyadic relationships (quality of relationship with partner) was also associated with poorer physical QoL in this study (Pisula & Porebowicz-Dorsmann, 2017). In family caregivers of adolescents with depression, family functioning was one of the strongest assessed predictors of physical HRQoL (Zhang et al., 2020). It is possible that our findings are not aligned with these previous studies due to the nature of our sample. As more children in our sample had at least one internalizing disorder (95%) in comparison to at least one externalizing disorder (55%), the lack of association

may suggest that caring for children with internalizing disorders is less physically demanding and burdening, thus negating the association between family functioning and physical HRQoL. Future research is needed to explore this hypothesis, as it is in contrast to some previous findings (Zhang et al., 2020), and to examine whether the HRQoL of parent caregivers varies depending on the diagnoses of their offspring.

In contrast, our results are consistent with some studies that showed no association between family functioning and parental physical HRQoL (Johnson et al., 2011; Ribé et al., 2018). The lack of association between family functioning and parents' physical HRQoL may suggest that disruptions to family functioning for parent caregivers may not substantially impact their physical HRQoL in comparison to other factors. This has been identified in other studies that have included caregiver burden or parental stress and identified them as more strongly related to parental physical HRQoL than family functioning (Johnson et al., 2011; Khanna et al., 2011; Ribé et al., 2018). Other factors including social support and coping mechanisms may also impact caregivers' abilities to mitigate stressors (Khanna et al., 2011; Ribé et al., 2018), and it is possible that caregivers with better coping strategies and supports are more equipped to reduce the negative impact of family dysfunction on their HRQoL. In addition, sociodemographic characteristics including lower socioeconomic status (Jeyagurunathan et al., 2017; Lee et al., 2009) and female sex (Gutierrez-Maldonado et al., 2005) of caregiver have been closely related to poorer physical HRQoL. Findings are mixed; therefore, more research is needed to discern for which caregivers this association is supported and relevant.

5.3.1.1 Parental Education Associated with Parental Physical HRQoL.

Greater level of education in parents was associated with better physical HRQoL. This finding is mirrored in several previous studies of family caregivers (Gutierrez-Maldonado et al.,

2005; Wong et al., 2012; Lua & Bakar, 2011; Chen et al., 2014). Jeyagurunathan et al. (2017) found that primary caregivers with less formal education reported significantly poorer physical, social, and environmental HRQoL. The authors proposed that caregivers with greater education may have more knowledge and strategies to effectively deal with stressful circumstances (Jeyagurunathan et al., 2017). More education has also been associated with lower levels of caregiver burden (Li et al., 2007; Caqueo-Urizar & Gutierrez-Maldonado, 2006), and this may be due to caregivers with greater education having increased knowledge of their relative's illness and availability of resources to acquire better treatment for their family member, thereby decreasing burden (Caqueo-Urizar & Gutierrez-Maldonado, 2006). It has been proposed that higher education may act as a buffer against high levels of caregiver burden, and potentially poorer HRQoL, as parents with more education have demonstrated lower levels of cognitive preoccupation with their child and fewer feelings of ongoing responsibility for their child (Cook et al., 1994). Parent caregivers with less formal education may have less knowledge, resources, coping strategies, and support systems available to mitigate the negative impacts of caregiving and related stressors on their physical HRQoL.

Other researchers have suggested that more education is related to better HRQoL through easier financial access to information, treatment, and resources that help with caregiving strains, as greater education attainment is usually related to higher income (Chen et al., 2014; Magana et al., 2007; Wong et al., 2012). However, household income was not significantly associated with parental physical HRQoL, therefore it is thought that increased knowledge, strategies, and social resources gained through education allowed parents with higher education increase their physical HRQoL. It is also possible that caregiver occupation and employment plays a role (Caqueo-Urizar & Gutierrez-Maldonado, 2006), although this was not able to be measured in the current

study due to limited sample size. Psychoeducation may be an appropriate intervention for caregivers with less formal education, as they may have less knowledge regarding their child's illness, where to find supports, and may have less social and economic resources available (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Wong et al., 2012). Family psychoeducation interventions have demonstrated to be effective in improving experiences of caring (Yesufu-Udechuku et al., 2015) and HRQoL, (Verma et al., 2019), and reducing psychological distress (Yesufu-Udechuku et al., 2015) and caregiver burden (Hubbard et al., 2016; Sin et al., 2017) in family caregivers of individuals with severe mental illness.

5.3.1.2 Externalizing Disorder Related to Parental Physical HRQoL.

A child externalizing disorder was related to poorer parental HRQoL. As the association between family functioning and parental physical HRQoL was non-significant, it is possible that child externalizing disorder mediated this association. Family functioning has been related to externalizing symptoms; lower family cohesion has been associated with more externalizing problems in adolescents (Joh et al., 2013). Increased frequency of family communication has been negatively correlated with youth externalizing symptoms (Elgar et al., 2013). Children with improved parent-adolescent communication developed through an intervention demonstrated reduced conduct problems over time (Molleda et al., 2017).

More externalizing symptoms have previously been related to worse caregiver HRQoL (Wu et al., 2018). It is thought that caring for children with externalizing disorders has greater negative physical health impacts than caring for children with internalizing disorders as youth with externalizing disorders may need more attention from their caregiver (Wu et al., 2018). Physical health problems and complaints have been reported in parent caregivers of children with mental illness (Ha et al., 2008), although it is unclear if these outcomes differ among

various types of disorders. Our result suggests that caring for a child with an externalizing disorder may be more physically draining and demanding than caring for a child with an internalizing disorder. Therefore, as poorer family functioning has been previously related to greater externalizing symptoms, and child externalizing disorder was affiliated with worse caregiver physical HRQoL, it is conceivable that child externalizing disorder mediated the association between family functioning and parental physical HRQoL.

5.3.1.3 Parental Psychological Distress Associated with Parental Physical HRQoL.

Greater psychological distress among parent caregivers was related to poorer parental physical HRQoL. This is in line with previous research that indicates that greater caregiver burden and mental health issues among family caregivers are associated with worse physical health (Chang et al., 2010). It has been identified that caregiver mental health may be a better predictor of physical health of caregivers than caregiver burden (Chang et al., 2010; Grov et al., 2006). Our result indicates that caring for a child with mental illness and related stressors can have negative repercussions on parental mental health, which may in turn adversely impact parental physical HRQoL. The directionality of the association between physical HRQoL and psychological distress is not well established, as poorer physical health status significantly predicted greater depressive symptoms in family caregivers of individuals with schizophrenia (Thunyadee et al., 2015). Thus, it is possible that caring for a child with mental illness led to poorer physical HRQoL, which subsequently contributed to worse caregiver mental health. In addition, previous literature suggests that greater severity of mental health problems, particularly depression, is related to poorer physical HRQoL (Fattori et al., 2017). Therefore, it is likely that the relationship between physical HRQoL and psychological distress is bidirectional, and that these outcomes were impacting one another.

As mental and physical HRQoL are closely related, and likely impact one another (Ohayon & Schatzberg, 2003), and levels of psychological distress (Chang et al., 2010), it is important that interventions aim to improve both physical and mental HRQoL of family caregivers. More cost-effective and accessible interventions that strive to improve physical and mental HRQoL should continue to be developed and offered for family caregivers. Moderate physical activity was found to be an effect modifier in the association between parenting stress and social relationships and environmental QoL in working mothers during the COVID-19 pandemic (Limbers et al., 2020). It is noteworthy that exercise decreased the adverse repercussions of parenting stress on mother's environment QoL, as family members spend substantially more time at home during the pandemic (Limbers et al., 2020). Other interventions that aim to improve psychological distress and the HRQoL of parent caregivers such as support groups, psychoeducation, and family-focused practices in child psychiatry are recommended.

5.3.2 Association between Family Functioning and Parental Mental HRQoL

Poorer family functioning was associated with lower parental mental HRQoL. This finding is consistent with the majority of previous research on parent caregivers; Ji et al. (2014) demonstrated that general family functioning was a better predictor of parental caregivers' mental HRQoL than their physical HRQoL. In parents of children with autism, higher discrepancies between expectations and reality of family functioning were related to poorer mental HRQoL of both mothers and fathers, but not worse physical HRQoL (Johnson et al., 2011). Mothers perceived greater discrepancies between expectations and reality of family functioning than fathers, although their scores were positively related (Johnson et al., 2011). For fathers in this study, greater discrepancies in family functioning mediated the impact of personal and family stress on father's mental HRQoL (Johnson et al., 2011). In addition, for family

caregivers of individuals with mental illness, interruptions to family leisure and interactions were associated with poorer QoL in all domains (Grover & Dutt, 2011). In family caregivers of individuals with schizophrenia, worse family adaptability and affective responsiveness was related to lower mental HRQoL, although not physical HRQoL of caregivers (Meng et al., 2021).

It is possible that the demands related to the child's mental illness increase strain on the family system, leading to dysfunctional family functioning, which in turn decreases parental mental HRQoL. This is probable as the onset of youth mental illness is also associated with family dysfunction (Hughes & Gullone, 2008). Therefore, it is likely that the added stressors related to caring further exacerbate existing family tensions, which then reduce parental mental HRQoL. As the directionality of the association between family functioning and parental HRQoL is not confirmed, it is also conceivable that poor parental HRQoL results from caregiving demands, which then negatively influences family functioning. It is possible that this association is bidirectional, creating a cycle of worsening family dysfunction and caregiver HRQoL, which subsequently impacts the child's prognosis and the health of the whole family (Lee et al., 2009; Sin et al., 2017). Thus, it is important to monitor family functioning and HRQoL of family caregivers to improve health outcomes for all family members.

It is unclear from the current study which aspects of family functioning were most closely related to parental mental HRQoL. As previous studies have demonstrated that family caregivers report disruptions in several areas of family functioning, including poorer communication (Chen et al., 2014), reduced support from other family members (Johnson et al., 2011), increased conflict (Esposito-Smythers et al., 2006), lower cohesion (Murphy & Flessner, 2015), worse problem solving (Kandemir et al., 2014), reduced family adaptability (Meng et al., 2021), and poorer affective expression and responsiveness (Friedmann et al., 1997; Kandemir et al., 2014),

it is likely that many aspects of family functioning are adversely affected by having a child with mental illness in the family. It should be considered that parental mental HRQoL may be improved through enhancing existing family strengths and resources through interventions such as family-centered care and family psychoeducation.

Family dysfunction and low parental HRQoL are both related to poorer outcomes in their ill children including worse long-term response to medication and treatment (Chazan et al., 2011; Crawford & Manassis, 2001), lower child QoL (Eiser et al., 2005; van der Kolk et al., 2014), more symptoms and greater severity of mental disorder (Browne et al., 2013; Hughes et al., 2008), and poorer overall functioning (Hughes et al., 2008). Low HRQoL in parent caregivers is also associated with poor parenting practices and impaired ability to care for their children, which may in turn impact child and family health outcomes (Chen et al., 2014; Lee et al., 2009). Family-centered interventions such as family-centered care, family psychoeducation, and support groups for parents have demonstrated to be effective at reducing patient readmissions, improving caregiver and patient HRQoL, and decreasing caregiver anxiety and depression (M. Park et al., 2018; Verma et al., 2019; Douma et al., 2021). Further implementation of these interventions is recommended in order to support the health of the caregiver, ill child, and the rest of the family.

As healthcare professionals have been previously reluctant to implement family-centered practices within child psychiatry due to various barriers (Osher & Osher, 2002; Skärsäter et al., 2018; MacKean et al., 2012; Skundberg-Kletthagen et al., 2020), this study highlights the probable benefits that increased implementation of these practices would have on family health outcomes. Greater awareness of the important role that the family can play in improving the patient's health by clinicians will conceivably lead to increased involvement of family members in interventions. It has been previously suggested that healthcare professionals consider

conducting assessments on all family members to monitor their HRQoL and mental health (Zhang et al., 2020) in order to promote better family health.

5.3.2.1 Association between Parental Psychological Distress and Parental Mental HRQoL.

As seen with physical HRQoL, greater parental psychological distress was related to poorer parental mental HRQoL. This is consistent with previous research; in a clinical study of primary caregivers of individuals with mental illness, greater symptoms of depression were associated with poorer HRQoL in psychological wellbeing (Jeyagurunathan et al., 2017). Greater symptoms of anxiety in caregivers were only affiliated with reduced HRQoL in social relationships (Jeyagurunathan et al., 2017). Alternatively, in family caregivers of youth with obsessive-compulsive disorder, greater anxiety and depressive symptoms were correlated with poorer HRQoL (Wu et al., 2018). In addition, caregiver symptoms of depression were the only significant predictor of their HRQoL (Wu et al., 2018). It has been proposed that greater caregiver burden may be related to the development of psychiatric illness and poorer HRQoL (Cicek et al., 2013). The association between increased parental psychological distress and worse parental mental HRQoL suggests that strains related to caring and the child's mental illness may have taken a toll on parental mental health, which in turn decreased their mental HRQoL. This has been suggested in previous research (Jeyagurunathan et al., 2017; Angermeyer et al., 2006). It is also possible that low parental mental HRQoL led to the development of greater psychological distress in parent caregivers. As psychological distress and mental HRQoL are similar concepts, it is possible that there is shared variance between these variables, although it is important to emphasize that they are separate constructs. Psychological distress has been defined as the unique unsettling emotional state experienced in response to a specific stressor that causes

harm, either temporary or permanent, while mental HRQoL includes mental functioning and well-being (Ridner, 2004; Hays & Reeve, 2008).

Future research should investigate relationships between caregiver burden, psychological distress, and HRQoL among family caregivers. It is unclear whether increased psychological distress in caregivers negatively impacts their HRQoL, whether decreased HRQoL leads to symptoms of psychiatric illness in caregivers, or if these constructs impact one another. Therefore, it is recommended that clinicians monitor both of these outcomes in at-risk family caregivers and tailor interventions appropriately.

As greater psychiatric symptoms and worse HRQoL in family caregivers can subsequently negatively impact child clinical prognosis (Chazan et al., 2011; Lee et al., 2009; Agha et al., 2017), it is suggested that treatments for children involve families to promote the health of all family members. This finding supports the increased development, research, and implementation of novel and accessible interventions that strive to improve family caregivers' psychological wellbeing and HRQoL. As family psychoeducation, support groups for caregivers, family therapy, and FCC have demonstrated to improve caregiver outcomes including HRQoL and levels of psychological distress, and patient outcomes such as better recovery and functioning (M. Park et al., 2018; Verma et al., 2019; Douma et al., 2021; MacKean, 2012; Foroughe et al., 2019), improved and increased uptake of these interventions is recommended.

5.4 Objective 3

None of the assessed potential effect modifiers—externalizing disorder in the child, child age, child sex, and parent psychological distress—were significant in augmenting the associations between family functioning and parental physical and mental HRQoL. These findings are not accordant with our hypotheses; it is possible that this result is due to the small sample size in the

current study. Since no interactions were detected, it is possible the associations between family functioning and parental physical and mental HRQoL were not directly impacted by these proposed moderators.

Similar to our results, child age did not moderate the association between family leisure and family quality of life in a meta-analysis (Hodge et al., 2017). In contrast, sex of spouse significantly moderated the association between family communication and HRQoL in cancer caregivers (Lim & Shon, 2018). No known previous research has assessed these moderators in this target population, therefore future research is needed to further explore these variables and other possible mediators and moderators of these associations in larger clinical samples.

5.5 Application to Theoretical Framework – Pearlin’s Stress Process Model

Our findings partially support our proposed theoretical framework that was based on Pearlin’s Stress Process Model (Pearlin et al., 1981; Pearlin et al., 1990; Ferro, 2015). The association between family functioning and parental physical HRQoL was non-significant, which was not consistent with our hypothesis or some previous research. The relationship between family functioning and parental mental HRQoL was significant, which provides partial support for our theoretical framework. We were able to account for several parent and child sociodemographic and clinical variables which provides stronger support for the proposed theoretical model. Due to the use of reliable and valid measures to measure family functioning and HRQoL, it is likely that the association between family functioning and parental mental HRQoL is robust. Therefore, this provides stronger evidence that family mechanisms are related to parental mental HRQoL in clinical families, and that aiming to improve family functioning may subsequently support the HRQoL of family caregivers. As the results only provide moderate support for our proposed theoretical model, further research is needed to explore additional

relevant factors impacting these associations, such as secondary stressors and mediators that are part of Pearlin's Stress Process Model, including job-caregiving conflict, self-esteem, mastery, social support, and coping mechanisms (Pearlin et al., 1990).

5.6 Implications for Public Health and Clinical Interventions

5.6.1 Family-Centered Care

Family-centered care aims to share and build on existing knowledge, strategies, and resources the family uses (MacKean et al., 2012). Continued uptake of FCC within child psychiatry care settings is important to improve family functioning and the HRQoL of parent caregivers, and in turn the health of the whole family. Increased knowledge and support from FCC can positively affect parents' abilities to care for their children, leading to better health for all family members, including lower family stress, increased well-being of the child and family, and better responses to treatment and functioning in the child (MacKean, 2012).

Implementation of FCC in child psychiatry is relatively new compared to other fields, and there is an existing gap between research and practice (Chou et al., 2014). Following increased uptake of FCC in Canada, some family members have reported a continuing lack of support, sharing of information, and aims to collaborate from healthcare workers (McNeil, 2013). Families noted difficulties due to confidentiality, lack of funding, and discrimination from healthcare workers, although family members did not label discrimination as so (McNeil, 2013). In addition, poor quality of FCC has been associated with worse HRQoL of family caregivers (Hsiao et al., 2017). Therefore, greater education of healthcare professionals on how FCC should be best implemented is recommended to support the continued uptake of FCC in Canada. It has been previously suggested that clinical practitioners continue to aim to shift their values to view

the family as a resource with vital skills, knowledge, and experiences of what is helpful (Skundberg-Kletthagen et al., 2020).

As the delivery of psychiatry services including FCC transitions to being primarily online due to COVID-19, it is important that health professionals are aware of difficulties that can arise including possible information loss, communication problems, and difficulties in building the therapeutic alliance (Matheson et al., 2020). In addition, healthcare providers must mitigate the additional barriers that online delivery can create for families who may not have reliable access to internet or who may lack technology literacy by making appropriate accommodations (Hart et al., 2020). Mental health professionals should be provided with additional strategies and resources to effectively deliver FCC in an online format during the COVID-19 pandemic.

5.6.2 Family Psychoeducation

Family psychoeducation interventions provide information about the illness, emotional and practical supports, and tips to improve crisis management and problem-solving skills (Dixon et al., 2000). As the majority of these interventions have been for caregivers of individuals with schizophrenia or bipolar disorder (Yesufu-Udechuku et al., 2015), development of these interventions for other mental illnesses is recommended. Greater caregiver knowledge of the illness through psychoeducation has been previously associated with lower family burden and enhanced patient recovery in individuals with schizophrenia (Ribé et al., 2018). Less family dysfunction and tension and more positive family member attitudes have also been reported as outcomes of psychoeducation (Richardson et al., 2013).

Family psychoeducation can improve caregiver wellbeing, which is associated with increased capacity to provide appropriate support, that can subsequently positively impact patient prognosis (Sin et al., 2017). Due to the likely improvements in several caregiver, family, and

patient factors through participation in family psychoeducation, it is suggested this intervention be considered by healthcare professionals for families with a child with an internalizing disorder. In the context of COVID-19, studies have already demonstrated that telehealth interventions for family caregivers are effective at enhancing caregiver outcomes including psychological health, satisfaction with interventions, knowledge or skills, QoL and social support (Chi & Demiris, 2014).

5.6.3 Support Groups

Online support groups are recommended as another possible intervention for parent caregivers. Support groups have demonstrated to be effective at decreasing psychological distress and improving caregiving experiences in this target population, although the overall quality of evidence in previous studies was low, and future research is needed (Yesufu-Udechuku et al., 2015). Support groups are already well developed to be delivered online (Friedman et al., 2018), facilitating the transition to being delivered primarily online during the COVID-19 pandemic. Benefits of online support groups have already been identified, including greater time flexibility, having found writing therapeutic after a difficult event, and improved relationships with their children (Perron, 2002; Baum, 2004). Online support groups have also demonstrated to be effective at improving social isolation and increasing companionship in family caregivers (Friedman et al., 2018), which may be more important throughout the pandemic (Gallagher & Wetherell, 2020). An online group intervention for parents using cognitive behavioural therapy was associated with decreased parental anxiety and depression over time in comparison to a waitlist control group (Douma et al., 2021). Future studies are needed to affirm the effectiveness of online support groups for parent caregivers of children with various mental illnesses.

Previous research has demonstrated that family caregivers with more caregiving demands and strains were more likely to use online peer support groups (Friedman et al., 2018). This may differ in the context of the pandemic, as a study reported that 60% of family caregivers experiencing depressive symptoms did not access any form of psychological support (Gallagher & Wetherell, 2020). Increased efforts should be made by healthcare professionals to identify and monitor at-risk parent caregivers and ensure that they have quick access to supports, such as online support groups. As an online intervention may be more accessible and time-flexible for some, it is hoped that more family caregivers will utilize this intervention to help mitigate the negative impacts of caregiving on caregiver, child, and family health outcomes.

5.6.4 Other Interventions

Child psychotherapy programs with parent support, such as The Incredible Years Program, the Triple P, and Coping Power should be considered as possible interventions (Webster-Stratton, 2016; Turner & Sanders, 2006; Lochman & Wells, 2002). Child psychotherapy involving parents has demonstrated to be more effective in improving treatment outcomes than therapy only involving children (Dowell & Ogles, 2010). Parent participation engagement in treatment is associated with better child functioning and less impairment (Haine-Schlagel & Walsh, 2015).

Various family therapies are recommended for families with a child with mental illness. As previously mentioned, Emotion-Focused Family Therapy is a relatively novel intervention that has demonstrated to improve both parent and child health outcomes (Foroughe et al., 2019). Functional Family Therapy is an established intervention involving cognitive behavioural therapy to alleviate family dysfunction, and is effective for adolescent conduct disorder, juvenile delinquency, and substance abuse (Alexander et al., 2013; Limoncelli et al., 2019). Functional

Family Therapy has been helpful in increasing the self-efficacy, psycho-social functioning, and communication skills of family members (Limoncelli et al., 2019).

Interventions aimed at parents have demonstrated to be effective in enhancing child and parent health. Parents Plus programs are parent training group interventions that may improve child behaviour, goal attainment, and parent satisfaction, while reducing parental stress (Carr et al., 2017). Parent-based interventions have shown to benefit child behaviour in children with externalizing behaviour issues (Mingebach et al., 2018). Mindfulness interventions for parents can reduce parenting stress and in turn improve child externalizing and cognitive outcomes (Burgdorf et al., 2019).

5.7 Strengths and Limitations

There are several strengths of the current study. First, several gaps in the literature have been addressed, including the lack of literature on Canadian parent caregivers in clinical samples (Cappe et al., 2018), lack of previous work assessing broad clinical samples of children with comorbid mental illnesses, and limited research on parents of children with mental illnesses such as MDD and GAD. Although comorbidity is the norm in child psychiatry (Willner et al., 2016), few previous studies have assessed samples of families of children with co-occurring mental illnesses. The current study filled this gap by assessing parents from a clinical sample where the majority of children had comorbid mental disorders. In addition, as the sample consisted of children with various internalizing and externalizing disorders receiving inpatient or outpatient care, it is possible that the results will generalize to parents of children receiving tertiary care within Ontario. The ability to include many relevant covariates allowed us to generate adjusted and unbiased associations between family functioning and parental physical and mental HRQoL. As the SF-36 is the most widely validated instrument used to measure HRQoL (Contopoulos-

Ioannidis et al., 2009), it is likely that the estimates of parental HRQoL are valid and robust. The measure of family functioning used is also a valid and reliable measure for use in this population (Kabacoff et al., 1990; Byles et al., 1988), thus it is probable that the observed significant association is accurate. Since very few assessments of parental HRQoL have been previously conducted in Canada, it is hoped that this research will bring attention to this issue from relevant stakeholders, in order to support the increased uptake and improvement of family-centered practices including FCC and family psychoeducation in child psychiatry care settings within Canada.

There are also limitations to consider when interpreting our findings. First, several variables of interest were unable to be measured due to the secondary nature of the data, including caregiver burden, marital satisfaction, physical outcomes such as physical morbidities and limitations, and other family members' HRQoL and functioning. This limits the applicability of the findings, as the impact that these unmeasured factors may have on these associations remains unknown. Second, the direction of effects was not able to be established, therefore it is unclear whether family functioning was directly impacting parental mental HRQoL, vice versa, or if there was a bidirectional association. Third, only certain common mental disorders were screened, and therefore it is difficult to apply the findings to parents of children with other mental illnesses such as bipolar disorder or eating disorders. Fourth, the generalizability and representativeness of the sample are limited as the majority of participants were from white, middle- or upper-class families. As low socioeconomic status is related to higher proportions of adverse childhood experiences (Mersky et al., 2013), it is possible that the study underrepresented families experiencing high levels of adversities and environmental stress.

In light of the strengths and limitations, the results of this study support further improvement and implementation of interventions such as FCC, family psychoeducation, and parent support groups in child psychiatry settings. By aiming to support caregiver HRQoL through family-focused practices, it is likely that enhancements in caregiver HRQoL will also positively impact child and family health, which has been demonstrated in previous research (MacKean et al., 2012).

5.8 Future Directions

5.8.1 Other Family Members

Future studies can assess possible discrepancies in family functioning between family members, and how this may differentially influence health outcomes in various family members. Additionally, future research should investigate the role that other family members, such as siblings and grandparents, may play as additional caregivers, how their HRQoL may be impacted, and how their role can influence the functioning and health of the rest of the family. Subsequent research should examine the effects of family-centered care and other family-centered interventions on other family members, including on sibling functioning and health.

5.8.2 COVID-19 Implications

Future studies should assess the repercussions that the COVID-19 pandemic has on parent caregivers of children with mental illness. Approximately one-third of families surveyed in Canada have stated that they feel very or extremely worried about family stress due to shelter in place COVID-19 restrictions (Statistics Canada, 2020), it is important to investigate the presumably unique consequences that the pandemic is having on families with a child with a mental illness. Due to the likely increases in caregiving stressors from the social and economic consequences of the pandemic, caregiver HRQoL could impact dyads within the family, and in

turn overall family functioning (Prime et al., 2020). As mental healthcare moves primarily to an online format due to COVID-19, a change that is likely to remain (Matheson et al., 2020), it is important to assess whether outcomes of family-focused practices delivered online differ from those previously delivered in person.

5.8.3 Family-Centered Care

It has been previously recommended that the core values of FCC (dignity and respect, information sharing, participation, and collaboration) be integrated within research goals to aim to actively involve children and their families in research (MacKean et al., 2012). By continuing to amplify the voices of children and their families, it is hoped that researchers, educators, healthcare professionals, and policy makers will value families as collaborators who bring important solutions to the table (MacKean et al., 2012). The Institute of Families for Child and Youth Mental Health has hosted a research forum where families and children worked with researchers, health professionals, and policy makers to establish future research goals (Davidson et al., 2010). It is recommended that similar organizations strive to increase collaboration between all relevant stakeholders, in an effort to address this issue at all levels.

5.8.4 Variations between Disorders

Future research should aim to identify variations in family functioning and parental HRQoL in broad clinical samples to examine which domains of family functioning and physical and mental HRQoL are most impacted in caring for children with certain mental illnesses (e.g., GAD vs. MDD) and distinct clinical profiles (e.g., internalizing, externalizing, or comorbid). As this study demonstrated that a child externalizing disorder is associated with poorer parental physical HRQoL, further research should assess mechanisms influencing this association and examine whether comorbidities play a role in impacting the HRQoL of caregivers.

5.8.5 Mediating Effects

Future research should assess possible mediating effects in the associations between family functioning and parental physical and mental HRQoL, such as caregiver burden, marital satisfaction, child comorbidity status, and variables from Pearlin's Stress Process Model including job-caregiving conflict, self-esteem, mastery, social support, and coping mechanisms. By exploring these variables as possible mediating effects, the theoretical model can be further refined and supported for use in subsequent research.

Conclusion

The results of this study demonstrate that parent caregivers of children with mental illness from a clinical sample report significantly poorer physical and mental HRQoL than Canadian populations norms. This demonstrates that parents of children receiving tertiary care may be struggling with their own health due to caregiving and associated stressors. Additionally, the results suggest that family functioning is associated with parental mental HRQoL, although not parental physical HRQoL. This is important to consider for clinical implications, as interventions aimed at improving family functioning may be effective to increase parental mental HRQoL, but not parental physical HRQoL. Clinical interventions such as family-centered care, family therapy, and family psychoeducation as well as caregiver-oriented interventions such as support groups are important to enhance family functioning and parental HRQoL. Other interventions such as exercise and parent support groups may be effective in promoting improved parental HRQoL, although more research is needed.

References

- Aaronson, N. K., Acquadro, C., Alonso, J., Apolone, G., Bucquet, D., Bullinger, M., Bungay, K., Fukuhara, S., Gandek, B., Keller, S., Razavi, D., Sanson-Fisher, R., Sullivan, M., Wood-Dauphinee, S., Wagner, A., & Ware, J. E. (1992). International quality of life assessment (IQOLA) project. *Quality of Life Research, 1*(5), 349–351.
<https://doi.org/10.1007/BF00434949>
- Aarti, Ruchika, Kumar, R., & Varghese, A. (2019). Depression and quality of life in family caregivers of individuals with psychiatric illness. *International Journal Of Community Medicine And Public Health, 6*(2), 715. <https://doi.org/10.18203/2394-6040.ijcmph20190196>
- Abidin, R. R. (1983). *Parenting Stress Index: Manual, Administration Booklet, [and] Research Update*. Pediatric Psychology Press.
- Abidin, R. R. (1997). *Parenting Stress Index: A measure of the parent–child system*. In C. P. Zalaquett & R. J. Wood (Eds.), *Evaluating stress: A book of resources* (pp. 277–291). Scarecrow Education.
- Agha, S. S., Zammit, S., Thapar, A., & Langley, K. (2017). Maternal psychopathology and offspring clinical outcome: a four-year follow-up of boys with ADHD. *European Child & Adolescent Psychiatry, 26*(2), 253–262. <https://doi.org/10.1007/s00787-016-0873-y>
- Albert, U., Salvi, V., Saracco, P., Bogetto, F., & Maina, G. (2007). Health-related quality of life among first-degree relatives of patients with obsessive-compulsive disorder in Italy. *Psychiatric Services, 58*(7), 970–976. <https://doi.org/10.1176/ps.2007.58.7.970>
- Alexander, J. F., Waldron, H. B., Robbins, M. S., & Neeb, A. A. (2013). Research on FFT Outcomes. In *Functional Family Therapy for Adolescent Behavior Problems* (p. 37–62). American Psychological Association. <https://doi.org/10.2307/j.ctv1chs69t.6>

- Anastasiadou, D., Sepulveda, A. R., Sánchez, J. C., Parks, M., Álvarez, T., & Graell, M. (2016). Family Functioning and Quality of Life among Families in Eating Disorders: A Comparison with Substance-related Disorders and Healthy Controls. *European Eating Disorders Review, 24*(4), 294–303. <https://doi.org/10.1002/erv.2440>
- Anastopoulos, A. D., Guevremont, D. C., Shelton, T. L., & Dupaul, G. J. (1992). Journal of Abnormal Child Psychology, 20, 503-520. *Journal of Abnormal Child Psychology, 20*, 503–520. <https://doi.org/10.1007/BF00916812>
- Andrade, E. M., Geha, L. M., Duran, P., Suwwan, R., Machado, F., & do Rosário, M. C. (2016). Quality of life in caregivers of ADHD children and diabetes patients. *Frontiers in Psychiatry, 7*, 7–12. <https://doi.org/10.3389/fpsy.2016.00127>
- Angermeyer, M. C., Kilian, R., Wilms, H. U., & Wittmund, B. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry, 52*(3), 278–285. <https://doi.org/10.1177/0020764006067186>
- Armstrong, M. I., Birnie-Lefcovitch, S., & Ungar, M. T. (2005). Pathways between social support, family well being, quality of parenting, and child resilience: What we know. *Journal of Child and Family Studies, 14*(2), 269–281. <https://doi.org/10.1007/s10826-005-5054-4>
- Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers: A review. *PharmacoEconomics, 26*(2), 149–162. <https://doi.org/10.2165/00019053-200826020-00005>
- Azazy, S., Nour-Eldein, H., Salama, H., & Ismail, M. (2018). Quality of life and family function of parents of children with attention deficit hyperactivity disorder. *Eastern Mediterranean Health Journal, 24*(6), 579-87. <https://doi.org/10.26719/2018.24.6.579>

- Barnett, R. A., & Hunter, M. (2012). Adjustment of Siblings of Children with Mental Health Problems: Behaviour, Self-Concept, Quality of Life and Family Functioning. *Journal of Child and Family Studies*, 21(2), 262–272. <https://doi.org/10.1007/s10826-011-9471-2>
- Baum, L. S. (2004). Internet parent support groups for primary caregivers of a child with special health care needs. *Pediatric nursing*, 30(5), 381-401.
- Beauchaine, T. P., & McNulty, T. (2013). Comorbidities and continuities as ontogenic processes: toward a developmental spectrum model of externalizing psychopathology. *Development and psychopathology*, 25(4 Pt 2), 1505–1528. <https://doi.org/10.1017/S0954579413000746>
- Bell, J. M. (2013). Family Nursing Is More Than Family Centered Care. *Journal of Family Nursing*, 19(4), 411–417. <https://doi.org/10.1177/1074840713512750>
- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial Psychometric Evidence. *Journal of Social and Personal Relationships*, 12(3), 463–472. <https://doi.org/10.1177/0265407595123009>
- Berzon, R., Hays, R. D., & Shumaker, S. A. (1993). International use, application and performance of health-related quality of life instruments. *Quality of Life Research*, 2(6), 367–368. <https://doi.org/10.1007/BF00422214>
- Biederman, J., Faraone, S. V., Mick, E., Williamson, S., Wilens, T. E., Spencer, T. J., Weber, W., Jetton, J., Kraus, I., Pert, J., & Zallen, B. (1999). Clinical correlates of ADHD in females: Findings from a large group of girls ascertained from pediatric and psychiatric referral sources. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38(8), 966–975. <https://doi.org/10.1097/00004583-199908000-00012>
- Biederman, J., Milberger, S., Faraone, S. V., Kiely, K., Guite, J., Mick, E., Ablon, S., Warburton, R., & Reed, E. (1995). Family-Environment Risk Factors for Attention-Deficit

- Hyperactivity Disorder: A Test of Rutter's Indicators of Adversity. *Archives of General Psychiatry*, 52(6), 464–470. <https://doi.org/10.1001/archpsyc.1995.03950180050007>
- Biederman, J., Munir, K., Knee, D., Armentano, M., Autor, S., Waternaux, C., & Tsuang, M. (1987). High rate of affective disorders in probands with attention deficit disorder and in their relatives: a controlled family study. *American Journal of Psychiatry*, 144(3), 330-3. <https://doi.org/10.1176/ajp.144.3.330>
- Bögels, S. M., & Brechman-Toussaint, M. L. (2006). Family issues in child anxiety: Attachment, family functioning, parental rearing and beliefs. *Clinical Psychology Review*, 26(7), 834–856. <https://doi.org/10.1016/j.cpr.2005.08.001>
- Bowen, M. (1978). Family therapy in clinical practice. Aronson.
- Breinholst, S., Esbjørn, B. H., Reinholdt-Dunne, M. L., & Stallard, P. (2012). CBT for the treatment of child anxiety disorders: A review of why parental involvement has not enhanced outcomes. *Journal of Anxiety Disorders*, 26(3), 416–424. <https://doi.org/10.1016/j.janxdis.2011.12.014>
- Browne, D., Verticchio, D., Shlonsky, A., Thabane, L., Hoch, J., & Byrne, C. (2010). The family standpoint of investigation: Examining the correlates and costs of parental stress in a sample of families involved with Ontario child welfare. *Canadian Journal of Community Mental Health*, 29(2), 131–154. <https://doi.org/10.7870/cjcmh-2010-0027>
- Browne, D. T., Norona, J., Busch, A., Armstrong, K., Crouch, S., Ernst, T., Darrow, S., Smith, J. A., & Ihle, E. C. (2020). “Is it us or is it me?”: Family experiences of connectedness following a reflecting team intervention. *Journal of Marital and Family Therapy*. <https://doi.org/https://doi.org/10.1111/jmft.12468>
- Browne, D. T., Plamondon, A., Prime, H., Puente-Duran, S., & Wade, M. (2015). Cumulative

risk and developmental health: an argument for the importance of a family-wide science. *Wiley Interdisciplinary Reviews: Cognitive Science*, 6(4), 397–407.

<https://doi.org/10.1002/wcs.1349>

Browne, D. T., Rokeach, A., Wiener, J., Hoch, J. S., Meunier, J. C., & Thurston, S. (2013).

Examining the Family-Level and Economic Impact of Complex Child Disabilities as a Function of Child Hyperactivity and Service Integration. *Journal of Developmental and Physical Disabilities*, 25(2), 181–201. <https://doi.org/10.1007/s10882-012-9295-z>

Burgdorf, V., Szabó, M., & Abbott, M. J. (2019). The effect of mindfulness interventions for parents on parenting stress and youth psychological outcomes: A systematic review and meta-analysis. *Frontiers in Psychology*, 10(June). <https://doi.org/10.3389/fpsyg.2019.01336>

Byles, J., Byrne, C., Boyle, M. H., & Offord, D. R. (1988). Ontario Child Health Study:

Reliability and Validity of the General Functioning Subscale of the McMaster Family Assessment Device. *Family Process*, 27(1), 97–104. <https://doi.org/10.1111/j.1545-5300.1988.00097.x>

Byrne, C., Browne, G., Roberts, J., Mills, M., Bell, B., Gafni, A., Jamieson, E., & Webb, M.

(2006). Changes in children's behavior and costs for service use associated with parents' response to treatment for dysthymia. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(2), 239–246.

<https://doi.org/10.1097/01.chi.0000190351.13818.d7>

Canadian Institute for Health Information. (2019). *Health System Resources for Mental Health and Addictions Care in Canada*. <https://www.cihi.ca/sites/default/files/document/mental-health-chartbook-report-2019-en-web.pdf>

Canadian Mental Health Association. (2018). *Mental Health in the Balance: Ending the Health*

Care Disparity in Canada. <https://cmha.ca/wp-content/uploads/2018/09/CMHA-Parity-Paper-Full-Report-EN.pdf>

- Cappe, E., Bolduc, M., Rougé, M. C., Saiag, M. C., & Delorme, R. (2017). Quality of life, psychological characteristics, and adjustment in parents of children with Attention-Deficit/Hyperactivity Disorder. *Quality of Life Research*, *26*(5), 1283–1294. <https://doi.org/10.1007/s11136-016-1446-8>
- Cappe, É., Poirier, N., Sankey, C., Belzil, A., & Dionne, C. (2018). Quality of life of French Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors. *Quality of Life Research*, *27*(4), 955–967. <https://doi.org/10.1007/s11136-017-1757-4>
- Caqueo-Urizar, A., Alessandrini, M., Urzúa, A., Zendjidjian, X., Boyer, L., & Williams, D. R. (2017). Caregiver's quality of life and its positive impact on symptomatology and quality of life of patients with schizophrenia. *Health and Quality of Life Outcomes*, *15*(1), 1–9. <https://doi.org/10.1186/s12955-017-0652-6>
- Caqueo-Urizar, A., & Gutiérrez-Maldonado, J. (2006). Burden of care in families of patients with schizophrenia. *Quality of Life Research*, *15*(4), 719–724. <https://doi.org/10.1007/s11136-005-4629-2>
- Caqueo-Urizar, A., Rus-Calafell, M., Urzúa, A., Escudero, J., & Gutiérrez-Maldonado, J. (2015). The role of family therapy in the management of schizophrenia: Challenges and solutions. *Neuropsychiatric Disease and Treatment*, *11*, 145–151. <https://doi.org/10.2147/NDT.S51331>
- Caron, C., & Rutter, M. (1991). Comorbidity in Child Psychopathology: Concepts, Issues and Research Strategies. *Journal of Child Psychology and Psychiatry*, *32*(7), 1063–1080.

<https://doi.org/10.1111/j.1469-7610.1991.tb00350.x>

Carr, A., Hartnett, D., Brosnan, E., & Sharry, J. (2017). Parents Plus Systemic, Solution-Focused

Parent Training Programs: Description, Review of the Evidence Base, and Meta-Analysis.

Family Process, 56(3), 652–668. <https://doi.org/https://doi.org/10.1111/famp.12225>

Centre for Addiction and Mental Health. (2016). *Mental Health and Primary Care Policy*

Framework. [https://www.camh.ca/-/media/files/pdfs---public-policy-](https://www.camh.ca/-/media/files/pdfs---public-policy-submissions/primarycarepolicyframework_march2016-pdf.pdf)

[submissions/primarycarepolicyframework_march2016-pdf.pdf](https://www.camh.ca/-/media/files/pdfs---public-policy-submissions/primarycarepolicyframework_march2016-pdf.pdf)

Chang, H. Y., Chiou, C. J., & Chen, N. S. (2010). Impact of mental health and caregiver burden

on family caregivers' physical health. *Archives of Gerontology and Geriatrics*, 50(3), 267–

271. <https://doi.org/10.1016/j.archger.2009.04.006>

Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: Examining the

distinction. *Gerontologist*, 42(6), 772–780. <https://doi.org/10.1093/geront/42.6.772>

Chazan, R., Borowski, C., Pianca, T., Ludwig, H., Rohde, L. A., & Polanczyk, G. (2011). Do

phenotypic characteristics, parental psychopathology, family functioning, and

environmental stressors have a role in the response to methylphenidate in children with

attention-deficit/hyperactivity disorder?: A naturalistic study from a developing coun.

Journal of Clinical Psychopharmacology, 31(3), 309–317.

<https://doi.org/10.1097/JCP.0b013e318217b4df>

Chen, V. C. H., Yeh, C. J., Lee, T. C., Chou, J. Y., Shao, W. C., Shih, D. H., Chen, C. I., & Lee,

P. C. (2014). Symptoms of attention deficit hyperactivity disorder and quality of life of

mothers of school-aged children: The roles of child, mother, and family variables.

Kaohsiung Journal of Medical Sciences, 30(12), 631–638.

<https://doi.org/10.1016/j.kjms.2014.09.001>

- Chi, N.C., & Demiris, G. (2014). A systematic review of telehealth tools and interventions to support family caregivers. *Journal of Telemedicine and Telecare*, 21(1), 37–44.
<https://doi.org/10.1177/1357633X14562734>
- Chien, W. T., & Norman, I. (2009). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review. *International Journal of Nursing Studies*, 46(12), 1604–1623.
<https://doi.org/10.1016/j.ijnurstu.2009.04.003>
- Child and Adolescent Mental Health Services. (2008). *Children and young people in mind: The final report of the national CAMHS review*. https://dera.ioe.ac.uk/10845/1/dh_090398.pdf
- Cicek, E., Cicek, I. E., Kayhan, F., Uguz, F., & Kaya, N. (2013). Quality of life, family burden and associated factors in relatives with obsessive-compulsive disorder. *General Hospital Psychiatry*, 35(3), 253–258. <https://doi.org/10.1016/j.genhosppsych.2013.01.004>
- Clark, R. E., & Drake, R. E. (1994). Expenditures of time and money by families of people with severe mental illness and substance use disorders. *Community Mental Health Journal*, 30(2), 145–163. <https://doi.org/10.1007/BF02188626>
- CMHA BC Division. (2014). *Mental Illnesses in Children and Youth*.
<https://cmha.bc.ca/documents/mental-illnesses-in-children-and-youth-2/>
- Contopoulos-Ioannidis, D. G., Karvouni, A., Kouri, I., & Ioannidis, J. P. A. (2009). Reporting and interpretation of SF-36 outcomes in randomised trials: Systematic review. *BMJ (Online)*, 338(7687), 152–154. <https://doi.org/10.1136/bmj.a3006>
- Cook, J. A., Lefley, H. P., Pickett, S. A., & Cohler, B. J. (1994). Age and family burden among parents of offspring with severe mental illness. *American journal of orthopsychiatry*, 64(3), 435–447. <https://doi.org/10.1037/h0079535>

- Cooper, P. J., Fearn, V., Willetts, L., Seabrook, H., & Parkinson, M. (2006). Affective disorder in the parents of a clinic sample of children with anxiety disorders. *Journal of Affective Disorders, 93*(1-3), 205–212. <https://doi.org/10.1016/j.jad.2006.03.017>
- Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health, 13*(6), 537–548. <https://doi.org/10.1080/09638230400017004>
- Cosgrove, V. E., Rhee, S. H., Gelhorn, H. L., Boeldt, D., Corley, R. C., Ehringer, M. A., Young, S. E., & Hewitt, J. K. (2011). Structure and etiology of co-occurring internalizing and externalizing disorders in adolescents. *Journal of abnormal child psychology, 39*(1), 109–123. <https://doi.org/10.1007/s10802-010-9444-8>
- Crawford, A. M., & Manassis, K. (2001). Familial predictors of treatment outcome in childhood anxiety disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(10), 1182–1189. <https://doi.org/10.1097/00004583-200110000-00012>
- Cumsille, P. E., & Epstein, N. (1994). Family Cohesion, Family Adaptability, Social Support, and Adolescent Depressive Symptoms in Outpatient Clinic Families. *Journal of Family Psychology, 8*(2), 202–214. <https://doi.org/10.1037/0893-3200.8.2.202>
- Cussen, A., Sciberras, E., Ukoumunne, O. C., & Efron, D. (2012). Relationship between symptoms of attention-deficit/hyperactivity disorder and family functioning: A community-based study. *European Journal of Pediatrics, 171*(2), 271–280. <https://doi.org/10.1007/s00431-011-1524-4>
- Danielson, C. B., Bissell, B. H., & Fry, P. W. (1993). *Families, health, and illness: Perspectives on coping and intervention*. Mosby.
- Davidson, J., Anderson, K., & Kutcher, S. (2010). *Child & youth mental health day research*

forum. <https://familysmart.ca/files/Research-Forum-2010.pdf>

Delacre, M., Lakens, D., & Leys, C. (2017). Why psychologists should by default use Welch's t-test instead of Student's t-test. *International Review of Social Psychology*, *30*(1), 92–101.

<https://doi.org/10.5334/irsp.82>

Dey, M., Paz Castro, R., Haug, S., & Schaub, M. P. (2019). Quality of life of parents of mentally-ill children: A systematic review and meta-analysis. *Epidemiology and Psychiatric Sciences*, *28*(5), 563-577. <https://doi.org/10.1017/S2045796018000409>

Diener, E., & Suh, E. (1997). Measuring quality of life: Economic, social, and subjective indicators. *Social Indicators Research*, *40*(1–2), 189–216.

<https://doi.org/10.1023/A:1006859511756>

Dixon, L., Adams, C., & Lucksted, A. (2000). Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin*, *26*(1), 5–20.

<https://doi.org/10.1093/oxfordjournals.schbul.a033446>

Dose, C., Hautmann, C., Bürger, M., Schürmann, S., & Döpfner, M. (2020). Negative parenting behaviour as a mediator of the effects of telephone-assisted self-help for parents of pharmacologically treated children with attention-deficit/hyperactivity disorder. *European Child and Adolescent Psychiatry*. <https://doi.org/10.1007/s00787-020-01565-w>

Dosser, D.A., Handron, D., McCammon, S., & Powell, J.Y. (Eds.). (2001). *Child Mental Health: Exploring Systems of Care in the New Millennium: Exploring Systems of Care in the New Millennium* (1st ed.). The Haworth Press, Inc.

<https://doi.org/10.4324/9781315786155>

Douma, M., Maurice-Stam, H., Gorter, B., Krol, Y., Verkleij, M., Wiltink, L., Scholten, L., & Grootenhuis, M. A. (2021). Online psychosocial group intervention for parents: Positive effects on anxiety and depression. *Journal of Pediatric Psychology*, *46*(2), 123–134.

<https://doi.org/10.1093/jpepsy/jsaa102>

Dowell, K. A., & Ogles, B. M. (2010). The effects of parent participation on child psychotherapy outcome: A meta-analytic review. *Journal of Clinical Child and Adolescent Psychology*, 39(2), 151–162. <https://doi.org/10.1080/15374410903532585>

Duchovic, C. A., Gerkenmeyer, J. E., & Wu, J. (2009). Factors associated with parental distress. *Journal of Child and Adolescent Psychiatric Nursing*, 22(1), 40–48. <https://doi.org/10.1111/j.1744-6171.2008.00168.x>

Easter Seals. (2009). *Easter Seals' living with autism study*. <https://utahparentcenter.org/wp-content/uploads/2015/10/Easter-Seals-Autism-Study.pdf>

Eiser, C., Eiser, J. R., & Stride, C. B. (2005). Quality of life in children newly diagnosed with cancer and their mothers. *Health and Quality of Life Outcomes*, 3, 1–5. <https://doi.org/10.1186/1477-7525-3-29>

Elgar, F. J., Craig, W., & Trites, S. J. (2013). Family Dinners, Communication, and Mental Health in Canadian Adolescents. *Journal of Adolescent Health*, 52(4), 433–438. <https://doi.org/10.1016/j.jadohealth.2012.07.012>

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9(2), 171–180. <https://doi.org/10.1111/j.1752-0606.1983.tb01497.x>

Epstein, N. B., Bishop, D. S., & Levin, S. (1978). The McMaster Model of Family Functioning. *Journal of Marital and Family Therapy*, 4(4), 19–31. <https://doi.org/10.1111/j.1752-0606.1978.tb00537.x>

Esposito-Smythers, C., Birmaher, B., Valeri, S., Chiappetta, L., Hunt, J., Ryan, N., Axelson, D., Strober, M., Leonard, H., Sindelar, H., & Keller, M. (2006). Child comorbidity, maternal

- mood disorder, and perceptions of family functioning among bipolar youth. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(8), 955–964.
<https://doi.org/10.1097/01.chi.0000222785.11359.04>
- Falkov, A. (2012). *The family model handbook: An integrated approach to supporting mentally ill parents and their children*. Pavilion.
- Farivar, S. S., Cunningham, W. E., & Hays, R. D. (2007). Correlated physical and mental health summary scores for the SF-36 and SF-12 Health Survey, V.1. *Health and Quality of Life Outcomes*, 5, 3–10. <https://doi.org/10.1186/1477-7525-5-54>
- Fattori, A., Neri, L., Bellomo, A., Vaggi, M., Mencacci, C., & Group, the I. S. (2017). Depression severity and concentration difficulties are independently associated with HRQOL in patients with unipolar depressive disorders. *Quality of Life Research*, 26(9), 2459–2469. <https://doi.org/10.1007/s11136-017-1595-4>
- Ferro, M. A. (2015). Mediated moderation of the relation between maternal and adolescent depressive symptoms: role of adolescent physical health. *Social Psychiatry and Psychiatric Epidemiology*, 50(11), 1743–1751. <https://doi.org/10.1007/s00127-015-1103-5>
- Foroughe, M., Stillar, A., Goldstein, L., Dolhanty, J., Goodcase, E. T., & Lafrance, A. (2019). Brief Emotion Focused Family Therapy: An Intervention for Parents of Children and Adolescents with Mental Health Issues. *Journal of Marital and Family Therapy*, 45(3), 410–430. <https://doi.org/https://doi.org/10.1111/jmft.12351>
- Friedman, E. M., Trail, T. E., Vaughan, C. A., & Tanielian, T. (2018). Online peer support groups for family caregivers: Are they reaching the caregivers with the greatest needs? *Journal of the American Medical Informatics Association*, 25(9), 1130–1136.
<https://doi.org/10.1093/jamia/ocy086>

- Friedman, M. M., Bowden, V. R., & Jones, E. (2003). *Family nursing: Research, theory & practice* (5th ed.). Prentice Hall.
- Friedmann, M. S., McDermut, W. H., Solomon, D. A., Ryan, C. E., Keitner, G. I., & Miller, I. W. (1997). Family Functioning and Mental Illness: A Comparison of Psychiatric and Nonclinical Families. *Family Process*, 36(4), 357–367. <https://doi.org/10.1111/j.1545-5300.1997.00357.x>
- Fung, W. Y., & Chien, W. T. (2002). The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Archives of Psychiatric Nursing*, 16(3), 134–144. <https://doi.org/10.1053/apnu.2002.32951>
- Gallagher, S., & Wetherell, M. A. (2020). Risk of depression in family caregivers: unintended consequence of COVID-19. *BJPsych Open*, 6(6), 1–5. <https://doi.org/10.1192/bjo.2020.99>
- George, L. K., & Gwyther, L. P. (1986). Caregiver Well-Being: A Multidimensional Examination of Family Caregivers of Demented Adults. *The Gerontologist*, 26(3), 253–259. <https://doi.org/10.1093/geront/26.3.253>
- Gerkenmeyer, J. E., Perkins, S. M., Scott, E. L., & Wu, J. (2008). Depressive Symptoms Among Primary Caregivers of Children With Mental Health Needs: Mediating and Moderating Variables. *Archives of Psychiatric Nursing*, 22(3), 135–146. <https://doi.org/10.1016/j.apnu.2007.06.016>
- Ginsburg, G. S., Siqueland, L., Masia-Warner, C., & Hedtke, K. A. (2004). Anxiety disorders in children: Family matters. *Cognitive and Behavioral Practice*, 11(1), 28–43. [https://doi.org/https://doi.org/10.1016/S1077-7229\(04\)80005-1](https://doi.org/https://doi.org/10.1016/S1077-7229(04)80005-1)
- Goldberg-Arnold, J. S., Fristad, M. A., & Gavazzi, S. M. (1999). Family psychoeducation: Giving caregivers what they want and need. *Family Relations*, 48(4), 411-417.

<https://doi.org/10.2307/585249>

Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17*(2), 190–198. <https://doi.org/10.1037/0278-6133.17.2.190>

Goodyer, I. M., Herbert, J., Tamplin, A., Secher, S. M., & Pearson, J. (1997). Short-term outcome of major depression: II. Life events, family dysfunction, and friendship difficulties as predictors of persistent disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 36*(4), 474–480. <https://doi.org/10.1097/00004583-199704000-00009>

Griffith, J. L., Griffith, M. E., & Slovik, L. S. (1989). Mind-Body Patterns of Symptom Generation. *Family Process, 28*(2), 137–152. <https://doi.org/https://doi.org/10.1111/j.1545-5300.1989.00137.x>

Grov, E. K., Fosså, S. D., Sørebo, Ø., & Dahl, A. A. (2006). Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden. *Social Science and Medicine, 63*(9), 2429–2439. <https://doi.org/10.1016/j.socscimed.2006.06.008>

Grover, S., & Dutt, A. (2011). Perceived burden and quality of life of caregivers in obsessive-compulsive disorder. *Psychiatry and Clinical Neurosciences, 65*(5), 416–422. <https://doi.org/10.1111/j.1440-1819.2011.02240.x>

Gudmundsson, Ó. Ó., & Tómasson, K. (2002). Quality of life and mental health of parents of children with mental health problems. *Nordic Journal of Psychiatry, 56*(6), 413–417. <https://doi.org/10.1080/08039480260389325>

Gutiérrez-Maldonado, J., & Caqueo-Úrizar, A. (2007). Effectiveness of a psycho-educational intervention for reducing burden in latin american families of patients with schizophrenia.

- Quality of Life Research*, 16(5), 739–747. <https://doi.org/10.1007/s11136-007-9173-9>
- Gutiérrez-Maldonado, J., Caqueo-Úrizar, A., & Kavanagh, D. J. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 40(11), 899–904. <https://doi.org/10.1007/s00127-005-0963-5>
- Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: report of a national study. *Journal of Health and Social Behavior*, 49(3), 301–316. <https://doi.org/10.1177/002214650804900305>
- Haine-Schlagel, R., & Walsh, N. E. (2015). A Review of Parent Participation Engagement in Child and Family Mental Health Treatment. *Clinical Child and Family Psychology Review*, 18(2), 133–150. <https://doi.org/10.1007/s10567-015-0182-x>
- Haley, J. (1987). *The Jossey-Bass social and behavioral science series. Problem-solving therapy (2nd ed.)*. Jossey-Bass.
- Haley, W. E. (2003). Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *The Journal of Supportive Oncology*, 1(Suppl 2), 25–29.
- Hamilton, E., & Carr, A. (2016). Systematic Review of Self-Report Family Assessment Measures. *Family Process*, 55(1), 16–30. <https://doi.org/10.1111/famp.12200>
- Hart, J. L., Turnbull, A. E., Oppenheim, I. M., & Courtright, K. R. (2020). Family-Centered Care During the COVID-19 Era. *Journal of Pain and Symptom Management*, 60(2), e93–e97. <https://doi.org/10.1016/j.jpainsymman.2020.04.017>
- Hays, R. D., & Reeve, B. B. (2008). Measurement and modeling of health-related quality of life. In J. Killewo, H. K. Heggenhougen, & S. R. Quah (Eds.), *Epidemiology and Demography in Public Health* (pp. 195-205). <https://doi.org/10.1016/B978-012373960-5.00336-1>

- Heru, A. M., Ryan, C. E., & Vlastos, K. (2004). Quality of life and family functioning in caregivers of relatives with mood disorders. *Psychiatric Rehabilitation Journal*, 28(1), 67–71. <https://doi.org/10.2975/28.2004.67.71>
- Ho, S. C., Chan, A., Woo, J., Chong, P., & Sham, A. (2009). Impact of caregiving on health and quality of life: A comparative population-based study of caregivers for elderly persons and noncaregivers. *Journals of Gerontology: Series A*, 64A(8), 873–879. <https://doi.org/10.1093/gerona/glp034>
- Hodge, C. J., Duerden, M. D., Layland, E. K., Lacanienta, A., Goates, M. C., & Niu, X. M. (2017). The Association Between Family Leisure and Family Quality of Life: A Meta-Analysis of Data from Parents and Adolescents. *Journal of Family Theory and Review*, 9(3), 328–346. <https://doi.org/10.1111/jftr.12202>
- Högberg, C., Billstedt, E., Björck, C., Björck, P. O., Ehlers, S., Gustle, L. H., Hellner, C., Höök, H., Serlachius, E., Svensson, M. A., & Larsson, J. O. (2019). Diagnostic validity of the MINI-KID disorder classifications in specialized child and adolescent psychiatric outpatient clinics in Sweden. *BMC Psychiatry*, 19(1), 1–10. <https://doi.org/10.1186/s12888-019-2121-8>
- Holtom-Viesel, A., & Allan, S. (2014). A systematic review of the literature on family functioning across all eating disorder diagnoses in comparison to control families. *Clinical Psychology Review*, 34(1), 29–43. <https://doi.org/10.1016/j.cpr.2013.10.005>
- Hopman, W. M., Towheed, T., Anastassiades, T., Tenenhouse, A., Poliquin, S., Berger, C., Joseph, L., Brown, J. P., Murray, T. M., Adachi, J. D., Hanley, D. A., & Papadimitropoulos, E. (2000). Canadian normative data for the SF-36 health survey. *CMAJ*, 163(3), 265–271.
- Hsiao, C. Y., Lee, C. Te, Lu, H. L., & Tsai, Y. F. (2017). Living with schizophrenia: Health-

- related quality of life among primary family caregivers. *Journal of Clinical Nursing*, 26(23–24), 5151–5159. <https://doi.org/10.1111/jocn.14063>
- Hsiao, Y. J. (2016). Pathways to mental health-related quality of life for parents of children with autism spectrum disorder: Roles of parental stress, children's performance, medical support, and neighbor support. *Research in Autism Spectrum Disorders*, 23, 122–130. <https://doi.org/10.1016/j.rasd.2015.10.008>
- Hsiao, Y. J. (2018). Parental Stress in Families of Children With Disabilities. *Intervention in School and Clinic*, 53(4), 201–205. <https://doi.org/10.1177/1053451217712956>
- Huang, Y. P., Chang, M. Y., Chi, Y. L., & Lai, F. C. (2014). Health-related quality of life in fathers of children with or without developmental disability: the mediating effect of parental stress. *Quality of life research*, 23(1), 175–183. <https://doi.org/10.1007/s11136-013-0469-7>
- Hubbard, A. A., McEvoy, P. M., Smith, L., & Kane, R. T. (2016). Brief group psychoeducation for caregivers of individuals with bipolar disorder: A randomized controlled trial. *Journal of Affective Disorders*, 200, 31–36. <https://doi.org/10.1016/j.jad.2016.04.013>
- Hughes, A. A., Hedtke, K. A., & Kendall, P. C. (2008). Family Functioning in Families of Children With Anxiety Disorders. *Journal of Family Psychology*, 22(2), 325–328. <https://doi.org/10.1037/0893-3200.22.2.325>
- Hughes, E. K., & Gullone, E. (2008). Internalizing symptoms and disorders in families of adolescents: A review of family systems literature. *Clinical Psychology Review*, 28(1), 92–117. <https://doi.org/10.1016/j.cpr.2007.04.002>
- Hughes, S. L., Giobbie-Hurder, A., Weaver, F. M., Kubal, J. D., & Henderson, W. (1999). Relationship between caregiver burden and health-related quality of life. *Gerontologist*, 39(5), 534–545. <https://doi.org/10.1093/geront/39.5.534>

- Ipsos. (2017). *Children and Youth Mental Health Survey: Getting Help in Ontario*.
https://www.ipsos.com/sites/default/files/ct/news/documents/2017-11/Children%20and%20Youth%20Mental%20Health%20Survey%20Findings_FINAL_Nov.pdf
- Isa, S. N. I., Aziz, A. A., Rahman, A. A., Ibrahim, M. I., Ibrahim, W. P. W., Mohamad, N., Othman, A., Rahman, N. A., Harith, S., & Van Rostenberghe, H. (2013). The impact of children with disabilities on parent healthrelated quality of life and family functioning in kelantan and its associated factors. *Journal of Developmental and Behavioral Pediatrics*, 34(4), 262–268. <https://doi.org/10.1097/DBP.0b013e318287cdfc>
- Jeyagurunathan, A., Sagayadevan, V., Abdin, E., Zhang, Y. J., Chang, S., Shafie, S., Rahman, R. F. A., Vaingankar, J. A., Chong, S. A., & Subramaniam, M. (2017). Psychological status and quality of life among primary caregivers of individuals with mental illness: A hospital based study. *Health and Quality of Life Outcomes*, 15(1), 1-14.
<https://doi.org/10.1186/s12955-017-0676-y>
- Ji, B., Zhao, I., Turner, C., Sun, M., Yi, R., & Tang, S. (2014). Predictors of health-related quality of life in chinese caregivers of children with autism spectrum disorders: A cross-sectional study. *Archives of Psychiatric Nursing*, 28(5), 327–332.
<https://doi.org/10.1016/j.apnu.2014.06.001>
- Joh, J. Y., Kim, S., Park, J. L., & Kim, Y. P. (2013). Relationship between family adaptability, cohesion and adolescent problem behaviors: Curvilinearity of circumplex model. *Korean Journal of Family Medicine*, 34(3), 169–177. <https://doi.org/10.4082/kjfm.2013.34.3.169>
- Johnson, B. H. (2000). Family-centered care: facing the new millennium. Interview by Elizabeth Ahmann. *Pediatric Nursing*, 26(1), 87–90.

- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism Spectrum Disorder: Parenting Stress, Family Functioning and Health-Related Quality of Life. *Families, Systems and Health, 29*(3), 232–252. <https://doi.org/10.1037/a0025341>
- Johnston, C., & Mash, E. J. (2001). Families of children with attention-deficit/hyperactivity disorder: Review and recommendations for future research. *Clinical Child and Family Psychology Review, 4*(3), 183–207. <https://doi.org/10.1023/A:1017592030434>
- Kabacoff, R. I., Miller, I. W., Bishop, D. S., Epstein, N. B., & Keitner, G. I. (1990). A psychometric study of the McMaster Family Assessment Device in psychiatric, medical, and nonclinical samples. *Journal of Family Psychology, 3*(4), 431–439. <https://doi.org/10.1037/h0080547>
- Kandemir, H., Kiliç, B. G., Ekinçi, S., & Yüce, M. (2014). An evaluation of the quality of life of children with ADHD and their families. *Anatolian Journal of Psychiatry 15*(3), 265-271. <https://doi.org/10.5455/apd.46202>
- Karimi, M., & Brazier, J. (2016). Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics, 34*(7), 645–649. <https://doi.org/10.1007/s40273-016-0389-9>
- Keitner, G. I., Heru, A. M., & Glick, I. D. (2009). *Clinical manual of couples and family therapy*. American Psychiatric Publishing Inc.
- Keller, S. D., Ware, J. E., Bentler, P. M., Aaronson, N. K., Alonso, J., Apolone, G., Bjorner, J. B., Brazier, J., Bullinger, M., Kassa, S., Leplège, A., Sullivan, M., & Gandek, B. (1998). Use of structural equation modeling to test the construct validity of the SF-36 Health Survey in ten countries: Results from the IQOLA Project. *Journal of Clinical Epidemiology, 51*(11), 1179–1188. [https://doi.org/10.1016/S0895-4356\(98\)00110-3](https://doi.org/10.1016/S0895-4356(98)00110-3)

- Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *41*(9), 1214–1227. <https://doi.org/10.1007/s10803-010-1140-6>
- Kim, Y., Kim, B., Chang, J. S., Kim, B. N., Cho, S. C., & Hwang, J. W. (2014). Parental quality of life and depressive mood following methylphenidate treatment of children with attention-deficit hyperactivity disorder. *Psychiatry and Clinical Neurosciences*, *68*(7), 506–514. <https://doi.org/10.1111/pcn.12155>
- Kousha, M., Attar, H. A., & Shoar, Z. (2016). Anxiety, depression, and quality of life in Iranian mothers of children with autism spectrum disorder. *Journal of Child Health Care*, *20*(3), 405–414. <https://doi.org/10.1177/1367493515598644>
- Kousha, M., & Kakrodi, M. A. (2019). Can parents improve the quality of life of their children with attention deficit hyperactivity disorder? *Iranian Journal of Psychiatry*, *14*(2), 154–159. <https://doi.org/10.18502/ijps.v14i2.995>
- Kwan, Y. H., Fong, W. W. S., Lui, N. L., Yong, S. T., Cheung, Y. B., Malhotra, R., Østbye, T., & Thumboo, J. (2016). Validity and reliability of the Short Form 36 Health Surveys (SF-36) among patients with spondyloarthritis in Singapore. *Rheumatology International*, *36*(12), 1759–1765. <https://doi.org/10.1007/s00296-016-3567-3>
- Labrum, T. (2018). Caregiving for Relatives with Psychiatric Disorders vs. Co-Occurring Psychiatric and Substance Use Disorders. *Psychiatric Quarterly*, *89*(3), 631–644. <https://doi.org/10.1007/s11126-017-9557-0>
- Las Hayas, C., Padierna, J. Á., Bilbao, A., Martín, J., Muñoz, P., & Quintana, J. M. (2014). Eating disorders: Predictors of change in the quality of life of caregivers. *Psychiatry*

Research, 215(3), 718–726. <https://doi.org/10.1016/j.psychres.2013.12.028>

Lauber, C., Keller, C., Eichenberger, A., & Rössler, W. (2005). Family burden during exacerbation of schizophrenia: Quantification and determinants of additional costs. *International Journal of Social Psychiatry*, 51(3), 259–264.

<https://doi.org/10.1177/0020764005057376>

Lee, G. K., Lopata, C., Volker, M. A., Thomeer, M. L., Nida, R. E., Toomey, J. A., Chow, S. Y., & Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 24(4), 227–239. <https://doi.org/10.1177/1088357609347371>

Leng, A., Xu, C., Nicholas, S., Nicholas, J., & Wang, J. (2019). Quality of life in caregivers of a family member with serious mental illness: Evidence from China. *Archives of Psychiatric Nursing*, 33(1), 23–29. <https://doi.org/10.1016/j.apnu.2018.08.010>

Li, J., Lambert, C. E., & Lambert, V. A. (2007). Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. *Nursing and Health Sciences*, 9(3), 192–198.

<https://doi.org/10.1111/j.1442-2018.2007.00327.x>

Lim, J. W., & Shon, E. J. (2018). The Dyadic Effects of Family Cohesion and Communication on Health-Related Quality of Life: The Moderating Role of Sex. *Cancer Nursing*, 41(2), 156–165. <https://doi.org/10.1097/NCC.0000000000000468>

Limbers, C. A., McCollum, C., & Greenwood, E. (2020). Physical activity moderates the association between parenting stress and quality of life in working mothers during the COVID-19 pandemic. *Mental Health and Physical Activity*, 19(October), 100358.

<https://doi.org/10.1016/j.mhpa.2020.100358>

- Limbers, C. A., Ripperger-Suhler, J., Boutton, K., Ransom, D., & Varni, J. W. (2011). A comparative analysis of health-related quality of life and family impact between children with ADHD treated in a general pediatric clinic and a psychiatric clinic utilizing the PedsQL. *Journal of Attention Disorders, 15*(5), 392–402. <https://doi.org/10.1177/1087054709356191>
- Limoncelli, K. E., Wolff, K. T., & Celinska, K. (2019). The role of parental problems in functional family therapy outcomes. *Children and Youth Services Review, 106*(August), 104483. <https://doi.org/10.1016/j.childyouth.2019.104483>
- Liu, M., Lambert, C. E., & Lambert, V. A. (2007). Caregiver burden and coping patterns of Chinese parents of a child with a mental illness: Feature article. *International Journal of Mental Health Nursing, 16*(2), 86–95. <https://doi.org/10.1111/j.1447-0349.2007.00451.x>
- Lochman, J. E., & Wells, K. C. (2002). Contextual social-cognitive mediators and child outcome: A test of the theoretical model in the Coping Power program. *Development and Psychopathology, 14*(4), 945–967. <https://doi.org/10.1017/S0954579402004157>
- Loebach, R., & Ayoubzadeh, S. (2017). Wait times for psychiatric care in Ontario. *University of Western Ontario Medical Journal, 86*(2), 48–50. <https://doi.org/10.5206/uwomj.v86i2.2027>
- Loge, J. H., & Kaasa, S. (1998). Short Form 36 (SF-36) health survey: Normative data from the general Norwegian population. *Scandinavian Journal of Public Health, 26*(4), 250–258. <https://doi.org/10.1177/14034948980260040401>
- Loukissa, D. A. (1994). Concept and models for the study of caregiver burden. *Journal of Psychiatric and Mental Health Nursing, 1*(3), 151–156. <https://doi.org/10.1111/j.1365-2850.1994.tb00038.x>
- Lua, P. L., & Bakar, Z. A. (2011). Health-related quality of life profiles among family caregivers

of patients with schizophrenia. *Family and Community Health*, 34(4), 331–339.

<https://doi.org/10.1097/FCH.0b013e31822b54ad>

Lucksted, A., Mcfarlane, W., Downing, D., & Dixon, L. (2012). Recent developments in family psychoeducation as an evidence-based practice. *Journal of Marital and Family Therapy*, 38(1), 101–121. <https://doi.org/10.1111/j.1752-0606.2011.00256.x>

Ma, N., Roberts, R., Winefield, H., & Furber, G. (2015). Utility of qualitative metasynthesis: Advancing knowledge on the wellbeing and needs of siblings of children with mental health problems. *Qualitative Psychology*, 2(1), 3–28. <https://doi.org/10.1037/qup0000018>

Ma, N., Roberts, R., Winefield, H., & Furber, G. (2017). The quality of family relationships for siblings of children with mental health problems: a 20-year systematic review. *Journal of Family Studies*, 23(3), 309–332. <https://doi.org/10.1080/13229400.2015.1108994>

Machnicki, G., Allegri, R. F., Ranalli, C. G., Serrano, C. M., Dillon, C., Wyrwich, K. W., & Taragano, F. E. (2009). Validity and Reliability of the SF-36 Administered to Caregivers of Patients with Alzheimer’s Disease: Evidence from a South American Sample. *Dementia and Geriatric Cognitive Disorders*, 28(3), 206–212. <https://doi.org/10.1159/000236912>

MacKean, G., Spragins, W., L’Heureux, L., Popp, J., Wilkes, C., & Lipton, H. (2012). Advancing family-centred care in child and adolescent mental health: A critical review of the literature. *Healthcare Quarterly*, 15, 64-75. <https://doi.org/10.12927/hcq.2013.22939>

Mackinaw-Koons, B., & Fristad, M. A. (2004). Children with bipolar disorder: How to break down barriers and work effectively together. *Professional Psychology: Research and Practice*, 35(5), 481–484. <https://doi.org/10.1037/0735-7028.35.5.481>

Macleod, S. H., Elliott, L., & Brown, R. (2011). What support can community mental health nurses deliver to carers of people diagnosed with schizophrenia? Findings from a review of

the literature. *International Journal of Nursing Studies*, 48(1), 100–120.

<https://doi.org/10.1016/j.ijnurstu.2010.09.005>

Magaña, S. M., Ramírez García, J. I., Hernández, M. G., & Cortez, R. (2007). Psychological distress among Latino family caregivers of adults with schizophrenia: The roles of burden and stigma. *Psychiatric Services*, 58(3), 378–384. <https://doi.org/10.1176/ps.2007.58.3.378>

Manderscheid, R. W., Ryff, C. D., Freeman, E. J., McKnight-Eily, L. R., Dhingra, S., & Strine, T. W. (2010). Evolving definitions of mental illness and wellness. *Preventing chronic disease*, 7(1), A19.

Marsh, D. T. (1992). *Families and mental illness: New directions in professional practice*. Praeger.

Martín, J., Padierna, A., Aguirre, U., González, N., Muñoz, P., & Quintana, J. M. (2013). Predictors of quality of life and caregiver burden among maternal and paternal caregivers of patients with eating disorders. *Psychiatry Research*, 210(3), 1107–1115. <https://doi.org/10.1016/j.psychres.2013.07.039>

Martín, J., Padierna, A., van Wijngaarden, B., Aguirre, U., Anton, A., Muñoz, P., & Quintana, J. M. (2015). Caregivers consequences of care among patients with eating disorders, depression or schizophrenia. *BMC Psychiatry*, 15(1), 1–10. <https://doi.org/10.1186/s12888-015-0507-9>

Mash, E. J., & Johnston, C. (1990). Determinants of Parenting Stress: Illustrations from Families of Hyperactive Children and Families of Physically Abused Children. *Journal of Clinical Child Psychology*, 19(4), 313–328. https://doi.org/10.1207/s15374424jccp1904_3

Matheson, B. E., Bohon, C., & Lock, J. (2020). Family-based treatment via videoconference: Clinical recommendations for treatment providers during COVID-19 and beyond.

International Journal of Eating Disorders, 53(7), 1142–1154.

<https://doi.org/10.1002/eat.23326>

McDonnell, M. G., Short, R. A., Berry, C. M., & Dyck, D. G. (2003). Burden in schizophrenia caregivers: impact of family psychoeducation and awareness of patient suicidality. *Family process*, 42(1), 91-103. <https://doi.org/10.1111/j.1545-5300.2003.00091.x>

McDowell, I. (2006). *Measuring health: a guide to rating scales and questionnaires*. Oxford University Press.

McNeil, S. (2013). Understanding Family-Centered Care in the mental health system: Perspectives from family members caring for relatives with mental health issues. *Social Work in Mental Health*, 11(1), 55–74. <https://doi.org/10.1080/15332985.2012.720662>

Mendenhall, A. N., & Mount, K. (2011). Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused interventions. *Families in Society*, 92(2), 183–190. <https://doi.org/10.1606/1044-3894.4097>

Meng, N., Chen, J., Cao, B., Wang, F., Xie, X., & Li, X. (2021). Focusing on quality of life in the family caregivers of patients with schizophrenia from the perspective of family functioning: A cross-sectional study. *Medicine*, 100(5), e24270. <https://doi.org/10.1097/MD.00000000000024270>

Mental Health Commission of Canada. (2010). *Together We Can*.

https://www.mentalhealthcommission.ca/sites/default/files/Diversity_Together_We_Can_ENG_0_1.pdf

Mental Health Commission of Canada. (2013). *Making the case for investing in mental health in Canada*.

https://www.mentalhealthcommission.ca/sites/default/files/Investing_in_Mental_Health_FI

Mental Health Commission of Canada. (2015). *Informing the Future: Mental Health Indicators for Canada*.

https://www.mentalhealthcommission.ca/sites/default/files/Informing%252520the%252520Future%252520-%252520Mental%252520Health%252520Indicators%252520for%252520Canada_0.pdf

Mersky, J. P., Topitzes, J., & Reynolds, A. J. (2013). Impacts of adverse childhood experiences on health, mental health, and substance use in early adulthood: A cohort study of an urban, minority sample in the U.S. *Child Abuse and Neglect*, 37(11), 917–925.

<https://doi.org/10.1016/j.chiabu.2013.07.011>

Miller, I. W., Kabacoff, R. I., Keitner, G. I., Epstein, N. B., & Bishop, D. S. (1986). Family functioning in the families of psychiatric patients. *Comprehensive Psychiatry*, 27(4), 302–312. [https://doi.org/10.1016/0010-440X\(86\)90006-4](https://doi.org/10.1016/0010-440X(86)90006-4)

Miller, I. W., Keitner, G. I., Whisman, M. A., Ryan, C. E., Epstein, N. B., & Bishop, D. S. (1992). Depressed Patients With Dysfunctional Families: Description and Course of Illness. *Journal of Abnormal Psychology*, 101(4), 637–646. <https://doi.org/10.1037/0021-843X.101.4.637>

Mingebach, T., Kamp-Becker, I., Christiansen, H., & Weber, L. (2018). Meta-meta-analysis on the effectiveness of parent-based interventions for the treatment of child externalizing behavior problems. *PLoS ONE*, 13(9), 1–21. <https://doi.org/10.1371/journal.pone.0202855>

Minuchin, S. (1974). *Families & family therapy*. Harvard U. Press.

Molleda, L., Estrada, Y., Lee, T. K., Poma, S., Terán, A. M. Q., Tamayo, C. C., Bahamon, M., Tapia, M. I., Velázquez, M. R., Pantin, H., & Prado, G. (2017). Short-Term Effects on

- Family Communication and Adolescent Conduct Problems: Familias Unidas in Ecuador. *Prevention Science*, 18(7), 783–792. <https://doi.org/10.1007/s11121-016-0744-2>
- Morgan, S., Rickard, E., Noone, M., Boylan, C., Carthy, A., Crowley, S., Butler, J., Guerin, S., & Fitzpatrick, C. (2013). Parents of young people with self-harm or suicidal behaviour who seek help - a psychosocial profile. *Child and Adolescent Psychiatry and Mental Health*, 7(1), 1–10. <https://doi.org/10.1186/1753-2000-7-13>
- Mosby's medical dictionary*. (2009). (8th ed.). Mosby Elsevier.
- Muris, P., Meesters, C., & van den Berg, S. (2003). Internalizing and Externalizing Problems as Correlates of Self-Reported Attachment Style and Perceived Parental Rearing in Normal Adolescents. *Journal of Child and Family Studies*, 12(2), 171–183. <https://doi.org/10.1023/A:1022858715598>
- Murphy, Y. E., & Flessner, C. A. (2015). Family functioning in paediatric obsessive compulsive and related disorders. *British Journal of Clinical Psychology*, 54(4), 414–434. <https://doi.org/10.1111/bjc.12088>
- Noghani, F., Seyedfatemi, N., Karimirad, M. R., Akbarzadeh, A., & Hasanpour-Dehkordi, A. (2016). Health related quality of life in family caregivers of patients suffering from mental disorders. *Journal of Clinical and Diagnostic Research*, 10(11), VC05–VC09. <https://doi.org/10.7860/JCDR/2016/19671.8792>
- Ohaeri, J. U. (2003). The burden of caregiving in families with a mental illness: a review of 2002. *Current Opinion in Psychiatry*, 16(4), 457–465. <https://doi.org/10.1097/01.yco.0000079212.36371.c0>
- Ohayon, M. M., & Schatzberg, A. F. (2003). Using chronic pain to predict depressive morbidity in the general population. *Archives of General Psychiatry*, 60(1), 39–47.

<https://doi.org/10.1001/archpsyc.60.1.39>

Okun, A., Stein, R. E. K., Bauman, L. J., & Silver, E. J. (1996). Content validity of the Psychiatric Symptom Index, CES-Depression Scale, and State-Trait Anxiety Inventory from the perspective of DSM-IV. *Psychological Reports, 79*(3), 1059–1069.

<https://doi.org/10.2466/pr0.1996.79.3.1059>

Oland, A. A., & Shaw, D. S. (2005). Pure versus co-occurring externalizing and internalizing symptoms in children: The potential role of socio-developmental milestones. *Clinical Child and Family Psychology Review, 8*(4), 247–270. <https://doi.org/10.1007/s10567-005-8808-z>

Olasoji, M., Maude, P., & McCauley, K. (2017). Not sick enough: Experiences of carers of people with mental illness negotiating care for their relatives with mental health services. *Journal of Psychiatric and Mental Health Nursing, 24*(6), 403–411.

<https://doi.org/10.1111/jpm.12399>

Orme, J. G., Reis, J., & Herz, E. J. (1986). Factorial and discriminant validity of the center for epidemiological studies depression (CES-D) scale. *Journal of Clinical Psychology, 42*(1), 28–33. [https://doi.org/10.1002/1097-4679\(198601\)42:1<28::AID-JCLP2270420104>3.0.CO;2-T](https://doi.org/10.1002/1097-4679(198601)42:1<28::AID-JCLP2270420104>3.0.CO;2-T)

Osher, T. W., & Osher, D. M. (2002). The Paradigm Shift to True Collaboration with Families. *Journal of Child and Family Studies, 11*(1), 47–60.

<https://doi.org/10.1023/A:1014715527823>

Owens, P. L., Hoagwood, K., Horwitz, S. M., Leaf, P. J., Poduska, J. M., Kellam, S. G., & Ialongo, N. S. (2002). Barriers to Children's Mental Health Services. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(6), 731–738.

<https://doi.org/10.1097/00004583-200206000-00013>

- Parents for Children's Mental Health. (2013). *The Position of Families on Transformation of the Child and Youth Mental Health System*.
http://www.pcmh.ca/documents/2013_The%20Position%20of%20Families%20Report2.pdf
- Park, M., Giap, T.-T.-T., Lee, M., Jeong, H., Jeong, M., & Go, Y. (2018). Patient- and family-centered care interventions for improving the quality of health care: A review of systematic reviews. *International Journal of Nursing Studies*, 87, 69–83.
<https://doi.org/https://doi.org/10.1016/j.ijnurstu.2018.07.006>
- Park, S. S. (2021). Caregivers' Mental Health and Somatic Symptoms During COVID-19. *The Journals of Gerontology: Series B*, 76(4), e235–e240.
<https://doi.org/10.1093/geronb/gbaa121>
- Patterson, J. M., & Garwick, A. W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine*, 16(2), 131–142.
<https://doi.org/10.1093/abm/16.2.131>
- Pearlin, L. I., Menaghan, E. G., Lieberman, M. A., Joseph, T., Lieberman, M. A., & Mullan, J. T. (1981). The Stress Process. *Journal of Health and Social Behavior*, 22(4), 337–356.
<https://doi.org/10.2307/2136676>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30(5), 583–594.
<https://doi.org/10.1093/geront/30.5.583>
- Pereira, M. G., & De Almeida, J. M. (1999). The repercussions of mental disease in the family. A study of the family members of psychotic patients. *Acta Medica Portuguesa*, 12(4-6), 161-8. <https://doi.org/10.20344/amp.2148>
- Perlick, D. A., Miklowitz, D. J., Lopez, N., Chou, J., Kalvin, C., Adzhiashvili, V., & Aronson, A.

- (2010). Family-focused treatment for caregivers of patients with bipolar disorder. *Bipolar Disorders*, 12(6), 627–637. <https://doi.org/10.1111/j.1399-5618.2010.00852.x>
- Perlick, D. A., Rosenheck, R. A., Miklowitz, D. J., Chessick, C., Wolff, N., Kaczynski, R., Ostacher, M., Patel, J., Desai, R., & STEP-BD Family Experience Collaborative Study Group (2007). Prevalence and correlates of burden among caregivers of patients with bipolar disorder enrolled in the Systematic Treatment Enhancement Program for Bipolar Disorder. *Bipolar Disorders*, 9(3), 262–273. <https://doi.org/https://doi.org/10.1111/j.1399-5618.2007.00365.x>
- Perron, B. (2002). Online support for caregivers of people with a mental illness. *Psychiatric Rehabilitation Journal*, 26(1), 70–77. <https://doi.org/10.2975/26.2002.70.77>
- Pharoah, F., Mari, J., Rathbone, J., & Wong, W. (2010). Family intervention for schizophrenia. *The Cochrane Database of Systematic Reviews*, (12), CD000088. <https://doi.org/10.1002/14651858.CD000088.pub2>
- Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLoS ONE*, 12(10), 1–19. <https://doi.org/10.1371/journal.pone.0186536>
- Prime, H., Wade, M., & Browne, D. T. (2020). Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*, 75(5), 631–643. <https://doi.org/10.1037/amp0000660>
- Radloff, L. S. (1977). The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1(3), 385–401. <https://doi.org/10.1177/014662167700100306>
- Raphael, J. L., Zhang, Y., Liu, H., & Giardino, A. P. (2010). Parenting stress in US families:

- implications for paediatric healthcare utilization. *Child: Care, Health and Development*, 36(2), 216–224. <https://doi.org/https://doi.org/10.1111/j.1365-2214.2009.01052.x>
- Regan, K. M., Curtin, C., & Vorderer, L. (2017). Paradigm shifts in inpatient psychiatric care of children: Approaching child- and family-centered care. *Journal of Child and Adolescent Psychiatric Nursing*, 30(4), 186–194. <https://doi.org/10.1111/jcap.12193>
- Ribé, J. M., Salamero, M., Pérez-Testor, C., Mercadal, J., Aguilera, C., & Cleris, M. (2018). Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support. *International journal of psychiatry in clinical practice*, 22(1), 25-33. <https://doi.org/10.1080/13651501.2017.1360500>
- Richardson, M., Cobham, V., McDermott, B., & Murray, J. (2013). Youth Mental Illness and the Family: Parents' Loss and Grief. *Journal of Child and Family Studies*, 22(5), 719–736. <https://doi.org/10.1007/s10826-012-9625-x>
- Ridner, S. H. (2004). Psychological distress: Concept analysis. *Journal of Advanced Nursing*, 45(5), 536–545. <https://doi.org/10.1046/j.1365-2648.2003.02938.x>
- Rodríguez-Sánchez, E., Pérez-Péaranda, A., Losada-Baltar, A., Pérez-Arechaederra, D., Gámez-Marcos, M. Á., Patino-Alonso, M. C., & García-Ortiz, L. (2011). Relationships between quality of life and family function in caregiver. *BMC Family Practice*, 12, 1–7. <https://doi.org/10.1186/1471-2296-12-19>
- Ross, C. N., Blanc, H. M., McNeil, C. B., Eyberg, S. M., & Hembree-Kigin, T. L. (1998). Parenting stress in mothers of young children with oppositional defiant disorder and other severe behavior problems. *Child Study Journal*, 28(2), 93–110.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12(1), 33–41.

<https://doi.org/10.1023/A:1023513218433>

- Saunders, J. C. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing, 24*(2), 175–198. <https://doi.org/10.1080/01612840305301>
- Schene, A. H. (1990). Objective and subjective dimensions of family burden - Towards an integrative framework for research. *Social Psychiatry and Psychiatric Epidemiology, 25*(6), 289–297. <https://doi.org/10.1007/BF00782883>
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., & Hong, J. (2004). Accommodative coping and well-being of midlife parents of children with mental health problems or developmental disabilities. *American Journal of Orthopsychiatry, 74*(2), 187-195. <https://doi.org/10.1037/0002-9432.74.2.187>
- Sheehan, D. V., Lecrubier, Y., Sheehan, K. H., Amorim, P., Janavs, J., Weiller, E., Hergueta, T., Baker, R., & Dunbar, G. C. (1998). The Mini-International Neuropsychiatric Interview (M.I.N.I.): The development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *The Journal of Clinical Psychiatry, 59*(Suppl 20), 22–33.
- Sheehan, D. V., Sheehan, K. H., Shytle, R. D., Janavs, J., Bannon, Y., Rogers, J. E., Milo, K. M., Stock, S. L., & Wilkinson, B. (2010). Reliability and validity of the mini international neuropsychiatric interview for children and adolescents (MINI-KID). *The Journal of Clinical Psychiatry, 71*(3), 313-326. <https://doi.org/10.4088/JCP.09m05305whi>
- Sheehan, R. (2017). Mental illness in children: Childhood illness and supporting the family. *Brain Sciences, 7*(8), 6–9. <https://doi.org/10.3390/brainsci7080097>
- Sin, J., Gillard, S., Spain, D., Cornelius, V., Chen, T., & Henderson, C. (2017). Effectiveness of psychoeducational interventions for family carers of people with psychosis: A systematic

review and meta-analysis. *Clinical Psychology Review*, 56, 13–24.

<https://doi.org/10.1016/j.cpr.2017.05.002>

Sin, J., & Norman, I. (2013). Psychoeducational interventions for family members of people with schizophrenia: A mixed-method systematic review. *Journal of Clinical Psychiatry*, 74(12).

<https://doi.org/10.4088/JCP.12r08308>

Skärsäter, I., Keogh, B., Doyle, L., Ellilä, H., Jormfeldt, H., Lahti, M., Higgins, A., Meade, O., Sivast, J., Stickley, T., & Kilkku, N. (2018). Advancing the knowledge, skills and attitudes of mental health nurses working with families and caregivers: A critical review of the literature. *Nurse Education in Practice*, 32, 138–146.

<https://doi.org/10.1016/j.nepr.2018.07.002>

Skundberg-Kletthagen, H., Gonzalez, M. T., Schröder, A., & Moen, Ø. L. (2020). Mental Health Professionals' Experiences with Applying a Family-Centred Care Focus in Their Clinical Work. *Issues in Mental Health Nursing*, 41(9), 815–823.

<https://doi.org/10.1080/01612840.2020.1731028>

Skundberg-Kletthagen, H., Hedelin, B., Wangensteen, S., & Hall-Lord, M. L. (2015). Burden, Health and Sense of Coherence among Relatives of Depressed Inpatients. *Open Journal of Nursing*, 05(03), 163–172. <https://doi.org/10.4236/ojn.2015.53020>

Spielberger, C. D., Gonzalez-Reigosa, F. E., Martinez-Urrutia, A. N., Natalicio, L., & Natalicio, D. S. (1971). Development of the Spanish edition of the state-trait anxiety inventory. *Interamerican Journal of Psychology*, 5(3-4), 145-158.

Statistics Canada. (2020). *Canadian Perspective Survey Series 1: Impacts of COVID-19 Study Documentation Metadata Production*. <https://www150.statcan.gc.ca/n1/daily-quotidien/200408/dq200408c-eng.htm>

- Steinglass, P. (1987). A systems view of family interaction and psychopathology. In *Family interaction and psychopathology* (pp. 25-65). Springer.
- Sullivan, A. E., Judd, C. M., Axelson, D. A., & Miklowitz, D. J. (2012). Family Functioning and the Course of Adolescent Bipolar Disorder. *Behavior Therapy, 43*(4), 837–847.
<https://doi.org/10.1016/j.beth.2012.04.005>
- Suresky, M. J., Zauszniewski, J. A., & Bekhet, A. K. (2008). Sense of coherence and quality of life in women family members of the seriously mentally ill. *Issues in Mental Health Nursing, 29*(3), 265–278. <https://doi.org/10.1080/01612840701869601>
- Tamplin, A., Goodyer, I. M., & Herbert, J. (1998). Family functioning and parent general health in families of adolescents with major depressive disorder. *Journal of Affective Disorders, 48*(1), 1–13. [https://doi.org/10.1016/S0165-0327\(97\)00105-5](https://doi.org/10.1016/S0165-0327(97)00105-5)
- Tarlov, A. R., Ware Jr, J. E., Greenfield, S., Nelson, E. C., Perrin, E., & Zubkoff, M. (1989). The Medical Outcomes Study: An Application of Methods for Monitoring the Results of Medical Care. *JAMA, 262*(7), 925–930. <https://doi.org/10.1001/jama.1989.03430070073033>
- Thunyadee, C., Sitthimongkol, Y., Sangon, S., Chai-Aroon, T., & Hegadoren, K. M. (2015). Predictors of depressive symptoms and physical health in caregivers of individuals with schizophrenia. *Nursing & Health Sciences, 17*(4), 412–419.
<https://doi.org/https://doi.org/10.1111/nhs.12205>
- Torrance, G. W. (1987). Utility approach to measuring health-related quality of life. *Journal of Chronic Diseases, 40*(6), 593–600. [https://doi.org/10.1016/0021-9681\(87\)90019-1](https://doi.org/10.1016/0021-9681(87)90019-1)
- Trepal, H. C., Wester, K. L., & Macdonald, C. A. (2006). Self-Injury and Postvention: Responding to the Family in Crisis. *The Family Journal, 14*(4), 342–348.
<https://doi.org/10.1177/1066480706291128>

- Tung, L. C., Huang, C. Y., Tseng, M. H., Yen, H. C., Tsai, Y. P., Lin, Y. C., & Chen, K. L. (2014). Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism. *Research in Autism Spectrum Disorders*, 8(9), 1235–1242. <https://doi.org/10.1016/j.rasd.2014.06.010>
- Turner, K. M. T., & Sanders, M. R. (2006). Dissemination of evidence-based parenting and family support strategies: Learning from the Triple P—Positive Parenting Program system approach. *Aggression and Violent Behavior*, 11(2), 176–193. <https://doi.org/https://doi.org/10.1016/j.avb.2005.07.005>
- van der Kolk, A., Bouwmans, C. A., Schawo, S. J., Buitelaar, J. K., van Agthoven, M., & Hakkaart-van Roijen, L. (2014). Association between quality of life and treatment response in children with attention deficit hyperactivity disorder and their parents. *J Ment Health Policy Econ*, 17(3), 119-29.
- Verma, P. K., Walia, T. S., Chaudhury, S., & Srivastava, S. (2019). Family psychoeducation with caregivers of schizophrenia patients: Impact on perceived quality of life. *Industrial Psychiatry Journal*, 28(1), 19–23. https://doi.org/10.4103/ipj.ipj_2_19
- Wang, J., Mansfield, A. K., Zhao, X., & Keitner, G. (2013). Family functioning in depressed and non-clinical control families. *International Journal of Social Psychiatry*, 59(6), 561–569. <https://doi.org/10.1177/0020764012445260>
- Ware, J. E., & Sherbourne, C. (1992). The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual Framework and Item Selection. *Medical Care*, 30(6), 473- 483.
- Ware, J. E., Snow, K. K., Kosinski, M., Gandek, B. (1993). *SF-36 Health Survey: Manual and Interpretation Guide*. The Health Institute, New England Medical Center.
- Webster-Stratton, C. (2016). The Incredible Years Series: A Developmental Approach. In M.

- Van Ryzin, K. Kumpfer, G. Fosco, & M. Greenberg (Eds.), *Family-Based Prevention Programs for Children and Adolescents: Theory, Research, and Large-Scale Dissemination* (pp. 42-67). Psychology Press.
- Weissman, M. M., Sholomskas, D., Pottenger, M., Prusoff, B. A., & Locke, B. Z. (1977). Assessing depressive symptoms in five psychiatric populations: A validation study. *American Journal of Epidemiology*, *106*(3), 203–214. <https://doi.org/10.1093/oxfordjournals.aje.a112455>
- Willner, C. J., Gatzke-Kopp, L. M., & Bray, B. C. (2016). The dynamics of internalizing and externalizing comorbidity across the early school years. *Development and psychopathology*, *28*(4 Pt 1), 1033–1052. <https://doi.org/10.1017/S0954579416000687>
- Wingrove, C., & Rickwood, D. (2019). Parents and carers of young people with mental ill-health: What factors mediate the effect of burden on stress? *Counselling Psychology Quarterly*, *32*(1), 121–134. <https://doi.org/10.1080/09515070.2017.1384362>
- Witt, W. P., & Deleire, T. (2009). A family perspective on population health: The case of child health and the family. *Wisconsin Medical Journal*, *108*(5), 240–245.
- Wong, D. F. K., Lam, A. Y. K., Chan, S. K., & Chan, S. F. (2012). Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: Roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services. *Health and Quality of Life Outcomes*, *10*(1), 1–9. <https://doi.org/10.1186/1477-7525-10-15>
- Woodward, L., Taylor, E., & Dowdney, L. (1998). The parenting and family functioning of children with hyperactivity. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *39*(2), 161–169. <https://doi.org/10.1017/S0021963097001790>
- Wu, M. S., Hamblin, R., Nadeau, J., Simmons, J., Smith, A., Wilson, M., Eken, S., Small, B.,

- Phares, V., & Storch, E. A. (2018). Quality of life and burden in caregivers of youth with obsessive-compulsive disorder presenting for intensive treatment. *Comprehensive Psychiatry*, *80*, 46–56. <https://doi.org/10.1016/j.comppsy.2017.08.005>
- Xiang, Y. T., Luk, E. S., & Lai, K. Y. (2009). Quality of life in parents of children with attention-deficit–hyperactivity disorder in Hong Kong. *Australian & New Zealand Journal of Psychiatry*, *43*(8), 731–738. <https://doi.org/10.1080/00048670903001968>
- Yesufu-Udechuku, A., Harrison, B., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E., & Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: Systematic review and meta-analysis. *British Journal of Psychiatry*, *206*(4), 268–274. <https://doi.org/10.1192/bjp.bp.114.147561>
- Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2013). The association between mental health, stress, and coping supports in mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*(6), 1380–1393. <https://doi.org/10.1007/s10803-012-1693-7>
- Zahid, M. A., & Ohaeri, J. U. (2010). Relationship of family caregiver burden with quality of care and psychopathology in a sample of Arab subjects with schizophrenia. *BMC Psychiatry*, *10*. <https://doi.org/10.1186/1471-244X-10-71>
- Zendjidjian, X., Richieri, R., Adida, M., Limousin, S., Gaubert, N., Parola, N., Lançon, C., & Boyer, L. (2012). Quality of life among caregivers of individuals with affective disorders. *Journal of Affective Disorders*, *136*(3), 660–665. <https://doi.org/10.1016/j.jad.2011.10.011>
- Zhang, Y., Yang, M., Guo, X., & Chen, Q. (2020). Quality of life in family caregivers of adolescents with depression in China: A mixed-method study. *Patient Preference and Adherence*, *14*, 1317–1327. <https://doi.org/10.2147/PPA.S265867>

Appendix A

Hypothesized Models

Step 1: Adds family functioning:

$$Y_i = \beta_0 + \beta_1 \text{FAD}_i + \varepsilon_i; \quad i = 1, \dots, n$$

Step 2: Adds age of parent, age of child, sex of parent, sex of child, household income, and education level of parent:

$$Y_i = \beta_0 + \beta_1 \text{FAD}_i + \beta_2 \text{ParentAge}_i + \beta_3 \text{ChildAge}_i + \beta_4 \text{ParentSex}_i + \beta_5 \text{ChildSex}_i + \beta_6 \text{Income}_i + \beta_7 \text{Education}_i + \varepsilon_i; \quad i = 1, \dots, n$$

Step 3: Adds child externalizing disorder:

$$Y_i = \beta_0 + \beta_1 \text{FAD}_i + \beta_2 \text{ParentAge}_i + \beta_3 \text{ChildAge}_i + \beta_4 \text{ParentSex}_i + \beta_5 \text{ChildSex}_i + \beta_6 \text{Income}_i + \beta_7 \text{Education}_i + \beta_8 \text{EXT}_i + \varepsilon_i; \quad i = 1, \dots, n$$

Step 4: Adds parental stress and parental psychological distress:

$$Y_i = \beta_0 + \beta_1 \text{FAD}_i + \beta_2 \text{ParentAge}_i + \beta_3 \text{ChildAge}_i + \beta_4 \text{ParentSex}_i + \beta_5 \text{ChildSex}_i + \beta_6 \text{Income}_i + \beta_7 \text{Education}_i + \beta_8 \text{EXT}_i + \beta_9 \text{PSS}_i + \beta_{10} \text{CESDSTAI}_i + \varepsilon_i; \quad i = 1, \dots, n$$

Step 5: Adds family functioning*child age, family functioning*child sex, family functioning*child externalizing disorder, and family functioning*parental psychological distress in separate models:

$$Y_i = \beta_0 + \beta_1 \text{FAD}_i + \beta_2 \text{ParentAge}_i + \beta_3 \text{ChildAge}_i + \beta_4 \text{ParentSex}_i + \beta_5 \text{ChildSex}_i + \beta_6 \text{Income}_i + \beta_7 \text{Education}_i + \beta_8 \text{EXT}_i + \beta_9 \text{PSS}_i + \beta_{10} \text{CESDSTAI}_i + \beta_{11} \text{FAD} * \text{ChildAge}_i + \beta_{12} \text{FAD} * \text{ChildSex}_i + \beta_{13} \text{FAD} * \text{EXT}_i + \beta_{14} \text{FAD} * \text{CESDSTAI}_i + \varepsilon_i; \quad i = 1, \dots, n$$