

**CARING FOR YOUTH WITH SEVERE DISABILITIES: IMPACTS ON
PARENTS' QUALITY OF LIFE**

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A Thesis
Submitted to the School of Graduate Studies
of the University of Lethbridge
in Partial Fulfillment of the
Requirements for the Degree

MASTER OF SCIENCE, HEALTH SCIENCES

Faculty of Health Sciences
University of Lethbridge
LETHBRIDGE, ALBERTA, CANADA

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Date of Defence: March 31, 2017

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DEDICATION

I dedicate this thesis to God, my wife, and my daughters. A special dedication goes to my wife, Rania Elfangary, who has been supporting, encouraging, and loving me since we met long time ago. I am sorry for all times that I have been away, and I promise I will make it up to you.

ABSTRACT

Little is known about parents' Quality of Life (QOL) when their children with disabilities become youth and young adults. This study compared parents' QOL versus child's age and severity of disability conditions. Secondary data analysis of Statistics Canada's General Social Survey Cycle 26 was completed. This study focused on parents who were "caregivers" to their disabled children aged between 0-29 years. The analyses of 193 parents' overall life satisfaction showed significant differences based on their child(ren)'s age (0-10, 11-19, 20-29) and disability severity (mild, moderate, and severe). Parents reported significant low QOL's scores when their children were in the group of 11-19 years old and their disability severity was moderate or severe. The findings highlighted the need for evidence-based family support for families of youth with moderate or severe disabilities.

Key words: parents' quality of life, children's age, disability severity, family support

ACKNOWLEDGMENTS

My deepest appreciation goes to my supervisor, Dr. Oluwagbohunmi Awosoga, for his great support, advice, and encouragement throughout my research adventure. He dedicated countless hours reflecting, reading, and encouraging, and, most of all, his patience throughout the entire process. I appreciate his professionalism, personal guidance and his smiles during the hard times.

I want to thank my committee members who were more than generous with their expertise and precious time. Special thanks to Dr. Cheryl Currie and Dr. Fangfang Li for agreeing to serve on my committee. I feel so grateful to them for their support, guidance, and advice and for taking time out of their busy schedule to provide me with valuable feedback. I thank Dr. Sharon Yanicki for agreeing to chair my thesis oral defense.

I would like to acknowledge and thank the School of Graduate Studies and Faculty of Health Sciences at The University of Lethbridge for providing me with a fellowship, without which I would not have been able to complete my studies.

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CHAPTER ONE

INTRODUCTION

The World Health Organization (WHO) estimated that 5% of children aged 0-14 years of age are suffering from moderate to severe form of disability (WHO, 2004). Similarly, it has been estimated that 3.7% of children below 15 years of age in Canada live with one or more types of developmental disability (Khanlou, Mustafa, Vazquez, Haque, & Yoshida, 2015).

Parents of children with disabilities are confronted with persistent challenges, which eventually may influence their own overall quality of life. Parenting a child with a disability may entail physical, psychological, and emotional consequences, which, in turn, may lead to serious parental mental and health issues (Davis & Gavidia-Payne, 2009, p. 153).

In 2006, over 60% of the Canadian parents in families having children with disabilities reported that they “sometimes” to “always” felt that they were under stress. This strain affects all aspects of their family life, including “parental marital satisfaction, parental physical and emotional health, as well as the ability to perform care giving tasks and responsibilities” (Khanlou et al., 2015, p. 660).

Family demands, expectations, and satisfaction may change through their life cycle and may vary per the severity of their disabled child condition (Wang et al., 2004, p. 90). Although governmental funds were allocated toward individuals with disabilities, supplementary funding should embrace the variable and fluctuating needs of their families (Brown, Schalock, & Brown, 2009, p. 4). For instance, parents of children with complex or severe disabilities may face more difficulties daily in comparison to parents

of children with lesser degrees of disabilities resulting in varying degrees of the QOL experienced.

An in-depth understanding of the link between variations in family satisfaction with their quality of life and two of the demographic characteristics of their disabled children, such as their condition's severity and age, may shed some light on the urgent needs for introducing enhanced designs of service delivery models. These models should have the abilities to identify families' different needs and respond to them effectively and efficiently.

This study investigates the challenges, and effects of parenting a child with disability on the parents' Quality of Life (QOL), and the effects of disabled children's age and severity of their disability on the parent's QOL.

Quality of Life (QOL)

There are many different approaches and definitions for the concept of QOL. QOL is a multidimensional construct that includes personal and environmental elements and entails objective and subjective features (Schalock & Verdugo, 2002). QOL seems to be perceived by most people in similar ways; yet, cultural contexts and beliefs may influence one's reflection of his/her own QOL (Renwick, Brown, & Raphael, 2000). QOL, as a notion, has been used as a guiding reference to conceptualize a framework that is ultimately aiming to enhance persons' well-being (Brown & Brown, 2003).

In the context of families with disabilities, QOL construct has been utilized as a fundamental principal to assess and evaluate family needs. QOL assessment in those families should guide and improve the different policies and approaches that shape all the services and supports provided to them (Schalock, Gardner, & Bradley, 2007).

Quality of Life, as a program improvement tool, should be applied in an evidence-based fashion and implemented through systematic practices (Brown & Brown, 2005). Yet, there has been an evident lack in QOL research that addresses the challenges, such as residential supports (Werner, Edwards, & Baum, 2009), which does not only affect those families, but constitute a challenge for policy makers as well (Wang & Brown, 2009).

Turnbull et al. (as cited in Park et al., 2003) suggested a modern definition of family quality of life: "Conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them" (p. 368). QOL research has provided solid grounds for growth in the family QOL. Research about the welfare of families has grounded and extended the conceptual framework of individual QOL to families of people with disabilities (Zuna, Turnbull, & Summers, 2009, p. 25).

Disability

In 2013, the World Health Organisation (WHO) introduced the International Classification of Functioning (ICF), Disability and Health. WHO defined disability as "an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" (p. 8). Relating ICF to a clinical context, WHO (2013) classified disability as:

- (1) Mild, the problem is present less than 25% of the time, with a tolerable intensity, and has only rarely occurred in the last thirty days;

- (2) Moderate, the problem is present between 25% and 50% of the time, with an intensity that sometimes interferes with daily life;
- (3) Severe, the problem is present between 50% and 95% of the time, with an intensity that occurs frequently and partially alters daily life; and
- (4) Complete, the problem is present more than 95% of the time, with an intensity that totally alters daily life. (p. 61)

Disability definition in the ICF document does not state differences between normal and abnormal individuals; rather, it conceptualizes a framework that could be adapted to the purpose of the operational definition, such as policy evaluation, research, or clinical settings. That being said, Kostanjsek et al. (2013) defined the term disability as “multidimensional and experienced at various points on a continuum, from minor difficulties to major effects on a person’s life, and major barriers encountered” (p. 1065).

Moreover, Larson et al. (2001, p. 1) defined developmental disability as a chronic mental or physical condition that is “likely to continue indefinitely,” resulting in substantial functional limitations in three or more areas of daily life activities, such as “self-care, receptive or expressive language, learning, self-direction, capacity for independent living, and economic self-sufficiency.” These functional limitations require care, treatment, or other services for lifelong or extended period (p. 1).

Parenting a Child with Disability and Parental QOL

Numerous studies concluded that parents of children with disabilities, especially mental disabilities, reported more child-related stress than parents of children with normal development (Beckman, 1991; Reddon, McDonald, & Kysela, 1992; Sanders & Morgan 1997; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999). Furthermore,

psychological distress has been reported in many literatures to be elevated in mothers to larger extent than fathers of children with different kinds of disabilities including mental, developmental, neurological, and physical disabilities (Emerson, 2003; Emerson & Llewellyn, 2008; Ehrlich, von Rosenstiel, Grootenhuis, Gerrits, & Bos, 2005; Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003; Singer, 2006; Weiss, 2002).

In families of children with disabilities, parents are challenged with specific responsibilities, in addition to their usual parenting obligations (Ziviani, Darlington, Feeney, Rodger, & Watter, 2013, p. 7). Moreover, families of children with complex medical conditions are even challenged with more daunting responsibilities, which add additional burdens on them (Gravelle, 1997, p. 738).

Several factors may contribute to the increased stress among parents of children with disabilities. These factors include (a) child factors such as age, type and severity of disability, and presence of emotional disorders; (b) parental factors, such as burdens of caregiving and style of coping; (c) social support and socio-economic status (Emerson & Llewellyn, 2008; Hastings, 2002; Veisson, 1999).

Severity of Child's Disability and Parental QOL

Most research that evaluated the severity of a child's disability through the presence of severe associated behaviours found that the severity of a child's disabilities was linked to lower family QOL. However, when severity of the child's disability was measured through different and broader scales, research results were controversial (Wang et al., 2004, p. 83).

Severity of a child's disability was found to be positively correlated with his/her mother's stress in the age group below three years of age (Hanson & Hanline, 1990), had

an impact on his/her family adjustment with mean age at 6.6 years old (Blacher, Nihira, & Meyers, 1987), and was related more strongly to parental stress within families with mentally retarded adults (Seltzer & Krauss, 1989).

On the other hand, the severity of a child's disability was unrelated to maternal depression in families with young children with developmental disabilities (Bristol, Gallagher, & Schopler, 1988). Moreover, mothers' feelings of competence were unrelated to the severity of health status of their children with Down syndrome (Haldy & Hanzlik, 1990). According to Wang et al., (2004, p. 91), further research would be required to inform the debate about the impact of disability severity on the parental and family QOL.

Age of Children with Disability and Their Parents' QOL

Over the last two decades, there has been a considerable growth in the research about family QOL in families with individuals with disabilities. However, much of that research concentrated on families of children below 10 years of age, mostly those families whose children were subjected to early intervention programs (Boehm, Carter, & Taylor, 2015; Epley, Summers, &Turnbull, 2011).

Few studies have focused on families of teenage children, young adults, or grown adults with disabilities (Bertelli, Bianco, Rossi, Scuticchio, & Brown, 2011; Boehm et al., 2015), and there has been little knowledge about parental QOL in families of youths and adults with disabilities (Ferrer, Vilaseca, & Bersabé, 2016).

Parents of youth and teenage with disabilities reported lower QOL than parents of youth and teenage of normal development (Carter, Austin, & Trainor, 2012; Ferrell,

2010). For example, Lounds, Seltzer, Greenberg, and Shattuck (2007) noted that maternal depression and anxiety increased during the high school period of youth with autism.

In addition, there was not so much of information about the parental QOL when comparing different age groups of individuals with disabilities (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005, p. 49). Accordingly, QOL in families whose children with disabilities grew to become teenagers and adults needs to be both fully investigated, and compared to other age groups as well. That comparison may guide further adjustments, if any, in the currently provided support programs and their overriding policies.

In conclusion, greater knowledge about parental QOL during the different family life cycles is crucial. Having a comprehensive understanding of those families' experiences while their children with disabilities grow up could eventually inform policy makers of what could support those families in term of funding or supportive social programs.

Overview of Methodology

This study employed a secondary data analysis with a quantitative research design approach. The original data were collected as part of the general Statistics Canada (2013) *Social Survey, Cycle 26: Caregiving and Care Receiving* questionnaire. Statistics Canada conducted that questionnaire in the period from March 2012 to January 2013 across Canada's 10 provinces.

Secondary data analysis is defined as "further analysis of an existing dataset to address a different research question or to conduct research with data that was not collected for research purposes" (Windle, 2010, p. 322). Secondary analysis of survey

data entails many advantages. It allows comparisons across different groups, nations, and time. It could be considered an inexpensive research design in comparison to other types of designs (e.g. experimental research). It facilitates asking new research questions that are unrelated to the original survey purpose (Neuman, 2011, p. 374).

Additionally, the general social survey is “the best-known set of survey data used by social researchers for secondary analysis” (Neuman, 2011, p. 376). These types of surveys are usually accessible for low costs. They are also available in many computer formats, and their data sets and codebooks could be used or copied by researchers without obtaining permission (p. 376).

Nonetheless, secondary data analysis may have some limitations. The researcher must have in-depth knowledge about the research topic. The researcher also should carefully consider that the units of his/her research are matching the units within the original survey. Finally, the researcher should avoid overloading the data with excessive statistics to acquire a desirable research rigor (Neuman, 2011, p. 375).

Philosophical Stance

This study adopts the post-positivist’s paradigm. The post-positivist paradigm is a modern altered approach to the positivism, which is seeking probabilistic evidence and searching for the truth through what is probably to be (Polit & Beck, 2013, p. 8). Also, the post-positivist scientists believe in objectivity, and they exert every effort to be neutral and unbiased. Nonetheless, they acknowledge that perfect objectivity is still hard to reach because of the nature of human beings (p. 8).

Purpose of the Study

The purpose of this research was two-fold:

1. Investigate the differences in the parental self-rating of their life satisfaction in families of members with disabilities across different self-rating severities of their disabled children (i.e., mild, moderate, and severe) and among three children age groups (below 10 years of age, between 11 to 19, and between 20 to 29 years of age); and
2. Learn about the impacts of the individuals' condition severity and age group on their parental scores of their QOL domains. Even though there have been very few studies that have investigated the relationship between such individual characteristics and parental QOL across such wide age ranges and multiple disability types, those studies have provided a framework for determining the domains and indicators for the parental QOL (i.e., the dependent variables) that were utilized in the current study.

Research Question

The research questions for this study were:

1. Is there a difference in the parental life satisfaction based on their child(ren)'s condition of severity and age in Canada?
2. What are the impacts of severity and age of individuals with disabilities on their parents' QOL in Canada?

Knowledge Translation

Successful knowledge transfer with crossing of the theory-practice boundaries between the researcher and the stakeholders would entail sensible usage of a rhetorical triangle (Van de Ven, 2007, p. 243). This triangle includes logos (i.e., logical validity), pathos (i.e., power of persuasiveness), and ethos (i.e., a credible and legitimate speaker) (p. 243). Effective knowledge interpretation with crossing of the semantic translation boundaries between the researcher and the stakeholders should occur through different strategies and techniques, which fit according to the unique character of the intended stakeholder. These strategies may include a trace explanation, strategic explanation, and deep explanation (p. 249).

Yet, the pragmatic boundaries and useful knowledge transformation constitute a challenging step through the way of the implementation of any research findings (Carlile, 2004, p. 559). The researcher of this study would exert every effort to identify and transfer study results and implications to the study-related target audiences or stakeholders.

Chapter Summary

To advance our understanding of various demographic variables that may affect parental QOL in families of children with disabilities, it is essential to conduct as many studies as possible that deeply examine such relationships from different angles. There is a salient lack of knowledge about parental QOL among families of teenage and young adults with disabilities and about the interaction between age and severity of the individuals' disability in relation to their parents' QOL and their family life.

Additionally, the concept of QOL needs to be established as an evidence-based tool to evaluate and improve families' outcomes in the disability field. Accordingly, there is a requirement to employ consistent QOL measurement domains and indicators within family quality of life research, and different studies should acknowledge any limitations when the fully adapted QOL domains have not been investigated before making any further inferences, generalization, or recommendations.

The uniqueness of this study is three-fold. Firstly, this study compared parents' QOL among different and wide-age groups of their children, youth, and adults with disabilities; the age groups included below 10 years old, between 11 to 19 years old, and between 20 to 29 years old respectively. These age groups correspond to three different developmental stages, which include the teenage or the transition stage and the early adulthood stage, in addition to the usually investigated childhood stage. This wide comparison shed some lights on the different experiences of the parents whose children had grown up.

Secondly, this study investigated parental QOL of children and young adults who had almost all types of disabilities (i.e., developmental, mental, physical, and neurological disabilities), which would enrich the knowledge about the unique effects of the study's independent variables through the different family life cycles regardless of the disability type of their member with disabilities. Lastly, the participants in this study were selected through stratified random sampling from Canada's 10 provinces, which not only reduced the selection biases by having a reasonable representation of the entire population under research, but it also has not been utilized in most of the research about family QOL, mainly because of its high cost.

CHAPTER TWO

LITERATURE REVIEW

The purpose of this literature review is six-fold. The first presentation is an overview of the different concepts and approaches of the term Quality of Life (QOL) from the individual's prospective and families' prospective. The second consideration is the theoretical framework. The third consideration reflects the impacts of parenting children with disability on the parents' QOL. The fourth topic is focused on the relationship between individuals' disability severity and their parents' QOL. The fifth topic is focused on relationships between parents' QOL and their disabled child(ren)'s age. Finally, the supports to families of children with disabilities are presented. This review encompasses published research from 1986 to 2016.

Quality of Life (QOL)

Definitions and Approaches

QOL is a broad construct, which is combining the individual's mental health, bodily health, independence level, community relations, individual principles, and their relationship to significant structures of the surroundings (Mugno, Ruta, D'Arrigo, & Mazzone, 2007, p. 2). The basic comprehension of QOL could be reached by a lot of people; yet, as QOL is a complex human paradigm, the individual interpretation and reflection of the term QOL would be different across different contexts and among different populations (Raphael, Renwick, Brown, & Rootman, 1996, p. 66). QOL continued to challenge a general agreement on a definition because of its multifaceted and multidimensional nature (Haas, 1999, p. 215).

In their 1997 *Quality of Life Assessment*, the WHO defined quality of life as persons' views of their situation in life in the setting of their community and value structures, in which they have been present and relative to their objectives, prospects, ideals, and apprehensions. WHO also identified five basic QOL domains, which include physical health, psychological health, social relationships, level of independence, and environment.

Additionally, in their 1998 *Quality of Life Assessment*, the WHO has considered QOL as a multidimensional model that cannot be simply likened to the terms mental health, health position, life style, and life fulfillment. Instead, QOL integrates the person's satisfaction of these factors and other facets of life. Regardless of the different approaches for QOL, the concepts generally pertain to sense of welfare, the chances to achieve individual potentials, and the sense of sociable participation (Park et al., 2003, p. 368). The different reviewed approaches about QOL's related definitions are presented in Table 1.

Table 1. *Approaches and Definitions of QOL*

Approach	Definition
Health related	<p>Health-related QOL refers to "the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and health care policy" (Spieth & Harris, 1996, p. 76).</p> <p>Schipper et al. (as cited in Haas, 1999, Table 1, p. 217) defined QOL as "the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient. Four broad domains include physical, functional, psychological state and social and somatic sensation."</p>

Table 1 continued

Approach	Definition
Holistic approach (mainly subjective approach)	“[QOL] is a multidimensional evaluation of an individual’s current life circumstances in the context of the culture and value systems in which they live and the values they hold. [QOL] is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions” (Haas, 1999, p. 219).
Holistic approach (subjective and objective approach)	“Overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, productive, emotional and civic well-being all weighted by a personal set of values” (Felce, 1997, p. 132).
Disability-related approach	Schalock (as cited in Raphael et al., 1996, p. 69) defined QOL as “the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings (family, recreational, school, and work.” Cummins (as cited in Umb-Carlsson & Lindstedt, 2011, p. 241) mentioned that according to IASSID SIRG-QOL, “[QOL] may be conceptualized as a construct that: (1) it is multidimensional and influenced by personal and environmental factors and their interactions; (2) it has the same components for all people; (3) it has both subjective and objective components; and (4) it is enhanced by self-determination, resources, purpose in life, and a sense of belonging.”
Children related approach	Lindstrom (as cited in Zekovic & Renwick, 2003, p. 26) defined QOL as “the total existence of an individual, a group, or a society describing the essence of existence as measured objectively, and perceived subjectively by the individual or group or society.”
Individual QOL approach (IQOL)	Schalock et al. (as cited in Werner, Edwards, Baum, Brown, Brown, & Isaacs, 2009, p. 502) summarized the main domains included in IQOL as follows: “emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.”

There were many different approaches and handlings for the concept of QOL. Yet, not all of them was applicable for addressing the exact wants of individuals with disabilities and their families (Zekovic & Renwick, 2003, p. 23). Accordingly, the International Association of Scientific Studies on Intellectual Disability with Special Interest Quality of Life Group (IASSID SIRG-QOL, 2000) agreed on an international consensus document, which described the conceptualization, assessment, and implementation of QOL within the disability field (Brown, Anand, Fung, Isaacs, & Baum, 2003, p. 208).

IASSID SIRG-QOL (2000) conceptualized the principles of QOL for individuals with disabilities as follows:

- (a) QOL has subjective and objective elements, and the subjective part is more weighted as it reflects the individual's own evaluation of personal QOL;
- (b) QOL, as a coherent system, should be acknowledged by policy makers as a dependable tool that could be used to improve social service programs according to the consumer's needs;
- (c) one experiences better QOL when his/her basic needs are met and his/her life major goals are fulfilled;
- (d) QOL is a complex human construct that concerns the individual's well-being, and it includes family interactions, community involvement, personal health, surrounding environment, education, and financial well-being. (p. 12)

More recently, Zuna, Summers, Turnbull, Hu, and Xu (2010, p. 262) concluded a modern conceptualization of family quality of life, which is "a dynamic sense of well-

being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.”

QOL Domains and Indicators

QOL domains refer to the group of aspects constituting personal welfare and should be considered as the scale through which the QOL concept spreads (Verdugo, Schalock, Keith, & Stancliffe, 2005, p. 709). Most QOL researchers concluded that the number of domains was less significant than the acknowledgment of the multidimensional context of any proposed QOL model. Verdugo et al. (2005) concluded that the people were aware of what was essential to them, and one of the important features of any set of domains was that they were representing in total the whole QOL structure (p. 709). The most commonly referenced QOL domains include social interactions, community involvement, individual's progress, physical and mental health, safety, general well-being, human rights, surrounding condition, family welfare, and enjoyment potentials (p. 709).

QOL indicators refer to the satisfaction or attitude toward QOL domain, which indicates an individual's welfare (Verdugo et al., 2005, p. 709). QOL indicators constitute the foundation for judging QOL outcomes in addition to its strategic significance as well (p. 709). Recent research identified six QOL domains, which include physical, psychological, material, social, civic, and material welfare (Park et al., 2003, p. 368).

Schalock et al. (2007) mentioned that QOL for individuals with disabilities included similar domains as individuals without disabilities. In contrast, Hatton (as cited in Park et al., 2003, p. 368) stated that the practices of individuals with disabilities could

be limited owing to the restrictions forced by their disability circumstances, and consequently, these restricted practices may lead to altered indicators of QOL.

Measurement

QOL measurement is commonly constructed on at least three principles. First, QOL is essential for all humans, including persons with disabilities. Second, measuring QOL is mandatory to comprehend the level to which individuals live in a state of welfare. Third, assessing QOL reveals the combination of two connotations of QOL, which include (a) universal meanings that are generally comprehended by any one, and (b) culture-related meanings, which have become valued by people as they live within their own communities (Verdugo et al., 2005, p. 708).

Measuring QOL can place emphasis on either the subjective fulfillment by the individual, in relation to the QOL domains with their associated indicators, or the objective measurement of personal satisfactions to the defined domains and indicators (Verdugo et al., 2005, p. 709). Schalock and Felce (as cited in Verdugo, et al., 2005, p. 710) proposed that both subjective and objective measurements were needed for evaluating QOL.

The way QOL measurement is completed, however, is determined mainly by its expected use. For instance, if the purpose of the measurement is to evaluate the satisfaction of a group of people toward their lives in relation to other population subgroups, one would use the subjective measurement of QOL. On the other hand, if the purpose of the study is to investigate the service design or program, the objective measurement of the specific QOL domains and indicators would be employed (Verdugo et al., 2005, p. 710).

Compared to individual QOL, Family Quality of Life (FQOL) tackles the effect of each family member's QOL on the family and the relations and interaction between the family members as they create the overall FQOL (Poston et al., 2003, p. 319). Family outcomes could be defined as "impacts (either positive or negative) experienced by families because of supports and services for themselves and/or their children with disabilities" (Summers, Poston et al., 2005, pp. 777–778).

Borthwick-Duffy (as cited in Park et al., 2003, p. 368) concluded that it was crucial to pay attention to the distinctiveness of each person, and each family, in theorizing and creating an effective assessment for QOL in families. The FQOL research resulted in the progress of three main FQOL measures: (a) Beach Center FQOL tool, (b) the International FQOLS-2006, and (c) Latin American FQOL Scale (Zuna, Turnbull, & Summers, 2009, p. 25).

Furthermore, over a 3-year period, a set of applied researchers from Australia, Canada, and Israel concluded nine domains and six dimensions that appeared to be crucial to FQOL in families with members with disabilities. These domains included family interactions, family's health, disability-related services, employment, financial welfare, life enjoyment, impact of ideals, social relations, and assistance by others (Werner, Edwards, Baum, Brown et al., 2009, p. 502). Moreover, The International FQOLS-2006 assessed FQOL through nine domains. That assessment tool was mainly aimed to offer legislators and service providers a way of evaluating the effectiveness of the provided services in response to family requirements and, eventually, improve service provision (p. 503).

In conclusion, the reviewed QOL definitions and measurements come from different contexts, and they conceptualize different approaches to QOL. However, there are common elements between these approaches, which include: (a) the acknowledgement of the multidimensional framework of QOL; (b) the subjective and objective components of QOL; and that (c) QOL should include shared universal QOL domains and indicators, in addition to the cultural and social related ones.

Theoretical Framework

Research about the welfare of families extended the concept of individual QOL to families of peoples with disabilities (Zuna, Turnbull, & Summers, 2009, p. 25). Jokinen, Brown and Summers et al. (as cited in Werner, Edwards, Baum, Brown et al., 2009, p. 502) explained that the model of FQOL advanced out of the border of individual QOL work and was functional to families of children with disabilities. Brown and Brown (2003) confirmed that FQOL arise from acknowledgment of the extremely significant role of families in preserving operational and continual steadiness of all human communities.

Furthermore, the governmental funding in developed countries is usually either provided directly to families who have care giving responsibilities toward one of their members with disabilities or to social services to provide those families with various services and programs. However, research about parental and families' QOL in families of members with disabilities did not start to evolve until recently (Brown et al., 2003, p. 208). Not surprisingly, applied research of FQOL is not only still sparse, but it is also not uncommon to be faulty implemented in practice as well (Zuna, Turnbull, & Summers, 2009, p. 26).

Theory of FQOL

Zuna, Turnbull, and Summers (2009) recently proposed the unified theory of FQOL. That theory encompassed four explanatory concepts; these concepts had the power of predicting and changing the FQOL outcomes (p. 26). Each concept could be used separately, or in combined interaction with the others, to give a comprehensive picture of a particular FQOL (p. 26).

In discussing the unified theory of FQOL, Zuna, Turnbull, and Summers (2009, p. 27) stated,

Systems, policies, and programs directly impact individual and family-level supports, services, and practices. Individual member concepts (i.e., demographics, characteristics, and beliefs) and family-unit concepts (i.e., dynamics and characteristics) are direct predictors of FQOL and interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family strengths, needs, and priorities that re-enter the model as new input resulting in a continuous feedback loop throughout the life cycle.

For this study, individual-member concepts were highlighted in this section. The individual-member concept refers to the demographics, beliefs, and characteristics of any member within the family (see Figure 1). Demographics may include any basic personal traits, such as the age of the family member with disability, condition severity, and the type of disability or the parental age, sex, and education level. Beliefs are defined as “a family member’s attributions of meaning, expectations, or understanding about a phenomenon, such as the meaning of the individual’s disability, expectations about the

individual's future, or expectations about parental roles in partnership with professionals in meeting their needs" (Zuna, Turnbull, & Summers, 2009, p. 29). Individual's characteristics refer to the complex individual traits that may vary over time, such as parental mental health and siblings' health status.

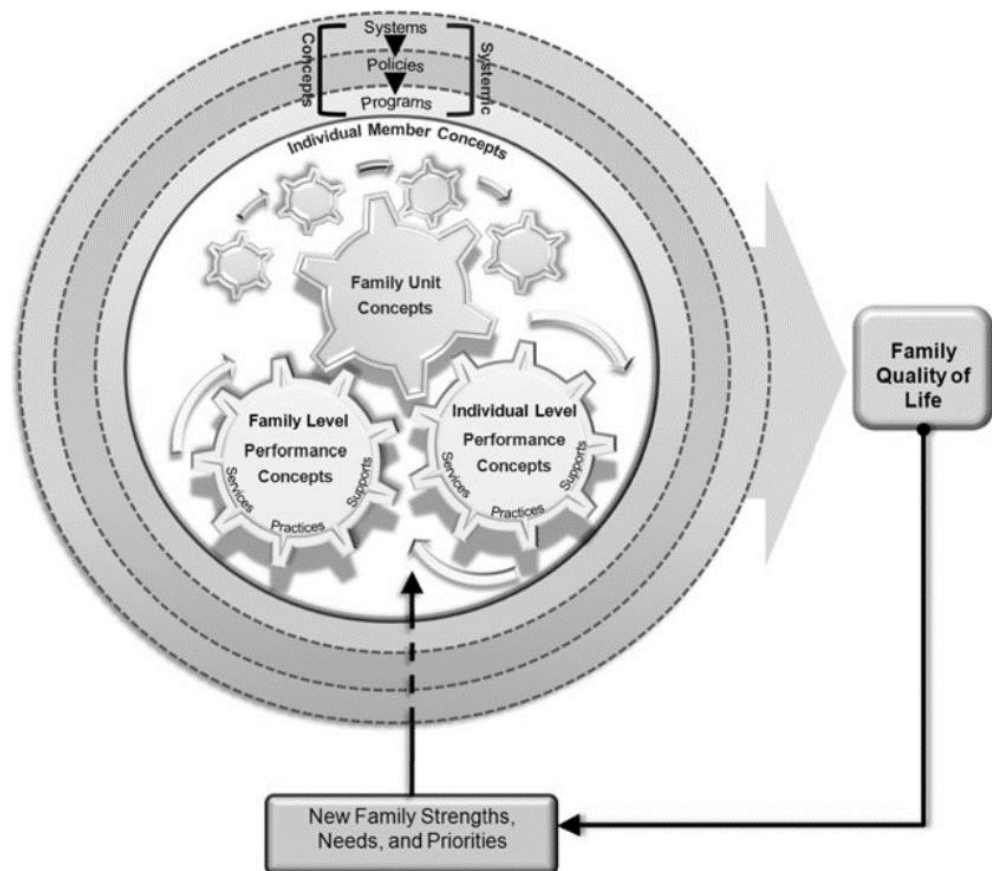


Figure 1. Unified Theory of FQOL.

Source: "Family Quality of Life: Moving from Measurement to Application," by N. Zuna, A. Turnbull, & J. A. Summers, 2009. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), p. 27. Copyright 2009 by Zuna et al.

It is good to note that parental and family QOL could be theoretically altered based on the variations in the individual-member concepts alone or in combination with the other three concepts. Accordingly, changes in the severity degree of the disability and

changes in the age of family member with disability are theoretically expected to have a substantial role in the variations of parental QOL during the different family life cycle.

In conclusion, parental and family QOL are changing during the family life; these changes are elicited by any change in the individual-member concepts or family unit concepts, and these changes could reflect positive or negative experiences based on each family's unique context. FQOL outcomes should be utilized to improve the system, policies, and procedures that deal with those families.

Impacts of Parenting a Child with Disabilities on Parents' QOL

Families with individuals with disabilities are more different than similar. Those families share the situation of having one of their members with a disability condition, yet, each family has a unique context depending on, for example, type, severity, and age of the individual with disabilities. Those families differ in other multidimensional factors, like parental education levels, socio-economic status, residence, religion, or even the presence of other psychological issues with other family members (e.g., alcohol abuse) (Swenson & Lakin, 2014, pp. 185–186).

Parents of children with disabilities are generally challenged with additional responsibilities that are added to the usual parenting responsibilities of parents of children without disabilities (Swenson & Lakin, 2014, p. 186). Not surprisingly, many professionals who are dealing with children with disabilities have the perception that there is a decreased QOL among parents of those children and their family members (Bode, Weidner, & Storck, 2000, p. 354).

Generally, families with disabled children tend to have lower FQOL than families with normally developed children. Families of children with major behavioural problems

tend to have lower FQOL than those of children without those behaviours. Mothers of children with severe disabilities are more likely to develop depression than mothers of children without any disabilities (Zuna, Turnbull, & Summers, 2009, p. 29).

Many factors could be responsible for the lowered QOL in families of children with disabilities. Firstly, one obvious factor could be the persistent and long-term challenges that confront those families, which will eventually influence their overall QOL (Davis & Gavidia-Payne, 2009, p. 153). Parenting a child with a disability, with the burden of extra caregiving responsibilities, could entail a substantial drainage of the parental emotional energy, physical energy, and financial resources (Raver, Michalek, & Gillespie, 2011, p. 116). Additionally, parents and siblings may feel and experience variable emotions toward adjusting their caregiving duties according to the changing needs of the person with disabilities, while trying to maintain their work and life balances (Plant & Sanders, 2007; Raina et al., 2004).

For example, in a quantitative cross-sectional study conducted at Ulm, Germany by Bode et al. (2000), parents expressed their views, through questionnaires, toward QOL in their families that have a member with disability, which were compared to another group of parents with no disabilities among their members. Results obtained from 145 parents in families of children with different types of disability and different ages, ranging from seven to 14 years of age, compared to 279 parents of families without disabilities, revealed that QOL for all members in families of children with disabilities is lower than QOL for families of children without disabilities (Bode et al., 2000). However, questions used within that questionnaire were defined only by the authors and did not cover all the main domains of FQOL.

Worthy of discussion, in a qualitative study with a phenomenological approach, seven families of children participated in a series of interviews (Worcester, Nesman, Mendez, & Keller, 2008). The children had different types of disabilities with different underlying diagnosis and were in the age group of two years one month to three years seven months. However, all children showed challenging behaviours, such as tantrums, noncompliance, possessions damage, and self-injury. Results indicated that parents' negative experiences could be categorized into five core areas as follows: (a) lack of precise and beneficial information, (b) lack of services and supports, (c) economic pressure, (d) anxiety between members of the family, and (e) social separation (Worcester et al., 2008).

Secondly, the complications of parenting a child with a disability may bring more impacts than a simple change in the parental QOL. In a quantitative study, Cadman et al. conducted a survey about the psychological and emotional impacts on parents of children with chronic health conditions (Wallander & Varni, 1998). The surveyed fathers and mothers of 1,800 families were a representative sample of the Ontario population. Mothers of children with chronic health conditions reported more negative effects than those of children without chronic health condition. Moreover, fathers and mothers of children with chronic health conditions reported two to three times more mental health treatments in comparison to those parents of children without chronic health conditions, and there was no difference in community isolation or alcohol issues (p. 38). However, that study was limited, as it was done at one point-in-time and did not search in depth into the relationship between such psychological disorders and mental treatment and parenting a child with disability (p. 38).

Moreover, Bailey, Golden, Roberts, and Ford (2007) conducted a review of the studies that investigated the maternal depression in mothers of children with disabilities compared to mothers with normally developing children. They recognised 17 studies that concluded mothers of children with disabilities showed more depressive symptoms than the control group.

However, the effects of parenting children in terms of only maternal depression has been criticized, as there has not been a balanced measurement of the other FQOL domains. These measurements could have concluded other positive impacts on those parents and recognized the fact of the FQOL being a multidimensional complex construct (Zuna, Selig, Summers, & Turnbull, 2009, p. 112).

Presented in this section, from two different studies that used a qualitative design, were quotes from some parents' own words about their positive and negative experiences and some of the challenges faced while providing care giving to their child with a disability. The first study conducted at the University of Toronto, reported results from an international study conducted to assess QOL in 34 families of children with disabilities at two large urban areas in Canada (Brown et al., 2003). Regarding health of the family, one family said, "It is difficult to get appointments and to find someone whom we can work with. Language barriers make it hard to understand what specialists say" (p. 211).

Regarding professional services and support, two families from Brown et al. (2005) said:

The challenge is that services come and go. The services are there, but are very thin, and when they cannot deliver, there are no alternatives. (p. 218)

Figuring out the maze of finding the right professionals in the system is quite a challenge. You are not sure, who to talk to, or what questions to ask. We do not know where to go for services. (p. 218)

The second study was a qualitative study with phenomenological approach; this study conducted at the University of Florida with eight parents representing seven families (Worcester et al., 2008). One mother in Worcester et al.'s (2008) study expressed her strife with having a service coordinator, who agreed on her involvement in service choices, and mentioned,

You know, early intervention made my life more difficult, because instead of giving me the services that my daughter needed, every conversation with them was stressful. I had to do major research and major documentation to justify any decision. (p. 518)

Regarding community isolation, another family said,

Definitely inhibits our ability to go out into the community. Lenny is unpredictable and he is destructive not only to our own family unit, but to people around him. We cannot take him normally to places like cinemas. (p. 520)

However, in Worcester et al.'s study, a family's positive experience toward professional support was presented, when one family said,

I was just excited that she would take the time on a Saturday to come out, and spend time with us. She gave up her own personal time at home, and even offered to go to the mall with me; she is definitely willing to help. (p. 521)

Thirdly, parental QOL in families with members with disabilities could be perceived differently due to other variables that moderate the parenting burden either in

negative or positive ways. For example, families of children with intellectual disabilities, in which both parents were present, showed higher QOL than families with only single parent. Additionally, socioeconomic status was found to correlate with the parental QOL in families with disabilities, as parental QOL was lower in families with lower household income (Giné et al., 2015).

Moreover, employment status was found to be correlated with parental QOL, as parents of children with disabilities who are employed showed higher QOL than parents who stayed at home to take care of their children with disabilities (Ferrer et al., 2016). In addition, social support was found to be correlated with FQOL, as families who had little social and network support showed lower QOL than families who had adequate social support (Davis & Gavidia-Payne, 2009).

Finally, the parental perception toward their child's condition was found to impact the parental satisfaction of their QOL. Parents who had positive perception and greater acceptance of their child's disability condition showed a higher sense of well-being and more QOL ratings (Greer, Grey, & McClean, 2006; Kayfitz, Gragg, & Orr, 2010). More knowledge and positive perception of the parents toward their child(ren)'s condition was correlated with higher QOL in parents of children with autism (Kuhn & Carter, 2006). Knowledge was found to be more protective, especially maternal depression symptoms (Blacher & McIntyre, 2006).

In conclusion, parenting a child with a disability results in various impacts and consequences on the parental QOL and FQOL. These impacts occur because of many influences, such as (a) additional parental care-giving responsibilities; (b) interactions and perceptions of the family members toward the child's disability status; (c) external

support that the family gets from the society in forms of intervention programs, health services, and community support; and last, but not least, (d) the policies and procedures, or in other words, the system that provides the family with solutions to meet their daily needs and wants.

Relationships between Severities of Disabilities and Parental QOL

The research about the impacts of the severity condition of individuals with disability on their parental and family's well-being has looked at the severity, as a variable and concept, in different ways. Numerous researchers have defined the severity as the challenging behaviours, such as self-injury, property destruction, tantrums, noncompliance, and excessive crying, that the individual with disability showed versus no associated behavioural concerns (Baker et al., 2003; Essex, Seltzer, & Krauss, 1999; Floyd & Gallagher, 1997; Wang et al., 2004).

On the other hand, other research conceptualized the disability severity as the degree of the underlying medical condition or the degree of the limitation in one of the major life areas. For example, disability severity was measured as the degree of mental retardation (Halby & Hanzlik, 1990), level of communication impairment (Frey, Greenberg, & Fewell, 1989), or severity of spina bifida (Kazak & Clark, 1986). Not surprisingly, there have been mixed research results on the impacts and associations between the disability severity and parental and family QOL. One obvious factor could be the obtuse nature of the concept of severity itself and the manner of its objective measurement (Wang et al., 2004).

Another factor that could play a role in the inconsistency of the research results about the relationship between the individuals' health-related condition severity and their

parental QOL is the perceptions of the parents toward their child(ren)'s condition severity. Those perceptions could either directly impact their subjective satisfaction of their QOL or at least mediate the effects of the objective assessment of their child(ren)'s condition severity toward their satisfaction of their well-being either in a negative or positive way (Schulz et al., 2012; Zheng et al., 2014).

This could be explained by the theoretical model proposed by Wilson and Cleary (1995), in which they conceptualized a link between clinical variables, such as condition severity, and health-related outcomes, including QOL. In presenting their model, Wilson and Cleary tried to blend the traditional clinical biomedical model with the social QOL model into a matrix that could be used to improve the health-related QOL. They acknowledged the complexity of the social and psychological interactions between the individual and his/her immediate surroundings, such as his/her family members, and the environment in the context of the individual's health-related variables, such as his/her severity condition. They also pointed out that the personal perceptions of the QOL, as being influenced by the objective health condition evaluation, could be mediated by the subjective perception of that health condition.

Regardless of the disability type, parenting a child with challenging behaviours seemed to have significant impacts on the parental QOL. Fox, Vaughn, Wyatte, and Dunlap (2002) conducted a qualitative study using a semi-structured interview format with 20 family members of children in the age group between three to 12 years old who had challenging behaviours. In their study, they aimed to improve the positive behavioural support interventions. The authors concluded that the child's challenging

behaviours affect all aspects of family functioning, and those families would highly value the support from others.

Likewise, Worcester et al. (2008) conducted a qualitative study with a phenomenological approach that included seven families of children with challenging behaviours and who were diagnosed with different types of disabilities; the children age group was between 25 to 43 months old. The authors concluded that raising a child with challenging behaviours could entail a certain degree of financial strains, some sort of community isolation, stress among immediate and extended family members, and a crucial need for both accurate information and adequate services.

The severity of a disability seemed to be a principal factor that could contribute to parental stress and apprehension (Plant & Sanders, 2007). That could be explained, in part, because of the potential burdens of the long-term care responsibilities and duties that do not only add additional roles, but they also necessitate significant reorganisation of priorities and drain additional energy within those families as well (Raina et al., 2004).

Parents, especially college-educated, of children with severe forms of disabilities were more likely to lose control over their lives, especially the day-to-day life events. Those parents reported more deterioration in their families' economic situations and more distress in their marital relationships. Sadly, one mother even reported losing her husband because of the increasing caregiving demands. Those parents, however, reported that they felt enriched by their caregiving responsibilities (Raver et al., 2011).

Moreover, parents of children with severe mental health problems seemed to have higher levels of physical symptoms, depression, and alcohol abuse symptoms at their mid-life. Those parents, however, appeared to have normal forms of educational and

occupational achievement and marital status (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Additionally, parenting a teenage with severe mental disabilities was associated with increased levels of parental health problems and psychological distress (Gallagher & Mechanic, 1996; Seltzer, Greenberg, & Krauss, 1995), higher incidence of work-related disturbances (Maurin & Boyd, 1990), and more financial strains (Clark & Drake, 1994).

Additionally, in a quantitative study, a cross-sectional survey design conducted with 131 children identified as having attention deficit hyperactive disorder (ADHD), recruited over a 12-months period, at British Columbia Children Hospital's ADHD clinic. The results revealed that all aspects of psychosocial well-being, family stability, family activities, and the psychosocial summary scores were significantly lower in families of children with ADHD compared to Australian and American population norms (Klassen, Miller, & Fine, 2004). However, that study did not exclude the possibility of the concluded lower health-related QOL of those families to be a result of the reduced health-related quality of services at the clinic itself. In addition, it was limited in the variations within the sample population regarding socioeconomic status, age, gender, and the differently offered health care systems because of the absence of Canadian norms or cross-country comparisons (p. e546).

On the other hand, parents of children with lesser degrees of developmental disabilities reported similar responses to the parents of children without disability in terms of educational satisfaction, marriage, psychological health, and physical health (Seltzer et al., 2001). That finding could be explained by the resiliency in well-being amongst those families (Greer et al., 2006) and the successful coping strategies that those families exerted (Meirsschaut, Roeyers, & Warreyn, 2010). For example, those parents

could effectively adapt to the special needs of their children with disabilities by redistributing the different roles of family members, such as more caregiving duties allocated to the mothers and siblings if the fathers are working extra hours (Keogh, Garnier, Bernheimer, & Gallimore, 2000).

In contrast, research reported that individuals' severities of their disability conditions were not correlated to their parental QOL. For example, Luijkx (2016) concluded that QOL in parents of children with different types of disability did not vary significantly based on their child(ren)'s condition severity, and the parental satisfaction toward the quality of the services provided to their child(ren) was not dependant on their child(ren)'s condition severity. However, those parents reported that their leisure activity was correlated with their child(ren)'s condition severity. Additionally, Lin et al. (2009) suggested that the parental QOL for parents of children and adolescents with intellectual disability was not associated with the severity of their child(ren)'s disability condition.

In conclusion, there have been contradictory results about the effects of the individuals' condition severity on their parents' QOL. Parental, mostly maternal, QOL seemed to be correlated with the severity of the child(ren)'s condition, especially in the domain of physical and mental health. Severe forms of disabilities, especially the intellectual disabilities or the disabilities that are associated with challenging behaviours, appeared to affect the parental QOL domains of family interactions, family finance, employment, community involvement, and leisure activities.

On the other hand, some families showed better resiliency and coping strategies that empowered them to manage the severities of their child(ren)'s conditions. They were able to reprioritize their responsibilities, which eventually provide them with a balanced

QOL. However, the QOL in those families was changing throughout their life cycles. Those results warrant more comprehensive research about the effects of the child(ren)'s condition severities on their parental QOL, in terms of investigating different types of disabilities and different family contexts through different parental life cycles.

Relationships between Parental QOL and Their Disabled Child(ren)'s Age

The parental needs and anticipations may vary with the changing responsibilities within the family life cycles. Consequently, comparing parental QOL of children with disabilities during their different growing stages and studying the relationship of the disabled child's age to his/her parental QOL can call for different service systems (Summers, Hoffman et al., 2005, p. 49).

Within the researcher's literature review for this study, very few studies in the literature examined or even compared the parental satisfaction with their QOL across different age groups of their children with disabilities. Little is known about the parental QOL when their children with disabilities grow up and become young adults or even in the transition stage from childhood to adolescence (Boehm et al., 2015, p. 396).

Understanding the parental QOL and experiences during the transition and adolescence stages of their child(ren) with disability is mandatory because of many reasons. Firstly, several demographic factors have been linked to the parental QOL during the childhood period of the individuals with disability, such as condition severity (Wang et al., 2004) and household income (Hu, Wang, & Fei, 2012), which could interact differently for families of youth with disabilities.

For example, the presence of children's challenging behaviours could contribute to more unsatisfactory parental QOL during the youth period of those children (Carter et

al., 2012). Additionally, the emerging of maladaptive behaviours that are experienced by some of the individuals with severe disabilities in their youth could be impacting their parents' QOL negatively (Ferrell, 2010).

Secondly, parents of youth with disabilities could face new challenges, as their children will move from the normal stream of the educational system to different systems as they grow up, such as vocational organizations, living activities, or even residential homes (Kraemer & Blacher, 2008). Those challenges will convey another parental cycle of adaptations and new strategies of coping with different sets of prioritization, which could be very stressful for those families (Neece, Kraemer, & Blacher, 2009).

Thirdly, families' doubts, projections, knowledge, and expectations may vary significantly during the youth transition period based on the underlying disability type or medical diagnosis. This could be explained, in part, through the effects of maturation changes, which would be experienced differently according to the type of disability (Blacher, Kraemer, & Howell, 2010, p. 4).

For instance, parents of young adults with autism reported significantly more worry about the transition periods than parents of young adults with Down syndrome and cerebral palsy. Also, parents of young adults with Down syndrome showed more expectation that their son/daughters would be able to have work employment and community involvement than parents of young adults with autism, who showed more restrictive expectations (Blacher et al., 2010).

Research results about the parental QOL and families' experiences during the youth and young adult periods of their children with disabilities have been controversial. For instance, Seltzer and colleagues (2001) demonstrated that parents in their early 50s

whose child has severe mental health issues were more likely to have alcohol dependence problems (mostly fathers), more likely to report significant elevations of their physical health and depressive symptoms (mostly mothers), and low ratings of their psychological well-being scores. That could be explained, in part, by the hypothesis of “greater mid-life strain for the parents of persons with severe mental health problems” (p. 278).

Additionally, Lounds et al. (2007) noted that maternal depression and anxiety increased during the high school period of youth with autism. On the other hand, Greenberg, Seltzer, Krauss, Chou, and Hong (2004) concluded that mothers of adults with Down syndrome reported better QOL, mainly in the domain of relationship. Moreover, mothers of youth with cerebral palsy rated their well-being lower than mothers of youth with Down syndrome, but higher than mothers of youth with autism (Blacher & McIntyre, 2006).

Conversely, Boehm and colleagues (2015) concluded that parents of youth and young adults with disabilities were generally satisfied with their QOL. Higher parental QOL rating reports were associated with lower severities of the youth with disabilities, and higher parental QOL ratings were also associated with more religious strengths. Similarly, Povee, Roberts, Bourke, and Leonard (2012) found that parental and family QOL scores in parents of Down syndrome individuals in the age range of 4-25 years old, especially in the domains of family interactions, community interactions, and leisure activities, were high with more family happiness.

On the other hand, parents of younger children with disabilities tend to report higher satisfaction of their QOL than parents of older-aged children (Summers, Hoffman et al., 2005, p. 56). For instance, Wang et al. (2006) noted that parents of children with

disabilities in the kindergarten stage reported higher ratings of QOL. In addition, Epley et al. (2011) concluded that parents of children with disabilities who receive early intervention programs reported high ratings of their QOL.

Further worth noting, in a quantitative study conducted to investigate satisfaction with their primary service provider of 147 parents of children with disabilities in three different age groups (< 3 years old, 3-6 years old, and 6-12 years old), the parents finished the Beach Center Family-Professional Partnership Scale. The results revealed that parents of children between 6 to 12 years old were less satisfied than parents of children in the other groups (Summers, Hoffman et al., 2005). However, the small sample size of some subgroups in that study in addition to the non-random sample selection of the parents, as they were considerably involved in their child(ren)'s programs, was an important limitation of that study (p. 56).

In summary, the knowledge gap about the parental QOL of parents of youth and young adults with disabilities is salient. There has been little research in the literature that compared the parental QOL between the parents whose children are in different growing stages (i.e., childhood, teenage, and early adulthood).

The current knowledge suggests that the parental QOL could be impacted during the teenage and the high school years, or in other words, during the transition between childhoods to adulthood. The impact, however, is controversial and could be linked to the disability severity, the disability type, or the total household income.

Supports to Families of Members with Disabilities

Families are the central units of any community. Supporting parents and families of children and adults with disabilities is fundamental for the stability of both the social

and health-related long-term services. Providing satisfactory supports to parents of families of individuals with disability has been positively related to enhance QOL outcomes for the individuals with disabilities and their parents and families as well (Davis & Gavidia-Payne, 2009, p. 159). The importance of providing sufficient and satisfactory services stems from three reasons: (a) family support, (b) caregiving provided by parents and families, and (c) nationwide human capital.

Family support not only enables the families to function as one unit, but it also helps them to provide caregiving and assistance to their members with disabilities according to each family's unique dynamics and circumstances. Moreover, tailored family support could lead to better inclusion of those families in their communities. Therefore, family support should enhance the QOL of the individuals with disabilities and their families (Wang & Brown, 2009, p. 150).

Caregiving provided by parents and families to their members with disabilities is invaluable, constituting the most crucial factor in the sustainability of the long-term social services and programs. For example, it was estimated that around 42 million families provided caregiving assistance to an adult with a disability on any given day in 2009 in the US. That caregiving included bathing, cooking, living events, and leisure activities. The unpaid cost of those caregiving services was around \$450 billion US dollars per year (Swenson & Lakin, 2014, p. 186). Accordingly, the system should strive to support Parents of children and adults with disabilities to empower them with the tools that they can utilize to provide high-quality caregiving, and avoid the high costs that would arise if those parents failed to provide their caregiving obligations.

Thirdly, as caregivers, parents of families that have members with disabilities constitute part of the human capital nationwide (Swenson & Lakin, 2014, p. 188). As noted by Lazarov and Petreski (2016, p. 41),

[Human capital refers to] people's knowledge, skills, and their motivation, which increase the economic productivity and accelerate the economic growth and it corresponds to any stock of knowledge or characteristics the worker has (either innate or acquired) that contributes to his or her productivity.

Accordingly, supporting those parents should preserve and improve a part of the country's human capital through allowing these caregivers to do their jobs and continue to take advantage of what they learned and trained for.

A lot of research has indicated that implementing family-centred practices, whether directly as active procedures or indirectly as guiding policies, would have better QOL outcomes for the parents and families of individuals with disabilities as well as the community (Dunst, 2002, p. 141). Moreover, Parish, Pomeranz, Hemp, Rizzola, and Braddock (2001) recommended that providing services to children and adults with disabilities would be ideally occurring, if it is carried out within the context of their families' lives and needs.

Turnbull, Summers, Lee, and Kyzar (2007) compared family support to various kinds of support that could be offered to families of children and adults with disabilities, including emotional support, financial assistance, information support, logistical support, community support, or professional support. They posited that families should manage their own supports in collaboration with the support providers; this should be designed based on families' strengths and their cultural values.

Fundamental principles of family-centred practices include (a) Parents or guardians' involvement in the decisions about any support, services, or programs offered to their children with disabilities and to them; (b) Families are the main caregiver and helper to their members with disabilities, and they are the main influencers in their lives; and (c) Families are the most resourceful reference to the needs, expectations, and well-being of their children with disabilities (Dempsey & Keen, 2008; Dunst, 2002).

A holistic model called "the life needs model" offers the assumption that if services are designed through a mechanism that address the specific and changing needs of children and adults with disabilities and those around them, this would significantly improve opportunities in their individual lives and will be reflected in better QOL for them (King et al., 2002, p. 58).

Presenting their life needs model; King et al. (2002) identified the main kinds of requirements for children, their families, and the community. They incorporated a family-centred approach to service provision, with the awareness that interventional programs and different services should be organized to identify and collaborate with the families, based on their children's age-specific needs and to support children's involvement in all areas of life (p. 58).

Turnbull and colleagues (2007) argued the need to consider the sociodemographic features of the families (e.g., the age of children or adults with disabilities, the type and severity of the disability, and household income) and the available social support. Therefore, the parental and family QOL domains and indicators should be the foundations for the creation, implementation, and evaluation of any provided services and programs to families with children and adults with disabilities.

The objective and subjective assessment of the caregiving burdens among parents of children and adults with disabilities may entail better resource allocations, more efficient services, and eventually more tailored family support systems (Savundranayagam, Montgomery, & Kosloski, 2011). For example, occasional relief, condition-specific parental education, and parental stress management education are amidst many procedures that should be incorporated within family support programs (Carona, Pereira, Moreira, Silva, & Canavarro, 2013).

The relationship between caregiving variables is not automatically linear, and it differs based on many other sociodemographic variables (Carona et al., 2013, p. 983). In other words, the same procedure that may work for one family does not necessarily work for another family. Accordingly, family supports should have the flexibilities to adapt to the unique family circumstances. For example, more respite care, information, and education supports would be more valuable to parents with low socioeconomic status (Swenson & Lakin, 2014, p. 188).

Unfortunately, family satisfaction with their provided disability services in Canada, like Australia and South Korea, was among the lowest scores of the surveyed FQOL domains. In addition, parents reported their vulnerable needs would be toward family supports, such as financial, information, and disability-related services support (Wang & Brown, 2009, p. 159).

The family-centred service, as a theoretical framework, has been established in the field of social work and family services. Yet, the field is still lacking the conceptual frameworks and practical guidelines that, firstly, can identify, provide, and evaluate the different family needs according to their different demographic variables and contexts.

Secondly, these frameworks and guidelines must be empowered by provincial and federal funding that make them sustainable and efficient (Wang & Brown, 2009, p. 159).

Chapter Summary

The complexity of the term “Quality of Life” arises from its multidimensional constructions, the unique integration of its subjective and objective components, and the diverse features of its contextual application. Therefore, the concepts of parental QOL in families of youth and young adults with disabilities need to have thoughtful understanding, proper conceptualization, and evidence-based measurements.

There is a need for different conceptual frameworks in conducting disability-related research, in terms of (a) dealing with a disability as a difference, rather than a defect; and (b) concentrating on QOL as solid grounds for evaluating and measuring family support services.

There are changes in parents' experiences in families with members with disabilities, in comparison to families with normally developed children and youth. These changes could have direct negative parental impacts, unfavourable future consequences, or positive consequences. Accordingly, more governmental investments should be allocated toward conducting more research on how to utilize efficient resources, creating evidence-based supports, and managing sustainable systems that could empower parents of youth and adults with disabilities to have better coping and resiliency in the context of their unique situations and needs.

This study focused on the individual member concepts (i.e., demographics, and characteristics) as one of the four concepts that could predict the FQOL outcomes. More specifically, the researcher hypothesized that the parental QOL outcomes should differ

based on the variations of the age and severity condition of the families' members with disabilities.

CHAPTER THREE

METHODOLOGY

In this chapter, the researcher explains the conceptual frameworks that guided this study, the research assumptions and hypotheses, and the research methodologies. A description of the data collection, study sample, measures and operational definitions, and data analysis is also provided.

Conceptual Framework

Based on the conclusions from the literature review, more specifically the work of Zuna, Turnbull, and Summers (2009), this study adopted six conceptual frameworks, which are detailed in this section.

1. QOL is a holistic complex notion with many domains and dimensions;
2. QOL could be measured subjectively and objectively;
3. Parents' QOL is both an active process and an outcome;
4. Being a dynamic process, parents' QOL would be altered over time, either positively or negatively;
5. Parenting a child, youth, and young adult with a disability may result in various impacts and consequences on the parents' and the families' QOL; and
6. There are possible relationships between some demographic variables, such as the severity of the individuals' disability and their age stage and their parents' life experiences and satisfactions of their QOL.

Research Assumptions

This study employed the following research assumptions: (a) As demonstrated in Figure 2, the individuals' age and disability severity would impact their parents' QOL. That impact would be affected by another confounding factor, such as the total household income, the province of residence, the health status of the parents, and family support. The parents' QOL would affect individuals with disability in a feedback cycle; (b) Parents' QOL would change as their children grow up into the teenage and young adulthood stages, and it would be lower as the children grow up into the transitional stages and young adulthood; and (c) Parents' QOL would change with their children's degree of disability and would be lower among parents whose children exhibit severe degrees of disabilities.

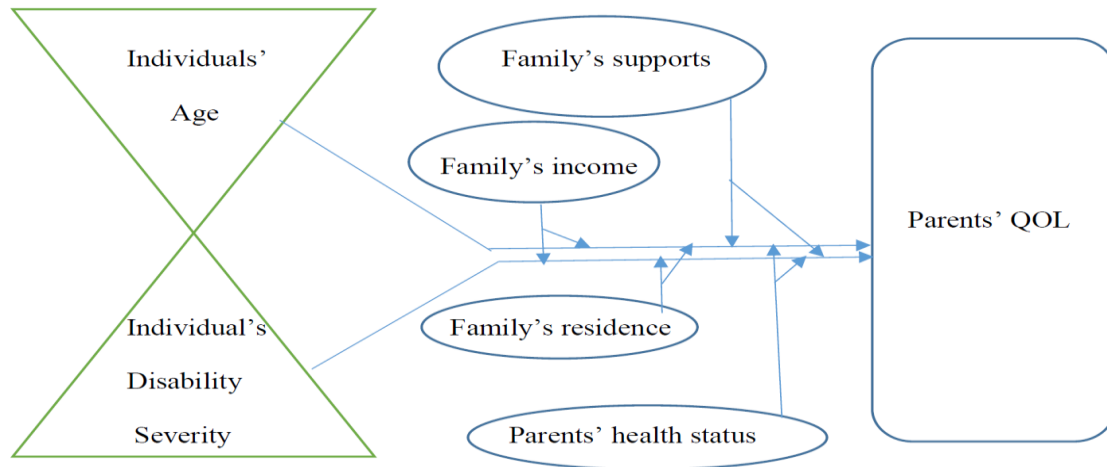


Figure 2. Diagrammatic representation of the assumed impacts of individuals' disability severities and age on their parents' QOL.

Research Hypothesis

The proposed research hypotheses were:

1. Parents' life satisfaction scores would differ based on their child(ren)'s age group and disability severity. (Null hypothesis: There is no significant differences in the life satisfaction scores of the parents whose child(ren)'s age is either 0-10, 11-19, or 20-29 years old, and their child(ren)'s condition severity is either mild, moderate, or severe); and
2. Percentage of parents who report their experiences about their different QOL domains would be different based on either their child(ren)'s age group or disability severities. (Null hypothesis: There is no differences in the percentages of the parents who reported their experiences about their different QOL domains regardless of their child(ren)'s age group or their disability severity).

Data Collection

GSS Cycle 26

Statistics Canada conducted its sixth General Social Survey (GSS cycle 26) on the topic of caregiving and care receiving over the period from March 2012 to January 2013. The target population for GSS Cycle 26 of the GSS included all persons 15 years of age and older in Canada, excluding (a) residents of the Yukon, Northwest Territories, and Nunavut; and (b) full-time residents of rehabilitation institutions. Stratified random sampling was used, with each of the Canadian 10 provinces divided into strata (i.e., geographic areas). Then, each province was divided into different strata, for a total of 27 strata, and within each stratum, the respondents were selected through the random digit dialling (RDD) method (Statistics Canada, 2013).

Computer-assisted telephone interviewing (CATI) was used to collect GSS data, and respondents were interviewed in the official language of their choice. The final sample size for GSS 26 was 23,093. The published data file contains one basic weighting factor for the analyses at the person level, and 500 bootstrap-weight variables for design-based variance estimations (Statistics Canada, 2013).

The public use microdata file (PUMF), which had been released and become publicly accessible through Statistics Canada by September 2013, was the basic data file for the secondary analyses of the current study (Statistics Canada, 2013). That dataset was downloaded and extracted through the University of Lethbridge library in June 2015. The dataset file had become available in many formats, including SPSS, STATA, and SAS files. The researcher received the dataset as anonymized data; there was no possible link that could reveal the identity of survey respondents.

Sample

For this study, data preparation was conducted using the Statistical Package for the Social Sciences program, version 22 (SPSS, v.22). The following criteria were employed for the study sample: (a) respondents are parent “primary caregivers”, (b) primary care receiver has a disability, and (c) primary care receiver’s age was between 0 to 29 years old. More details on these criteria are provided in this section.

The respondents were the primary caregivers who are parents, and this was conducted through selecting only the cases from the variable PRG_Q10 that had the values of either 3 (son of respondent) or 4 (daughter of respondent) for the analysis. The variable PRG_Q10 corresponded to “the relationship of the primary care receiver to the respondents.”

The primary care receiver had a type of disability, which included developmental disability, physical disability, mental conditions, or any other neurological condition, and this was conducted through selecting only the cases from the nominal variable PRP_Q10 that had the values of 17, 27, 11, and 13 respectively. The variable PRP_Q10 corresponded to “the main health condition or problem for which the primary care receiver received help by the respondents.”

The primary care receiver's age, which was one of the two main independent variables, was between 0 to 29 years of age. This was conducted through selecting the cases from the variable PRN_Q20 that corresponds to the values of that age groups and re-categorizing them into three age groups of 0-10, 11-19, and 20-29 years of age. Other respondents who did not have the previously mentioned criteria were excluded from the analyses.

Measures

In this section, the researcher discussed the independent, covariate, and dependent variables used for this study. The questions used for the analysis in this research are presented in Appendix A.

Independent Variables

The independent variables are age of the individual with disability and degree of disability severity. Severity was measured through the nominal variable PRP_Q15, which was a variable self-rated by the respondents to their care-receiver degree of condition severity. That variable was re-categorized into a new variable with the name “degree of disability” to exclude the option of “Not asked.” Thus, the new variable was a nominal variable with the options of “mild, moderate, and severe.”

Covariate Variables

Based on the literature review, study assumptions, conceptual framework, and the preliminary data cleaning and explorations, the following confounding variables were employed in the current study analyses as covariates:

1. The total household income, which was measured through the variable INCMHSD, was re-categorized into a new variable with the name "Total household income" to exclude the options of "Not asked" and "Don't know;"
2. The province of residence, which was measured through the variable PRV; and
3. The health status of the respondent, which was measured through the variable PRA_Q10.

Dependent Variables

Based on the work of Werner, Edwards, Baum, Brown et al. (2009), the overall life satisfaction about one's QOL significantly correlated with the composite scores obtained from all QOL domains. In addition, parents' QOL could be measured through nine domains, which includes "Health of the Family, Financial Well-Being, Family Relationships, Support from Other People, Support from Disability-related Services, Influence of Values, Careers and Preparing for Careers, Leisure and Recreation, and Community Interaction" (Isaacs et al., 2012, p. 18). Accordingly, parents' QOL was measured in the current study through two different means: (a) overall satisfaction of the parents, and (b) parents' responses related to their different QOL domains. Each will be discussed in this section.

Overall life satisfaction of the parents was measured through the categorical variable LSR_Q110 (see Appendix A). For this variable, the respondents were asked about “how they felt about their life as a whole right now through using a scale of 0 to 10, where 0 represented “Very dissatisfied” and 10 represented “Very satisfied”. This variable was re-categorized into an ordinal variable after the exclusion of the options “Not asked”.

Parents' responses about their different QOL domains were measured. The measured domains in the current study included: (a) parents' health; (b) family finances; (c) family interactions; (d) leisure and recreational activities; (e) community interaction; (f) government and professional supports; (g) parents' needs; (h) influence of values, coping, and rewarding; and (i) careers and employment. The next section includes the variables employed to measure those nine domains.

Parents' health domain. Parents' health domain was measured through the question variables that asked about the physical and emotional burdens experienced by the parents during the last 12 months because of their caregiving responsibilities (see Appendix A). Those variables included: ICP_Q15, which was a nominal variable that asked about the “self-rated physical stress by the respondent. This variable was re-categorized into an ordinal variable “physical stress” after the exclusion of the option “Not asked,” where 1 represented “very strenuous” and 4 represented “Not at all strenuous”. ICP_Q10 was nominal variable that asked about the respondent's physical health. This variable was re-categorized into a dichotomous variable “physical health” after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Additionally, emotional health/stress were measured through the variables CRH_Q10, CRH_Q20, CRH_Q30, CRH_Q35, CRH_Q40, CRH_Q60, CRH_Q70, and CRH_Q80, which were nominal variables that asked if the respondent felt “tired,” “worried,” “overwhelmed,” “lonely or isolated,” “short tempered or irritable,” “resentful,” “depressed,” or experienced “loss of appetite” and “disturbed sleep” respectively. Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Family finance domain. This domain was measured through the question variables that asked about the financial burdens experienced by the parents during the last 12 months because of their caregiving responsibilities (see Appendix A). Those variables included ICF_Q210, ICF_Q220, ICF_Q230, ICF_Q240, ICF_Q250, ICF_Q260, ICF_Q270, and ICF_Q280, which were nominal variables that asked if the respondents had out-of-pocket expenses for “home modifications,” “professional services,” “hiring people,” “transportation,” “specialized aids,” “prescription or non-prescription drugs,” “other related expenses,” and “if the respondent had financial hardships” respectively. Those variables were re-categorized into dichotomous variables with the similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Furthermore, the financial situations of the parents were measured through another set of variables that inquired if the parents had to search for another money sources during the last 12 months because of their caregiving responsibilities. Those variables included ICF_Q290, ICF_Q300, ICF_Q310, ICF_Q320, and ICF_Q330, which

were nominal variables that asked if the respondents had to “borrow money from friend or family,” “take loans from banks,” “defer savings,” “modify spending,” “sell off assets,” and “file for bankruptcy” respectively; Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Family interactions domain. Family interactions domain was measured through the question variables that asked about the family life. Those variables included ICL_Q110, ICL_Q120, ICL_Q130, ICL_Q180, and ICL_Q210, which were nominal variables that asked if the respondents had to “spend less time with spouse or partner”, “spend less time with their children”, “spend less time with other family members”, “had strains with their family members”, and “had to move residence” respectively; Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Leisure and recreational activities domain. Parents' leisure and recreation activities domain was measured through the question variables that asked about the impacts of caregiving responsibilities during the last 12 months on how the parents spent their time and planned for their vacations (see Appendix A). Those variables included ICL_Q135, ICL_Q140, ICL_Q150, ICL_Q152, ICL_Q154, ICL_Q160, and ICL_Q170, which were nominal variables that asked if the respondents had to “spend less time with friends”, “spend less time on social activities or hobbies”, “spend less time on relaxing or taking care of yourself”, “spend less time volunteering”, “spend less time participating in political, social, or cultural groups”, “make holiday plans and change or cancel them”,

and “not to make holiday plans at all” respectively. Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Community interactions domain. Community interaction domain was measured through the question variables that asked about the different supports and interaction that the parents had with their surrounding community (see Appendix A). Those variables included ACD_Q30, ACD_Q40, ACD_Q50, and ACD_Q60, which were nominal variables that asked if the respondents received “help from extended family members”, “close friends or neighbours”, “community, spiritual community, or cultural or ethnic groups”, and “occasional relief or respite care” respectively; Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Government and organizational support domain. The domain of government and organizational support represented the supports that the parents received from the disability-related service resources. This domain was measured through the question variables that asked if the respondent received help from paid professional or the government (see Appendix A). Those variables included ACD_Q80, ACD_Q90, and HPO_Q10, which were nominal variables that asked if the respondents received “money from government programs”, “federal tax credits”, or “if the primary care receiver received help from professionals that is paid workers or organizations” respectively. Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Parents' needs domain. This domain was measured through the question variables that asked about the different needs and wants that the parents may require accommodating for their caregiving responsibilities (see Appendix A). Those variables included OAC_Q20, OAC_Q30_C01, OAC_Q30_C02, OAC_Q30_C03, OAC_Q30_C04, OAC_Q30_C05, OAC_Q30_C06, and OAC_Q30_C07, which were nominal variables that asked if the respondents needed “other supports”, “home care”, “financial support/government assistance/tax credit”, “information / advice”, “emotional support/counselling”, “help from medical professionals”, “occasional relief / respite care”, and “voluntary/community services” respectively. Those variables were re-categorized into dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Influence of values, coping, and rewarding domain. This domain was measured through the question variables that asked about “how the caregiving responsibilities were rewarding,” “how the religious and spiritual values influenced the parents,” and “how well the parents could cope with the burdens of their caregiving duties.” Those variables included: (a) ICS_Q10 and ICS_Q30 were nominal and ordinal variables, (b) RLR_Q110 was a nominal variable, and (c) ICL_Q100 was a nominal variable.

ICS_Q10 and ICS_Q30 were nominal and ordinal variables that asked if the respondents “had a choice in taking on your caregiving responsibilities” and “how rewarding caregiving experiences were” respectively. Those variables were re-categorized into dichotomous and ordinal variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively in

the dichotomous variable, and 1 represented “very rewarding”, and 4 represented “Not at all rewarding” in the ordinal variable.

RLR_Q110 was a nominal variable that asked about the “importance of the religious or spiritual beliefs to the way that respondents lived their life during the last 12 months.” This variable was re-categorized into an ordinal variable “religious and spiritual beliefs” after the exclusion of the option “Not asked” where 1 represented “Very important” and 4 represented “not important at all”.

ICL_Q100 was a nominal variable that asked about the “respondents’ coping with their caregiving responsibilities”. This variable was re-categorized into an ordinal variable “parent’ coping” after the exclusion of the option “Not asked” where 1 represented “Very well” and 4 represented “not well at all”.

Careers and employment domain. This domain was measured through the question variable that asked about the impact of caregiving on the parents’ employment in the last 12 months (see Appendix A). Those variables included ITL_Q30, ITE_Q10, ITO_Q10, ITO_Q20, INE_Q10, and IPR_Q20, which were nominal variables that asked if the respondents “reduced their regular weekly hours of work because of their caregiving responsibilities,” “quit a job because of their caregiving responsibilities”, “were fired, laid off, or asked to resign from a job because of their caregiving responsibilities”, “turned down a job offer or promotion, or decided not to apply for a job, because of their caregiving responsibilities”, “took a less demanding job because of their caregiving responsibilities”, “had been prevented from working at a paid job because of their caregiving responsibilities”, and “retirement would be affected because of their caregiving responsibilities” respectively. Those variables were re-categorized into

dichotomous variables with similar names after the exclusion of the option “Not asked,” where “yes” and “no” were coded as 1 and 2 respectively.

Data Analyses

Statistical analyses of the data were conducted through SPSS, v.22. The personal weight “WGHT_PER” variable was used to calculate for the new normalized weight of the data subset that was produced after the application of the inclusion criteria of the current study. The normalized weight was calculated by dividing the weight of each personal weight by the overall average weight of the newly produced data subset (Statistics Canada, 2013).

Conducting statistical analyses on weighted data counted for the “over- and under-representation of geographic areas, respondent types, and age-sex groups in the unweighted file.” However, it did not consider the stratification and complex sample design of the GSS. Yet, the variance analyses of the weighted data should yield more reasonable and more meaningful results and inferences (Statistics Canada, 2013).

Descriptive analyses of the demographic parents' variables were completed and presented. Percentage frequency distribution tables of each parents' QOL domain score based on their child(ren)'s age group and disability severity were presented. This enabled the researcher to understand the impacts of the parents' caregiving responsibilities on their different QOL domains based on their child(ren)'s age and disability severity.

In order to answer the first research question, differences in the QOL's scores of parents of child(ren) of different degrees of disability severity (i.e., mild, moderate, severe) and different age groups (i.e., parents of children 0-10 years old, parents of teenagers 11-19 years old, and parents of young adults aged 20-29 years old) were tested

with two-way analyses of covariance (two-way ANCOVA). The parents' life satisfaction scores were the dependant variable, and the analyses controlled for the total household income, the parents' province of residence, and the health condition of the parents. A post-hoc test using Bonferroni correction was used in order to understand where the significance existed between the subgroups of each independent variable.

ANCOVA test could be used to increase the statistical power by reducing the within-group error variance or the unexplained variances, which embraces error variance (e.g., individual differences), in addition to the effect of other factors. Another use of ANCOVA test is to adjust for the preexisting differences in the nonequivalent groups, which would aim at correcting for initial group differences that exists on DV among several intact groups; in that specific usage, participants cannot be made equal through random assignment, so covariates are used to adjust scores and make participants more similar than without them (Miller & Chapman, 2001).

A minimum confidence interval of 95% was considered for all the analyses performed in this study. *P*-values, effect-size measures, and partial Eta squared were presented for the comparison analyses. The partial eta-squared statistic represented the "proportion of total variance explained by the effect of interest," and it ranged from 0 to 1, where 0.0099, 0.0588, and 0.1379 were considered the cut-off points between small, medium, and large effect sizes respectively. The *p*-values represent "the probability of obtaining the observed mean sample difference if there are in fact no differences between groups in the population" (Cohen, 1988).

Chapter Summary

This chapter focused on the operational definitions and measurements of parents' QOL that were employed in this study. The researcher also explained the conceptual frameworks, and research hypothesis, in addition to data collections and analyses that were utilized within this research work. In the next chapter, the researcher presents the results and findings of this study.

CHAPTER FOUR

RESULTS

Sample Demographics

The units of analysis for the current study included the caregivers who were parents of individuals with disabilities ($N = 193$), whose children were in the age groups of 0-10, 11-19, and 20-29 years of age (28.3%, 34.6%, and 37.1% respectively); their disability conditions were mental, neurological, developmental, and physical disability (30.5%, 40.3%, 23.7%, and 5.5% respectively); their disability severity degrees were mild, moderate, and severe (24.5%, 36.6%, and 38.9% respectively); and their gender was male (63%) and female (37%).

As presented in Table 2, the parents were mothers (63%) and fathers (37%), who were mostly in the age group of 35-54 years of age (69.1%), and were mostly married (69.5%) or living with common-law partner (15.0%). The parents were residing within the 10 Canadian provinces, with the highest percentage from Ontario (42.2%), and the lowest percentage at 0.5% each from Prince Edward Island and Newfoundland and Labrador.

Looking at parents' employment status, most of the parents were paid workers (59.0%); yet, 23.9% of the sample were not asked. As for the parents' highest education level, it was almost equally distributed between a high school diploma (26.3%), college certificate (26.7%), and university degree at the bachelor and above the bachelor level (25.8%); the rest of the sample was distributed among other levels of education.

Table 2. *Characteristics of Parents of Individuals with Disabilities in Canada*

Variable	<i>n</i> (weighted %) <i>N</i> = 193	Variable	<i>n</i> (weighted %) <i>N</i> = 193
Parents' age group		Parents of individuals with disabilities' age:	
25-34	26 (13.2)	0-10	55 (28.3)
35-44	59 (30.8)	11-19	67 (34.6)
45-54	74 (38.3)	20-29	72 (37.1)
55-64	32 (16.7)		
65-74	2 (1.0)	Parents' labour work status	
Parents' gender		A paid worker	114 (59.0)
Male	71 (37.0)	Self-employed	30 (15.3)
Female	122 (63.0)		
Parents' marital status		Parents of individuals whose disability type was	
Married	134 (69.5)	Developmental	78 (40.3)
Living common-law	29 (15.0)	Neurological	46 (23.7)
Widowed	5 (2.4)	Mental	59 (30.5)
Separated	8 (4.2)	Physical	11 (5.5)
Divorced	10 (5.2)		
Single, never married	7 (3.8)	Parent' province of residence	
Parents' education level		Ontario	82 (42.4)
Less than high school diploma	21 (10.7)	British Columbia	26 (13.5)
High school diploma	51 (26.3)	Alberta	15 (7.8)
Trade certificate or diploma	10 (5.2)	Quebec	33 (16.8)
College or other	52 (26.7)	Manitoba	18 (9.2)
Non-university certificate		Saskatchewan	5 (2.8)
University certificate	5 (2.5)	Prince Edward Island	1 (0.5)
Bachelor degree	31 (16.2)	Nova Scotia	8 (3.9)
University certificate above the bachelor level	19 (9.6)	Newfoundland and Labrador	1 (0.5)
Parents of individuals, whose disabilities' degree was		Total household income:	
Mild	46 (24.5)	No income	1 (0.7)
Moderate	69 (36.6)	5000-19,999	7 (4.5)
Severe	73 (38.9)	20,000-29,999	13 (7.8)
		30,000-39,999	17 (10.6)
		40,000-49,999	7 (4.2)
		50,000-59,999	15 (9.3)
		60,000-79,999	18 (10.8)
		80,000-99,999	21 (12.6)
		100,000-149,999	44 (26.7)
		150,000 or more	21 (12.8)

As per the total household income, parents with annual household income of more than \$100,000 were around 39.5%, \$50,000 to \$99,999 were 32.7%, and below \$49,999 were 27.8%. However, around 15% of the sample did not answer the question about their total household income.

Descriptive Statistics

To understand the possible impacts of caregiving responsibilities on the parents' different QOL domains (i.e., the second research question of the current study), the weighted percentages of the parents' scores of all their QOL domains in relation to their child(ren)'s disability severity and age were explored in this section and were presented in Tables 3 to 12. To answer the first research question, a more formal analysis and inferential statistics were presented in the following subsection.

Impacts of Individuals' Disability Severity and Age on Their Parents' Health Domain

As presented in Table 3, looking at the degree of disability severity, it appeared that as the severity of the family member with disability increased from being mild to being moderate or severe, it was more likely that the percentage of the parents who reported that they felt depressed, experienced loss of appetite, experienced sleep disturbances, felt very strenuous physical stress, and had their physical health suffered increased by more than double. The percentage of the parents who reported they felt tired, worried, overwhelmed, or lonely increased by at least 75%.

Table 3. *Weighted Percentages of Parents' Scores of Their QOL Health Domain Based on their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Suffered physical health	20.0	45.0	35.0	35.0	40.0	25.0
Had very strenuous physical stress	12.5	25.0	62.5	25.0	60.0	15.0
Felt tired	22.0	40.0	38.0	33.9	35.4	30.7
Felt worried	21.6	41.6	36.8	27.6	37.4	35.0
Felt overwhelmed	22.9	40.6	36.5	39.8	33.7	26.5
Felt lonely	22.6	40.8	36.6	29.2	40.3	30.5
Felt irritable	19.0	43.0	38.0	35.0	39.0	26.0
Felt depressed	16.7	42.6	40.7	24.0	40.0	36.0
Experienced loss of appetite	12.5	40.6	46.9	33.0	45.0	22.0
Experienced disturbed sleep	19.1	41.5	39.4	32.0	36.0	32.0

On the other hand, as the severity moves from being moderate to being severe, there was no clear trend of the percentage of parents' reporting on their health domain except for the variable of very strenuous physical stress, where the increase in the percentage of the parents was more than double when the severity increased from moderate to severe. These results indicated that the parents of individuals with disabilities whose condition were either moderate or severe were more likely to be affected regarding to their health-related QOL domain.

Looking at the age of the individual with disability in Table 3, it was more likely that the percentage of parents of individuals with disabilities in the 11-19 age group who

reported that they felt depressed, experienced loss of appetite, experienced sleep disturbances, felt very strenuous physical stress, had their physical health suffered, or felt tired, worried, and lonely were more than the percentage of parents of the other two age groups. These results suggest that regarding the health-related QOL domain, the parents of the individuals with disability were more likely to be impacted by the burdens of caregiving when their children were in the 11-19 age group rather than the younger or older age groups.

Impacts of Individuals' Disability Severity and Age on Their Families' Finance Domain

As presented in Table 4, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported that they had to pay-out-of-pocket expenses for home modification, professional services, transportation, specialized aids, prescription or non-prescription drugs, and other related expenses doubled and even tripled in case of paying out-of-pocket expenses for hiring more people. Similarly, as seen in Table 5, it was more likely that the percentage of parents, who reported having financial hardships, borrowing money from friend or family, and taking loans from banks increased two-folds as the severity increased. This increase sometimes came to more than three-fold when they reported that they had to defer some savings, sell off some assets, or modify their spending. These results suggest that as the family member's disability severity increased from being mild to moderate or severe, it was more likely to be accompanied by an increase in more financial burdens on the parents.

Table 4. *Weighted Percentages of Parents' Scores of their QOL Finance Domain Based on Their Child(ren)'s Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Home modification	18.9	32.5	48.6	26.3	39.5	34.2
Professional services	20.9	53.5	25.6	40.0	40.0	20.0
Hiring people	13.0	34.8	52.2	41.7	25.0	33.3
Transportation	21.1	45.2	33.7	30.8	35.6	33.6
Specialized aids	20.5	38.6	40.9	32.6	23.9	43.5
Other related expenses	17.1	40.0	42.9	29.1	40.3	30.6
Prescription or non-prescription drugs	19.0	40.5	40.5	30.5	40.2	29.3

Table 5. *Weighted Percentages of Parents' Scores of their QOL Finance Domain Based on Their Child(ren)'s Increase in Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Borrowed money from friend or family	8.0	32.0	60.0	56.0	24.0	20.0
Took loans from banks	16.6	41.7	41.7	42.3	42.3	15.4
Deferred savings	9.8	51.2	39.0	38.6	34.1	27.3
Modified spending	10.9	41.8	47.3	38.6	35.1	26.3
Sold off assets	18.2	27.3	54.5	54.5	45.5	0.0
Had financial hardships	19.0	40.5	40.5	30.5	40.2	29.3

Looking at the age of individuals with disability, it was more likely that a higher percentage of parents of individuals in the 11-19 age group would report that they had to pay out-of-pocket expenses for home modification, professional services, transportation,

prescription or non-prescription drugs, and other related expenses. Consequently, more of these parents experienced financial hardships and needed to take loans than the other two age groups. However, that was not the case for the other variables of the parents' financial domain, as the percentage of parents of individuals in the 0-10 age group was likely to be higher than the other two older age groups. Parents of the 0-10 age group reported that they had to pay out of their pocket for hiring more people, and they had to borrow from friends or family, defer some savings, modify their spending, and sell off some assets.

These results indicated that it was more likely that the parents would face different forms of financial burdens and would need to take different responses to accommodate those burdens when their children with disability were in the age groups of 0-10 and 11-19 more than when their children entered the 20-29 age group.

Impacts of Individuals' Disability Severity and Age on their Families' Interactions Domain

As seen in Table 6, looking at the individuals' disability severity, it was more likely that the percentage of parents who had to spend less time with their spouses or partners, their children, or other family members; had strains with one of their family members; or had to move their residence were higher by at least 50% when the severity was either moderate or severe as compared to the mild degree. These results indicated that as the severity increased from mild to moderate or severe, the parents would be more likely to have lower QOL in their family interaction-related domain.

Table 6. *Weighted Percentages of Parents' Scores of Their QOL As Regards Their Family's Interaction Domain Based on Their Children's Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Spend less time with spouse or partner	23.0	35.0	42.0	35.5	32.9	31.6
Spend less time with their children	21.4	32.1	46.5	40.7	37.3	22.0
Spend less time with other family members	17.0	35.4	47.6	27.6	37.1	35.3
Had strains with their family members	19.2	37.0	43.8	32.4	40.3	27.3
Had to move residence	27.8	38.9	33.3	72.2	16.7	11.1

Looking at the age of individuals with disability, it was more likely for a higher percentage of parents of children in the 0-10 age group to report spending less time with their spouses or partners, spending less time with their children, and having to move their residence than parents of the other two older age groups. On the other hand, it was more likely for a higher percentage of parents of individuals in the 11-19 age group to report spending less time with other family members and having strains with their family members than the other two age groups.

These results indicated that it was more likely that the parents would have some degree of instability in their family interactions when their children with disability were in the age groups of 0-10 and 11-19 than when their child(ren) reached the 20-29 age group.

Impacts of Individuals' Disability Severity and Age on Their Parents' Leisure and Recreational Activities Domain

As presented in Table 7, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported that they spent less time with friends or spent less time on social activities or hobbies, relaxing or taking care of themselves; volunteering; participating in political, social, or cultural groups; made holiday plans and changed or cancelled them; or were not able to make holiday plans at all were higher by at least 50%. These results suggest that the parents were more likely to have certain impacts on their leisure and recreational activity as the degree of disability of their child(ren) went higher, from mild to moderate or severe.

Table 7. *Weighted Percentages of Parents' Scores of Their QOL Leisure and Recreational Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' disability severity			Age of individuals with disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Spent less time with friends	20.5	38.4	41.1	33.6	33.6	32.8
Spent less time on social activities or hobbies	19.5	40.7	39.8	34.0	32.5	33.5
Spent less time on relaxing or taking care of yourself	21.3	40.9	37.8	33.3	33.3	33.4
Spent less time volunteering	20.2	38.1	41.7	39.8	29.5	30.7
Spent less time participating in political, social, or cultural groups	23.0	37.8	39.2	33.8	31.2	35.0
Made holiday plans and change or cancel them	19.5	40.2	40.2	34.5	25.0	40.5
Had not to make holiday plans at all	22.4	34.2	43.4	35.4	30.4	34.2

On the contrary, looking at the age of individuals with disability in Table 7, there was no clear trend or differences in the parents' reporting among the three age groups of their children with disabilities. These results suggest that there were no differences in the impacts of caregiving responsibilities on the parents' leisure and recreational activity domain of their QOL based on their child(ren)'s age group.

Impacts of Individuals' Disability Severity and Age on Their Parents' Community Interactions Domain

As seen in Table 8, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported they had not received help from extended family members, close friends or neighbours, community, spiritual community or cultural or ethnic groups, or occasional relief or respite was higher by at least 50%. This suggested that the parents were more likely to have lower community support or at least interaction as the degree of disability of their child(ren) went higher from mild to moderate or severe.

As shown in Table 8, there was an increasing trend in the percentage of parents who reported that they had not received help from extended family members, close friends or neighbours, community, spiritual community or cultural or ethnic groups, or had not received occasional relief or respite in their child(ren)'s age group of 20-29 than when their children were in the 0-10 or 11-19 age groups. These results suggest that as the individual with disabilities aged, their parents were more likely to receive less help from their surrounding community or less occasional relief or respite.

Table 8. *Weighted Percentages of Parents' Scores of Their QOL Community Interaction Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Had not received help from extended family members	22.1	40.4	37.5	16.5	35.8	47.7
Had not received help from close friends or neighbours	21.8	33.9	44.3	22.2	34.2	43.6
Had not received help from community, spiritual community or cultural or ethnic groups	21.1	35.4	43.5	27.5	36.3	36.2
Had not received occasional relief or respite care	28.0	33.6	38.4	26.4	28.7	45.0

Impacts of Individuals' Disability Severity and Age on Their Parents' Government and Organizational Support Domain

As presented in Table 9, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported that they did not receive money from government programs, did not receive federal tax credits, nor received help from professionals who were paid workers or organizations was higher by at least 50%. These results pointed out that the parents were more likely to have less governmental support and higher payment to get professional support as the degree of disability of their child(ren) went higher from mild to moderate or severe.

Looking at the age of individuals with disability in Table 9, an increasing trend is seen in the percentage of parents who reported that they did not receive money from government programs and did not receive federal tax credits. There were no clear

differences between the three age groups for the parents' reporting about paid professional help. These results suggest that as the individual with disabilities aged, their parents were more likely to receive less governmental help and support.

Table 9. *Weighted Percentages of Parents' Scores of Their QOL Government and Organizational Support Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Did not receive money from government programs	25.3	40.4	34.3	20.4	32.0	47.6
Did not receive federal tax credits	27.5	28.6	43.9	23.0	28.0	49.0
Received help from professionals that is paid workers or organizations	21.6	38.5	39.9	30.2	34.9	34.9

Looking at the age of individuals with disability in Table 9, an increasing trend is seen in the percentage of parents who reported that they did not receive money from government programs and did not receive federal tax credits. There were no clear differences between the three age groups for the parents' reporting about paid professional help. These results suggest that as the individual with disabilities aged, their parents were more likely to receive less governmental help and support.

Impacts of Individuals' Disability Severity and Age on Their Parents' QOL Needs Domain

As presented in Table 10, as the severity increased from mild to moderate or severe, there were obvious increasing trends in the percentage of parents who reported

that they needed home care, information advice, emotional and counselling support, and occasional relief and respite care. Additionally, it was more likely that the percentage of parents who reported that they needed financial support, government assistance, tax credit, help from medical professionals and voluntary and community services was higher by at least 50%. These results suggest that the parents were more likely to need home care, emotional support, more counselling, occasional relief and respite care, community support, and governmental assistance if the conditions of their children with disability were moderate or severe.

Table 10. *Weighted Percentages of Parents' Scores of Their QOL Needs Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Needed other supports	13.9	43.5	42.6	32.1	36.6	31.3
Needed home care	5.9	35.3	58.8	5.3	36.8	57.9
Needed financial support / government assistance / tax credit	20.9	44.2	34.9	33.3	40.0	26.7
Needed information / advice	31.6	26.3	42.1	38.1	33.3	28.6
Needed emotional support / counselling	15.8	31.6	52.6	14.3	52.4	33.3
Needed help from medical professionals	16.0	44.0	40.0	25.9	48.2	25.9
Needed occasional relief / respite care	6.9	27.6	65.5	36.4	42.4	21.2
Needed voluntary / community services	7.1	64.3	28.6	33.3	33.3	33.3

Looking at the age of individuals with disability in Table 10, it was more likely that the percentage of parents of individuals with disabilities in the 11-19 age group who reported that they needed financial support, government assistance, tax credit, help from medical professionals, emotional support and counselling support, and occasional relief and respite care was more than the percentage of the parents of the other two age groups. Additionally, parents of individuals with disabilities in the 20-29 age group were more likely to report a higher percentage need to have home care.

These results suggest that as regard to the parents' needs-related QOL domain, the parents of the individuals with disability were more likely to need financial support, government assistance, tax credit, help from medical professionals, emotional and counselling support, and occasional relief and respite care when their children grew to the age of 11-19 years than the younger or older age groups. These parents were more likely to need more home care when their child(ren) grow up to become adults in the age group of 20-29 years of age.

Impacts of Individuals' Disability Severity and Age on their Parents' QOL

Influence of Values, Coping, and Rewarding Domain

As presented in Table 11, most of the parents who reported that their coping with their caregiving responsibilities was not going very well at all and found their caregiving experiences were not rewarding at all were the parents of individuals with a severe degree of disabilities. Moreover, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported that they did not have a choice in taking on their caregiving responsibilities and found religious and spiritual beliefs not very important for them was higher by at least 40%.

Table 11. *Weighted Percentages of Parents' Scores of Their QOL Influence of Values, Coping, and Rewarding Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Did not have a choice in taking on your caregiving responsibilities	25.0	37.1	36.9	30.7	40.9	28.4
Caregiving experiences were not rewarding at all	8.3	8.3	83.4	33.3	58.3	8.4
Found religious and spiritual beliefs not very important	27.1	35.1	37.8	40.5	45.9	13.6
Coping with their caregiving responsibilities was not very well at all	0.0	33.3	66.7	0.0	100.0	0.0

These results suggest that the parents were more likely to have difficulty in coping, and their answer reflected that their caregiving experiences were not rewarding for them if the conditions of their children with disability were severe. Additionally, the parents were more likely to have less religious and spiritual beliefs if the conditions of their children with disability were moderate or severe.

Looking at the age of individuals with disability in Table 11, it was more likely that a higher percentage of parents of individuals in the 11-19 age group, who reported that coping with their caregiving responsibilities was not very well at all, found their caregiving experiences were not rewarding at all. They did not have a choice in taking on their caregiving responsibilities, and they found religious and spiritual beliefs not very important for them, as compared to parents of the younger and older age groups. These

results indicated that the parents of youth with disabilities for the 11-19 age group were more likely to report less coping, rewarding, and religious and spiritual values than the parents of the younger and older age groups of 0-10 and 20-29 years of age respectively.

Impacts of Individuals' Disability Severity and Age on their Parents' QOL Careers and Employment Domain

As presented in Table 12, as the severity increased from mild to moderate or severe, it was more likely that the percentage of parents who reported that they had to reduce their regular weekly hours of work because of their caregiving responsibilities, turn down a job offer or promotion, decide not to apply for a job because of their caregiving responsibilities, take a less-demanding job because of their caregiving responsibilities, or that their retirement would be affected because of their caregiving responsibilities were higher by at least two fold. These results pointed out that parents were more likely to have substantial changes in their employment QOL-related domain as the degree of disability of their children went higher from mild to moderate or severe.

Looking at the age of individuals with disability in Table 12, it was more likely that a higher percentage of parents of individuals in the age group of 11-19 years of age reported that they had to quit a job because of their caregiving responsibilities than the other two age groups. On the other hand, parents of children in the 0-10 age group were more likely to report that they had been prevented from working at a paid job because of their caregiving responsibilities than the parents of the older age groups. However, parents of adults with disabilities (i.e., age groups of 20-29 years) were more likely to report that their retirement would be affected because of their caregiving responsibilities than the younger age groups. These results suggest that the impact of caregiving

responsibilities would more likely be different on the parents' QOL employment-related domain.

Table 12. *Weighted Percentages of Parents' Scores of Their QOL Careers and Employment Domain Based on Their Children' Disability Severity and Age (N = 193)*

Variable	Individuals' Disability Severity			Age of Individuals with Disability		
	Mild	Moderate	Severe	0-10	11-19	20-29
Reduced their regular weekly hours of work because of their caregiving responsibilities	20.0	60.0	20.0	37.9	41.4	20.7
Quit a job because of their caregiving responsibilities	25.0	33.3	41.7	15.4	61.5	23.1
Turned down a job offer or promotion, or decided not to apply for a job, because of their caregiving responsibilities	10.6	44.7	44.7	34.1	43.9	22.0
Took a less demanding job because of their caregiving responsibilities	6.5	38.7	54.8	41.9	25.8	32.3
Had been prevented respondent from working at a paid job because of their caregiving responsibilities	22.7	31.8	45.5	50.0	25.0	25.0
Retirement would be affected because of their caregiving responsibilities	23.8	61.9	14.3	19.0	28.6	52.4

Inferential Statistics

To answer the first research question of this study, a two-way analysis of covariance (ANCOVA) was conducted to evaluate the differences in the parents' overall quality of life ($N = 156$). QOL was based on their child(ren)'s condition severities (i.e.,

mild, moderate, or severe) and their child(ren)'s age groups (i.e., 0-10, 11-19, 20-29) after controlling for the differences in the parents' provincial residences, total household incomes, and main health conditions.

The dependent variable was the self-rating overall QOL by the parents; the dependent variable was not normally distributed; accordingly, square root transformation was utilized. A normal weight variable was created and utilized as a weighing variable. The means and standard deviations for each group are presented in Table 13; the estimated marginal means are presented in Figure 3. Additionally, the mean error bars of the parents' self-rating overall QOL, based on their child(ren)'s age groups and condition severities, without controlling for any covariates were presented in Figure 4.

Table 13. Means and Standard Deviations of Parents' QOL for the Two Independent Variables

Age Group (<i>N</i> = 156)	Disability Severity Degree (<i>N</i> = 156)			Total <i>M</i> (<i>SD</i>)
	Mild (<i>n</i> = 41) <i>M</i> (<i>SD</i>)	Moderate (<i>n</i> = 57) <i>M</i> (<i>SD</i>)	Severe (<i>n</i> = 58) <i>M</i> (<i>SD</i>)	
0-10 years' old (<i>n</i> = 44)	8.25(1.22)	7.43(1.55)	6.83(1.09)	7.40(1.39)
11-19 years' old (<i>n</i> = 58)	7.29(1.45)	6.95(1.87)	6.14(2.25)	6.74(1.95)
20-29 years' old (<i>n</i> = 54)	8.25(1.86)	7.17(1.83)	7.33(1.33)	7.46(1.71)
Total <i>M</i> (<i>SD</i>)	7.85(1.56)	7.16(1.76)	6.72(1.74)	7.17(1.74)

The whole model was significant, $F_{(11,144)} = 7.4$, $p < .001$, and accounted for 36.1 % of the variances in the Parents' QOL scores (Adjusted $R^2 = .361$), the ANCOVA obtained significant main effect of the age group, $F_{(2, 144)} = 5.5$, $p < .01$, partial $\eta^2 = 0.071$, the ANCOVA obtained significant main effect of the condition severity degree,

$F_{(2, 144)} = 8.8, p < .001, \text{partial } \eta^2 = 0.109$. However, The ANCOVA did not obtained significant main effect of the interaction between the severity and the age groups of the children with disability, $F_{(4, 144)} = 2.1, p = 0.07, \text{partial } \eta^2 = 0.057$.

The ANCOVA obtained significant covariate effects of the parental health condition $F_{(1, 144)} = 30.3, p < .001, \text{partial } \eta^2 = 0.174$, the income $F_{(1, 144)} = 7.5, p < .001, \text{partial } \eta^2 = 0.049$, and the province $F_{(1, 144)} = 5.2, p < .05, \text{partial } \eta^2 = 0.035$.

These results suggest that when controlling for the income, the province, and the parental health condition, there was a significant main effect of the child(ren)'s age on their parents' QOL and a significant main effect of the child(ren)'s condition severities on their parents' QOL. Thus, the researcher can conclude that the parents' QOL would change based on their child(ren)'s age and disabilities' degree of severity.

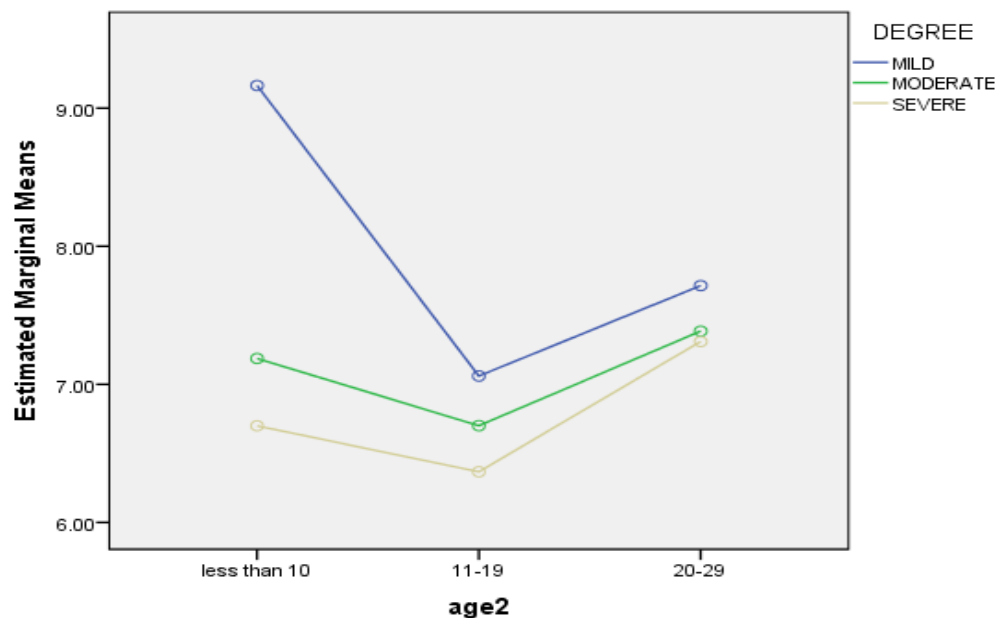


Figure 3. Estimated marginal means of parents' QOL based on their child(ren)'s age and disabilities' condition severity after controlling for the parents' residence, total household income, and health conditions.

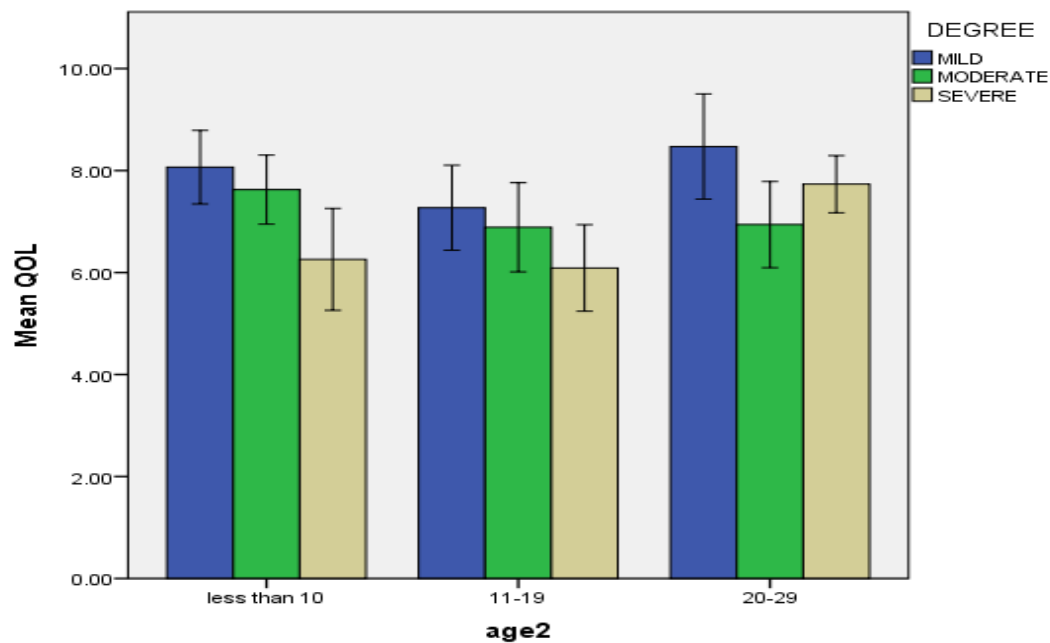


Figure 4. Error bars with 95% confidence interval for raw data means of Parents' QOL based on their child(ren)'s age and disabilities' condition severity.

In order to understand the differences between the age and severity subgroups, follow-up pairwise comparisons with Bonferroni correction were used for comparing pairwise group means, which are presented in Tables 14 and 15. Looking at the condition severity comparisons in Table 14, a significant difference had been obtained between mild and severe degrees, $p < .001$, and between mild and moderate degrees, $p = 0.01$. However, there was no significant difference between moderate and severe degrees, $p = 0.7$. These results suggest that the parents' QOL would be impacted and tended to be lower when their child(ren)'s disability conditions were moderate or severe in comparison to being mild.

As shown in Table 15, there was a significant difference between age groups 0-10 and 11-19, $p = 0.01$, and between age groups 20-29 and 11-19, $p < .05$. However, there was no significant difference between age groups 0-10 and 20-29, $p = 1.0$. These results

indicated that parents' QOL tended to be lower when their children grew up to the age group of 11-19 years of age than when they had been younger in the age group 0-10 or older in the age group of 20-29.

Table 14. *Pairwise Comparisons among the Three Degrees of Disability Condition*

(I) DEGREE	(J) DEGREE	Mean Difference (I-J)	Std. Error	Significance. ^b
Mild	Moderate	-.205*	.069	.010
	Severe	-.280*	.068	.000
Moderate	Mild	.205*	.069	.010
	Severe	-.075	.063	.704
Severe	Mild	.280*	.068	.000
	Moderate	.075	.063	.704

Dependent Variable: Parents' QOL sqrt
 Based on estimated marginal means
 *. The mean difference is significant at the .05 level.
 b. Adjustment for multiple comparisons: Bonferroni.

Table 15. *Pairwise Comparisons among the Three Age Groups*

(I) age2	(J) age2	Mean Difference (I-J)	Std. Error	Significance ^b
< 10	11-19	-.202*	.069	.011
	20-29	-.032	.070	1.000
11-19	< 10	.202*	.069	.011
	20-29	.170*	.064	.026
20-29	< 10	.032	.070	1.000
	11-19	-.170*	.064	.026

Dependent Variable: Parents' QOL sqrt
 Based on estimated marginal means
 *. The mean difference is significant at the .05 level.
 b. Adjustment for multiple comparisons: Bonferroni.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to explore the differences in the parents' QOL across the different age groups and disability condition severities of their children in Canada. The discussion in this chapter focused on three areas: (a) interactions between the individuals with disabilities' age and their parents' QOL, (b) interactions between the individuals' disability severity and their parents' QOL, and (c) interactions between the individuals' disability severity and age and their parents' QOL.

Interactions between the Individuals with Disabilities' Age and Their Parents' QOL

This research study hypothesized that the parents' QOL would be impacted by the age of their children with disabilities or, in other words, by the developmental stage of the individuals with disabilities. The study findings revealed that with medium effect size, parents' overall life satisfactions were significantly different based on their child(ren)'s age group, which supported the researcher's assumptions and hypothesis and answered the first research question of the current study: Is there a difference in the parental life satisfactions based on their child(ren)'s condition severity and age in Canada? Moreover, the parents' QOL tended to be significantly lower in the transitional age group (i.e., age group 11-19) relative to both the younger age group (0-10 years of age) and the older age group (20-29).

Despite the differences in the overall parental satisfaction ratings based on their child(ren)'s age groups, the parents' ratings were not uniform across all the measured domains of their QOL in the current study. The results indicated that parents of youth and

young adults with disabilities are more likely to be impacted in their QOL-related domains of health-related, parents' needs, and coping, rewarding, and religious and spiritual beliefs. Parents of young children (0-10) and youth (11-19) with disabilities were more likely to have more instability in their financial, employment, and family interaction QOL domains. Parents of adults (20-29) with disabilities were more likely to have more impacts in their community interactions and government support domains. Those results answered the age's part of the second research question: What are the impacts of the severity and the age of individuals with disabilities on their parental QOL in Canada?

These results were consistent with the findings of Meral, Cavkaytar, Turnbull, and Mian (2013), who concluded that the age of individuals with disability can impact the parents' life satisfactions. In addition, this study results agreed with Kim and Turnbull (2004) that the transitional stages during the growth of individuals with disabilities could entail additional stress and doubts, which, in turn, would impact their parents' QOL negatively.

Results from this study results were also consistent with the findings of Brown et al. (2003) as regards lower satisfactions in the areas of community interactions and governmental and organizational support for parents of adults with disabilities. Furthermore, there was agreement in the impact of youth disabilities on the family interaction domain in terms of strains among family members. However, the current study findings disagreed with Brown et al. in the QOL domain areas of health-related; parents' needs; and coping, rewarding, and religious and spiritual beliefs of the parents of youth and young adults with disabilities.

This study results were also in agreement with the finding of Johnson, Frenn, Feetham, and Simpson (2011) and Smith, Greenberg, and Mailick (2012) about the parents' health-related QOL domain. They concluded that parents of young adults with autistic spectrum disorders were more likely to develop more physical health concerns, such as fatigue, headache, and gastrointestinal discomforts, in comparison to parents of young adults without disabilities.

The conclusions of Smith and Anderson (2014) provided a plausible explanation to the current study findings, as they suggested that the psychological distress of the parents whose children with disabilities are in their transitional stage could be explained through the interaction of multiple stressors. They listed these stressors as (a) child-related challenges such as challenging behaviours and educational difficulties; (b) financial burdens, which tended to increase during the transition stage mainly because of the growing needs of the individuals with disabilities, such as new devices, home modifications, and hiring more paid professionals; and (c) social stigma with unsupportive social networks.

Additionally, in the context of the daily life experiences, parents of youth and young adults with disabilities may face different, but increasing, challenges and stresses as the physical and emotional changes of their growing children with disabilities are usually not matching their school peers. These changes could add another pressure on the parents as to how to handle emerging new concerns by their children, such as school bullying (Montes & Halterman, 2006).

For example, the levels of worry and anxiety increased among parents of children with autistic spectrum disorders in their transitional stage, specifically before the exit of

their children from high school, or because of the future uncertainty about their child(ren)'s post-secondary education (Camarena & Sarigiani, 2009). These parents faced a different and larger parental role in the coordination of the services and activities of their children once they exited from high school (Lawrence, Alleckson, & Bjorklund, 2010).

Although those stressors existed since the child with disability was born, the interaction between them takes different forms when the child with disability grows up to the stage of a teenager and young adult. The differences in the interactions and the emergence of new challenges and burdens in this stage of the child growth create new physical and emotional stresses on the parents, which require different forms of coping and handling.

In comparison to parents of youth with normal development, parents of youth with disabilities are more likely to have lesser degrees of adaptation and coping to the physiological changes of their growing children (Carter et al., 2012; Ferrell, 2010). For example, Seltzer and colleagues (2001) demonstrated that parents in their early 50s whose child has severe mental health issues were more likely to have alcohol dependence problems (mostly fathers), more likely to report significant elevations of their physical health and depressive symptoms (mostly mothers), and low ratings of their psychological well-being scores. That could be explained, in part, by the hypothesis of "greater mid-life strain for the parents of persons with severe mental health problems" (p. 278).

On the contrary, the current study results were not in line with the findings of Boehm and colleagues (2015), who concluded that parents of youth and young adults (between 13 to 21 years old) with disabilities were generally satisfied with their QOL.

However, that study did not compare the reported parents' QOL of that specific age group to either the parents of the younger or the older age groups, and it included parents of individuals with only autistic spectrum disorders; no other types of disabilities were included, which was not the case for the current study.

Further worth noting is that the overall parental satisfaction in the in the current study were fairly high (i.e., above 6), regardless of the age group of the individuals with disabilities. That result was consistent with the results of Brown et al. (2003), who concluded that the families of children with disabilities were usually rating their overall QOL on the higher side. Brown et al. noted this as an indication that the parents usually found their way of adaptation regardless of the challenges or the obstacles of parenting a child with disabilities.

Interactions between the Individuals' Disability Severities and Their Parents' QOL

The researcher of the current study hypothesized that the parents' QOL would be impacted based on the degree of condition severity of their children with disabilities or, in other words, by the condition severity being mild, moderate, or severe. The current study findings revealed that with medium effect size, the parents' overall life satisfactions were significantly different based on their children's degree of disability severity, which supported the researcher's assumptions and hypothesis and answered the first research question of the current study.

Moreover, the parents' QOL tended to be significantly lower when their child(ren)'s disability conditions were moderate or severe in comparison to being mild. These results were consistent across all nine domains of the parents' QOL, where the parents' QOL was more likely to be impacted when their children's disability condition

was moderate or severe, which answered the disability severity part of the second research question of the current study.

These results agreed with the findings of Hu et al. (2012) and Wang et al. (2004). The authors of these studies concluded that the severity of child(ren)'s disability is a significant predictor of his/her parent's QOL, and a lower parental QOL would be associated with severe degrees of their child(ren)'s disability condition severity.

Additionally, results from this study also agree with the findings of Worcester et al. (2008), who concluded that the financial, community interactions, and parents' needs QOL-related domains were impacted by their child(ren)'s higher degrees of disability severity. Moreover, the current study findings aligned with the findings of Raver et al. (2011), who concluded that the parents of children with severe forms of disabilities reported more deterioration in their financial and family interaction QOL-related domains. However, Raver et al.'s parents reported more enrichment in their rewarding and coping QOL-related domains, which contradict the current study results.

Worth noting is that in regards to the parents' health-related QOL domain, the current study results were consistent with many authors' conclusions (Clark & Drake, 1994; Gallagher & Mechanic, 1996; Seltzer et al., 2001). These authors had concluded that children's severe degrees of disabilities would impact their parents' physical and mental health negatively.

The effects of the long-term care responsibilities and increasing caregiving demands on the parents of children with severe degrees of disabilities could explain the findings of the current study. As the disability condition of the child becomes severe, more psychological and physical health burdens on the parents are anticipated. Moreover,

the parents of children with more complex conditions would need to pay out-of-their-pocket expenses to accommodate the needs of their children, such as specialized aids, home modifications, and transportation.

In addition, the social stigma toward parents and families of children with severe conditions and the community withdrawal from supporting those parents, which sometimes include extended family members and close friends, pile up the burdens on those parents. Those burdens would eventually impact most of the parents' QOL domains, in different ways, based on each family context.

However, the results of this study indicate that there is no significant difference between the means of the parents' QOL and their child(ren)'s disability condition of moderate and severe degrees. This result can be explained by the subjective nature of the measured severity variable as there were no clear borderlines between the two severity degrees (moderate or severe) from the parents' perspective. Thus, the inability of the researcher of the current study to find a significant difference between those two severity degrees may not mean that it does not exist. Rather, it is very likely that the researcher was unable to detect the differences between the moderate and severe degrees because of the way the severity variable itself was measured.

On the contrary, the current study findings disagreed with the findings of Lin et al. (2009), who suggested that parental QOL for parents of children and adolescents with intellectual disability was not associated with the severity of their children's disability condition. Moreover, the current research results were not in line with the findings of Luijkx (2016), who reported that parental satisfaction toward the quality of the services

provided to their children with different types of disabilities was not dependant on their children' condition severity in Netherland.

Interactions between the Individuals' Disability Severities and Age and Their Parents' QOL

The study findings revealed that with medium effect size, the interaction between the age and severity of disability had a main effect on the parents' overall life satisfaction, with scores near the significant values ($p = .07$). Moreover, the lowest reported mean of the parents' QOL scores in this study was 6.1, which was for the group of parents of youth with severe disabilities degrees.

These findings are consistent with conclusions made by of Gallagher and Mechanic (1996) and Seltzer et al. (1995). These researchers concluded that parenting a teenage with severe mental disabilities was associated with increased levels of parental health problems and psychological distress. Also, the current study results were in line with the findings of both Clark and Drake (1994) and Maurin and Boyd (1990), who suggested that parents of teenage individuals with severe mental disabilities are more likely to have higher incidences of work-related disturbances and more financial strains.

Chapter Summary

In summary, the age and disability severity of individuals with disabilities can impact their parents' QOL. The impact is more likely to be a negative one, especially for parents of teenagers, and with moderate or severe disability degrees. The practical and policy implications of those findings are going to be discussed in the next chapter, as well as study limitations and conclusion.

CHAPTER SIX

IMPLICATIONS AND CONCLUSIONS

Practical Implications

Looking at the social work and special education literature, there are striking gaps about the best practices and specialized programs that support families of youth and young adults with disabilities. The current study provides preliminary evidences about the parents' QOL and the needs of the parents of children with disabilities who are in a transitional stage of their development.

Based on the current study findings, parents and families of youth and young adults, especially those with severe disabilities, are in obvious need of many forms of family supports. These include emotional and counselling support, financial support, health-related service, community, and governmental support.

Building on the principles of family-centred practices by Dempsey and Keen (2008) and Dunst (2002), the current policies and procedures of the system that supports families of teenagers and young adults with disabilities need to be enhanced toward more holistic life needs models. These models would guide the practitioners and social workers on how to take the family-level needs and strengths into their consideration when they deal with teenagers with disabilities, and how to utilize the scales of the families and parents' QOL as outcome measures of the efficacy and efficiency of the provided programs and services to those families.

For example, these families need to be offered an ongoing counselling and information support sessions by special educators and social workers who are dealing with their children. One of the fundamental goals of those sessions would be to provide

the parents with the skills and strategies that could help them to deal and cope with their children's and their families' needs at home and in the community. In addition, these families could also be linked to the other available resources that are physically near to them. Examples include local organizational and governmental programs that could advise them how to deal with their financial needs, how to apply for the different available governmental support programs, or even how to get in touch with the required health services.

An excellent and practical exemplar on linking parents and families to their tailored needs is the patient-centred primary care model or philosophy. This model has been adapted, improved, and implemented widely within the primary health care systems in the US and Canada. This model “encourages providers and care teams to meet patients where they are, from the simplest to the most complex conditions. It is a place where patients are treated with respect, dignity, and compassion, and enable strong and trusting relationships” (Patient-Centered Primary Care Collaborative, 2015, para. 1).

Based on the established and well-designed early intervention programs for families of young children with disabilities, there is a call for similar evidence-based and structured intervention programs for families of youth and young adults with disabilities. Those intervention programs need to be able to handle and address the challenging needs that are facing these families.

Moreover, community-based support constitutes a crucial tool for supporting families of youth and young adults with disabilities. Accordingly, community-based organizations and community efforts need to be prioritized to provide these families with

additional supports. Those supports can take different forms, such as occasional reliefs, better community engagement, vocational training, and outing activities.

Finally, supporting parents and families of youth and young adults with disabilities is not only important for improving their QOL, but it is also, in part, crucial for the sustainability and stability of long-term services systems, whether social or healthcare. In addition, more federal and provincial supports need to be tailored towards assisting these families. For example, more affordable housing options in terms of creating specific policies that could allow these families house rental or purchasing settlement allowances when they need to move to accommodate for their child(ren)'s new needs.

Implication for Future Research

Future research could focus on creating evidence-based systems of intervention programs that can improve the parents' QOL and help them to provide the best caregiving to their children with disabilities when they grow up to the transitional stages of their development.

Furthermore, future research could encourage the utilization of subjective and objective QOL measures as an outcome measurement tool. Such measurement tools could aide service providers to evaluate and improve the service delivery models. Having a consistent method of measurement to help with future systematic reviews of the different FQOL-related research findings could eventually pave the way to credible guidelines.

Study Limitations

There were several limitations to this study. Firstly, this study was a secondary data analysis of a cross-sectional general social survey and did not study the impact of the children's disability severity and age on their parents' QOL in a longitudinal investigation. Secondly, the data used in the analysis for the study were only self-reported data, and the parental "caregivers" may have been hesitant or did not want to answer some sensitive questions, which may have led to an underestimation of some of the difficulties that they face.

Lastly, no data were available for parental "caregivers" of children in the same age groups with normal development to be used as control groups. Such data could have helped to further expand our understanding of the difficulties and burdens that the parents of children with disabilities are facing.

Conclusion

In closing, this study represents an attempt to explore the differences in the parents' QOL outcomes based on their children with disability with respect to their age and disability severity in Canada. The results highlight the impacts of the children's age, especially in their transition stage, and children's degree of disability, especially the moderate and severe degrees, on their parents' QOL.

Furthermore, this study provides new intuitions into the QOL among parents of youth and young adults with different types of disabilities. These findings help to fill in a gap in the FQOL literature by exploring the parents' QOL in families of children who are navigating the transition to adulthood.

Lastly, this study supports the FQOL literature in following and employing the recently developed FQOL domains as an outcome measure for evaluating or understanding parents' QOL. Thus, these findings could be built upon by following FQOL research in systematic and evidence-based manner.

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APPENDIX A: QUESTIONS ANALYZED FOR THE CURRENT STUDY¹

Caring for youth with severe disabilities- Impacts on Parents' Quality of Life in Canada

Age group of the respondent (groups of 10).**AGEGR10**

- 01 15 to 24
- 02 25 to 34
- 03 35 to 44
- 04 45 to 54
- 05 55 to 64
- 06 65 to 74
- 07 75 years and over

Sex of respondent.**SEX**

- 1 Male
- 2 Female

Marital status of the respondent.**MARSTAT**

- 1 Married
- 2 Living common-law
- 3 Widowed
- 4 Separated
- 5 Divorced
- 6 Single, never married

PRV**Province of residence of the respondent.**

- 10 Newfoundland and Labrador
- 11 Prince Edward Island
- 12 Nova Scotia
- 13 New Brunswick
- 24 Quebec
- 35 Ontario
- 46 Manitoba

¹ Statistics Canada. (2013, September 11). *GSS 2012 – Cycle 26 – Caregiving and Care Receiving Analytical File*. Available from <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4502>

- 47 Saskatchewan
- 48 Alberta
- 59 British Columbia

Parents' education level.**EOR_Q04**

What is the highest level of education that you have completed?

- 01 Less than high school diploma or its equivalent
- 02 High school diploma or a high school equivalency certificate
- 03 Trade certificate or diploma
- 04 College, CEGEP or other non-university certificate or diploma (other than trades certificates or diplomas)
- 05 University certificate or diploma below the bachelor's level
- 06 Bachelor's degree (e.g. B.A., B.Sc., LL.B.)
- 07 University certificate, diploma, degree above the bachelor's level
- 97 Not Asked

Total Household Income.**INCMHSD**

- 01 No income or loss
- 02 Less than \$5,000
- 03 \$5,000 to \$9,999
- 04 \$10,000 to \$14,999
- 05 \$15,000 to \$19,999
- 06 \$20,000 to \$29,999
- 07 \$30,000 to \$39,999
- 08 \$40,000 to \$49,999
- 09 \$50,000 to \$59,999
- 10 \$60,000 to \$79,999
- 11 \$80,000 to \$99,999
- 12 \$100,000 to \$149,999
- 13 \$150,000 or more

Parents' working activities**WET_Q120**

- 1 A paid worker
- 2 Self-employed
- 3 An unpaid family worker
- 7 Not Asked

Health Problems that Require Help (PRP)***PRP_Q10***

What is/was the main health condition or problem for which your primary care receiver received help?

- 01 Arthritis (e.g., rheumatoid arthritis, osteoarthritis, lupus or gout) 0 0
- 02 Osteoporosis 0 0
- 03 Cardiovascular disease (including angina, heart attack, stroke and hypertension) 0 0
- 04 Kidney disease 0 0
- 05 Asthma 0 0
- 06 Chronic bronchitis, emphysema or chronic obstructive pulmonary disease (COPD) 0 0
- 07 Diabetes 0 0
- 08 Migraine 0 0
- 09 Back problems 0 0
- 10 Cancer 0 0
- 11 Mental illness (e.g., depression, bipolar disorder, mania or schizophrenia) depression, bipolar disorder, mania or schizophrenia)
- 12 Alzheimer's disease or dementia
- 13 All other neurological diseases (e.g., Parkinson's disease, multiple sclerosis, spina bifida, cerebral palsy)
- 14 Urinary or bowel incontinence
- 15 Digestive disease (e.g., celiac disease, irritable bowel syndrome, stomach ulcers, Crohn's disease)
- 16 Fibromyalgia, chronic fatigue syndrome or multiple chemical sensitivities
- 17 Developmental disability or disorder
- 18 Injury resulting from an accident
- 19 Aging / old age / frailty
- 20 Other
- 21 Eye problems
- 22 Joints problems
- 23 Addictions (drugs, alcohol)
- 24 Surgery
- 25 Liver diseases
- 26 Mobility problems
- 27 Physical disabilities
- 97 Not Asked

Relationship of the care-receiver to the care-giver***PRG_Q10***

What is/was the relationship of your primary care receiver to you?

- 01 Spouse/partner of respondent
- 02 Ex-spouse/Ex-partner of respondent
- 03 Son of respondent
- 04 Daughter of respondent

- 05 Father of respondent
- 06 Mother of respondent
- 07 Brother of respondent
- 08 Sister of respondent
- 09 Grandson of respondent
- 10 Granddaughter of respondent
- 11 Grandfather of respondent
- 12 Grandmother of respondent
- 13 Son-in-law of respondent
- 14 Daughter-in-law of respondent
- 15 Father-in-law of respondent
- 16 Mother-in-law of respondent
- 17 Brother-in-law of respondent
- 18 Sister-in-law of respondent
- 19 Nephew of respondent
- 20 Niece of respondent
- 21 Uncle of respondent
- 22 Aunt of respondent
- 23 Cousin of respondent
- 24 Close friend of respondent
- 25 Neighbour of respondent
- 26 Co-worker of respondent
- 27 Other
- 97 Not Asked

PRP_Q15

Would you say that this condition is mild, moderate or severe?

- 1. Mild
- 2. Moderate
- 3. Severe
- 4. Don't know

LSR_Q110

Using a scale of 0 to 10, where 0 means "Very dissatisfied" and 10 means "Very satisfied", how do you feel about your life as a whole right now?

- 0. Very dissatisfied
- 1. |
- 2. |
- 3. |
- 4. |
- 5. |
- 6. |
- 7. |

8. |
- 9.
10. Very satisfied
11. Don't know

Questions Related to Parents' Health Domain

ICP_Q15

During the past 12 months, how physically strenuous were your caregiving responsibilities? Were they:

1. ... very strenuous?
2. ... strenuous?
3. ... somewhat strenuous?
4. ... not at all strenuous?
5. Don't know

ICP_Q10

During the past 12 months, has your overall health suffered because of your caregiving responsibilities?

1. Yes
2. No
3. Don't know

CRH_Q10

During the past 12 months, have your caregiving responsibilities caused you to feel tired?

1. Yes
2. No
3. Not asked

CRH_Q20

During the past 12 months, have your caregiving responsibilities caused you to feel worried or anxious?

1. Yes
2. No
3. Not asked

CRH_Q30

During the past 12 months, have your caregiving responsibilities caused you to feel overwhelmed?

1. Yes
2. No
3. Not asked

CRH_Q35

During the past 12 months, have your caregiving responsibilities caused you to feel lonely or isolated?

1. Yes
2. No
3. Not asked

CRH_Q40

During the past 12 months, have your caregiving responsibilities caused you to feel short-tempered or irritable?

1. Yes
2. No
3. Not asked

CRH_Q60

During the past 12 months, have your caregiving responsibilities caused you to feel depressed?

1. Yes
2. No
3. Not asked

CRH_Q70

During the past 12 months, have your caregiving responsibilities caused you to experience loss of appetite?

1. Yes
2. No
3. Not asked

CRH_Q80

During the past 12 months, have your caregiving responsibilities caused you to experience disturbed sleep?

1. Yes
2. No
3. Not asked

Questions Related to Family Finance Domain**ICF_Q210**

In the past 12 months, have you had any out-of-pocket expenses for home modifications to accommodate your care receiver's/care receivers' needs?

1. Yes
2. No
3. Not asked

ICF_Q220

In the past 12 months, have you had any out-of-pocket expenses for professional services for your care receiver's/care receivers' healthcare or rehabilitation?

1. Yes
2. No
3. Not asked

ICF_Q230

In the past 12 months, have you had any out-of-pocket expenses for hiring people to help with your care receiver's/care receivers' daily activities?

1. Yes
2. No
3. Not asked

ICF_Q240

In the past 12 months, have you had any out-of-pocket expenses for transportation, travel or accommodation because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

ICF_Q250

During the past 12 months, have you had any out-of-pocket expenses for specialized aids or devices for your care receiver's/care receivers' use?

1. Yes
2. No
3. Don't know

ICF_Q260

In the past 12 months, have you had any out-of-pocket expenses for prescription or non-prescription drugs for your care receiver's/care receivers' use?

1. Yes
2. No
3. Not asked

ICF_Q270

During the past 12 months, have you had any other out-of-pocket expenses because of your caregiving responsibilities that we haven't covered so far?

1. Yes
2. No
3. Not asked

ICF_Q280

During the past 12 months, have you experienced financial hardship because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

ICF_Q290

Have you had to borrow money from family or friends?

1. Yes
2. No
3. Not asked

ICF_Q300

Have you had to take loans from a bank or financial institution?

1. Yes
2. No
3. Not asked

ICF_Q310

Have you had to use or defer savings?

1. Yes
2. No
3. Not asked

ICF_Q320

Have you had to modify your spending?

1. Yes
2. No
3. Not asked

ICF_Q330

Have you had to sell off assets?

1. Yes
2. No
3. Not asked

ICF_Q340

Have you had to file for bankruptcy?

1. Yes
2. No
3. Not asked

Questions Related to Family Interactions Domain**ICL_Q110**

In the past 12 months, have your caregiving responsibilities caused you to spend less time with your spouse or partner?

1. Yes
2. No
3. Not asked

ICL_Q120

In the past 12 months, have your caregiving responsibilities caused you to spend less time with your children?

1. Yes
2. No
3. Not asked

ICL_Q130

In the past 12 months, have your caregiving responsibilities caused you to spend less time with other family members?

1. Yes
2. No
3. Not asked

ICL_Q180

In the past 12 months, have your caregiving responsibilities caused you to move residences?

1. Yes
2. No
3. Not asked

ICL_Q210

In the past 12 months, have your caregiving responsibilities caused strain in your relationship with family members or friends?

1. Yes
2. No
3. Not asked

Questions Related to Leisure and Recreational Activities Domain**ICL_Q135**

In the past 12 months, have your caregiving responsibilities caused you to spend less time with friends?

1. Yes
2. No
3. Not asked

ICL_Q140

In the past 12 months, have your caregiving responsibilities caused you to spend less time on social activities or hobbies?

1. Yes
2. No
3. Not asked

ICL_Q150

In the past 12 months, have your caregiving responsibilities caused you to spend less time on relaxing or taking care of yourself?

1. Yes
2. No
3. Not asked

ICL_Q152

In the past 12 months, have your caregiving responsibilities caused you to spend less time volunteering for an organization?

1. Yes
2. No
3. Not asked

ICL_Q154

In the past 12 months, have your caregiving responsibilities caused you to spend less time participating in political, social or cultural groups?

1. Yes
2. No
3. Not asked

ICL_Q160

In the past 12 months, have your caregiving responsibilities caused you to make holiday plans and change or cancel them?

1. Yes
2. No
3. Not asked

ICL_Q170

In the past 12 months, have your caregiving responsibilities caused you to not make holiday plans at all?

1. Yes
2. No
3. Not asked

Questions related to community interactions domain**ACD_Q30**

To accommodate your caregiving duties, have your extended family members provided you with help?

1. Yes
2. No
3. Not asked

ACD_Q40

To accommodate your caregiving duties, have your close friends or neighbours provided you with help?

1. Yes
2. No
3. Not asked

ACD_Q50

To accommodate your caregiving duties, have your community, spiritual community, or cultural or ethnic groups provided you with help?

1. Yes
2. No
3. Not asked

ACD_Q60

To accommodate your caregiving duties, have you had occasional relief or respite care?

1. Yes
2. No
3. Not asked

Questions Related to Government and Organizational Support Domain**ACD_Q80**

To accommodate your caregiving duties, have you received money from government programs?

1. Yes
2. No
3. Not asked

ACD_Q90

Have you received any Federal tax credits for which caregivers may be eligible (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)?

1. Yes
2. No
3. Not asked

HPO_Q10

During the past 12 months, has your primary care receiver received help from professionals that is paid workers or organizations?

1. Yes
2. No
3. Not asked

Questions Related to Parents' Needs Domain**OAC_Q20**

Is there any other type of support that you would like to have to help with your caregiving duties?

1. Yes
2. No
3. Not asked

OAC_Q30_C01

What kinds of support would you like to have? Home care / support provided to recipient?

1. Yes
2. No
3. Not asked

OAC_Q30_C02

What kinds of support would you like to have? Financial support / Government assistance / Tax credit?

1. Yes
2. No
3. Not asked

OAC_Q30_C03

What kinds of support would you like to have? Information / Advice?

- 1 Yes
- 2 No
- 3 Not asked

OAC_Q30_C04

What kinds of support would you like to have? Emotional support / Counselling?

- 1 Yes
- 2 No
- 3 Not asked

OAC_Q30_C05

What kinds of support would you like to have? Help from medical professionals?

- 1 Yes
- 2 No
- 3 Not asked

OAC_Q30_C06

What kinds of support would you like to have? Occasional relief / Respite care?

- 1 Yes
- 2 No
- 3 Not asked

OAC_Q30_C07

What kinds of support would you like to have? Voluntary / Community services

- 1 Yes
- 2 No
- 3 Not asked

Questions Related to Influence of Values, Coping, and Rewarding Domain**ICS_Q10**

Do you feel you had a choice in taking on your caregiving responsibilities during the past 12 months?

1. Yes
2. No
3. Not asked

ICS_Q30

How rewarding has your caregiving experiences been during the past 12 months? Were they:

1. very rewarding?
2. rewarding?
3. somewhat rewarding?
4. not at all rewarding?
5. Not asked

RLR_Q110

How important are your religious or spiritual beliefs to the way you live your life? Would you say they are:

1. very important?
2. somewhat important?
3. not very important?
4. not important at all?
5. Not asked

ICL_Q100

In general, how have you been coping with your caregiving responsibilities? Would you say:

1. very well?
2. generally well?
3. not very well?
4. not well at all?
5. Not asked

Questions Related to Careers and Employment Domain**ITL_Q30**

Did you reduce your regular weekly hours of work because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

ITE_Q10

During the past 12 months, did you quit a job because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

ITO_Q10

During the past 12 months, did you turn down a job offer or promotion, or decide not to apply for a job, because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

ITO_Q20

Did you take a less demanding job because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

INE_Q10

Have your caregiving responsibilities prevented you from working at a paid job?

1. Yes
2. No
3. Not asked

IPR_Q20

Was the timing of your retirement/Will the timing of your retirement be affected because of your caregiving responsibilities?

1. Yes
2. No
3. Not asked

**APPENDIX B: WEIGHTED PERCENTAGES OF PARENTS' SCORES OF
THEIR QOL BASED ON THEIR DEMOGRAPHIC VARIABLES**

Caring for youth with severe disabilities: Impacts on Parents' Quality of Life in Canada

Table B-1. *Weighted Percentages of Parents' Scores of Their QOL Health Domain Based on some of Their Demographic Variables (N = 193)*

Variable	Felt tired	Felt worried	Felt overwhelmed	Felt lonely	Felt irritable	Felt depressed
Parents' age group						
25-34	14.1	9.4	18.6	12.5	13.0	9.1
35-44	34.4	33.9	36.1	33.3	37.0	29.1
45-54	37.5	41.7	34.0	38.9	39.0	41.8
55-64	14.1	13.4	11.3	15.3	11.0	20.0
65-74	0.0	1.6	0.0	0.0	0.0	0.0
Parents' gender						
Male	32.3	33.1	23.7	23.6	36.0	26.8
Female	67.7	66.9	76.3	76.4	64.0	73.2
Parents' marital status						
Married	65.4	66.4	61.5	60.6	68.0	63.6
Living common-law	16.5	16.4	19.7	14.1	16.0	14.5
Widowed	2.4	3.9	3.1	4.2	2.0	3.6
Separated	4.7	3.9	4.2	5.6	3.0	1.8
Divorced	6.3	6.3	7.3	9.9	7.0	12.9
Single, never married	4.7	3.1	4.2	5.6	4.0	3.6
Parents' education level						
Less than high school diploma	11.7	11.1	12.4	11.1	12.9	1.8
High school diploma	22.7	22.2	23.7	23.6	23.8	28.6
Trade certificate or diploma	7.0	7.2	7.2	11.1	6.8	12.5
College or other Non-university certificate	30.5	31.7	38.1	34.7	31.7	33.9
University certificate	0.8	3.2	1.0	1.4	2.0	1.8
Bachelor degree	17.1	13.5	10.4	11.2	10.9	14.3
University certificate above the bachelor level	10.2	11.1	7.2	6.9	11.9	7.1
Parents' labour work status						
A paid worker	73.3	72.1	70.6	75.7	72.5	68.2
Self-employed	26.7	27.9	29.4	24.3	27.5	31.8

Table B-1. *Weighted Percentages of Parents' Scores of Their QOL Health Domain Based on some of their demographic variables (continued) (N = 193)*

Variable	Suffered physical health	Had very strenuous physical stress	Experienced loss of appetite	Experienced disturbed sleep
Parents' age group				
25-34	8.4	25.0	9.4	11.3
35-44	44.1	29.2	40.6	30.9
45-54	37.3	37.5	40.6	45.4
55-64	10.2	8.3	9.4	12.4
65-74	0.0	0.0	0.0	0.0
Parents' gender				
Male	13.1	28.0	18.8	23.5
Female	86.9	72.0	81.3	76.5
Parents' marital status				
Married	60.0	47.8	59.4	59.8
Living common-law	21.6	30.4	15.6	20.6
Widowed	1.7	4.4	0.0	3.1
Separated	1.7	4.4	9.4	4.1
Divorced	10.0	13.0	12.5	6.2
Single, never married	5.0	0.0	3.1	6.2
Parents' education level				
Less than high school diploma	10.2	26.1	9.4	12.4
High school diploma	25.4	17.4	31.3	20.6
Trade certificate or diploma	8.5	21.7	9.4	8.3
College or other Non-university certificate	37.3	26.1	25.0	34.0
University certificate	2.7	0.0	0.0	1.0
Bachelor degree	11.9	0.0	18.8	11.3
University certificate above the bachelor level	4.0	8.7	6.1	12.4
Parents' labour work status				
A paid worker	68.0	75.0	68.2	72.7
Self-employed	32.0	25.0	31.8	27.3

Table B-2. *Weighted Percentages of Parents' Scores of Their QOL Finance Domain Based on Their Demographic Variables (N = 193)*

Variable	Home modification	Professiona l services	Hiring people	Specialized aids	Transportat ion	Prescriptio n or non- prescriptio n drugs
Parents' age group						
25-34	18.9	6.7	12.0	4.4	15.0	13.4
35-44	21.7	35.5	44.0	31.2	32.7	35.4
45-54	40.5	46.7	40.0	44.4	30.8	34.1
55-64	18.9	11.1	4.0	20.0	19.6	17.1
65-74	0.0	0.0	0.0	0.0	1.9	0.0
Parents' gender						
Male	45.9	26.7	50.0	39.1	39.3	36.6
Female	54.1	73.3	50.0	60.9	60.7	63.4
Parents' marital status						
Married	55.4	66.7	70.8	84.8	65.4	76.5
Living common-law	41.4	15.6	4.2	8.7	20.6	9.9
Widowed	31.6	0.0	0.0	0.0	4.7	2.5
Separated	0.0	6.7	12.5	0.0	2.8	3.7
Divorced	0.0	8.9	4.2	0.0	4.6	4.9
Single, never married	2.6	2.1	8.3	6.5	1.9	2.5
Parents' education level						
Less than high school diploma	21.6	4.3	0.0	0.0	15.7	14.6
High school diploma	16.2	6.5	12.5	18.2	17.6	20.7
Trade certificate or diploma	13.0	8.7	0.0	4.5	5.6	3.7
College or other Non-university certificate	27.0	39.2	41.7	45.5	31.5	28.0
University certificate	0.0	2.2	0.0	2.3	2.8	1.2
Bachelor degree	22.2	21.7	20.8	22.7	17.6	22.0
University certificate above the bachelor level	0.0	17.4	25.0	6.8	9.2	9.8
Parents' labour work status						
A paid worker	81.5	72.0	60.4	58.8	73.0	61.8
Self-employed	18.5	28.0	39.6	41.2	27.0	38.2

Table B-2. *Weighted Percentages of Parents' Scores of Their QOL Finance Domain Based on Their Demographic Variables (continued) (N = 193)*

Variable	Borrowed money from friend or family	Took loans from banks	Deferred savings	Modified spending	Sold off assets	Had financial hardships
Parents' age group						
25-34	28.0	16.0	11.6	14.2	41.7	13.6
35-44	44.0	36.0	25.6	26.8	41.7	30.4
45-54	24.0	24.0	44.2	42.9	16.6	40.7
55-64	4.0	24.0	18.6	16.1	0.0	15.3
65-74	0.0	0.0	0.0	0.0	0.0	0.0
Parents' gender						
Male	20.0	28.0	25.0	19.6	25.0	37.7
Female	80.0	72.0	75.0	80.4	75.0	76.3
Parents' marital status						
Married	61.5	66.7	63.6	64.3	61.5	62.7
Living common-law	11.5	25.0	18.2	14.3	7.7	16.9
Widowed	0.0	0.0	0.0	0.0	0.0	0.0
Separated	3.8	4.2	4.5	5.4	15.4	5.1
Divorced	11.2	4.1	4.5	7.1	7.7	6.8
Single, never married	11.5	0.0	9.2	8.9	7.7	8.5
Parents' education level						
Less than high school diploma	16.0	32.0	16.3	12.5	45.5	15.5
High school diploma	24.0	8.0	18.6	17.9	0.0	17.2
Trade certificate or diploma	12.0	12.0	9.3	12.5	0.0	12.1
College or other Non-university certificate	28.0	28.0	37.2	37.5	27.3	36.2
University certificate	4.0	4.0	2.3	1.7	9.0	1.7
Bachelor degree	16.0	16.0	14.0	16.1	18.2	15.6
University certificate above the bachelor level	0.0	0.0	2.3	1.8	0.0	1.7
Parents' labour work status						
A paid worker	63.7	75.0	79.5	73.4	58.3	72.9
Self-employed	36.3	25.0	21.5	26.6	41.7	27.1

Table B-3. *Weighted Percentages of Parents' Scores of Their QOL Family's Interaction Domain Based on Their Demographic Variables (N = 193)*

Variable	Spend less time with spouse or partner	Spend less time with their children	Spend less time with other family members	Had strains with their family members	Had to move residence
Parents' age group					
25-34	11.8	10.3	18.8	9.2	44.4
35-44	34.2	46.6	23.5	39.5	27.8
45-54	40.8	31.0	44.7	42.1	27.8
55-64	13.2	12.1	10.6	9.2	0.0
65-74	0.0	0.0	2.4	0.0	0.0
Parents' gender					
Male	31.6	31.0	32.1	32.9	33.3
Female	68.4	69.0	67.9	67.1	66.7
Parents' marital status					
Married	72.4	72.4	58.8	54.5	66.7
Living common-law	27.6	15.5	21.2	23.4	22.1
Widowed	0.0	0.0	2.3	0.0	0.0
Separated	0.0	3.4	4.7	6.5	5.6
Divorced	0.0	3.4	5.9	9.1	5.6
Single, never married	0.0	5.3	7.1	6.5	0.0
Parents' education level					
Less than high school diploma	8.1	8.6	10.6	12.2	27.8
High school diploma	25.7	19.0	17.6	25.7	5.5
Trade certificate or diploma	9.5	1.7	9.5	10.8	5.6
College or other Non-university certificate	32.4	43.1	37.6	33.8	16.7
University certificate	2.8	1.7	3.5	2.7	0.0
Bachelor degree	14.9	13.8	10.6	10.8	22.2
University certificate above the bachelor level	6.6	12.1	10.6	4.0	22.2
Parents' labour work status					
A paid worker	69.1	74.1	73.0	71.6	62.4
Self-employed	30.9	25.9	27.0	28.4	37.6

Table B-4. *Weighted Percentages of Parents' Scores of Their QOL Leisure and Recreational Domain Based on Their Demographic Variables (N = 193)*

Variable	Spent less time with friends	Spent less time on social activities or hobbies	Spent less time on relaxing or taking care of yourself	Spent less time participating in political, social, or cultural groups	Made holiday plans and change or cancel them	Had not to make holiday plans at all
Parents' age group						
25-34	14.7	12.7	14.4	19.4	14.3	16.2
35-44	30.1	33.3	31.1	28.6	32.1	27.5
45-54	39.7	38.1	42.4	36.4	35.7	38.8
55-64	13.8	14.3	12.1	13.0	17.9	17.5
65-74	1.7	1.6	0.0	2.6	0.0	0.0
Parents' gender						
Male	33.0	37.8	35.6	31.2	32.5	29.1
Female	67.0	62.2	64.4	68.8	67.5	70.9
Parents' marital status						
Married	61.5	64.3	64.4	56.4	64.2	69.6
Living common-law	18.8	18.3	16.7	16.7	20.2	7.6
Widowed	4.4	2.4	2.3	6.4	3.6	3.8
Separated	3.4	4.0	4.5	3.8	2.4	5.1
Divorced	6.8	6.2	7.6	9.0	6.0	10.1
Single, never married	5.1	4.8	4.5	7.7	3.6	3.8
Parents' education level						
Less than high school diploma	9.4	11.8	12.3	10.4	12.0	10.0
High school diploma	21.4	20.5	23.8	15.6	30.1	26.3
Trade certificate or diploma	6.8	7.1	7.0	8.8	3.6	6.3
College or other Non-university certificate	33.3	29.9	32.3	33.8	30.1	31.3
University certificate	2.6	3.9	1.5	5.2	1.2	2.3
Bachelor degree	18.0	18.1	15.4	18.2	15.7	20.0
University certificate above the bachelor level	8.5	8.7	7.7	8.0	7.3	3.8
Parents' labour work status						
A paid worker	73.0	72.5	72.4	74.0	74.3	75.3
Self-employed	27.0	27.5	27.6	26.0	25.7	24.7

Table B-5. *Weighted Percentages of Parents' Scores of Their QOL Community Interaction Domain Based on Their Demographic Variables (N = 193)*

Variable	Had not received help from extended family members	Had not received help from close friends or neighbours	Had not received help from community, spiritual community or cultural or ethnic groups	Had not received occasional relief or respite care
Parents' age group				
25-34	8.3	10.3	11.5	10.7
35-44	26.9	29.9	32.9	30.1
45-54	40.7	34.2	36.2	39.8
55-64	22.2	23.9	18.1	17.5
65-74	1.9	1.7	1.3	1.9
Parents' gender				
Male	31.2	41.9	36.5	32.0
Female	68.8	58.1	63.5	68.0
Parents' marital status				
Married	61.5	68.4	63.1	64.8
Living common-law	15.6	12.8	18.8	17.6
Widowed	3.7	2.6	2.0	2.9
Separated	6.3	3.4	4.7	3.9
Divorced	8.3	7.7	6.7	6.9
Single, never married	4.6	5.1	4.7	3.9
Parents' education level				
Less than high school diploma	11.1	13.7	10.0	11.7
High school diploma	25.9	23.1	29.1	30.1
Trade certificate or diploma	4.6	6.0	6.1	6.7
College or other Non-university certificate	25.9	26.5	26.4	26.2
University certificate	3.7	3.3	3.1	5.9
Bachelor degree	18.5	19.7	16.2	11.6
University certificate above the bachelor level	10.3	7.7	8.1	7.8
Parents' labour work status				
A paid worker	78.7	73.1	27.7	71.0
Self-employed	21.3	26.9	27.3	29.0

Table B-6. *Weighted Percentages of Parents' Scores of Their QOL Government and Organizational support Domain Based on their demographic variables (N = 193)*

Variable	Did not receive money from government programs	Did not receive federal tax credits	Received help from professionals that is paid workers or organizations
Parents' age group			
25-34	10.7	15.8	13.8
35-44	31.0	24.8	30.9
45-54	38.9	41.6	38.2
55-64	17.5	15.8	15.8
65-74	1.9	2.0	1.3
Parents' gender			
Male	32.0	30.0	38.2
Female	68.0	70.0	61.8
Parents' marital status			
Married	64.7	65.2	67.1
Living common-law	17.7	14.9	17.1
Widowed	2.9	5.0	2.0
Separated	3.9	4.0	4.6
Divorced	6.9	6.9	5.3
Single, never married	3.9	4.0	3.9
Parents' education level			
Less than high school diploma	11.7	11.0	10.5
High school diploma	30.1	35.0	22.4
Trade certificate or diploma	5.8	8.0	6.6
College or other Non-university certificate	26.2	22.0	29.6
University certificate	6.7	3.0	3.3
Bachelor degree	11.7	13.0	17.1
University certificate above the bachelor level	7.8	8.0	10.5
Parents' labour work status			
A paid worker	70.3	64.5	79.8
Self-employed	29.7	34.5	20.2

Table B-7. *Weighted Percentages of Parents' Scores of Their QOL Needs Domain Based on Their Demographic Variables (N = 193)*

Variable	Needed home care	Needed financial support / government assistance / tax credit	Needed emotional support or counselling	Needed help from medical professionals	Needed occasional relief / respite care	Needed voluntary / community services
Parents' age group						
25-34	0.0	4.4	5.0	7.4	9.3	0.0
35-44	15.8	46.7	30.0	33.4	25.0	57.1
45-54	57.9	40.0	55.0	44.4	46.9	21.4
55-64	26.3	8.9	10.0	14.8	18.8	14.3
65-74	0.0	0.0	0.0	0.0	0.0	7.2
Parents' gender						
Male	31.6	31.1	15.0	37.0	27.3	20.0
Female	68.4	68.9	85.0	63.0	72.7	80.0
Parents' marital status						
Married	73.7	72.7	55.0	81.5	67.7	33.3
Living common-law	15.8	15.9	20.0	11.1	9.7	26.7
Widowed	0.0	0.0	0.0	0.0	0.0	6.7
Separated	0.0	4.5	10.0	3.7	9.6	13.3
Divorced	5.2	4.5	15.0	3.7	6.5	20.0
Single, never married	5.3	2.4	0.0	0.0	6.5	0.0
Parents' education level						
Less than high school diploma	5.2	10.9	5.0	7.7	9.4	7.1
High school diploma	47.4	23.9	35.0	26.9	18.8	21.4
Trade certificate or diploma	0.0	6.5	15.0	7.7	9.4	7.1
College or other Non-university certificate	15.8	26.1	15.0	19.2	34.4	42.9
University certificate	0.0	2.2	0.0	3.8	0.0	7.3
Bachelor degree	26.3	21.7	15.0	23.2	25.0	7.1
University certificate above the bachelor level	5.3	8.7	15.0	11.5	3.0	7.1
Parents' labour work status						
A paid worker	68.5	77.8	69.0	75.0	75.1	89.3
Self-employed	31.5	22.2	31.0	25.0	24.9	10.7

Table B-8. *Weighted Percentages of Parents' Scores of Their QOL Influence of Values, Coping, and Rewarding Domain Based on Their Demographic Variables (N = 193)*

Variable	Did not have a choice in taking on your caregiving responsibilities	Caregiving experiences were not rewarding at all	Found religious and spiritual beliefs not very important	Coping with their caregiving responsibilities was not very well at all
Parents' age group				
25-34	15.6	18.2	8.1	0.0
35-44	35.9	54.5	54.1	33.3
45-54	35.2	27.3	32.4	66.7
55-64	13.3	0.0	5.4	0.0
65-74	0.0	0.0	0.0	0.0
Parents' gender				
Male	38.6	33.3	40.5	0.0
Female	61.4	66.7	59.5	100.0
Parents' marital status				
Married	68.3	58.3	51.4	66.7
Living common-law	15.1	0.0	29.7	0.0
Widowed	2.4	0.0	2.7	0.0
Separated	4.6	16.7	0.0	0.0
Divorced	5.6	8.3	10.8	33.3
Single, never married	4.0	16.7	5.4	0.0
Parents' education level				
Less than high school diploma	10.3	9.1	16.3	0.0
High school diploma	24.6	63.6	29.7	0.0
Trade certificate or diploma	7.1	0.0	5.4	0.0
College or other Non-university certificate	28.6	18.2	24.3	100.0
University certificate	1.7	0.0	0.0	0.0
Bachelor degree	19.8	9.1	16.2	0.0
University certificate above the bachelor level	7.9	0.0	8.1	0.0
Parents' labour work status				
A paid worker	68.9	41.7	73.2	100
Self-employed	31.1	58.3	26.8	0.0

Table B-9. *Weighted Percentages of Parents' Scores of Their QOL Careers and Employment Domain Based on Their Demographic Variables (N = 193)*

Variable	Reduced their regular weekly hours of work because of their caregiving responsibilities	Quit a job because of their caregiving responsibilities	Took a less demanding job because of their caregiving responsibilities
Parents' age group			
25-34	3.4	15.4	16.2
35-44	41.4	30.8	22.6
45-54	34.5	23.0	41.9
55-64	20.7	30.8	16.1
65-74	0.0	0.0	3.2
Parents' gender			
Male	36.7	16.7	51.6
Female	63.3	83.3	48.4
Parents' marital status			
Married	63.3	83.4	58.0
Living common-law	30.1	0.0	22.6
Widowed	0.0	0.0	9.7
Separated	3.3	0.0	0.0
Divorced	0.0	8.3	6.5
Single, never married	3.3	8.3	3.2
Parents' education level			
Less than high school diploma	10.0	8.3	9.4
High school diploma	3.3	22.2	34.4
Trade certificate or diploma	10.1	6.5	9.4
College or other Non-university certificate	50.0	29.6	15.6
University certificate	3.3	3.7	9.4
Bachelor degree	10.0	16.7	18.8
University certificate above the bachelor level	13.3	13.0	3.0
Parents' labour work status			
A paid worker	76.7	76.9	90.3
Self-employed	23.3	23.1	9.7

Table B-9. *Weighted Percentages of Parents' Scores of Their QOL Careers and Employment Domain Based on their demographic variables (continued) (N = 193)*

Variable	Turned down a job offer or promotion, or decided not to apply for a job, because of their caregiving responsibilities	Had been prevented respondent from working at a paid job because of their caregiving responsibilities	Retirement would be affected because of their caregiving responsibilities
Parents' age group			
25-34	12.5	26.1	0.0
35-44	30.0	26.1	0.0
45-54	42.5	34.8	90.0
55-64	12.5	13.0	10.0
65-74	2.5	0.0	0.0
Parents' gender			
Male	46.3	8.7	38.1
Female	53.7	91.3	61.9
Parents' marital status			
Married	65.0	70.8	47.4
Living common-law	12.5	12.5	21.1
Widowed	7.5	0.0	15.8
Separated	2.5	4.2	0.0
Divorced	10.0	4.2	10.5
Single, never married	2.5	8.3	5.2
Parents' education level			
Less than high school diploma	7.1	30.4	4.8
High school diploma	19.0	26.1	14.3
Trade certificate or diploma	7.1	4.3	9.4
College or other Non-university certificate	23.8	26.2	28.6
University certificate	7.1	0.0	0.0
Bachelor degree	28.6	13.0	28.6
University certificate above the bachelor level	7.3	0.0	14.3
Parents' labour work status			
A paid worker	78.0	0.0	78.6
Self-employed	22.0	0.0	21.4