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Family Quality of Life When There is More Than One Child With a Developmental Disability

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Abstract

This study explored whether Family Quality of Life (FQOL) differs in families with two or more children with developmental disability (DD) compared to families with only one child with DD and examined predictors of FQOL including child, family, and context variables. The current study used convenience sample information from a nationwide survey completed by 209 parents of children with severe DD across Canada. The two subgroups were compared using independent t-tests and, contrary to our original hypothesis, families with more than one child with DD had significantly higher FQOL ($t(177) = -2.35$, $p = .02$) with a medium effect size. However, a hierarchical regression revealed that no additional variance was accounted for by whether there were one or multiple children with DD in the family after accounting for other child, family and parent, and context variables. These findings suggest that having two or more children with DD has no major negative impact on families' QOL compared to having only one child with DD. In conclusion, these caregivers seem to be resilient despite the extra time and effort they devote to their multiple care giving roles. Furthermore, previous care giving experiences may have enhanced their resiliency to cope positively with their current circumstances.

This study aimed to include participants with many different developmental disabilities (DD). The term DD will therefore be used as an umbrella term to encompass children or adolescents with an intellectual disability (ID), autism spectrum disorder (ASD), physical disability (e.g., cerebral palsy, seizures) and all other forms of disabilities, such as Down syndrome, fragile X syndrome, etc. Indeed, many individuals with one disability, for instance ID, often have a co-morbid diagnosis of another, such as ASD, including the individuals in the present study.

Previous research has suggested that families of children with ASD or other DDs are at risk for higher levels of distress or less optimal Family Quality of Life (FQOL) compared to families of typically developing children (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Cuzzocrea, Larcan, Baiocco, & Costa, 2011; Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005). Care of a child with a DD places additional financial, psychological, and interpersonal demands upon the members of the family (Goudie, Narcisse, Hall, & Kuo, 2014; Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2012). In particular, parents of children with ASD not only report higher levels of stress but are also at a higher risk for mental illnesses such as major depressive disorder. Additionally, parents of children with ASD commonly report feeling incompetent as caregivers, habitually frus-

trated and tend to isolate themselves (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Lach et al., 2009). Likewise, families of children with a DD have been found to experience lower FQOL compared to families of children without a disability (Brown, MacAdam-Crisp, Mian Wang, & Iarocci, 2006; Gupta, 2007).

It is well known that there is increased risk of having more than one child in the family with ASD as the result of various genetic, epigenetic, and non-genetic factors (e.g., Perry, Koudys, Dunlap, & Black, 2017) and that families can have more than one child with other forms of DD (Percy, Brown, & Fung, 2017). However, the impact of having more than one child with a DD on a family's QOL, has yet to be been investigated.

There are several reasons that the presence of more than one child with a DD in a family might exacerbate the stress already experienced by families of individuals with a DD. The additional stress could be derived from the increased level of dependence and time demands of the children with the DD, or the additional emotional and financial burden (Kuo, Cohen, Agrawal, Berry, & Casey, 2011; McCann, Bull, Winzenberg, 2012). Thus, it is imperative to investigate how the presence of multiple children with a DD affects overall FQOL.

Objectives

There are two main objectives in the current study; first, we investigated how family quality of life differs between families with two or more children with DD compared to families with only one child with a DD. We hypothesized that families with multiple children with a DD would have lower family quality of life compared to families with only one child with a DD. Second, we examined predictors of family quality of life including child, family and parent, and context factors. Child factors include adaptive and maladaptive skills. Family and parent factors include marital status, parent socialization, mental health, positive experiences related to parenting a child with a DD (positive gain), and marital support and satisfaction. Context factors include median income of residential area, school satisfaction, child socialization, and support from neighbours. We hypothesized that having more than one child with a DD would be a significant predictor of family quality of life, above and beyond these other predictors.

Methods

This study is part of a larger study, namely the Great Outcomes for Kids Impacted by Severe Developmental Disabilities project (GO4KIDDS). This study was an Emerging Team grant funded by the Canadian Institutes of Health Research (PI: Perry). GO4KIDDS included a number of studies using different methodologies, including several different caregiver surveys. The objective of the overall project was to provide a better understanding about the health, well-being, and social inclusion of school-aged children and youth with severe DDs and the experiences of their families. Recruitment materials stated the sample being invited to participate was parents of children with intellectual disabilities in the moderate, severe, or profound range, with or without autism, with or without physical disabilities, and with or without mental health or behavioural challenges. That is, the sample was intended to include children with significant and multiple needs (see below for specific child characteristics of the sample in the present study). Researchers gained ethics approval from the Human Participants Review Committee at York University and caregivers provided informed consent.

Participants were recruited through approximately 500 agencies across Canada, and postings on websites and social media sites. Over 400 caregivers of children and adolescents with DDs completed the Basic Survey (Perry & Weiss, 2008a) online or by paper and pencil. About half of these families then went on to complete an Extended Survey (Perry & Weiss, 2008b) with additional questions to provide a more in depth understanding of their family dynamics. The present study utilizes data collected from both the GO4KIDDS Basic and Extended Surveys.

Please contact authors if further detail regarding the study methodology is required.

Participants

The participants in this study were part of the GO4KIDDS Extended Survey that made use of a convenience subsample of 209 caregivers of children and adolescents with severe DDs. Of the participants who completed the survey, 66% reported having one child with a severe DD, while 34% reported having two or more (up to four) children with a DD. If parents reported having more than one child with a DD, they

were asked to complete the survey based on their child with the most severe DD. The following participant details are based on the child with the most severe DD in these families; information regarding the other child(ren) with DD (or additional siblings without a DD) in these families was not collected. The primary individuals with DD ranged in age from 3 to 18 years with a mean of 10.8 (*SD* = 3.5). The 122 individuals who did not have a sibling with a DD had an average age of 10.7 (*SD* = 3.44) and the average age of the 87 individuals who had one or more siblings with a DD was 10.4 (*SD* = 3.36). The majority of the individuals with a DD were male (71.4%). Of the families who had only one child with a DD, 67.5% reported their child being male. Similarly, of the families who had more than one child with a DD, 77.4% reported their child with the most severe DD to be male.

The 209 families included in our analysis inhabited both rural and urban areas from 11 different provinces and territories ranging all across Canada. Of these families, the majority of the caregivers completing the survey were the biological parent (91.3%), with the remaining 8.7% being comprised of adoptive parents, stepparents, and grandparents. The caregivers in these families were predominately female (90.7%) and had an average age of 42 years (range = 24 to 57). Over half (57.4%) were employed, and 81.1% reported their highest level of education as beyond high school. Three quarters (75.6%) of the caregivers were married and the median income of the family's neighbourhood was $65,516.66 (derived from the forward sortation index of their postal code) based on the 2006 census from Statistics Canada (Statistics Canada, 2006).

Measures

Table 1 provides details about all measures included in the study.

Table 1. Constructs and Measures Included in Study

Construct	*Name of Measure*	*Type of Measure*	*# of Items*	*Scale*	α
Child					
Age	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Continuous	1	N/A	N/A
Gender	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Dichotomous	1	1 = Male 2 = Female	N/A
Diagnosis	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Nominal	1	1 = ASD 2 = ID 3 = other	N/A
* Adaptive Skills	SIB-R-Age Equivalent (Bruininks, Woodcock, Weatherman, & Hill, 1996)	Ordinal	35	4-point	0.95
* Maladaptive Skills	SIB-R (Bruininks, et al., 1996)	Ordinal	8	Standardized score, based on 6 point frequency and 5 point severity ratings for each item, standardized for age. Scores range from most severe (-70) to average range (-10 to +10)	0.80

** construct used in regression*

continued on following page

Table 1. Constructs and Measures Included in Study (continued)

Construct	*Name of Measure*	*Type of Measure*	*# of Items*	*Scale*	α
Parent/Family					
Gender	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Dichotomous	1	1 = Male 2 = Female	N/A
Relation to child	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Nominal	1	1 = Biological 2 = Adoptive 3 = Step 4 = Grandparent 5 = Other	N/A
* # of children in family w/ DD	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Dichotomous	1	1 = 1 child with a DD 2 = 2 or more children with a DD	N/A
* Marital Status	GO4KIDDS Basic Survey (Perry & Weiss, 2008)	Nominal	1	1 = Married or common law 2 = Separated, divorced, single or widowed 3 = Other	N/A
Maternal Employment	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Nominal	1	1 = Not currently 2 = Full or part time	N/A
* Socialization	GO4KIDDS Basic Survey (Perry & Weiss, 2008)	Ordinal	7	5-point ranging from -2 (much less than others) to +2 (much more than others)	0.81
* Mental Health	Kessler-6 (Kessler et al., 2003)	Ordinal	6	5-point	0.89
* Positive Experience	(Positive Gain Scale [PGS]: Pit-ten Cate, 2003).	Ordinal	7	5-point	0.85
Family Stress	Excerpt from Family Stress and Coping Interview (Nachshen, Woodford, & Minnes, 2003)	Ordinal	11	4-point	0.87
* Marital Satisfaction	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Ordinal	2	5-point	0.71

** construct used in regression*

continued on following page

Table 1. Constructs and Measures Included in Study (continued)

Construct	*Name of Measure*	*Type of Measure*	*# of Items*	*Scale*	α
Context					
Median Income of neighbourhood (postal code)	Stats Canada (Statistics Canada, 2006).	Continuous	1	N/A	N/A
* SES	Barratt Simplified Measure of Social Status (Barratt, 2012)	Ordinal	2	Based on combination of Education (7 levels) and Occupation (9 categories)	N/A
# of Services	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Continuous	20	# out of 20	N/A
* School Satisfaction	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Ordinal	9	5-point	0.92
* Child Socialization	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Continuous	7	# out of 7 social and recreational activities	0.70
* Neighbour Support	GO4KIDDS Extended Survey (Perry & Weiss, 2008)	Ordinal	1	5-point	N/A
Dependent Variable					
* FQOL	Beach Center FQOL Scale (Hoffman et al., 2006)	Ordinal	25	5-point	.94

** construct used in regression*

Results

Prior to comparing the FQOL scores in the two subgroups, we examined several potential factors that, if different in the two groups, might confound the comparison. This included child characteristics (age, gender, diagnosis, adaptive and maladaptive behaviour) and SES variables (median income of their neighbourhood, and Barratt (2012) – proxies for SES based on parents' education and occupation). Independent *t*-tests showed no subgroup differences for children's age, adaptive skills, maladaptive behaviour, or SES variables (see Table 2). Also, two chi-squared tests showed there was no difference in the percentage of the two subgroups of children who had ASD (57.4% of families with one child with DD; 56.5% of families with multiple children with a DD; $\chi^2 = 0.014$; Fisher exact $p = .51$) and no difference in the percentage of the sample who were boys (67.5% versus 77.4%, $\chi^2 = 1.95$, Fisher exact $p = .11$). Thus, there seemed to be no differences between the groups on any of the examined child or SES factors that might confound the comparison of the two subgroups.

These two subgroups were then compared on the remaining parent/family (parent mental health, socialization, positive gain, family stress, marital support and satisfaction) and context factors (median income, Barratt SES, number of services, school satisfaction, child socialization and neighbour support). In general, the two groups did not differ with the exception of their amount of posi-

tive experiences as a result of having a child with DD (Positive Gain Scale [PGS]: Pit-ten Cate, 2003), which was significantly higher in families who had multiple children with a DD. There was also a trend for stress to be lower and neighbour support to be higher in families with two or more children with a DD. These *t*-test comparisons are also provided in Table 2.

Table 2. Comparison of Subgroups With One Child With DD vs. Two or more Children With DD

Group	*1 or 2+ children with DD*	*N*	*M*	*SD*	*t (p)*
Child Factors					
Age	One	122	10.7	3.45	0.52
	Two or more	62	10.4	3.36	(p = .61)
Adaptive Behaviour	One	122	42.4	29.64	0.63
	Two or more	62	39.5	31.52	(p = .53)
Maladaptive Behaviour	One	122	-15.6	12.84	0.52
	Two or more	62	-16.7	13.23	(p = .61)
Parent/Family Factors					
Mental Health Problems	One	120	1.2	0.90	0.39
	Two or more	60	1.1	0.85	(p = .70)
Parent Socialization	One	121	-1.13	0.69	-0.25
	Two or more	61	-1.09	0.73	(p = .80)
Positive Gain	One	120	4.04	0.62	-2.03
	Two or more	61	4.25	0.72	(p = .04)
Family Stress	One	121	2.75	0.63	1.89
	Two or more	60	2.55	0.69	(p = .06)
Marital Support & Satisfaction	One	98	7.52	1.64	-0.11
	Two or more	54	7.56	2.14	(p = .91)
Context Factors					
Median Income	One	121	$63,853.00	$16,813.73	-1.67
	Two or more	58	$68,364.95	$17,239.82	(p = .10)
Barratt SES	One	122	39.6	14.04	1.80
	Two or more	59	35.4	15.65	(p = .07)
Number of Services	One	122	10.60	3.55	0.22
	Two or more	61	10.48	3.47	(p = .82)
School Satisfaction	One	118	3.53	1.02	0.25
	Two or more	60	3.49	1.09	(p = .80)
Child Socialization	One	93	19.43	4.49	-0.08
	Two or more	47	19.49	4.23	(p = .94)
Neighbour Support	One	98	2.41	0.74	-1.80
	Two or more	50	2.66	0.92	(p = .07)
Dependent Variable					
Family Quality of Life	One	119	3.58	0.63	-2.35
	Two or more	60	3.82	0.71	(p = .02)

Finally, to test hypothesis 1, we compared the Family Quality of Life score (Hoffman et al., 2006), between groups. Contrary to our original hypothesis, families in the group with two or more children with a DD reported a significantly *higher* family quality of life score. See last line of Table 2.

In order to address the second research question, which was to explore factors related to FQOL, and choose variables for the regression analysis, including child factors, parent/family, and context variables, we began by examining relevant correlations. Child factors were examined first to see whether they were related to FQOL. Child's age was not correlated with FQOL (r = -.057, ns) and a scatter plot revealed no non-linear relationship with age. Child's diagnosis did not seem to be strongly related to FQOL either as the FQOL scores for the group with ASD, though slightly lower, did not differ significantly (M = 3.59, SD = .63) from the group without ASD (M = 3.77, SD = .70; $t(190)$ = 1.90, p = .06). However, children's level of adaptive skills was significantly, though weakly, correlated with FQOL (r = .20, p = .005) as were maladaptive behaviour problem scores (r = .35, p < .001). Thus, in terms of child characteristics, child age and diagnosis were unrelated to FQOL, but higher FQOL was associated with higher adaptive skills and lower levels of problem behaviour.

Parent and family variables (parent mental health, socialization, positive gain, family stress, marital support and satisfaction) as well as contextual factors (median income, Barratt SES, number of services, school satisfaction, child socialization and neighbour support) were also examined in relation to FQOL scores using either Pearson correlations for continuous variables or independent t-tests as appropriate (see Table 2). Most of the parent/family variables were significantly related to FQOL. Parent mental health problems and family stress were negatively correlated with FQOL (r = -.47, p < .001 and r = -.44, p < .001 respectively). Marital satisfaction, parent socialization, and positive gain were all positively correlated with FQOL (r = .53, p < .001, r = .31, p < .001, and r = .48, p < .001 respectively). Married respondents (n = 143, M = 3.72, SD = .62) reported significantly higher FQOL than single parents (n = 45, M = 3.47, SD = .78, $t(186)$ = 2.30, p = .023). However, there was no difference in FQOL scores between respondents who were employed or not currently employed (3.62 vs. 3.70, $t(190)$ = -.81, p = .42). Contextual factors were somewhat related as well. School satisfaction was correlated with FQOL (r = .37, p < .001) as was children's activity participation (r = .33, p < .001). The two SES measures were only weakly related to FQOL (r = -.17, p = .02 for Barratt SES, and r = .08, p = .296 for median neighbourhood income).

Next, a hierarchical multiple regression analysis was performed in order to determine how child, parent/family, as well as context variables contributed to the overall FQOL score, and whether families having one child with a DD versus having more than one child with a DD accounted for any unique variance in FQOL above and beyond predictors in the other steps of the model. Only pertinent variables that were shown to be associated with FQOL were included in the regression analysis. Results are shown in Table 3. Child factors, specifically adaptive and maladaptive behaviours, were entered as the first predictors (step 1), followed by parent and family factors (parent socialization, mental health, positive gain, marital status, satisfaction and support) (step 2). Next, contextual factors were entered into the model (child social participation, school satisfaction, total Barratt score and neighbour support) (step 3) and finally having one child with DD or multiple children with DD in the family was entered as the final step (step 4).

The results from step 1 indicate that child factors significantly contributed to the regression model and accounted for 16% of the variance. Introducing the parent and family variables at step 2 accounted for an additional 34% of the variance and this change was significant. At this step, all child variables remained significant. Furthermore, of the family variables, positive gain, marital support, and parental mental health were significant. Next, the addition of context variables at step 3 accounted for another 5% of the variance and this change was significant. At this step, parent mental health was no longer significant but neighbour support, child variables, positive gain, as well as marital support remained significant. Finally, the addition of the one child with DD or multiple children with DD in the family variable at step

Table 3. Predictors of Family Quality of Life

Step	*Predictors*	ΔR^2	*ß*	*p*
1	**Child Factors**			
	Adaptive Behaviour	$R^2 = .162$	.132	.062
	Maladaptive Behaviour		.151	.046
2	**Parent & Family Factors**	**.338**		
	Parent Socialization		-.068	ns
	Mental Health	*F* for change	-.125	ns
	Positive Gain	$p < .001$	.194	.011
	Marital Status		.020	ns
	Marital Support & Satisfaction		.363	< .001
3	**Context Factors**	**.054**		
	Child Socialization		.142	ns
	School Satisfaction	*F* for change	.126	ns
	Total Barratt Score	$p = .017$	-.094	ns
	Neighbour Support		.134	.050
4	1 or 2+ Children with DD	**.014**	**.014**	ns
		F for change		
		$p = .073$		
	Final Model	**Final R^2 = .567**		
	$F(12,104) = 11.37$, $p < .001$			

4 accounted for only 1% of additional variance and therefore was not significant. The final model (see table 3) accounted for a substantial 57% of the variance in FQOL ($F_{(12,104)} = 11.37$, $p < .001$) and included the following significant predictors: maladaptive behaviour, positive gain, marital support, and neighbour support.

Discussion

The purpose of this study was to report on the FQOL experienced in families with more than one child with DD. We compared families who had multiple children with DD to families who had only one child with a DD. With regard to our first objective, our hypothesis that families who have multiple children with DD will have a lower FQOL than families with only one child with a DD, was rejected. Surprisingly, families with two or more children with a DD reported experiencing a slightly higher level of FQOL than families with only one child with a DD. Furthermore, with regard to our second objective, our hypothesis that having more than one child with a DD would be a significant predictor of FQOL, after taking other variables into account, was also rejected. Moreover, the regression indicated that 16% of the variance was accounted for by child factors, an additional 34% by parent factors, and a further 5% by context factors. However, there was no additional variance accounted for by whether there were one or multiple children with DD in the family.

These findings may suggest that, after having the initial child with a DD, additional caregiving roles may not add significant additional strain on the family. Rather, additional caregiving roles may be a straightforward adaptation, as these families have already experienced caring for an individual with a DD. Furthermore, these families may now have a better understanding of their additional child's needs and have possibly become experts at their caregiving roles. For instance, these caregivers may have become better prepared and equipped with knowledge about the service system, advocacy skills, and empathy required to care for an individual with a DD. Thus, pertinent coping skills and caregiving skills may have already been developed after caring for an initial child with a DD.

Similar to previous reports of having one child with a DD (McMillen & Fisher, 1998), the Positive Gain Scale was found to be a significant predictor of FQOL in families with more than one child with a DD. Furthermore, scores on the Positive Gain Scale, which assesses positive experiences associated with raising a child with DD, were higher in families with more than one child with DD. This may be a result of families who have more than one child with DD gaining an even stronger sense of purpose and fulfillment in their lives. Additionally, an optimistic perspective may be an integral part of a parent's ability to cope with the presence of a DD in family members.

Limitations and Future Research

Although this study is statistically sophisticated and examines information that very little research has attempted to investigate before, there are limitations present. For instance, the current study relied on self-report measures and convenience sampling methodology, which can lead to biases in the results. In addition, the current study is cross sectional and therefore does not reflect dynamic factors. FQOL may change over time and researchers may find cumulative effects of variables. Therefore, longitudinal research is needed to examine the long-term impact of caring for multiple individuals with DD. Likewise, in order to gain a more comprehensive understanding of families who care for multiple children with DD, further in-depth, and perhaps qualitative research may prove beneficial. Other factors that might be advantageous to examine in order to gain a more comprehensive understanding of FQOL in families with one or more children with DD include caregivers' total time spent caring for their children, use of specific coping strategies, specific diagnoses, sibling diagnosis and dependence level, as well as the dependence level and number of siblings without DD in each family.

Managing multiple caregiving roles undoubtedly presents considerable challenges for parents. However, the caregivers in the present study seem to be resilient despite the extra time and effort they presumably have to devote to their multiple caregiving roles. Furthermore, previous caregiving experiences may have enhanced their resiliency to cope positively with their current circumstances. This knowledge helps us better understand the context of families caring for more than one child with DD and has important clinical relevance. Moreover, the identification of potential risk factors and protective factors associated with FQOL will allow professionals to provide services that are more catered to the needs of families who have multiple children with a DD. As well, this knowledge may help alleviate stress, and enlighten families on what they can expect with regard to having one or multiple children with DD.

Key Messages From This Article

People with disabilities. It is important for people with disabilities and their families to have good quality of life. Different people might have different ideas about what good quality of life is, but usually it means things like being healthy, happy, having friends, having enough money, etc. In this study, families who have more than one child with a disability told us that their quality of life was just as good, or even better, than families who had only one child with a disability.

Professionals. A subset of parents we work with have more than one child with a disability. It is important to bear this in mind for goal setting and family work with these families. Parents who have multiple children with disabilities may be quite resilient, in spite of having many challenges, and do not necessarily experience less optimal Family Quality of Life than parents with only one child with a disability.

Policymakers. It is important to remember that a substantial proportion of families of children with disabilities have more than one affected child. This may require reconsideration of certain policies (e.g., waitlist management).

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