Family quality of life: perceptions of parents of children with developmental disabilities in Bosnia and Herzegovina

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The goal of the present study was to assess the family quality of life (FQOL) in families with children with developmental disabilities in Bosnia and Herzegovina. We examined the FQOL in relation to parents' demographic variables (gender, age, employment status), children's gender and age, type of children's disability (mild and moderate intellectual disability, autism spectrum disorder) and parent's depression, anxiety, and stress levels. The sample consisted of 270 parents of children with disabilities; 90 parents of children with autism spectrum disorder, 90 parents of children with mild intellectual disability, and 90 parents of children with moderate intellectual disability. We also included a control group of 90 parents of typically developing children. The results of this study showed that parents of children with autism spectrum disorder and parents of children with moderate intellectual disability had statistically significantly lower FQOL than parents of children with mild intellectual disability and parents of typically developing children. Child's gender had a significant effect on FQOL. Also, depression, anxiety and stress levels significantly affected FQOL, while the parents' gender, age, and employment status did not have a significant effect. Implications of these findings are discussed and some measures on supporting parents are proposed.

Keywords: Family quality of life, parents, intellectual disability, autism spectrum disorder

Quality of life (QOL) has become a major topic of many scientific disciplines including public health, economics and social sciences (Cummins 2005, Davis *et al.* 2008). This wide interest in QOL is not surprising given the importance it has for everyday functioning and the value people ascribe to it (Pennacchini *et al.* 2011, Ventegodt *et al.* 2003). However, defining QOL is not an easy task as there are numerous conceptualizations on what it is and what components it encompasses. Researchers in most scientific fields agree that QOL is a multidimensional construct, consisting of objective and subjective dimensions, and that QOL has the same basic components for all people (Cummins 2000, Santacreu *et al.* 2016, Verdugo *et al.* 2012). One of the most widely used models in the area of intellectual disability includes eight QOL domains: (1) emotional well-being; (2) interpersonal relations; (3) material well-being; (4) physical well-being; (5) personal development; (6) self-determination; (7) social inclusion; and (8) rights (Schalock and Verdugo 2012).

QOL has received a central focus of research in the disability field as well. It has long been shown that disability, and various types of disability affect QOL (Barker *et al.* 2009, Fellinger *et al.* 2005). However, determining in what way and in what amount disability affects QOL is rather difficult (Memisevic *et al.* 2017). Although the main focus in QOL research has been in the area of individual QOL, some authors have tried to conceptualize the construct of family QOL (FQOL) as a natural extension of the work on individual QOL (Poston *et al.* 2003). FQOL research, among other things, incorporates experiences of siblings, parents, cultural contexts, and service delivery perspectives (Blacher *et al.* 2005). The concept of FQOL has become an important outcome for people with disabilities and their families (Park *et al.* 2003).

However, the research in FQOL is not as extensive as the research in individual QOL and its conceptualizations are quite limited. In the last decade, this began to change and increasing number of studies have a FQOL as their main focus (Summers *et al.* 2005). As is the case for individual QOL, the domains, subdomains, and

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Table 1 Descriptive data on the participants

	Parents of children			
	ASD	MoID	MiID	TDC
Parent's gender				
Mother	58	58	51	49
Father	32	32	39	41
Parent's mean age	40.2	43.1	43.6	38.5
Child's gender				
Boys	70	45	45	45
Girls	20	45	45	45
Child' mean age	11.4	12.0	11.8	11.6
Parents' employed				
Yes	45	46	39	65
No	45	44	51	25

Note. ASD- Autism Spectrum Disorder; MoID- moderate intellectual disability; MiID- Mild intellectual disability; TDC- typically developing children.

indicators of FQOL might differ among models. For example, some researchers have identified ten domains of FQOL: Advocacy, Health, Productivity, Emotional Well-being, Social Well-Being, Physical Environment, Daily Family Life, Family interaction, Financial Well-Being, and Parenting (Poston *et al.* 2003). Given the importance of this topic, there is almost no children's' medical condition and disability category for which there are no studies on FQOL. For example, numerous studies have examined the parents' QOL in relation to children different conditions such as: asthma (Cerdan *et al.* 2012), epilepsy (Taylor *et al.* 2011), heart disease (Arafa *et al.* 2008), cerebral palsy (White-Koning *et al.* 2008), phenylketonuria (Fidika *et al.* 2013), Attention Deficit Hyperactivity Disorder (Xiang *et al.* 2009), specific learning disability (Karande and Kulkarni 2009), etc.

FQOL is increasingly becoming a topic of great interest to researchers in the field of developmental disabilities (Brown *et al.* 2009, Mactavish *et al.* 2007). Research has shown that presence of disability has a profound effect on FQOL (Chou *et al.* 2007, Hu *et al.* 2012, Leung and Li-Tsang 2003, Misura and Memisevic 2017). This is related to the additional challenges that these families have in supporting a family member with a disability. Studies have shown that parents of children with disabilities have a higher risk for various psychological problems than parents of typically developing children (Cramm and Nieboer 2011, King *et al.* 1999) and these problems can have a negative effect on their QOL. Numerous studies have examined the effects of developmental disabilities such as Autism Spectrum Disorder and Intellectual Disability on health-related QOL and FQOL (Allik *et al.* 2006, Boehm *et al.* 2015, Čolić *et al.* 2019, Lee *et al.* 2009, Malhotra *et al.* 2012, Shu 2009). The findings of these studies indicate that parents of children with developmental disabilities have lower QOL in comparison with parents of children without disabilities.

A number of factors can affect FQOL. Exploration of these factors can help practitioners and support workers to assist families in more meaningful way, to better support them and consequently to increase FQOL. One of the variables that has been examined in relation to parent's QOL is the gender. Although, most of the studies pointed that mothers had lower self-reported QOL than fathers (Allik *et al.*, 2006), this finding is equivocal, as there are also studies that found no differences in QOL between mother and fathers (Davis *et al.* 2010). Further studies are needed to resolve this issue. Another area that has not been systematically explored is the effects of child's gender on FQOL. Thus, in this study we set the following objectives:

1. To examine whether there are differences in FQOL of parents of children with intellectual disability and autism spectrum disorder, and parents of typically developing children.
2. To examine the effects of parents' gender, age, employment status, child's gender, age and parents' depression, anxiety and stress levels on FQOL.

The hypothesis we set in this study are:

1. Parents of typically developing children will have higher FQOL then parents of children with developmental disabilities;
2. Parents of children with autism spectrum disorder will have lower FQOL then parents of children with mild and moderate intellectual disability;
3. Parents' gender, age, employment status, child's age and gender, and parents' depression, anxiety and stress level will have a significant impact on FQOL.

Methods

Participants

The sample for this study comprised 270 parents (mean age- 42.3 years, SD- 7.4 years) of 270 school-age children with developmental disabilities, out of which 90 parents of children with autism spectrum disorder, 90 parents of children with mild intellectual disability and 90 parents of children with moderate intellectual disability. In relation to gender, there were 167 mothers (61.9%) and 103 (38.1%) fathers. Only one parent (mother or father) in the family filled the questionnaire. Children were aged between ages 7 and 16 (mean age- 11.7 years; SD- 2.7 years). The inclusion criteria were that children attended school and had diagnosis of intellectual disability or diagnosis of autism spectrum disorder. The control group consisted of 90 parents (49 mothers, 41 fathers; mean age- 38.5 years, SD- 6.3 years) of school-aged, typically developing children (mean age 11.6 years; SD- 2.3 years). Descriptive data regarding the participants is presented in Table 1.

Procedure

Regular and special education schools in 8 cities in Bosnia and Herzegovina were contacted regarding the goals of the study. Principals of the schools agreed to

Table 2 FQOL scores in relation to child's diagnosis

Diagnosis	Mean	SD
Autism spectrum disorder	48,39	14,66
Mild intellectual disability	64,37	20,83
Moderate intellectual disability	55,96	25,10
Typically developing	68,46	22,39

participate and provided us with full support regarding meetings with parents. Parents were explained the goals of the study and asked to participate. They were told that information collected will be used anonymously, solely for the purposes of this research. Information about diagnosis of autism spectrum disorder and level of intellectual disability were contained in children's educational records. We did not collect information on intellectual functioning of children with diagnosis of autism spectrum disorder, so it is possible that some number of them also had intellectual disability. Only the records with full information and signed consent forms were included in the analysis. The control group sample of parents was recruited from the regular schools in Bosnia and Herzegovina. Parents were asked to fill two questionnaires: FQOL questionnaire and DASS scale.

FQOL- The Family Quality of Life Scale (FQOL) is a 25-item questionnaire on a 5 point Likert-type scale (Hu *et al.* 2011). Its purpose is to measure several aspects of families' perceived QOL. Family QOL is measured under five domains: Family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. Numerous cross-cultural studies have shown that the instrument has very good psychometric properties (Misura and Memisevic 2017, Verdugo *et al.* 2005). In this study, the internal consistency of FQOL scale was excellent as Cronbach alpha was .91.

*Depression, Anxiety Stress Scales (DASS)- T*he DASS is a 42-item self report instrument designed to measure the three related negative emotional states of depression, anxiety and tension/stress (Lovibond and Lovibond 1995). As the scores on subscales were highly correlated (above .90) there was an issue of colinearity. Thus, we used mean score from these scales (DAS score) as a dependent variable (Depression + Anxiety + Stress)/ 3. DASS has excellent internal consistency and temporal stability (Brown *et al.* 1997) and has been successuly used cross-culturally (Musa *et al.* 2007, Sardá Jr *et al.* 2008, Tonsing 2014). In this study, the internal consistency of DASS was excellent as Cronbach alpha was .94.

The study was approved by the Ethical Board of the Faculty of Educational Sciences at the University of Sarajevo.

Statistical analysis

We presented descriptive data (means and SD) for all groups of parents on FQOL questionnaire. To answer the first research question, differences between groups on FQOL, we performed an ANOVA test, followed by posthoc Tukey test. We then performed a regression analysis to determine what factors significantly impact the FQOL. An alpha level of .05 was set for all statistical tests.

Table 3 Tukey post-hoc test for testing group mean differences of parents FQOL

Group			Mean
TD	A		68,46
MilD	A		64,37
MoID		B	55,96
ASD		B	48,39

Note. TD- parents of typically developing children, MilD- Parents of children with mild intellectual disability, MoID- parents of children with moderate intellectual disability, ASD- parents of children with Autism Spectrum Disorder. Groups not connected by same letter are statistically significantly different.

Results

We first present FQOL values (mean values and SD) for the four groups of parents. There results are shown in Table 2.

As can be seen from Table 2, parents of children with autism spectrum disorder had lowest scores on FQOL, followed by parents of children with moderate intellectual disability, than parents of children with mild intellectual disability. Parents of typically developing children achieved best scores on FQOL. We further wanted to examine whether these differences in the mean FQOL scores are statistically significant. According to a one-way ANOVA test, the group means are statistically significant, F(3, 356)=16.2; $p<.001$. A Tukey post-hoc test revealed what group means were statistically signifcant. This is presented in Table 3.

Table 3 indicates that parents of children with autism spectrum disorder and parents of children with moderate intellectual disability statistically differ from parents of children with mild intellectual disability and parents of typically developing children.

We next wanted to examine the effects of several predictors on FQOL of parents of children with disabilities. In particular we examined the effects of parents' gender and age, child's gender and age, employment status, and DAS score on FQOL. The results of the multiple regression are shown in Table 4.

This regression model was statistically significant, F (6, 263)=3.5, p=.003. However, the model explained only 7% of the variance in QOL scores. The only statistically significant predictors in this model were child's gender (p=.001) and DAS score (p=.009). Parents who had daughters reported higher FQOL than those who had sons. Also, higher depression, anxiety and stress levels were related to lower FQOL. This relationship between DAS scores and FQOL was small (r=-.18), but statistically significant (p=.004). We already mentioned high correlations between the constructs of anxiety, depression and stress. If we have used a single subscale

Table 4 Regression analysis summary for predicting parent's QOL

	B	Std. Error	Beta	t	p
Age of parents	−.090	.189	−.031	−.476	.634
Parents gender	−.532	2.889	−.012	−.184	.854
Employment	−.951	2.742	−.022	−.347	.729
Child's gender	8.524	2.613	.194	3.263	.001
Child's age	.368	.488	.047	.755	.451
DAS	−.347	.131	−.160	−2.642	.009

Note. R^2=.07 (*N*=270; *p*=.003). DAS- mean Depression, Anxiety and Stress score..

instead of mean scores we would have obtained similar results. All other predictor variables did not come close to statistical significance. The same model applied to parents of children of typically developing children was not significant, F(6, 83)= 0.64; *p*=.70, and none of the predictors came close to reaching statistical significance (all p'$s > .26$).

Further, as the DAS scale had a statistically significant effect on the model, we wanted to examine whether there was a relationhip between parents's gender, parents' employment status, and child's diagnosis on DAS. Again, in relation to gender, mean differences between parents' DAS scores were not statistically significant, t (268)= 1.25; *p*=.21. However, parents employment status had a significant effect. Parents who are unemployed had significantly higher mean DAS scores than parents who are employed, t (268) = 2.5; *p*=.001. There was no interaction effects of parents' gender and employment status on QOL, F (2, 264) = 0.59; *p*=.55. Lastly, we examined whether there are differences in DAS scores in relation to child's diagnosis (autism spectrum disorder, mild intellectual disability, moderate intellectual disability). One way ANOVA indicated no statistically significant differences in mean DAS scores among various groups, F (2, 267) = 0.23; *p*=.79.

Discussion

The goal of the present study was to examine the FQOL reported by parents of children with intellectual disability and parents of children with Autism Spectrum Disorder and to compare it with FQOL of parents of typically developing children. The results of this study indicated lower FQOL in parents of children with developmental disabilities. However, this relationship was not uniform across conditions. Statistically significant differences in FQOL were found between the groups of parents of children with Autism Spectrum Disorder and parents of children with moderate intellectual disability on one hand and parents of children with mild intellectual disability and parents of typically developing children on the other. There were no differences in FQOL between parents of typically developing children and parents of children with mild intellectual disability. Similarly no statistically significant differences were observed between parents of children with Autism Spectrum Disorder and parents of children with moderate intellectual disability. This finding is in accordance with earlier studies that found that severity of disability was a significant predictor of parents' ratings of QOL (Leung and Li-Tsang 2003, Wang *et al.* 2004). Severity of impairment plays a significant role in parents reported QOL for other developmental disabilities such as cerebral palsy (Arnaud *et al.* 2008). Parents of children with Autism Spectrum Disorder reported lowest FQOL in this study. Again, this finding is in line with earlier studies examining QOL in this parent group. In a review of twelve studies regarding the QOL of parents of children with Autism Spectrum Disorder, the authors concluded lower QOL across the studies (Vasilopoulou and Nisbet 2016). The variables associated with lower QOL in the above mentioned review were child behavioral difficulties, unemployment, being a mother, and lack of social support. Other studies have also identified factors such as severity of the disorder, behavior problems, social supports, and coping strategies as factors affecting FQOL (Pozo *et al.* 2014). After parents of children with Autism Spectrum Disorder, parents of children with moderate intellectual disability reported second lowest FQOL. Again, this is not surprising given that children with moderate intellectual disabilities have more adaptive and behavioral challenges than children with mild intellectual disability (Dekker *et al.* 2002). Also, by definition children with moderate intellectual disability require higher levels of social supports, yet another factor related to FQOL. A possible explanation on why parents of children with autism spectrum disorder and parents of children with moderate intellectual disability had reported lower FQOL is that the needed family support levels are higher and children's behavioral challenges are greater than for children with mild intellectual disability and typically developing children. In this study there were no statistically significant differences in FQOL of parents of children with mild intellectual disability and parents of typically developing children. This was somehow an unexpected result, as most of the studies conducted thus far have found differences in QOL between the two groups. One possible explanation could be a gradual societal change in attitudes towards children with intellectual disability and efforts of school system to support all students in regular schools in Bosnia and Herzegovina (Dizdarević *et al.* 2017, Memisevic and Hodzic 2011).

As for the predictors of FQOL in parents of children with developmental disabilities we found that only two predictors had statistically significant effects, namely child's gender and parents' depression, anxiety and stress levels. To the best of our knowledge, no studies have explored the effects of child's gender on FQOL in these categories of children. We found that parents who have daughters with developmental disabilities had reported higher FQOL than parents who have sons. One possible explanation might be that the groups of boys and girls were systematically different in relation to the severity of behavioral difficulties and thus the difference in FQOL scores. This is a viable explanation as the total number of boys and girls was not the same across conditions. In particular the Autism Spectrum Disorder group had much larger proportion of boys and this might have had an impact on FQOL. Another, less likely explanation given the sample size in this study, is that we might have committed a type 1 error, and found effect where there is none. Future studies should elaborate these findings in more details. The second significant predictor of FQOL was a level of depression, anxiety and stress. Parents who reported higher levels of depression, anxiety and stress had lower FQOL. This finding was expected and is in line with existing studies. Many studies have shown the increased risk of psychopathology, especially depression, anxiety, and stress among parents of children with developmental disabilities (Blacher *et al.* 2005, Bumin *et al.* 2008). Stress is also related to FQOL. It has been unequivocally shown that as the stress increases, QOL decreases (Browne and Bramston 1998). Studies have shown that mothers are particularly vulnerable to depression. It has been found that around 45-50% of mothers of children with Autism Spectrum Disorder and Intellectual Disability have elevated depression scores (Olsson and Hwang 2001). Results in this study found no statistically significant differences on mean DAS scores between mothers and fathers. Evidently, there are ambiguous results on the psychological wellbeing of mothers and fathers of children with developmental disabilities and this issue warrants further scientific exploration. However, regardless of the mean differences regarding the parents gender, it is evident that parents' psychological wellbeing affects FQOL and both mothers and fathers need support to reduce the burden of raising a child with disability (Heiman 2002). Parents of children with disabilities in Bosnia and Herzegovina have limited access to support services. Thus, in line with these findings, it is of utmost importance to create programs that will provide different social and psychological supports to these parents. Family-centered support services have a great positive impact on FQOL (Wang and Brown 2009). There are many programs aimed at supporting parents of children with disabilities that might be helpful in reducing the stress of parents, while simultaneously empowering them to successfully cope with everyday challenges. One such program with positive effects on parental functioning is the *Parent to Parent* support (Ainbinder *et al.* 1998). It is aimed to create a community of people with similar challenges who listen and support each other. In addition to this, social and family supports are also positively related to better family outcomes, including the improvement in parental well-being (Kyzar *et al.* 2012, White and Hastings 2004). Providing more supports to parents will lead to better FQOL.

In this study, several other predictors, such as parents' gender, age, employment status and child's age did not have a significant effect on FQOL. Ambiguous results exist in the literature regarding QOL in relation to parents' gender. Some studies have found the differences between mothers and fathers QOL (Allik *et al.* 2006), while the others reported no differences (Dardas and Ahmad 2014). However, as a cautionary note, it does not seem justified to compare QOL of parents across different studies. First, the samples are not matched, children are not matched, the instrument for measuring the QOL construct is not the same across studies (some have focus on health-related QOL, others on FQOL), and there are some socio-cultural factors related to the perceived FQOL. Thus, these comparisons across studies should serve only as guideposts on potential differences in QOL in relation to parents' gender. As for the age of parents, older and younger parents did not differ in their perceived FQOL. Also, child's age was not a significant predictor of FQOL. Again, this was somehow an unexpected finding as challenges in families increase as the child ages (Hanson and Hanline 1990). It is possible that due to similar support services that all children with disabilities receive at school, parents reported similar levels of FQOL. It is also possible that age of children was not equally distributed across conditions and the real effect of child's age on FQOL could not be determined.

One of the most unexpected results in this study was the lack of effect of employment status on FQOL. A plethora of studies have shown that employment status has a positive effect on QOL (O'Neill *et al.* 1998, Ra and Kim 2016). It is our assumption that it is possible that employment status had an indirect effect on FQOL. Our results have shown that employment had an effect on DAS scores, which in turn had an effect on QOL. However, this assumption has yet to be confirmed or refuted in future studies.

Limitations of the study

There are several limitations in this study that need to be noted. First of all, we did not collect information regarding the intellectual functioning of children with autism spectrum disorder. It is very likely that some of them also had intellectual disability and that is one variable that needs to be controlled in future studies. It is possible that quality of life differs in families with children who have both, Autism Spectrum Disorder and Intellectual Disability then those who have Autism Spectrum Disorder only. Next limitation of this study is the limited number of variables included in the prediction model. There are many potentially important variables that we have not included in the model. These include, but are not limited to, child's behavior repertoire, severity of diagnostic categories (e.g. severity of autism spectrum disorder), parents' health, parents' marital status, parents' psychological supports, religiousness, quality of schools and many others. Future studies should aim to find even better models of predicting FQOL which in turn will help support workers to improve their services and thus improve the FQOL.

Conclusions

Parents of children with developmental disabilities have lower family quality of life than parents of typically developing children. Parents of children with autism spectrum disorder and moderate intellectual disability have lower family quality of life than parents of children with mild intellectual disability and children of typically developing children. The significant predictors of family quality of life are the child's gender and parents' depression, anxiety and stress scores. It is important to create parental support groups to improve their overall family quality of life.

Disclosure statement

No potential conflict of interest was reported by the authors.

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