



Quality of Life of Parents of Children with Intellectual Disabilities in Croatia

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Abstract

The goal of the present study was to examine the quality of life (QOL) of parents of children with intellectual disability. An additional goal was to examine the effects of gender and educational status on the QOL of these parents. The sample for this study consisted of 50 parents of children with intellectual disabilities and 50 parents of children without disabilities as a control group. As a measure of QOL, we used Family Quality of Life Survey. Results have shown that there is a statistically significant difference between the perceived QOL of parents of children with intellectual disabilities and parents of typically developing children. The effects of gender and educational status on QOL of parents of children with intellectual disabilities were also statistically significant. However, there were no interaction effects of gender and educational status on the QOL. Given the lower QOL of parents of children with intellectual disability, it is important to provide them with support programs in order to improve their QOL.

Keywords: quality of life, parents of children with intellectual disabilities, gender effects, educational status.

1. Introduction

Studies regarding quality of life (QOL) have become very prevalent in the last three decades and are at the center of interest to many scientific disciplines (Schalock, 2000). QOL is a complex concept, as there is no consensual definition of it and it can mean different things to different people (Memisevic et al., 2017). However, most authors agree that the QOL is a multidimensional concept consisting of objective and subjective dimensions. Felce and Perry (1995) defined QOL as the general well-being that includes objective factors and subjective evaluation of physical, material, social and emotional well-being, including personal development and purposeful activity. Verdugo et al. (2012) conceptualized QOL as consisting of the following domains: personal development, self-determination, interpersonal relations, participation, rights, emotional well-being, physical well-being and material well-being.

In line with this, family quality of life (QOL) is increasingly becoming the topic of great interest to researchers in many fields (Brown et al., 2006). This is especially evident for families of people with intellectual disabilities (Brown, Schalock, & Brown, 2009; Mactavish et al., 2007; Wang & Brown, 2009). It is well established that parents of children with disabilities have a higher risk of developing various psychological problems in comparison with parents of typically developing children (King et al., 1999). These problems, in turn, can have a detrimental effect on their QOL. Thus, knowing the determinants of family QOL might help the community in creating better support programs for these families. In line with this, assessment of family QOL can serve as a guide for organizational change in terms of support services and serve as an outcome measure for support providers (Hu, Wang & Fei, 2011).

Earlier studies have shown that parents of children with disabilities feel the sense of failure, helplessness and guilt (Dervishalaj, 2013). In addition to this guilt, birth of a child with disabilities can have an adverse effect on the relationship

between the parents (Leutar and Oršulić, 2015). Additional pressure and stress due to changes in family dynamics especially affects the mothers because they usually take the major part of responsibility of caring for the child. As a consequence of this, they are often faced with a sense of incompetence and failure and are also more likely to experience depressive symptoms than their husbands (Bristol, Gallagher, & Schopler, 1988). Aras (2014) in her study stated that mothers of children with hearing impairments do less well than fathers in dimensions of health on the SF-36 health status questionnaire, and that their QOL related to health is poorer in physical, emotional and social terms. In such cases there is a possibility of social isolation, which can cause mother's exclusion from the social environment (Veisson, 1999). Dervishalijaj (2013) states that parental stress reciprocally influences their child with disability - as parents are more dissatisfied, they are poorer at meeting the child's needs. It is very important to mention the high rate of stress in parents due to financial difficulties, which parents of children with disabilities often have (Singer & Farkas, 1989).

Additional difficulty for the parents stems from the lack of social support services and through deprivation of their basic rights (Byrne and Cunningham, 1985; Jones and Passey, 2005). Some studies have indicated that support services and resources in general can have a protective effect against increased stress (Meppelder et al., 2014).

Lin et al. (2009) found the reduced quality of life of caregivers of children with intellectual disabilities, which are caused by factors such as health of caregivers, family income and the stress caused by a lack of social supports. Many studies have shown that economic status plays a significant role for the QOL; the higher socioeconomic status, the higher is QOL (Wang et al., 2004; Chou, Pu, Kroger, 2008; Chiu, 2013). Yau and Li-Tsang (1999) found that better financial situation makes it easier to cope with the costs related to the health of a child with disability and facilitates adaptation of parents to the situation. Park, Turnbull & Turnbull (2002) argued that the families of children with disabilities were more affected by poor financial conditions than families of children with typical development, particularly in the aspect of health, productivity, housing conditions, emotional well-being and family relationships.

In contrast to these objective difficulties, it is important to emphasize some positive aspects that parents of children with disabilities have experienced. For example, in a study by Stainton and Besser (1998), parents reported a number of positive things that a birth of a child with intellectual disability had on their lives such as increased sense of purpose, increased tolerance and understanding, positive impact on others/society etc.

Current research about the QOL of parents of children with disabilities has been mainly conducted in USA, Australia, UK and Sweden. There are very few such studies conducted in the western Balkans countries. Thus, the goal of the present study was to investigate the quality of life of parents of children with intellectual disabilities in Croatia and to compare it with the quality of life of parents of children without intellectual disability. Additional objectives were to examine the influence of gender and educational status on the quality of life of parents of children with intellectual disabilities.

2. Methods

2.1 Participants

The study included 50 parents of children with intellectual disabilities (25 mothers and 25 fathers) and 50 parents of typically developing children (25 mothers and 25 fathers) serving as a control group. Children of all parents were primary school children, between the ages 7 and 15. The mean age of parents of children with intellectual disabilities was 38.6 years (SD = 6.1), and in parents of typically developing children mean age was 39.5 years (SD = 6.2). There were no statistically significant differences in the mean age of parents in two groups ($t = 0.74$, $p = 0.46$). Parents were recruited from two primary schools in Virovitica-Podravina and a primary school in Vukovar-Srijem County (Republic of Croatia). Parents of children with intellectual disabilities were divided into two groups based on their educational status: parents who have completed elementary/high school and parents who have completed college/university.

2.2 Instruments

Beach Center Family Quality of Life Scale (2015) was used for assessing the QOL. This scale contains 25 items which are divided into dimensions of family interaction, parenting, emotional well-being, physical/material well-being and support related to the difficulty. This questionnaire gives an overall score for QOL and the total score was used as the dependent variable in this study. The questionnaire was not previously applied in Croatia, but many cross-cultural studies have shown that the instrument is valid and reliable for use in various cultures (Verdugo, Córdoba & Gómez, 2005; Hu et al., 2011). Participants provide their answers on a 1-5 point Likert scale and rate their satisfaction with specific QOL

aspects (1- not at all important, 5- very important). Numerous studies have confirmed the excellent psychometric properties of the questionnaire (Hoffman, Marquis, Poston, Summers & Turnbull, 2006). Also, the validity of the instrument is satisfactory (Summers et al., 2005). Cronbach alpha of the whole questionnaire in this study was .93, which is consistent with previous findings.

2.3 Procedure

Parents were invited for a school meeting where the principal author explained the goals of the study. It was emphasized that the participation is voluntary and the data will be analyzed anonymously. Participants were then given a QOL questionnaire. Completed questionnaires were collected two weeks later.

2.4 Statistical analysis

For the purposes of this study, we used descriptive and inferential statistics. To assess the differences in QOL between parents of children with intellectual disability and parents of typically developing children we conducted an independent t-test and as a measure of effect size we calculated a Cohen's coefficient d. Two-factor analysis of variance was made to check the influence of gender and professional education on QOL. For all the tests, we set the alpha level at 0.05. The data were analyzed with a computer program SPSS v.13 for Windows.

3. Results

The results of the mean scores on the QOL scale are shown in Table 1.

Table 1. The mean scores of quality of life of parents of children with intellectual disability and parents of typically developing children

Parents	M	SD	t-test	Cohen'd
Parents of children with intellectual disabilities	98.3	14.1	4.93*	-0.99
Parents of typically developing children	110.4	10.1		

Note: *p<.001; n=100.

As can be seen from table 1, parents of typically developing children reported their QOL to be much better than parents of children with intellectual disability. Besides statistical significance in the scores, an effect size, according to Cohen's coefficient was also large.

In practical terms it means that parents of typically developing children reported their QOL scores to be nearly one standard deviation higher than the scores of parents of children with intellectual disability.

Secondly, we wanted to assess the impact of gender and educational level of parents of children with intellectual disability on their QOL scores. The cross-tabulated mean scores are shown in Table 2.

Table 2. Mean scores on QOL in relation to gender and educational level in parents of children with intellectual disability

Gender	Level of education	M	SD	N
female	Elementary/high school	86.0	21.8	10
	College/university	96.9	10.5	15
	Total	92.5	16.5	25
male	Elementary/high school	99.0	8.1	10
	College/university	107.5	5.6	15
	Total	104.1	7.8	25
total	Elementary/high school	92.5	17.4	20
	College/university	102.2	9.9	30
	Total	98.3	14.1	50

Two-factor analysis of variance showed a statistically significant effect of gender on the quality of life ($F(1,46) = 11.2; p < .01$), and statistically significant effect of educational level on the quality of life ($F(1,46) = 7.5; p < .01$). However, there

was no statistically significant interaction of gender and educational level on the QOL ($F(1,46) = 0.2; p = 0.74$). As can be seen from table 2, fathers had a better QOL than mothers, and parents with a higher level of education had a better quality of life.

4. Discussion

The goal of the present study was to examine the quality of life (QOL) in parents of children with intellectual disability. An additional goal was to assess the effects of gender and educational level on the QOL. The results of this study clearly show that parents of children with intellectual disability report a much lower QOL in comparison with parents of typically developing children. This was an expected finding, as the studies conducted elsewhere revealed the similar pattern. For example, Brown et al. (2006) indicated that parents of children with typical development have a better quality of life than parents of children with developmental disabilities in all domains of quality of life. On the other hand, in a study by Leung and Li-Tsang (2003), the authors found that parents of children with disabilities had lower QOL in the domain of social relationships and environmental support but not in the domain of physical and psychological health. Other studies have found a profile of differences in all QOL domains between the groups of parents (Juhásová, 2015). In addition to reduced QOL, parents of children with intellectual disabilities report higher levels of depression and anxiety (Gallagher et al., 2008).

It is important to note inherent difficulties in comparing the QOL across studies as the methodology was not the same. However, the results can give us some indications as to where the differences are. QOL is affected by many factors. We already mentioned that social supports can play a positive role in increasing one's QOL. Family's QOL is dependent on the supports among family members (Meral et al., 2013), so keeping good relationships between family members is of the utmost importance.

In relation to the effects of gender and educational level of parents, we also confirmed the existing findings. Mothers of children with intellectual disabilities reported lower QOL than fathers, and the same goes for parents with lower educational level. Kazmi, Perveen, Karamat & Khan (2014) reported a lower quality of life of mothers of children with disabilities and the more frequent depression in mothers than in fathers. Mothers of children with other forms of disabilities also have lower QOL. Romeo et al. (2010) found that the QOL of mothers of children with cerebral palsy is lower than fathers'. Also, the publication IASSIDD (2014) states that mothers of children with disabilities are the ones who report increased level of stress and poorer physical and mental health. Dervishalić (2013) stated that parents of children with disabilities often feel incompetent and helpless, and this is especially the case for mothers of children. In relation to the educational level, higher education was correlated with higher QOL. Higher education usually means better socio-economic status (SES), so the effect of educational level might be mediated through the influence of SES. Higher income means less exposure to emotional and physical stress and in turn can lead to higher QOL (Ross, & van Willigen (1997). Higher educational level has a positive impact on QOL in both mothers and fathers.

The results of this study can have large practical implications. As many studies have previously demonstrated, stronger social support leads to better QOL. Croatia, as a European Union country, has a lot of room for improvement in this segment. For example, support services for parents of children with disabilities should be established across the country, so the parents in all parts of Croatia have necessary information, advice and support. As is already used in other countries, QOL outcomes can serve as a measure of efficacy of service providers (Schalock, Bonham, & Verdugo, 2008). Parents should be provided with individual and group support in coping with the everyday challenges. Individual counseling will help them in development of competences for parental role and empower them to advocate for the rights of their children. As the mothers are more vulnerable in this sense, they should be a priority for support provision. The position of mothers can be facilitated with additional financial resources from the state, which will help in getting a better childcare and better child treatments. Mothers should also have some benefits regarding their employment status in the sense of flexible working hours. Society as a whole should recognize the efforts mothers make in supporting their children with disabilities. Higher QOL of parents will almost certainly mean higher QOL of people with disabilities.

Let us finally mention some of the limitations of this study. Due to the small sample size, we should be cautious in generalizing these results for all parents in Croatia. Next, we used only a total score of QOL scale as the outcome variable. It would be useful and informative to evaluate the QOL profiles across the five QOL scale domains. QOL should be in the central focus of studies regarding the quality of support programs for both people with disabilities and their families.

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