

UNIVERSITY OF BELGRADE - FACULTY OF SPECIAL
EDUCATION AND REHABILITATION

THE EUROPEAN ASSOCIATION ON EARLY
CHILDHOOD INTERVENTION

EUROPEAN ASSOCIATION OF SERVICE PROVIDERS
FOR PERSONS WITH DISABILITIES

Eurlyaid Conference 2017

**Early Childhood Intervention:
For meeting sustainable
development goals of the
new millennium**

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Community Participation and Family Quality of Life – Comparative Study of Children with Cerebral Palsy and Children with Typical Development¹

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Children with developmental disabilities, including cerebral palsy (CP), often experience restriction in community participation. The previous empirical and theoretical consideration of community participation of children with CP did not take into account the family quality of life (FQOL) as a potential factor that could have affected the participation of these children. The aim of this study was to examine the association between community participation of children with CP and FQOL and draw comparisons with their peers with typical development (TD). The sample of this descriptive, cross-sectional and comparative research consisted of 109 families with children with CP and 133 families with children with TD, both genders, aged between seven and 18 years. The Participation and Environment Measure for Children and Youth (PEM-CY) and The Beach Center Family Quality of Life Scale (Beach FQOL Scale) were used. The Spearman's rank-order correlation coefficients were calculated to test the strength of a relationship between two sets of data for each group separately. The results indicate interrelation between the subjective dimension of community participation as expressed through parental desire for change, and both parenting aspect of family life ($\rho=-.24$) and social and emotional support within the family emotional well-being ($\rho=-.20$) in the group of children with CP. However, a greater number of statistically significant correlations is confirmed in the group of children with TD. Comparing the distribution of results between the two groups, the most noticeable is the absence of connection between FQOL and diversity and frequency of community participation in the group of children with CP, which is confirmed in the group of children with TD. The conclusion

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underlines that the reflection of changes that affect family life after the birth of a child with CP can be seen in various aspects of FQOL.

Key words: *community participation, family quality of life, cerebral palsy, family life*

INTRODUCTION

The World Health Organization's *International Classification of Functioning, Disability and Health* (ICF) defines participation as 'involvement in a life situation' while restriction is defined as 'problems an individual may experience in involvement in life situations' (WHO, 2001, 2007). Numerous studies have shown that children with developmental disabilities, including cerebral palsy (CP), often experience restriction in participation (Blum, Resnick, Nelson & St Germaine, 1991; Engel-Yeger, Jarus, Anaby & Law, 2009; Imms, Reilly, Carlin & Dodd, 2008; King et al., 2003, 2006; King, Law, Hurley, Petrenchik & Schweltnus, 2010; Law et al., 2004, 2006, 2013; Majnemer et al., 2008). Additionally, previous studies have focused on the impact of children with disabilities on family functioning, as well as on the impact of various types of family functioning on child development (Drotar, 1997; Dyson, Edgar & Crnic, 1989; Giallo & Gavidia-Payne, 2006; Hauser-Cram, Warfield, Shonkoff & Krauss, 2001; Van Riper, Ryff & Pridham, 1992). In recent years, disability studies have moved their focus from on an individual quality of life to an evaluation of the quality concerning the whole family (Hu, Summers, Turnbull & Zuna, 2011; Park et al., 2003; Parpa et al., 2016; Summers, Hoffman, et al., 2005).

The construct of family quality of life (FQOL) refers to the needs of all family members, emphasizes the family's strengths and their priorities, and highlights the importance of partnership between families and professionals (Smith-Bird & Turnbull, 2005). Still, the previous empirical and theoretical consideration of participation of children with CP did not take into account the FQOL as a potential factor that could have affected the participation of these children.

This study is part of a larger research project focused on the FQOL and participation of children with CP living in Serbia. The purpose of this part was to examine the association between community participation of children with CP and FQOL and draw comparisons with their peers with typical development (TD). To meet this objective we pursued the following aims: 1) examine the association between the pattern of community participation and FQOL in the group of children with CP, and 3) draw comparisons with their peers with TD. We hypothesized that there was a positive relationship between community participation and FQOL in the examined groups.

METHOD

Sample and procedure

Participants were recruited using convenience sampling. The general inclusion criteria were as follows: children of both genders, aged 7–18 years, residing with their families on the territory of the Republic of Serbia. The inclusion criteria of the group of children with CP were cerebral palsy diagnosis according to the 10th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10; World Health Organization, 2004). Data were gathered from June 2014 to April 2015. Informed consent was obtained from all parents/caregivers included in the study.

The first group consisted of 109 families with children with CP, 61 boys and 48 girls, the average age of 12 years 8 months ($SD=3$ years 5 months). The second group included 133 families with children with TD, 66 boys and 67 girls, the average age of 11 years 11 months ($SD=3$ years 1 month). There were no statistically significant differences between groups in relation to age ($t(240)=1.721, p=.087$) and gender of children ($\chi^2(1)=.728, p=.394$).

INSTRUMENTS AND VARIABLES

The Serbian versions of the *Participation and Environment Measure for Children and Youth* (PEM-CY; Coster, Law, & Bedell, 2010) and the *Beach Center Family Quality of Life Scale* (Beach FQOL Scale; Hoffman, Marquis, Poston, Summers & Turnbull, 2006) were used. Both are reliable and valid parent/caregiver-report instruments. Detailed information about their conceptual basis, development, and psychometric properties have been described elsewhere (Bedell et al., 2013; Bedell, Khetani, Cousins, Coster & Law, 2011; Coster et al., 2011, 2012; Hoffman et al., 2006; Jorge, Levy & Granato, 2015; Khetani et al., 2014; Law et al., 2013; Milićević, 2017; Summers, Poston, et al., 2005).

Four PEM-CY group summary scores were calculated: 1) percentage of activities in which children never participated, as a measure of diversity (theoretical range: 0–100%); 2) average frequency excluding the *never* responses (theoretical range: from 1=*once in the last 4 months* to 7=*daily*); 3) average involvement level (theoretical range: from 1=*minimally involved* to 7=*very involved*); and 4) percentage of activities in which change was desired (theoretical range: 0–100%). The latter score represents an indirect indicator of the parents' satisfaction with the children's current participation and represents a subjective dimension of participation. The pattern of community participation represents an objective dimension of participation, which includes diversity, frequency and involvement level.

Six FQOL Scale scores were included: 1) Family Interaction, 2) Parenting, 3) Emotional Well-being, 4) Physical/Material Well-being, 5) Disability-Related

Support, and 6) overall FQOL (theoretical range: from 1=*very dissatisfied* to 5=*very satisfied*). A higher score indicates that parents are satisfied to a greater extent with different aspects of family life.

Statistical analysis

Descriptive data and inferential statistics are presented. Data independence across child variables was checked using χ^2 test and the independent-samples t-test. The Spearman's rank-order correlation coefficients were calculated to test the strength of a relationship between two sets of data for each group separately. All analyses were performed in SPSS, version 23 (IBM, Armonk, NY, USA), and a significance level of .05 was established to consider the results significant.

RESULTS AND DISCUSSION

In accordance with the findings of previous studies, overall community participation of children with CP is lower compared to the participation of children with TD (Bedell et al., 2013; Coster et al., 2011; Engel-Yeger et al., 2009; Majnemer et al., 2008; Mc Manus, Corcoran, & Perry, 2008; Michelsen et al., 2009). Children with CP participated in fewer community-based activities, less frequently and had lower levels of involvement than children with TD. More parents of children with CP confirmed that they would like to see their child's community participation change and that they were less satisfied with all aspects of family life (Table 1).

Table 1 – Community participation and family quality of life: descriptive statistics

Variables		CP group	TD group
Community participation	Diversity	49.45 (20.36)	24.81 (14.95)
	Frequency	4.04 (1.32)	4.87 (.76)
	Involvement	3.16 (1.07)	4.65 (.51)
	Change desired	72.66 (23.20)	34.66 (27.35)
Family Quality of Life	Family interaction	4.02 (.66)	4.29 (.58)
	Parenting	3.99 (.57)	4.27 (.52)
	Emotional well-being	3.54 (.72)	4.06 (.65)
	Physical/material well-being	3.66 (.65)	4.11 (.61)
	Disability-related support	3.81 (.71)	n.a.
	Overall family quality of life	3.83 (.51)	4.20 (.50)

Note. CP group – children with cerebral palsy ($n=109$); TD group – children with typical development ($n=133$); n.a. – not applicable. Values are given in M (SD) format.

Table 2 – Relationship between the pattern of community participation and family quality of life

Community participation	Family Quality of Life											
	Family interaction		Parenting		Emotional well-being		Physical/mat. well-being		Disability-r. support		Overall FQOL	
	CP	TD	CP	TD	CP	TD	CP	TD	CP	CP	TD	
Diversity	.01	-.26**	-.03	-.26**	.04	-.37**	-.04	-.25**	.00	-.01	-.33**	
Frequency	.01	.28**	.04	.28**	.17	.30**	.01	.14	-.15	.04	.28**	
Involvement	-.01	.12	.09	.16	-.11	.06	-.05	.10	.11	-.01	.11	
Change desired	-.14	-.24**	-.24*	-.27**	-.20*	-.25**	-.14	-.23**	-.03	-.18	-.29**	

Note. Physical/Mat. Well-being – Physical/Material Well-being; Disability-r. support – Disability-related support Overall FQOL – Overall FQOL Scale score; CP – group of children with cerebral palsy ($n=109$); TD – group of children with typical development ($n=133$). Spearman's rank-order correlation coefficients are presented.

* $p < .05$, two-tailed. ** $p < .01$, two-tailed.

According to the results, correlations are generally low, with the exception of a few moderate correlations (Table 2). In relation to the total number, far more statistically significant correlations are calculated within the group of children with TD than in the group of children with CP (14 and two, respectively). As presented, correlations are predominantly positive. Exceptions are those correlations of the variables that are defined as reversed by their nature, which includes the following two: activities in which children never participated (higher score indicates less diversity), and activities in which change was desired (higher score indicates a lower level of parental satisfaction with the participation achieved).

When it comes to the pattern of community participation, only the involvement level is not significantly correlated with the domains of quality of life of families with children with TD (Table 2). However, the frequency is positively correlated with most FQOL scores. Therefore, more frequent participation of children with TD is associated with greater parental satisfaction with family life in all domains excepting *Physical/Material Well-being*. The strength of the relationship of these variables can be interpreted as small (ρ from .28 to .30, $p < .01$). In the case of diversity of community participation, a greater number of activities in which children with TD participate is followed by a family life with whose quality parents are more satisfied. The strength of these correlations can be interpreted as small to medium (ρ from .25 to -.37).

There are small and negative statistically significant correlations between the number of activities in which parents of children with CP have expressed their desire for change and the *Parenting* ($\rho = -.24$, $p < .05$) and *Emotional Well-being domains* ($\rho = -.20$, $p < .05$). In other words, if parents are more satisfied with family life that relates to support for children, or activities that adult family members do

to help children grow and develop, as well as with emotional and internal aspects of family life, then the level of satisfaction with community participation of their child with CP is higher (Table 2).

The level of parental satisfaction with community participation, expressed through the desire for change, statistically significantly correlates with all domains of quality of life of families with children with TD (Table 2). More precisely, if there is a greater number of activities in which change is desired, then the level of satisfaction with all aspects of family life decreases. The strength of the relationship between the variables is, however, small (ρ from $-.23$ to $-.29$, $p < .01$).

Finally, it should be noted that in the group of children with CP, the statistical significance of correlations between support for the family member with a disability and all the characteristics of community participation is not confirmed (Table 2).

Based on the results, it can be noticed that there are correlations between certain dimensions of community participation and the quality of life of both families with children with CP and children with TD (Table 2). The results, nevertheless, point to certain exceptions from the assumed correlations.

Thus, no association between diversity, frequency and level of involvement, on the one hand, and parental aspect of family life and social and emotional support within the family emotional well-being, on the other hand, was found in the group of children with CP. As opposed to that, in the group of children with TD, the association between level of involvement and all FQOL scale domains was not confirmed only. At the same time, the results show that a better quality of life at the level of the entire family could have a positive effect on certain characteristics of participation of children with CP. Furthermore, the results clearly show that CP leads to changes in the relationship between the overall well-being at the family level and the involvement of a member with CP in life situations. This finding is important and relevant for special education and rehabilitation because it explains a part of the changes that affect family life after the birth of a child with CP and whose reflection can be noticed in different aspects of the association of the child's participation in the community and the quality of family life. Consequently, the finding confirms the need for wider understanding of the factors of connection between the quality of family life and the participation of children and adolescents from this population.

CONCLUSION

Bearing in mind the presented findings, on the one hand, and the assumed outcome of the analysis, on the other hand, it cannot be confirmed that all the characteristics of community participation are positively associated with all aspects of FQOL in the examined groups. In conclusion, the initial hypothesis is not fully supported by empirical findings.

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