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

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Predictors of Quality of Life of Families with Children with Cerebral Palsy – Implication for Early Intervention[1]

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Research subject: *During the last two decades, families have been increasingly encouraged to take continuous care of their child with cerebral palsy. Consequently, the way of changing of family life and its quality has become a research subject in disability studies.*

Method: *The aim of this study was to explore the impact of child, family, environment and service support characteristics as potential predictors on the quality of life in families with children with cerebral palsy residing in the Republic of Serbia. The sample was recruited using convenience sampling and consisted of 110 families of children with cerebral palsy, of both genders, between 7 and 18 years of age (M=12,67, SD=3,41). A hierarchical multiple regression was calculated to predict family quality of life based on four sets of independent variables. Child and family characteristics, frequency and magnitude of perceived physical, attitudinal, and policy barriers, and parental perceptions and experiences with professional support were included.*

Results: *Child's challenging behavior was one of the strongest predictors of the quality of family life, b=-.29, t (106)=-3.18, p<.01. The household income also accounted for a significant proportion of unique variance in predicting the quality of family life, b=-.21, t(106)=-2.17, p<.05. Moreover, household income was no longer a significant predictor when the extent of challenging behavior exhibited by the child and the magnitude of perceived environmental barriers entered the regression model. The results confirm that household income and perceived everyday care-giving difficulties are associated with the reduced quality of family life.*

Conclusion: *The conclusion underlines the importance of the environment in improving the quality of family life. However, the reinforcing intervention in the domain of environmental barriers could contribute to the quality of family life by overcoming the lower income and behavioral problems.*

Key words: *quality of family life, cerebral palsy, predicting, environmental impact*

INTRODUCTION

Gradual changes in the nature of caring for children with disabilities began in the middle of the 20th century. Until then, parents were generally considered insufficiently able to raise their children with disabilities, and institutional care was imposed as the only choice (Rosenbaum, King, Law, King & Evans, 1998). Briefly, the key factors in changing the nature of caring for children with disabilities are parental advocacy for change, criticism of the medical model, the deinstitutionalization movement, the elaboration of the theory of social systems, with increased willingness of politicians to consider adopting the principles of family-centered practice (Allen & Petr, 1996).

Families with a child with disabilities are faced with numerous challenges that have an impact on various aspects of family life (Davis & Gavidia-Payne, 2009). Families have been increasingly encouraged to take continuous care of their child with cerebral palsy (CP) during the last two decades (Milićević & Klić, 2014). Consequently, the way of changing of family life and its quality has become a research subject in disability studies.

Recently, family quality of life (FQOL) is a commonly used concept in the fields of developmental disabilities study (Hu, Summers, Turnbull & Zuna, 2011; Park et al., 2003; Parpa et al., 2016; Summers, Hoffman et al., 2005; Zuna, Selig, Summers & Turnbull, 2009). In order to assess the quality of family life as satisfying, certain prerequisites must be met. More specifically, family needs need to be fulfilled; family members should enjoy a common life and have the opportunity to do those things they find important (Park et al., 2003)

The aim of this study was to explore the impact of child, family, environment and service support characteristics as potential predictors on quality of life of families with children with CP residing in the Republic of Serbia.

METHOD

Sample and procedure

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

The final sample consisted of 110 families of children with CP, 61 (55%) boys and 49 (45%) girls. The average age of children was 12 years 8 months (*SD*=3 years 5 months).

Instruments and variables

Child and family characteristics and data on environmental barriers and professional support were operationalized and measured by several instruments. Detailed information about their conceptual basis, development, and psychometric properties have been described elsewhere (Bjerre et al., 2004; Bourke-Taylor, Pallant & Law, 2014; Hoffman, Marquis, Poston, Summers & Turnbull, 2006; King, King & Rosenbaum, 2004; McCauley et al., 2013; Milićević, 2017; Palisano et al., 2000; Palisano, Rosenbaum, Bartlett & Livingston, 2008; Park et al., 2003; Summers, Poston, et al., 2005; Whiteneck et al., 2004; Taboroši, 2015).

The 25-item *Beach Center Family Quality of Life Scale* (Hoffman et al., 2006) was used to calculate overall FQOL score as a measure of parental satisfaction with different aspects of FQOL (rated on a 5-point Likert scale from 1=*very dissatisfied* to 5=*very satisfied*).

The five-level *Gross Motor Function Classification System – Expanded & Revised* (GMFCS – E&R; Palisano, Rosenbaum, Bartlett, & Livingston, 2007) was used to categorize the child's present abilities and limitations in gross motor function. A higher GMFCS level indicates higher functional limitations.

The impact of developmental strengths and difficulties on independence at home was expressed by total FIM score (*Functional Independence Measure for Children – WeeFIM*; Msall et al., 1994). Higher FIM values indicate greater independence levels.

Child's behaviors that are challenging were rated by the 9-item *Child's Challenging Behaviour Scale* (CCBS; Bourke-Taylor et al., 2014). Higher CCBS scores indicate that the child exhibits behaviors that are more challenging.

Household income was categorized into five levels according to average monthly income, while family type was dichotomized as two- or one-parent family.

Two dimensions of environmental impact were derived from the *Craig Hospital Inventory of Environmental Factors for Children – Parent Version* (CHIEF-CP; McCauley et al., 2013). Frequency of perceived physical, attitudinal, and policy barriers was rated on a 5-point scale (from 0=*never* to 4=*daily*), and magnitude on a 3-point scale (from 0=*no problem* to 2=*big problem*). Additionally, a frequency-magnitude product score was calculated, indicating the overall impact of environmental barriers.

Parental perceptions and experiences with professional support were evaluated by *Measure of Processes of Care* (MPOC-20; King et al., 2004). Five MPOC-20 scores were included: *Enabling and partnership*, *Providing general information*, *Providing specific information about the child*, *Coordinated and comprehensive care*, and *Respectful and supportive care*. Higher scores indicate that parents perceive the service delivery as being family-centered to a greater extent.

Statistical analysis

The relationships among variables were investigated using Pearson correlation coefficient. A hierarchical multiple regression was calculated to predict FQOL based on several sets of independent variables. 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

Child and family characteristics, frequency, magnitude and overall impact of environmental barriers, as well as parental perceptions and experiences with professional support were included in hierarchical multiple regression analysis. First, the relationships among these variables and overall FQOL were explored. As shown in Table 1, one family, child and environmental characteristics were found to be significantly associated with overall FQOL. Significant negative correlations were found between overall FQOL and both CCBS ($r=-.41$, $p=.001$), and CHIEF magnitude scores ($r=-.34$, $p=.013$). Among other characteristics, a significant positive correlation was identified between overall FQOL score and household income ($r=.31$, $p=.031$).

Table 1 – Relationship between the selected child and family characteristics, impact of environmental barriers and professional support and family quality of life

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Child's age	—	.04	-.03	-.04	-.13	.09	-.18	-.15	-.06	-.09	-.03	-.04	-.00	-.07	-.02
2. GMFCS		—	-.80**	-.17	-.24*	.11	-.03	.08	-.11	-.03	-.04	.04	-.03	.04	-.06
3. WeeFIM			—	.06	.22*	-.14	.14	.00	.15	.07	.09	.01	-.06	-.03	.10
4. CCBS				—	-.08	.06	.01	-.10	.03	.00	-.02	.03	.23*	.11	-.41**
5. H.income					—	-.29**	-.02	-.09	-.12	-.08	-.04	-.06	-.16	-.08	.31*
6. F.type						—	.19	.24*	.05	.22*	.16	.00	.01	-.01	-.14
7. ep							—	.64**	.70**	.77**	.76**	-.12	-.11	-.08	.17
8. pgi								—	.63**	.62**	.65**	-.07	-.01	-.09	.16
9. psi									—	.65**	.71**	-.04	.00	-.06	.17
10. ccc										—	.83**	-.14	-.10	-.13	.14
11. rsc											—	-.17	-.13	-.16	.15
12. CHIEF frequency												—	.73**	.94**	-.09
13. CHIEF magnitude													—	.80**	-.34*
14. CHIEF total														—	-.08
15. FQOL															—

Note. GMFCS – Gross Motor Function Classification System (Expanded & Revised); WeeFIM – Functional Independence Measure for Children; CCBS – Child's Challenging Behaviour Scale;

H.income – Household income; F.type – Family type; ep – Enabling and partnership; pgi – Providing general information; psi – Providing specific information; ccc – Coordination and comprehensive care; rsc – Respectful and supportive care; CHIEF frequency – frequency of barriers; CHIEF magnitude – magnitude of barriers; CHIEF total – overall impact of barriers; FQOL – overall family quality of life. Pearson's correlation coefficients are presented.

$^*p<.05$, two-tailed. $^{**}p<.01$, two-tailed.

Therefore, as a control strategy, household income was entered in the first block of predictors (Table 2). The next variable to be entered was parental ratings of child's challenging behavior (Step 2), followed by the ratings of a magnitude of barriers (Step 3).

Household income was a significant predictor of FQOL during Step 1 and Step 2 of the regression (Table 2). However, it failed to account for a significant proportion of unique variance during Step 3. In addition, child behavior continued to be a significant predictor of FQOL in Step 3, after being added in Step 2, irrespective of the inclusion of the magnitude of environmental barriers.

Table 2 – Summary of the hierarchical regression analysis for variables predicting family quality of life in the group of children with cerebral palsy (n=110)

Model/Predictor	Step 1 (β)	Step 2 (β)	Step 3 (β)
Household income	.21*	.18*	.16
Child's challenging behavior		-.29**	-.26**
Magnitude of environmental impact			-.15*
Model R^2	.04	.13	.15
Adj. R^2	.03	.11	.12
ΔR^2	.04	.09	.02
F (df1, df2)	4.73 (1, 106)*	7.63 (2, 105)**	6.04 (3, 104)**

Note. β – standardized beta coefficient; R^2 – determinant multiple correlation coefficient; Adj. R^2 – adjusted multiple correlation coefficient; ΔR^2 – multiple correlation coefficient change.

$^*p<.05$. $^{**}p<.01$.

Furthermore, child's challenging behavior was one of the strongest predictors of FQOL, explaining 9% of its variance. The household income also accounted for a significant proportion of unique variance in predicting FQOL (4%). Nevertheless, household income was no longer a significant predictor when the extent of challenging behavior exhibited by the child and the magnitude of perceived environmental barriers were entered in the regression model, explaining 15% of the FQOL variance in total (Table 2).

A more thorough overview of the FQOL predictors showed that the higher average monthly income could mostly attribute to higher quality of family life. Negative predictors for FQOL, however, were the child's challenging behavior and the size of the problem that barriers had typically presented. Although expected, the results confirmed that household income and perceived everyday caregiving difficulties were associated with reduced quality of family life. Some

studies have indicated that behavioral problems are in negative and family income in a positive correlation with FQOL, as well as that disability level has no statistical significance in FQOL predicting (Davis & Gavidia-Payne, 2009). On the other hand, the level of disability is statistically stronger FQOL predictor compared to family income (Wang et al., 2004). Our results have not confirmed the association of FQOL with CP severity nor with independence level.

However, an interesting dynamic of changes in the predictive power of selected variables was found. The child's challenging behavior continued to be an important negative predictor of FQOL, but its predictive power decreased when environmental barriers were included in the final step. As highlighted previously, financial difficulties, service unavailability, inaccessibility of information and relationship with professional staff were identified as major obstacles to improving FQOL (Čagran, Schmidt & Brown, 2011).

Similarly, household income was a significant predictor only in the first steps of regression, before both perceived professional support and social support from family were finally included in the analysis. Yet, child's behavioral problems and perceived social support remained significant predictors of FQOL regardless of the inclusion of professional support (Davis & Gavidia-Payne, 2009). In our study, the statistical significance of a correlation between professional support and overall FQOL was not confirmed preliminarily; therefore, these variables were not included in the analysis. Moreover, an absence of a relationship between these constructs suggests a possible insufficient family-centeredness of professional services in our country. Previous studies highlighted that parental perceptions and experiences with family-centered practices were one of the strongest predictors of FQOL and that family-centered helpgiving was related to positive child, parent and family outcomes indirectly, through enabling and empowering of parents of young children with disabilities (Davis & Gavidia-Payne, 2009; Dunst, Trivette & Hamby, 2007). This raises a question in terms of the quality of the services provided to families with children with CP and their effect not being reflected in the quality of family life. It is important to acknowledge that biopsychosocial frameworks require family-centeredness, not only rehabilitation interventions focused primarily on the child (Raina, 2005). Our results can be explained by the importance given to the immediate family when the quality of family life is concerned (Rillotta, Kirby, Shearer & Nettelbeck, 2012).

Our results suggested that environmental barriers that are rated as a bigger problem could predict the lower FQOL. Here, the reinforcing intervention in the domain of environmental barriers could play an important role. It has been shown earlier that barrier-free environment could lead to positive changes of community participation and quality of life of children and adolescents with CP (Law, Petrenchik, King & Hurley, 2007). As environment is potentially modifiable, previous authors suggested that interventions focused on environmental changes could contribute to the improvement of life quality (Badia et al., 2016).

Interventions aimed at improving of socioeconomic, financial and material status of families are also recommended (Meral, Cavkaytar, Turnbull & Wang, 2013).

Caring for a child with developmental disabilities, including children with CP, often represents a source of a burden that puts new demands on parents and, in addition to difficult child behavior during caregiving tasks and the persisting psychological and social problems, leads to higher and prolonged parental stress levels (Plant & Sanders, 2007; Weber et al., 2016). Frequent hospitalization, getting out of bed at night to take care of the child, physically and time demanding feeding and dressing are just some of the activities that parents do every day (Bulić, Joković Oreb & Nikolić, 2012). Child's challenging behavior was one of the strongest predictors of FQOL in our study and previous studies had confirmed the overall higher presence of behavioral problems in children with CP in comparison to their peers with typical development (Carlsson, Olsson, Hagberg & Beckung, 2008; Milićević, 2014; Sipal, Schuengel, Voorman, Van Eck & Becher, 2010). Thus, it is important to highlight that the overcoming of behavioral and emotional problems and everyday problems in caregiving should be in the focus of early intervention (Weber et al., 2016).

CONCLUSION

Bearing in mind the presented findings, empirical findings show that the role of family characteristics has to be interpreted along with interactional effects of both child and environmental characteristics when referring to the quality of family life. Our results suggest that relevant interventions should be used that promote implementation of support to family in managing the daily life of their family member with CP.

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