Parental Stress of Parents with Children with Disabilities - Correlation between Stress and other Variables in Croatian Context

Natalija Lisak1, Sonja Alimović1, Ana Wagner Jakab1
Faculty of Education and Rehabilitation Sciences, University of Zagreb, Croatia1

Abstract
Parenting brings significant changes in people's lives and becomes one of the most important significant events in the life courses of persons, partners and family (Priestley, 2001). The birth of a child with disabilities contributes to changes that lead to stress that could negatively affect the well-being of the family, the quality of the relationship between the partner and the relation of the parent to the child. This could create a chronic stress that causes dysfunction in the family more than other types of stressors and therefore these parents are a highly vulnerable group (Watson et al, 2011). The purpose of the research was to determine the significant correlations between parental stress and other variables such as gender, parental education, marital status, income, number of children, wellbeing, emotional regulation and support. The results show that: mothers experience significantly more stress than fathers; parents who have high education level and high level of stress; parents living in extramarital relation experience a higher level of stress; the lowest level of parental stress is experienced by parents with lowest income; interestingly the highest level of parental stress is reported by parents of only one child. Parents who experience less parental stress are more aware of their feelings, have better results on emotional warmth and use less negative communication also feel to get more support from partner and belong to community. These parents are able to engage in goal directed activities and engage strategies to emotion regulation. Parents reported high level of parental stress and this is important to do further investigations to find the causes of this high level of stress in order to plan the support.

Key words: parental stress, families, children with disabilities, support to parents

Corresponding address: Natalija Lisak, Faculty of Education and Rehabilitation Sciences, Borongajska cesta 83f, 10 000 Zagreb, Croatia. E-mail: natalija.lisak@erf.hr

INTRODUCTION
Prevalence of children with disabilities in general population of children is 4.4%. (Benjak, 2017). That also means that there might be about 4% of parents of children with disabilities in general population of parents in Croatia. Children with disabilities lives mostly within family (97.5%), some of them are in foster care (0.6%), and 0.7 % children with disabilities lives within the institutions. The fact is that those parents are vulnerable group with some specific needs.
Families with young children with disabilities are often full of expectations, active and focused on providing the best possible services of support for their children. Law regulation from 2012 regulates early intervention, even though services and education for early intervention started about six years earlier. Still, there is a huge difference in number, variety, quality and availability of support services between Zagreb and big cities in compare with small cities and rural or/and distant parts of Croatia. That is why parents report feeling of frustration and dissatisfaction with the lack of information as well as incompatibility and poor coordination between services (Pećnik et al, 2013).

Furthermore, several studies showed that parents reported lack of support not only for their children but also for them in terms of psychological and emotional support especially in period during and after setting up a diagnosis to their children. (Leutar & Štambuk 2007; Milić Babić & Leutar 2014; Pećnik et al, 2013). Parents also showed dissatisfaction with unprofessional attitudes of experts towards them. (Milić Babić & Leutar 2014).

Results of one study show that parents of children with disabilities receive support primarily from family members, then co-workers, Church community, Non-governmental organizations (NGO-s) and finally from social workers from Social welfare Centre (Leutar & Štambuk 2007).

During school period parents report lack of support from school especially misunderstanding and poor communication with teachers. Mothers cited as a reason of broken marital relations lack of father role and figure and transfer of responsibilities from father to mother. Mothers state that fathers are insufficiently engaged with their children with disabilities. Despite the fact that most mothers stated that they have support from their spouse still mothers carry most of the burden. Not only that mothers support their children in learning and rehabilitation process but also they advocate for their rights (Veldić 2012. according to Igrić et al. 2014).

On the other hand, parents in families with elder children with disabilities are often isolated, exhausted, tired, old and sometimes ill. There is a serious lack of services for senior people with disabilities and their families. They rely on their own strength. They receive support from close family members or neighbors. While aging, they have less and less energy to take their children to Day care centers or NGO-s if they even have that opportunity. The biggest worry to them is how to secure care to their children if they would not be able to do that by themselves or they passed away (Wagner Jakab at al., 2016).

Specific education and support for parents of children with disabilities is provided within programs of educational and social institutions. Usually, parents receive individual support or
small group support. Support usually includes topics like improving parental skills and teaching a parent how to support a child in acquiring a new skill or how to deal with the problem behavior. The support is usually more informal and the quality of support usually depends on motivation and effort of individual special teacher or other staff and is not systematically delivered within the institution. It is also not planned or evaluated in most of the institutions.

In general research shows that parenthood is associated with significant changes in parents’ life and parenting in itself can be stressful. In the family context, stress negatively influences parents’ wellbeing, the quality of their relationship and the quality of parent-child interaction.

Studies have shown that families parenting a child with disabilities experience higher levels of stress compared to families with children with a typical development (Delambo, Chung, & Huang, 2011; Lee, 2013). Having a child with disabilities requires more effort and involvement from parents (i.e. long term psychological therapies, medical treatments). The stress faced by families raising children with special needs may continue during adolescence and adult life of their children, influencing the quality of family relationships on a long term.

This could create a chronic stress that causes dysfunction in the family more than other types of stressors and therefore these parents are a highly vulnerable group (Watson et all, 2011).

The purpose of the research was to determine the significant correlations between parental stress and other variables such as gender, parental education, marital status, income, number of children, wellbeing, emotional regulation and support.

**METHODOLOGY**

**Sample**

Questionnaires were collected from 187 parents, 119 of them were mothers (63.6%), 51 of them were fathers (27.3%), and 17 (9.1%) of them gave no information about the gender.

Most parents (51.4%) were aged between 35 and 44 years of age, we had only 15.3% of parents younger than 35.

Most of them finished high school (48.3%), a lot of them had some university diploma (45.3%), and only some of them finished middle (5.8%), or no school at all (0.6%) school.
Most of the researchers have found high divorce rate among parents of children with disabilities (Risdal and Singer, 2004). Nevertheless, in our research most of them were still married or in extramarital relation (88%), 4.9% claimed to be divorced, 6% were single, and we also had two widowers.

Most parents were employed, working 40 hours a week or more (56.7%). Some of them used their legal right and worked less than 40 hours a week, mainly half time (20.3%). Some of parents gave no answer, assuming they used their legal right to use social beneficiaries (11.3%), and 11.8% were unemployed. Monthly income of most parents (50.3%) were among the average (500 – 1500 €) for Croatia. More parents (27.3%) had higher income than average, then lower (13.9%) income. Many parents (8.6%) did not answer this question.

Most parents (45.2%) had two children, 24.3% had one child, 25.4% had three or four children, and 3.4% had more than four children.

Most children had multiple disabilities (51.8%) which is more than stated in national statistical data about the types of disabilities in children (Benjak, 2017). Nevertheless, since we had a problem involving parents of children included in regular schools, our data are expected to be different. Children with single disability attend regular schools, and only children with multiple disabilities attend Centers for rehabilitation. Besides children with multiple disabilities, large number of parents has children with learning disabilities (13.3%) and ADHD (12.7%). Those are mostly parents who took on-line survey with the same questionnaire.

**Procedures of data collection and methods of analyse**

The questionnaire is developed by the team of Erasmus+ project, Building Bridges: Promoting Social Inclusion and Wellbeing for Families of Children with Special Needs. After finalizing the questionnaire we did double translation from English. First, three of them were administrated to parents of children with no disabilities to check how understandable and easy it is for answering the questions.

This survey assessed aspects of family stress, coping strategies, and communication in family, emotions experienced by parents, social support, marital satisfaction and parents’ well being. Socio-demographic variables were measured by items about age, gender, marital status, income, number of children, education, and type of child’s disability. The survey contained measurements of the following variables:
Parental stress was assessed with The Parental Stress Scale (Berry & Johnson, 1995). The scale contains 18 items, answered using a 5-point Likert scale (1 – strongly disagree; 5 – strongly agree).

Questionnaires were physically delivered to several Centers in Zagreb and Zagreb County, and it was also available on-line, and webpage link was send to several parents’ associations in Zagreb and Zagreb County. In each Center we had one key person in charge for administering the questionnaires. They gave the questionnaires, informed consent and a proposal for participation in further activities of the project to parents. All those papers were in separate envelopes. After filling the questionnaires at their homes, parents gave them back in closed envelopes, and brought back informed consents and proposal to further participation separately. Persons from the Centers brought closed envelopes and signed informed consents to researchers.

The methods of analyze that were used are descriptive statistics, Spearmans Rho coefficient to analyze the correlations between variables, t-test for gender differences in parental stress and ANOVA with Bonferoni Post Hoc Test only for testing variables describing differences in Emotional Regulation Scale regarding parents’ education.

**RESULTS**

The results have shown that higher level of stress correlates to gender, education level, marital status, number of children and income of parents with children with disabilities.

Analyzing the gender differences on Parental stress scale (t= -5.003; df=112.931; p=0.000), we found out that mothers experience more stress (M=2.82) than fathers (M=2.20). Mothers claim to pay attention to how they feel, have no idea how they are feeling and are more confused about how they feel than fathers.

Parental Stress correlates to Parent’s Education (rs=0.328; p=0.000), where parents who have higher education level claim to have higher level of stress. Parental Stress also correlates to Marital status (rs= -0.184; p=0.016). According to results parents living in extramarital relation experience a bit higher level of Parental Stress (M=2.76) and single parents experience the lowest level of Parental Stress (M=2.23).

Parental Stress is also in correlation with Income (rs=0.220; p=0.006). It is interesting that lowest level of Parental Stress is experienced by parents with lowest income (M=1.2).
Nevertheless, only 4 parents had such a low income. The highest level of Parental Stress was found in parents with middle value of income (M=2.64).

As one could have expected, Parental Stress is correlated to Number of Children (rs=-0.185; p=0.006), but interestingly the highest levels of Parental Stress is reported by parents of only one child (M=2.46). Parental Stress gets lower with an increase of number of children respectively until (M=2.0) in parents with more than four children.

Level of stress also correlates to support, emotional regulation and general stress. Parents who experience lower level of stress feel more supported by partner (rs=-0.336; p=0.000), are able to accept their emotions better (rs=0.220; p=0.004) and are able to manage impulses during negative emotions (rs=0.300; p=0.000). Parents who experience less Parental Stress experience also less General Stress in life (rs=0.488; p=0.000).

DISCUSSION

According to our results, higher level of stress correlates to gender, education level, marital status, number of children and income of parents with children with disabilities.

Most research results about stress of parents with children with disabilities are collected from mothers. So we found no researches about differences in stress level between mothers and fathers in available literature.


Nomaguchi and Johnson (2016) found that for fathers a high level of stress is connected to unemployment, but also to workplace inflexibility. On the other hand, for mothers it is connected to unemployment but also to frequencies of engagement with children.

Fathers from our sample were mostly employed and from our practical experience, employers are rather flexible towards parents of children with disabilities. Most mothers from sample had high level of education, but they have stayed at home, frequently engaging with their children.

Bulić (2012) investigated the time involvement of parents, relatives and others in the everyday life activities with children with disabilities in continental and coastal Croatia. Sample consisted of 114 mothers of children with disabilities in age range from 6 months to 6 years. There were
54 mothers from continental and 60 mothers from coastal Croatia. In both regions of Croatia mothers were most involved in everyday activities with children with disabilities. Results show statistically significant differences between the regions in the time involvement of family members and others in everyday activities with children with disabilities. In continental Croatia the most committed members of the family after mothers are fathers, while in coastal Croatia the most committed members after mothers are relatives and then fathers. In coastal Croatia relatives spend more time in everyday activities with children with disabilities than in continental Croatia.

According to our results, parents with higher socio-economic status, higher level of education and less than 3 children experience more stress than parents of lower socio-economic status, lower school degree and more than 3 children. This is quite interesting. Especially since authors found that employment and therefore increase of income of parents have positive influence on their parental stress (GYamfi et al. 2001; Riberio et al 2014).

Nomaguchi and Brown (2011) found that less educated mothers gain more new life meaning from their children. Parents from our study who have higher education and better income are the parents who work, and, even though they do not report high level of stress from work, might be that they have a feeling not to spend enough time with their own children. On the other hand, parents with lower socio-economic status and more than four children receive social benefits, and have ability to use benefit as a caregiver to a child. So, the difference between salary and social benefits are not too high.

Even though parents estimate to receive a lot of support from their partner, fathers are estimating their supportive dyadic coping to be better than mothers. Fathers think that they give, but also receive more support from their spouses than mothers. Previous researchers also found different coping processes and support regarding gender, but gender roles are greatly influenced by cultural norms (Giuliano and Nunn, 2013; Bodenmann, 2005; Xu et al., 2016).

Although our results show rather high satisfaction of parents of children with disabilities, we have to be very cautious with the interpretation, since we had limited sample. Almost all parents were from Zagreb, the capitol city of Croatia, where they have different programs of education and rehabilitation for their children and them. Most of them were included in early childhood intervention programs and received support in their homes very early in child’s life. Therefore, we should analyze our results also in relation to provided support for children and families, in relation to program the child is attending and also in relation to a level of support which child
needs. We should also involve more parents from different parts of Croatia to analyze the differences in family wellbeing and support provided in those parts of Croatia.

CONCLUSION

According to our results, parents from our sample are rather satisfied with their relations, their emotional regulation and support they receive. Nevertheless, they experience quite a lot of parental stress, much more than general stress caused by everyday problems. In this study we found that high level of stress is connected to level of parent’s education, income, number of children and marital status. According to the results, parents with higher socio-economic status and higher level of education and less than three children experience more stress than parents of lower socio-economic status, lower school degree and more than three children. It is important to do further investigations to find the causes of this high level of stress in order to plan the support for parents. Also it is very important for further researches to include control group of parents of children with typical development with focus on sample characteristic gender, parental education, marital status, income, number of children, to compare the level of stress and possible predictors that could contribute to stress experience.

REFERENCES


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