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Comparison of quality of life of families with children with disability and families with children without disability

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Abstract

The paper focuses on the quality of life of families with a child with disabilities, and the site of psychological, physical, social and environmental performance compared to families with a child without disabilities. We bring theoretical and empirical findings experts dealing with the problems of families with child with disability. Below are the options how to offer available social support for family. Survey was conducted in middle of Slovakia focusing on the detection quality of life after the above sites, and for families with children with disabilities compared to families with a child without disabilities. The survey was conducted on a sample of 100 respondents. The biggest difference in the quality of life among families was observed after the site environment, the second is the difference psychologically, the third in physical and in fourth place in the social site.

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Keywords: Quality of life; Family;. Child with disability; Child without disability.

1. Introduction

All of us have our visions of parenthood and are well aware of the fact that the birth of a child brings along not only joy, but also a lot of worries to the family. With parenthood, parents enter an entirely new and exciting stage of life which, however, can unexpectedly steal their dreams and ideals. Childbirth and early development is one of the

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most critical stages in life of every human and it may be connected with risks. The causes of damage may vary and regardless of the type or extent of disability, it is a big blow to parents. A child with disability represents a heavy psychological, physical, social and economical burden for a family and it is important to provide support to the whole family, not only to a child with disability itself. Ondrejka (2001, in: Jakabčic, Poláková, 2006) introduces a global form of Goode´s principles related to quality of life of people with disability:

- quality of life of people with disability is influenced by the same factors and relationships that are important for the intact people,
- we become aware of quality of life when basic human needs are threatened and when we have an opportunity to achieve our goals; the significance of quality of life can be consensually assessed by a wider range of people, including the views of people with disability, their families and practitioners,
- quality of individual´s life is linked to quality of life of people surrounding them.

According to Poston, Turnbull, Park, Mannan, Marquis, Wang (2003) individual quality of life research has produced sufficient momentum to result in an international consensus document, family quality of life is at the very beginning of the conceptualization process. Family quality of life as a policy/program outcome is a natural extension from the work on individual quality of life, especially given the strong emphasis in the disability field on a family-centered service delivery model. Since the mid-to-late 1980s, there has been a growing recognition of the importance of family-centered service delivery characterized by family choice, a family strengths perspective, and the family as the unit of support (Allen & Petr, 1996; Bailey & McWilliam, 1993; Dunst, Johnson, Trivette, & Hamby, 1991; Turnbull, Turbiville, & Turnbull, 2000). Bailey and colleagues (1998) have proposed quality of life of families who have a child with disabilities as a "useful indicator of outcomes of policy initiatives" (p. 322). Conceptualization of family quality of life outcomes has been extremely limited to date. In addition to focusing on the personal outcomes of individuals with disabilities, Gardner and associates (Accreditation Council, 1995) have also provided one of the few conceptualizations that includes family-oriented outcomes for the early intervention lifespan stage only. Currently, research on family quality of life is also being conducted in a three-country study involving Australia (Brown, Davey, Shearer, & Kyrkou, in press), Canada (Brown, Isaacs, McCormack, Baum, & Renwick, in press), and Israel (Neikrug, Judes, Roth, & Krauss, in press).

If a family develops in a healthy way, the positive development affects also the development of a child with disability. The child´s disability affects the whole family. Practitioners are present only in certain moments of life of a child with disability. The biggest part of care for a child with disability is undertaken by the family and a part of their local community willing to help the family in a difficult life situation. The presence of such child affects quality of life of a family in different ways. In our research, we are investigating quality of life of families with a child with disability in Slovakia from physical, psychological, social and environmental aspect compared to families with a child without disability. Moreover, we are investigating how the respondents themselves rate quality of their life and how they are satisfied with their health. The key component of the empirical part is a survey processed using a standardized questionnaire method.

2. The aim and subject of a pre-survey

The aim of the survey is to find out about quality of life of families with a child with disability in the town of Šaľa from the parents' point of view compared to families with a child without disability, namely from physical, psychological, social and environmental aspect. Moreover, we are investigating how the respondents themselves rate quality of their life and how they are satisfied with their health.

Accordingly, we have set out the following partial objectives:

1. To find out how quality of life is rated by parents from families with a child with disability and from families with a child without disability.
2. To find out how satisfied with their health are parents from families with a child with disability and from families with the child without disability.
3. To find out about quality of life of a family with a child with disability from physical aspect compared to a family with the child without disability.

4. To find out about quality of life of a family with a child with disability from psychological aspect compared to a family with a child without disability.
5. To find out about quality of life of a family with a child with disability from social aspect compared to a family with a child without disability.
6. To find out about quality of life of a family with a child with disability from environmental aspect compared to a family with a child without disability.

From these partial objectives, following survey questions emerged:

1. How do mothers and fathers from families with a child with disability rate quality of their life compared to families with a child without disability?
2. What is the difference between how the parents from families with a child with disability and how the parents from families with a child without disability are satisfied with their health?
3. What is the quality of life of a family with a child with disability from physical aspect compared to a family with a child without disability?
4. What is the difference between the level of quality of life of a family with a child with disability and of a family with a child without disability from psychological aspect?
5. What is the quality of life of a family with a child with disability from social aspect compared to a family with a child without disability?
6. How will families with a child with disability score compared to families with a child without disability rating quality of life from environmental aspect?

Our survey questions, after a thorough study of literature and other materials on a given subject, have led us to the hypotheses below.

Pre-survey hypotheses:
H1: Mothers and fathers from families with a child with disability will rate quality of their life as poorer compared to families with a child without disability.
H2: There will be minimal difference between how parents from families with a child with disability and parents from families with a child without disability are satisfied with their health.
H3: Quality of life of a family with a child with disability from physical aspect will be significantly poorer than that of a family with a child without disability.
H4: From psychological aspect, there will not be a significant difference between the level of quality of life of a family with a child with disability and of a family with a child without disability.
H5: From social aspect, quality of life of a family with a child with disability will be approximately the same as that of a family with a child without disability.
H6: From environmental aspect of quality of life, families with a child without disability will score higher than families with a child with disability.

3. Survey methods

The above mentioned hypotheses were tested using the method of a standardized questionnaire of the World Health Organization for assessment of quality of life WHOQOL-BREF (1996), more precisely its Slovak version by the author Kováč, D. (WHOQOL-BREF. Bratislava, WHO – ÚEPs SAV, 1996). This questionnaire measures quality of life by means of four domains – areas of life which contribute to the overall level of quality of life:

1. *Physical domain* – maps the extent to which pain affects the individual's life and to which they are dependent on medical care. Questions feeding these dimensions investigate how people are satisfied with their own mobility, sleep, sufficiency of energy and to what extent they feel discomfort in a physical area.

2. *Psychological domain* – investigates the extent to which people are satisfied with their life, if they perceive it as meaningful and joyful. It also focuses on the frequency of the occurrence of negative emotional states as despair, depression, anxiety.

3. *Social domain* – reflects the satisfaction with personal relationships, sex life as well as with the support that

people receive from their friends and local community.

4. *Environmental domain* – is fed with questions investigating the level of quality of life with regard to environmental factors – feeling of safety and quality of environment of people, accessibility of financial and information resources or health services.

The questionnaire is anonymous, consists of three pages with 26 closed-ended questions, of which the first two are evaluated independently and the rest in a way described on the first page of the questionnaire. Respondents circle the number associated with the answer that is according to their personal opinion right. Respondents have to pick from 5 kinds of answers. An accompanying letter asking respondents to fill it in containing justification, the purpose of a questionnaire, acknowledgement and a signature was attached to each questionnaire.

4. Processing of survey results

The survey was carried out from 1.3.2014 to 31.4.2014. The first two questions of the questionnaire were evaluated independently, collected data was written down in a table and graphs were designed for better visual illustration of differences. Data collected from questionnaires starting with the question No. 3 was transferred into a table following the rules of evaluation on the first page of the questionnaire using methods of quantitative analysis. In the next step, t-tests were used. This test serves to find significant differences between two groups. More specifically, arithmetic mean and "t" values indicating if differences between groups are significant (of statistical importance) were observed. This data was subsequently written down in a table and other tables pointing out to individual domains of quality of life were created which were later transformed into graphs.

All collected data was processed in Microsoft Excel. Each finding is, besides a table or a graph, complemented by a statement and analysis of the result.

5. Sample set

Respondents forming a survey sample were mothers and fathers from families with a child with disability and mothers and fathers from families with the child without disability in the town of Šaľa. 2 questionnaires were handed out (mother, father) in each family in cooperation with employees of Special elementary school in Šaľa and Elementary school on Bernolákova Street in Šaľa. The criterion for handing out a questionnaire in a particular family was the presence of roughly the same socio-economic indicators: income, parental employment, completeness of a family and number of children. Families with children without disabilities were used as a *control set* necessary for comparison of quality of their life with quality of life of families with a child with disability.

Questionnaires were filled in by 100 respondents (25 mothers and 25 fathers from families with a child with disability and 25 mothers and 25 fathers from families with a child without disability).

6. Discussion

The aim of the research was to find out about quality of life of families with a child with disability in the town of Šaľa from parents' point of view compared to families with a child without disability, namely from physical, psychological, social and environmental aspect. Moreover, we were investigating how the respondents themselves rate quality of their life and how they are satisfied with their health. Our sample set consisted of respondents from two groups – mothers and fathers from families with a child without disability and mothers and fathers from families with a child with disability.

Following statements could be made as far as the set out hypotheses are concerned:

H1: Mothers and fathers from families with a child with disability will rate quality of their life as poorer compared to families with a child without disability.

In order to test a given hypothesis, we used the questionnaire question No. 1. Research results show that most respondents from families with a child with disability rated quality of their life as neither poor nor good, other respondents as rather poor. Respondents from families with a child without disability mostly rated quality of their

life also as neither poor nor good, however, the rest of the respondents as rather good. Therefore, we can state that quality of life of a family with a child with disability in the town of Šaľa from the parents' point of view is, as we hypothesized, rather poorer than quality of life of a family with a child without disability. This statement is understandable, as the family with a child with disability is, as we mentioned above, affected by the child's disability in its life, which may negatively interfere with particular dimensions (or aspects) of life.

H2: There will be minimal difference between how parents from families with a child with disability and parents from families with a child without are satisfied with their health.

In order to test a given hypothesis, we used the questionnaire question No. 2. Results show that there is, as we hypothesized, minimal difference between how parents from families with a child with disability and parents from families with a child without disability are satisfied with their health. We understand it in the sense that living in a family with a child with or without disability has no influence on the level of satisfaction of a mother or father with their health.

H3: Quality of life of a family with a child with disability from physical aspect will be significantly poorer than that of a family with a child without disability.

The results above show that quality of life of a family with a child with disability from physical aspect is poorer than quality of life of a family with a child without disability, the difference being, as we hypothesized, significant. Therefore, we can state that families with a child with disability are less satisfied with their own mobility, sleep, sufficiency of energy and perceive higher level of discomfort in a physical area than families with a child without disability.

H4: From psychological aspect, there will not be a significant difference between the level of quality of life of a family with a child with disability and of a family with a child without disability.

The obtained results show that there is a significant difference between the level of quality of life of a family with a child with disability and of a family with a child without disability. Hence, we can state that respondents from families with a child with disability perceive their life as meaningful and joyful to a smaller extent compared to families with a child without disability. Although we didn't hypothesize such a result, it is understandable that the presence of a child with disability markedly affects even this area of life and it is also connected with a higher frequency of occurrence of negative emotional states as despair, depression, anxiety.

H5: From social aspect, quality of life of a family with a child with disability will be approximately the same as that of a family with a child without disability.

The results show that quality of life of a family with a child with disability from social aspect is, as we hypothesized, approximately the same as that of a family with a child without disability. Therefore, we can state that families with a child with disability are approximately equally satisfied with personal relationships (parents or married couples also with their sexual relationships) and support that they receive from friends and local community as families with a child without disability.

H6: From environmental aspect of quality of life, families with a child without disability will score higher than families with a child with disability.

The results show that from environmental aspect of quality of life, families with a child without disability scored, as we hypothesized, higher than families with a child with disability. The difference emerging from the results is markedly significant, actually the biggest from all domains. Therefore, we can state that the level of feeling of safety and quality of environment of a family with a child with disability, hence the accessibility of financial and information resources and health services, is much lower than of a family with a child without disability. This

domain involves mainly the economic side, so it's understandable that a family with a child with disability perceives a higher level of discomfort in this area, as it needs more financial resources in order to satisfy all its needs and proper functioning than a family with a child without disability.

According to Bratská (2006), coping with burdensome situations appears as a significant indicator of quality of life. She distinguishes between two terms – adaptation and coping. According to her, *adaptation* means coming to terms with ordinary and increased burden (within limits of our tolerance of burden, we apply methods of solving burdensome situations to which we have predispositions and experience). *Coping* represents a higher level of adaptation that is necessary for dealing with limit and extreme burden (we find ourselves at the limit of our tolerance of burden, it's a matter of solving sudden, unusual burdensome situations which often overreach our resources; we need to find, examine, test and adopt necessary coping methods first). Křivohlavý (2002) understands coping with life burdens as a *dynamic process* in which it comes to transactions (mutual interactions between a person and a given situation). On one hand, there is a given person (or a family) with certain resources, possibilities, values, beliefs. On the other hand, there is a disability imposing certain requirements on a person (or a family) and influences them variously.

Few research studies have explored how the level of a child's behaviour problems leads to psychological distress in parents of children with autism. Jones**,** Hastings**,** Totsika**,** Keane Rhule (2014) explored whether psychological acceptance and mindfulness mediated this relationship between child behaviour and parental distress. Seventy-one mothers and 39 fathers of children with autism participated, by reporting on their own positive and negative psychological well-being and their child's behaviour problems. Psychological acceptance was found to act as a mediator variable for maternal anxiety, depression, and stress, and for paternal depression. General mindfulness and mindful parenting had significant mediation effects for maternal anxiety, depression, and stress. These results contribute to evidence that mindfulness and acceptance may be important parental psychological processes, with implications for parent support.

In Slovakia, there are several volunteer organizations, associations and clubs the aim of which is to help the people with disability and their families and to promote and support all measures with the intention to help and improve social inclusion of persons with disability. Organizing gives families a better opportunity to expand their knowledge of the issue of disability, exchange experience and gain both mental and material support, mutual understanding and help. It is an old truth that sharing your problems with others helps to reach emotional balance. Most parents receive help from professionals and friends and seek families with children with similar issues. Parents can associate informally in a group of a few persons with similar fate, life situation or a comparable problem or join existing organizations supporting these activities. Parental activities are beneficial not only for parents, but also for their children. It is up to families themselves, if they want to join this process or not.

7. Conclusion

Every family forms an original system with its specific rules and ways of coexistence. Nowadays, the number of families with a child with disability has risen mainly as a consequence of improving health care for newborns who often wouldn't survive without the help of professional personnel. Initially, parents often don't realize what the presence of a child with disability means for the whole family. The family has to adjust its life to such child, with all limitations and increased burden imposed on all family members. Child's disability thus affects life of the whole family, more specifically its quality from various aspects.

In our research we used a standardized questionnaire to compare quality of life of a family with a child with disability to quality of life of a family with a child without disability in the town of Šaľa from parents' point of view considering its different aspects. We found out that the biggest difference to the disadvantage of a family with a child with disability exists in quality of life from environmental aspect. This comes as no surprise, as families with a child with disability need in general more financial resources for satisfying their needs than families with a child without disability; however, support of such families from the state (or the town) is not sufficient. The slightest, almost minimal difference was observed in quality of life from social aspect. This means that families with a child with disability in the town of Šaľa are approximately equally satisfied with personal relationships and support that they receive from friends and local community as families with a child without disability.

As far as physical and psychological aspect of quality of life is concerned, families with a child with disability report lower level of satisfaction than families with the child without disability; however, the difference is not as marked as observed in environmental aspect.

It is important that the society gives greater attention to supporting families with a child with disability, creates room for social integration and provides support in the area of comprehensive rehabilitation in the sense of networking of health, social and pedagogical-psychological services.

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