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QUALITY OF LIFE OF FAMILIES OF PREMATURE CHILDREN

KVALITET ŽIVOTA PORODICA PREVREMENO ROĐENE DECE

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Summary

Introduction. The quality of family life is defined as the well-being of a family in which the individual and family needs constantly interact. Families are continually adapting to various changes in the course of life, until they reach a balance in functioning. Premature birth is a challenge for parents. Many parents develop symptoms of depression or anxiety, and impaired family functioning continues to manifest years after the premature birth itself. All this significantly affects the quality of life of these families. **Material and Methods.** This research included 101 families of premature children in the territory of Autonomous Province of Vojvodina. The following assessment instruments were used: a general questionnaire and the Beach Center Family Quality of Life Scale. **Results.** The primary family is the most common living environment. More than half (61.5%) of children spend the most of their time with their primary family. The majority of parents included in this research are satisfied with family interactions. The emotional component of this category was rated as "very satisfied" by most of the parents (61.5%). A large percentage of parents (86.5%) are involved in the Association of Parents of Premature Children and this is an important factor in improving their quality of life and making transitions easier. **Conclusion.** Premature birth of a child significantly affects the family quality of life. A clinical approach to these families is not sufficient. A holistic, family-oriented approach could potentially be very useful in working with these families. Addressing both the physical and psychological needs of these families can provide very useful information and guidelines for further work in improving their quality of life.

Key words: Quality of Life; Family; Parenting; Infant, Premature; Psychosocial Support Systems; Personal Satisfaction; Child

Sažetak

Uvod. Kvalitet života porodica je definisan kao dobrobit porodice u kojem su potrebe pojedinca i porodice u konstantnoj interakciji. Porodice se konstantno prilagođavaju različitim promenama u životnom toku, sve dok ne postignu ravnotežu u funkcionisanju. Prevremeni porođaj predstavlja izazov za roditelje. Mnogi roditelji razviju depresivne simptome ili anksioznost, a narušeno porodično funkcionisanje ispoljavaju i godinama nakon samog prevremenog porođaja. Sve ovo značajno utiče na kvalitet života ovih porodica. **Materijal i metode.** Istraživanjem je obuhvaćena 101 porodica sa prevremeno rođenim detetom na teritoriji Autonomne Pokrajine Vojvodine. Korišćeni su sledeći instrumenti procene: Opšti upitnik i Skala porodičnog kvaliteta života (engl. *Beach Center Family Quality of Life Scale − Beach FQOL Scale*). **Rezultati.** Primarna porodica predstavlja najučestaliji ambijent življenja. Više od polovine dece, tačnije 61,3% najveći procenat vremena provode u krugu svoje primarne porodice. Zadovoljstvo porodičnim interakcijama je prisutno kod najvećeg broja roditelja uključenih u ovo istraživanje. Emocionalna komponenta ove kategorije je kod većine roditelja (61,5%) označena kao „veoma zadovoljan". Veliki procenat roditelja, odnosno 86,6% je uključeno u Udruženje roditelja prevremeno rođene dece, te ovo predstavlja bitnu kariku u poboljšanju njihovog kvaliteta života i lakši prolazak kroz tranzicije. **Zaključak.** Prevremeno rođenje deteta značajno utiče na kvalitet života porodice. Klinički pristup u radu sa ovim porodicama nije dovoljan. Holistički pristup, orijentisan na porodicu, potencijalno bi mogao da bude veoma koristan u radu sa ovim porodicama. Sagledavanje kako fizičkih, tako i psihičkih potreba ovih porodica može nam dati veoma korisne podatke i smernice za dalji rad u oblasti poboljšanja njihovog kvaliteta života.

Ključne reči: kvalitet života; porodica; roditeljstvo; prevremeno rođeno dete; sistemi psihosocijalne podrške; personalna satisfakcija; dete

Introduction

The quality of family life is defined as the well-being of the family in which the individual and the family needs interact [1]. According to the family systems theory, the relationship between family members may significantly affect the psychosocial well-being of the child [2]. In the period when the family is the greatest source of support, hope, and strength for a child, as a consequence, the sensitivity of the child to the psychological state of the parents increases [2].

The construct of the quality of family life is greater than both the needs of a single family member and the mother-child dyad, emphasizing the family unity and the needs and strengths of all the family members [3].

In Serbia, around 4,000 babies are born prematurely [4]. According to the World Health Organization (WHO), the rate of preterm births ranges from 5% to 18% and it is highest in developing countries. Also, the WHO points to even higher rate of prematurity in the following period [4]. Premature birth, and conse-

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Abbreviations
FQOL – family quality of life
WHO – World Health Organization

quentially low birth weight are the primary problems in healthcare throughout the world [5]. Today, the survival rate of premature children rises, especially among newborns of extremely low birth weight, but it may cause higher risk of cognitive, motor, and social impairment, as well as psychiatric conditions [5].

Premature birth is a challenge for parents, who unexpectedly find themselves in a new situation, in which they face many new questions. In an ecological sense, the family and its surroundings have the greatest influence on the child's development [6]. There is evidence that premature babies with poor general health show better outcomes if they are surrounded by warm family affection [6]. The parental mental health is an important link in the chain of developmental encouragement. The first link which endangers this aspect of functioning is hospitalization. The interaction between a mother and her child, their physical contact is of great importance to a newborn child and the development of its identity and security [7]. This precious contact can be lost during hospitalization. The United Nations Children's Fund in Serbia has, exactly for this reason, carried out a series of programs intended to raise donations for the purpose of acquiring the necessary equipment for skin-to-skin contact between mother and child, nursing chairs for comfortable experience of mother and child during contact, as well as devices intended for breastfeeding and storage of mother's milk, the best food for a newborn [7].

The main goal of this research is to determine the specificity of the quality of family life of families of premature children.

Based on the set goals, the following hypotheses were evaluated:

1. There is a delay in the premature child's psychomotor development and the parents feel the need for stimulation programs, primarily in the domain of motor and speech-language development.
2. In over 50% of cases the parents involve experts of various profiles in establishing the psychomotor status of premature children.
3. A satisfaction with family interactions exists within families of premature children.
4. There is a satisfaction with parenting in families of premature children.
5. There is a physical/material satisfaction in families of premature children.
6. There is a satisfactory level of support for families of premature children.

Material and Methods

This research was conducted in the territory of the Autonomous Province of Vojvodina from April to August of 2020. Due to the epidemiological situation, the research was conducted over the internet (online questionnaire). Parents who were members of the Association of Parents of Premature Children "Optimistic" were sent questionnaires by email with consent forms and instructions on how to fill them out. The research included 101 families of premature children.

For the purpose of data collection, the following instruments were used:

1. General questionnaire

The questionnaire was designed for the purpose of this research.

It consists of three parts complementing each other and providing a holistic view of the families. The first part of the questionnaire deals with sociodemographic characteristics of families: parental age, degree of education, economic status, housing conditions, number of children, and others.

The second part of the questionnaire deals with the premature child, parental age at childbirth, as well as determinants of the child development (Apgar score), newborn weight, whether it was a twin pregnancy, who the child spent most of the time with, and others.

The third part of the questionnaire consists of closed-ended questions where the parents were asked to describe their parenting, to rate the significance of information received on regular appointments, whether they were involved in support programs, and others.

2. Beach Center Family Quality of Life (FQOL) Scale by Hoffman, Marquis, Poston, Summers, and Turnbull from 2006, was the second instrument [8]. The scale was translated into Serbian [9] and a consent for its use in this research was obtained.

The scale is intended for families with children from birth to the age of 21.

The scale includes 25 items assessing family perception of satisfaction with various aspects of family life. The parents' satisfaction was rated on a 5-point scale (1 - very dissatisfied and 5 - very satisfied). In the end, a score demonstrating the average value of given answers in every domain is calculated.

The instrument has good psychometric characteristics [9]. According to the author, a very good internal consistency of the FQOL scale exists in the scale as a whole ($\alpha = 0.930$), as well as a good internal consistency with the lowest recorded value being 0.743 in the domain of Emotional well-being, and the highest in Family interaction ($\alpha = 0.875$). The authors of the scale report the following psychometric characteristics: the Cronbach α of 0.88 for the scale as a whole, and 0.90 in the domain of Family interaction, 0.86 in the domain of Parenting, 0.84 for Emotional well-being, 0.74 in the domain of Physical/Material well-being, and 0.85 in the domain of Disability-related support [8].

The recorded data was analyzed using the descriptive method of statistical analysis.

Results

The primary family is the most common living environment in the analyzed sample. A smaller part (31.4%) lives with extended family, and just 3% of children live only with their mother. The highest percentage of the respondents lives in their own housing (80.4%).

Table 1. Gestational week (GW) at birth
Tabela 1*. Gestacijska nedelja rođenja deteta*

To 26 GW *do 26. nedelje*	27 - 29 GW *27–29. nedelja*	30 - 32 GW *30–32. nedelja*	33 - 35 GW *33–35. nedelja*	36 - 37 GW *36–37 nedelja*
10 (10%)	12 (12%)	33 (32.7%)	43 (42.3%)	4 (3.9%)

Table 2. Aspects of the development of premature children where parents noticed a delay or a need for stimulation
Tabela 2. *Aspekti razvoja prevremeno rođenog deteta u kojima roditelji uočavaju kašnjenje ili potrebu za stimulacijom*

Gross motor skills/*Gruba motorika*	18 (22.5%)
Fine motor skills/*Fina motorika*	23 (28.7%)
Speech-language development/*Govorno-jezički razvoj*	27 (33.8%)
Cognitive development/*Kognitivni razvoj*	12 (15%)
Socio-emotional development/*Socio-emocionalni razvoj*	15 (18.8%)
Other (hyperactivity and the like)/*Ostalo (hiperaktivnost i slično)*	3 (3.9%)
No deviations in the development/*Nije prisutno odstupanje u razvoju*	22 (28.2%)

There were 42.2% of two-children families and 40.2% were one-child families. One-third of the study sample has premature children from twin pregnancies. Fifteen children (14.7%) were conceived in vitro, and 87 (85.3%) were conceived naturally.

Table 1 shows that premature birth commonly occurs at 33 to 35 week of gestation in the analyzed children. Extremely premature children account for 10% of the sample.

Forty four (43.1%) children had a birth weight less than 1,500 grams. A birth weight of less than 2,500 grams was found somewhat more frequently, in 54 cases (52.9%). Only 4 (3.9%) newborns had a birth weight over 2,500 grams.

Table 2 shows that the largest percentage of parents noticed a deviation in their child's speech-language development, followed by difficulties in gross and fine motor skills. This result confirms the hypothesis number 1. It is important to note that some children required additional stimulation in multiple areas.

More than half of parents reported that they visited experts of various profiles for the purpose of child's psychomotor status evaluation (67 parents/66.3% of the sample). Most visited pediatricians, neurologists, pulmonologists, and cardiologists. This confirms the hypothesis number 2. However, 70 (69.3%) children were not involved in a program of early childhood intervention focusing on the family and the child, but programs of medical model-based response to challenges that arose during the development.

Table 3. Percentage of satisfaction with family interactions
Tabela 3. *Procenat zadovoljstva porodičnim interakcjama*

	Very satisfied *Veoma zadovoljan*	Satisfied *Zadovoljan*	Neither *Ni zadovoljan ni nezadovoljan*	Dissatisfied *Nezadovoljan*	Very dissatisfied *Veoma nezadovoljan*
My family enjoys spending time together. *Moja porodica uživa u vremenu koje provodimo zajedno.*	51 (49.5%)	47 (45.6%)	5 (4.9%)		
My family members talk openly with each other. *Članovi moje porodice otvoreno razgovaraju jedni sa drugima.*	40 (38.5%)	53 (51%)	9 (8.7%)	2 (1.9%)	
Our family solves problems together. *Naša porodica zajednički rešava probleme*	40 (38.5%)	49 (47.1%)	12 (11.5%)	3 (2.9%)	
My family members support each other to accomplish their goals./*Članovi moje porodice podržavaju jedni druge u ostvarenju ciljeva.*	41 (39.4%)	53 (51%)	7 (6.7%)	2 (1.9%)	1 (1%)
My family members show that they love and care for each other./*Članovi moje porodice pokazuju da vole i da brinu jedno za drugo.*	64 (61.5%)	32 (30.8%)	5 (4.8%)	2 (1.9%)	1 (1%)
My family is able to handle life's ups and downs. *Moja porodica se snalazi u životnim usponima i padovima.*	41 (39.8%)	53 (51.5%)	8 (7.8%)	1 (1%)	

Table 4. Overview of the "parenting" subcategory
Tabela 4. *Prikaz potkategorije „roditeljstva"*

	Very Satisfied *Veoma zadovoljan*	Satisfied *Zadovoljan*	Neither *Ni zadovoljan ni nezadovoljan*	Dissatisfied *Nezadovoljan*	Very Dissatisfied *Veoma nezadovoljan*
My family members teach the children how to be independent./*Članovi moje porodice pomažu deci da budu samostalna.*	42 (40.4%)	49 (47.1%)	9 (8.7%)	4 (3.8%)	
My family members help the children with their schoolwork./*Članovi moje porodice pomažu deci oko školskih zadataka.*	30 (30.9%)	50 (51.5%)	12 (12.4%)	4 (4.1%)	1 (1%)
My family members teach the children how to get along with others./*Članovi moje porodice uče decu kako da se slažu sa drugima.*	55 (53.4%)	44 (42.7%)	3 (2.9%)	1 (1%)	
Adults in our family teach the children to make good decisions./*Odrasli u našoj porodici uče decu da donose dobre odluke.*	47 (45.2%)	49 (47.1%)	6 (5.8%)	2 (1.9%)	
Adults in my family know other people in the children's lives (friends, teachers, etc.). *Odrasli u mojoj porodici poznaju druge osobe u životima dece (prijatelje, nastavnike, itd.)*	33 (33%)	56 (56%)	9 (9%)	1 (1%)	1 (1%)
Adults in my family have time to take care of the individual needs of every child. *Odrasli u mojoj porodici imaju vremena da se brinu o individualnim potrebama deteta.*	41 (40.2%)	47 (46.1%)	12 (11.8%)	1 (1%)	1 (1%)

Table 3 shows the percentage of satisfaction with family interactions. The quality of family interactions has a basic role in child development. The items related to the emotional component of family interaction ("My family members show that they love and care for each other") take the first place in this category. These results confirm the hypothesis number 3.

Table 4 shows the degree of satisfaction with parenting. A large number of parents are very satisfied with activities inside the family related to the child's ability to cooperate. A small percentage is dissatisfied with the activities of the family regarding schoolwork. This confirms the hypothesis number 4.

Table 5 shows the degree of satisfaction of parents with their physical/material well-being, which speaks in favor of the hypothesis number 5.

Table 5. Overview of the subcategory "physical/material well-being"
Tabela 5. *Prikaz potkategorije „fizičko/materijalno blagostanje"*

	Very Satisfied *Veoma zadovoljan*	Satisfied *Zadovoljan*	Neither *Ni zadovoljan ni nezadovoljan*	Dissatisfied *Nezadovoljan*	Very Dissatisfied *Veoma nezadovoljan*
My family members have transportation to get to the places they need to be./*Članovi moje porodice imaju prevoz da stignu tamo gde treba.*	47 (45.2%)	47 (45.2%)	6 (5.8%)	3 (2.9%)	1 (1%)
My family gets medical care when needed. *Moja porodica dobija medicinsku negu kada je potrebna.*	39 (37.5%)	49 (47.1%)	13 (12.5%)	3 (2.9%)	
My family has a way to take care of our expenses. *Moja porodica ima načina da vodi računa o našim troškovima.*	27 (26%)	57 (54.8%)	16 (15.4%)	4 (3.8%)	
My family gets dental care when needed. *Moja porodica ima stomatološku zaštitu kada je potrebno.*	41 (39.4%)	47 (45.2%)	12 (11.5%)	4 (3.8%)	
My family feels safe at home, work, school, and in our neighborhood./*Moja porodica se oseća bezbedno u kući, na poslu, u školi i u našem naselju.*	39 (37.5%)	53 (51%)	11 (10.6%)	1 (1%)	

Table 6. Overview of the "emotional well-being" subcategory
Tabela 6. *Prikaz potkategorije „Emocionalno blagostanje"*

	Very Satisfied *Veoma zadovoljan*	Satisfied *Zadovoljan*	Neither *Ni zadovoljan ni nezadovoljan*	Dissatisfied *Nezadovoljan*	Very Dissatisfied *Veoma nezadovoljan*
My family has the support we need to relieve stress./*Moja porodica ima podršku koja nam je potrebna da ublažimo stres.*	33 (31.7%)	48 (46.2%)	18 (17.3%)	4 (3.8%)	1 (1%)
My family members have friends or others who provide support./*Članovi moje porodice imaju prijatelja ili nekoga ko ih podržava.*	35 (34%)	54 (52.4%)	13 (12.6%)		1 (1%)
My family members have enough time to pursue our own interests./*Članovi moje porodice imaju vremena za naša zajednička interesovanja.*	36 (35%)	48 (46.6%)	14 (13.6%)	5 (4.9%)	
My family has outside help available to us to take care of special needs of all family members. *Mojoj porodici stoji na raspolaganju pomoć spolja kako bismo se pobrinuli za posebne potrebe svih članova.*	32 (31.7%)	37 (36.6%)	24 (23.8%)	6 (5.9%)	2 (2%)

Table 6 shows that the majority of parents have a friend or someone else who supports them. These results confirm the hypothesis number 6.

Discussion

Premature birth is a source of stress for both parents [10]. Mothers and fathers of newborns have increased levels of depression, anxiety and posttraumatic stress when compared to parents of full-term children. The study showed that around 40% of mothers and fathers reported symptoms of depression and half reported symptoms of anxiety soon after the premature birth of a child. These symptoms are significantly more notable with parents of premature children and during the child's development [10].

The quality of life of any family, including one of a premature child, cannot be observed isolated from social factors. Generally, parents who report a greater need for social support, tend to have lower levels of life satisfaction, consequentially bringing on more parental stress [1]. It is very important to mention that the premature birth itself presents a risk factor for the parental mental health [10]. Taking this into account, a systematic and integrated response is needed to promote well-being, monitor mental health and ease access to evidence-based early childhood intervention for families of premature children. Parents, as well as their babies, spend months at a time in the hospital, opening up the possibility for screening and support in the intensive care unit. At the same time, parents need help with contacting external services, to be informed of their rights and available possibilities [10]. A research conducted in our country [11] found that the most common obstacle regarding services is the lack of awareness that they exist. More than half of the interviewed parents did not know which services were available to them [11].

Intervention after premature birth should be [10] adaptive, individualized and multilayered, with mandatory direct psychological support for the parents. The support should be provided for the parents after learning about the health condition of the child, in order to face and overcome stress in the long run and adapt to their new life circumstances [12]. All of the experts involved should work toward a common goal, which is encouragement of the development of the child and support for the parent-baby relationship [10].

To evaluate the physical status of the newborn and the need for reanimation, the well known Apgar score was developed [13]. The research [14] that included premature children born at the Institute for Neonatology, reported that 22.4% of children had an Apgar score of 4 at 1 minute, while 20% of children had an Apgar score less than 6 at 5 minute. This data significantly matches the data obtained in our study. More recent researches [15] report a 75 - 80% greater risk of an autism specter disorder in children with a low or medium Apgar score at birth.

While progress in the neonatal care brought on a greater survival rate of these children, the developmental consequences persist. A research [16] analyzing 4,122 premature children showed results in line with ours. This research also showed that a large percentage of children exhibited difficulties in speech-language development.

When looking at things as a whole, our research showed positive results. When interpreting the data, it is very important to take into account that the parents involved in this research are active members of the Association of Parents of Premature Children. They may get additional support which undoubtedly affects their positive outlook. Expanding the sample by including parents who are not members of the Association would provide more complete understanding of the situation.

Conclusion

Parenting comes with many responsibilities. Being a parent of a premature child comes with additional difficulties and challenges. Based on the data of our research, we can conclude that lives of these families depend on a multitude of factors. A clinical approach to both the child and the family is not sufficient when approaching families of premature children. A holistic approach to both their physical and emotional needs is necessary.

Early support for families of premature children is important, in order to use the sensitive period of early development, because it affects the quality of their life in a positive manner. Supporting families in the aim of improving their quality of life consists of considering their strengths and resources, advisory work, as well as connecting them to other people and associations.

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