



Assessment of the Quality of Life of Families of Children With Autism

Original scientific paper

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Abstract

Being a parent of a child who exhibits atypical developmental patterns and encounters numerous difficulties necessitates parents to assume the roles of advocates and coordinators for their child's services, thereby limiting the scope for personal fulfillment. This research endeavors to ascertain whether disparities exist in the quality of life between parents of typically developing children and parents of children with autism. Additionally, it aims to explore parental satisfaction with parenthood and the experience of parental stress. The study encompassed a cohort of 90 families, comprising 45 families with typically developing children and 45 families with children diagnosed with autism. To facilitate data collection, a comprehensive questionnaire was devised, capturing fundamental information. Furthermore, two scales, namely the Parental Satisfaction Scale and the Parental Stress Scale, were employed to assess parental perspectives. The results, obtained through nonparametric group comparison techniques, substantiate a significantly heightened level of parental stress among parents of children with autism. Moreover, noteworthy discrepancies were observed across essential domains of parental satisfaction. An unprecedented finding arising from this investigation, not documented in extant literature, pertains to the prevalent inclination of parents whose firstborn and solitary child has autism to conceive another child, motivated by apprehensions of autism recurrence and concerns surrounding their capacity to devote sufficient attention to a child with autism.

Keywords: *parents, family, autism, development, stress*

Parenthood

Parenthood, a multifaceted phenomenon, encompasses an intricate tapestry of tasks, roles, rules, communication, and interhuman dynamics that adults embark upon when engaging with their offspring. It is within this complex framework that parenthood unfolds as a dynamic and reciprocal social process. Bearing witness to a gamut of emotions, parenthood can engender profound feelings of exultation, pride, self-actualization, and

the affirmation of one's identity and integrity. Simultaneously, it is not uncommon for the parenting journey to be punctuated by weariness, exertion, and stress, sometimes even leading to the relinquishment of personal avenues of self-fulfillment (Cudina-Obradovic & Obradovic, 2003; Klarin, 2006). Parenthood transcends a mere compendium of child-centric activities; rather, it assumes a significant facet of an adult's personal identity, interwoven within the context of their relationship with their child (Rudic et al., 2013). As such, it exerts a

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profound influence on the development and transformation of individuals in the parental role. The presence of a child alone serves as a catalyst, eliciting an amalgamation of intense positive and negative affective states, reshaping the cognitive landscape, emotional contours, and behavioral patterns of parents, while simultaneously influencing their own self-perception and the societal perceptions surrounding them (Sabatell & Waldron, 1995). The subjective encounter with parenthood delves into the inner recesses of parental psyche, encompassing attitudes, emotions, and the very essence of their perception of parenthood, thereby shaping motivational orientations, the sense of parental competence, satisfaction derived from assuming the parental role, educational values, and overarching aspirations (Kohn et al., 1986).

Autism

Autism is a neurodevelopmental disorder characterized by significant impairments in reciprocal social interactions, patterns of communication, as well as restricted, stereotypical, and repetitive behaviors, interests, and activities (Glumbic, 2009).

Pervasive developmental disorders encompass a range of early-onset disorders that affect multiple domains of psychomotor development and are marked by abnormalities in social interactions, communication, limited repertoire of interests and activities varying in degree of severity, and often accompanied by diminished intellectual functioning. These disorders profoundly alter three fundamental areas of human development: speech, communication, and social interaction (Stepanovic, 2018). Due to the morbidity, disease outcomes, impact on families, and societal economic burden, autism represents one of the most challenging developmental disorders for society (Resic et al., 2007). The differential diagnosis of autism commonly involves other pervasive developmental disorders, conditions with clinical presentations resembling autism, and disorders with associated autism. The key to distinguishing autism from other pervasive developmental disorders lies in adhering to the diagnostic criteria outlined in the prevailing classification systems

(Milacic, 2008a). Currently, two prominent diagnostic systems are in use: the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) (Glumbic, 2009).

Clinical Picture

The clinical presentation of autism varies among children and depends on the manifestation of symptoms, age, and intellectual capacities, which can also significantly vary within the same child as they grow (Bujas-Petkovic & Skrinjar, 2010). Parents most commonly notice developmental problems around the age of two when previously the child's development appeared typical. This manifestation of impairment is referred to as secondary autism. In cases where parents observe developmental issues from birth, it is referred to as primary autism (Mitic, 2011, Stepanovic, 2018). Autistic infants exhibit reduced attention to social stimulation, diminished smiling and eye contact, and have a weaker response to their own name. Older children often display a lack of eye contact and significant deficits in nonverbal communication (Brown et al., 2012). Individuals with autism are often described as being "in their own world" and unwilling to communicate, but this is not due to a desire to avoid communication but rather an inability to effectively communicate. Communication abnormalities in autism manifest in various ways, ranging from complete absence of speech, speech delay, difficulties initiating or maintaining conversations, presence of echolalia (repeating words spoken by others), to repetitive or idiosyncratic language (Stepanovic, 2019). Difficulties in comprehending oral information are also frequently observed (Rey, 2013). Approximately 40% of individuals with autism experience sensory disturbances. While parents are usually the first to notice symptoms, they do not always immediately seek professional help (Milacic, 2004). Some professionals are hesitant to provide an early diagnosis to avoid stigmatizing the child or making diagnostic errors, and there are cases in which parents refuse to accept the diagnosis and seek opinions from

multiple experts (Milacic-Vidojevic, 2008a). When there is suspicion of autism spectrum disorder, the child should be referred to a multidisciplinary team for evaluation. All team members should have relevant experience, and at least one member should be trained in administering standardized tests for diagnosing autism spectrum disorder. It is also recommended to observe the child in at least two different environments, structured and unstructured (Rey, 2013).

Family and Parenting

The family represents a dynamic entity, a system in which changes within one subsystem lead to changes in other subsystems (parental subsystem, child subsystem, marital subsystem). As a system, the family has unified boundaries within which all interactions among its members take place. Viewing the family in this manner clarifies that any problem experienced by an individual family member will manifest within the family as a whole (Goldner-Vukov, 1994). The term “healthy, functional family” refers to one that can grow despite the challenges it encounters. In healthy families, there is also flexibility in assigning roles, allowing members to express individual differences. In contrast to functionality, we differentiate the concept of dysfunctionality. Family dysfunctionality can occur at the structural level as well as at the level of emotional processes (Milojkovic et al, 1997). Each family member, including parents and siblings, has a need for personal time and space. Parents also have a need for partner time. Facilitating time for everyone’s needs sometimes presents a challenge in finding a balance between closeness and distance, as well as a balance between roles - being an individual, separate entity, and a family member (Breton & Tong, 2005). Regardless of different value systems and ways of life, there are three fundamental tasks of parenthood: protecting the child, successfully raising them, and establishing a good relationship with their adult child (Stepanovic, 2019). The ultimate goal of every parent is to enable their child to have a higher quality of life in adulthood, thus ensuring a more peaceful and carefree old age for themselves. Parents are not expected to care for their adult children (Bujas-Petkovic & Skrinjar, 2010). However, the

birth of a child with developmental disorders or their subsequent identification, especially if they are of a chronic nature with uncertain outcomes, leads to numerous psychological reactions in parents and poses a threat to the entire family life (Mitic, 2011).

Experience of Parenthood

The experience of parenthood refers to the subjective parental assessment of their own success in fulfilling the socially set parenthood norms. The term parental satisfaction is used to describe satisfaction with the parental role, or satisfaction with children. (Mouton & Tuma, 1988). The subjective feeling of parenthood includes three dimensions: satisfaction with parenthood, stress and demands of the parental role, and a sense of parental competence. Therefore, satisfaction with parenting refers to satisfaction with the parent-child relationship, satisfaction with oneself as a parent, satisfaction with the child’s behavior, and satisfaction with the spouse in the parental role. Parental sense of competence includes parental assessment of performance (self-efficacy) in the role of parent and assessment of satisfaction with fulfilling the parental role (Sanders & Woolley, 2005). Parents’ marital satisfaction also changes under the influence of the experience of parenthood. Married couples differ significantly in the degree of parental satisfaction and sense of competence (Belsky & Rovine, 1990). For the emergence of a positive experience of parenthood in both parents, the division of duties and jobs after the birth of a child is extremely important (Cowan & Cowan, 1992).

The Parent of Children With Disabilities

The demands placed on families and their members regarding children with developmental disabilities are complex and can significantly impact and jeopardize both individuals and the family as a whole. Raising children, particularly those with developmental disabilities, introduces new challenges to families that they have not previously encountered. Accepting a child with developmental disabilities represents a novel experience, and how it is perceived depends on various factors (Krstic, 2013). These parents not only face

the challenges associated with their child's disability but also encounter daily difficulties related to their child's condition, such as finding appropriate care or dealing with complex behaviors (Krstic, 2013; Mitic, 2011). To embrace their role as parents of children with developmental disabilities, parents are often tasked with completely redefining their internal caregiving model regarding themselves, their child, and their relationship, aligning it with expectations and the idealized image of a child (Zeanah et al., 1985; Zeanah et al., 1900). In order to adapt their caregiving model to the needs of caring for a real child with developmental disabilities, parents must cognitively understand the implications of the diagnosis and emotionally express and accept all feelings associated with the knowledge of the diagnosis and its implications (Barnett et al., 2003). This process is defined in the literature as resolution. Resolution is linked to a parent's ability to accept their child's diagnosis and its implications, be realistic about the child's health condition, recognize the child's strengths and limitations, and respond adequately to the child's needs. A parent who has not achieved resolution focuses on the moment of discovery, is emotionally overwhelmed, which hinders their progression over time and leads to unrealistic expectations of the child. Resolution involves integrating caregiving models into a new model that is adapted to the reality of the current situation (Marvin, 1996). The birth of a child with autism alone represents a stressor that places unique burdens on the family and parents over an extended period (Milacic-Vidojevic, 2008b).

Parental stress

Source of stress, or stressor, can be an internal or external stimulus, an isolated event, or a series of events that an individual perceives as threatening to their life, material goods, and self-esteem, which, given such perception, can disrupt the individual's daily life (Lazarus & Folkman, 2004). Parental stress represents the perception of inadequate financial, emotional, physical, and social resources that would enable coping with the consequences of key life situations or the inability, incapacity, adjustment, and functioning with upcoming life crises. Parental stress is a distressing feeling that is

related to the demands of the parental role and is qualitatively different from stress in other areas of life (Profaca & Arambasic, 2004). Parental stress is a rejecting psychological reaction to the demands of parenting; it is a complex process that links the demands of parenting, behavior, and the psychological state of parents, the quality of parent-child relationships, and the child's social adjustment. Parental stress is experienced as a negative feeling towards oneself and the child/children attributed to the demands of parenting (Deater-Deckard, 1998). Significantly elevated levels of stress that can jeopardize health occur under certain circumstances that hinder or prevent the attainment of necessary adaptation in this role (Rudic et al., 2013). Parental stress can be situational (unexpected and of limited duration) and chronic stress (stress with the most severe consequences for the individual) (Rose, 1987). If a parent cannot successfully cope with the demands of parenting, chronic stress in the parental role arises (Deater-Deckard, 1998). Family stress depends on numerous factors: the size of the family, family, and child characteristics, emotional climate in the family, social context, concerns for the child and their future (Damjanovic et al., 2014). Families raising a child with developmental disabilities, in addition to regular parental demands and tasks, face a series of additional tasks resulting from the child's condition. Parents experience psychological stress and disappointment to a great extent because the child has not fulfilled their hopes and expectations, which are directed towards having a healthy offspring (Barnett et al., 2003). Stress related to raising a child with developmental disabilities can be seen as a combination of increased caregiving needs for the child and parents' emotional reactions to the child's impairment (McCubbin et al., 1983). The birth of a child with any developmental difficulties represents a stressful event accompanied by various emotional reactions from parents. The experience of stress for parents of children with disabilities varies in intensity and has a negative impact on the entire family (Sullivan & Knutson, 2000). Regardless of when they learned about the child's diagnosis, they talk about it as a period of great crisis when expectations regarding the child change, family routines are disrupted, feelings of guilt arise, or the

cause of the child's condition is sought, which alters their perception of themselves as caregivers (Heiman, 2002). Family resilience is the response that occurs when the family is allowed to make unusual efforts to observe, experience, and define a new situation, as well as to take specific actions to return to the usual routines of everyday life (Dyk & Schwaneveldt, 1987). There may be two different ways of coping with stress for parents of children with disabilities: coping through resistance - collective family efforts to minimize and reduce the impact of stressors, and adaptive coping - joint efforts to reorganize and consolidate the family and restore the order it had before the stressor disrupted the family unit (Margalit & Kleitman, 2006).

Quality of Life and the Importance of Social Support

Quality of life is a concept that overlaps with concepts of health status, disability, and impairment. Although achieving a high quality of life is a postulate of modern medicine, there is no general consensus on the actual meaning of this concept (Mustur et al., 2009). In a document assessing quality of life in 1995, the World Health Organization provided a definition in which quality of life is defined as the individual's perception of their life situation within the context of cultural and value systems to which they belong, and in relation to their own goals, expectations, and standards (Gojceta et al., 2008). Nowadays, there are numerous reliable and valid questionnaires for assessing quality of life related to health, both general and specific to particular conditions (Kvrgic et al., 2001). Most quality of life studies utilize two basic measurement methodologies: objective-quantitative indicators (health, education, income, marital status) that relate to the fulfillment of social and cultural norms regarding material goods, social status, and physical well-being, and subjective indicators - what individuals experience (success, satisfaction, etc.), or their satisfaction with their circumstances. This means that a person can have a high quality of life even if they are dissatisfied with an area of life they do not consider important, or vice versa (Tatovic et al., 2011). Autism often represents a significant burden for families and requires family members

to significantly modify their daily activities to adapt to the new reality. Factors such as functional independence, severe maladaptive behaviors, and the severity of autism are closely related to parental distress and inversely related to quality of life (Kheir et al., 2012). Social support is one of the most significant factors contributing to quality of life. Many authors point out that social support is a broad concept that is difficult to define and that it actually encompasses various forms of supportive behavior from different people in the social environment. Social support acts directly and improves quality of life, alleviating the burden of stress and thereby increasing the person's quality of life. Research has shown that parents, after receiving a diagnosis, usually try around seven different treatments or therapies (Stepanovic, 2023). Due to the practice of multiple treatments simultaneously or in very short time intervals, it is often not possible to determine which treatment is truly beneficial and effective for the child (Rawson, 2012). Similarly, research indicates that early intervention, between the first and sixth year of a child's life, increases the likelihood of achieving maximum potential and acquiring skills, thus increasing the functioning level of children on the autism spectrum. These studies have raised important questions about the accessibility of early intervention and services, but one must also be aware of the pressure on the family to cope and provide these interventions for the child (Rawson, 2012). Autism has been described as a magnet for end-of-the-20th-century fraud. When parents perceive their situation as hopeless, they may be open to any treatment regardless of its effectiveness or substantial evidence for or against such treatment. Insufficient information and irresponsible encouragement from professionals to try every therapy contribute to this situation (Rawson, 2012). Research has shown that individuals who have material, social, and psychological support from people in their lives, such as parents, partners, friends, and extended family, have better physical and mental health than those who lack such support (Rawson, 2012).

Research Methodology and Instruments

Research Objectives

The main aim of this study was to examine the quality of life of parents of children with autism, including parental satisfaction, the significance and challenges of their parental role, and whether they differ from parents in the typical population.

Research Hypotheses

The primary hypothesis, from which the study was derived, posits that there are differences in parental satisfaction across key domains (parental role satisfaction, parental role challenges, and parental role significance) between parents of children with disabilities and parents in the typical population. Additionally, six specific hypotheses were formulated:

1. Parents of children with autism will express a lower level of parental satisfaction compared to parents in the typical population.
2. The overall level of parental stress among parents of children with developmental disorders will be higher compared to parents in the typical population.
3. The level of parental stress will be higher among parents who are married within the specific group (parents of children with autism) compared to divorced couples.
4. A higher level of stress is present among mothers of children with autism who have a higher educational level compared to mothers with a moderate educational level.
5. A higher level of stress is present among employed mothers of children with autism compared to unemployed mothers of children with autism.
6. A higher level of stress is present among mothers of children with autism who have experienced their children's disabilities for a longer period or whose children's disabilities manifested at a younger age.

Research Sample

The research involved 90 families. The first group consisted of 45 families - the

specific group, families of children with autism, and the second group consisted of 45 families - the control group, families of typically developing children. The age of the children whose parents participated in the research ranged from first to fourth grade of elementary school, that is, from 7 to 10 years old. Children from the specific group attended either a special school for children with developmental disabilities or a regular school. Prior to the research, approval was obtained from the school directors where the research was conducted, and parents were informed about the basic objectives of the research, as well as the information that the data would be used solely for research purposes; parents provided written consent.

Research Instruments

The basic data were obtained using a General Questionnaire created for the purposes of this research, which consisted of 33 questions (gender, child's age, and an additional section for parents of children with developmental disabilities regarding the specific disabilities and when they first noticed their occurrence). Two scales were employed in the study: 1. Parental Stress Scale (Berry & Jones, 1995), for measuring the level of experienced stress (18 questions), and 2. Parental Satisfaction Scale, which assesses parental satisfaction.

Results

Within the group of parents of children with autism, 84.4% were parents of male children, while 15.6% were parents of female children with autism. The children ranged in age from 7 to 10 years old. Parents first noticed symptoms between 6 months and 4 years, with an average duration of approximately 6 years. The number of children in families varied between the examined groups. Families of typically developing children had two to three children, while families of children with autism mostly had one child. The majority of participants were predominantly from urban areas. Marital statuses varied among subgroups, with the majority of parents in the typically developing population being married (97.8%), while about half of the parents in the group of parents of children with autism were married (51.1%), and the

other half were divorced (46.7%). The level of education among parents of typically developing children was predominantly high, with a high employment rate - 100% for fathers and 91.1% for mothers. In contrast, among parents of children with autism, the majority had a medium level of education, with a lower employment rate - 86.7% for fathers and 71.1% for mothers. Socio-economic status assessments varied between the two parent groups. Parents of typically developing children assessed their family situation as satisfactory, with material needs covered, while in the group of parents of children with autism, a small percentage of parents considered their material situation as satisfactory (33.3% all needs, 60.0% most needs, and 6.7% not satisfactory). The level of parental satisfaction showed statistically significant differences in the basic domains of parental satisfaction between the two groups of participants, both overall and in all three domains of parental satisfaction - satisfaction with the parental role, difficulties, and the importance of the parental role. The overall score on the scale indicated a significantly lower level of parental satisfaction and satisfaction with the parental role, but also a higher level of parental burden and lower significance of the parental role for parents of children with developmental disabilities. Parental stress was significantly higher among parents of children with developmental disabilities, and a significant negative correlation was found between the importance of the parental role and parental stress. Parents of children with autism perceived the parental role as more significant, and the results reported lower levels of parental stress. The research results show that the level of maternal parental stress among mothers of children with autism who are in a marital relationship is slightly higher compared to mothers who are divorced. Additionally, the level of parental stress is higher among mothers of children with autism who have a higher education compared to mothers with a medium level of education, as well as among employed mothers who experience significantly higher stress. Parental stress and the duration of the child's symptoms are correlated, and the research indicates that parental stress is highest among parents whose child's symptoms were noticed at an early age.

Discussion

Parenting involves numerous tasks and difficulties. Parents of children with developmental disorders face even greater challenges, requiring special forms of care and protection throughout their upbringing and support in all stages of life. The research idea itself stemmed from the intention to determine whether there is a statistically significant difference in the quality of life between families of children with autism and families of typical children. The aim of the research was to contribute to understanding the quality of life of families of children with autism, as well as parental stress - a potential predictor of lower parental satisfaction and enjoyment in the parenting role. By considering this aspect, the focus shifts from the negative consequences of the child's condition on the family to an approach that relies on the strengths and resources of the family. Knowledge of factors related to positive outcomes is important for intervention programs to facilitate the adaptation of a larger number of families. In situations where a child is diagnosed with a physical or developmental impairment, parents are often overwhelmed with emotions and experiences related to diagnosis and communication, which can have a significant and long-term impact on parental psychological well-being. The sample of this study was not random and consisted of parents of children with autism attending schools for primary and secondary education for children with developmental disorders, as well as parents of typical children involved in support programs. The question arises as to how parents whose children are not included in formal support systems would respond to these questionnaires. Sociodemographic characteristics such as marital status, education, employment, type of child's disorder, first signs of deviation were obtained through a general questionnaire and provided a sample of diverse nature. The majority of parents were in a marital union, while the number of divorced parents in the experimental group was higher than in the control group. Mothers were more likely to complete the questionnaire, which can be explained by the fact that a large percentage of mothers are not employed, they are solely dedicated to their child and follow all school-related information. An interesting finding

is that most families in the control group have at least two children, even three, while in the experimental group, there is a high percentage of families with only one child. Families with a child with autism as their first and only child are afraid of experiencing the same difficulties and anticipate having less time and opportunities to dedicate to the child with autism, who constantly requires attention. This is the reason we obtained such results in our sample. The literature does not provide much research on this topic, making it an interesting and significant subject for future research. Gender differences were also observed in the children, with a higher number of boys in the experimental group, which is consistent with other studies (Huber, 2016; Milacic-Vidojevic, 2008b; Rajic & Mihic, 2015). Differences were also noted in parental employment, with the majority of parents in the control group being employed, while in the experimental group, only one parent was employed (Dimitrijevic, 2014). The results of the study on parental satisfaction indicate the inability to achieve desired accomplishments associated with the parental role, and as a result, parents often struggle with their child's diagnosis, which increases the burden of the parental role (Coleman & Karraker, 2002; Delale, 2011; Mihic et al., 2016; Milacic-Vidojevic, 2008b). In terms of parental satisfaction, parental role satisfaction, parenting difficulties, and the importance of the parental role, statistically significant differences were found in the total score, indicating that parents of children without developmental disorders do not feel the burden of parenting, are more satisfied with the parental role, and attach greater importance to it compared to parents of children with autism, which is confirmed by other studies (Baker et al., 2003; Howe, 2006; Markie-Dadds & Sanders, 2006; Mihic et al., 2016; Pisterman et al., 1992). However, the study by Delale (2011) reached different conclusions, with high ratings of parental role satisfaction reported by mothers of children with developmental disorders in this research. Based on the obtained results, we can conclude that parents of children with autism face numerous obstacles and difficulties in raising and nurturing their children, and that they experience a greater burden of parental roles, leading to higher levels of dissatisfaction. Other studies

have confirmed that parenting stress is a significant predictor of reduced parenting quality, poorer parent-child relationships, and overall functioning (Hoffman et al., 2009; Lopez et al., 2008; Wiley & Renk, 2007). Total stress is a measure of the stress level experienced by a parent. The results only indicate the amount of parental stress arising from the parent-child relationship and the stress resulting from the child's behavior, not the stress from other life roles or events. The average score on the Parenting Satisfaction Scale for parents of children with developmental disorders, as shown in this study, is 68 out of a total of 90, indicating that parents of children with developmental disorders experience a high level of stress. Analyzing individual items from the Parenting Stress Scale reveals that parents of children with developmental disorders are less happy in their parental role and that caring for the child requires more time and energy than they have. It is more challenging for them to balance their responsibilities since having a child, and they have a less optimistic view of the future, although they enjoy spending more time with their child, which is consistent with other research (Fulgosi et al., 1998; Milacic-Vidojevic, 2008b; Mihic et al., 2016; Rajic & Mihic, 2015). Several studies highlight that parents of children with autism experience frustrations, increased stress, depression, anxiety, financial difficulties, marital problems, as well as reduced self-confidence and competence in performing tasks (Murphy & Tierney, 2014). In line with this, parents confirm that the birth of a child with developmental disorders changes the family's social life. There is less contact with extended family, friends, and neighbors, and parents have less time for their spouses. These families are primarily focused on families facing similar problems (Milacic-Vidojevic, 2008a). Comparative studies show higher levels of stress, depression, anxiety, and emotional exhaustion among parents of children with autism compared to parents of children with Down syndrome or some other form of intellectual disability (Sofronoff & Farbotco, 2002). Mothers of children with autism report difficulties in taking their child to public places compared to mothers of children with Down syndrome, as well as greater demands of these children, but fewer

activities in which they can engage (Johnson et al., 2011). The results of this study showed that the percentage of parents from the typical population who were in a marital relationship (97.8%) was significantly higher compared to families of children with autism (51.1% married, 46.7% divorced). The comparison of groups also revealed that married mothers reported slightly higher levels of parenting stress compared to divorced mothers. However, the presence of disagreement between parents of children with autism can have a greater impact on successful family relationships than on their marital status, separation, or divorce. The official status of the relationship between parents is not significant for functioning, regardless of their marital status as a couple (Baeza-Velasko et al., 2013; Benson & Kersh, 2001). Saini et al. (2015) found that mothers of children with autism emphasized the importance of spending time without a partner and children as a major factor influencing marital harmony, while mothers of typically developing children did not identify this component as significant for maintaining marital success (Saini et al., 2015). Regarding the level of professional qualifications, the results obtained showed a higher level of parental stress among mothers with higher professional qualifications compared to mothers with a moderate level of education, which may suggest that satisfaction with the parental role in families of children with autism is associated with parents' expectations regarding their child. Positive parenting experiences and parenting competencies were only observed in those parents who were well-prepared and had realistic expectations of their future parenting role (Delmore-Ko et al., 2000). When it comes to employment status, employed mothers of children with autism report significantly higher levels of parental stress compared to unemployed mothers of children with autism. These results indicate that employed mothers of children with autism do not have enough time to devote to their child and everything that is needed during the day because they spend much more time at work, and it is assumed that they have to work due to their socio-economic situation. Most mothers are the primary caregivers of autistic children. All the time is spent taking care of their children without any time for other types of activities. Daily routines,

professional lives, and academic plans are affected. Most mothers have stopped working or studying, completely changing their lives (Maciel de Aguiar & Pereira Ponde, 2018). Correlation analyses have shown that the duration of disturbances affects the level of parental stress, and parents who noticed disturbances in their children at an earlier age have higher levels of parental stress compared to parents of children in whom disturbances were noticed later, which is consistent with other studies on the same topic. Older children create more stress for parents for several reasons: parents' perception of the permanence of the handicap, lack of support services for older children, mismatch between the needs of the child and the parent, concern for the child's future (Milacic-Vidojevic, 2008a). The results indicate the need for the development of intervention programs that would reduce parental stress and increase parental satisfaction. Changing the experience of parenthood can alter parents' behavior towards the child and improve the quality of the parent-child relationship, thus creating favorable conditions for the child's development. Difficulties faced by children with developmental disabilities in their daily lives impose the need for continuous work with parents, along with support for the development of parenting skills while respecting the specific functioning of children with developmental disabilities. The best results are achieved when this support is provided in a timely manner, within the framework of early intervention in children. Social support focused on the needs of parents strengthens their perception of competence in parenting, which directly or indirectly influences the child's development and reduces problematic behavior (Almand, 2004; Borstein, 2006; Keen et al., 2010). Parents of typically developing children assess the family's situation as satisfactory, ensuring that all material needs are met. However, in a group of parents of children with autism, as many as 60% consider the financial situation to be less satisfactory and inadequate to meet all the family's needs. Research studies confirm these findings (Pipp-Siegel et al., 2002). A study conducted to examine depression and quality of life in mothers of children with pervasive developmental disorders revealed that low family income and lack of community

support, compared to other aspects of quality of life, highlight the lack of financial resources that could provide assistance in caring for the child during certain times of the day. This would help mothers focus on work or relax during their free time. These mothers experienced significant limitations in enjoying life and achieving satisfaction (Favero-Nunes & Santos, 2010). Cazin et al. (2014) conducted a study in Ogulin to determine the attitudes of healthcare professionals towards parents of children with developmental disabilities. The results have shown that healthcare workers have significantly better access to mothers of children with developmental disabilities, primarily due to the prejudice that mothers of children with developmental disabilities are sensitive to the doctor-child-parent relationship. A literature review has established that about two-thirds of parents speak of periodic feelings of sadness, disappointment, stress, and concern when they attempt to cope with the knowledge of their child's developmental disorders. As the child grows, they increasingly differ from their peers, and parents must face the realities of their child's abilities. Therefore, it is important for professionals to assess the strengths of parents, their weaknesses, the availability of family and social support, in order to provide adequate support for the children (Fortier & Wanlass, 1984; Wikler et al., 1981). However, some research has shown that in cases of stable marriage, high socioeconomic status of the family, and community care for individuals with disabilities, there can be positive outcomes for the whole family. Research conducted in Croatia with the aim of examining the quality of life of parents of children on the autism spectrum, what influences it, and what measures could improve it, involved 346 parents, including 177 parents of children on the autism spectrum and a control group of 169 parents of typically developing children. The results showed that parents of children on the autism spectrum have a lower level of quality of life compared to parents of children in the general population. Both groups showed the least satisfaction with the aspect of future security. However, 38% of parents of children on the autism spectrum reported a quality of life in line with or above the average of the general population in Croatia, indicating that they have developed

resilience in the existing situation (Benjak, 2011). The results of our research indicate the need for the development of intervention programs that would reduce parental stress and increase parental satisfaction in parents of children with autism. Changing the experience of parenthood can alter parents' behavior towards their child and improve the quality of the parent-child relationship, thereby creating favorable conditions for the child's development (Almand, 2004; Bornstein, 2006; Keen et al., 2010).

Conclusion

Changes that affect family life after the birth of a child with autism can be observed in everyday family activities and various aspects of family life. Daily family dynamics change and patterns of family life adapt to the functioning of the child with autism (Axelsson et al., 2013). Families of children with autism grow and develop in this context. The greatest burden and responsibility fall on parents who serve as advocates and coordinators of their child's services. Research has recently begun to focus on this topic and increasingly emphasizes support for these families due to the reduced quality of life and increased stress resulting from the lack of all the needs necessary for raising a child with autism (Milicevic, 2015). This study confirmed all six hypotheses. It was confirmed that parents of children with autism have a lower quality of life, experience higher stress in raising their child, and have a lower sense of satisfaction with their parental role compared to parents of typically developing children. During the research, parents of children with autism indicated the need for improvement in support systems, consultations, and assistance, particularly highlighting the importance of early intervention. The goals of early intervention are to support parents in raising children with developmental disorders, stimulate the child's development in specific areas, and prevent difficulties and problems in the future. As the child's functioning improves, the role of parents becomes less demanding, and the quality of life improves. Through the education of parents and family members, progress, facilitation, and satisfaction can be observed in a short period, thereby improving the quality of life for families of children with autism.

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