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DOCTORAL THESIS

QUALITY OF LIFE OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM
DISORDER: INDIVIDUAL AND PSYCHOEDUCATIONAL FACTORS

SCIENTIFIC COORDINATOR

Prof. univ. dr. Camelia Popa

DOCTORAL STUDENT

Ana Dragu

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INTRODUCTION

Autism Spectrum Disorder (ASD) refers to a group of heterogeneous disorders with varying degrees of severity and a significant genetic component, where recovery aims to achieve the maximum potential of those affected. This process directly depends on the mental health and quality of life of families, who are the primary socialization environments for ASD patients.

The incidence of autism spectrum disorders is increasing globally. Developed countries allocate significant funds for treating individuals with ASD and offer complex psychotherapy programs aimed at rehabilitation and the development of independent living skills. Despite substantial state investments and active equality in treatment, some children with autism progress more rapidly, acquiring basic skills and becoming functionally independent, while others evolve more slowly or experience setbacks.

This doctoral thesis, titled "Quality of Life of Parents of Children with Autism Spectrum Disorder: Individual and Psychoeducational Factors," emerged from several research questions. To address these questions, four studies were conducted involving primarily children and their caregivers from my psychotherapeutic practice at the Autism Europe Association – "Little Prince" Autism Resource and Reference Center in Bistrița, as well as from other centers of non-governmental organizations. The "Little Prince" Center, established in 2009, has served thousands of direct beneficiaries diagnosed with autism and other neurodevelopmental disorders, providing psychological and social services to parents, teachers, and community representatives.

My practice and the specialized literature indicated that families of children diagnosed with ASD, experiencing high levels of stress, are vulnerable to mental health issues – burnout, anxiety, depression, psychotic disorders, obsessive-compulsive disorder. If untreated, these issues negatively affect ASD children and create a negative feedback cycle that delays the positive effects of behavioral interventions on children.

This doctoral study provides the first research evidence in Romania on the vulnerabilities of parents of children with autism, which is the primary originality of this work. Parents were psychologically evaluated, and various components of their quality of life – physi-

cal, emotional, social, cognitive functioning, communication, worry, daily activities, and family relationships – were investigated.

Additionally, the first step in adapting the PedsQL™ – Family Impact Module to the Romanian population was taken, an indispensable tool for evaluating the well-being of this group and establishing care standards comparable to those in developed countries.

In exploring the lives of families affected by autism, recognizing their diversity was crucial, as each family brings a unique set of strengths, challenges, and adaptation mechanisms to the child's therapy and progress.

This doctoral thesis comprises seven chapters, three theoretical – "The Concept of the Autism Continuum," "Children's Autism and Primary Caregivers' Quality of Life," and "Empowering Parents as Co-Therapists," which synthesize existing research evidence (studies and therapeutic best practice guides), and four applied studies – "Study 1: Parental Efficiency vs. Inefficiency in Managing ASD," "Study 2: Quality of Life of Parents of Children with ASD as a Care Standard," "Study 3: Relationship Between Parental Psychopathology, Demographic, Economic, Social Factors and Quality of Life," and "Study 4: Needs for Improving Parents' Quality of Life." Developing a psychological guide to improve the quality of life of families dealing with ASD was a practical outcome of the thesis.

Regarding the author's contributions to the field of autism

As a clinical psychologist and psychotherapist, Ana Dragu has dedicated her career to improving the quality of life of children with ASD and their families. The author's contributions to the field of autism have had a significant impact on the local and national community and the lives of many families.

CHAPTER 1: THE CONCEPT OF THE AUTISM CONTINUUM

Childhood mental disorders bring significant changes in how children learn, behave, manage emotions, and adapt to their environment. The most common mental disorders with onset in childhood include attention deficit hyperactivity disorder (ADHD), emotional disorders, autism spectrum disorders, and behavioral disorders.

Autism spectrum, also known as the autism continuum, encompasses a group of complex neurodevelopmental disorders caused by differences in the brain that affect communica-

tion and behavior. According to the Diagnostic and Statistical Manual of Mental Disorders, DSM-5 (APA 2022), individuals with ASD may experience: *communication difficulties* (expressing emotions, understanding nonverbal language, and maintaining conversations); *social interaction difficulties* (understanding rules, forming friendships); *repetitive behaviors* (hand-flapping, walking on toes, playing with the same objects); *restricted interests* (only in certain subjects or activities); *excessive or insufficient sensitivity to sensory stimuli* (sounds, lights, textures); and *other symptoms that can affect functioning in the community, school, or profession*.

Early detection of autism remains a complex, interdisciplinary process involving several key components: clinical screening, observation in natural environments, medical and developmental assessments, and interdisciplinary collaboration (Thabtah & Peebles 2019; Zwaigenbaum et al. 2015).

Autism Spectrum Disorders in the Context of Psychiatric Pathology

ASD falls into the category of developmental disorders with onset in early childhood, representing the most severe form of these manifestations. In recent years, the incidence and prevalence of autism diagnoses have skyrocketed, according to data collected by the Center for Disease Control (CDC) in the USA, from 1:5,000 diagnosed with ASD in 1975 to 1:110 in 2009 and 1:36 in 2023 (Maenner, Warren, Williams et al. 2023).

Current studies indicate a combination of genetic and non-genetic factors. Initially believed to have psychological origins, an improved understanding of genetics' role in human health suggested otherwise. Folstein and Rutter (1977) conducted twin studies, finding that the incidence of autism among siblings was 50 times higher than in the general population. Monozygotic twins had a higher likelihood of sharing the same diagnosis than dizygotic twins.

In a meta-analysis of prenatal factors related to pregnancy, Gardner et al. (2009) identified maternal gestational diabetes, maternal bleeding during pregnancy, and maternal medication. Exposure to intrauterine infections also significantly correlated with an increased risk of autism.

Historical Diagnosis of Autism and Current Criteria

The term autism spectrum refers to a wide range of symptoms, abilities, and levels of functioning in individuals with ASD. Autism affects each person differently. Some have few symptoms, while others have many. There are children and adults with ASD who are fully capable of performing all daily life activities, equipped with cognitive and learning skills, and children/adults who require substantial support to perform basic activities.

Specific Comorbidities

ASD rarely presents alone as various medical conditions overlap: epilepsy, gastrointestinal diseases, neurodevelopmental diagnoses – intellectual disability or language delay; mental disorders – ADHD, anxiety, depression, obsessions and compulsions, or genetic conditions – Fragile X syndrome and tuberous sclerosis (Al-Beltagi 2021).

Screening, Evaluation, Diagnosis, and Early Intervention

Early detection of autism involves clinical screening. Standardized tools such as the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) administered by professionals specializing in developmental disorder assessment are used. Screening relies on direct behavioral observations of the child and interviews with parents/caregivers to identify characteristic signs and symptoms (Rapin & Tuchman 2008).

Autism Therapies

Among the most utilized therapies in ASD are: Applied Behavior Analysis (ABA), Early Start Denver Model (ESDM), Pivotal Response Therapy (PRT), TEACCH® Autism Program, and Verbal Behavior Therapy.

Medication

Given the heterogeneity of ASD and limited evidence regarding its origin and causes, no targeted and effective medication has yet been discovered. Current medications do not cure autism, though they cannot be denied some effectiveness in controlling destructive and self-destructive behaviors, treating comorbidities, and reducing irritability, varying from case to case.

Approaching Associated Psychiatric Conditions

Individuals with autism spectrum disorders are vulnerable to developing comorbid psychiatric conditions. Adverse life events significantly increase their stress levels. Cognitive rigidity, problems with emotional regulation, and intolerance of uncertainty associated with ASD can predispose this population to high levels of stress, anxiety, and depression – emotional regulation deficits represent a transdiagnostic phenomenon (Martinsen et al. 2009).

CHAPTER 2: CHILDREN'S AUTISM AND PRIMARY CAREGIVERS' QUALITY OF LIFE

The illness as a major stressor

ASD severely impacts various aspects of family life, involving household expenses, parents' economic status, emotional and physical health, marital relationships, meeting the needs of other children in the family, sibling relationships, relationships with extended family, friends, and neighbors, recreational activities, and free time. This cluster of severe neurobiological developmental disorders affecting the child's thinking, emotions, language, and interactions generates major stress threatening family unity.

The relationship between parental stress and severe behavioral problems in children with autism is bidirectional – problems increase parental stress and vice versa. Karst and Van Hecke (2012) demonstrated that increased parental stress perpetuates and aggravates maladaptive behaviors in children. Increased parental stress has been attributed in other studies to: the severity of the child's emotional and behavioral problems (Baker et al. 2012; Karst & Van Hecke 2012; Leyfer et al. 2006); exhaustive caregiving demands associated with poor parental adaptation capacities and lack of support (Papadopoulos 2021; Weiss et al. 2014); economic burden (Ou et al. 2015) or difficulty understanding ASD manifestations, which influences treatment decisions (Ilias et al. 2018).

Although low parental efficacy has been a constant in all studies, the situation was better in high-income countries than in poorer ones (Hao et al. 2021).

Social Support Networks and Parental Psychotherapy

Social support networks – including family members, friends, therapists, teachers, health and community professionals – provide emotional, informational, and practical support to families affected by autism to cope with difficulties and stress (Haney et al. 2018; Smith et al. 2012). These networks offer safe environments where individuals with autism express feelings and concerns, develop self-confidence, and social skills.

CHAPTER 3. EMPOWERING PARENTS AS CO-THERAPISTS

Empowering parents as co-therapists is essential in autism therapy. Behavioral therapy programs based on consistency, environment, and reinforcements cannot be conducted without parents taking an active role in them. A child whose parents are not involved in the therapy program may still achieve results but over a longer time and with greater difficulties. Family involvement facilitates goal achievement, improves therapy efficiency, and reduces the time needed to acquire skills.

To be effective, parents must correctly use both positive and negative reinforcement in managing behaviors. They must also provide the same response or introduce and remove the same stimulus to reinforce a specific behavior.

Family as a Support Unit

Receiving an ASD diagnosis is a heavy blow for the family, followed by an attitude change that generates a strong need for support and adaptation to the new reality (Critchley et al. 2021). All parents expect to have a healthy baby who will grow up to become an independent adult. When this expectation is not met, they must reconfigure their hopes and plans for their future and the child's, continuously adapting to re-experience satisfaction and well-being (Cuevas et al. 2018; Hsiao et al. 2017; Bana 2015). As shown, the disabilities of children with autism spectrum disorders significantly affect family life (Losada-Puente et al. 2022), which must be supported in the adaptation process, including creating new life contexts to ensure the stimulation, development, and education of these children (Benito & Carpio 2017; Vidriales et al. 2017; Turnbull 2003).

Early Intervention Teams

Autism, characterized by a wide spectrum of symptoms, requires appropriate early interventions to facilitate the development of affected children and improve their quality of life. Early intervention teams are essential for providing comprehensive interdisciplinary approaches to meet the complex needs of children with autism and their families.

Parental Training – Psychoeducation and Scientifically Validated Training Types

Increasing the adaptive functioning of autistic children is the central objective of all parental training programs. Young children with ASD consistently present deficits in daily living activities – toileting, dressing, using tools, and play skills, and their adaptive functioning involves positive developments in all these affected areas. Parental training is an early intervention aimed at equipping parents with the skills, knowledge, and strategies needed to interact effectively with their children to facilitate their development.

PART TWO: RESEARCH EVIDENCE IN THE PROBLEMATIC OF PARENTS OF CHILDREN WITH ASD IN ROMANIA

The second part of the doctoral thesis comprises four studies conducted on the target population.

In the first study, three relevant cases were presented for managing the child's autism spectrum disorder, conducted in my psychotherapeutic practice at the "Little Prince" Autism Resource and Reference Center in Bistrița.

STUDY 1: PARENTAL EFFICIENCY VS. INEFFICIENCY IN MANAGING ASD

Study Objective

This qualitative research aimed to understand and highlight the behaviors of parents of children diagnosed with autism manifested at critical points in the child's journey to distinguish idiographic performance-adaptive behaviors from those that hinder adaptation to ASD, the latter having a negative impact on family quality of life. This qualitative method can pro-

vide information about how a person adapts to a specific reality, and the details captured regarding this single case bring additional understanding about a characteristic common to a broader category of individuals (Popa 2018).

Psychoeducational and Attitudinal Factors of Parents in Approaching ASD

This qualitative research highlighted the behaviors of three parents of children diagnosed with autism spectrum disorder at critical moments in their children's journey to distinguish idiographic performance-adaptive behaviors from those that hinder adaptation to the disease and deteriorate their quality of life. Psychoeducational factors that intervene in parents' accurate knowledge of ASD aspects and allow them to effectively exercise the co-therapist role essential in all care plans were also investigated.

STUDY 2: QUALITY OF LIFE OF PARENTS OF CHILDREN WITH ASD AS A CARE STANDARD

Overview

The quality of life of parents of children with ASD has not been a target of Romanian government health policies. The previous study showed that an autistic child modifies the life trajectory of parents, from practicing their profession to their social circle and daily habits. The family's entire energy focuses on raising and recovering the child to form independent living skills, and the parents' overall quality of life suffers. They frequently report: persistent fatigue, a carousel of negative feelings, discouragement, lack of perspectives, significant financial difficulties, and unimaginable physical efforts.

Objectives

This study had two objectives: testing the psychometric properties of the Romanian version of the PedsQL™ – Family Impact Module (PedsQL™ – FIM), an instrument evaluating the quality of life of parents of children with chronic diseases, and a general characterization of the quality of life for 108 parents of children with autism using this instrument.

Regarding the utility of the PedsQL™ – Family Impact Module in research

Valuable information can be obtained about how children's health affects families' overall quality of life and the resilience strategies mobilized by parents. The instrument is suitable for comparing families affected by different children's somatic and psychological conditions and measuring changes in marital functioning and quality of life indicators after specific interventions/treatments.

STUDY 3: RELATIONSHIP BETWEEN PARENTAL PSYCHOPATHOLOGY, DEMOGRAPHIC, ECONOMIC, SOCIAL FACTORS, AND QUALITY OF LIFE

Overview

The quality of life of parents of children with ASD is a subject of great interest, considering the significant impact autism spectrum disorders have on the entire family. Parents of children with ASD face stress, anxiety, and depression, negatively affecting all their functioning areas.

In this study, a sample of 84 parents was evaluated using the PedsQL-FIM quality of life scale, the PDSQ psychiatric disorders screening questionnaire, and an empirical questionnaire for demographic and clinical factors (marital status, current age of children, age of children at diagnosis, weekly hours of psychotherapy, problems of hetero or self-aggression, ASD comorbidities, parents' educational level, and financial situation). Statistical analysis revealed significant correlations between parental psychopathology and various quality of life dimensions. Depressive disorders, post-traumatic stress disorder, and anxiety disorders had the most significant negative impact on quality of life. Other factors influencing parents' quality of life were also identified – financial status had a considerable impact on most quality of life parameters.

A central concern of parents of children with ASD is the worry about the future (Ogston, Mackintosh & Myers 2011), referring to repetitive thinking about potential negative outcomes of future events (Borkovec, Robinson, Pruzinsky & DePree 1983).

Objectives

The main objectives of this study were: to examine how psychopathology influences the quality of life of parents of children and young people with autism spectrum disorders (ASD) in Romania and to identify demographic, economic, and social factors that can also influence quality of life parameters.

Discussions

Regarding parental psychopathology

The study's results confirmed on a Romanian sample the international research evidence showing that parents of children with ASD face high clinical levels of mental disorders such as anxiety and depression, which decrease their overall quality of life (Alkhateeb et al. 2022; Ilias et al. 2018; Padden & James 2017; Al-Farsi et al. 2016; Lai et al. 2015; Bitsika et al. 2013; Wang et al. 2013; Hodge et al. 2011).

Regarding the impact of demographic, economic, and social factors on parents' quality of life

The results obtained on the Romanian sample showed that financial status, the child's gender and behaviors, as well as gender differences, parental roles, and access to adequate resources significantly influence the quality of life of parents of children with ASD, causing variations in: physical and mental health, family relationships, and daily functioning. These results are supported by the literature (Montes & Halterman 2008; Hartley & Sikora 2009; Lavelle et al. 2014).

STUDY 4: NEEDS FOR IMPROVING PARENTS' QUALITY OF LIFE

Overview

The previous study showed a massive deterioration of all quality of life indicators in parents of children with ASD. Identifying the needs of this vulnerable population and understanding them in-depth to establish quality of life as a care standard is thus justified.

Developed countries' concerns for the quality of life of children, adolescents, and adults with ASD and their families are strong and permanent. They provide infrastructure re-

sources for ASD individuals and access to scientifically validated therapies, ensuring financial, medical, and school support. All support measures aim to recover as much as possible the deficient skills or, in some cases, compensate for the lack of these skills (Hyman, Levy & Myers 2020; CDC 2024).

In conclusion, the impact of autism spectrum disorders on families is profound, affecting all aspects of life, from parents' emotional and mental health to their socioeconomic status and social relationships (Gray 2002; Yamada et al. 2007). Therefore, it is essential to develop and implement support programs that address the multiple needs of families and promote their well-being (Karst & Van Hecke 2012; Nolcheva & Trajkovski 2015).

Objectives

This observational and open survey study aimed to assess the situation of people with ASD in Romania by 2022, the support they receive, and the difficulties they face to design a best practice guide focused on improving families' quality of life. It had two objectives: 1. identifying factors that influence access to recovery therapy and 2. investigating the problems and needs of families living with ASD.

Qualitative Analysis

The analysis of results for open-ended items was thematic (categorical analysis grids) following the steps described by Braun and Clarke (2006).

Discussions

Although the results of this study cannot be generalized due to the sample size, they serve not only to analyze the ASD problem affecting families but also to inform policymakers. They can be summarized as follows: therapy expenses far exceed families' incomes; Romania has too few therapists specializing in ASD; the private sector and NGOs provide most therapy services; adults with ASD do not receive free psychological support or job placement, and the number of support teachers in mainstream schools is low.

FINAL CONSIDERATIONS – TOWARDS A PSYCHOLOGICAL GUIDE FOR IMPROVING THE QUALITY OF LIFE OF FAMILIES DEALING WITH ASD

This doctoral thesis contains significant original research evidence on the influence of psychopathology on the quality of life of parents of children with autism spectrum disorders (ASD) in Romania, enriching the specialized literature in the field. The studies included in the thesis, among the few conducted on this vulnerable population, provide a detailed and comprehensive perspective on the demographic, clinical, and psychosocial factors affecting families living with autism. The obtained data can contribute to the foundation of public policies and specific interventions that address the needs of the ASD community.

An Applied Direction of This Research: The Guide for Improving the Quality of Life of Families Dealing with ASD

This doctoral research highlighted the need to provide, through a guide, a comprehensive set of recommendations for Romanian professionals working with ASD individuals and their families to improve their quality of life. The developed guide promotes collaboration between psychologists and other professionals in multidisciplinary care teams, as well as collaboration between these teams and families at all intervention stages.

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