

Areas and Indicators of Family Life in Families of Children with Autism Spectrum Disorders

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Abstract

Quality of life (QOL) is the level of functional well-being in many areas of an individual's life. It is increasingly recognized as a dimension of work in the study of disturbances in the social functioning of the individual. The conceptualization of the results of the quality of family life has been extremely limited so far. In contrast to the quality of individual life, the quality of family life addresses the impact of the quality of individual life on the family – individual interaction and influence because they produce the concept of quality of family life. Having a child with autism spectrum disorder is associated with stress in caring for children, as well as less time for parents to meet their needs. In order to identify areas and indicators of family quality of life in the families of children with autism spectrum disorder we organized two focus groups, the first of which were – 1 doctor, 2 psychologists, 3 therapists, 1 social worker, 2 teachers, and a second focus group with 7 parents who have children with autism spectrum disorder, who come from both rural and urban areas.

Keywords: autism, quality of life, indicators.

1. Introduction

The concept of quality of life appears in the twentieth century in the fields of knowledge such as philosophy, political and social sciences, the issue of “good living being taken over by other fields, such as sociology, urbanism, social geography, social assistance, environmental and medical sciences” (Bălătescu, 2007)

The exact origin of the term Quality of Life (QOL) is not known, but Samuel Ordway and Fairfield Osborn were among the first to use the concept. In 1964, at a political meeting, US President Lyndon B. Johnson used the term quality of life in his speech stating that “goals cannot be measured by the size of our bank account, they can only be measured by the quality of life they lead. our people (Johnson, 1964). In the 1960s, there was a growing interest from scientists in the issue of quality of life. They become interested in the relationship between social and economic indicators of quality of life, but also in their subjective evaluation. After the Second World War, new medical technologies are introduced, which dramatically increase both patients' life expectancy and indirectly their quality of life. In the early 1970s, the concept of quality of life became increasingly popular. Numerous quality of life studies are published in various fields.

According to Oşvat's ideas, quality of life is a multidimensional construct that includes both the involvement of policy makers in addressing well-being, and the development of each dimension and its evaluation. There are several components of well-being both personally (emotionally, motivational, relational) and socially (quality, ease and quantity of services provided) (Oşvat, 2012).

The following definition of quality of life, according to the WHO (1980), allows us to measure the extreme extension of this concept: in which he lives in relation to his goals, expectations, norms and anxieties. It is a very broad concept, influenced in a complex way by the physical health of the subject, the psychological state, the level of independence, the social relations as well as the relationship with the essential elements of his environment. The essential elements of the environment include financial resources, safety, work (job), personal fulfillment, spiritual life (religion, beliefs)" (WHO, 1980).

Quality of Life (QOL) is defined as "an individual's perception of his or her position in life in the context of the culture and value systems in which he or she lives and in relation to goals, expectations, standards, and concerns" (WHOQOL Group, 1993). According to Shu, there are six broad areas for QOL: physical health, psychological state, levels of independence, social relationships, environmental characteristics, and spiritual concerns, including personal beliefs (Shu, 2009).

1.1 Quality of family life

Although research on the quality of individual life has generated enough momentum to lead to an international consensus, the quality of family life is a growing concept. The quality of family life as a result of a policy/program is a natural extension of work on the quality of individual life. The quality of life aspect thus acquires a strong emphasis in the field of disruption of family-centered service delivery models (Poston et al., 2003).

Since the mid-1980s, there has been a growing recognition of the importance of providing family-centered services. This is because the image of the family becomes fused with that of a support unit (Allen, Petr & Gore, 1996; Dunst, Johanson, Trivette & Hamby, 1991; McWilliam & Bailey Jr, 1993; Turnbull, Turbiville & Turnbull, 2000).

Campbell, Converse and Rodgers (1975) conducted some of the first studies on the quality of family life. They assessed the dimensions of satisfaction with the quality of family life through indicators, sets of personal characteristics and perceptions of relationships with family members. Based on this study, it was highlighted that a major contribution to satisfying the family quality of life is the relationship with the children and the spouse. In their study, the authors found lower life satisfaction and quality of well-being in areas such as living standards, savings, housing, number of schools and neighborhoods.

In contrast to the quality of individual life, the quality of family life addresses the impact of the quality of individual life on the family – individual interaction and influence because they produce the concept of quality of family life.

Family adjustment is often used as an indicator of the quality of family life. It refers to "the quality of family life at the systemic level, such as the well-being, competence, strengths and weaknesses of a family" (Shek & Lee, 2007).

Addressing the quality of family life is "generating a paradigm shift" in the provision of services for people with disabilities, as it moves from fixation to support, from deficits to strength and from child to family, as a support center (Turnbull et al., 2000). Families in which there is a child with autism spectrum disorder are well supported when their unique efforts are

built on a family-centered intervention model based on strengths, rather than focusing on their weaknesses.

Parents and family members of a child with autism spectrum disorder received a positive focus on the quality of life of the individual, but often expressed the need for service providers to consider the whole family system and the quality of life. In response to this need, the quality of family life began to emerge as a valuable concept at the beginning of the millennium, and its assessments began to emerge shortly thereafter.

The study of the literature shows that many efforts have been made to assess certain areas of family life in which there is a child with autism spectrum disorder, such as leisure and recreation in the family, lack of spontaneity in these activities, stress, burden and worry of family caregivers, impact on siblings. However, there have been few attempts to measure family life in which there is a child with autism spectrum disorder in a holistic global way, perhaps because his or her nature is complex.

1.2 Dimensions of quality of life

The concept of quality of life being approached multidimensional, can refer to the standard of living of the population starting from aspects such as: economic situation, living conditions, level of education, social life, income, and is consistent with experience, values and expectations individual (Oşvat, 2012; Pop, 2010).

There is a distinction in the literature between the quality of individual and family life. Given that, in the field of developmental disabilities, as well as in the case of autism spectrum disorder, the emphasis is on a model of family-centered service delivery, the quality of family life should be a natural extension of the quality of individual life (Turnbull et al., 2004).

Compared to the quality of individual life, the quality of family life addresses the impact of the quality of individual life on the family and the interaction of individual members, because they produce the concept of quality of family life (Poston et al., 2003).

Based on the work of a team of international researchers, a consensus document for the quality of individual life was developed, which focused on conceptualization, measurement and application (Verdugo, Schalock, Keith & Stancliffe, 2005). Eight areas for the individual quality of life of people with disabilities were included; (1) emotional well-being; (2) interpersonal relationships; (3) material well-being; (4) personal development; (5) physical well-being; (6) self-determination; and (7) inclusion and social rights. The areas listed for individual quality of life were considered to be applicable to family quality of life as well.

The literature reveals that ten areas of quality of family life were developed, which included 6 individual orientations: health, productive well-being, positive emotions, physical and social well-being, social support. Family adjustment includes the daily interactions of the family, financial well-being and the relationship with the parents. The quality of family life is a relatively new construction that focuses on family-centered practices and individual quality of life (Algood, 2013).

2. Methodology

In order to identify areas and indicators of family quality in the families of children with autism spectrum disorder in Bihor County we organized two focus groups, the first of which were – 1 doctor, 2 psychologists, 3 therapists, 1 social worker, 2 teachers education, and a second focus group with 7 parents who have children with autism spectrum disorder, who come from both rural and urban areas.

Participants in the group meetings were asked to identify those areas and related indicators that best capture aspects of family quality of life. The following 6 important areas of quality of life were thus identified in such a study: health and services, education (formal and informal), material / housing status, family, social relations (social / relational – leisure, physical environment / neighborhood, interfaith closeness, etc.), subjective / psychological well-being (emotional life, etc.). For each area, participants identified related indicators.

2.1 Focus group results

INDICATORS:

Domain: health and services

Specialists: number of cases / family doctor, number of cases / specialist (neuropsychiatrist), number of cases / therapist (behavioral therapist, speech therapist, physiotherapist), prevalence of cases, situations in the basic population, genetic predisposition (existence or absence of similar cases within the family), existing therapeutic services.

Family: registration with the specialist doctor (neuropsychiatrist), enrollment in a specialized therapeutic program, number of therapy sessions / year, number of check-ups at the specialist doctor, classification in a degree of disability / existence of personal assistant (family member), the existence of associated pathologies (epilepsy, psychomotor retardation, ADHD, etc.), establishing a drug treatment scheme, following a personalized diet, parents suffering from chronic diseases, parents suffering from psychiatric diseases, siblings suffering from chronic diseases, brothers with autism spectrum pathology, expenses with therapeutic programs, need for therapeutic / intervention treatments, number of tantrums (behavioral crises), quality of associated health care (need for a special medical attitude), access to specialized services, the share of expenses with specialized services.

INDICATORS:

Domain: formal education

Specialists: schools / kindergartens / specialized centers (on therapeutic intervention) in relation to the needs, the figure regarding the school integration at county – urban / rural level, the school and vocational orientation of the child with ASD.

Family: attendance of kindergarten / school / center, access to the desired school / kindergarten / center, results / school / therapeutic progress, number of hours in which the child receives support from parents / siblings for the continuity of the therapeutic process, number of meetings between therapist and parent for discussing the child's therapeutic situation (progress), number of absences from the therapeutic program / school, number of interactions (positive / negative) with group colleagues, parents' integration aspirations, number of relational / contextual undesirable behavioral reactions, distance from home to school – with what is traveled (on foot, by car / school / kindergarten / center, by public transport).

Domain: informal education

Specialists: number of specialized therapy centers, number of events and activities dedicated to the situation of the child with ASD organized by specialists, number of means of transport to ensure home-school transport.

Family: number of activities and events in which parents participate with children with ASD – theater, shows, concerts, trips, celebrations, contests / competitions, number of extracurricular activities in which the child participates, leisure activities organized with colleagues.

INDICATORS:

Domain: material status and housing

Family: income / family member, income obtained from other sources (sponsorships, dividends, etc.), high family expenses (installments, etc.), safety of parents' workplace, employment of family members (full-time, part-time), dwelling – personal property / rent / other form, number of rooms, child own room, durable goods / endowment dwelling, other property (land, etc.), car, books, toys, sums spent for complementary therapeutic intervention, amounts spent by parents for supportive therapy as a parent (parents / siblings) of the child with ASD, positioning of the home (suburb, center...), neighbors – quality of relationship, daily basket / week / month, quality / quantity of food, how many meals the child eats per day, clothing / supplies, dentist costs, parent volunteer, child pocket money, participation of the child in camps / excursions / activities / extracurricular therapeutic courses paid.

INDICATORS:

Domain: family – organized family – marriage or cohabitation, single parent family, active involvement of parents and other members in the evolution and development of the child with ASD, involvement of the child with ASD in the family routine, quality of parent-child relationship, quality of parent-child relationship, quality communication in the family, sources of satisfaction of the child with ASD (emotional relationship, reward system), relationships with other members of the extended family, who deals with the continuity of the therapeutic program of the child (mother / father / siblings), the number of hours allocated by parent (mother / father) of the child, how many hours do the parents allocate to the child's school activities, how many hours do the parents allocate to the structured leisure activities of the child with ASD, the distribution of family activities – active and functional inclusion of the child with ASD in someone else's care (therapist / extended family / supervisor), reasons for family quarrels, transgender traditions family / values (ideas / ideals / prejudices / values).

INDICATORS

Domain: social relations (family context / neighborhood / interfamily proximity)

Family – number of contacts with extended family, number of leisure activities spent with parents / siblings / grandparents, interactions with other children (except colleagues, relatives), family friends of parents, activities in which they participate with other children, organized therapeutic activities for leisure, quality of relationship (acceptance / non-acceptance) with neighbors, type of help received from neighbors (support, acceptance), help sought and received from the church, safety of the living area, playground nearby housing, private and specialized playgrounds for children with ASD, the quality of the parent / child relationship, social interaction skills, social interactions with other families that have a child with ASD.

INDICATORS

Domain: subjective / psychological well-being (emotional life, etc.) – parents and child are in a process of psychotherapy (psychotherapeutic support and counseling – acceptance and psycho-emotional management that involves the existence of a child with ASD in the family), implementation a therapeutic program aimed at knowing and managing emotions and feelings, identifying the states of satisfaction and frustration of the child, developing skills to relate to others.

3. Conclusions

New indicators were identified in all researched areas: health and services, formal education, informal education, financial status and housing, family, social relations (family context / neighborhood / interfamilial closeness), subjective / psychological well-being (emotional life, etc.).

Having a child with autism spectrum disorder is associated with stress in caring for children, as well as less time for parents to meet their needs. Compared to the parents of children who normally develop, parents of children with autism spectrum disorder report a higher family difficulty, thus being exposed to a higher risk of physical and mental stress (Fox et al., 2002; Lee et al., 2008; Schalock et al., 2002). In addition, it has been observed that the level of emotional distress in parents is associated with the level of the child's behavioral disorder and does not correlate with the child's ability to communicate functionally (Allik, Larsson & Smedje, 2006; Baker, Blacher, Crnic & Edelbrock, 2002; Fombonne, 2005). At the same time, there are financial challenges, because a child with autism spectrum disorder is associated with high medical costs due to therapies, compared to the costs incurred in an unaffected family.

The impact that children with autism spectrum disorders have on families of origin falls into three general categories: (1) stress, depression or the need for care resulting from the child's disability; (2) how the child affects the functioning of the family; and (3) adaptations to family changes caused by disability (Algood, 2013; Hoffman, Marquis, Poston, Summers & Turnbull, 2006).

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