Quality of Life of Parents of Children With Disabilities

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ABSTRACT

This study negotiates the quality of life of 59 parents of children with disabilities. The WHOQOL-BRIEF (1996) psychometric tool was used to assess participants' quality of life. Also, the influence of the parent's gender, the type of disability of the child, the existence of other children without disability in the family and the socio-economic level of the family was investigated. The results of the study demonstrated a statistically significant relation between the gender of the parent and the variables of WHOQOL-BRIEF. The results also showed that the type of disability of the child and the socio-economic level of the family had an effect on some of the parameters of the quality of life of parents of children with disabilities.

Keywords: parents of children with disabilities, quality of life.

I. INTRODUCTION

Nowadays, the term "quality of life" is increasingly projected in relation to the past and concerns a variety of sectors and activities. It is a fact that many definitions are found, as any assessment of quality of life is essentially subjective [1]. At the same time, quality of life is a multidimensional and volatile concept, which is difficult to be defined and measured.

Quality of life is a social construct [2] and can be defined as the individual's overall expectations for well-being, which includes both physical and psychological health-related dimensions [3].

According to the World Health Organization, quality of life concerns the subjective perception of the individual [4] about his place in life according to the cultural context and value system in which he lives and develops, depending on his personal its goals, expectations, interests, standards and concerns [5], [6]. Quality of life means the positive or negative characteristics, which determine the way of life of a person compared to the considered as standard characteristics of the way of life of another person [1].

In fact, the term "quality of life" in its broadest sense is a set of parameters and is achieved through the interaction of many factors. It includes both material and non-material factors. More specifically, quality of life includes a person's standard of living, education, health and its maintenance, his emotional state, well-being, his relationships with his wider social environment, and the opportunities that a person has for leisure and relaxation [7], [8]. The main dimensions of quality of life according to Wehmeyer & Schalock [9] are emotional well-being, interpersonal relationships, material well-being, physical well-being, social integration, rights, personal development and self-determination.

"Family quality of life" is defined as the degree to which families of individuals with disabilities can meet their basic needs, enjoy their time together and have free time, interests and activities [10]. The concept of family quality of life (FQOL) covers family satisfaction in the light of the internal and external potentials that are being developed, as well as the availability of support [11].

It is a fact that the development of a child with a disability within the family affects its life in many ways, both positive and negative [12]. Negative ways of influencing may include lack of sleep, stress, and lack of parental free time [13]. After being diagnosed with a child's disability, parents experience many stages of difficulty and experience a variety of emotional states, including rejection, embarrassment, anxiety, psychotic disorders, and more [14]. Research has shown that the stress levels of a family with a child with a disability can be increased, compared to the stress levels of a family without a child with a disability [13]. As a result, having a child with a disability within a family undoubtedly affects the quality of life of their parents.
Some of the factors that affect family life and have an impact on the quality of life of its members - and especially parents - are the child's personality, the type of disability he presents, the family style [19], the severity of the child's disability [20], [21], stress, environmental and social impact, and level of support. Parents who have children with disabilities often report that they have physical and psychological problems related to the care of their children, which has an impact and affects their quality of life [22].

According to Hsiao [23], parents of children with disabilities often experience higher levels of stress than parents of children without disabilities, regardless of the category of disability. Understanding parental stress can lead to appropriate interventions and support for these parents and their children with disabilities.

The family is the main support network for children, but also in many cases for adults with autism [24]. The existence of a child who falls within the range of autism (ADHD) is one of the factors that affects the quality of life of the family in which it lives and develops (e.g. additional stress) [11], [25]-[27]. Given that caring for a child with autism is a lifelong endeavor [28], [29], it has been observed that parents of children with autism, and especially mothers, have a tendency to experience higher stress, compared with parents of children of typical development or children with other types of disorders such as cystic fibrosis, Down syndrome, behavioral problems or learning difficulties [30]-[33] psychological disorders and depression [34], [35]. These parents are also more likely to develop mental problems, depression, physical discomfort, feelings of social isolation and exhaustion [36], [37]. In addition, they are twice as likely to separate as parents who do not have a child with autism. This can be attributed to poor family functioning and less marital happiness.

Research by Mugno, Ruta, D'Arrigo & Massone [38] demonstrated that the quality of life of mothers of children with PDDs (Pervasive Developmental Disorder) showed a tendency to be lower compared to the quality of life of fathers of children with PDDs. A statistically significant difference between fathers and mothers was found only in the area of physical health where mothers were lagging behind in their performance. More specifically, mothers of children with PDDs showed lower physical health, difficulty in interpersonal relationships, problems related to their psychological state and generally a worse perception of their quality of life and health. The fathers showed a worse perception of their psychological state, shortcomings in the overall quality of life, as well as in their social relationships.

The research conducted by Kazmi et al. [39] showed that mothers of children with intellectual disabilities had lower scores in terms of their quality of life compared to fathers of children with intellectual disabilities. The aim of the study by Misura & Memisevic [40] was to examine the quality of life of parents of children with intellectual disabilities. An additional goal was to examine the effects of gender and educational level on the quality of life of these parents. The sample of this study consisted of 50 parents of children with mental disabilities and 50 parents of children without disabilities as a control group. The results showed that there is a statistically significant difference between the quality of life of parents of children with mental disabilities and parents of typically developing children. However, there were no interaction effects of their gender and educational level to their quality of life. The researchers concluded that it is important to be provided support to parents of children with disabilities in order to improve their quality of life.

Majd & Karini [41] conducted a study in Hashtrud, which focused on comparing the quality of life of 35 parents of children with Down syndrome and 35 parents of children of typical development. The data were collected using the SF36 questionnaire, as well as a simple questionnaire with demographic information. The results of the research showed that the parents of children with typical development had a higher quality of life. According to these results, the quality of life between fathers and mothers of children with Down syndrome was no different, and the same was true for parents of children without disabilities. At the same time, there was a correlation between the quality of life of parents of children with Down syndrome and their level of education. Parents with a higher level of education had a better quality of life.

Leun & Li-Tsang [22] conducted a study involving 71 parents of children with disabilities and 76 parents of children without disabilities, which focused on exploring their quality of life. The results of the research showed that the parameters of social relations and environment did not differ between the two groups of participating parents. The same study found that the quality of life of parents of children with disabilities was related to the severity of their child's disability. Also, research conducted by Haimour & Rādi [42] on 306 parents of children with various types of disabilities and learning difficulties (learning disabilities, autism, mental disability, etc.) showed that the type and severity of the disability or problem of the child affects the quality of life of the parents. It turned out that the parents of children with learning difficulties had a better quality of life. The parents of children with physical disabilities and mental retardation followed, while the parents of children with autism had the worst quality of life.

Oliveira & Limongi [43] studied the quality of life of 31 parents / caregivers of children and adolescents with Down syndrome, as well as the effect of certain demographic characteristics on it. To assess the quality of life of the participants, they used the short form of the psychometric tool WHOQOL. 84% of parents / caregivers said they had a "good" quality of life and 55% said they were "satisfied" with their health. The lowest performance score was observed in the parameter "environment" and it was found that it was associated with certain socio-demographic characteristics, such as the educational and socio-economic level of the participants, which affected it.

The Pocinho & Fernandes survey [44], which had 871 participants, of whom 403 were parents of children with disabilities and 468 were parents of children without disabilities, with most of the children having mental disabilities, autism and multi-disability, was intended in assessing parental depression and anxiety, taking into account the gender, age of the parents and their children, as well as the level of education of the parents. It turned out that parents of children with disabilities had higher levels of anxiety and depression than parents of children with typical...
development. Stress and depression levels are related to the age of children with disabilities (higher levels related to older ages) and negatively to the level of parental education (higher levels associated with lower education).

These results underscore the need to think more deeply about the need to design intervention programs aimed at developing coping strategies to prevent or minimize parental stress and depression. Intervention programs are crucial in making it easier for families to cope with these adverse conditions, thus promoting the mental health and psychological well-being of parents and children with disabilities.

The purpose of this study is to investigate the quality of life of parents of children with disabilities. Our goal is to explore the four parameters of their quality of life (physical health, psychological health, social relationships and the environment) with the WHOQOL-BRIEF psychometric tool (1996). Our aim is also to investigate the effect of certain demographic characteristics such as parental gender, type of child disability, the existence of other children without disability in the family and the socioeconomic level of the family, on the quality of life of parents of children with disabilities.

II. METHOD

A. Participants

The study included 59 parents of children with disabilities. Of these, 32 (54.2%) had a child with Down syndrome and 27 (45.8%) had a child with autism. In terms of gender, 16 (27.1%) of the participants were men, fathers of children with disabilities and 43 (72.9%) were women, mothers of children with disabilities. 17 (28.8%) participants had no other children without disabilities in their family, while 42 (71.2%) had. Regarding the socio-economic level of the family, 18 (27.1%) participants belonged to a low socio-economic level, 14 (23.7%) belonged to a medium and 14 (23.7%) belonged to a high socio-economic level. The distinction of the socio-economic level of the family was made according to the categorization of Vamvoukas (1988), based on the father's profession.

B. Procedure

During the elaboration of this research study, all the rules and scientific ethics appropriate to the research studies were observed, in terms of the methodological approach, which includes sample collection, tools and data collection process, statistical data analysis and their interpretation. In order to carry out this research work, the assistance of parents of children with disabilities or special educational needs was requested. In the present study, the participating parents were sought through associations of parents and friends of children with disabilities.

The criteria for admission to the research were that the participants were parents of children with disabilities or special educational needs. In particular, parents should have the care of a child or more children with disabilities and / or special educational needs, wish to take part in the research and have given their consent either orally or in writing, by letter given or sent to them, which was accompanied by the questionnaire. Based on the above, the consent of each parent was requested and granted, after informing him of his participation in the conduct of this research. Finally, following the rules of ethics, the participants were assured of anonymity and confidentiality of their personal data.

C. Psychometric tool

WHOQOL-BRIEF (1996) has been translated into 50 languages, including Greek. The translation, weighting and cultural validity of this questionnaire for its administration to the Greek population was carried out by the Medical School of the University of Athens in collaboration with the Aeginite Psychiatric Hospital [45]. It includes 26 questions and evaluates the four dimensions of quality of life: Physical Health, Psychological Health, Social Relationships and Environment. It is addressed to parents of children with disabilities. Prior to the administration of the aforementioned psychometric tool, participants were given a preliminary questionnaire to collect some of the demographic information needed.

D. Data Analysis

For the quantitative data analysis, the Statistical Package SPSS, 21.0 was used. A probability level of p < .05 was set for all tests of statistical significance.

III. RESULTS

For the processing and statistical analysis of the data, the statistical package SPSS version 21.0 was applied. In particular, the statistical criteria T-test, One Way ANOVA and Linear Bivariate Correlation were used. The sample follows a normal distribution (n = 59> 30, & normality test Kolmogorov-Smirnov). Table 1 shows the performance of parents of children with disabilities regarding the four parameters of their quality of life. It turns out that parents of children with disabilities performed better in the Physical Health parameter and in the Environment parameter. This was followed by a performance in the Psychological Health parameter. The performance of parents of children with disabilities was low in relation to the social relationships parameter.

| TABLE 1: MEANS OF THE FOUR PARAMETERS OF QUALITY OF LIFE OF PARENTS OF CHILDREN WITH DISABILITIES (N=59). |
|---------------------------------------------------|-----------------|-----------------|
| Parameters                                        | M               | Std. Deviation  | Std. Error Mean |
| Physical health                                   | 3.55            | .87             | .11             |
| Psychological health                              | 3.13            | .68             | .08             |
| Social relationships                              | 2.91            | .87             | .11             |
| Environment                                       | 3.45            | .79             | .10             |

During the investigation of the relation between the variables of physical health and gender of parents of children with disabilities, a statistically significant relationship between them emerged (Sig. =.02<0.05), because the observed level of statistical significance was lower than the theoretical (Table 2). Also, during the investigation of the relation between the variables psychological health and gender of parents of children with
disabilities, a statistically significant relation emerged (Sig. = .02 < .050), (Table 2). Thus, between the variable social relationships and gender of parents of children with disabilities (Sig. = .000 < .05), environment and gender of parents of children with disabilities, a statistically significant relation emerged (Sig. = .00 < .05), (Table 2).

### TABLE II: CORRELATION OF QUALITY OF LIFE AND GENDER PARAMETERS

| Parameters | Gender | N   | M    | S.D. | Std. Error M |
|------------|--------|-----|------|------|--------------|
| Ph. H.     | 1      | 16  | 4.37 | .50  | .12          |
|            | 2      | 43  | 3.25 | .78  | .12          |
| Ps. H.     | 1      | 16  | 4.06 | .25  | .06          |
|            | 2      | 43  | 2.79 | .41  | .06          |
| S. R.      | 1      | 16  | 4.12 | .34  | .08          |
|            | 2      | 43  | 2.46 | .50  | .07          |
| E.         | 1      | 16  | 4.68 | .48  | .11          |
|            | 2      | 43  | 3.00 | .00  | .00          |

Note: Ph. H. = Physical Health, Ps. H. = Psychological Health, S.R. = Social Relationships, E. = Environment, Gender (1 = father, 2 = mother).

The bivariate correlation analysis showed a strong linear correlation with a positive direction between the variables physical and psychological health (r = .79), social relationships and environment (r = .82), environment and psychological health (r = .80), psychological health and social relationships (r = .85). A moderate linear correlation with a positive direction emerged between social relationships and psychological health (r = .48), as well as between physical health and the environment (r = .46).

Investigating the relation between the variables psychological health of parents of children with disabilities and the type of child’s disability resulted in a statistically significant relation Sig. = .03 < .05 (Table 3). That is, the results showed that parents of children with Down Syndrome had better psychological health than parents of children with autism.

### TABLE III: CORRELATION OF PSYCHOLOGICAL HEALTH OF PARENTS OF CHILDREN WITH DISABILITIES AND THE TYPE OF CHILD’S DISABILITY.

| Type of disability | N   | M    | S.D. | Std. Error M |
|--------------------|-----|------|------|--------------|
| Psychological Health |     |      |      |              |
| Down Syndrome      | 32  | 3.28 | .72  | .12          |
| Autism             | 27  | 2.96 | .58  | .11          |

Investigating the relation between the variables environment of parents of children and the type of child’s disability resulted in a statistically significant relation Sig. = .00 < .05 (Table 4). It turned out that the parents of children with Down Syndrome performed better in the environment parameter than the parents of children with autism.

### TABLE IV: CORRELATION OF VARIABLES ENVIRONMENT OF PARENTS OF CHILDREN WITH DISABILITIES AND THE TYPE OF CHILD’S DISABILITY.

| Type of disability | N   | M    | S.D. | Std. Error M |
|--------------------|-----|------|------|--------------|
| Environment        |     |      |      |              |
| Down Syndrome      | 32  | 3.65 | .90  | .15          |
| Autism             | 27  | 3.22 | .57  | .11          |

During the investigation of the relation between the variables physical health of parents of children with disabilities and socio-economic level of the family, a statistically significant relation emerged F (4.520) = .01 p < .05. The Post hoc test (Bonferroni, Tukey HSD test) found that parents of children with disabilities from families with medium socio-economic level performed better in physical health, compared to participants from families with high socio-economic level. Similarly, during the investigation of the relation between the variables psychological health of parents of children with disabilities and socio-economic level of the family, a statistically significant relation emerged F (3.861) = .03 p < .05. The Post hoc test (Bonferroni, Tukey HSD test) found that parents from families with medium socio-economic level performed better on the psychological health parameter than participants from families with high socio-economic level.

During the investigation of the relation between the variables environment of parents of children with disabilities and socio-economic level of the family, a statistically significant relation emerged F (3.409) = .04 p < .05. The Post hoc test (Bonferroni, Tukey HSD test) showed that parents from families with medium socio-economic level performed better on the environment parameter, compared to participants from families with high socio-economic level.

### IV. DISCUSSION

Based on the results of the present study, it was found that the performance of parents of children with disabilities was low in some of the parameters of their quality of life. Similar findings have been made in previous studies [46], [47]. The results of the research conducted by Kumar et al. (2013) showed that parents of children with disabilities had lower quality of life compared to parents of children without disabilities. A survey conducted by Kotzampanopoulou [12] on parents of children with disabilities in Greece and, among other things, explored the views of parents themselves regarding their quality of life, showed that children with disabilities are the focus of attention of their families and that their quality of life depends on them.

From the results of Christodoulou et al’s research [48], conducted in Greece, was found that parents of children with cerebral palsy have increased anxiety. In addition, they were found to have a major problem with finding support on a personal level [48]. In the present study, the performance of parents of children with disabilities was quite low in terms of the social relationships parameter. It is a fact that daily activities are based on the needs of their children and so parents have reduced social activities due to lack of free time [13]. Also, the fathers of children with disabilities had a better quality of life compared to the mothers of children with disabilities.

Other previous studies have shown gender differences in the quality of life of parents of children with disabilities [38], [30]-[33]. Research by Mugno, Ruta, D’Arrigo & Mazzone [38] showed that the quality of life of mothers of children with PDDs (Pervasive Developmental Disorder)
showed a tendency to be lower compared to the quality of life of fathers of children with PDDs.

According to the results of a study conducted by Lamb & Laumann-Billings [49], parents of children with disabilities have a different way of perceiving a child with a disability. The father usually focuses on the future impact and consequences of disability on the child's life, as well as on the child's attempt to adopt socially acceptable behaviors. In contrast, the mother focuses more on the present demands and needs of the child with a disability. Probably the way a child with a disability is perceived affects the quality of life of every parent. In addition, in these cases the mother's personality is more affected, mainly due to her responsibilities and her role in the family. It is very stressful for a mother to be burdened with the demanding care of a child with a disability combined with possible financial problems, as long as she does not work, but also with her other daily chores [50].

The research conducted by Kazmi, Perveen, Karamat, & Khan [39] aimed at investigating the depression and quality of life of 100 parents of children with disabilities (50 mothers and 50 fathers), who had children with a disability aged 3-12 years, showed that the mothers of the children scored higher in the depression factor, as well as showed lower quality of life compared to the fathers of these children.

In particular, as mentioned above, correlations were also found between the variables physical health and psychological health, social relationships and environment, physical health and social relationships, physical health and environment, psychological health and environment, psychological health and social relationships, and social relationships and environment. Based on the above findings, one can easily understand the dynamic interdependence that exists between the parameters of the quality of life of the individual.

At the same time, the present research showed that there is a correlation between the socio-economic level of the family and the parameters of quality of life, physical health, psychological health and environment. Previous research has shown that demographic characteristics related to family income are a strong predictor of family quality of life [20], [21], [24], [51].

Finally, the results of the present study showed a statistically significant relation between certain parameters of the quality of life of parents of children with disabilities and the type of disability. Research conducted by Haimour & Radi [42] has shown similar results, as it has shown that the type and severity of a child's disability or problem affects the quality of life of the parents. In particular, in the present study, a correlation was found between the parameters of quality of life, psychological and environment of parents of children with disabilities and the type of disability of the child. Parents of children with Down Syndrome had a better quality of life compared to parents of children with autism.

In conclusion, and given the fact that the quality of life of parents of children with disabilities has an impact on the effective treatment of children with disabilities, it is considered that in the case of a child with a disability within a family, a broad, supportive network is required to help parents, through specialized advice [52], to successfully meet their increased obligations. At the same time, the same factor will contribute positively, so that parents have a better quality of life. When parents have a better quality of life and children with disabilities will have a better quality of life.

The results of this study should be accepted with some reservations, due to the following limitations to which the research is subject: a) The study of correlations included in the work attempts to establish correlations of factors and not causal relationships between them, b) The study’s sample is not large enough to allow the generalization of the results to the entire population of parents of children with disabilities. However, despite the aforementioned limitations, it is considered that the results are significant in terms of their contribution to the field of research.

Given the limitations of this research and the shortcomings identified in the literature, not only in Greece but also internationally, it would be useful to conduct similar research in the future, which will focus on exploring the same parameters as the present study, using the same assessment tool, but a larger number of participants, so that the results are more representative of the population of parents of children with disabilities. It would also go a long way in deepening the issue, a qualitative survey where parents will be able to express their views and suggestions for improving their quality of life.

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