**Quality of life of mothers of children with intellectual-developmental disabilities in Israel**

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**Summary**

The purpose of the study is to examine how mothers of children with intellectual-developmental disabilities perceive their quality of life.

The study included Thirty mothers of children with moderate intellectual-developmental disabilities, aged eight to twelve, who attend special education elementary schools in Israel. The research method was qualitative, and the research tool was a semi-structured interview. The findings revealed that the child himself was considered a source of love and joy. The mothers discovered dissatisfaction with their family, social and emotional lives, but found satisfaction with the support they receive, especially from the extended family and the therapeutic-educational framework of their children, as factors that may affect their quality of family life. The main conclusion is that mothers perceive their quality of life as low due to general conditions they face, due to the presence of the child with intellectual-developmental disabilities, but when they receive support, their quality of life improves.

**Introduction**

The subject of the study is the perception of mothers of children with intellectual-developmental disabilities of their quality of life. Children with intellectual-developmental disabilities need emotional acceptance to improve their functioning and integration within society; families of these children, especially mothers, are a cornerstone of the lives of those children. There is a consensus among the researchers that "quality of life" is a multidimensional concept, consisting of different areas of content and intertwined with these that include objective aspects and subjective aspects of life. In an integrative definition, the "quality of life" of the individual is a function of his satisfaction with the correlation between his needs and aspirations and the satisfaction of his life, The higher the adaptation between an individual and his environment, the higher his quality of life. Most studies in the Western world have found that various factors affect the family quality of life among children with intellectual developmental disabilities, such as family relationships, values, and family health. Children with intellectual-developmental disabilities present a special reality due to their uniqueness, a reality that involves different adaptive, perceptual, social, and practical characteristics.

Recently, the importance and interest in the family context of a child with intellectual-developmental disabilities have been emphasized, the assumption is that his well-being is significantly affected by the well-being of his parents and family in general. For these children to grow up in a healthy and functioning environment, it is necessary to take care of their families for reasonable welfare conditions. Family quality studies for children with intellectual-developmental disabilities have emphasized the importance of the factors and resources that parents of these children should have, such as health, financial condition, family ties, leisure, career, support from others, service support, and community and cubic engagement.

**Parents of children with intellectual-developmental disabilities**

Intellectual and developmental disability is characterized by limited functioning in perceptual, social, and practical adaptive skills (AAIDD, American Society for Intellectual and Developmental Disability, Welfare; DSM-V(2013) – American Psychiatric Association, 2013). This disability requires a special coping that affects the relationship between family members, and the social situation, economic and mental state of the parents (Neikrug et al.,2011). The definition of the American Psychiatric Association APA - DSM-V (2013) refers to three components of disability: intellectual function, adaptive function, and limitation during development (American Psychiatric Association, 2013). Studies on the parenting experience for children with intellectual and developmental disabilities show that parenting is an experience that creates a tension that is shaped by the gap between the heavy sense of responsibility that applies to the person due to being a parent, and the lack of resources available to him in terms of knowledge, support, and guidance (Cohen, 2011). Parents of such a child feel increased stress and concern in the family, and their coping is becoming increasingly complex. The feeling of tension of parents of children with a large disability relative to parents of ordinary children (Hedov, Anneren&Wikblad, 2002), and begins from the moment the news is received and adds to feelings of guilt and concern the complexity of coping is expressed in the child himself, in the couple relationship, in the healthy siblings of a child with a disability and their interaction (Peer & Hillman, 2014). In addition, parenting a child with intellectual disabilities can trigger feelings accompanied by anxiety, shame, and guilt (Beresford, Rabiee &Sloper, 2007; Ha, Hong, Seltzer & Greenberg, 2008). These emotional difficulties vary by type of disability of the child and by age (Blacher& Baker, 2002). Studies have found seven main areas of difficulty: financial difficulty, a resulting from the need for medications, hospitalizations, equipment, medical advice, and special treatments; Family-emotional difficulty, which is manifested in stressful emotional relationships, overprotection, lack of time and appeals to the rest of the family, blaming the spouse as genetically responsible for their child's condition and a general increase in the level of tension and family conflicts; changes in family conduct, such as difficulties in utilizing leisure time, and giving up promotion at work; Difficulties in social life, the embarrassment of parents from their son's behaviors and appearance, reactions from friends and neighbors, restrictions of various types that can lead to the social isolation of the family; load from the daily care of the child and the functioning of the family; The family's contact with institutions can also be a great difficulty, as a result of dependence on the institution that needs to provide medical services and education to the child; In daily physical and mental burdens, economic burdens, and the huge investment in various life skills – learning, leisure, play and social participation. Children with intellectual disabilities depend on their parents for the long term, and sometimes, parents find it difficult to find frameworks suitable for their child's needs (Levi-Schiff and Shulman, 1998).

Past studies have focused on children's disability, while recent studies expand observation and touch on other factors related to these children, including family, community environmental support and family quality of life. Today, the quality of family life is measured in two main tools: the Beach Center FQOL Scale; Beach Center On Disability, 2005), developed by a team of researchers at the University of Kansas Disability Beach Center, and quality of life survey (FQOLS-2006), Developed by an international team of researchers, it serves as a central research tool with nine key dimensions that make a special contribution to family quality of life, such as family health, economic well-being, family relations, support from other people, support from services operating in the field of special needs, cultural and spiritual beliefs, careers or career preparations, leisure activities and interactions with the community (FQOLS-2006).

**Quality of life**

The question that preoccupied the researchers from different fields of opinion was what a good life was. Thus, a new concept called Quality of Life was created, which over time became a focus of interest and research (Keng&Hooi, 1995). Sullivan,1992). Three main approaches are used to define the concept of "quality of life": the objective-social approach, the subjective-psychological approach, and the approach of adaptation (social policy) (Schaluk, 1998). There is agreement among the researchers that "quality of life" consists of dimensions from different fields and includes objective aspects and subjective aspects of life (Nicrogue, Roth, Judas, and Zemiro, 2006).

According to the objective-social approach, quality of life includes external objective conditions that depend on the environment such as health, public safety, education, the standard of living, place of residence, and leisure (Landesman, 1986). Since the dimensions are external and environmentally dependent (related to the environment), Shye (1979; 1989) argues that quality of life should be distinguished from environmental quality, meaning that the quality of the environment examines the degree to which the environment promotes the quality of life of the living individual within it (Shye, 1979; Therefore, the objective dimensions do not represent the quality of life of the individual, but rather the quality of his environmental conditions (Evans, Burns, Robinson & Garrett, 1985).

According to the subjective-psychological approach, the concept of "quality of life" refers to the individual's self-perception of his quality of life. This definition refers to psychological mental well-being, interpersonal relationships, personal development, self-realization, and also refers to the level of satisfaction, that is, the degree of positive attitudes of the individual towards his life (Andrew &Withey, 1976; Haycox, 1995

The third approach, the Goodness of fit approach, combines the two previous approaches and believes that the "quality of life" of the individual is a function of his satisfaction with the correlation between his needs and aspirations and the satisfactions of his life (positive attitudes towards his life). The higher the match between the individual and his environment, the higher his quality of life (Lehman, 1988; Schalock,1990). According to this model, improving quality of life depends on the planning of the environment in a way that will suit the characteristics of the individual (Schalok, 1998).

Researchers who defined the concept of family quality of life pointed to great difficulty in defining it because the concept is inclusive, flexible, and multidimensional (Turnbull et al., 2004b). In recent years, family quality of life has been defined as a dynamic sense of family well-being both in terms of the personal subjective perception of every detail within the family about his life, and in terms of the general feeling of the family system as a single entity (Zuna, Summers, Turnbull, Hu & Xu, 2010). The concept began to develop in the 1980s when studies focused on a person with disabilities and his family began publishing intervention programs to support them (Brown, 2010). As a result of these studies, governments of modern countries began to call for increased provision of services to families of these children, because they concluded that parents were the main caregivers of this child and were responsible for the conduct of his life (Brown, Schalock& Brown, 2009; Samuel et al., 2012).

The purpose of the current study is to examine how mothers of children with intellectual-developmental disabilities perceive their quality of life. The question of the study is how the presence of a child with intellectual-developmental disabilities affects the quality of life of mothers.

**Research method**

The study is based on a qualitative research method, which is a method that allows studying reality as reflected in the eyes of the subjects, and emphasizes a deeper understanding of the person, his thoughts, assumptions, and behavior.

qualitative research makes an in-depth investigation of research subjects exploring, behaviour and experiences through such methods as semi-structured and unstructured interviews. Qualitative research, broadly defined, means *"any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification"* (Strauss and Corbin, 1990, p. 17). The in-depth understanding allows entry into the world of the subjects and the recognition of their hidden points of visibility and assumptions (Creswell, J. W. 2009.). Studies in the qualitative approach offer an interpretive description that tries to reach a subjective understanding of the subject without a prior hypothesis but through learning and experience. The qualitative research method was chosen, since the study focuses on the quality of life of mothers as perceived by them, and since the term quality of life is a term that refers to subjective aspects.

**Study participants**

The study included thirty mothers of children with intellectual-developmental disabilities at the medium level, between the ages of eight and twelve, who attend special education elementary schools in northern Israel.

The two criteria for selecting the participants were a moderate level of functioning of the child and an average age between eight and twelve. Moderate functioning – because too difficult or too mild can lead to extreme and misleading consequences; the children's age was chosen to be between eight and twelve, and the reason for this is similar, that is, to avoid too young an age, in which the mothers are still stuck in the shock stages, therefore, the selection criteria are designed to maintain the non-bias of the results.

**Research field**

The researcher chose a comfort sample for selecting the participants, most of the interviews were conducted in the homes of the interviewees, some of which were conducted at the workplace of the mothers, in the north of the country. The field was selected out of geographic proximity considerations, in addition, to accessibility and availability.

**Research tool**

The research tool included the use of semi-structured in-depth interviews (Appendix1). Interviewing is a tool that allows a technique for collecting data from people through asking questions and receiving verbal answers. The purpose of using the interview is to try to understand in depth the person's inner world (Gilat and Hertz-Lazarovitz, 2010) and the meaning it gives to his experiences. An in-depth interview allows the interviewee to contribute detailed information according to his wishes and bring his point of view and experiences fully (Fontana & Frey, 2000; Turner, 2010).

The interview guide was based on an integration of the content that emerged from the interview, which was conducted at the beginning of the study, in which one open question was asked: "Tell what it means to raise a child with intellectual-developmental disabilities in the family", and the aspects that emerged in the literature review, thus, the sub-questions were selected, which addressed different aspects of family quality of life.

The interview was constructed as a funnel: the first part dealt with a general description of the experience of motherhood for a child with intellectual-developmental disabilities, and the changes in family life according to the perception of mothers after the birth of the child with intellectual-developmental disabilities; the second part of the interview focused on the family's relationship and how they dealt with daily life.

**Research process**

To collect the data, children, and mothers who matched the criteria selected for the study participants were identified: the researchers contacted the school administration, and the subject of the study and its purpose was explained, and the criteria for selecting the participants. After the agreement was reached in principle from the School Administration and the Supervision of Supervision, the appropriate families were identified to carry out the study. The school secretariat sent the families letters explaining the study and attached requests for participation in the study.

The researchers contacted the families by telephone, and coordinated, in the first stage, the first interview, as an exploratory study, with two mothers. The pilot interview focused on one open question: "Tell me what it means to raise a child with intellectual-developmental disabilities in the family." Based on the pilot and the literature review, sub-questions were selected for the study, in addition to the first open question (Appendix 1).

The interviewees who gave their consent to participate in the study signed a consent letter.

It is important to note that it was made clear to the participants at the beginning of each interview about the interviewer's commitment to anonymity. In addition, and for the sake of secrecy, pseudonyms were used during the study, and the real names of the participants were not mentioned at all. After the interviews were recorded and transcribed, the researchers destroyed the recordings.

**Data analysis method**

Data analysis was carried out using a qualitative method as an analytical process, using their intuitive characteristics, to generate meaning and interpretation. After transcription of each of the interviews, the transcripts were analyzed in a multi-stage manner, to identify categories, by cross-referencing information from different interviewees. Repetitive categories were found, the categories were mapped, and major categories were built in Creswell, J. W. 2009)).

The first stage of data analysis was conducted while listening and transcribing the interviews, writing footnotes. After initial categories were detected and defined, by identifying repetitive sentences, more precise categories were defined, and in the third stage the categorization was reexamined, and the corresponding category was assigned. In the latter stage, the nuclear categories were identified, and categories were consolidated into some major issues according to these categories (Ayalon and Sabra Ben-Yehoshua, 2010; Gambaton, 2006).

The next chapter will present the findings from the analysis of the interviews, with the aim of examining how mothers of children with intellectual-developmental disabilities perceive their quality of family life.

**Findings**

In this chapter, the main findings from the interviews will be detailed in reference to the categories that arose, and later the meanings that arose from the texts will be explained and supported from the interviews conducted will be explained.

Of the interviews conducted for Thirty mothers of children with intellectual developmental disabilities, four main category was identified: a family puzzle that included relationships and parenting; social wonder, which included avoiding participation in events and avoiding interpreter interaction; Support, which mainly included the support of the extended family and the support of their children's educational framework; and emotional wonder, which included the general feeling of stress in most areas of life, a concern that accompanies the mothers all the time, feeling different, feeling disappointed, feeling lonely, these in addition to different positive emotions.

The first category emerging from the findings is family aspects. This category focused on marital relationships and parenthood, factors influencing the maternal family quality of life. This finding aligns with Zuna et al.'s definition (2010) of family life quality, which is a dynamic sense of familial well-being, both subjectively personal in each family member's perception of their lives within the family and in the overall perception of the family system as a unit.

Mothers addressed difficulties in their marital relationships, particularly when both spouses began to suffer from extreme mood swings due to the pressures accompanying their child with cognitive disabilities. They discussed their unmet needs and those of their spouses, as well as their parenting for a child with disabilities and their other children. This finding receives significant support in the literature. It suggests that coping with a child with cognitive disabilities in a family involves more complexity than parenting a typically developing child. The parental stress associated with children with disabilities is heightened, compared to parents of typically developing children. The complexity in coping manifests in the child themselves, the marital relationship, healthy siblings, and interactions among them (Peer & Hillman, 2014). Parenting a child with cognitive disabilities might evoke emotions accompanied by anxiety, shame, and guilt, potentially influencing the maternal perception of parenting.

In this case, we're dealing with compromised mental well-being. Mental well-being is one of the key factors in perceiving family life quality. Relationships within the family are identified as a primary dimension influencing family life quality, where it's reasonable to assume that the individual's perception of family life quality rises when these relationships are good (Brown et al., 2006). Consequently, strained relationships and their perceived deficiencies indicate a poor perception of life quality, as articulated in the mothers' statements.

This current research finding highlights dissatisfaction in the realm of family relationships, manifested in recurring conflicts between spouses and dissatisfaction from mothers towards their children with cognitive disabilities in terms of the time they allocate and the interactions they engage in with them. This impacted their perception of parenting. This finding aligns with Ajuwon and Brown's research (2012), which indicated that tense family relationships negatively impact family life quality.

However, this finding contradicts other studies (Brown et al., 2010; Schmidt & Kober, 2010) that found that the majority of families with children having cognitive disabilities expressed satisfaction, among other aspects, regarding the relationships within the family.

It's important to note that the findings from the current research contradict findings from studies on family life quality conducted in Israel among parents of children with cognitive-developmental disabilities. In those studies, family relationships as a measure of life quality were notably satisfactory, especially within the Arab community (Neikrug & Omietanski, 2006; Neikrug et al., 2014; Neikrug et al., 2011).

Social aspects, in general, were expressed through dissatisfaction with social connections and interpersonal interactions, which affected their life quality. Mothers' participation in events, from their perspective, involves a unique organization: finding a safe space for the child, concerns about their care during the event, or worries about potentially embarrassing or annoying questions if they chose to bring the child along.

According to literature, families of individuals with disabilities often confront numerous social obstacles, including isolation, rejection, and humiliation. Disability is sometimes perceived as degrading and embarrassing for the family, to the extent of avoiding assisting the disabled person out of reluctance to expose themselves (Barakat, 1993).

The reasons mothers raised regarding their avoidance of events and reluctance to form interpersonal connections also appear in a review by Mccubbin and Huang (1989). The researchers presented seven areas of difficulty, one being the challenges in societal aspects of life, such as parental embarrassment from the behavior or appearance of their child, reactions from friends and neighbors, or limitations causing the family's social isolation. Families face many challenges in raising a child with special needs, including social relationships (Guyard et al., 2012, Neikrug et al., 2011).

In Israeli society, there are negative attitudes toward individuals with disabilities (Sikron, 2013). The stigma affecting people with disabilities in Israel impacts various aspects of their lives and leads to isolation and social distancing (Naon, 2009). Specifically within the Arab society, due to the emphasis on collective values and interdependence, parents of children with special needs tend to distance themselves from social interactions to avoid uncomfortable social situations (Dwairy, 2004; Hagg-Yaish, 1994).

The majority of mothers expressed satisfaction from support in two primary realms of their lives, considered significant components influencing their family life quality. Firstly, the support from their close-knit circle, particularly their families and their spouses' families, played a crucial role. Secondly, the support from the educational systems in which their children were involved. Studies illustrate that parenting is an experience fraught with tension, shaped by the gap between the heavy sense of responsibility felt by the parent and the scarcity of available resources in terms of knowledge, support, and guidance (Cohen, 2011). At times, parents struggle to find suitable frameworks tailored to their children's needs and their personal requirements or support frameworks with specialized professional assistance (Levi-Shif & Shulman, 1988).

The research highlights that the overwhelming majority of mothers addressed two sources of support practically and emotionally: their families and their spouses' families provided assistance in various aspects, including child care, aiding in their education and development, empowering and strengthening them, and significantly contributing to the child's acceptance process. The second source of support was the educational system, serving as a source of knowledge and guidance on the child's care, and a soothing place that reduced their stress. Some mothers viewed the educational framework as a place that helped them navigate uncertainties about their child's life. These same mothers expressed high trust in the professionalism of the therapeutic team within the educational system.

This topic finds validation in research literature, such as the work of Zuna and colleagues (Zuna et al., 2009), who address systemic factors explaining family life quality. These factors can include governmental policies, laws, intervention programs, and entities providing support services such as education and welfare. Zuna and colleagues' theory regarding quality of life indicates a model that integrates all interacting factors affecting family life quality. Systems, policies, and intervention plans influence personal and familial support and the provision of services and implementation of regulations, serving as predictors of family life quality. Additionally, individual and family characteristics interact with the services and support provided to them, also acting as predictors of family life quality (Zuna et al.).

Furthermore, empirical studies have found the impact of factors such as support from services catering to special needs and community engagement significant. This was observed in research utilizing life quality questionnaires examining nine dimensions contributing to family life quality (Brown et al., 2006).

Contrary to recent research that found mothers' satisfaction with support from their child's educational system, other contemporary studies discovered lower satisfaction with personal support and assistance from services specializing in special needs (Brown et al., 2010; Schmidt & Kober, 2010). These findings contradict the research by Ajuwon and Brown (2012), which showed that support from services negatively impacted parental family life quality. Moreover, this current research did not corroborate findings from studies conducted in central Israel, indicating parental dissatisfaction with external life quality domains such as support from others or support from services and community resources (Neikryg et al., 2011).

The texts in the interviews were filled with emotional references. The interviewees addressed feelings of stress, pressure, fear, worry, anomalies, disappointment, longing, and loneliness. Alongside these emotions, positive feelings emerged while being close to their intellectually disabled child. This finding implies that the presence of a child with intellectual disability significantly impacts the mothers' quality of life.

This finding resonates with research indicating that parenting a child with intellectual disability may evoke anxiety, shame, and guilt (Berfesford et al., 2007; Ha et al., 2008), although emotional difficulties vary depending on the type and age of the child's disability (Baker & Blacher, 2002).

Upon receiving the news of having a child with intellectual disability, the entire family experiences shock, anger, fear, guilt, and concerns about the future (Banach et al., 2010; Gardiner & Iarocci, 2012). Subsequently, the family faces numerous challenges in raising their children, which involve both physical and mental efforts (Guyard et al., 2012; Neikrug et al., 2011). Mccubbin and Huang (1989) identified seven areas of difficulty among parents of children with intellectual disabilities, including emotional-family difficulties, evident in strained emotional relationships, excessive protection, stress in meeting the child's daily care, and family functioning.

An intriguing sub-category emerged in emotional aspects: alongside the negative emotions expressed by mothers, most of them expressed genuine love for their disabled child, found joy in their child's happiness, and cherished their proximity. Most mothers were content with their reality and did not seek any special treatment from their environment, especially distancing themselves from feelings of pity directed either towards them or their child.

The dissatisfaction of mothers with the family aspects of raising a child suggests that if general conditions improve, the perception of family life among mothers will also improve. In other words, the state could provide various resources to enhance overall quality of life, such as assistance with tasks and professional guidance to cope with relationship management and parenting properly.

Mothers also expressed discontent in social aspects due to unsuitable environmental and societal conditions, struggles in coping and organizing, and detrimental social reactions. This indicates that the child themselves does not cause these social hardships; rather, it is the surrounding life circumstances. If official bodies worked to explain and alter societal perceptions regarding children with intellectual disabilities, institutional activity aimed at changing perceptions might alleviate the social difficulties causing parental dissatisfaction, enabling mothers to enjoy normal social lives.

Support from the family and educational framework could enhance life quality and mitigate the negative emotional aspects found in the research. Consequently, the mere presence of a child with intellectual disabilities necessitates a special approach that influences life quality. Proper treatment in all accompanying aspects of the child with intellectual disability could contribute to the well-being and life quality of mothers.

In summary, mothers perceive their family life as low due to general conditions like lack of resources and societal circumstances due to the presence of a child with intellectual disability. However, when they receive support, their quality of life improves. The child themselves is seen as a source of love and happiness, not a hindrance to life quality.

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