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

**Abstract**

The purpose of this 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 mothers considered the children themselves a source of positive emotions. Nevertheless, they expressed dissatisfaction with their family, social and emotional lives while recognising the support they receive as factors that improve their quality of family life. Of note was the support provided by their extended families and therapeutic-educational frameworks. The primary conclusion of this study is that mothers perceive their quality of life as low due to the challenging circumstances they face with children with intellectual-developmental disabilities. However, when they receive support, their quality of life improves.

**Keywords: FIVE KEYWORDS NEEDED**

**Background**

The subject of this study is mothers of children with intellectual-developmental disabilities and their perceptions 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 these children. There is a consensus among researchers that “quality of life” is a multidimensional concept consisting of various intertwined facets of both objective and subjective natures. An integrative definition of “quality of life” is that it is a function of an individual’s satisfaction with the correlation between their needs and aspirations and their satisfaction with their lives. The higher the adaptation between an individual and his environment, the higher their quality of life. Most studies in the Western world have found that various factors affect the quality of life of families containing 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, more attention has been paid to the families of children with intellectual-developmental disabilities on the assumption that children’s well-being is significantly affected by the well-being of their parents and families. For these children to grow up in a healthy and functional environment, it is necessary to take care of their families so that reasonable welfare conditions can prevail. Quality of life studies of families of children with intellectual-developmental disabilities have emphasised that in order to provide for the well-being of these children, their parents need good health, financial resources, strong family ties, access to leisure, career opportunities, support from others, service support, and community and public engagement.

*Parents of children with intellectual-developmental disabilities*

An intellectual and developmental disability is characterised by limited functioning in perceptual, social, and practical adaptive skills [American Society for Intellectual and Developmental Disability (AAIDD) 2013]. This disability demands special coping mechanisms that affect the relationships between family members and the social, economic, and mental state of 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.

Studies on the parents of children with intellectual and developmental disabilities show that parenting in such cases creates considerable tension. This tension is often the result of the heavy sense of responsibility felt by parents and a lack of resources in the form of knowledge, support, and guidance (Cohen 2011). Parents of children with intellectual-developmental disabilities experience increased stress and anxiety and find it difficult to cope. Feelings of tension among parents of children in this category are significantly greater as compared to parents of typical children (Hedov *et al*. 2002). The tension, which begins from the moment the news is received, adds to feelings of guilt and anxiety about coping and is expressed in the children themselves, in the parents’ relationships, and in the healthy siblings of a child with a disability (Peer & Hillman 2014).

In addition, parenting a child with intellectual disabilities can trigger feelings of anxiety, shame, and guilt (Beresford *et al*. 2007; Ha *et al*. 2008). 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 & Shulman, 1998). These emotional difficulties vary by the disability type and age (Blacher & Baker 2002). Studies have found seven main areas of difficulty: 1) financial difficulties resulting from the need for medications, hospitalisations, equipment, medical advice, and special treatments; 2) family and emotional difficulties manifested as stressful emotional relationships, overprotectiveness, time poverty, 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; 3) changes in family conduct, such as difficulties in utilising leisure time and giving up opportunities for professional advancement; 4) difficulties in social life, embarrassment resulting from disabled children’s behaviours and appearance, reactions from friends and neighbours, restrictions of various types that can lead to the social isolation of the family; 5) the burden caring for a child with special needs alongside the day-to-day management of a home and family; 6) the family’s contact with institutions can also cause immense difficulty where the family becomes dependent on institutions to provide medical services and education for their children; 7) the daily physical and mental burdens, economic burdens, and the huge investment in various life skills – learning, leisure, play and social participation.

Past studies have focused on children’s disability. In contrast, recent studies have expanded the field observation to encompass other factors related to these children, including family, community environmental support, and family quality of life. Today, the quality of family life is measured using two primary 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 the quality of life survey (FQOLS-2006), developed by an international team of researchers. The latter metric considers nine key dimensions that are particularly important for 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, career or studies, leisure activities and interactions with the community (FQOLS-2006).

*Quality of life*

The question of what actually constitutes a “good” life has preoccupied researchers in various fields. A new concept called “quality of life” was created. Over time this has become 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 adaptation approach (social policy) (Schaluk, 1998). There is agreement among researchers that “quality of life” consists of dimensions from different fields and includes objective aspects and subjective aspects of life (Nicrogue *et al*. 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, standards 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. Environmental quality concerns 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 *et al*. 1985).

According to the subjective-psychological approach, the concept of “quality of life” refers to an individual’s self-perception of their quality of life. This definition refers to psychological and mental well-being, interpersonal relationships, personal development, and self-realisation. It 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 an individual’s “quality of life” is a function of their satisfaction with the correlation between their needs and aspirations and how satisfied they are with their life outcomes (positive attitudes towards his life). The higher the match between the individual and their environment, the higher their quality of life (Lehman 1988; Schalock 1990). According to this model, improving quality of life depends on planning 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 his life and in terms of the general feeling of the family system as a single entity (Zuna *et al*. 2010). The concept began to develop in the 1980s when studies focusing on people with disabilities and their families began publishing intervention programmes to support them (Brown 2010). As a result of these studies, governments in developed countries began to call for increased provision of services to families of these children. This was done on the basis of the parents being the main caregivers of these children and responsible for their life outcomes (Brown *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 research question at the heart of this study concerns how having children with intellectual-developmental disabilities affects mothers’ quality of life.

**Method**

The study is qualitative. Qualitative research allows us to study reality as reflected in the eyes of the subjects and emphasises a deeper understanding of the person, their thoughts, assumptions, and behaviours.

Qualitative research requires in-depth investigation of research subjects, exploring their behaviour and experiences using instruments like semi-structured and unstructured interviews. Qualitative research is broadly defined as “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 of a phenomenon gained using qualitative methods gives researchers access to the world of the subjects while also requiring them to recognise their blindspots and biases as observers (Creswell 2009.). Studies in the qualitative frame offer interpretive descriptions that try 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 for this study were a moderate level of functioning of the child and an average age between eight and twelve. Moderate functioning was required because extreme or mild conditions could skew the data. The age range was chosen for similar reasons. When children are too young, mothers may still be in shock. The selection criteria were designed to maintain unbiased 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 were conducted at the workplace of the mothers in the north of Israel. The field was selected based on geographic proximity, accessibility, and availability.

*Research instrument*

The research instrument used was the semi-structured in-depth interview (Appendix 1). Interviewing is a technique that allows researchers to collect data from people by 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 & Hertz-Lazarovitz 2010) and the meaning it gives to his experiences. In-depth interviews allow interviewees to contribute information in as much detail as they are comfortable with and to offer their points 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: “What does it mean to raise a child with intellectual-developmental disabilities in the family?” Aspects that emerged in the literature review were used as the basis for sub-questions that 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 as perceived by mothers after the birth of the child with intellectual-developmental disabilities. The second part of the interview focused on the family’s relationships and how they cope with daily life.

*Research process*

Children and mothers who matched the study criteria were identified through the researchers contacting school administrations, explaining the study, and its purpose, along with the selection criteria for participants. After an agreement was reached in principle, families were identified to take part in 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 the first interviews. The first stage was 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).

Interviewees who gave their consent to participate in the study signed a consent letter. Participants were assured anonymity at the beginning of each interview. In addition, 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 intuitive characteristics to generate meaning and interpretation. After the transcription of each of the interviews, the transcripts were analysed in a multi-stage manner to identify categories by cross-referencing information from different interviewees. Repeated categories were found, categories were mapped, and major categories were built (Creswell 2009).

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

The next section presents 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.

**Results**

In this section, the main findings from the interviews are explored in reference to the categories that arose, and later, the meanings that arose from the texts are explained and supported by the interviews conducted.

Of the interviews conducted with thirty mothers of children with intellectual-developmental disabilities, four main categories were 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 concerned aspects of the family. This category focused on marital relationships and parenthood: factors influencing maternal quality of life within the family. This finding aligns with the definition of family life quality in Zuna *et al.* (2012) as 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 associated with parenting children 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 is far more complex than parenting a developmentally typical child. The parental stress associated with children with disabilities is far greater than their peers caring for typical children. The struggle to cope manifests in the children themselves, the marital relationship, healthy siblings, and interactions among them (Peer & Hillman 2014). Parenting a child with cognitive disabilities might evoke emotions of anxiety, shame, and guilt, potentially influencing mothers’ perceptions of parenting.

Negative emotions and a failure to cope constitute compromised mental well-being. Mental well-being is one of the key factors in family life quality perception. Relationships within the family are identified as a primary dimension influencing family life quality. It is reasonable to assume that an individual’s perception of family life quality rises when these relationships are good (Brown *et al*. 2006). Consequently, strained relationships and their perceived deficiencies correlate to a perception of poor quality of life, as articulated in the mothers’ statements.

This research finding highlights dissatisfaction in the realm of family relationships, manifested in recurring conflicts between spouses and dissatisfaction on the part of mothers towards their children with cognitive disabilities in terms of the time they allocate to them and their interactions with them. These factors affect their perception of parenting. This finding aligns with that of Ajuwon and Brown (2012), who indicated that tense family relationships negatively impact family life quality.

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

It is important to note that the findings from this study contradict the findings of 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*. 2011/2014).

Social aspects, in general, were expressed in terms of dissatisfaction with social connections and interpersonal interactions with a negative impact on quality of life. Mothers described how their participation in events required unique organisational challenges that included 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 to social gatherings.

According to the 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 that assistance in caring for the disabled person is avoided out of reluctance to expose themselves (Barakat, 1993).

The reasons mothers raised for their avoidance of events and reluctance to form interpersonal connections also appear in a review by Mccubbin and Huang (1989), who presented seven areas of difficulty, one being the challenges in societal aspects of life, such as parental embarrassment from the behaviour or appearance of their child, reactions from friends and neighbours, 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 affects various aspects of their lives and leads to isolation and social distancing (Naon, 2009). Specifically within 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 at the support received in two primary realms of their lives considered significant factors influencing their family life quality. Firstly, they noted the value of the support they received from their close-knit circle, particularly their families and their spouses’ families, played a crucial role. Secondly, the support from the educational systems catering to their children was noted positively. Studies illustrate that parenting is an experience fraught with tension, resulting from 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 specialised professional assistance (Levi-Shif & Shulman 1988).

The findings of this study highlighted that the overwhelming majority of mothers relied heavily on two sources of practical and emotional support: their families and their spouses’ families. The mothers cited that family networks assist in various aspects, including child care, educational and developmental support, emotional support, and contributing to the acceptance of the children. The second source of support was the educational system. It is perceived as serving as a source of knowledge and guidance regarding care for their children and a significant factor in reducing their stress levels. 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 teams assigned to them within the educational system.

This finding is backed up by the research literature, such as the work of Zuna *et al*. (2009), who address systemic factors explaining family life quality. These factors can include governmental policies, laws, intervention programmes, and entities providing support services such as education and welfare. Zuna *et al*.’s (2009) theory regarding quality of life offers 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 the implementation of regulations are 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*. 2009).

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

Contrary to recent research that found mothers to be satisfied with the support received from their children’s educational system, other contemporary studies discovered lower satisfaction with personal support and assistance from special needs services (Brown *et al*. 2010; Schmidt & Kober, 2010). These findings contradict Ajuwon and Brown (2012), who showed that support from services negatively impacted parental family life quality. Moreover, this study 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 interviews were laden with emotional language. The interviewees addressed feelings of stress, pressure, fear, worry, disappointment, longing, and loneliness. Alongside these emotions, positive feelings that emerged while being close to their intellectually disabled child were described. This finding implies that the presence of a child with intellectual disability significantly affects 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 effort (Guyard *et al*. 2012; Neikrug *et al*. 2011).

An intriguing sub-category emerged in the emotional aspects. Alongside the negative emotions expressed by mothers, most of them expressed genuine love for their disabled children, found joy in their children’s happiness, and cherished feelings of closeness. 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.

**Discussion**

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 resources to enhance the overall quality of life of mothers, such as assistance with tasks and professional guidance to cope with relationship management and proper parenting.

Mothers also expressed discontent in social aspects due to unsuitable environmental and societal conditions, struggles in coping and organising, and detrimental social reactions. This dissatisfaction with environmental factors indicates that the children themselves do 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 frameworks could enhance life quality and mitigate the negative emotional aspects revealed in the findings. Consequently, the mere presence of a child with intellectual disabilities necessitates a special approach that influences life quality. Proper treatment of every aspect of the life of a child with an intellectual disability could contribute to the well-being and life quality of mothers.

In summary, mothers perceive their family life quality 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 is seen as a source of love and happiness, not a hindrance to life quality.

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