تأثير الاطفال ذوي الاحتياجات الخاصة على جودة حياة الأسرة

Children with Disabilities on Families' Quality of Life

إعداد

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المستخلص:

الغرض من هذه الدراسة هو لقياس تأثير الأطفال ذوي الاحتياجات الخاصة على نوعية حياة أسرهم من خلال مراجعة أدبية للدراسات المتعلقة بهذا الموضوع. بالإضافة إلى معالجة العوامل المؤثرة بشكل كبير على نوعية حياة أسر الأطفال ذوي الاحتياجات الخاصة. كما أنه تتضمن هذه الدراسة مجموعة من الأطفال والمراهقون وكذلك البالغون من ذوي الاحتياجات الخاصة والذين يعانون من مجموعة متنوعة من حالات الإعاقة المختلفة. العديد من الدراسات أشارت إلى أن درجات الرضا والرخاء والصحة هي العوامل الرئيسية التي تؤثر على نوعية حياة الأسرة. بالإضافة إلى ذلك، أظهرت الأبحاث أن هناك عوامل أخرى يمكن أن تؤثر على نوعية حياة الأسر، مثل العامل الاجتماعي، والعامل البدني، والعامل العاطفي، والصحة العقلية، والدعم، والنفقات المالية، والعلاقات الأسرية، بالإضافة الى العامل الأسري. كما كشف هذا البحث أن الأطفال ذوي الاحتياجات الخاصة يمكن أن يكون لهم تأثير على نوعية حياة أسرهم أو على الوضع المالي للعائلة، وكانت درجات الرضا والرخاء وكذلك الصحة هي العوامل الرئيسية التي تؤثر على جودة حياة الأسرة.

Abstract:

The purpose of this study is to review research literature related to testing the impact that children with disabilities have on their families' quality of life, as well as addressing the factors that have the greatest effect on quality of life in families of children with disabilities. The research participants included children, adolescents, and adults with disabilities with a variety of disability conditions. Several studies indicated that satisfaction scores, well-being, and health were the main factors that affect families' quality of life. In

addition, research demonstrated that there were other factors that can affect families' quality of life, including social functioning, physical functioning, emotional functioning, mental health, support, out-of-pocket expenses, family relationships, and family functioning. This research revealed that children with disabilities can have an impact on their families' quality of life or on the financial status of the family, and satisfaction scores, well-being, and health were the main factors that affect FQoL.

All children need love and encouragement, especially those with learning disabilities. Moreover, positive reinforcement can help to ensure that these children emerge with a strong sense of self-worth, confidence, and the determination to continue even when circumstances are tough (Kemp, Smith, & Segal, 2016). The most common source that can help children with disabilities to find love, encouragement, and support is the family, since parents and siblings are the most interested in providing the appropriate services to their family members with disabilities. This could sometimes affect parents, specifically on the levels of Family Quality of Life (FQOL) and finances.

Many Saudi students with disabilities study in Jordan, because there are not enough care centers for students with disabilities in Saudi Arabia. Therefore, there is a financial load on such families of children with disabilities. Thus, this study will investigate whether children with disabilities can have an impact on families, specifically in the areas of FQOL and finances. This study will look not only at children with disability needs, but also at every member in the family. The family of a child with a disability might face many challenges in supporting its child. Therefore, the aim of this study is to investigate the impact of children with disabilities on parents. More specifically, it will investigate the impact of children with disabilities on the financial states of parents and the family's quality of life. The following question will be investigated in this paper: Is there an impact of children's disabilities on the financial status of the family or on the family's quality of life?

There are several different measurements that will be utilized in this study. Some of these measurements include the following: out-of-pocket expenses other than childcare, disability-related expenditures for substitute child care; and the *Beach Center* FQOL Scale, which measures parental perceptions of the importance of different aspects of FQOL and satisfaction with quality of life. Finally, there are measurements to evaluate parents' views about the services that were provided for them and for their children with special needs. In summary, this study will investigate whether there is an impact of children with disabilities on the family's quality of life or on the financial status of the family.

Review of the Literature

Lukemeyer, Meyers, and Smeeding (2000) carried out a study to explore the costs resulting from children with disabilities in low-income families. This study was divided into two phases: the first phase was conducted on 2,214 families in 1993. Two years later, in 1995, the researchers started the second phase using 1,764 families located in the United States. The researchers collected all of the data using a telephone survey, one which was available in English and Spanish. The researchers used multivariate models to measure the following: out-of pocket expenses other than childcare, disability-related expenditures for substitute child care, and mothers' labor force participation. There was a statistical difference between families with no severely disabled children and families with at least one severely disabled child, $t = -1.69$, $p < 0.01$. Their study found evidence that 20% of children with disabilities are in the welfare population. In addition, the care of these children generated more direct and indirect costs for their families. The weakness of this article is that the researchers did not know whether the participants reported the entire cost that they incurred in caring for children with a disability or only the extra cost of children with a disability. Thus, the researchers assumed that the reported cost of children with disabilities represented only the extra or special expenses. The strength of this study is that the researchers used multivariate models to measure how the cost of children with disabilities affects the families financially.

Brown, MacAdam–Crisp, Wang and Iarocci (2006) conducted a study using British, Columbian, and Canadian participants. The purpose of this study was to better understand the issues that primary caregivers are dealing with, as well as the perspectives of parents on their qualities of life. The researchers used a quantitative method by mailing surveys to 51 families, where 33 of the participating families had children with Down syndrome and 18 had children with autism. The researchers had interviewed the participants face-to-face and relied on a telephone survey to collect as much information as possible in support of the study, with ten individuals from the autism group and 16 from the Down syndrome group responding to a follow-up interview. Children's ages ranged from 3 to 13 years old, while the parents' ages ranged from 38 and 45 years old. The omnibus F-tests showed significance for the following dependent variables: health at $F = 9.25$, $p < 0.001$; financial well-being at $F = 4.34$, $p < 0.05$; and family relationships at $F = 14.28$, $p < 0.001$. For the domain of financial well-being, the control group also differed significantly from both the Down syndrome and autism groups at $p < 0.05$. The researchers found that the satisfaction scores were much greater in the families that do not have children with disabilities when compared to the families that have children with disabilities. The weakness of this study is that the number of participants was small and limited. In addition, most of the participants were women. A strength of this study is that the researchers not only conducted quantitative research but also carried out qualitative research. This helped in better explaining why the satisfaction scores were much greater in families that do not have children with disabilities as opposed to families that have children with disabilities.

Davis and Gavidia-Payne (2009) carried out a study in which their purpose was to understand the relationship between parental perceptions and experiences with family-centered professional caregiving and family quality of life (FQOL). The participants included 64 children with a developmental delay or disability, with ages ranging from 3 to 5 years old, who were part of programs at 14 different centers in the northern, western, and eastern suburbs of Melbourne, Australia. The mothers' ages ranged between 25 to 65 years' old. In addition, their household incomes ranged from $25,000 and $75,000 for 37 families while two families received less than $25,000 and 25 families earned more than $75,000 per year. The researchers utilized the *Beach Center* FQOL Scale to measure parental perceptions of the importance of different aspects of FQOL as well their satisfaction with quality of life, the *Pro Processes of Care* (MPOC-56) to evaluate the family centeredness of services and measures parental perceptions, and *Child Behavior/Needs.* The participants completed a questionnaire package and returned it by mail. This study indicated that FQOL were significantly higher than their satisfaction with quality of life, M = 3.74, SD = 0.69, < *M = 3.74, sd = 0.69* – Statistics are italicized.> $t(63) = 7.26$, $p < .001$. Their study also provided evidence to suggest that parental perceptions and experiences with family-centered professional support are associated with FQOL. However, the results of this study revealed no significant associations between the severity of a child's disability and FQOL. The weakness of this study is that the response rate of the families who participated in this study was 16%, a factor which could explain the difference in results between families who were motivated to complete the questionnaire and families who were not. A strength of this study was its highlighting the importance of delivering services to families of children with disabilities in a supportive and useful way, as well as making parents feel that they are being treated as an active ingredient in their child’s effective care.

Werner et al. (2009) examined the utility of the family quality of life. The participants in their study were 35 participants including 23 mothers, 7 fathers, and 3 siblings from 26 families located in the Canadian city of Toronto. The mean age of the participants was between 25 and 43 years old. There were two types of participants; family members who identified themselves as the main caregivers of individuals with ID and family members who did not identify themselves as such. The researchers used the *Family Quality of Life Survey* FQOLS- 2006 in this study. The researchers followed up with a phone call after mailing the survey to the participants. Also, each participant completed the survey on an individual basis. The study results revealed a correlation between global satisfaction and FQOL that was found to be significant from the nine domains, $r = 0.62$, $p < 0.001$. The researchers found that actions were determined to be significantly lower for support from others than for financial wellbeing, health, family service, support relationships, careers, leisure, and community interaction. The weaknesses of this study are that the methodology and findings could not be useful in other countries, where statistical significance testing could be more difficult, which may threat the results. Also, in this study, it was not possible to compare FQOL across disability groups since the majority of the participants were family members of individuals with autism. Moreover, the two central agencies were in the same city, so the two groups of participants were served in very similar aspects. A strength of this study is that the researchers used the FQOLS-2006, a scale which is adaptable to numerous situations and life stages. In addition, the researchers examined each life domain according to its various dimensions.

Jokinen and Brown (2005) explored issues of family needs and concerns from the perspective of older parents of adults with ID. The participants in this study numbered 15 in total, three fathers and 12 mothers, and they were all from Canada. Their ages ranged from 62 to 87 years. The ages of the adult participants’ children ranged from 41 to 52 years, ten of whom were single and three of whom were married. Two of the children had Down syndrome, one had autistic tendencies, one had Fragile X, and another had multiple disabilities. The other adults’ children did not have a specific ID. Information about the participants was gathered through local service agencies, focus groups, and interviewing the participants. The participants also completed a survey questionnaire. The researchers also used the *Family Quality of Life Survey*. The survey that was used in this study had 32 questions that covered nine domains of life: family relations, health, finances, spiritual and cultural beliefs, contribution to community and civic affairs, leisure, support from others, support from services and work. Ten parents described their family quality of life as being normal. One hundred percent of the participants were satisfied with several aspects of their family life. However, the areas of civic affairs and contribution to community received the lowest rating of satisfaction at 54.5%. The result of this this study indicated parents’ reporting of positive aspects of lifelong caregiving and FQOL. There were also concerns for the health of all family members, the social lives of their children, long-term living arrangements, and the role of siblings. The weakness of this study was that the results threaten the validity because the researchers did not carry out any tests to determine whether there was any significance in the results. Furthermore, all of the statistics provided were expressed in percentages. The strength of this study is that this was the only study that was found which focused on adult children with ID and FQOL.

Clark, Brown and Karrapaya (2011) aimed to establish a preliminary appreciation of the quality of life of families who have children with disabilities. Moreover, through this study results, the researchers aspired to improve the quality of life of the participating families. The participants in this study were 53 families from Malaysia, while the average of the participants' ages was 39.2 years. The average age of their children with disability was 7.5 years, while the number of children with disabilities numbered 54. The children's disabilities included Down Syndrome, Cerebral palsy, autism, and several others. After gathering the participants from two services, the Main Center and Stepping Stone, the researchers used a short version of the Family Quality of Life Survey to interview the participants with one of two languages: Bahasa Malaysia or English. The families were provided with an option to complete the interview in their homes or by way of the two services. The study measured six quality of life dimensions across the financial domain for families who had children with disabilities. The results showed that the dimension of "importance" was rated as significantly higher than the other five dimensions at $r = 0.53$, $p < 0.01$. "Satisfaction" ratings were also relatively high at $r = 0.90$, $p <0.01$. Moreover, the correlation between attainment and mean satisfaction was significant at the level $p < 0.05$, $r = 0.61$, Also, the correlation between global satisfaction with quality of life score and mean overall satisfaction was significant at the level $p < 0.01$, $r = 0.68$. However, "Opportunities," "initiative," "attainment," and/or "stability" ratings were significantly lower when compared to those for "Importance" and "Satisfaction." The weaknesses of this study are its requiring a broader sample which includes more families who were not receiving services. Also, the survey that was utilized in this study does not provide the opportunity for any elaboration in responses. The strength of this study is that the information it uncovered could help in the development of a better understanding for the reasons behind higher levels of satisfaction across all the domains.

Viecili and Weiss (2015) investigated Pediatric Quality of Life (PedsQL) in individuals with intellectual and developmental disabilities, as well as in individuals with autism spectrum disorder. In addition, their intention was to assess the feasibility, reliability, and validity of the PedsQL parent-proxy report in a diverse sample of

Canadian children with disabilities. The participants included 359 caregivers of youth and young adults with IDD, where the average age of each participant was 49.2 years old. For the youth and young adults with disabilities, 81% had IDD, 34% had ASD, 18% had Down syndrome, 6% had fetal alcohol spectrum disorder, and 6% had cerebral palsy. The researchers collected the participants through the Special Olympics in Ontario, Canada, which ran from 2012 to 2013. The researchers communicated with the participants by email and mail, with the participants completing the survey by paper and pencil or online. The researchers used a Pediatric Quality of Life PedsQL scale to measure physical functioning, emotional functioning, social functioning, and school/work functioning. In this study, the *Strengths and Difficulties Questionnaire* (SDQ) Emotional Symptom scale was negatively correlated with the PedsQL Emotional Functioning scale ($r = -0.70$, $p < 0.001$). Also, the PedsQL Social Functioning scale was negatively correlated with the SDQ Peer Problems scale ($r = -0.57$, $p < 0.001$), and positively correlated with the SDQ Prosocial scale ($r = 0.27$, $p < 0.001$). The results of this study showed that the PedsQL Generic Core Scales maintained their psychometric properties in a sample of children with IDD, including discriminant validity, internal consistency, construct validity and convergent validity. The weakness of this study is that the researchers had chosen the participants just through the Special Olympics, so the result might not be consistent with a sample unrelated to the Special Olympics. The strength of this study is the importance and uniqueness of the results, since the researchers used a community sample as opposed to a clinical sample.

Kuhlthau et al (2009) aimed to measure Health-Related Quality of Life (HRQoL) in a group of children with autism in order to understand the relationship between the severity of a child’s autism and HRQoL. Between 2006 and 2008, through a hospital and clinic that is a member of the Autism Treatment Network, the researchers recruited 286 children from 15 autism centers across the United States and Canada. The ages of the participants ranged from 2 to 18 years old. The participants had received a survey that included 23 items and was intended to evaluate the following four distinct areas of health-related functioning: physical functioning, emotional functioning, social functioning, and school functioning. The researchers had provided the survey in an English version. In addition, the researchers used the parent-report version of the *Pediatric Quality of Life* (PedsQL) because communication with children with ASD presented some difficulties. The researcher used Bonferroni adjustments to measure statistical significance related to comparisons within instruments. In this study, the average total PedsQL score for the ASD sample was (65.2 ± 15.9). This score is significantly lower than the national norm for a generally healthy population (82.3 ± 15.6), as well as significantly lower than the norm for children with chronic conditions (73.1 ± 16.5), ($p < 0.001$) for both comparisons. The results of this study indicate that ASD-related behaviors will have an adverse effect on HRQoL. The reported HRQoL scores of parents who had children with ASD were poorer than those scores reported by parents of typically developing children. The weaknesses of this study are that the researchers collected all of the children with autism from clinics in academic medical centers where they were being treated, so the result could not represent the full range of experience of children with autism. Also, the result is based on a parent proxy-report rather than a child self-report. The strength of this study is that it is considered the first study to examine the HRQoL of children with autism. Thus, the result would be valuable to further exploration of child with autism.

Parish, Cloud, Huh and Henning (2005) carried out a study to examine the quality of child care among low-income families' preschool-aged children with disabilities as contrasted with low-income family children without disabilities. This study contained 5065 children, including 321 children with disabilities and 4744 children without disabilities from the state of North Carolina in the United States. The researchers also used the *National Survey of America's Families* (NSAF) with the participants by way of telephone. The NSAF examined various factors including health, economic factors, and the social well-being of children and adults as well as the children's participation in child care. In addition to these, several components were measured like cost, the quality that was used to describe whether a child was in care, and expenditures for child care in the previous month. In this study, 45.5% of the disabled sample had family earnings below the federal poverty line, while 38.3% of the nondisabled children had family earnings below the federal poverty line ($X^2 = 6.61$, $p < 0.01$). This indicates that within the low-income sample, disabled children were poorer than nondisabled children. Also, nondisabled children living with two parents were much less likely to use a center as a primary form of care than were disabled children. Differences in the caregiver ratios were not found for children living in single parent homes, but trend-level differences ($F = 2.0$, $p < 0.05$) were found between the children living in two-parent homes. The findings of this study indicate that even though the number of care arrangements did not differ for disabled and nondisabled children in single-parent homes, the number of care arrangements was higher for these children than for children in two-parent homes. The weakness of this study is that the relationship between parental employment and use of children with disabilities and children without disabilities cannot be directly measured, since the sample of children drawn from the NSAF data was randomly selected. So It is possible that the nondisabled children in this study might have had disabled siblings, whose influenced their parents' employment, and thereby would have caused biased employment. Moreover, the number of children with disabilities in this study was small compared to the children without disabilities. The strength of this study is the result an important predictor of the impact, particularly financial, that disabled children have on their families.

Eker and Tüzün (2004) aimed to estimate the quality of life of mothers of children with cerebral palsy (CP), as well as understand the burden of care on these mothers compared with those who have children with minor health problems. The researchers collected the data of 40 mothers with children suffering from CP from an in-patient clinic of the PM&R hospital, and health centers HC in Turkey. Also, 44 mothers with a child suffering from minor health problems. The researchers used a *Short Form Health Survey* (SF-36) in addition to eight multi-item scales containing between 2 and 10 items each to measure the dimensions of physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Also, the *Gross Motor Function Classification System* (GMFCS) to measure the severity of child's motor disability. The researchers interviewed the participants to determine the socio-demographic characteristics of the respondents such as age, highest educational level, marital status, type of residence, and number of children. The age of the children in this study ranged between 2 to 12 years old. In this study, significant linear correlations were found between GMFCS ($r = - 0.70$, $p < 0.001$), vitality ($r = 70.35$, $p < 0.05$), mental health ($r = 70.48$, $p < 0.01$), and emotional role ($r = 70.47$, $p < 0.01$) subscales. The first finding of this study was that the quality of life pattern of the mothers who have children with CP was different from those who have children with minor health problems. Also, mothers of children with CP had significantly lower quality of life scores in all subscales of the SF-36 but not for the PF subscale. The weaknesses of this study were that the design of the study did not allow causality to be established and the researchers used a small sample size. Thus, the children with CPs could not represent all children with CP in Turkey. The strength of this study is that it is considered the first study to estimate the quality of life of mothers of children with CP compared with mothers who have children with minor health problems.

Lee, Harrington, Louie and Newschaffer (2007) examined Quality of Life (QOL) and parental concerns in children with autism (ASD) compared to children with Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) in the United States. The researchers depended on data from the National Survey of Children's Health (NSCH), where the information was collected from 50 states and the District of Columbia in the U.S. The children's ages ranged from 3 to 17 years old. The participants in this study had 78.5% of the participants being mothers, 17.3% who were fathers, and 4.2% who were other. The children in this study were divided to three groups—autism, ADD/ADHD, and unaffected controls—with the total number of children with autism being 483, 6319 children who had ADD/ADHD, and 13,398 children who were in unaffected control group. The subscales of QOL that were measured in this study were the following: caring burden, family outing, religious service attendance, number of days in missing school, activity participation, whether the child had repeated a grade, independence, and community service. The researchers used both bivariate and multivariate analyses in this study. Families of the autism group reported significantly greater child caring burden than the ADD/ADHD and unaffected control groups with coefficients $OR = 1.29$, $P < 0.05$, and $OR = 2.58$, $P < 0.05$. respectively. Children with autism attended religious services at a significantly lower frequency compared to ADD/ADHD, $OR = 0.51$, $P < 0.05$, and children with autism attended religious services at a significantly lower frequency compared to unaffected controls $OR = 0.38$, $P < 0.0$. The findings of this study indicate that parents of children with autism have higher levels of concerns about their child's well-being than do parents of children with ADD/ADHD or unaffected children. The weakness of this study is that not all of the questions that were asked were suitable for all children's ages, since some items were limited to children how they were performing in school. The strength of this study is that it provides initial information about aspects of quality of life and parental concerns that most affect families of children with ASD at different developmental levels.

Mackie, Jessen and Jarvis (1998) aimed to describe the influence of disabilities on the lives of children with cerebral palsy and their families. The researchers collected data of 691 children with cerebral palsy from the North-East England Cerebral Palsy Register, all of whom were born between 1960 and 1985. In this study, the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) was used to guide the researchers’ focused in terms of quality of life and health status measurement. The researchers used several methods to develop measurements for the quality of life of children with cerebral palsy and their families. The first method was the *Lifestyle Assessment Questionnaire* (LAQ), which consists of 37 questions focused on the actual functioning of the child in everyday life. The second was LAQ[CP], which was used to measure the total impact score for children with cerebral palsy in families’ quality of life. There was a significant correlation between LAQ and LAQ[CP] ($r = 0.97$, $P < 0.0001$). The results of this study showed that this newly developed measurement is an applicable measurement in this area of research. Also, the results indicate that the quality of life of parents who have children with cerebral palsy can be affected by their children with cerebral palsy. The weakness of this study is that the researchers focused on physical independence and mobility, while they had only discussed other dimensions in a marginal way and assessed children's experiences on the basis of categorization scales which lack precision. The strength of this study is that it was the first to be published which described the development and properties of a tool for measuring the influence of disabilities on the lives of children with cerebral palsy and their families.

Escobar (2005) aimed to assess the quality of life (QOL) of children with diagnosed attention deficit/hyperactivity disorder (ADHD) as compared with asthmatic children and healthy children.

The researcher had chosen 237 participants and divided them into three groups according to the areas of age, gender, and health care. In this study, the participants included 124 children with ADHD, 93 asthmatic children, and 120 healthy children from Spain. The participants' ages ranged between 6 to 12 years old. The researcher used a *Child Health Questionnaire* (CHQ) to measure QOL, which included 50 items that were distributed to measure behavior, social limitations attributable to physical problems, emotional impact on parents, and family activities. This study used parents' evaluation of their children's conditions instead of evaluations by clinicians. In this study, the QOL of children with ADHD was rated lower than that of asthmatic children for most domains. A great mean difference was found between the QOL of children with ADHD, asthmatic children, and behavior ($F(-27.18, -17.71) = -22.44$), ($p < 0.0001$). Also, the QOL of children with ADHD was also rated lower than that of healthy children for most domains. There was a significant mean difference found between the QOL of children with ADHD, healthy children, and family activities ($F(-31.85, -22.71) = -27.28$), ($p < 0.0001$). The results of this study indicate that children with ADHD and their families have problems in their everyday lives, since the results showed that children with ADHD have lower impaired psychosocial functioning compared with asthmatic children, as well as lower physical and psychosocial functioning compared with healthy children. The weakness of this study is that the data collected relied on information from parents rather than from the patients themselves. It is possible that the health perceptions of the children might have differed from the perceptions of their parents. The strength of this study is that the result is a significant finding, since one of the goals of health care is to improve patients' perceptions of their health. This is especially important given the extent to which patients' health problems interfere with their QOL.

Karande, Bhosrekar, Kulkarni and Thakker (2008) aimed to measure and analyze the parent-reported health-related quality of life (HRQL) of children with newly diagnosed specific learning disability (SpLD), as well as to assess the influence of clinical and socio-demographic characteristics on their HRQL. In this study, the participants were 150 parents who can read and understand English from Mumbai, India, where their mean age was 41.4 years and the ages of their children—who studied in English medium schools—ranged between 5 to 18 years. Their study involved a team of multidisciplinary specialists, including a pediatrician, counselor, clinical psychologist, and special educator, who were tasked with assessing each child. The researchers used the *Child Health Questionnaire-Parent* (CHQ-PF50), which has 50 items, to measure HRQL; the *Wechsler Intelligence Scale for Children* to measure the children's global intelligence; *Physical Summary* (PhS) score, and *Psychosocial Summary* (PsS) score which are an 'overall' measures of the physical and psychosocial well-being, respectively were used in this study. In order to measure the families' socio- economic statuses, the researchers utilized a modified version of Kuppuswami's classification. The HRQL for each of the studied children was compared with U.S. children's norms. Those children who had one or more associated "non-academic" problem(s) and first-born status showed significantly lower (PhS) scores at ($p = 0.003$, $p < 0.05$) and ($p = 0.009$, $p < 0.05$), respectively. A one-way analysis of variance between HRQL and socioeconomic status showed non significant PhS scores ($p = 0.257$, $p < 0.05$). Also, Multivariate analysis confirmed that having one or more associated 'non-academic' problem(s) or co-occurring ADHD 'independently' predicted a poor PsS score outcome ($p < 0.0001$, $OR = 0.1$, and $p = 0.005$, $OR = 0.2$) respectively. The result of this study indicated that all 12 of the CHQ-PF50 mean domain scores of the children studied in Mumbai, India, were lower than the norm among U.S. children. The weakness of this study is that all the information analyzed was reported by parents rather than children, so this could have affect the result since it is possible that the health perceptions of these children might have differed from parents' reports. The strength of this study is that the results are useful for counselors in improving children's and families' quality of life (FQOL), as well as being useful for pediatricians in gaining more information about poor school performance whenever they come across any child having behavioral problems.

Sullivan et al (2004) aimed to evaluate the effect of gastrostomy feeding on the quality of life (QOL) of caregivers of children with cerebral palsy (CP). The researchers interviewed the caregivers to obtain information about each child's nutritional state and the time that was spent on feeding the child. The caregivers included 57 participants from Oxford, Manchester, and Watford in the United Kingdom. 44 of these individuals were mothers, 4 were fathers, 2 were grandmothers, and 7 were foster parents. The median age of children with CP was 4 years and 4 months, with female children numbering 28 and male children numbering 29. The researchers used a *Short-Form 36* (SF-36 II) questionnaire to measure the QOL of the children with CP on three occasions: the first time before the gastrostomy, the second time after six months, and a final time after 12 months. Moreover, the Wilcoxon signed rank test was used to evaluate the changes over time in the length of time caregivers had to spend in feeding their children with CP per day. In this study, the quality of life of the caregivers was significantly lower than that of the general population due to physical problems ($p = 0.003$), social functioning ($p = 0.0003$), mental health ($p < 0.0001$), role limitations due to emotional problems ($p = 0.0003$), and energy/vitality ($p < 0.0001$). The result of this study indicated that mothers' well-being when having a child with a severe disability was associated significantly with quality of life, due to social functioning, mental health, and energy/vitality being compared with the population norms.

Also, the result showed a significant reduction in feeding times and reduced concern about their child's nutritional status, which helped in bringing about a major improvement in the quality of life of caregivers after the introduction of gastrostomy feeding. The weaknesses of this study are that the sample size was too small. Also, the researchers in this study merely measured the effect of gastrostomy feeding on the QOL, so the results of this study cannot be generalized to all caregivers of children with CP. The strength of this study is that it was the first study that measured the effect of gastrostomy tube feeding on the quality of life of caregivers of children with CP.

Yuen Shan Leung and Wai Ping Li-Tsang (2003) aimed to understand the quality of life (QOL) of parents of children with disabilities compared to parents of children without disabilities. The researchers obtained approval from the Ethical Research Committee of the Hong Kong Polytechnic University to assess and interview 147 parents using a convenience sampling method, where 71 of the parents had children with disabilities from a special school for the disabled and 76 had children without disabilities from a primary school. The ages of the children in this study ranged from 6 to 12 years old. The disabilities of the children in this study included cerebral palsy, mental retardation, Down syndrome, and developmental delay. The researchers conducted interviews with parents by way of telephone. In addition, they used the *World Health Organization's Quality of Life Measure Abbreviated* version (WHO-QOL BREF [HK]) to measure the QOL, as well as the *Wee Functional Independence Measure* to measure the children's disability levels. The researchers used an independent *t*-test to compare QOL between the parents of children with disabilities those of children without disabilities. In this study, the three domains of parental QOL—physical health ($r = 0.361$, $p < 0.05$), psychological health ($r = 0.371$, $p < 0.05$), and environment ($r = 0.358$, $p < 0.05$)—had strong correlations with the severity of the children’s disability. The results of this study indicated that parents of children with disabilities had lower quality of life (QOL) scores in the environment domains and social relationships. The weakness of this study is that the sample size was small, especially with parents of children with disabilities. The strength of this study is that the findings can help professionals to understand the problems of children with disabilities and how these have some impact on their parents’ QOL.

Schneider, Gurucharri, Gutierrez and Gaebler-Spira (2001) aimed to measure the health-related quality of life (HRQL) in children with cerebral palsy (CP). The participants in this study were 30 caregivers of children with CP, with the mean age of the children being 8 years and 6 months. The caregivers in this study included 19 mothers, 5 fathers, 2 grandmothers, 2 foster parents, and 2 that were classified as other from the city of Chicago, Illinois. The researchers interviewed the caregivers who were fluent in the English language after they had made agreements to participate. The researchers utilized the *Caregiver Questionnaire* (CQ) to measure the caregivers’ difficulties and satisfaction with their children’s progress, as well as the *Wee-Functional Independence measure* (WeeFIM) to track disability in children with CP. Also, the generic CHQ was used to measure the physical and psychosocial well-being of children above 5 years of age. In this study, there was a significant relationship that was found between the CHQ subscale Parental Impact–Time and the CQ total score ($r = 0.431$, $p < 0.05$) and a significant relationship found between the CHQ subscale Parental Impact–Time and CQ Physical subscale score ($r = 0.386$, $p < 0.05$). In addition, there was a significant relationship found between the CQ total score and the WeeFIM total score ($r = 0.460$, $p < 0.05$). The result of this study demonstrated that even while the children of caregivers in this study had significant disabilities, quality of life issues did not correlate well with function. However, CQ scores reflected the negative impact of the children’s health statuses on the participants’ time. The weakness of this study is that the WeeFIM was not designed to measure social participation or psychosocial experience, which are both included in the CQ. The strength of this study is that the results of this study can improve the focus of clinicians toward the areas that are most important for child/family functioning and quality of life.

Pit-ten Cate, Kennedy and Stevenson (2002) aimed to understand the effect of severity of condition and family resources on quality of life (QOL) in children with spina bifida and hydrocephalus. The researchers obtained information on 1249 families of children with spina bifida and/or hydrocephalus from the Association for Spina Bifida and Hydrocephalus (ASBAH) in the United Kingdom, with only 544 participants having responded. The children's ages ranged between 6 to 13 years old, where 62 of the children had spina bifida, and 354 had hydrocephalus, and 128 children had spina bifida as well as hydrocephalus. The caregivers of children with spina bifida and hydrocephalus completed the survey questionnaires and then mailed them back to the researchers. The researchers used *Child Health Related Quality Of Life* (CQOL) to measure the quality of life, the *Family Needs Survey* (FNS) to measure family resources, and the *Caregiving Self-Efficacy Scale* (CSES). They also utilized ANOVA, MANOVA, and *t*-tests in order to determine the effect that children's disabilities and the severity of their condition had on quality of life. There was a significant relationship between severity of condition and CQOL ($r = 0.352$, $p < 0.001$). Also, after the researchers made adjustments for severity, medical problems at birth and epilepsy maintained an association with a significantly poorer CQOL ($F(1, 428) = 4.10$, $p < 0.05$, $F(1, 403) = 40.00$, $p < 0.001$), respectively). The results of this study indicated that there was an association between severity of condition and CQOL. Also, there was a relationship with epilepsy in that it was associated with poorer quality of life in children with SB. The weakness of this study is the result cannot be generalized, as the researchers depended upon the parents' reports on children's quality of life, which may have produced some biases that affected the result. The strength of this study was the number of participants that were recruited, since it included a wide range of families who had been in contact with ASBAH. Also, the combined score in this study was very helpful for determining the impact of different disabilities on the various aspects of an individual's daily functioning and QOL.

Khanna et al. (2010) aimed to compare the health-related quality of life (HRQOL) of caregivers of children with autism to those of general caregivers of children in the United States. The researchers mailed the participants a survey packet which included a cover letter and a survey booklet with relevant study measures. A total of 304 participants returned the completed survey and agreed to participate. In this study, 93.1% of the participants were female and 95.7% were white, with the average age of the participants being 38.9 years. The researchers used the *Medical Outcomes Study Short-Form Health Survey version 2* (SF-12v2) to measure HRQOL among caregivers of children with autism; the *Caregiver Strain Questionnaire* (CGSQ) was used to assess caregiver burden; the *Multidimensional Scale of Perceived Social Support* (MSPSS) was used to assess social support; the *General Functioning Scale* (GFS) and the *McMaster Family Assessment Device* (FAD) were used to measure parents' reporting on their family functioning; the *Childhood Autism Rating Scale-Parent version* (CARS-P) was used to assess autism severity in children; and the *Developmental Behavioral Checklist* (DBC-P24) was used to measure behavioral problems as perceived by caregivers. In this study, there was a negative association between caregiver mental HRQOL and the extent of behavioral problem (r = -0.32, p < 0.01) and care recipient level of functional impairment (r = -0.30, p < 0.01). Also, a significant positive association was found between social support and mental HRQOL (r = 0.37; p < 0.01). After using Hierarchical Regression analysis to identify factors predicting caregivers' HRQOL, functional status ($b = -0.16$, $p < 0.01$), social support ($b = 0.13$, $p < 0.05$), and burden ($b = -0.37$, $p < 0.001$) were found to be the significant predictors of caregivers' mental HRQOL. The result of this study indicated that there were significant effects of caring for a child with autism on the caregiver's HRQOL, with parents being found to have lower scores in the physical and mental health as compared to the general population. The strength of this study that it represented the first to compare the health-related quality of life (HRQOL) of caregivers of children with autism to those of the general caregivers of children in the U.S. The weakness of this study was the insufficiency of the small numbers of male participants, so the results cannot be generalized to the U.S. male population.

Dardas and Ahmad (2014) aimed to assess the differences in the Quality of Life (QoL) between fathers and mothers of children with autism in the Arabic world, as well as measure the psychosocial correlates of the QoL of Arabic parents of children with autism. The researchers contacted 184 caregivers of children with autism through special education centers, where the mean of the parents' ages was 37 years old. The researchers utilized the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR) to assess children under the guidance of certified licensed professionals; The *World Health Organization Quality of Life Assessment-BREF self-administered instrument* (WHOQOL-BREF) was used to measure the QoL; the *Parenting Stress Index-Short Form* (PSI-SF) was used to assess stress in parents; and the *Ways of Coping Checklist-Revised* (WCC-R) was used to measure coping in parents when having to deal with stress. In this study, the highest correlation between QoL and stress scales appeared with mothers' parent distress subscale ($r = -.64$, $p < .001$) and in the fathers' stress subscale ($r = -.53$, $p < .001$). Also, there was a significant correlation between fathers, mothers, and Difficult Child (DC) ($r = 0.43$, $p < 0.01$), ($r = 0.54$, $p < 0.01$), respectively. The result of this study indicated that parents of children with autistic disorders have poor QoL levels. Also, the lowest QoL scores in this study were reported by mothers and fathers of children with autistic disorders in the environmental health domain. The weakness of this study is that the results may be limited, since the researchers measured stress, coping styles, and QoL of parents of children with autism and all of these domains can be altered over time. The strength of this study is that it was the first to examine the QoL of parents of children with autism in the Arabic world.

Results:

These studies on the relationship between children with disabilities and their families' QOL and finances supported the contention that such children have an effect on these two areas. Results from 17 of the 20 studies showed with significance that FQoL, HRQoL, and financial well-being were all affected by having children with disabilities.

In these studies, QOL and finances were examined across a variety of children with disabilities. Six studies were conducted utilizing children with autism, six studies used children with ADHD, four studies used children with Down syndrome, three studies used children with developmental disabilities, three studies used children with ID, two studies used children with ADHD, two studies used children with ASD, one study used children with ADD, one study used children with spina bifida, one study used children with multiple disabilities, and one study was centered on children who have learning disabilities or mental retardation. The results of the study by Sullivan et al. (2004) indicated that mothers' well-being when having a child with a severe disability was associated significantly with quality of life due to social functioning, mental health, and energy/vitality as compared with the population norms.

Seven studies examined social functioning and physical functioning, five studies examined emotional functioning, five studies examined mental health, two studies examined supports, one study examined out-of-pocket expenses, one study examined family relationships, one study examined family functioning, and one study focused on autism severity and its impacts on FQoL and finances. The results of Escobar’s (2005) study indicated that children with ADHD and their families have problems in their everyday lives, since the findings showed that children with ADHD had lower impaired psychosocial functioning compared to asthmatic children. In addition, they had lower physical and psychosocial functioning compared with healthy children.

Seventeen studies showed that FQoL was affected by children with disabilities. The study by Sullivan et al. (2004) indicated that mothers’ well-being when having a child with a severe disability was significantly associated with quality of life as a result of social functioning, mental health, and energy/vitality when compared with the population norms. Interestingly, the results showed that with appropriate treatments for children with disabilities, FQoL can improve. The results of Sullivan et al. (2004) showed a significant reduction in feeding times, as well as a reduced concern on mothers’ parts concerning their children’s nutritional status, which helped in bringing about a major improvement in the quality of life of caregivers after the onset of gastrostomy feeding.

About six studies reported a small sample size, a factor which may have affected the results of these studies. For example, Eker and Tüzün (2004) had interesting results which indicated that the quality of life pattern of the mothers who had children with CP was different than those who had children with minor health problems. Also, mothers of children with CP had significantly lower quality of life scores in all subscales of the SF-36 study. However, this study used a small sample, so the children with CPs could not be generalized to represent all children with CP in Turkey. Also, many studies collected participants from one specific clinic. This affected the results because it could not represent the full range of experiences among children and their families. For example, Kuhlthau et al. (2009) was the first study that examined the HRQoL of children with autism with the intention that the results would be valuable in further exploring children with autism. However, the researchers obtained all of the participating children with autism from an academic medical center where the children were being treated, so the results could not represent the full range of experiences of children with autism.

Discussion

Although there are many factors that affect FQoL, the three most important factors in this study were satisfaction scores in families with children who have disabilities, well-being, and health. The first factor that affects FQoL is satisfaction. The results of Brown, MacAdam–Crisp, Wang and Iarocci (2006) proved that the satisfaction scores were much greater in families who did not have children with disabilities than in families who had children with disabilities. Moreover, Werner et al. (2009) revealed a correlation between global satisfaction and FQOL that was found to be significant across the nine domains. A second factor is well-being and how it affects FQoL. Pit-ten Cate, Kennedy and Stevenson (2002) indicated in their research that there were associations between the severity of conditions and health-related quality of life. Also, the results of Dardas and Ahmad (2014) showed that the lowest QoL scores were reported by mothers and fathers of children with autism disorder in the environmental health domain. Moreover, Khanna et al. (2010) indicated that there were significant effects in caring for a child with autism on a caregiver’s HRQOL. Parents were found to have lower scores in the physical and mental health when compared to the general population. Finally, well-being was also one of the main factors that was shown to have affected FQoL. Lee, Harrington, Louie and Newschaffer (2007) showed that parents of children with autism had higher levels of concern about their children’s well-being than did parents of children with ADD/ADHD or unaffected children. In addition, the findings of Sullivan et al. (2004) demonstrated that mothers’ well-being when having children with a severe disability was associated significantly with quality of life compared with the population norms.

In most studies, the participants were female, with most of them being mothers of children with disabilities. In Khanna et al. (2010), 93.1% of the participants were female. Most of the participants in these studies were also parents who had children with disabilities. Only three of the studies included parents of youth with disabilities, while two studies included parents of adults with disabilities. The ages of the children in Brown, MacAdam–Crisp, Wang and Iarocci (2006) ranged from 3 to 13 years old, with the results of their study suggesting that there is a negative impact on the FQoL of families who have children with disabilities. Jokinen and Brown (2005) included adult children, whose ages ranged from 41 to 52 years old. The results of this study indicated parents’ reporting of positive aspects of lifelong caregiving and FQOL. According to these studies’ results, children with disabilities may have more negative impacts on FQoL than adults with disabilities.

The main scales that were used to measure FQol included social functioning, physical functioning, emotional functioning, and mental health. However, there were two main factors that could have affected the results in these studies. First, most of the studies were reported by parents, so that may have affected the scales in containing biases. Karande, Bhosrekar, Kulkarni and Thakker (2008) indicated that all the information in this study was reported by parents rather than the children; thus, this could have affected the results because it was possible that the health perceptions of these children might have differed from parents’ reports. The same was true with the study by Pit-ten Cate, Kennedy and Stevenson (2002), in which the researchers also depended on the parents’ reports concerning children’s quality of life. Also, there were many studies that contained a small sample size, which cannot be generalized to the population as a whole. Sullivan et al. (2004) conducted one of the studies that contained a small sample size. In addition, the study by Yuen Shan Leung and Wai Ping Li-Tsang (2003) had a small sample size comprised especially of parents who had children with disabilities, which ultimately may have affected the results.

Results from 17 of the 20 studies showed that FQoL, HRQoL, or financial well-being in parents was each significantly affected by their children having disabilities. This demonstrates that children with disabilities can affect FQoL, HRQoL, or financial well-being. Satisfaction scores, well-being, and health were the main factors that were shown to have an effect on FQoL or financial well-being. However, there were other considerations that may have affected FQoL. The results of the study by Sullivan et al. (2004) showed a significant reduction in mothers' feeding times and reduced concern about their children's nutritional status, which helped in contributing to a major improvement in the quality of life of caregivers after the introduction of gastrostomy feeding. This raises a crucial point regarding the importance of the use of therapies in improving FQoL. Also, there were other factors that were shown to have an impact on FQoL. For example, the study by Werner et al. (2009) found that actions were determined to be significantly lower for support from others than for financial well-being, health, family service, support relationships, careers, leisure, and community interaction.

Conclusion

In this study, there were 20 studies which investigated many factors that can affect the FQoL among families of children with disabilities. Seventeen studies out of the of 20 showed that children with disabilities have an effect on FQoL. The main factors that were shown to have the greatest impact on FQoL in these studies were satisfaction scores, well-being, and health. However, much remains to be learned about other factors that might affect FQoL which were neglected in most of the studies except that of Sullivan et al. (2004). Specifically, Sullivan et al. (2004) explained the impact of feeding times and disabled children’s nutritional status on FQoL. In addition, they offered suggestions as to what ought to be done in order to gain a better understanding of the impact that children with disabilities have on FQoL, as well as the impact of therapy on FQoL.

The strengths of these studies is that they provide further insight into many of the factors that can affect FQoL. For example, one of the interesting results is how parents of adults with disabilities reported positively on their FQoL and how specific therapies can have a positive impact on FQoL. The weakness of these studies is that almost all of them were affected by biases from parents reporting about their children’s conditions and their own satisfactions as pertaining to QoL.

Further studies are needed in order to understand why parents of children with disabilities have a negative impact on FQoL, while parents of adults with disabilities see positive impacts on their FQoL. Moreover, Lukemeyer, Meyers, and Smeeding (2000) showed that the care of children generated more direct and indirect costs for their families, to the extent that mothers of children with disabilities sometimes needed to work outside of the house to obtain higher income. Since this could have a significant effect on FQoL, further studies are needed in order to better understand the extent of its importance.

Some countries do not provide enough special education schools for all children with disabilities. For instance, as was mentioned in the introduction, there are not enough care centers for students with disabilities in Saudi Arabia. Therefore, because this factor could affect FQoL, what should be done in future study is investigating the impact of not having enough special education schools in Saudi Arabia, and how that can affect FQoL. Especially, when they need to travel to other countries in order to proved a proper education for the children with disabilities.

In short, the reviewed studies indicated that satisfaction scores in families with children who have disabilities can affect these families’ quality of life. Moreover, well-being is an important factor that can affect FQoL. In addition, the health factor is considered to have one of the greatest impacts on FQoL, as well as other factors such as social functioning, physical functioning, emotional functioning, mental health, supports, out-of-pocket expenses, family relationships, and family functioning. Finally, children with disabilities have an effect on family quality of life and finances.

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